Autism, anxiety and extended school nonattendance: Understanding the lived experience of children and young people through a neurodiversity lens

A thesis submitted to the University of Manchester for the degree of Doctor of Educational and Child Psychology in the Faculty of Humanities

2023

Claire N. Neilson

Manchester Institute of Education
School of Environment, Education and Development

Contents

Word count (excluding references and appendices): 21,964

List of tables

Paper One

Paper Two

Paper Three

List of figures

Paper One

Paper Two

Paper Three

List of appendices

List of abbreviations

ANOVA	Analysis of Variance
APA	American Psychological Association
ASC	Autism Spectrum Condition
ASC-ASD	Anxiety Scale for Children with Autism Spectrum Disorder
ASD	Autism Spectrum Disorder
CAMHS	Child and Adolescent Mental Health Service
CPD	Continuing Professional Development
CYP	Children and Young People
DECP	Doctorate in Educational and Child Psychology
EBPP	Evidence-Based Practice in Psychology
EBSA	Emotionally-Based School Avoidance
EHCP	Education, Health and Care Plan
EP	Educational Psychologist
EPS	Educational Psychology Service
ERIC	Education Resources Information Centre
EWO	Education and Welfare Officer
HCPC	Health Care & Professions Council
IPA	Interpretative Phenomenological Analysis
ISPA	International School Psychology Association
JORSEN	Journal of Research in Special Educational Needs
LA	Local Authority
MIE	Manchester Institute of Education
NHS	National Health Service
NI	Narrative Interview
NW	North West
PBE	Practice-Based Evidence
PI	Participatory Inquiry
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta Analyses
P1	Parent 1

P2	Parent 2
P3	Parent 3
RCT	Randomised Control Trials
RTA	Reflexive Thematic Analysis
SEND	Special Educational Needs and Disabilities
SLR	Systematic Literature Review
UK	United Kingdom
UREC	University Research Ethics Committee
WoE	Weight of Evidence
YP	Young People

Abstract

Background: Anxiety is a commonly cooccurring mental health condition for autistic children and young people (CYP), however literature indicates a fractured understanding of the distinction between the concepts of autism and anxiety. One expression of anxiety is nonattendance from school, which has become an area of pertinent interest for researchers and practitioners. Autistic CYP are at an increased risk of experiencing this phenomenon that has immediate and long-term adverse consequences. Papers One and Two respond to the call from the neurodiversity paradigm for a shift towards qualitative and participatory research methodologies to understand autistic CYP's lived experiences.

Methods/Participants: Paper One describes a systematic literature review (SLR) of ten studies exploring the experience of anxiety for school aged autistic CYP. Informed by the PRISMA framework, studies were appraised for methodological quality and relevance of focus. Paper Two, an empirical study, adopted a Participatory Inquiry design to explore effective support to meet the needs of autistic young people (YP) who have experienced extended school nonattendance. Unstructured interviews with two YP explored their perspectives; supported by three parental viewpoints. Paper Three reports a strategy to disseminate and evaluate the impact of research.

Analysis/Findings: SLR papers were analysed using thematic synthesis and reported heterogeneous experiences which vary across contexts with complex interactions between autistic characteristics and neurotypical environments. The participatory design of the empirical study enabled autistic YP to identify the themes of time, the internal processes of control and motivation, relationships and safe environments. Findings have been disseminated to a range of stakeholders and professionals.

Conclusion/Implications: Neurotypical environments may have a significant impact upon anxiety amongst CYP and effective support is conceptualised through an understanding and acceptance of individual lived experience of autism. Implications for policy, practice and research are considered.

Declaration

No portion of the work referred to in the thesis has been submitted in support of an application for another degree of qualification of this or any other university or other institute of learning.

Copyright statement

i. The author of this thesis (including any appendices and/or schedules to this thesis) owns certain copyright or related rights in it (the "Copyright") and they have given the University of Manchester certain rights to use such Copyright, including for administrative purposes.

ii. Copies of this thesis, either in full or in extracts and whether in hard or electronic copy, may be made **only** in accordance with the Copyright, Designs and Patents Act 1988 (as amended) and regulations issued under it or, where appropriate, in accordance with licensing agreements which the University has from time to time. The page must form part of any such copies made.

iii. The ownership of certain Copyright, patents, designs, trademarks and other intellectual property (the "Intellectual Property") and any reproductions of copyright works in the thesis, for example graphs and tables ("Reproductions"), which may be described in this thesis, may not be owned by the author and may be owned by third parties. Such Intellectual Property and Reproductions cannot and must not be made available for use without the prior written permission of the owner(s) of the relevant Intellectual Property and/or Reproductions.

iv. Further information on the conditions under which disclosure, publication and commercialisation of this thesis, the Copyright and any Intellectual Property and/or Reproductions described in it may take place is available in the University IP Policy (see https://documents.manchester.ac.uk/DocuInfo.aspx?DocID=24420), in any relevant Thesis restriction declarations deposited in the University Library, the University Library's regulations (see https://www.library.manchester.ac.uk/about/regulations/) and in the University's policy on Presentation of Theses.

Acknowledgments

Firstly, I would like to acknowledge and thank the support from the research site, since without your views and generosity my thesis would not have been possible. Special thanks to the contact I had at the specialist setting, who was invaluable throughout the research and Kas and Z who were an inspiration – I learned so much from you both!

I have grown as a researcher and practitioner due to a wonderful team of supervisors and am particularly grateful for the additional support you provided when it was needed during Year 2. Thanks to Caroline Bond for supervising my thesis – your insightful feedback and questions have contained me when needed and built my confidence exponentially. Thanks also to my fantastic placement supervisors, Joanne Snee and Yad Campbell, I have loved working with you both and your expertise and knowledge has nurtured and facilitated my journey towards being the type of EP I aspire to become.

I have also been supported by a wonderful set of friends, particularly Viki, Jo and Anna. Thank you for the walks, shoulders to cry on, proof readers and most importantly fun during the last few years. I am also grateful for a fabulous cohort of trainees who have been an irreplaceable source of support, knowledge and friendship.

Mum and Dad, you always believe in me and have given me so much invaluable love, encouragement and practical, financial and emotional support over the last few years. Thank you so much!

Finally, thanks so much to my family! To Ronnie, who is the most amazing husband and dad to our kids. I know it has not always been easy to remain patient, but I am so grateful for everything! Josh and Zac, what can I say? I am so proud of you both and love you loads!! I hope ‘fun mum’ is around more regularly now!

The author

The author holds a BA (Hons) degree in Theatre Studies with English Literature from the Lancaster University and MA degree in Applied Arts from the University of Manchester. The author worked for a number of years as a prison lecturer and freelance applied arts practitioner for a range of applied arts organisations and community film companies. More recently, the author applied her skills within a secondary school's inclusion department and completed an MEd in Psychology of Education at the University of Manchester. The author is motivated to qualify as an Educational and Child Psychologist and continue her passion overcoming barriers to participation and promoting social justice amongst marginalised groups and communities.

Introduction

Definition of key terms and their application to Papers One and Two

Neurodiversity paradigm: The neurodiversity paradigm characterises autism within "the range of natural diversity that exists in human neurodevelopment" (Pellicano & den Houting, 2022, p. 386) and offers challenge to the traditional medical approach to autism. In comparison to diagnosis due to deficits, the neurodiversity paradigm recognises disability as socially constructed by physical and social environments that are constructed for individuals who exist within a typical range of neurodevelopment (Pellicano & den Houting, 2022). This has resulted in a commitment to developing participatory research methodologies; to ensure research represents the concerns and enables the active involvement of the autistic community (Fletcher-Watson & Happé, 2019; Pellicano & den Houting, 2022).

Ecological model: An ecological approach to supporting autistic pupils who experience extended school nonattendance is supported by recent literature (Knage, 2021; Leduc et al., 2022) that informed the author's approach to Paper Two. This approach is informed by Bronfenbrenner and Morris' (2007) bioecological model of human development. The premise of this model is that individual development is influenced by the interaction of individual, social and organisational factors across time. The nested model originates at the proximal level of the individual's microsystem, which involves direct interactions with contexts such as home and school. The mesosystem encompasses connections that occur between a micro-system, for example between parents and teachers. The outer, distal level of an individual's macrosystem includes wider cultural and ideological belief systems. Finally, the chronosystem highlights the implication of context and time.

Participatory inquiry (PI): A PI methodology can be defined as a paradigm which is experiential and perceives the acquisition of knowledge as a transaction or direct encounter (Heron & Reason, 1997). PI is "done by people with each other, not by researchers on other people or about them" (Heron & Reason, 1997, p. 284). It is essentially a democratic and transformative methodology whereby participants are central to decisions about the content and methods used in research (Heron & Reason, 1997). This accommodated a flexible and reflexive structure suitable for research that took place in a complex social environment (Cornwall & Jewkes, 1995) and supported the individual needs of the autistic YP.

Overview of research aims

Autism is a lifelong neurodevelopmental condition and diagnostically defined by social communication and interaction difficulties and restrictive or repetitive behaviours, interests and activities which include sensory sensitivity (APA, 2013). In contrast to the medical model, this thesis is aligned with a definition of autism coined from the neurodiversity paradigm as an individualised collection of strengths and needs that are divergent across contexts and the lifespan (Fletcher-Watson & Happé, 2019). The neurodiversity paradigm prioritises a social model of disability, whereby autism is considered within the context of neurotypical environments (Fletcher-Watson & Happé, 2019) and proposes that difficulties may be experienced within social environments that are suboptimal for neurodivergent individuals (Pellicano & den Houting, 2022). Anxiety is a commonly cooccurring condition for autistic CYP (Happé & Frith, 2020; Lai et al., 2019) and literature suggests that anxiety is a significant risk factor and more pervasive than among neurotypical counterparts (Loffler & Dwyer, 2022). Extended school nonattendance is a possible consequence of anxiety and a problematic phenomenon for autistic pupils who experience high prevalence rates (Adams et al., 2022; Munkhaugen et al., 2019).

The central aim of this thesis was to respond to the call from the neurodiversity paradigm for qualitative and participatory research to understand autistic CYP's lived experiences (Fletcher-Watson et al., 2019) of anxiety and extended school nonattendance. Paper One was a thematic synthesis review and focused on the experience of anxiety for autistic CYP. This review aimed to answer the research question: 'How is the experience of anxiety described by autistic CYP and their parents?' Paper Two adopted a PI methodology and had the following research aim: 'How do autistic YP who have experienced extended school nonattendance describe effective support to meet their needs?' Finally, Paper Three synthesised the findings from Papers One and Two and aimed to present a strategy to disseminate and evaluate the impact of this research. The author's superordinate aims are for an improved understanding of the social model of autism and that research implications enable professionals, environments, policy and practice to effectively support the individual needs of autistic CYP who experience anxiety and barriers to accessing education.

Maintaining independence in the context of a research commissioning model

The University of Manchester allocates thesis topics via a research commissioning process. This thesis was commissioned by an EPS who are concerned about the challenges of re-engaging autistic pupils experiencing extended school nonattendance. The initial research proposal was broad, which allowed the author to maintain independence and take an original and innovative approach to Papers One and Two. The author gained support throughout the research process from their thesis supervisor. The supervisory relationship established a safe space for learning and enabled reflection upon the research process and opportunities for professional learning (Gibbs et al, 2016). Furthermore, the thesis supervisor complemented quality assurance processes such as inter-rater coding a number of the papers included in the SLR.

The author carried out a preliminary study to explore perspectives from the viewpoint of multi-agency professionals of: the profiles of autistic pupils who experience extended school nonattendance and effective support to encourage re-engagement with education. The findings supported an application of themes to a model, informed by the bioecological paradigm of human development (Bronfenbrenner & Morris, 2007). Furthermore, the study highlighted that parental support and their distinct needs are interlinked with their child's and this promoted future research with autistic CYP and parents. There are currently only three published studies to explore support for this cohort of pupils (Melin et al., 2022; O'Hagan et al., 2022; Preece & Howley, 2018). Previous research is dominated by researcher-led case-study methodologies and therefore participatory research from the perspective of autistic YP and their parents makes a novel contribution to the literature-base.

The overall research strategy

The neurodiversity paradigm prioritises qualitative methodologies, whereby research is situated in the autistic communities every-day realities and embraces individual and diverse perspectives (Guldberg, 2017; Pellicano & den Houting, 2022). Furthermore, the movement promotes participatory approaches which allow for meaningful engagement in research (Fletcher-Watson et al., 2019) and are consistent with positive outcomes identified by the autistic community (Guldberg, 2017). These premises underpinned the researcher's overall thesis strategy.

A pragmatic rationale influenced the decision to explore autism and anxiety for Paper One since there was a paucity of research into effective support for autistic CYP experiencing extended school nonattendance. The author's professional experience, and concerns from the commissioning EPS, suggested that supporting school nonattendance once it has become entrenched is very challenging. Therefore, it would be beneficial for EPs, and wider professionals working with autistic pupils, to develop an understanding of the experience of anxiety across contexts. A thematic synthesis review was appropriate since the approach values the specificity and complexity of the reviewed literature and generates original, analytic themes (Thomas & Harden, 2008). Paper Two explored idiographic accounts of effective support to meet the needs of autistic pupils experiencing extended school nonattendance through PI. The unique perspectives of autistic CYP were not prioritised in previous research and therefore Kas and Z's voices were placed centre stage. A reflective and flexible approach to research prioritised their preferences and involvement at each stage of the process. Theme development was an iterative process with the participants, whereby the author returned the identified themes to the YP across a number of sessions to ensure the author's meaning-making of their experiences was accurate. It is recognised that parental experiences and perspectives are inextricably linked with their children's when working towards supporting school attendance. Therefore, parental interviews provided additional data which was considered vis-à-vis YP's themes. Paper Three identified a mutually beneficial relationship between evidence-based practice in psychology (EBPP) and practice-based evidence (PBE) in research and discussed a strategy for the effective dissemination of research from Papers One and Two at the differing levels of research site and organisational and professional levels.

The researcher's professional background and relevant experience

The author has over 20-years of experience working within different roles to overcome barriers to inclusion in education and promote social justice. She initially trained in applied arts and taught in a young offenders' prison and facilitated and accredited many arts-based projects in diverse contexts. Her passion for supporting individuals experiencing barriers to participation encouraged her to apply her skills to a role within the inclusion centre of a mainstream secondary school. A key aspect of this role was the delivery of interventions to promote the inclusion of autistic pupils in a mainstream environment and to support individuals to overcome barriers to accessing education. These previous experiences have instilled genuine compassion and commitment to carry out research with autistic CYP and their families and the creative practitioner skills to authentically elicit their voices.

Rationale for engagement and positioning for data access

The commissioning EPS have had long-term involvement with the research site for Paper Two: a specialist setting for CYP with medical and mental health needs. Senior staff members were interested in developing their practice to support the needs of autistic pupils with extended school nonattendance. The author arranged several meetings with staff from the setting to ensure the aims of the project were fully understood and the setting perceived reciprocal benefit from engagement in the research. A key member of staff was also identified during this time to support with all stages of engagement. The process of identifying and gaining consent for YP who fit the inclusion criteria, and for whom engagement would be appropriate, was time-consuming. Kas and Z expressed an interest in contributing to the research and the author is indebted to their articulate and insightful contributions. Consent was gained for the involvement from a third YP, who initially met for a rapport-building, introductory session with the author, but ultimately did not contribute to the research due to exam commitments. The key member of staff's therapeutic skills were invaluable in creating a safe space for the YP to share their views and their capacity for involvement was facilitated by senior leader's commitment to the research. Consistent with the priorities of the neurodiversity paradigm, the young people represented by this research had diverse and individual experiences and perceptions.

Specific ethical issues

The author's empirical research was classed as high-risk and ethical approval was received from the University of Manchester's Ethical Research Committee. Participants were viewed as vulnerable YP and research took place within a highly specialist setting. The author implemented rigorous protocols to ensure that risk was minimised and benefit maximised. During the research development, the author consulted with an autistic adult who advocates for autistic CYP, which highlighted the importance of the research meeting the individual needs of the participants. The researcher gained informed opt-in consent ahead of involvement which was checked at each stage of the research process. The author collaborated closely with the setting to establish a distress protocol and ensured the research adhered to the setting's safeguarding policies. A key member of staff, with an established positive relationship with the YP, was present at all sessions and the potential impact of their attendance in sessions should be acknowledged. The author prioritised benefit to the participants being maximised, and the presence of a trusted adult facilitated trust and a positive rapport being established with the YP. It is possible that the YP would not have contributed so confidently and eloquently without the reflective and affirmative validations provided by this individual.

The PI methodology also contributed to the research being deemed high-risk and this approach was elaborated upon to the ethics committee. It was emphasised that the study took an emancipatory approach and had a strengths-based aim. The author has extensive creative arts experience and the approach to data gathering was flexible and guided by the

YP. No further ethical issues arose during the course of the research and evaluation suggested that the participants benefited from involvement in the study.

Evaluation of ontological, epistemological and axiological stance

An evaluation of the ontological, epistemological and axiological stance ensures consistency in the research strategy between how the author "view[s] our world(s), what we take understanding to be, what we see as the purposes of understanding and what is deemed valuable" (Cohen, et al, 2018, p. 3.). Ontology is concerned with the nature of being and reality which influences epistemological assumptions around inquiry into the nature of reality (Cohen et al., 2018). This research adopted a social constructionist epistemological position, which views knowledge inextricably linked with its socio-historical context (Gergen, 1985). Social constructionism emphasises the diverse meanings attributed to experiences by individuals (Weinberg, 2014) and presents knowledge as the product of social interaction (Gergen, 1985). The author agrees with the perspective that ontological claims are inconsistent with social constructionism, since reality is viewed as socially created, and only assumed an epistemological stance (Andrews, 2012). Research underpinned by the social model of autism is consistent with the author's epistemological approach since disability is also conceived to be socially constructed and experiences are contextually situated (Biklen, 2000).

Axiology refers to the author's values and beliefs (Cohen et al., 2018), influenced by previous personal, educational and professional experiences. It is integral for transparency that key decision-making processes are acknowledged. The author's background in the applied arts has resulted in a commitment to empowerment influenced by the pedagogy of Paulo Freire's (2017). PI, as a methodological approach for Paper Two, was consistent to the author's epistemological and axiological positions. PI has the potential to be transformative (Heron & Reason, 1997) and fundamental to participatory designs is the transference of power to participants (Brown, 2022; Cornwall & Jewkes, 1995). The author recognised that in real-world research participation is situated on a continuum (Brown, 2022) and influenced by the complex social environment of the research location (Cornwall

& Jewkes, 1995). The author valued the needs of the participants throughout the research process and flexibility is highlighted as a principle of good practice in participatory research with the autistic community (Pickard et al., 2022).

References

Adams, D., McLucas, R., Mitchelson, H., Simpson, K., & Dargue, N. (2022). Form, function and feedback on the school refusal assessment scale-revised in children on the autism spectrum. *Journal of Autism and Developmental Disorders*, *52*(5), 2156–2167. https://doi.org/10.1007/s10803-021-05107-4

APA. (2013). *Diagnostic and Statistical Manual of Mental Disorders.* (5th Ed.). American Psychiatric Association.

Andrews, T. (2012). What is social constructionism? *Grounded Theory Review 11*(1). https://groundedtheoryreview.com/2012/06/01/what-is-social-constructionism/

Biklen, D. (2000). Constructing inclusion: Lessons from critical, disability narratives. *International Journal of Inclusive Education, 4*(4), 337-353. https://doi.org/10.1080/13603110050168032

Bronfenbrenner, U. & Morris. P. (2007). The bioecological model of human development. In W. Damon & R. Lerner. (Eds.), *Handbook of Child Psychology.* (pp. 793-828). Wiley.

Brown, N. (2022). Scope and continuum of participatory research. *International Journal of Research and Method in Education*, 1–12. https://doi.org/10.1080/1743727X.2021.1902980

Cohen, L., Manion L., & Morrison, K. (2018) *Research Methods in Education.* (8th Ed.). Routledge.

Cornwall, A., & Jewkes, R. (1995). What is participatory research? *Social Science and Medicine*, *41*(12), 1667–1676. https://doi.org/10.1016/0277-9536(95)00127-S

Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J. R., & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism*, *23*(4), 943–953. https://doi.org/10.1177/1362361318786721

Fletcher-Watson, S., & Happé, F. (2019). *Autism: A new introduction to psychological theory and current debate*. Routledge.

Freire, P. (2017). *Pedagogy of the oppressed.* Penguin Modern Classics.

Gergen, K. J. (1985). The Social Constructionist Movement in Modern Psychology. *American Psychologist*, *40*(3), 266–275. https://doi.org/10.1037/0003-066X.40.3.266

Gibbs, S., Atkinson, C., Woods, K., Bond, C., Hill, V., Howe, J., & Morris, S. (2016). Supervision for school psychologist in training: Developing a framework from empirical findings. *School Psychology International, 37*(4), 410-431. https://doi.org./10.1177/0143034316653443

Guldberg, K. (2017). Evidence-based practice in autism educational research: can we bridge the research and practice gap? *Oxford Review of Education*, *43*(2), 149–161. https://doi.org/10.1080/03054985.2016.1248818

Happé, F., & Frith, U. (2020). Annual Research Review: Looking back to look forward – changes in the concept of autism and implications for future research. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, *61*(3), 218–232. https://doi.org/10.1111/jcpp.13176

Heron, J., & Reason, P. (1997). Inquiry Paradigm. *Qualitative Inquiry*, *3*(3), 274–294. https://doi.org/10.1177/107780049700300302

Knage, F. S. (2021). Beyond the school refusal/truancy binary: Engaging with the complexities of extended school non-attendance. *International Studies in Sociology of Education*, 1–25. https://doi.org/10.1080/09620214.2021.1966827

Lai, M. C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., Szatmari, P., & Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. *The Lancet Psychiatry*, *6*(10), 819–829. https://doi.org/10.1016/S2215-0366(19)30289-5

Leduc, K., Tougas, A. M., Robert, V., & Boulanger, C. (2022). School refusal in youth: A systematic review of ecological factors. *Child Psychiatry and Human Development*, 1–19. https://doi.org/10.1007/s10578-022-01469-7

Loffler, D., & Dwyer, E. (2022). Supporting anxiety and wellbeing. In J. Gaisborough. *Educational Psychology Perspectives on Supporting Young People: Insights from Experience, Practice and Research* (pp. 127-156). Jessica Kingsley Publishers.

Melin, J., Jansson-Fröjmark, M., & Olsson, N. C. (2022). Clinical practitioners' experiences of psychological treatment for autistic children and adolescents with school attendance problems: A qualitative study. *BMC Psychiatry*, *22*(1), 1–12. https://doi.org/10.1186/s12888-022-03861-y

Munkhaugen, E. K., Torske, T., Gjevik, E., Pripp, A. H., & Diseth, T. H. (2019). Individual characteristics of students with autism spectrum disorders and school refusal behavior.

Autism, *23*(2), 413–423. https://doi.org/10.1177/1362361317748619

O'Hagan, S., Bond, C., & Hebron, J. (2022). Autistic girls and emotionally based school avoidance: Supportive factors for successful re-engagement in mainstream high school. *International Journal of Inclusive Education*, 1–17. https://doi.org/10.1080/13603116.2022.2049378

Pellicano, E., & den Houting, J. (2022). Annual Research Review: Shifting from 'normal science' to neurodiversity in autism science. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, *63*(4), 381–396. https://doi.org/10.1111/jcpp.13534

Pickard, H., Pellicano, E., den Houting, J., & Crane, L. (2022). Participatory autism research: Early career and established researchers' views and experiences. *Autism*, *26*(1), 75–87. https://doi.org/10.1177/13623613211019594

Preece, D., & Howley, M. (2018). An approach to supporting young people with autism spectrum disorder and high anxiety to re- engage with formal education – the impact on young people and their families the impact on young people and their families. *International Journal of Adolescence and Youth*, *23*(4), 468–481. https://doi.org/10.1080/02673843.2018.1433695

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, *8*(45), 1–10. https://doi.org/10.1186/1471-2288-8-45

Weinberg, D. (2014). *Contemporary Social Constructionism.* Temple University Press.

Paper One: The experience of anxiety for autistic children and young people: A thematic synthesis review

Prepared for in accordance with author guidelines for submission to the journal, Research in Autism Spectrum Disorders (Appendix 1)

Abstract

Background: Anxiety is a commonly co-occurring mental health condition for autistic children and young people (CYP). Literature indicates a fractured conceptualisation of the construct of anxiety and measurement tools may be insensitive to unique autistic presentations. The neurodiversity paradigm calls for a shift towards qualitative research methodologies situated within everyday realities. The purpose of this review is to synthesise experiences of anxiety for autistic CYP from their perspective and the viewpoint of parents.

Method: Informed by PRISMA guidelines, this systematic review searched for empirical studies published within the last 10 years reporting on the experience of anxiety for school aged autistic CYP. 10 studies fulfilled inclusion and quality appraisal criteria. Data were analysed using thematic synthesis.

Findings: Findings suggest heterogenous experiences of anxiety which vary across contexts and are understood inconsistently between CYP and their parents. Parents report behavioural expressions of anxiety and CYP views enable a greater understanding of related cognitive processes and emotions. Autistic CYP appear to experience trait anxiety, which is interchangeable with autistic characteristics, however neurotypical environments potentially contribute to state anxiety. Autistic CYP report a potentially unique relationship with time which impacts upon or mediates experiences of anxiety.

Conclusions: Important implications for policy and practice includes the priority for authentically eliciting the views of cognitively-able and less-able autistic CYP with cooccurring anxiety across contexts in assessment and research. This review highlights the need for significant investment in social environments that seek to minimise anxiety in neurodiverse CYP.

Keywords: Autism, Neurodiversity, Anxiety, Experience, Children and Young People, Parents

Introduction

This thematic synthesis review examines the experience of anxiety for autistic children and young people (CYP). The introduction provides a brief review of existing literature: a neurodiverse model of autism is described and an overview of perspectives around anxiety as a common co-occurring condition for autistic CYP. The language attributed to autism is currently carefully considered and debated to ensure stigmatising or deficit-focused terminology is reduced (Fletcher-Watson & Happé, 2019). Kenny and colleagues (2016) conducted a survey to explore the preferences of the autistic community and the use of identity-first language was approved by the majority of the respondents and therefore autistic CYP is used by the author as opposed to a CYP with, or has, autism.

A traditional medical model conceptualises autism as an individual characteristic (Pellicano & den Houting, 2022): a neurodevelopmental disorder diagnostically defined by social communication and interaction difficulties and restrictive or repetitive behaviours, interests and activities, which include sensory sensitives (APA, 2013). Pellicano & den Houting (2022, p.386) present a tripartite critique of the medical model: "an overfocus on deficits, an overwhelming emphasis on the individual as opposed to their social context and a narrowness of focus." In contrast, neurodiversity is a social model of disability driven by the autistic community (Happé & Frith, 2020; Pellicano & den Houting, 2022) and considers neurodivergence within the context of a neurotypical world (Fletcher-Watson & Happé, 2019). This model emphasises that social environments may be suboptimal for neurodivergent individuals (Pellicano & den Houting, 2022) and difficulties in social interaction are a bi-directional phenomenon (Milton, 2012); whereby, autistic individuals experience difficulties gaining insight into the perspectives of neurotypical counterparts, who similarly lack insight into autistic people. A neurodivergent perspective presents autism as a constellation of strengths and needs, which differ across context and the lifespan (Fletcher-Watson & Happé, 2019) and individual difference is prioritised and celebrated.

Autistic CYP experience higher rates of co-occurring mental health difficulties than their neurotypical counterparts (Happé & Frith, 2020; Lai et al., 2019). 40% of autistic CYP are reported to suffer from an anxiety disorder (Beesdo et al., 2009). The correlation between autism and anxiety is presented as bi-directional and social exclusion or bullying may lead to heightened levels of anxiety (Happé & Frith, 2020). Anxiety is presented as more significant among high functioning CYP (Van Steensel & Heeman, 2017) due to greater social engagement and language skills, which are hypothesised to interact with self-awareness (Vasa & Mazurek, 2015). For many it is the co-occurring anxiety that causes more difficulties than a diagnosis of autism (Happé & Frith, 2020).

Autism literature considers anxiety in relation to the state-trait model of anxiety, whereby ‘state-anxiety’ is a temporary response to an immediate stressor and ‘trait-anxiety’ is a generalised personality characteristic (Spielberger, 1966). Joliffe et al., (2022) found 83% of studies in their review identified higher trait anxiety in autistic participants than the neurotypical cohort. Mertens et al., (2017) also identified greater levels of trait anxiety, but noted autistic adolescents experience less biophysiological responses to situations known to elicit state anxiety, suggesting heightened social anxiety leads to biophysiological responses becoming desensitised to triggers of state anxiety. Despite literature presenting a compelling case to consider anxiety as a significant risk factor and more pervasive for autistic CYP (Loffler & Dwyer, 2022), there is a fractured approach to discriminating between autism and anxiety (Kerns & Kendall, 2014) and symptomology understood as anxiety can be indistinguishable from autistic characteristics, for example sensory-seeking or avoidant behaviours (Lai et al., 2019). Dominant paradigms of anxiety relating to autistic CYP result in the majority of interventions adopting psychosocial approaches; existing evidence would suggest the efficacy of cognitive-behavioural approaches (White et al., 2018). However, these approaches to intervention focus on an individual’s deficit as opposed to a neurodiverse perspective that would prioritise a holistic and contextual approach.

Measurement of anxiety in autistic CYP is recognised as challenging (Jolliffe et al., 2022; Kim & Lecavalier, 2022) and potentially insensitive to distinct autistic presentations (Loffler & Dwyer, 2022) since the construct of anxiety is potentially differential between autistic and neurotypical populations (Van Steensel & Heeman, 2017). The validity of outcomes from standardised measurements of anxiety developed for a neurotypical population are questionable since the psychometric properties for an autistic cohort are unknown (Jolliffe et al., 2022). Although an anxiety scale has been developed specifically for autistic CYP (Rodgers et al., 2016), the qualitative phase was only carried out with a parental group. A wider critique of self-report measures suggests constructs are mainly adult-determined and although these may provide insight into experiences of anxiety, they may not represent experiences prioritised by CYP themselves (Greco et al., 2016).

Critiques of standardised measures reflect concerns within the autistic community: the misalignment between their priorities and the positivist stance of traditional experimental designs (Guldberg, 2017). There is an emerging call for meaning derived from autism research to be situated within everyday realities (Crane & Pellicano, 2022; Guldberg, 2017) and a shift towards qualitative methodologies that explore broad, subjective and diverse perspectives (Crane & Pellicano, 2022; Guldberg, 2017; Pellicano & den Houting, 2022), whereby experiences of anxiety may vary across contexts (Adams, et al., 2019a). A thematic synthesis approach to elucidate autistic CYP's experiences of anxiety from the perspective of both children and young people and their parents will draw together a more in-depth understanding from differing perspectives, in comparison to positivist approaches or individual studies.

This review aims to answer the question: How is the experience of anxiety described by autistic children and young people and their parents? The thematic synthesis will help identify gaps in the literature and has pertinent implications for a range of stakeholders including autistic CYP and their families, national and local policy makers and professionals who work with autistic CYP in a range of contexts across school, home and the community.

Method

Search strategy and study selection

This review employed the systematic search strategy outlined by the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) (Page et al., 2021). Figure 1. provides an overview. Between August 2021 and February 2022, a systematic search was undertaken of PsychInfo, Education Resources Information Centre (ERIC) and Web of Science and the first ten pages of Google Scholar. Key search terms were generated through pilot searches and consultation with librarians with academic database expertise. Key search terms included: anxiety OR anxious AND autis* OR ASD OR ASC AND perception* OR perspective* AND child* OR adolescent* OR young person OR teenager OR adolescent*. The search terms were applied in a variety of combined arrangements; a consistent approach was taken between databases. Initial database searches were intentionally broad: they did not include a date range or specify a particular type of publication to provide an overview of literature. This was refined when the inclusion criteria were defined.

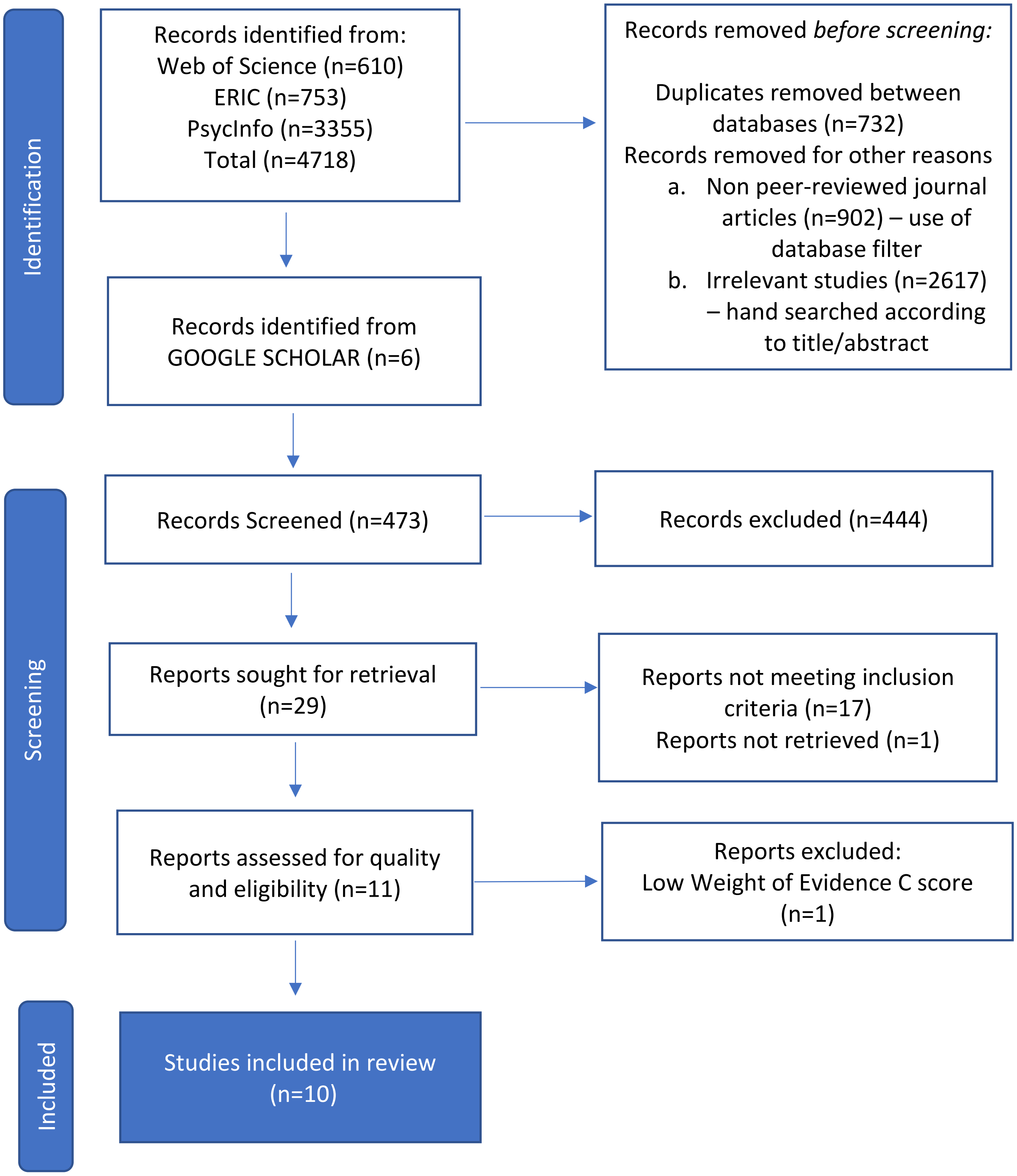


Figure 1. PRISMA systematic search strategy

Inclusion criteria

The initial search produced 4,718 records of which 4,245 were excluded as duplicates, not peer-reviewed empirical research or irrelevant studies. The screening stage initially excluded 444 records due to a range of exclusion criterion: neuroscientific or medication focus; intervention or correlational studies; participants with additional diagnoses; or studies about measurements of anxiety. 29 reports were sought for retrieval and their suitability was judged against the inclusion criteria (Appendix 2). Due to the paucity of research into autistic children and young people's experience of anxiety, the development of appropriate inclusion criteria was an iterative process through discussion between the author and their thesis supervisor. Parental perspectives were included since their assessment of CYP's anxiety is fundamental to any diagnostic process. It was essential that parental data was presented discretely in order to explore similarities and differences in viewpoints during the data analysis process. The agreed inclusion criteria were:

1. Published in the last 10 years.
2. Empirical study about the lived experience, symptomology or presentation of anxiety in school-age autistic CYP.
3. Parent and/or CYP perspectives.
4. Published in English language.
5. Aim of study consistent to this research question.

Quality appraisal

Eleven papers that met full inclusion criteria were assessed for methodological quality. Gough's (2007) Weight of Evidence (WoE) A assessed overall research quality and WoE C the appropriateness of evidence in relation to the research question. Woods (2020a, b) critical appraisal frameworks were used to evaluate qualitative and quantitative research and contained a maximum of 20 marks (Appendix 3). All appraised studies were assessed as high (scored 14-20) or medium (scored 7-13.75) quality research. To confirm inter-rater reliability, the thesis supervisor also coded 25% of the papers (Appendix 4). This ensured validity, scores achieved over 90% percentage agreement; and reliability, confirmation of the checklist being used in a meaningful way for this particular set of studies. The parameters for a judgement of WoE C were: a maximum of 1 point was awarded for the focus of the study being on autism and anxiety and a maximum of 1 point was awarded for the data representing contextual and experiential perspectives. Studies that reported exclusively experiential data around autism and anxiety achieved High (2 points), ones that met one parameter entirely and partly met the other achieved Medium (1.5 points) and studies that met both parameters partly or did not meet one parameter achieved Low WoE C (1 point and below). A quantitative paper (den Houting et al., 2018) received a Low WoE C score and was excluded from the review.

Data extraction and synthesis

This review adopted the three-stage thematic synthesis approach to data analysis (Thomas & Harden, 2008). This is consistent with another recent review which explored the experiences of underrepresented participants (Leedham et al., 2020). Initially, the first author carried out line-by-line inductive coding of the findings from each study: participant primary data and secondary researcher analysis. The codes from across the studies were grouped into initial themes which were subsequently synthesised to produce descriptive themes. The supervisory process supported the decision to include inferred experiences of anxiety. QSR International's NVIVO 12 facilitated the management and analysis of data for stages one and two of the process (Bazeley & Jackson, 2013). Stage three was an iterative review process of descriptive themes to generate an agreed set of superordinate analytic themes (Appendix 5). To prioritise the voices of the autistic community and provide reliability between data from individual studies and analytic themes generated, direct quotes and statistics are included.

Findings

Overview of included studies

Table 1 presents the characteristics of the ten studies included in this review. They were published between 2012 and 2022 and originated from: Australia (n = 5), UK (n = 3), USA (n = 1) and UK, USA & Singapore (n = 1). The participants were either, autistic CYP (n = 4), parents (n = 4), or both perspectives (n =2). They reported on a total of 679 CYP (male n = 551; and female n = 128) aged between 3 and 18. The studies were a combination of qualitative (n = 6) and mixed methods (n = 4) studies. Two studies selected for review had the primary focus of autistic girls' experience of school and learning (Jacobs et al., 2021; Tomlinson et al., 2022), since experience of anxiety was reported as a central theme. The number of male views represented was significantly larger than female across the other studies and including autistic girls' perspectives went some way to redress this balance. The analytic themes developed were: understanding the importance of context in autistic CYP's experience of anxiety, differential impact of an autism diagnosis upon sense of self and relationships with others, interaction between anxiety and CYP's autistic characteristics and therefore the extent to which anxiety is a state or trait construct for autistic CYP, centrality of behavioural expressions of anxiety in autistic CYP and distinct contribution of time.

Reference	**Country**	**Research Focus**	**No. of Parent Participants**	**No. of CYP Participants**	**Sex and age of CYP**	**Design**	**Analytic approach**	**Findings**	**WoE A**	**WoE C**
Acker et al (2018)	UK	Lived experience of anxiety at home and school	N/A	14	Male; 13-18	Qualitative; Semi-structured interviews	IPA	Participant's descriptions of anxiety were: congruent with neurotypical adolescents, such as a desire for social connectedness; they linked characteristics associated with a diagnosis to anxiety, for example sensory needs; the use of fantasy and role-play was identified as a possible autistic specific management of anxiety strategy.	H	H
Adams et al (2019b)	Australia	Parent views of anxiety: signs; management strategies and differences across contexts for their autistic children	173	N/A	139 males; 34 females; 6-13	Mixed methods; Questionnaire – open and closed questions and standardised measures	Quantitative data: IBM SPSS Descriptive statistics; group comparisons Qualitative data: Content analysis	Over half participants felt their child was anxious at home; increasing to over 70% at school and in the community. Parents reported presentations of anxiety differed between settings and most descriptions related to behavioural and observable signs.	M	M
Adams et al (2020)	Australia	Autistic YP's descriptions of their anxiety across settings	N/A	113	94 males; 19 females; 6-14	Mixed methods; Questionnaire - open and closed	Quantitative data: IBM SPSS – Descriptive	Challenge of identifying anxiety symptomatology and the importance of understanding anxiety across multiple settings. Children do not consistently	M	M

						questions and standardised measures	statistics; Within-subject ANOVA Qualitative data: Content analysis	believe others recognise signs of anxiety and support is not always available.		
Bearss et al (2016)	USA	Qualitative phase to develop candidate items for a parent-rated instrument of anxiety symptoms in autistic young people.	48	N/A	32 males; 13 females; 3-17	Qualitative; Semi-structured focus group	Open and axial coding	Situations and events that trigger anxiety; behavioural indicators of anxiety and management of anxiety. 52 candidate items for the instrument.	H	M
Jacobs et al (2021)	Australia	Secondary school experiences which helped or hindered learning and academic success.	N/A	5	Female; 12-14	Mixed-method design; Survey and semi-structured interviews	IPA	Enablers like the role teachers play in creating positive school experiences; negative impact of sensory, communication and social difficulties; influence of anxiety and executive functioning challenges.	M	M
Lau et al (2020)	UK, USA & Singapore	Caregiver-report of presentations of anxiety in autistic CYP	287	N/A	250 males; 37 females; Male;	Mixed methods; Standardised questionnai	Thematic analysis	In response to the open-ended question about YP fears more autism-related additional anxieties were reported for YP	M	M

		and relationship with individual characteristics .			6-18	re with a final open-ended question		whose autistic presentation was more severe.		
Ozsivadjian et al (2012)	UK	Understanding of anxiety triggers, presentation and cognitive processes in autistic CYP.	17	4	12 males; 7 females; 7-18	Qualitative; Focus groups	Thematic analysis	Parents reported similar triggers and presentation of anxiety; often expressed through behavioural changes; children found it difficult to express themselves verbally; impact of anxiety often more significant than impact of ASD.	H	H
Simpson et al (2020)	Australia	Parental perspectives of their child's anxiety across home and school.	10	N/A	5 males; 5 females; 5-8	Qualitative; Semi-structured interviews	Thematic analysis	Signs of anxiety were evident from a young age; recognising signs of anxiety and differentiating between other behaviours was difficult. Triggers related to sensory experiences, academic and social expectations and uncertainty.	H	H
Simpson et al (2021)	Australia	Autistic children's views about their	N/A	10	5 males; 5 females; 5-8	Qualitative; Computer Aided Interview	Directed content analysis	Descriptions of a range of situations that trigger anxiety and responses to anxiety. Children believed these	M	H

		experiences of anxiety.						responses may be not be interpreted as anxiety by other people.		
Tomlinson et al. (2021)	UK	Experience of attending a mainstream secondary school recognised for its good autism practice.	3	3	Female; 14-16	Qualitative; Multiple-case design, semi-structured interviews	Thematic analysis	Experiences are unique for each individual; there are common challenges including sensory issues resulting in anxiety and inconsistent understanding of individual need across staff members.	H	M

Table 1. Characteristics of included studies

General overview of the experience of anxiety for autistic CYP

This review aimed to explore the experience of anxiety[1] for autistic CYP across studies from their own perspective and their parents'. A longitudinal study in Australia highlights how pervasive anxiety is, since only 4 (3.5%) reported to not experience anxiety in any setting (Adams et al., 2020). Parents also highlighted that the negative impact of living with anxiety can be greater than the impact of autism. "I think she feels like every day is a mountain to climb [because of the anxiety] and it's overwhelming" (Parent; Ozsivadjian et al., 2012, p. 115).

Understanding the importance of context in autistic CYP's experience of anxiety

Mixed methods studies explored anxiety across contexts; home, community and school (Adams et al., 2019b; 2020). Autistic CYP and parents reported that it was most common for anxiety to be experienced in all three settings; 40.7% of CYP (Adams et al., 2020) and 42.6% of parents (Adams et al., 2019b). The increase in settings where anxiety was experienced also correlated with a higher reported score on the Anxiety Scale for Children with Autism Spectrum Disorder Parent and Child versions (ASC-ASD) (Adams et al., 2019b; 2020). CYP who reported anxiety in all three settings had an ASC-ASD score almost 150% higher than those reporting anxiety in one setting (Adams et al., 2019b).

Home

75.2% of children reported feeling anxious in the home environment with 77.6% stating that others at home knew of their anxiety and 85.9% believed there was someone who they could talk to and receive support from to reduce anxiety (Adams et al., 2020). In

---

[1] Adams and colleagues' (2020) study included an open-ended question which asked CYP to list words they would use to describe their experience of anxiety. "Scared" and "worried" were more frequent responses than "anxiety" (Adams et al., 2020, p. 607). This would suggest that it was appropriate to analyse findings from studies that referred to fears, worries or other synonyms in addition to perspectives directly citing anxiety.

comparison, only 52.6% of parents believed their child was anxious at home (Adams et al., 2019b).

School

The percentage of CYP and parents reporting CYP anxiety in the school context was similar between groups: 83.2% of CYP (Adams et al., 2020) and 77.6% of parents (Adams et al., 2019b). 50% of CYP believed that someone knew about their anxiety at school, however 76% had someone they could talk to in this context (Adams et al., 2020).

Qualitative data also presents school as a challenging context (Acker et al., 2018; Bearss et al., 2016; Jacobs et al., 2021; Simpson et al., 2020, 2021; Tomlinson et al., 2021). Three parents in a qualitative study described how signs of anxiety became more visible when their child started school and described it as “a challenging year”, when things “fell apart” and an “absolute nightmare” (Parents; Simpson et al., 2020, p. 575). CYP placed demands on themselves in relation to school achievement (Ozsivadjian et al., 2012; Simpson et al., 2020; Tomlinson et al., 2021) and parents connected anxiety at school with perfectionism (Simpson et al., 2020). Exam anxiety was discussed across CYP studies with stress emanating from an internal perspective (Acker et al., 2018) and external pressures (Tomlinson et al., 2021). The experience of anxiety also related to CYP not wanting to attend school due to the negative perception children have of themselves as a learner, “I don’t want to go to school, I only ever get Fs, I’m not good at school” (Parent; Simpson et al., 2020, p. 577), and demands from others who, “tell you do this, do this” (CYP; Simpson et al., 2021, p. 7). Overall, qualitative accounts suggest that anxiety is experienced in the context of school in relation to internal cognitive processes and external pressures.

Community

58.4% of CYP reported feeling anxious in the community (Adams et al., 2020), in comparison to 76.2% of parents reporting CYP anxiety in this context (Adams et al., 2019b). 40.6% of CYP believed that someone knew about their anxiety in the community and 45.3% believed there was someone available to talk to for support (Adams et al., 2020).

Differential impact of an autism diagnosis upon sense of self and relationships with others

The relationship individual autistic CYP had with their diagnosis was heterogeneous and related to their experience of anxiety. Two parents in the Tomlinson et al., (2021) study reported a reduction in masking behaviours post-diagnosis resulting in improved wellbeing. Some CYP in the study were in agreement with parental perception and believed that diagnosis had improved their own understanding of need and reduced anxiety (Tomlinson et al., 2021). Positive interactions with neurodiverse staff and peers was also perceived by CYP to be a mediating effect upon anxiety (Acker et al., 2018; Tomlinson et al., 2021). As one young man explained, “they’re all autistic, …. they all have their special way of fitting into reality, just like me” (CYP; Acker et al., 2018, p. 12).

It was not unequivocally agreed that an autism diagnosis brought self-awareness and reduction in anxiety.

> “I think it’s just my anxiety…. I don’t want to be seen as different […] even though I’ve got autism I find it hard to accept it…and I don’t really like to tell people” (CYP; Tomlinson et al., 2021, p. 8).

Anxiety related to perceived social evaluation was highlighted across a number of studies (Bearss et al., 2016; Jacobs et al., 2021; Lau et al., 2020) and impacted upon CYP’s acceptance of differentiated support (Bearss et al., 2016; Jacobs et al., 2021; Tomlinson et al., 2021). “My son is terrified of standing out, and he won’t use a computer at school or anything that makes him look different” (Parent; Bearss et al., 2016, p. 669). The concept of social evaluation relates to the broader issue of anxiety experienced in relation to being the centre of attention (Ozsivadjian et al., 2012; Simpson et al., 2021), as described by one young person, “my cheeks get red and my brain gets scared, I shake a lot” (CYP; Simpson et al., 2021, p. 7).

The interaction between anxiety and CYP's autistic characteristics and therefore the extent to which anxiety is a state or trait construct for autistic CYP

A pertinent concept to be discussed across parental studies related to the interaction between anxiety and autistic characteristics (Adams et al., 2019b; Bearss et al., 2016; Lau et al., 2020; Simpson et al., 2020). Parents reported a profile of both common and autistic-related anxiety in CYP and an interaction between autism and anxiety whereby parents of CYP with more severe autistic symptoms were likely to report at least one autistic-related anxiety (Lau et al., 2020). Bearss and colleagues (2016, p. 670) reported considerable deliberation by parents on whether "anxiety is a co-existing problem in children with ASD, a complication of ASD or in some way convergent with ASD."

Social Anxiety

The extent to which social anxiety was an autistic trait or related to a particular situation was explored across studies. Parental studies perceived social anxiety as "inherent" in autistic CYP (Ozsivadjian et al., 2012, p. 115) or as "an example of a complication of ASD" (Bearss et al., 2016, p. 670). Lau and colleagues (2020) provided a nuanced distinction between social anxiety which is also experienced by neurotypical CYP, which is related to common childhood fears, including anxiety around performance and achievement, and social anxiety which is conceptualised as autistic specific when concerned with social language and communication demands.

CYP and parental groups discussed challenges with peer relationships as central to autistic CYP's experience of anxiety (Acker et al., 2018; Bearss et al., 2016; Jacobs et al., 2021; Lau et al., 2020; Ozsivadjian et al., 2012; Simpson et al., 2020; Tomlinson et al., 2021). Parental groups presented the idea that CYP's awareness of their social difficulties may have been a contributing factor (Bearss et al., 2016; Ozsivadjian et al., 2012):

> "She's in the playground, and completely on her own. I think nowadays she notices and there's a growing amount of anxiety over that" (Parent; Ozsivadjian et al., 2012, p. 112).

Similarly, triggers for anxiety were linked to either an internal or external locus of control around situations. An internal locus of control was described by one CYP's explicit reference to "Overthinking! Very annoying! Makes it hard. I try to calm anxiety by taking a break… I'm not the best at socialising" (CYP; Jacobs et al., 2021, p. 205). In contrast, peers' responses were a cause of anxiety for another, "How are they gonna react to me? Are they gonna be nice to me or are they just gonna reject me?" (CYP; Acker et al., 2018, p. 13).

Bi-directional misunderstanding of social language, behaviour and interaction was also presented as a contributing factor to anxiety and discussed by parents to impact upon relationships with peers (Adams et al., 2019b) and teachers (Simpson et al., 2020). CYP demonstrated self-awareness of their misinterpretation of language and how this impacted upon anxiety and can result in negative secondary emotions:

> "I usually don't like it when I'm like anxious if other people start talking […] 'cause I take it emotionally often misinterpret what they're saying […] if they use an imperative sentence like say 'stop it' […that] accelerates the anxiety process 'cause I'm being told what to do, and I'm in a stressful situation and that can often lead to an angry outburst" (CYP; Acker et al., 2018, p. 13).

In the school context, anxiety is also experienced by autistic CYP as a consequence of frustration experienced when they are not understood by staff; in relation to misunderstanding of language (Jacobs et al., 2021, p. 206) or individual need (Jacobs et al., 2021; Tomlinson et al., 2021). This is exemplified through a supply teacher being cited to ask, "why is that girl there rocking? What's she doing?" (CYP; Tomlinson et al., 2021, p. 9).

Adolescent boys and girls reported that emotional attachments felt towards peers also interacted with anxiety (Acker et al., 2018; Jacobs et al., 2021). Girls presented emotional attachments as:

> "Linked with the pervasiveness of anxiety […] 'I get really close to people. It could be something like hyper-empathy… I feel a lot of empathy and get emotionally attached to things quickly, so then it really hurts me" (Jacobs et al., 2021, p. 206).

Similarly, boys reported a transference of negative emotions (Acker et al., 2018).

A novel finding was that for adolescent boys engaging with fantasy worlds and role play facilitated the development of social and anxiety management skills (Acker et al., 2018). "It helped me actually with, social interactions, like thinking about my word use and what effect certain words have" (CYP; Acker et al., 2018, pp. 15–16).

Sensory-related Anxiety

Sensory anxiety was a further category identified as autistic-specific (Lau et al., 2020): a characteristic which is inextricably linked with wider autistic experiences and potentially exemplified the involvement of trait anxiety for autistic CYP. The impact of sensory overload resulted in adolescent girls "feeling 'overwhelmed and teary' […] 'very nervous (with) a headache […] and 'stressed and uncomfortable'" (CYP; Jacobs et al., 2021, p. 205).

Sensory sensitivity was most related to loud auditory stimuli (Lau et al., 2020), which was supported by CYP and parent participants. Studies highlighted how auditory sensitivity was a barrier to engagement in various aspects school: PE lessons, the playground (Simpson et al., 2020) and lessons with supply teachers (Tomlinson et al., 2021). In addition to auditory sensitivity, autistic CYP's experiences of anxiety was also related to smells, sounds, touch, overcrowding and visual input (Acker et al., 2018; Jacobs et al., 2021; Lau et al., 2020; Ozsivadjian et al., 2012; Tomlinson et al., 2021).

Acker and colleagues (2018) reported a cyclical interaction between anxiety and sensory stimulation which heightened the anxiety produced:

> "Like for example if a baby really upsets me via crying I will go outside and I will start noticing that my clothes are annoying me…. it just all triggers everything" (CYP; Acker et al., 2018, p. 15).

The differential experiences of sensory-related anxiety highlighted heterogeneity, with sensory needs and preferences potentially acting as a trigger or a resultant of anxiety for autistic CYP.

Predictability versus unpredictability

The experience of anxiety in relation to change is a further reported distinct autistic-related anxiety across a number of parental studies (Bearss et al., 2016; Lau et al., 2020; Ozsivadjian et al., 2012). It was reported that anxiety may be experienced due to “surprises in films, new things at home, the unexpected, changes to routines/plan” (Parent; Lau et al., 2020, p. 1117). . Parents reported anticipating change and unexpected events as anxiety provoking (Ozsivadjian et al., 2012; Simpson et al., 2020, p. 578).

CYP accounts also confirmed the centrality of change in routine to lived experiences of anxiety (Acker et al., 2018; Adams, et al., 2020; Tomlinson et al., 2021). When asked what provokes their anxiety, 70% of CYP agreed with “when there is a change in routine” (CYP; Simpson et al., 2021, p. 8). CYP accounts also provided a degree of insight into their cognitions, with one young person describing how change in routine made them feel “really mad… Why did you lie to me?” (CYP; Simpson et al., 2021, p. 8).

Across the contexts of home, school and the community, a consistent approach for anxiety management were strategies that reduced the impact of change or unpredictability (Adams et al., 2020). The preference for and mediating effect of routine and predictability, also interacts with reported uncertainty around social interactions (Jacobs et al., 2021; Simpson et al., 2020, 2021; Tomlinson et al., 2021). The statement “when you don’t know what people think of you” was agreed by 70% of children as a trigger for anxiety (CYP; Simpson et al., 2021, p. 8). A parent explained:

> “I think he finds people very challenging, particularly new people because they are unpredictable... I think he finds children his own age quite unpredictable” (Parental; Simpson et al., 2020, p. 578).

CYP also identified unpredictability as a trigger:

> “I don’t know if I am going to have a panic attack or if someone might tease me. I don’t know what is going to happen that day” (CYP; Jacobs et al., 2021, p. 204).

A qualitative study reported a powerful description of one parent’s hypothesis around why autistic CYP are aversive to change:

> “There’s a visual [memory] bank already there…you don’t have to update it all the time [if things stay the same]. ‘I’ve seen this before, I’ve scanned it’, I’m not there thinking ‘oh my God, I have to log all of this, I can’t do this because it makes my head hurt. And also when I’m logging it, I’ve got to look out for lions and tigers because they might kill me.’ Their heads are full of junk and thy cannot process it…I think a lot of it is the basic desire to survive" (Parent; Ozsivadjian et al., 2012, p. 112).

This presented autistic CYP in a perpetually heightened state of arousal, compounded by difficulties knowing what stimuli to attend to when things change.

Bearss and colleagues (2016) propose a model of convergence between autism and anxiety which was supported by a parent in another study:

> “I don’t think we can separate insistence on the same and anxiety […] when things change, that provokes anxiety for her. So I think that they’re highly related. So I think that when she’s already anxious for other reasons, she’s even less flexible” (Parent; Simpson et al., 2020, p. 576)

This proposal and the findings in relation to other common autistic CYP’s experiences, social anxiety and sensory-related anxiety, appears to support the potential for autism and anxiety to co-exist and interact bi-directionally. This would suggest that findings from the literature reviewed provide some evidence that trait anxiety is interchangeable with core autistic characteristics, however state anxiety is also experienced as a consequence of environmental and contextual demands.

The centrality of behavioural expressions of anxiety in autistic CYP

The centrality of behavioural expressions of anxiety is a further dominant experience reported across studies. These behavioural manifestations are divergent between individual autistic CYP and across contexts.

A key difference between autistic and neurotypical CYP, identified by parents, is the primacy of behavioural over verbal expressions of anxiety (Adams, et al., 2020; Ozsivadjian et al., 2012). Furthermore, parents reported heightened anxiety to exacerbate autism characteristics, such as obsessional, repetitive and sensory behaviours (Ozsivadjian et al., 2012). Parents highlighted that it could be challenging to differentiate between typical autistic behaviours, behaviours that are related to anxiety and other challenging behaviours unrelated to either autism or anxiety (Simpson et al., 2020) and emphasised that distinguishing between these behaviours often relied on knowledge of their child.

Parental studies reported the dominance of observable signs of anxiety, behaviours which included: somatic symptoms, avoidance and challenging behaviours alternatively observed as verbal or physical aggression, or self-injurious (Acker et al., 2018; Adams, et al., 2019b; Bearss et al., 2016; Ozsivadjian et al., 2012; Simpson et al., 2020, 2021; Tomlinson et al., 2021). Behaviours were described to vary across settings: hiding or withdrawal were most common at school and clingy behaviour in the community (Adams etal., 2019b).

Parental reports discussed the potential for behaviours related to anxiety to be misinterpreted by others (Ozsivadjian et al., 2012; Simpson et al., 2020). This was particularly pertinent in the school context whereby behaviours might be misconstrued as “naughty” (Ozsivadjian et al., 2012, p. 112) or “shy” (Simpson et al., 2020, p. 579). CYP described techniques to deflect attention from their anxiety (Simpson et al., 2021).

> “I’d pick up my book and then throw it across the room and then I’m like, ‘Okay, who did that?’ And I would point to someone else” (CYP; Simpson et al., 2021, p. 7)

While others hid their anxiety:

> “I ask… can I please go to toilet, and she says ‘okay’ and I have a meltdown in the toilet” (CYP; Simpson et al., 2021, p. 7).

A parental perspective highlighted the potential for masking and described their child as “one of those champagne kids that come home and just let it all out” (Parent; Simpson et al., 2020, p. 577). In the CYP study centred around a contextual understanding of anxiety, a small number of children (10%) reported masking or camouflaging of anxiety in both home and community settings (Adams et al., 2020), which suggests that these behaviours occur in all contexts despite qualitative descriptions pertaining to school.

CYP challenge the dominance of behavioural explanations of anxiety and report both cognitive and emotional processes. For example, one CYP provided insight that “…when I’m anxious I get, very emotional very riled up, I can't control myself and sometimes it does come to violent ends" (CYP; Acker et al., 2018, p. 15). Furthermore, CYP referred to their mind going blank or experiencing difficulties with their brain working (Acker et al., 2018; Ozsivadjian et al., 2012; Simpson et al., 2021), whereas another likened the shift in their mind from calm to being in " a messy office" (CYP; Acker et al., 2018, p. 14). CYP also reported a range of secondary emotions experienced in conjunction with anxiety, which included: "humiliated or embarrassed […or…] exposed […or…] rage" (CYP; Acker et al., 2018, pp. 13–14), "weird […or…], nervous" (CYP; Simpson et al., 2021, p. 6) and "sadness" (CYP; Jacobs et al., 2021, p. 206). The additional understanding provided by CYP studies elucidates the cognitive processes and emotional responses that can only be authentically shared through reflection of lived experience.

Distinct contribution of perception of time

A further key difference highlighted across studies pertaining to autistic CYP's experience of anxiety in comparison to neurotypical CYP is a time delay between an event and expression of anxiety (Bearss et al., 2016; Ozsivadjian et al., 2012; Simpson et al., 2020). As one parent describes, there is habitually:

> "A 2-3 week delay between something happening and me being able to tell and by the end it's so embedded you've got to disentangle the whole thing before you get to the point" (Parent; Ozsivadjian et al., 2012, p. 114).

Time was a pertinent theme across CYP viewpoints and anxiety was experienced as an acceleration of cognitive processes (Acker et al., 2018; Ozsivadjian et al., 2012) with "thoughts racing out of control" (CYP; Ozsivadjian et al., 2012, p. 115). In the school context, concentrating across the school day was problematic and imposed time-frames for task completion were a trigger for anxiety (Acker et al., 2018; Jacobs et al., 2021; Simpson et al., 2021; Tomlinson et al., 2021). In contrast, a consistent mediating influence across studies was support that regulated the experience of time: to enhance organisational skills (Acker et al., 2018), support time-management (Jacobs et al., 2021) or take life at a self-directed pace

(Acker et al., 2018; Tomlinson et al., 2021). These perspectives suggest some autistic CYP may have a qualitatively different experience of time vis-à-vis their neurotypical peers.

Discussion and Implications

This current study aimed to thematically synthesise literature exploring the experience of anxiety for autistic CYP. These high quality studies supported understanding of CYP, and their parents', diverse perspectives of everyday realities (Crane & Pellicano, 2022; Guldberg, 2017), which supports recent priorities within autism literature to move beyond positivist and experimental research designs (Guldberg, 2017). This review offered important new insights and implications for policy, practice and research.

How is the experience of anxiety described by autistic children and young people and their parents?

The findings from this thematic synthesis highlighted key areas across the studies reviewed: the importance of context, the differential impact of an autism diagnosis upon sense of self and relationships with others, the interaction between anxiety and CYP's autistic characteristics, the centrality of behavioural expressions and the distinct contribution of autistic CYP's perception of time.

The impact of anxiety upon autistic CYP may be more significant than results from clinical samples reporting diagnostic co-occurring conditions would suggest (Lai et al., 2019; Van Steensel & Heeman, 2017; Vasa et al., 2020). In comparison to the frequently cited 40% of autistic school-aged children (Beesdo, et al., 2009), findings from this review suggest that up to 96.5% self-identify with experiences of anxiety (Adams, et al., 2020). Findings also potentially confirm that the impact of anxiety is persistent and has more impact upon quality of life than the diagnosis of autism (Happé & Frith, 2020).

A distinct finding from the review is that the experience of anxiety for autistic CYP varied across contexts. It has been proposed that neurotypical social environments may be intimidating for autistic CYP (Pellicano & den Houting, 2022) and there is an emerging interest pertaining to anxiety at school (Adams et al., 2019). A recent review of literature around the school experiences for autistic girls developed a thematic map with wellbeing at the centre (Tomlinson et al., 2019). Anxiety-based school avoidance is also a burgeoning area of interest, reported to disproportionately affect autistic CYP in comparison to their neurotypical peers (Munkhaugen et al., 2017). Although there is wider literature around community participation (Khalifa et al., 2020), the reviewed studies highlight a paucity of research into the experience of anxiety in home and community contexts.

In relation to factors measured across contexts there was a distinct lack of agreement between parental-child ratings which is consistent with a review of self-report studies which reported a poor to fair coefficients between parent-child scores (Kim & Lecavalier, 2022). Different findings were also of particular note among qualitative data. Parental studies focussed on externalised behavioural signs of anxiety, which were described to vary across contexts. Vasa and colleagues (2020) also highlight that from early development, externalising behaviours appear to be related to anxiety in autistic CYP. In contrast, CYP provided descriptions of cognitive processes, which were hitherto undisclosed through parental accounts and less thoroughly explored through wider literature or captured via standardised measures of anxiety.

Parental and CYP studies highlighted multi-faceted relationships with a diagnosis of autism. A reported positive outcome was the reduction of ‘masking’ or ‘camouflaging’ behaviours, which has a positive impact upon mental health (Carpenter et al., 2019). Similarly, some autistic CYP found relationships with other neurodiverse individuals supportive. The decision to reveal an autistic identity is differentially responded to across studies and the challenge of disclosure is explored across recent literature (Botha et al., 2022; Thompson-Hodgetts et al., 2020). Alternatively reported as embraced, in relation to social acceptance and insights into disability, or concealed, due to negative outcomes and stigma (Thompson-Hodgetts et al., 2020). An autistic-identity is defined by autistic adults as ‘value-neutral’ but tension exists between the perception they have of themselves and stigma from society which marginalises and pathologises difference (Botha et al., 2022). A study with autistic young people reported that overall higher autistic-identify satisfaction was associated with higher psychological wellbeing and lower social anxiety (Cooper et al., 2022), which would suggest that that self-acceptance of diagnosis would reduce the experience of anxiety.

The reviewed studies highlighted the challenges around whether atypical anxiety symptoms presented by autistic CYP should be conceptualised as “aspects of ASD, as comorbid anxiety, or as a novel behavioural dimension common to both disorders” (Kerns & Kendall, 2014, p.85). Findings highlight core autistic characteristics interact with autistic CYP’s experiences of anxiety and this may suggest that trait anxiety is prevalent among this cohort (Jolliffe et al., 2022). Evidence from the review appears to also support an alternative perspective, complementary to the neurodiversity paradigm, that many core autism features may be secondary to the condition itself and resultant from living within neurotypical environments (Loffler & Dwyer, 2022).

Social anxiety was described in a high number of the studies reviewed. A bi-directional misunderstanding of relationships, social language, behaviour and interaction was presented as central to autistic CYP’s experience of anxiety. This concurs with Spain et al., (2018) who also identified that these factors may be causal and/or maintain social anxiety. The ‘hyper-empathy’ described by an autistic adolescent girl featured in this review provides a challenge to traditional deficit models of autism and emphasises the possibility for hypo and hyperarousal responses to social situations (Yi et al., 2022).

A further autistic characteristic presented to interact with anxiety was a preference for routines and predictability and relates to the construct of ‘intolerance of uncertainty’ (Stark et al., 2021). A novel finding was the challenge autistic CYP experience in relation to updating their ‘visual memory bank’, hypothesised by one parent around aversion to change (Ozsivadjian et al., 2012), since basic survival mode overwhelms cognitive ability. This evokes parallels with wider neuropsychological theory that over stimulation of the amygdala can result in anxiety (Quirk & Gehlert, 2006). Autistic CYP in this review are described to be perpetually in heightened states and one parent described their son as ‘never actually happy – it’s [anxiety] his default setting’ (Ozsivadjian et al., 2012, p. 114).

A further finding suggested that some autistic CYP may have a qualitatively different relationship with time in comparison with neurotypical peers. The concern that anxiety is more persistent and intense (Loffler & Dwyer, 2022) mirrors avoidant behaviours from school, which are reported in literature focused on anxiety-based school avoidance, which is reported to be characterised by more prolonged absence (Munkhaugen et al., 2017). Of note, was parental report of a time delay between an event and expression of anxiety. A review of literature reported higher level temporal processing to be impaired in autism, which is the ability to consider time as an abstract concept and be aware of present time and plan for future events (Casassus et al., 2019). This may relate to CYP in the reviewed studies who reported mediating effects of support for their organisational and time-management skills upon experiences of anxiety.

Study Limitations

This review aimed to thematically synthesis the experience of anxiety for autistic CYP, as self-reported and by their parents. Several limitations should be considered in relation to findings. Due to time and financial constraints, only peer-reviewed articles published in English were included. The origins of the included studies, findings may suggest that only Westernised perspectives about autistic CYP who experience anxiety, who have self-selected for inclusion in research studies are represented. Findings from a reviewed study suggested that 96.5% of autistic CYP may experience anxiety (Adams et al., 2020). This finding may represent a skewed perspective and should be interpreted with caution, since the experience of anxiety may have positively impacted upon motivation to participate in the research and represent a self-selection bias.

Of primary importance to implications for practice and research, the CYP participants represented in this study were able to contribute either verbally, or via a computer assisted interview and therefore the views of less cognitively-able, or non-verbal autistic CYP may not be represented by this review.

Implications for policy and practice:

There are several implications for policy and practice following the findings from this review. At the level of diagnosis of autism or an exploration of co-occurring anxiety, it is imperative that professionals gather a range of perspectives across social contexts, since anxiety may not be consistently experienced. Furthermore, significant investment is required to develop environments that are more supportive of autistic CYP. In the school context, this may involve infrastructural change and training for staff around the neurodiversity model of autism. A greater awareness of the differential responses CYP may have towards their diagnosis and in particular due to perceived societal stigma, will support professionals to understand CYP's experiences of anxiety.

A further key implication for professional practice is the priority to authentically elicit the views and experiences of autistic CYP. The review highlights challenges with standardised measures of anxiety since they do not capture CYP's priorities, cognitive processes or emotions. The challenge for professionals is to explore diverse methods for engagement, sharing views and assessment for both cognitively and less able autistic CYP.

Implications for research:

This thematic synthesis has reviewed studies that elucidate autistic CYP's experiences of anxiety. It was useful to include the perspectives of parents and CYP, however there is a distinct lack of representation from the less cognitively-able or non-verbal cohort of autistic children. Further efforts should be made to enable their participation in future studies to gain an understanding of their experiences of anxiety. The range of studies reviewed included the voice of the autistic population and their families, however the neurodiversity paradigm emphasises a shift towards participatory methodologies that collaborate with the autistic community at each stage of research (Guldberg, 2017; Happé & Frith, 2020; Pellicano et al., 2018).

The review highlighted a paucity of studies relating to the experience of anxiety in home and community context, which should also be addressed in future research. Happé & Frith (2020) recommended research around the resilience factors for autistic individuals who do not experience mental health difficulties. Future research into resilience factors that sustain wellbeing across contexts of home, school and community would make a significant contribution to the existing literature base around an understanding of the anxiety amongst autistic CYP.

Conclusion

This thematic synthesis confirmed autistic CYP experience severe and prolonged anxiety. Findings from the review suggested that trait anxiety is prevalent among autistic CYP and experiences reported highlight an interaction with core autistic characteristics, which may be exacerbated by or consequences of living within neurotypical environments. The review highlighted heterogeneous experiences of anxiety across contexts and that this may be understood differently between CYP and their parents. Parents appear to report behavioural manifestations of anxiety, however CYP provided insight into cognitive processes and emotions. These findings have implications for policy, practice and research, particularly for all autistic voices to be kept central and problematise a reliance on standardised measures since they may not fully capture autistic CYP's priorities and experiences.

Acknowledgement

This project was funded through England's Department for Education (DfE) National College for Teaching and Learning (NCTL) ITEP award 2020-2022.

Conflict of Interest

No potential conflict of interest was reported by the authors.

References

Acker, L., Knight, M., & Knott, F. (2018). ‘Are they just gonna reject me?’ Male adolescents with autism making sense of anxiety: An Interpretative Phenomenological Analysis. *Research in Autism Spectrum Disorders*, *56*(July), 9–20. https://doi.org/10.1016/j.rasd.2018.07.005

Adams, D., Simpson, K., & Keen, D. (2020). Exploring Anxiety at Home, School, and in the Community Through Self-Report From Children on the Autism Spectrum. *Autism Research*, *13*(4), 603–614. https://doi.org/10.1002/aur.2246

Adams, D., Young, K., & Keen, D. (2019a). Anxiety in Children with Autism at School: a Systematic Review. *Review Journal of Autism and Developmental Disorders*, *6*(3), 274–288. https://doi.org/10.1007/s40489-019-00172-z

Adams, D., Young, K., Simpson, K., & Keen, D. (2019b). Parent descriptions of the presentation and management of anxiousness in children on the autism spectrum. *Autism*, *23*(4), 980–992. https://doi.org/10.1177/1362361318794031

APA (2013). *Diagnostic and Statistical Manual of Mental Disorders (DSM-5).* American Psychiatric Association.

Bazeley, P., & Jackson, K. (2013). *Qualitative Data Analysis with NVIVO.* (2nd Ed.). Sage.

Bearss, K., Taylor, C. A., Aman, M. G., Whittemore, R., Lecavalier, L., Miller, J., Pritchett, J., Green, B., & Scahill, L. (2016). Using qualitative methods to guide scale development for anxiety in youth with autism spectrum disorder. *Autism*, *20*(6), 663–672. https://doi.org/10.1177/1362361315601012

Beesdo, K., Knappe, S., & Pine, D. (2009). Anxiety and Anxiety Disorders in Children and Adolescents: Developmental issues and imlications for DSM-V. *Psychiatric Clinics of North America. 32*(3), 483-524. https://doi.org/10.1016/j.psc.2009.06.002

Botha, M., Dibb, B., & Frost, D. M. (2022). “Autism is me”: an investigation of how autistic individuals make sense of autism and stigma. *Disability and Society*, *37*(3), 427–453. https://doi.org/10.1080/09687599.2020.1822782

Casassus, M., Poliakoff, E., Gowen, E., Poole, D., & Jones, L. A. (2019). Time perception and autistic spectrum condition: A systematic review. *Autism Research*, *12*(10), 1440–1462. https://doi.org/10.1002/aur.2170

Carpenter, B., Happé, F., & Egerton, J. (2019). 'Where are all the Autistic Girls?' In B. Carpenter, F. Happé & J. Egerton (Eds.). *Girls and Autism: Educational, family and personal perspectives.* Routledge.

Cooper, K., Russell, A. J., Lei, J., & Smith, L. G. E. (2022). The impact of a positive autism identity and autistic community solidarity on social anxiety and mental health in autistic young people. *Autism*, *X*. https://doi.org/10.1177/13623613221118351

Crane, L., & Pellicano, E. (2022). Current Autism Research: Implications for Educational Practice. In J. Gaisborough. *Educational Psychology Perspectives on Supporting Young People: Insights from Experience, Practice and Research.* Jessica Kingsley Publishers

den Houting, J., Adams, D., Roberts, J., & Keen, D. (2018). Exploring anxiety symptomatology in school-aged autistic children using an autism-specific assessment. *Research in Autism Spectrum Disorders*, *50*, 73–82. https://doi.org/10.1016/j.rasd.2018.03.005

Fletcher-Watson, S., & Happé, F. (2019) *Autism: A new introducation to psychological theory and current debate.* Routledge.

Gough, D. (2007). Weight of Evidence: A framework for the appraisal of the quality and relevance of evidence. *Research Papers in Education 22*(2), 213-228. https//doi.org/10.1080/02671520701296189

Greco, V., Lambert, H. C., & Park, M. (2016). Capturing the Child’s Perspective: A Review of Self-Report Measures used with Children. *Occupational Therapy in Mental Health*, *32*(3), 228–244. https://doi.org/10.1080/0164212X.2016.1164104

Guldberg, K. (2017). Evidence-based practice in autism educational research: Can we bridge the research and practice gap? *Oxford Review of Education*, *43*(2), 149–161. https://doi.org/10.1080/03054985.2016.1248818

Happe, F., & Frith, U. (2020). Annual Research Review : Looking back to look forward – changes in the concept of autism and implications for future research. *The Journal of Child Psychology and Psychiatry*. https://doi.org/10.1111/jcpp.13176

Happé, F., & Frith, U. (2020). Annual Research Review: Looking back to look forward – changes in the concept of autism and implications for future research. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, *61*(3), 218–232. https://doi.org/10.1111/jcpp.13176

Jacobs, P., Beamish, W., & McKay, L. (2021). Please listen to us: Adolescent autistic girls speak about learning and academic success. *Improving Schools*, *24*(3), 196–209.

https://doi.org/10.1177/1365480220973112

Jolliffe, R., Adams, D., & Simpson, K. (2022). Trait Anxiety in Individuals on the Autism Spectrum: a Systematic Review. *Review Journal of Autism and Developmental Disorders*, *0123456789*. https://doi.org/10.1007/s40489-022-00308-8

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, *20*(4), 442–462. https://doi.org/10.1177/1362361315588200

Kerns, C., & Kendall, P., (2014). Autism and Anxiety: Overlap, similarities and differences. In Davis, T., White, S., & Ollendick, T. *Handbook of Autism and Anxiety.* Springer.

Khalifa, G., Rosenbaum, P., Georgiades, K., Duku, E., & Di Rezze, B. (2020). Exploring the participation patterns and impact of environment in preschool children with asd. *International Journal of Environmental Research and Public Health*, *17*(16), 1–15. https://doi.org/10.3390/ijerph17165677

Kim, S. Y., & Lecavalier, L. (2022). Evaluating the Use of Self-reported Measures in Autistic Individuals in the Context of Psychiatric Assessment: A Systematic Review. *Journal of Autism and Developmental Disorders*, *52*(10), 4355–4374. https://doi.org/10.1007/s10803-021-05323-y

Lai, M. C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., Szatmari, P., & Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. *The Lancet Psychiatry*, *6*(10), 819–829. https://doi.org/10.1016/S2215-0366(19)30289-5

Lau, B. Y., Leong, R., Uljarevic, M., Lerh, J. W., Rodgers, J., Hollocks, M. J., South, M., McConachie, H., Ozsivadjian, A., Van Hecke, A., Libove, R., Hardan, A., Leekam, S., Simonoff, E., & Magiati, I. (2020). Anxiety in young people with autism spectrum disorder: Common and autism-related anxiety experiences and their associations with individual characteristics. *Autism*, *24*(5), 1111–1126. https://doi.org/10.1177/1362361319886246

Leedham, A. T., Thompson, A. R., & Freeth, M. (2020). A thematic synthesis of siblings' lived experiences of autism: Distress, responsibilities, compassion and connection. *Research in Developmental Disabilities*, *97*, 103547. https://doi.org/10.1016/j.ridd.2019.103547

Loffler, D., & Dwyer, E. (2022). In J. Gaisborough. *Educational Psychology Perspectives on Supporting Young People: Insights from Experience, Practice and Research.* Jessica

Kingsley Publishers.

Mertens, J., Zane, E. R., Neumeyer, K., & Grossman, R. B. (2017). How Anxious Do You Think I Am? Relationship Between State and Trait Anxiety in Children With and Without ASD During Social Tasks. *Journal of Autism and Developmental Disorders*, *47*(12), 3692–3703. https://doi.org/10.1007/s10803-016-2979-y

Milton, D. (2012). On the ontological status of autism: the 'double empathy problem.' *Disabilty & Society, 27*(6), 883-887. https://doi.org/10.1.1080/09687599.2012.710008

Munkhaugen, E. K., Gjevik, E., Pripp, A. H., Sponheim, E., & Diseth, T. H. (2017). School refusal behaviour: Are children and adolescents with autism spectrum disorder at a higher risk? *Research in Autism Spectrum Disorders*, *41–42*(August), 31–38. https://doi.org/10.1016/j.rasd.2017.07.001

Ozsivadjian, A., Knott, F., & Magiati, I. (2012). Parent and child perspectives on the nature of anxiety in children and young people with autism spectrum disorders: A focus group study. *Autism*, *16*(2), 107–121. https://doi.org/10.1177/1362361311431703

Page, M., McKenzie, J., Bossuyt, P., Boutron, I., Hoffmann, I., Mulrow, C., Shamseer, L., Tetzlaff, J., Akl, E., Brennan, S., Chou, R., Glanville, J., Grimshaw, J., Hrobjartsson, A., Lalu, M., Tianjiing, L., Loder, E., Mayo-Wilson, E., McDonald, S., … Moher, D. (2021) The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMC Systematic Reviews 10*(89). *https://doi.org/10.1186/s13643-021-01626-4*

Pellicano, E., & den Houting, J. (2022). Annual Research Review: Shifting from ‘normal science’ to neurodiversity in autism science. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, *63*(4), 381–396. https://doi.org/10.1111/jcpp.13534

Pellicano, L., Mandy, W., Bölte, S., Stahmer, A., Lounds Taylor, J., & Mandell, D. S. (2018). A new era for autism research, and for our journal. *Autism*, *22*(2), 82–83. https://doi.org/10.1177/1362361317748556

Quirk, G., & Gehlert, D. (2006). Inhibition of the Amygdala: Key to pathological states? *Annals of the New York Academy of Sciences*, *985*(1), 263–272. https://doi.org/https://doi.org/10.1111/j.1749-6632.2003.tb07087.x

Rodgers, J., Wigham, S., McConachie, H., Freeston, M., Honey, E., & Parr, J. R. (2016). Development of the anxiety scale for children with autism spectrum disorder (ASC-ASD). *Autism Research*, *9*(11), 1205–1215. https://doi.org/10.1002/aur.1603

Simpson, K., Adams, D., Ambrose, K., & Keen, D. (2021). “My cheeks get red and my brain gets scared": A computer assisted interview to explore experiences of anxiety in young children on the autism spectrum. *Research in Developmental Disabilities*, *113*(August 2020), 103940. https://doi.org/10.1016/j.ridd.2021.103940

Simpson, K., Adams, D., Wheeley, E., & Keen, D. (2020). Parent Perspectives on the Presentation, Triggers, Impact, and Support of Anxiety in Young Children on the Autism Spectrum. *Journal of Child and Family Studies*, *29*(2), 572–582. https://doi.org/10.1007/s10826-019-01576-5

Spain, D., Sin, J., Linder, K. B., McMahon, J., & Happé, F. (2018). Social anxiety in autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders*, *52*(May), 51–68. https://doi.org/10.1016/j.rasd.2018.04.007

Spielberger, C. (1966). Theory and research on anxiety. In C. Spielberger (Ed.). *Anxiety and Behaviour.* Academic Press.

Stark, E., Stacey, J., Mandy, W., Kringelbach, M. L., & Happé, F. (2021). Autistic Cognition: Charting Routes to Anxiety. *Trends in Cognitive Sciences*, *25*(7), 571–581. https://doi.org/10.1016/j.tics.2021.03.014

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, *8*(45), 1–10. https://doi.org/10.1186/1471-2288-8-45

Thompson-Hodgetts, S., Labonte, C., Mazumder, R., & Phelan, S. (2020). Helpful or harmful? A scoping review of perceptions and outcomes of autism diagnostic disclosure to others. *Research in Autism Spectrum Disorders*, *77*(July), 101598. https://doi.org/10.1016/j.rasd.2020.101598

Tomlinson, C., Bond, C., & Hebron, J. (2019). The school experiences of autistic girls and adolescents: a systematic review. *European Journal of Special Needs Education*, *35*(2), 203–219. https://doi.org/10.1080/08856257.2019.1643154

Tomlinson, C., Bond, C., & Hebron, J. (2021). The mainstream school experiences of adolescent autistic girls. *European Journal of Special Needs Education*, *37*(2), 323–339. https://doi.org/10.1080/08856257.2021.1878657

Van Steensel, F. J. A., & Heeman, E. J. (2017). Anxiety Levels in Children with Autism Spectrum Disorder: A Meta-Analysis. *Journal of Child and Family Studies*, *26*(7), 1753–1767. https://doi.org/10.1007/s10826-017-0687-7

Vasa, Roma A. and Mazurek, M. O. (2015). An update on anxiety in youth with autism spectrum disorders. *Current Opinion Psychiatry*, *28*(2), 83–90. https://doi.org/:10.1097/YCO.0000000000000133

Vasa, R. A., Keefer, A., McDonald, R. G., Hunsche, M. C., & Kerns, C. M. (2020). A Scoping Review of Anxiety in Young Children with Autism Spectrum Disorder. *Autism Research*, *13*(12), 2038–2057. https://doi.org/10.1002/aur.2395

White, S. W., Simmons, G. L., Gotham, K. O., Conner, C. M., Smith, I. C., Beck, K. B., & Mazefsky, C. A. (2018). Psychosocial Treatments Targeting Anxiety and Depression in Adolescents and Adults on the Autism Spectrum: Review of the Latest Research and Recommended Future Directions. *Current Psychiatry Reports*, *20*(10). https://doi.org/10.1007/s11920-018-0949-0

Woods, K. (2020a). *Critical Appraisal Frameworks: Qualitative Research Framework.* Manchester: The University of Manchester (Education and Psychology Research Group).

Woods, K. (2020b). *Critical Appraisal Frameworks: Quantitive Research Framework.* Manchester: The University of Manchester (Education and Psychology Research Group).

Yi, L., Wang, Q., Song, C., & Han, Z. R. (2022). Hypo- or hyperarousal? The mechanisms underlying social information processing in autism. *Child Development Perspectives*, *00*, 1–8. https://doi.org/10.1111/cdep.12466

Paper Two: "After a long period of being in hibernation – these little green shoots were growing." Lived experiences of effective support for autistic young people who have experienced extended school nonattendance

Prepared for in accordance with the author guidelines for submission to JORSEN (Appendix 6)

Abstract

Extended school nonattendance has been identified across previous literature as problematic for autistic pupils and prevalence rates are considerably higher for this cohort than their neurotypical peers. The neurodiversity paradigm calls for a shift towards qualitative and participatory research methodologies to understand autistic young people's (YP) lived experiences. This participatory inquiry (PI) adopted a flexible and reflective approach with two autistic YP who have experienced extended school nonattendance and aimed to explore how Kas and Z described effective support to meet their needs. Autistic YP's perspectives were supported by three parental viewpoints. The participatory design allowed autistic YP to identify key themes of effective support: a nuanced relationship with time; internal processes of control and motivation; relationships and safe environments, and perspectives around their diagnosis of autism. A thematic map was developed to highlight the interaction between YP perspectives and parental viewpoints and the superordinate, researcher-identified theme of understanding and acceptance of individual lived experience of autism. The methodology and themes suggest considerations for professionals to develop practice to support autistic young people who experience extended school nonattendance. Implications for future research are discussed.

Key words: extended school nonattendance, autism, neurodiversity, anxiety, lived experience, effective support, pupil views

Introduction

The etiology of school attendance problems diverge between being emotionally-based, or due to withdrawal, exclusion or truancy (Heyne et al., 2019). Emotionally-based nonattendance is the focus of this study and is referred to by a number of terms including school refusal or emotionally based school avoidance. To avoid a within-child perspective that simplifies the complex interplay of multifactorial and ecological factors (Knage, 2021), this study will use the term 'extended school nonattendance'. This is consistent to recent research (Corcoran & Kelly, 2022) that highlighted perspectives of YP who dislike the terms 'refusal' or 'avoidance' since they fail to acknowledge that nonattendance is not a choice but a barrier based in chronic anxiety.

Extended school nonattendance has been identified across research as a problematic phenomenon for autistic pupils (Adams et al., 2022; Munkhaugen et al., 2019), with prevalence rates reported around 40-53% in comparison to 5-28% for neurotypical pupils (Munkhaugen et al., 2019). This is a congruent pattern to the pervasiveness of anxiety amongst autistic pupils; furthermore, clinical statistics potentially under-estimate self-reported experiences (Neilson, 2023). Contemporary research around extended school nonattendance for autistic pupils problematises viewing the construct through a neurotypical lens (Adams et al., 2022). This study is aligned with the social model of autism prioritised by the neurodiversity paradigm which conceptualises difficulties autistic individuals experience as resultant from living within neurotypical environments due to potentially incongruent social, physical and emotional expectations (Pellicano & den Houting, 2022). The views of autistic YP who experience extended school nonattendance around effective support to meet their needs merit further exploration; perspectives which this paper aims to elucidate.

Experiences of school for autistic pupils

Autistic pupils are reported to have positive and negative school experiences (Danker et al., 2016). However, the gap between the agenda to include autistic pupils and practice

(Humphrey & Lewis, 2008) highlights that many autistic pupils find mainstream settings challenging (Goodall & MacKenzie, 2019). Relational attributes of education are paramount (Goodall & MacKenzie, 2019) and in particular the quality of teacher-pupil relationships (Danker et al., 2016; Tomlinson et al., 2020). Calder et al., (2013) proposed the importance of social networks and highlighted that autistic children's perception of friendship may differ from their neurotypical peers, the expectations for social interactions may be overwhelming and some children expressed a preference for playing alone. Tomlinson et al., (2020) developed a model of school experience for autistic children and adolescents across individual, classroom and school levels with wellbeing in the centre. At the school level, pertinent factors included a school ethos that provided pupils with individual control to modify environmental demands. Withdrawal from social activities and avoidance of school was also highlighted as compensatory behaviour for anxiety in the school environment (Goodall & MacKenzie, 2019).

Autistic pupils' experiences of extended school nonattendance

Kearney's (2002) seminal research suggested that school nonattendance be understood as behaviour that fulfilled four functions. However, recent research suggested that the four-factor structure identified for neurotypical students was unsuitable to assess issues unique to autistic pupils (Adams et al., 2022). There is an emerging research focus around reasons specific to autistic pupils that impact the inception and maintenance of school nonattendance, for instance Munkhaugen, et al., (2019). These autism specific studies supported the broader perspective of viewing attendance difficulties through an ecological lens (Leduc et al., 2022; Tonge & Silverman, 2019) and as a multifactorial model (Knage, 2021). Leduc and colleagues (2022) identified a gap in the literature base pertaining to bidirectional factors within a young person's meso-system (such as relationships between parents and school staff) and macro-system (such as attendance policies within a school environment) and the interactions with proximal processes at the individual level.

To date, only three studies have researched effective support for autistic pupils who have experienced extended school nonattendance and detail multi-modal and ecological approaches to support (Melin et al., 2022; O’Hagan et al., 2022; Preece & Howley, 2018). The school-based studies promoted practical support such as effective collaboration between professionals and relationship building (O’Hagan et al., 2022; Preece & Howley, 2018). Melin and colleagues’ (2022) clinic-based study reported decontextualised approaches like behavioural activation, psychoeducation and motivational work, which is implied across the practical themes of eclectic and individualised approaches (O’Hagan et al., 2022; Preece & Howley, 2018).

Priority for participatory research with autistic YP

The voices of autistic YP are potentially peripheral and indistinguishable from their families and professionals in existing research into support for autistic pupils experiencing extended school nonattendance and dominated by researcher-led case study methodologies. Guldberg (2017) highlighted a potential mismatch between the focus of research and positive outcomes identified by autistic individuals. This concurs with a wider priority for the autistic community to participate meaningfully in research to understand diverse perspectives of lived experience (Fletcher-Watson et al., 2019; Pellicano & den Houting, 2022) . Terminology around participatory research is recognised as vague and ill-defined, however key attributes were identified for autism research: flexibility of participation, building relationships, communication and opportunities for two-way learning (Pickard et al., 2022). Best practice is described as emancipatory, whereby participants are supported to contribute in beneficial ways (Stone & Priestley, 1996).

There is an emergent literature base around eliciting the voice of autistic YP and encouraging accessible opportunities for engagement in participatory research (Simpson et al., 2022). The creation of a safe-space to encourage open discussion and support relationship building is paramount (Carroll & Twomey, 2021; Dewa et al., 2021) and creative and visual methods have been encouraged to facilitate the inclusion of autistic YP habitually excluded from participation in research (Rosqvist et al., 2019). Carroll & Twomey (2021) recommended the involvement of a familiar adult, who is knowledgeable of the young person’s communication style, to support data collection processes.

The current study will place the voice of the child centre stage. Current literature suggests that support and advocacy for parents is inextricably linked with effective practice for YP (Melin et al., 2022; O'Hagan et al., 2022) and therefore their perspectives with be included to capture wider contextual issues. This participatory inquiry (PI) will explore autistic YP's unique contribution around the following research aim:

1. How do autistic YP who have experienced extended school nonattendance describe effective support to meet their needs?

Method

Design

An overarching social constructionist epistemological position views knowledge as socio-historically situated and an artifact of social interaction (Gergen, 1985). Congruent to the priorities outlined by the neurodiversity paradigm and social constructionism, the current study adopted a PI design which conceives research as an experiential transaction between participants and researchers and has a transformative agenda (Heron & Reason, 1997).

Overview of research location and participants

This research study took place at a specialist provision for YP with complex medical needs and educates a high number of autistic YP who have experienced extended school nonattendance. After a prolonged period of engagement with the setting, a key professional was identified and he recommended Kas and Z as participants based on the following inclusion criteria: (1) diagnosis of autism and (2) currently receiving education from the setting after a period of extended school nonattendance.

The literature reviewed highlighted that experiences of parents are inextricably linked with their children's. The PI with YP was therefore supported by additional perspectives from parents of children attending the specialist provision (Appendix 7). Congruent with the neurodiversity research agenda and the aims of this study, the parental participants were a heterogenous group, whereby one was the parent of Kas and other two parents unrelated to Z. The parents' autistic children had divergent experiences and were at differing points in their journey, thus the parent participant group was not reductive or striving for a consistent end point for their children. Table 2 presents participant demographic information.

Participant	Gender of young person	Age of young person	Description of mainstream school nonattendance
*Kas	Female	17	3 years absence
*Z	Male	14	12% attendance in previous school year
Parent 1 (P1)	Female	17	3 years absence
Parent 2 (P2)	Female	15	Irregular attendance for 4 years of High School
Parent 3 (P3)	Female	10	2 ½ years absence

Table 2. Participant demographic information. *Kas and *Z were self-chosen pseudonyms.

Ethical considerations

Ethical approval was granted by the University of Manchester's Ethical Research Committee in January 2022 (Appendix 8). During the early stage of the study's development, researchers consulted an autistic community member and advocate for YP, who emphasised the prerogative for the research process to meet the individual needs of participants in addition to the researchers' priorities and requirements. The study was aligned with emancipatory approaches and had a strengths-based aim. Multi-layered and ongoing informed consent was sought from participants to ensure that traditional power structures inherent within educational settings were challenged (Kirby, 2020) (Appendix 9 & 10).

Data gathering and theme development

PI has a flexible and reflexive structure (Cornwall & Jewkes, 1995). The process of engagement with Kas and Z occurred across four steps, which were a combination of one-to-one and paired sessions. The author applied a combination of researcher and practitioner skills to create a therapeutic, safe space and maintained an interaction style based on the humanistic principles of congruence, unconditional positive regard and empathy (Rogers, 1957). The key professional from the setting attended all sessions, as per ethical approval, and contributed via reflections and summaries upon Kas and Z's views.

Step 1 – Rapport Building: To consider how Kas and Z wanted to contribute to the research process, a range of data gathering methods were discussed, including interview, writing and creative approaches. Kas and Z expressed the preference for taking a conversational approach and a group contract was developed (Appendix 11).

Step 2 – Initial data gathering: A narrative interview (NI) approach informed the process of eliciting Kas and Z views, whereby perspectives are conceived as a social event's representation generated through interaction in a particular "time, space and socio-historic context" (Muylaert et al., 2014, p. 186). A visual stimulus of the journey from nonattendance to engagement at the specialist provision (Figure 2) was presented to Kas and Z. This facilitated discussion and reflections about their experiences and the effective support that enabled positive change.

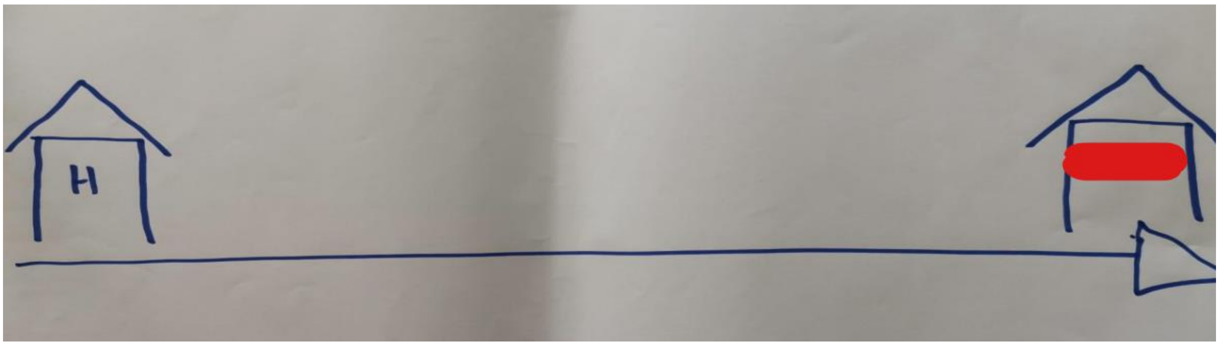


Figure 2. Visual stimulus

Step 3 – Theme development: The author produced a verbatim transcript of the previous session and proposed a number of themes to Kas and Z. Member reflection allowed participants to participate reflexively upon theme generation (Tracy, 2010). Kas and Z negotiated a set of co-produced themes and ranked them into individual hierarchies to express individual priorities and pertinence (Figures 3 & 4).

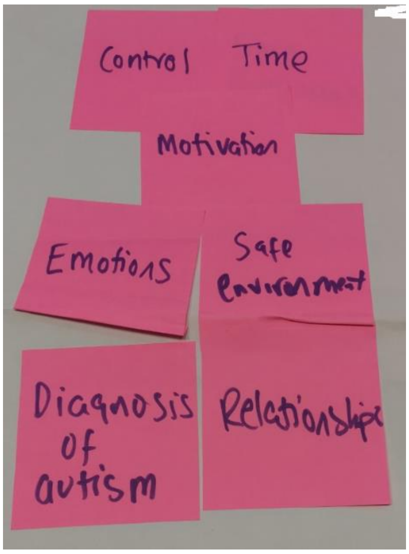


Figure 3. Kas' hierarchy of themes

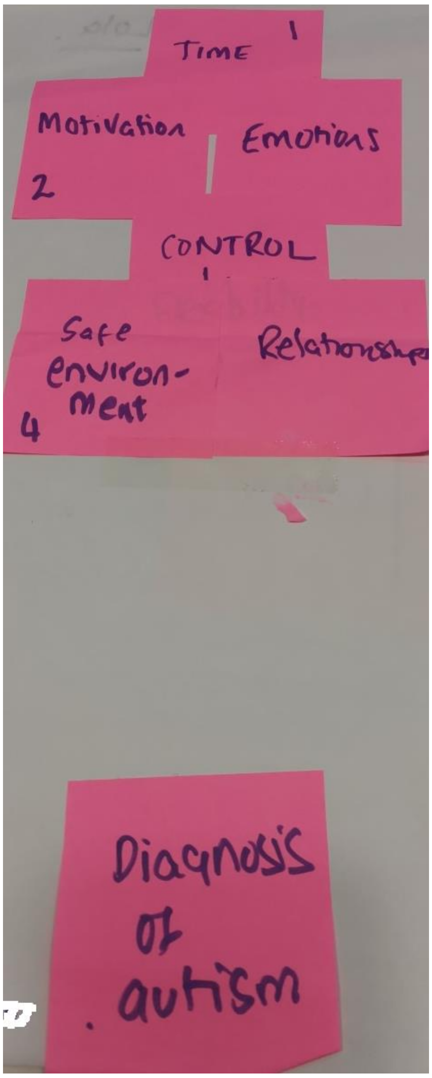


Figure 4. Z's hierarchy of themes

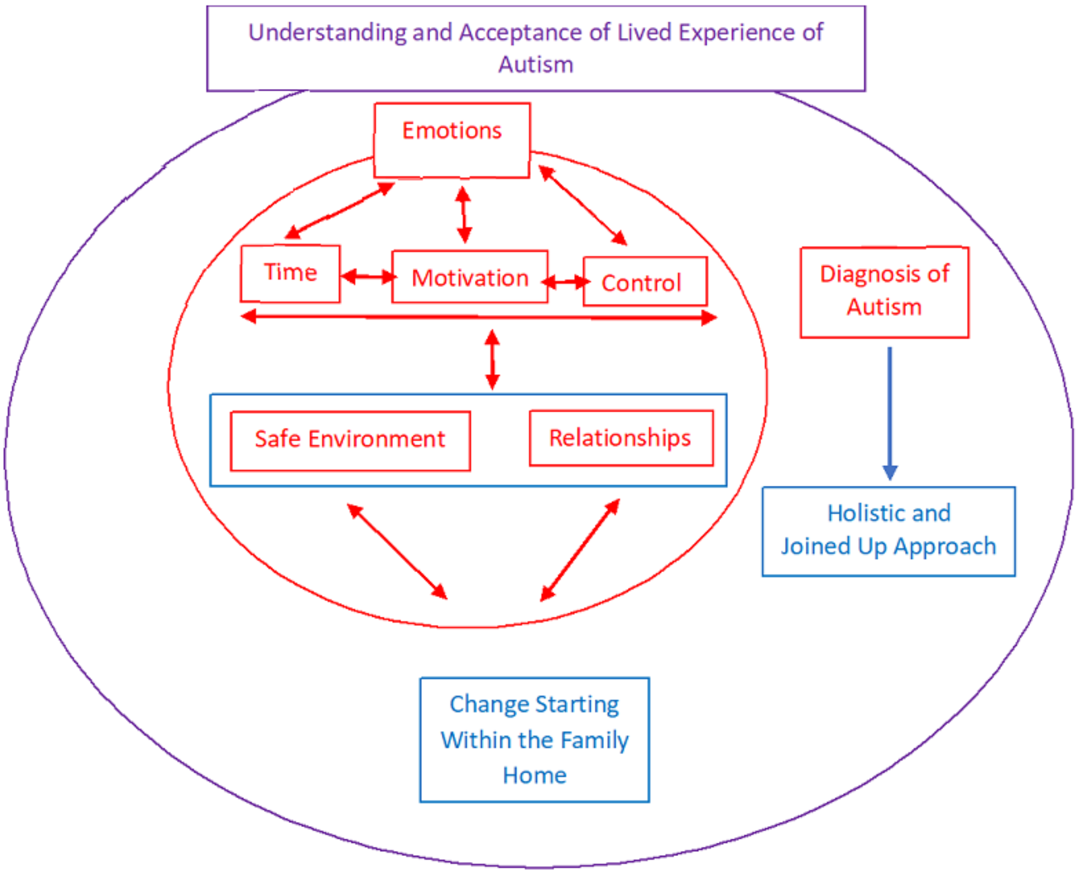
Step 4 – Theme consolidation and procedural reflection: To ensure the experiential knowledge of the participants was prioritised (Heron & Reason, 1997) further discussion around the identified themes confirmed researcher understanding accurately represented their meanings. The author was an active participant in theme development, through a double-hermeneutic approach, and synthesised Kas and Z's meaning-making of their experiences (Peat et al., 2019) to propose a superordinate theme for agreement by participants. Finally, Kas and Z reflected on the research process and their dissemination preferences.

The author also carried out individual semi-structured interviews with parental participants (Appendix 12): original transcripts were shared with participants to enhance the trustworthiness of the data for analysis. Reflexive thematic analysis (RTA) was a complementary analytic strategy for the parental data since it perceives reality to be contextually constructed from multiple perspectives (Braun & Clarke, 2021). Parental data was coded via a deductive-inductive approach to coding (Fereday & Muir-Cochrane, 2006), whereby parental perspectives were initially considered vis-à-vis Kas and Z’s a-priori themes (Appendix 13). Rigour of inductive coding was supported through discussion between the author and their thesis supervisor.

Findings

Overview

PI with Kas and Z developed seven co-produced themes: Time, Motivation, Control, Safe Environment, Relationships, Emotions and Diagnosis of Autism. Parental interview data supported the YP’s themes and Relationships and Safe Environment appeared most pertinent. Two further key themes were established through RTA of parental data and a superordinate theme was additionally developed by the author. The data was integrated to develop a tentative thematic model to conceptualise successful practice to meet the needs of the YP and their families (Figure 5).



Key:

🟥 = Kai and Z's Themes

🟦 = Parental Themes

🟪 = Author Theme

Figure 5. Thematic model of interaction between themes

Kas and Z's themes

Time

Time was ranked as most important for both Kas and Z, and there were differences and similarities between participants' descriptions of effective support.

Time away from school, permitted due to regular school holidays, was presented as a supportive factor that encouraged attendance at the specialist provision for Z, since it enabled the reduction of anxiety:

> *The 6 weeks, I had all that time to myself. I didn't have to worry, I was calming down […] it allowed me to contemplate things.'*

Z also described it as beneficial that he *'started with a new slate on a new year'*, since his integration coincided with new staff members' first day which created some immediate *'relatability.'*

Kas indicated a key aspect of success on her journey as being *'given the right amount of time […] I wasn't pushed or anything and I did it all in my own, in my own terms.'* Kas discussed this in relation to a range of contexts and relationships; her parents, Child and Adolescent Mental Health Service (CAMHS) caseworker and integration plan. The caseworker was:

> *Helpful in the sense that she didn't put any time constraints on things she said. "Whether you do this next week or next month or next year, any progress is good."*

Furthermore, Kas described the integration to the current setting as gradual.

There was agreement between Kas and Z about the negative impact of externally imposed timeframes for task completion. Kas described:

> *If I'm given a time-constraint and someone says, "You've got to do this by next Tuesday." I tend not to do by next Tuesday and it stresses me [….] Whereas, if someone says, "Hey I'd like you to do this as soon as possible but if not that's ok[….]" I'm a lot more willing to do it in my own time and I can go at my pace. It feels less stressful.'*

The emotional impact of deadlines was also highlighted by Z through emotive language: *'clam up' and 'destroyed me.'* He highlighted that when a time-constraint is removed '*things become a thousand times more interesting and you are not bothered by them so you actually start enjoying them.'*

Kas and Z referred to the contrast between mainstream school environments and their current specialist setting. Kas emphasised the link between a challenging fast-paced environment and eventual school nonattendance:

> *Mainstream there was so much going on, like […]. It was just go, go, go and it got the point where you were like, "This isn't stopping at any time soon. I might have to stop it myself!" And then you end up never going to school.*

Motivation

Motivation was ranked second for both YP and first explicitly referred to by Z in relation to a lack of time-constraints and more autonomy with homework.

Kas reflected upon her aspirations as providing the motivation for her to attend school since *'the outcome was getting to come into school and learn stuff and get my GCSEs and progress in life.'* Kas explained that the motivation to attend college encouraged her to *'suck it up a little bit and push myself'*. Kas also detailed a key motivating factor with schoolwork as:

> *If teachers give me lots of different bits of work […] it gives me that freedom and I'm much more likely to find my motivation than in big tasks*

Z described nonattendance when he *"lost the steam"* and *"ran out of energy"* and for him a motivating factor was looking forward to playing a computer game.

> *There's this game series that's very important to me. […] In a way it was kind of like what helped me get through the months preceding July […] there was many moments when I was like, "Er, I don't know how much longer I can do this?" But then I just thought about the game and I was like, "I'll wait," and I did, I made it.*

Z summarised the importance of Motivation upon Emotions:

> *If you are not motivated to do something then that is a huge problem. It's […] the whole reason why depression is so bad, it's the lack of motivation. People not going outside. […] So, motivation you need it. I continuously say that motivation or de-motivation is a killer. […] I can't think of any other feeling that makes me feel so down than de-motivation.*

Control

Control was ranked joint first importance for Kas and third for Z. The theme of Control relates to both themes of Time and Motivation, which was highlighted in relation to Kas and Z's perspectives upon choice in relation to school work being supportive to meet their needs. Kas described the pride experienced by doing work herself and in her own time:

> *It feels more like a positive experience and I feel more proud of my work. If I've done it myself – instead of being forced to*.

Similarly, Z discussed the importance of control in relation to curriculum choice; a flexibility afforded by the current setting:

> *You can do something by your own volition that really helps me […] I'm a big advocate for history […] I practically have my own curriculum, basically the entirety of history.*

Kas described how control and being able to say *'no'* was of central importance to support her across the contexts of home, CAMHS and school. Kas described parental support as:

> *I like to please them [parents] and I hate disappointing them. So, when they didn't show any outward emotion towards me refusing to go to school or refusing to do other things that really helped because it made me feel like I had a place where I could say "no".*

Kas described being involved in planning the dates and times of visits to the new setting with her CAMHS worker: *'it felt like I was choosing to do it instead of being told I was doing it.'* Kas highlighted this was an ongoing process, whereby she had the opportunity to negotiate and reflect on her timetable with a trusted staff member: *'It made me more willing to come in if I knew that I was a bit of control.'*

Z elucidated the importance of control at school: *'The freedom of choice is truly something that school needs in order for a few people to truly feel that they can handle it.'* A stark contrast to '*once you lose control, it sends you into a spiral of God knows what… anxiety and paranoia and such'* (Z).

Safe Environment

Safe Environment was ranked third for Kas and fourth for Z and appeared to interact bidirectionally with Relationships. They ordered Safe Environments and Relationships under the preceding topics, which suggested a conceptual hierarchy between the two sets of themes.

Kas clarified the importance of a school environment that is safe and how this related to the theme of Control:

> *If I didn't have a safe environment I wouldn't be in school. […] I needed a place where I felt in control.*

Kas and Z made explicit contrasts between the safe environment of the specialist setting, in comparison to their mainstream school. Kas referred to the specialist setting as a '*calm place; instead of a hectic running down corridors trying to get to your next lesson place.'* Z referred to pertinence of a school that celebrates individual difference, which resulted in pupils having to *'conform less to, let's call it societal norms in school terms.'*

Furthermore, a safe environment was described to have a positive impact upon Emotions:

> *The positive energy of this place is kind of too much to stay sad […] the school kind of forced me to be happy and now I actually feel better. (Z)*

A professional, from an established safe environment, who advocated for Kas and provided a bridge to a new environment was described as an effective strategy to facilitate it becoming safe:

> *After I'd had a session here [….] I mentioned that I had a meeting afterwards and she offered to sit in with me. And we set up […] a signal […] She really did stand up for me when I didn't feel I could myself.'*

Relationships

Relationships were a further theme identified as supportive to meet the YP's needs.

Z spoke of complex and contradictory social relationships both in and out of school. Positive relationships were described as possible within the specialist setting:

> *When I went to [mainstream] school it was hard to socialise with other people because I felt like I was going to break down crying or something. So, coming here, everyone, for one, was very welcoming. […], they are all friendly and it feels kind of like a family now.*

However, Z described an inconsistent attitude towards socialising:

> *I do enjoy socialising here but in general, I'm not a social person. I'd much rather you leave me alone than approach me and try to talk to me. Of course, it might be because, you know, I've grown close to quite a lot of people here and it feels like a safe environment. A safe environment to socialise in but I still… I just don't want to people to talk to me*

And a contradictory relationship with a close friend:

> *It's more nuanced than just please don't talk to me though - it's also a matter of pressure […] pressure from yourself. It's sort of guilt perhaps. […] If I turn him down […] it just piles up and I start feeling like a bad friend. And then I'm forced to do what I really… don't want to do.* (Z)

This multi-faceted complexity in social relationships was understood by Kas in relation to the expectation *'to be a socially acceptable person, who communicates with people how you're meant to.'* Kas described supportive relationships with peers who also didn't want to talk and staff who showed an understanding of self-chosen silence. This mutual insight was powerfully described in dialogue between Kas and Z:

> *K: 'Yeah, no-one really forced me to talk. If I came in and did not say a word, people just accept that I wasn't saying a word and they wouldn't try and force words out of me […] And that's exactly what I wanted. Just please do not talk to me, I will talk when I am ready or when I want to or maybe I won't and you won't hear from me for like week and that's cool too.*
> *Z: You really need a sign… a sign that I can flip that says, "You can talk to me"*
> *K: Oh god yeah…*
> *Z: That would be an amazing invention, I will copyright it and we will all get shares out of it.*
> *K: Like traffic lights on my glasses*

Kas identified key attributes of professional relationships established within the safe environments of CAMHS and the specialist school. In both environments, Kas referred to having *'a space to just be able to talk, even if it had nothing to do with, you know, working towards going to school again or working towards lowering anxiety level.'* Trust was described as a paramount quality that enabled the CAMHS caseworker to advocate for Kas when she was unable to speak up for herself. Kas also highlighted the importance of time for relationship building with a professional and:

> *The proof that you showed that when I do say something, it actually happened. That definitely helped that bit of reinforcement […] And a lot more willing to then show my feelings again.*

Emotions

Emotions featured in conjunction with all previous themes. It was ranked third highest for Kas and second by Z, who described Emotions to *'interact'* with Motivation.

Kas and Z highlighted that attending a school that met their needs improved their mental health. Z stated the specialist setting *'mentally recalibrated'* him, in comparison to time spent at home, when he described feeling *'empty'* with *'no purpose to [his] life.'* Kas summarised her emotional transformation:

> *I have weeks where everything's just fine […] I'm not worried about something that's coming up and the freedom that gives me, is… you just wouldn't believe. The feeling of not being scared of the future… it's amazing […] I am so grateful for this school, in every way.*

Diagnosis of Autism

This theme was ranked of least importance for both participants and extremely low on Z's hierarchy. Z received his diagnosis when he was nine years old and stated that: *'I sometimes forget that I have it.'*

In comparison, Kas received her diagnosis during the period of extended school nonattendance. Kas believed diagnosis was supportive because it was *'physical proof of why or some sort of explanation on why things were happening'* and people were *'more willing to accommodate.'* In relation to her forthcoming transition to college, she described the diagnosis as being like a *'safety net to fall onto.'* Kas referred to the support and understanding it provided others, both her mum who *'ran with it'* and professionals since:

> *Everybody knows what autism is […] If I just said, "I'm not going into school, I can't go into school and it makes me really, really anxious," they'll be like, "Right." […] But with a diagnosis of autism, I'm like, well, "It says right here that I can struggle and this is my struggle right now with it and you have to accept this because it's a diagnosis."*

Parental themes

Parental perspectives of effective support for their autistic children who had experienced extended school nonattendance revealed overlap with Kas and Z's themes. Safe Environment and Relationships were key themes reinforced by parental views.

P3 referred to relationships forged within the specialist setting, congruently to Z, as a *'family.'* The setting's ethos informed positive interactions between professionals and their children across the spectrum of staff members from headteacher to receptionist, whose attributes were highlighted by both P1 and P3. P1 highlighted that school staff members made her daughter *'feel seen, and heard, and understood […which] encouraged her to start to feel – maybe I do belong here, maybe this is going to be something that I can do.'* The theme of relationships was contextually different for P2, since their daughter was currently home educated, and ensured she had *'the opportunity to spend time with other people that are not just their parent.'*

RTA of parental interviews also revealed a further two themes: Holistic and Joined Up Approach and Change Starting within the Family Home.

<u>Holistic and Joined Up Approach</u>

P1 and P3 explicitly referred to how helpful it was when different professionals were *'working together.'* In comparison to, when the family *'were managing different aspects […on their] own'* (P1) or there was involvement from *'hundreds of different people for different things but nobody…like seemed to do the full picture together'* (P3). A holistic approach was pertinent for P2 and P3's daughters, who experienced a complex interaction between physical pain or illness, anxiety and autism.

The *'formality'* of an autism diagnosis appeared central to all three parents in enabling joined up and holistic support and described by P2 as the *'game-changer.'* P1 explained that the diagnosis reduced *'additional stressors'* upon the family such as, fines for attendance and *'bullying'* and *'cajoling'* practice from the mainstream setting, and consequently provided *'validation of the fact that [they] weren't being neglectful parents.'*

Change Starting Within the Family Home

P1 shared the positive impact of receiving family therapy from CAMHS which suggested that change started within the family home. P1 described increased confidence to respond to their daughter's difficulties differently and explained:

> *It was at that point that we started to feel like she was […] coming back to the social world a little bit. Just coming out of her room more and going out of the house more often and spending more time with us as well.*

The specialist setting was also described as providing initial support within the family home by P2 and P1. P2 described their child's current provision of a home tutor as *a 'stepping-stone'* towards engagement in a school setting. P2 suggested tuition to be supportive since their daughter is interacting with someone else, engaging in individualised work and a routine. However, there was evident frustration from P2, described as having *'hit kind of an obstacle,'* as no on-site educational setting was currently available. P1 also highlighted that prior to on-site engagement their child was provided with work to complete independently at home, which enabled her to:

> *Reconnect with that part of herself where she felt really secure, really happy, really fulfilled […] after a long period of being in hibernation – these little green shoots were growing.*

Author-identified theme

Understanding and Acceptance of Individual Lived Experience of Autism

The author reflected upon themes produced by Kas and Z and developed the superordinate theme of Understanding and Acceptance of Individual Lived Experience of Autism. Kas and Z highlighted the contrast between effective support offered by individuals and contexts and neurotypical environments:

> *A school meant for people who are able to keep up with a lot of work. Because everything is independent you know […] That kind of thing was overwhelming to me.* (Z)

The author discussed this potential theme with Kas and she agreed that if there had been an understanding of the link between autism and nonattendance *'things could have happened a bit quicker.'* The shift from a within-in child perspective of extended school nonattendance that encompassed self-blame and shame, to a contextual and interactional understanding was poignantly reflected upon by Kas:

> *Before I came here, I had no clue that this was actually a thing that happened to a lot of people and that it was linked to autism. I was just kind of like, "Well obviously I've got some sort of problem." … I genuinely thought … I had so little […] dedication to my own life that I just stopped going and I couldn't be bothered. And then I realised, oh, no it's an actual thing and I couldn't really have done anything without the proper support and that wasn't my fault. I can't blame myself for not going into school.*

Parental viewpoints reinforced the author identified theme: parents highlighted professional and contextual practice that did not meet their children's needs and all used the term *'fight.'* P2 shared a perspective about *'fighting with a system that is ableist'* and explained that when attitudes and practices are framed by:

> *The rosy glasses of ableism, they're always going to blame the disabled person for their condition […] in the attitude that if they don't provide the support, the person will cope… will learn to cope and they don't understand that that's abuse.*

In contrast, P1 described professional practice that accommodated and understood their daughter's individualised needs as supportive; by demonstrating patience and flexibility, allowing for failure and tolerating *'lots of plans, lots of refusals*.'

Reflections on the PI process

The author received the initial research commission around autism and extended school nonattendance from an EPS with extensive experience working within the specialist setting. PI was an effective methodology to curiously explore a complex and individualised phenomenon as opposed to applying perspectives to a predetermined framework. The author took a flexible and reflexive approach and collaborated throughout the research process with a range of autistic stakeholders including YP, parents, the setting, and an autistic community member. Her experience as a practitioner created a therapeutic safe space for Kas and Z, experiential experts, to share their views, and qualitative researcher skills supported the effective PI process.

The final step of data gathering incorporated time for participants to reflect upon involvement in the research process and feedback suggested the PI approach met their individual needs. Kas described it as positive *'to speak about how I find things without someone trying to dissect it, in a, like a psychological way'* and commented on working alongside another autistic YP:

> *To talk to Z about it as well […] It was weird to see […] how much some of our opinions were exactly the same and how much of them were totally opposite and yet it all still links together*.

Z reflected on it *'being nice to take an introspective look'* at his autism since before '*doing this research, I wasn't all that concerned.'* Z also hoped the research would help others:

> *I also hope people, who are in the same boat as me, will be able to empathise and relate to it […] something to feel like they are not alone. Because sometimes […] it gets lonely […] in this ship of mine.*

Discussion

This PI aimed to explore how autistic YP, who have experienced extended school nonattendance, described effective support to meet their needs. The integration of different perspectives developed a thematic model with autistic YP positioned centre-stage as experiential experts. Their lived experiences highlighted heterogeneity and contradictions between and within participants' perspectives. PI effectively supported the neurodiversity paradigm's agenda to encourage the autistic community to participate meaningfully in research and celebrate diversity of perspectives (Fletcher-Watson et al., 2019; Pellicano & den Houting, 2022). Kas and Z's reflections upon the process suggested they were supported to participate in beneficial ways (Stone & Priestley, 1996). Kas and Z's perspectives were extended by parental views and the principal researcher's superordinate theme. Key themes supported an ecosystemic approach to effective support; consistent to the existing literature base (Melin et al., 2022; O'Hagan et al., 2022; Preece & Howley, 2018). Figure 6 provides a visual representation of the themes applied to a model informed by Bronfenbrenner and Morris' (2007) bioecological paradigm of human development.

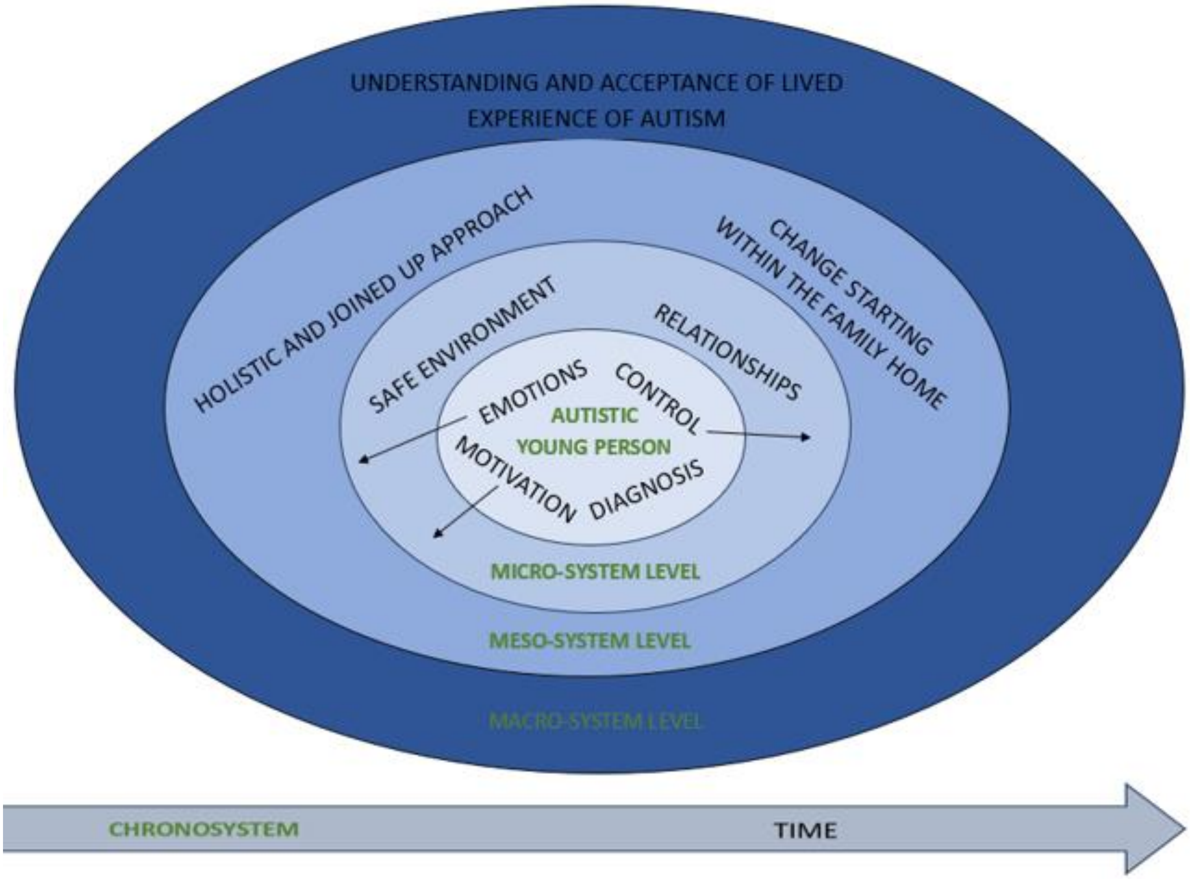


Figure 6. Thematic model of findings informed by the bioecological paradigm of human development (Bronfenbrenner & Morris, 2007).

Kas and Z’s first set of themes, namely Time, Motivation and Control, could be described as person-centred, proximal processes. Time, situated within the chronosystem, was a novel finding that extends other ecosystemic models of effective support for extended school nonattendance (Nuttall & Woods, 2013). The potential for autistic YP to experience time differentially to neurotypical YP was highlighted in a review of literature around autism and anxiety, which also promoted taking life at a self-directed pace (Neilson, 2023). Kas suggested that school nonattendance was consequential of incompatible demands and pace of her mainstream school. This protective mechanism is highlighted as a compensatory behaviour in wider literature (Goodall & MacKenzie, 2019). The theme of Motivation was previously introduced in literature around support for autistic pupils (Melin et al., 2022; O’Hagan et al., 2022; Preece & Howley, 2018). Z’s powerful comments around the impact of a lack of motivation upon mental health is supported by research reporting the impact of pervasive inertia upon autistic individuals’ wellbeing and daily functioning (Buckle et al.,

2021) . The source of motivation varied between participants: Kas discussed the motivation of attending college, whereas Z referred to a computer game. This highlighted the source of motivation as spanning home and school contexts. The theme of control concurs with best practice highlighted in a previous study with this cohort, whereby an individualised approach incorporated areas of interest and involvement in decision-making (Preece & Howley, 2018).

Kas and Z's second set of themes, Safe Environment and Relationships are situated within a young person's micro-systems and appeared to interact bi-directionally with each other and the preceding set. These themes are more practical and contextual to the environments autistic YP engage in, which potentially explains why they were supported by parental perspectives. The importance of safe environments is consistently reinforced in literature to promote wellbeing in autistic YP's experience of school and support for autistic pupils experiencing extended school nonattendance (Preece & Howley, 2018; Tomlinson et al., 2020). Existing literature promoted the importance of relational aspects of school (Goodall & MacKenzie, 2019; O'Hagan et al., 2022) and the current study concurred with the pertinence of positive relationships between autistic YP and professionals. Kas elaborated that time for relationship building is supportive to create a safe space in which to share her emotions which relates to methodological best practice in research for eliciting the views of autistic YP (Dewa et al., 2021). The current study challenged the perspective that friendships are always desired (O'Hagan et al., 2022) since social peer relationships were presented with multi-faceted complexity by Kas and Z. This reflected previous findings that autistic YP's perceptions of friendships may differ from neurotypical peers (Calder et al., 2013) and contributed a novel finding around Kas and Z's shared agreement of supportive practice removing the expectation for conversation to be a prerequisite of social relationships. Knage (2021) highlighted that research can redefine the perspective of difficulties; particularly in relation to when societal norms are challenged, who this is a problem for and why.

The positive impact of an autism diagnosis was discussed by Kas and parental participants and the perspective that diagnosis enabled effective support is aligned with previous research (O'Hagan et al., 2022). In comparison, Z did not perceive this as important theme, however a pertinent reflection upon the PI process related to increased consideration of his autistic identity. This finding is interesting to consider vis-à-vis research that suggests higher autistic-identity satisfaction to be positively associated with psychological wellbeing (Cooper et al., 2022).

The themes developed by Kas and Z were complemented by parental ones, which are potentially situated within the YP's meso-system. The parental theme of Joined Up and Holistic Approach is reflected in wider literature (O'Hagan et al., 2022; Preece & Howley, 2018), however the theme of Change Starting Within the Family Home is a novel finding from this study. The author-identified theme Understanding and Acceptance of Lived Experience of Autism highlighted the positive impact of a school setting that was perceived to meet the needs of autistic YP and is an example of macro-systemic influence. This theme is congruent to the pertinence of the environment highlighted by the neurodiversity paradigm (Pellicano & den Houting, 2022). Kas appeared to experience a shift of self-awareness about her extended school nonattendance from internalised blame and shame to a contextual and interactional perspective. This highlights the ongoing need for mainstream settings and environments to gain further understanding of the social model of autism and potential negative impact of incongruent social, physical and emotional expectations. Furthermore, findings support wider literature's recommendations that autistic YP may benefit from the opportunity to explore their autistic identities (Tomlinson et al., 2020). Kas and Z's themes indicate key principles for professionals to consider when supporting and eliciting the views of autistic YP who experience extended school nonattendance.

This PI embraces the contradictions and complexities of lived experience for a small number of autistic YP aligned with priorities from the neurodiversity paradigm (Guldberg, 2017), however there are several limitations to consider. Firstly, the autistic YP involved in this study were highly articulate and eliciting the views of a diverse range of autistic voices should be a priority in future research (Fletcher-Watson et al., 2019). Furthermore, the unique attributes of the author and support provided by the professional from the research site may limit theoretical generalisability. It may be beneficial for future participatory research to explore the application of key themes to a framework to support autistic YP experiencing extended school nonattendance. Kas reflected that she recognised that the fast pace and anxiety caused by the mainstream environment was ongoing so took potentially functional and meaningful action (Knage, 2021) by *'stopping'* attending school. Kearney's (2002) widely applied four-functions of school nonattendance behaviour may need modification to include factors pertinent to autistic pupils.

In summary, this PI aimed to elicit the views of autistic YP around effective support for extended school nonattendance. Kas and Z's voices were positioned centre-stage and supported by the integration of parental interviews and an author-developed theme. Findings were aligned with the social model of autism and highlighted the importance of individuals and contexts that understand and accept the lived experiences of autistic YP. The methodology and themes developed by the YP suggest key considerations for professionals to develop practice to support autistic YP who experience extended school nonattendance.

References

Adams, D., McLucas, R., Mitchelson, H., Simpson, K., & Dargue, N. (2022). Form, function and feedback on the school refusal assessment scale-revised in children on the autism spectrum. *Journal of Autism and Developmental Disorders*, *52*(5), 2156–2167. https://doi.org/10.1007/s10803-021-05107-4

Braun, V., & Clarke, V. (2021). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology*, *18*(3), 328–352. https://doi.org/10.1080/14780887.2020.1769238

Bronfenbenner, U., & Morris, P. (2007). The bioecological model of human develoment. In W. Damon & R. Learner. (Eds). *Handbook of Child Psychology.* (pp.793-828). Wiley.

Buckle, K. L., Leadbitter, K., Poliakoff, E., & Gowen, E. (2021). "No way out except from external intervention": First-hand accounts of autistic inertia. *Frontiers in Psychology*, *12*, 1–17. https://doi.org/10.3389/fpsyg.2021.631596

Calder, L., Hill, V., & Pellicano, E. (2013). "Sometimes i want to play by myself": Understanding what friendship means to children with autism in mainstream primary schools. *Autism*, *17*(3), 296–316. https://doi.org/10.1177/1362361312467866

Carroll, C., & Twomey, M. (2021). Voices of children with neurodevelopmental disorders in qualitative research: A scoping review. *Journal of Developmental and Physical Disabilities*, *33*(5), 709–724. https://doi.org/10.1007/s10882-020-09775-5

Cooper, K., Russell, A. J., Lei, J., & Smith, L. G. E. (2022). The impact of a positive autism identity and autistic community solidarity on social anxiety and mental health in autistic young people. *Autism*, *X*. https://doi.org/10.1177/13623613221118351

Corcoran, S., & Kelly, C. (2022). A meta-ethnographic understanding of children and young people's experiences of extended school non-attendance. *Journal of Research in Special Educational Needs*, 1–14. https://doi.org/10.1111/1471-3802.12577

Cornwall, A., & Jewkes, R. (1995). What is participatory research? *Social Science and Medicine*, *41*(12), 1667–1676. https://doi.org/10.1016/0277-9536(95)00127-S

Danker, J., Strnadová, I., & Cumming, T. M. (2016). School experiences of students with autism spectrum disorder within the context of student wellbeing: A review and analysis of the literature. *Australasian Journal of Special Education*, *40*(1), 59–78.

https://doi.org/10.1017/jse.2016.1

Dewa, L. H., Lawrence-Jones, A., Crandell, C., Jaques, J., Pickles, K., Lavelle, M., Pappa, S., & Aylin, P. (2021). Reflections, impact and recommendations of a co-produced qualitative study with young people who have experience of mental health difficulties. *Health Expectations*, *24*, 134–146. https://doi.org/10.1111/hex.13088

Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using Thematic Analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods*, *5*(1), 80–92. https://doi.org/10.1177/160940690600500107

Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J. R., & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism*, *23*(4), 943–953. https://doi.org/10.1177/1362361318786721

Gergen, K. J. (1985). The Social Constructionist Movement in Modern Psychology. *American Psychologist*, *40*(3), 266–275. https://doi.org/10.1037/0003-066X.40.3.266

Goodall, C., & MacKenzie, A. (2019). Title: what about my voice? Autistic young girls' experiences of mainstream school. *European Journal of Special Needs Education*, *34*(4), 499–513. https://doi.org/10.1080/08856257.2018.1553138

Guldberg, K. (2017). Evidence-based practice in autism educational research: can we bridge the research and practice gap? *Oxford Review of Education*, *43*(2), 149–161. https://doi.org/10.1080/03054985.2016.1248818

Heron, J., & Reason, P. (1997). Inquiry Paradigm. *Qualitative Inquiry*, *3*(3), 274–294. http://journals.sagepub.com/doi/pdf/10.1177/107780049700300302

Heyne, D., Gren-Landell, M., Melvin, G., & Gentle-Genitty, C. (2019). Differentiation between school attendance problems: Why and how? *Cognitive and Behavioral Practice*, *26*(1), 8–34. https://doi.org/10.1016/j.cbpra.2018.03.006

Humphrey, N., & Lewis, S. (2008). What does "inclusion" mean for pupils on the autistic spectrum in mainstream secondary schools? *Journal of Research in Special Educational Needs*, *8*(3), 132–140. https://doi.org/10.1111/j.1471-3802.2008.00115.x

Kearney, C. A. (2002). Identifying the function of school refusal behavior: A revision of the School Refusal Assessment Scale. *Journal of Psychopathology and Behavioral Assessment*, *24*(4), 235–245. https://doi.org/10.1023/A:1020774932043

Kirby, P. (2020). 'It's never okay to say no to teachers': Children's research consent and dissent in conforming schools contexts. *British Educational Research Journal*, *46*(4), 811–828. https://doi.org/10.1002/berj.3638

Knage, F. S. (2021). Beyond the school refusal/truancy binary: Engaging with the complexities of extended school non-attendance. *International Studies in Sociology of Education*, 1–25. https://doi.org/10.1080/09620214.2021.1966827

Leduc, K., Tougas, A. M., Robert, V., & Boulanger, C. (2022). School refusal in youth: A systematic review of ecological factors. *Child Psychiatry and Human Development*, 1–19. https://doi.org/10.1007/s10578-022-01469-7

Melin, J., Jansson-Fröjmark, M., & Olsson, N. C. (2022). Clinical practitioners' experiences of psychological treatment for autistic children and adolescents with school attendance problems: A qualitative study. *BMC Psychiatry*, *22*(1), 1–12. https://doi.org/10.1186/s12888-022-03861-y

Munkhaugen, E. K., Torske, T., Gjevik, E., Pripp, A. H., & Diseth, T. H. (2019). Individual characteristics of students with autism spectrum disorders and school refusal behavior. *Autism*, *23*(2), 413–423. https://doi.org/10.1177/1362361317748619

Muylaert, C. J., Sarubbi Jr, V., Gallo, P. R., Neto, M. L. R., & Reis, A. O. A. (2014). Narrative interviews: an important resource in qualitative research. *Revista Da Escola de Enfermagem Da USP*, *48*(2), 184–189. https://doi.org/10.1590/s0080-623420140000800027

Neilson, C. (2023). *Autism, Anxiety and Extended School Non-Attendance.* [Unpublished manuscript]. School of Environment, Education and Development, University of Manchester.

Nuttall, C., & Woods, K. (2013). Effective intervention for school refusal behaviour. *Educational Psychology in Practice*, *29*(4), 347–366. https://doi.org/10.1080/02667363.2013.846848

O'Hagan, S., Bond, C., & Hebron, J. (2022). Autistic girls and emotionally based school avoidance: Supportive factors for successful re-engagement in mainstream high school. *International Journal of Inclusive Education*, 1–17. https://doi.org/10.1080/13603116.2022.2049378

Peat, G., Rodriguez, A., & Smith, J. (2019). Interpretive phenomenological analysis applied to healthcare research. *Evidence-Based Nursing*, *22*(1), 7–9.

https://doi.org/10.1136/ebnurs-2018-103017

Pellicano, E., & den Houting, J. (2022). Annual Research Review: Shifting from ‘normal science’ to neurodiversity in autism science. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, *63*(4), 381–396. https://doi.org/10.1111/jcpp.13534

Pickard, H., Pellicano, E., den Houting, J., & Crane, L. (2022). Participatory autism research: Early career and established researchers’ views and experiences. *Autism*, *26*(1), 75–87. https://doi.org/10.1177/13623613211019594

Preece, D., & Howley, M. (2018). An approach to supporting young people with autism spectrum disorder and high anxiety to re- engage with formal education – the impact on young people and their families the impact on young people and their families. *International Journal of Adolescence and Youth*, *23*(4), 468–481. https://doi.org/10.1080/02673843.2018.1433695

Rogers, C. (1957). The necessary and sufficient conditions of therapeutic personality change. *Journal of Consulting Psychology*, *21*(2), 95–103. https://pdfs.semanticscholar.org/be0c/5e70f4c17f12252071a61ae038bb1edcb13d.pdf

Rosqvist, H. B., Kourti, M., Jackson-Perry, D., Brownlow, C., Fletcher, K., Bendelman, D., & O’Dell, L. (2019). Doing it differently: Emancipatory autism studies within a neurodiverse academic space. *Disability and Society*, *34*(7–8), 1082–1101. https://doi.org/10.1080/09687599.2019.1603102

Simpson, K., Imms, C., & Keen, D. (2022). The experience of participation: Eliciting the views of children on the autism spectrum. *Disability and Rehabilitation*, *44*(9), 1700–1708. https://doi.org/10.1080/09638288.2021.1903100

Stone, E., & Priestley, M. (1996). Parasites, pawns and partners: Disability research and the role of non-disabled researchers. *The British Journal of Sociology*, *47*(4), 699–716. https://doi.org/86.190.94.178

Tomlinson, C., Bond, C., & Hebron, J. (2020). The school experiences of autistic girls and adolescents: a systematic review. *European Journal of Special Needs Education*, *35*(2), 203–219. https://doi.org/10.1080/08856257.2019.1643154

Tonge, B. J., & Silverman, W. K. (2019). Reflections on the field of school attendance problems: For the times they are a-changing? *Cognitive and Behavioral Practice*, *26*(1), 119–126. https://doi.org/10.1016/j.cbpra.2018.12.004

Tracy, S. J. (2010). Qualitative quality: Eight a"big-tent" criteria for excellent qualitative research. *Qualitative Inquiry*, *16*(10), 837–851. https://doi.org/10.1177/1077800410383121

Paper Three: The dissemination of evidence to professional practice

Introduction

Paper Three will explore the concepts of EBPP and PBE in relation to the role of the EP. This will be followed by an application of these themes to the field of autism research. An overview of effective approaches to dissemination and the notion of research impact will be provided. The implications of research findings from Papers One and Two will be discussed across the contexts of the research site and organisational and professional levels. Finally, a strategy will be presented to disseminate and evaluate the impact of research.

EBPP and PBE and the role of the EP

EBPP has been defined as “the best available research with clinical expertise in the context of patient characteristics, culture and preferences” (APA, 2006, p. 273). EBPP refers to a diverse range of activities including consultation, assessment, formulation, therapeutic relationships and intervention (APA, 2006). The fundamentals of EBPP are encompassed in a number of the standards of proficiency outlined by the HCPC (2015) for all practitioner psychologists including: “be able to engage in evidence-based and evidence-informed practice, evaluate practice systematically and participate in audit procedures” (standard 12.1).

EBPP is underpinned by the notion of what works as opposed to an individual’s belief or opinion (APA, 2006) and traditionally the quality of the ‘best available research’ is evaluated by a hierarchy of research quality. Figure 6 highlights that systematic reviews of RCTs are widely accepted as the ‘gold standard’ whereas more qualitative designs including an expert’s opinion feature at the bottom of the hierarchy (Fox, 2003).

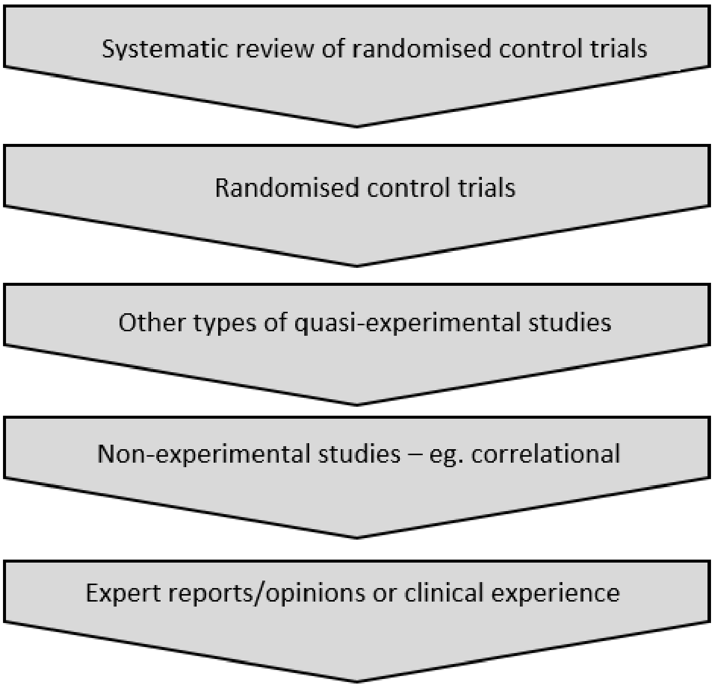


Figure 7. Hierarchy of research evidence (summarised from Fox, 2003, p. 93)

The relevance of this hierarchy for EPs to determine 'best available research' is contentious due to notable limitations in relation to the dominance of RCTs (Fox, 2003, 2011; Sedgwick & Stothard, 2021). RCTs and other experimental research methods are aligned with positivism that determines scientific knowledge to report upon an objective truth (Fox, 2003) and based on the assumption that monolithic approaches are acceptable for all (Fox, 2011). This epistemological perspective is potentially incongruent with the unique complexities inherent in real-world practice (Cook & Cook, 2016; Fox, 2011; Stewart-Brown et al., 2011). Boyle and Kelly (2017) discussed challenges within the research-practice gap and effectively implementing 'gold standard' research to real-world situations. The field of implementation science has made a significant contribution through highlighting the importance of implementation for intervention outcomes (Humphrey et al., 2018).

The second component of EBPP related to 'clinical expertise' and one definition of the role of the EP is "an agent of change across the core functions of consultation, assessment, intervention, training and practitioner research" (Boyle & Kelly, 2017, p. 29). The core function of research delineates the potential for EPs to be involved in PBE (Fox, 2003), further challenging the unquestioned supremacy of the traditional research hierarchy and

RCTs. PBE is conceptualised to embrace the 'messy real-world' and generate research that is simultaneously experiential, supported by practitioners, and contextual, emanating from practice in-situ (Cook & Cook, 2016; Kratochwill et al., 2012). Literature would suggest that the concepts of PBE and EBPP are not diametrically opposed but mutually reinforcing (Cook & Cook, 2016; Kovacs, 2015; Kratochwill et al., 2012). The knowledge developed through PBE can inform more contextually applicable and culturally informed EBPP (Kratochwill et al., 2012), which consequently supports further PBE (Cook & Cook, 2016). The approaches are also complementary since they address each other's limitations: there are no controls in place in PBE and therefore success could be attributed to flawed practice, whilst EBPP's efficacy is achieved in controlled environments which minimises the generalisation of evidence and fails to address issues around implementation (Cook & Cook, 2016). The reciprocally-beneficial, cyclical relationship is effectively encapsulated through Figure 7.

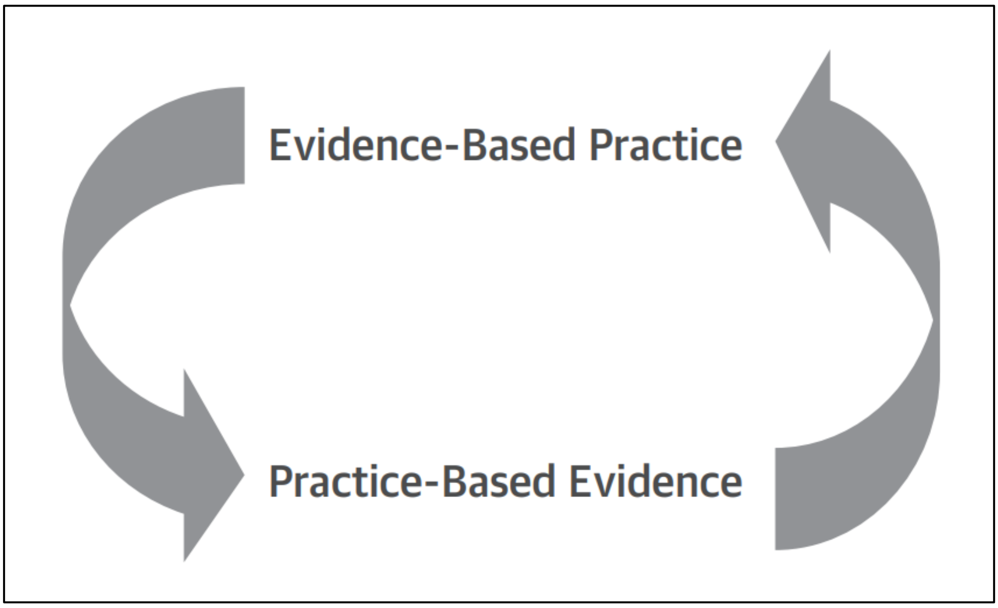


Figure 8. Graphical representation of the cycle between PBE and EBPP (Kovacs, 2015, p. 1235)

EBPP and PBE and autism research

Autism is a lifelong neurodevelopmental condition; characterised by the neurodiversity paradigm as a divergent collection of strengths and needs across contexts and the lifespan (Fletcher-Watson & Happé, 2019). Autism is believed to affect 1 in 100 individuals in the UK, however widely hypothesised to be higher (Happe & Frith, 2020) exemplified by a NHS (2022) report that detailed open referrals to have risen by almost a third during 2021.

Paper One reported high co-occurring rates with mental health difficulties (Happe & Frith, 2020; Lai et al., 2019) and Paper Two explored support for extended school nonattendance, which is a possible consequence of anxiety. Extended school nonattendance is described as problematic for autistic pupils with significant immediate and long-term adverse outcomes relating to poor educational experiences (Totsika et al., 2020) and poor quality of life, social participation and employment (Tonge & Silverman, 2019). Effective practice to support the inclusion of autistic pupils in education is therefore a priority area of consideration in relation to a discussion of EBPP and PBE.

EPs reported 30% of their caseload to be related to the implementation of interventions for autistic pupils (Robinson et al., 2018). There is an established literature base related to EBPP interventions for autistic pupils (Robinson & Bond, 2017; Wong et al., 2015), which targeted outcomes including academic, social, communication and behavioural (Robinson & Bond, 2017). Factors identified to impact upon EPs decision-making processes around the choice of intervention "were broadly consistent with models of EBPP and included: individual students' needs, values and preferences; available resources; and school context" (Robinson et al., 2018, p. 70).

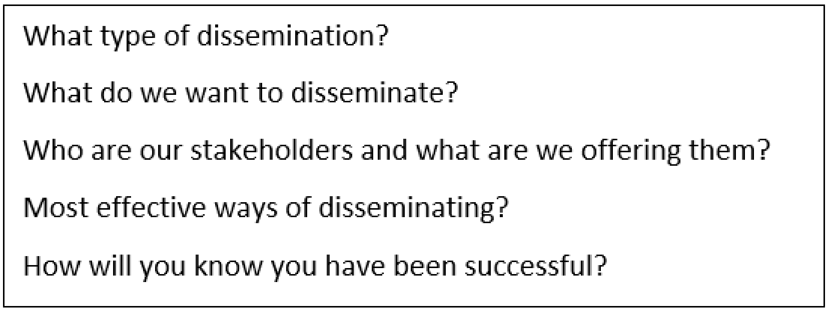
Autism research also highlighted a research-practice gap (Guldberg, 2017; Parsons & Kasari, 2013) and EBPP's applicability to school contexts. Issues related to fidelity of implementation are pertinent across literature (Robinson & Bond, 2017; Wong et al., 2015) since adaptations for the individual needs of pupils may negatively impact the efficacy (Robinson & Bond, 2017) and professional competence was also reported as a barrier to intervention delivery (Wong et al., 2015). School staff identified challenges to implementation of EBPP including training, time, support materials and mind-set (Silveira-Zaldivar & Curtis, 2019) and prioritised the social validity of interventions (McNeill, 2019). The potential of PBE was promoted through collaborative models of practice between school staff and researchers (Parsons et al., 2013) and the assertion that conducting school-based research can support the inclusion of marginalised children in research (Parsons & Kasari, 2013). Furthermore, empirical literature has reported positive outcomes for autistic pupils using PBE in comparison to an EBPP approach (Locke et al., 2019).

Contemporary autism research driven by the neurodiversity paradigm and autistic community extended a discussion around EBPP and PBE to interrogate how the outcomes of intervention are conceptualised (Milton, 2014). Intervention research is situated within the medical model of autism and underpinned by the premise of autistic pupils' deficits, particularly in relation to social skills (Locke et al., 2019; Silveira-Zaldivar & Curtis, 2019). Paper One highlighted an alternative perspective that difficulties experienced by the autistic community are a result of living within neurotypical environments (Fletcher-Watson & Happé, 2019; Pellicano & den Houting, 2022) and differences in neurological development representative of natural diversity between individuals (Milton, 2014).

Papers One and Two highlighted issues around EBPP and PBE in the context of research priorities for autism research. They reported a misalignment between the positivist experimental designs of traditional autism research and qualitative priorities of the autistic community (Guldberg, 2017): to situate research within habitual realities and celebrate broad, diverse and subjective perspectives (Crane & Pellicano, 2022; Guldberg, 2017; Pellicano & den Houting, 2022). Therefore, Paper Two adopted a PI methodology to ensure the meaningful participation of autistic YP (Fletcher-Watson et al., 2019; Happe & Frith, 2020; Pellicano & den Houting, 2022).

Effective dissemination and notions of research impact

The challenges discussed in relation to the research-practice gap suggests that dissemination of research is an integral step in the research process. A high degree of variability in the definition of dissemination has been acknowledged (Baumann et al., 2022). The following definition is perceived as applicable to Paper Three: "a planned process that involves consideration of target audiences and the settings in which research findings are to be received and, where appropriate, communicate and interacting with wider policy and health service audiences in ways that will facilitate research uptake in decision-making and practice" (Wilson et al., 2010, p. 2). Baumann (2022) has identified four constructs to consider vis-à-vis dissemination: process, determinants, strategies and outcomes. *Process* related to the steps a researcher carries out to disseminate research. The concept of *determinants* highlighted the importance of considering contextual factors that potentially act as facilitators or barriers to the success of dissemination. The construct of *strategies* helped structure the approach to dissemination. Finally, *outcomes* related to the knowledge to be gained through dissemination. Harmsworth & Turpin (2000) identified pertinent questions to ask in conjunction with the development of a dissemination strategy outlined in Table 3.



What type of dissemination?

What do we want to disseminate?

Who are our stakeholders and what are we offering them?

Most effective ways of disseminating?

How will you know you have been successful?

Table 3. Questions to underpin a dissemination strategy (summarised from Harmsworth & Turpin, 2000)

Harmsworth & Turpin proposed (2000) a three-level typology of dissemination: for awareness, understanding and action. At the first level of *awareness*, knowledge gained enables surface interest and knowledge of the research base. At the second level of *understanding*, a more targeted approach facilitates greater engagement and comprehension of research. At the final level of *action*, dissemination is provided for stakeholders well-positioned to apply research finding to policy and practice.

The choice of dissemination method varies according to a well-formulated strategy. Traditional dissemination methods, such as journal articles, books and contributions to conferences, have undergone a transformation in recent years due to increased access to the internet and digital network technologies (Deeken et al., 2020; Ross-Hellauer et al., 2020). Traditional formats have been digitised and new methods, including social media and blogs, gained acceptance and popularity (Ross-Hellauer et al., 2020). The popular social media site of 'Twitter' has been cited to increase the readership of journal articles; evidenced through increased numbers of downloads and views (Ibrahim et al., 2017). The benefits of innovative dissemination formats are discernible through decreased time-lags (Deeken et al., 2020) and greater access to research findings among a burgeoning audience

(Ross-Hellauer et al., 2020). Furthermore, the participation of non-research stakeholders and increased research collaborations has been identified as a strength of social media (Deeken et al., 2020; Ross-Hellauer et al., 2020). Geller (2022, p. 66) highlighted an alternative perspective, that social media typifies an endless propagation of opinions and advice related to psychological wellbeing that are potentially biased and misleading, which "makes the need for public dissemination of evidence-based applied psychological science ever more vital." Faster dissemination of research is also not viewed positively unilaterally; exemplified through reported concerns pertaining to the quality of research that was produced potentially too quickly during the COVID-19 pandemic (Khatter et al., 2021). The use of social media has the opportunity to complement traditional dissemination methods; however, literature suggests careful consideration of use.

The notion of research impact has been alluded to in relation to the importance of evaluating the impact of dissemination (Harmsworth & Turpin, 2000) and a distinction between academic and socio-economic impact has been proposed (Penfield et al., 2014). Reed and colleagues (2021) identified principles used to assess impact via *significance*, the intensity or size of effect upon stakeholders and *reach*, number or diversity of stakeholders that profit from the research. The cited study also highlighted differing levels of provenance between research and impact, whereby *necessary* refers to a significant contribution situated among a wider field, whereas *sufficient* denotes a unique contribution generated by the research alone (Reed et al., 2021). In relation to evidencing research impact, researchers reported the potential challenges of expertise, time and resources vis-à-vis benefits of a raised academic profile and future collaborations (Wilkinson, 2019). It has been proposed that the benefits of research is subjective and specific to epochal and socio-cultural factors (Reed et al., 2021). Therefore, a discussion of impact has a temporal dimension and may change both positively or negatively across time.

There are numerous types of evidence available to provide an overview of impact, which range from experimental and statistical approaches to qualitative methodologies testimonials and arts-based methods (Reed et al., 2021; Sordé Martí et al., 2020). In line with quality of evidence more broadly, positivist approaches are generally considered more favourably (Reed et al., 2021) and qualitative approaches criticised for an over-reliance on opinions and perspectives that cannot be triangulated or replicated (Sordé Martí et al., 2020). However, quantitative methods are potentially not sufficient to grapple with the complexities inherent within research from the domains of social sciences and humanities (Sordé Martí et al., 2020). Qualitative approaches on the other hand, have the potential to generate a holistic and contextual picture of impact, characterised by dialogue and the participation of stakeholders.

Policy, practice and research development implications from Papers One and Two

The following section will provide an overview of the research findings from Papers One and Two. Implications for policy, practice and/or research development at the research site, organisation level and professional level will also be summarised.

Overview of Research findings

Paper One, a thematic synthesis review, explored experiences of anxiety for autistic CYP from the perspectives of autistic CYP and their parents. This study concluded that experiences of anxiety are heterogeneous between CYP and across contexts. Experiences of anxiety are inconsistently understood between CYP and their parents, parents reported behavioural expressions of anxiety whereas CYP's views enabled a greater understanding of related cognitive processes and emotions. Autistic CYP appeared to experience trait anxiety, aspects of which are interchangeable with wider autistic characteristics, however neurotypical environments potentially contributed to state anxiety. Autistic CYP reported a potentially unique relationship with time, which impacted upon or mediated experiences of anxiety.

Paper Two, a PI design, adopted a flexible and reflective approach with two autistic pupils who experienced extended school nonattendance. This study aimed to explore how Kas and Z described effective support to meet their needs. They identified key themes of effective support: a nuanced relationship with time; internal processes of control and motivation; relationships and safe environments; and perspectives around their diagnosis of autism. These themes were complemented by parental perspectives and the author generated a superordinate theme of ‘Understanding and Acceptance of Individual and Lived Experience of Autism.’

Implications at the research site

Papers One and Two highlighted the importance of environments being supportive and accepting of autistic pupils and negative impact upon anxiety and school attendance of environments that maintained neurotypical norms and expectations. Paper Two outlined effective practices at the specialist setting that embraced individual difference and freed the YP from incongruent societal norms, particularly in relation to preferred forms of social communication and complexity of relationships. The YP agreed they sometimes preferred to be silent and a school environment where they were not forced to speak, and being among peers who felt the same, was supportive and encouraged school attendance. Furthermore, YP and parental perspectives highlighted that the school felt like a *‘family’* and safe environment. Paper Two, as a whole, identified key themes that described effective practice that should be celebrated by the research site. The implications from this research have the potential to be further imbedded into school policies and through training to ensure effective practice is maintained across time and staff members.

There are also important implications for autistic CYP. Paper Two provided Kas and Z with the opportunity to reflect upon the involvement in the research process, which suggested ways participation in a PI had met their individual needs. Kas highlighted the positive impact of being able to talk about her experiences without it being *‘dissected.’* Furthermore, she suggested that working alongside another autistic YP and hearing their experiences was helpful. Kas also discussed how gaining understanding that school nonattendance and autism could be related and happened to a lot of people encouraged a shift from internalised self-blame and shame to a contextual and interactional perspective. Similarly, Z reflected that it had been *‘nice to take an introspective look’* at his autism, which increased an interest in his autistic identity. These reflections suggest that it may be important to share the finding from Papers One and Two with other autistic young people for psychoeducation and also to highlight that they are not alone in experiencing anxiety and significant difficulties with attending school. Z stated that he hoped the research would benefit others; '*something to feel like they are not alone. Because sometimes […] it gets lonely […] in this ship of mine.'*

Implications at the Organisational Level

In Paper Two, effective support described for autistic YP experiencing extended school nonattendance involved multi-agency professionals across the LA, including mainstream schools, CAMHs, SEND teams and EWOs. The parental theme of 'Joined Up and Holistic Approach' highlighted the imperative that multi-agency professionals work collaboratively around the child. It would be important to disseminate findings from Papers One and Two to multi-agency professionals from across the LA. Furthermore, parental interviews identified a significant interaction between anxiety, autism and physical pain or illness, which would suggest that medical practitioners would also benefit from access to the findings. A key implication from Paper One for multi-agency professionals to consider is that an expression of anxiety may differ between contexts, and effective support identified in Paper Two occurred at different ecological levels. This emphasised the importance of multi-agency professionals viewing school nonattendance as an interactionist and ecosystemic phenomenon rather than maintaining a within-child perspective.

Papers One and Two are aligned with the neurodiversity paradigm and professionals at an organisational level may benefit from a greater understanding of key concepts around a social model of autism. A significant theme in Paper Two, 'Understanding and Acceptance of Individual Lived Experience of Autism' supported the findings from Paper One around the development of safe environments that avoid the identified pitfalls of maintaining a neurotypical lens around social, physical and emotional expectations. In Paper Two, Kas reflected upon school nonattendance as consequential of the incompatible demands from a mainstream school environment. At a policy level, a more unified approach across LAs is required to provide essential accommodations to autistic CYP. Papers One and Two identified autistic CYP to have a potentially unique relationship with 'Time.' Paper One highlighted that autistic CYP may experience more persistent and intense anxiety and suggested effective anxiety management strategies to support organisational and time-management skills. In Paper Two, 'Time' was identified as the most important theme by both YP: effective support for school nonattendance included life being taken at a self-directed pace and negative impact of externally imposed time-constraints for task completion was highlighted. Furthermore, supportive relationships were established over time. A significant implication here is to provide staff working with autistic CYP, experiencing difficulties attending school, adequate funding to provide bespoke and time-intensive support.

Implications at the Professional Level

This thesis was commissioned by an EPS who were keen to extend the research base around understanding the experiences of autistic pupils experiencing anxiety and extended school nonattendance. A key implication for the EP profession pertains to the high prevalence of autistic CYP experiencing anxiety and extended school nonattendance. If a pupil experiencing these difficulties does not have an autism diagnosis, EPs are well positioned to support multi-agency professionals to consider social communication and interaction need as a hypothesis. It is reported that over 70% of autistic pupils attend mainstream schools in England (NAS, 2021), however teachers have expressed a need for greater training around autism in order to achieve inclusive classrooms (Able et al., 2015). EPs can play a crucial role in supporting educational professionals to further develop their expertise in supporting autistic pupils (Bond et al., 2017). A key implication from Paper One for EPs relates to autistic CYP's various behavioural presentations of autism that have the potential to be misinterpreted. The key findings from Paper Two have been developed into a thematic map; EPs may find this model a useful starting point in practice to support autistic CYP, families and the professionals around them. Both Papers highlighted that a positive autistic identity may be a protective factor to reduce anxiety and increase wellbeing (Cooper et al., 2022): a key concept that EPs could support CYP and school staff to understand.

A further implication for EPs relates to authentic methods for capturing the views and priorities of autistic CYP. Paper One suggested standardised measures may prove insufficient when capturing cognitively and less cognitively able CYP's experiences of anxiety across different contexts. Paper Two adopted a PI approach, and prioritised a flexible and reflexive structure to data gathering with the young people, which ensured their preferences were respected. In this instance, Kas and Z expressed the wish to take a conversational approach whereby a visual aid was used as a stimulus for discussion. The author maintained an interaction style informed by humanistic principles and the presence of a familiar adult supported the creation of a safe space to enable the autistic YP to share their views. Wider research has highlighted the priority for practitioners to be innovative when finding ways to elicit the voice of autistic CYP's with communication and expression difficulties (Carroll & Twomey, 2021). Verbal methods may need to be extended with other more visual and creative methods (Carroll & Twomey, 2021) such as photo elicitation (Courcy & Koniou, 2022) and Lego building (Scott-Barrett et al., 2022).

Finally, Papers One and Two have crucial implications for further research into the field of autism, anxiety and extended school nonattendance. Paper One noted the utility of including the perspectives of parents and CYP, however that the voices of less cognitively-able or non-verbal CYP not represented: this should be addressed in future research. Secondly, the paper identified a significant paucity of empirical research around anxiety in the home and community contexts. Furthermore, Paper One concurred with Happé & Frith's (2020) recommendation around future research to explore resilience factors that sustain wellbeing in autistic CYP. Paper Two acknowledged that the unique characteristics of the author and support provided by the research setting's key professional may limit theoretical generalisability of the findings. Future participatory research, whereby the key themes are applied to an evaluated framework to support autistic CYP experiencing extended school nonattendance, would strengthen and extend Paper Two's findings. Finally, Paper Two suggested the utility of adapting Kearney's (2002) four-factor functional analysis of school nonattendance behaviour to encompass factors unique to autistic pupils.

Strategy to promote and evaluate the dissemination and impact for Papers One and Two

The overarching aim of this thesis was to respond to the call within the neurodiversity paradigm for qualitative and participatory research to understand autistic CYP's lived experiences (Fletcher-Watson et al., 2019). Paper Three has highlighted the importance of a well-planned dissemination strategy to overcome the discussed challenges associated with the research-practice gap.

An overview of the specific plan to disseminate findings and evaluate impact of research across the research site, organisational and professional level is presented in Table 4. Harmsworth & Turpin (2000) differentiated levels of dissemination: for awareness, understanding or action, however the supplementary level of *trustworthiness* has been added to meet the specific requirements of disseminating this research. Due to the idiographic nature and small sample size of research described in Paper Two, it is important that feedback is sought from key partners to assess face validity and acceptability (Lincoln & Guba, 1985). Reed and Colleagues (2021) proposed differing relationships between research and impact, whereby research is alternatively *necessary* or *sufficient.* Paper Two represents *necessary* research and it is important to highlight the author's commission is situated vis-à-vis wider commissions around school nonattendance. Furthermore, extended school nonattendance is currently a key area for EPs; the research is also positioned alongside professional developmental work being carried out within the commissioning EPS and practice placement EPS.

The author is keen to ensure that findings from Paper Two are disseminated to a range LA professionals to support professional practice. The author has commenced an action research cycle with a group of stakeholders, which includes EPs, and Director of an online community for autistic YP. The first cycle of feedback has been received from stakeholders (Appendix 14). The action research aims to develop a tool to support LA professionals' practice to provide effective support for autistic CYP who experience extended school nonattendance.

Furthermore, the author has submitted Papers One and Two for peer review for publication in academic journals in order to extend the reach and impact of the research. Paper One has been submitted to Research in Autism Spectrum Disorders, which publishes empirical articles and reviews that contribute to a better understanding of autism and cite psychological and medical cooccurring conditions as an under-researched field. Paper Two has been submitted to JORSEN for a forthcoming special edition on neurodiversity.

Conclusion

A discussion of EBPP and PBE in relation to the role of the EP identified a cyclical and mutually-beneficial relationship between the two concepts. Contemporary autism research highlighted a misalignment between traditional positivist research and the priorities of the autistic community and this thesis prioritised qualitative and participatory methodologies to explore the lived experiences of autistic CYP. Effective dissemination and evaluation of impact of research is integral to ensure that research is shared at the research site and organisational and professional levels. Finally, a specific dissemination strategy has been developed in order that Papers One and Two successfully informs future practice, policy and research to support autistic CYP who experience anxiety and extended school nonattendance.

Audience	Rationale for sharing research	Method of dissemination	Dissemination level(s)	Timescale	Evidenced or desired impact
Research site					
Research Participants	Paper Two • Understand findings • Celebrate participation in research	• Feedback of themes document (Appendix 15)	Understanding & Trustworthiness	March 2023	• Summative correspondence from participants
School staff	Paper Two • Celebration of identified positive practice • Opportunity for school staff to reflect on effective practice described	• Feedback of themes document • Workshop-style presentation that incorporates a presentation of Paper Two findings and opportunity for discussion	Understanding, Action & Trustworthiness	March 2023 Summer Term 2023	• Evaluation of workshop – including pre & post perspectives around positive practice • Action planning to develop policy • Described improved confidence and practice among staff • Increased attendance figures
Organisational level					
LA multi-agency professionals involved with supporting school	Paper Two • Awareness of research that has taken place within their LA, including prevalence of autistic pupils	• Research cited by commissioners during presentation around attendance (Appendix 16) • Research findings to inform training for schools around	Awareness Understanding & Action	October 2022 Summer & Autumn Term 2023	• LA EBSA pathway integrating research • Described improved confidence and

nonattendance (commissioning LA)	experiencing extended school nonattendance - Understanding of best practice described by YP and their families - Tools and approaches to improve professional practice	school nonattendance as part of LA's inclusion strategy			practice among multi-agency staff
LA multi-agency professionals involved with supporting school nonattendance (practice placement LA)	Papers One and Two - Awareness of research that has taken place around anxiety, autism and school nonattendance - Understanding of best practice described by YP and their families - Inform development of LA's strategy to support extended nonattendance - Tools and approaches to improve professional practice	- Presentation of Paper Two findings at a LA multi-agency EBSA meeting - Use of Microsoft Teams communication platform to share materials including articles	Awareness Understanding & Action	February 2023 Summer Term 2023	- Questions and feedback after presentation at LA multi-agency meeting - Described improved confidence and practice among multi-agency staff
Specialist setting (practice placement LA)	Paper Two - Understanding of best practice described by YP and their families - Supporting practitioner skills and confidence	- Workshop-style presentation that incorporates a presentation of Paper Two findings and opportunity for discussion	Understanding, Action & Trustworthiness	April 2023	- Evaluation of workshop – including pre & post perspectives confidence and skills to support

	working to support autistic pupils • Opportunity to reflect findings and apply to practice				nonattendance of autistic pupils • Discussion points from reflective questions (Appendix 17) • Described improved confidence and practice among staff • Increased attendance figures
Autistic community (NW online autistic community group)	Papers One & Two • Awareness of research that has taken place around anxiety, autism and school • Sharing information of best practice shared by autistic CYP and their parents • Opportunity for autistic community to feedback and reflect on findings	• Informal information sharing at a meeting with member of autistic community (Director of online group) • Attendance at writing workshops attended by autistic CYP and their parents to explore barriers to education • Workshop-style presentation that incorporates a presentation of Paper Two findings and opportunity for discussion • Co-production of young person friendly document	Awareness Awareness Understanding & Trustworthiness Understanding, Action & Trustworthiness	June 2022 July 2022 Summer – Autumn Term 2023	• Positive feedback provided to Director of online group after involvement in writing workshops • Reflections and questions around T2 findings • Feedback about young person friendly document

Professional level					
DECP Trainee and Lecturers	Paper One & Two • Key findings related to lived experience of anxiety • An overview of the key findings from Paper Two • Application to future research and current practice • Awareness of ways in which thesis fits in with wider research being carried out within EBSA project group	• Presentation at a DECP cross-cohort day – presentation of findings from a preliminary study that informed Paper Two's development (Appendix 18) • Overview of progress of research provided at EBSA project group meetings.	Awareness, Understanding, Action & Trustworthiness	March 2022 September 2022 & January 2023	• Invitation from my supervisor and a previous trainee to collaborate on a future research commission • Request to include T2 research in an application for an autistic symposium collaboration in 2024
MIE Postgraduate student	• Insight into processes of applying for high-risk ethical approval via UREC	• University supervisor used Paper Two as a case-study during a seminar around 'Ethical practices in high-risk research' (Appendix 19)	Understanding & Action	February 2023	• Improved ethical applications for high-risk research
EPs from commissioning EPS, practice placement EPS and nationally	Papers One & Two • Described experiences of anxiety by autistic CYP and their parents and synthesised thematic analysis • Insight into social model of autism and	• Iterative development of checklist for professional practice with commissioning EPs and at practice placement. • Presentation for EP CPD at practice placement – Paper One (Appendix 20)	Understanding, Action & Trustworthiness Understanding & Action	Summer – Autumn Term 2023 March 2023	• Feedback from colleague EPs around development of checklist for professional practice

	priorities from neurodiversity paradigm for participatory research • Overview of PI methodology and application of approach to research and practice • Understanding of lived experience around effective support for autistic YP who experience extended school nonattendance • Opportunity to reflect and apply T2 findings to professional practice	• CPD session at practice placement – Workshop-style presentation that incorporates a presentation of Paper Two findings and opportunity for discussion and application to practice • CPD session at commissioning EPS – Workshop-style presentation that incorporates a presentation of Papers One & Two findings and opportunity for discussion and application to practice • Presentation of Papers One and Two findings at NW EP conference (Appendix 22) • Contribution to a chapter around autism and school nonattendance for an online CPD course https://edpsyched.co.uk/ebs-horizons	Understanding, Action & Trustworthiness Understanding, Action & Trustworthiness Understanding & Action Understanding & Action	Autumn Term 2023 Autumn Term 2023 December 2022 Summer Term 2023	• Response via Mentimeter (Interactive presentation software) to reflective questions on Paper One from CPD delivered to EPs at practice placement (Appendix 21) • NW EP conference evaluation (Appendix 23)
International School Psychologists and Researchers	Paper Two • Insight into social model of autism and priorities from neurodiversity paradigm for participatory research	• Presentation of research at 44th Annual ISPA conference https://2023.ispaweb.org/call-for-papers/	Understanding & Action	July 2023	• Notes from discussion after presentation and participant evaluation

	• Overview of Participatory Inquiry methodology and application of approach to research to EP practice • Understanding of lived experience around effective support for autistic YP who experience extended school nonattendance • Application of findings to professional practice				

Table 4. Strategy to disseminate research and evaluate impact

References

Able, H., Sreckovic, M. A., Schultz, T. R., Garwood, J. D., & Sherman, J. (2015). Views from the trenches: Teacher and student supports needed for full inclusion of students with ASD. *Teacher Education and Special Education*, *38*(1), 44–57. https://doi.org/10.1177/0888406414558096

APA Presidential Task Force on Evidence-Based Practice. (2006). Evidence-based practice in psychology. *The American Psychologist, 61*(4), 271-285. https://doi.org/10.1037/0003-066X.4.271

Baumann, A. A., Hooley, C., Kryzer, E., Morshed, A. B., Gutner, C. A., Malone, S., Walsh-Bailey, C., Pilar, M., Sandler, B., Tabak, R. G., & Mazzucca, S. (2022). A scoping review of frameworks in empirical studies and a review of dissemination frameworks. *Implementation Science*, *17*(1), 1–15. https://doi.org/10.1186/s13012-022-01225-4

Bond, C., Hebron, J., & Oldfield, J. (2017). Professional learning among specialist staff in resourced mainstream schools for pupils with ASD and SLI. *Educational Psychology in Practice*, *33*(4), 341–355. https://doi.org/10.1080/02667363.2017.1324406

Boyle, J., & Kelly, B. (2017). The role of evidence in educational psychology. In. B. Kelly, L. Woolfson & J. Boyle. (Eds.). *Frameworks in Practice in Educational Psychology*. (2nd Ed.). Jessica Kingsley Publishers

Carroll, C., & Twomey, M. (2021). Voices of children with neurodevelopmental disorders in qualitative research: A scoping review. *Journal of Developmental and Physical Disabilities*, *33*(5), 709–724. https://doi.org/10.1007/s10882-020-09775-5

Cook, B., & Cook, L. (2016). Leveraging evidence-based practice through partnerships based on practice-based evidence. *Learning Disabilities: A Contemporary Journal*, *14*(2), 143–157.

Cooper, K., Russell, A. J., Lei, J., & Smith, L. G. E. (2022). The impact of a positive autism identity and autistic community solidarity on social anxiety and mental health in autistic young people. *Autism*, *X*. https://doi.org/10.1177/13623613221118351

Courcy, I., & Koniou, I. (2022). A scoping review of the use of photo-elicitation and photovoice with autistic and neurodiverse people. Moving towards more inclusive research? *Disability and Society*, 1–22.

https://doi.org/10.1080/09687599.2022.2137391

Crane, L., & Pellicano, E. (2022). Current Autism Research: Implications for Educational Practice. In J. Gainsborough. (Ed). *Educational Perspectives on Supporting Autistic Young People.* Jessica Kingsley Publishers

Deeken, A. H., Mukhopadhyay, S., & Jiang, X. 'Sara.' (2020). Social media in academics and research: 21st-century tools to turbocharge education, collaboration, and dissemination of research findings. *Histopathology*, *77*(5), 688–699. https://doi.org/10.1111/his.14196

Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J. R., & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism*, *23*(4), 943–953. https://doi.org/10.1177/1362361318786721

Fletcher-Watson, S., & Happé, F. (2019). *Autism: A new introduction to psychological theory and current debate*. Routledge

Fox, M. (2003). Opening Pandora's Box: Evidence-based practice for educational psychologists. *Educational Psychology in Practice*, *19*(2), 91–102. https://doi.org/10.1080/02667360303233

Fox, M. (2011). Practice-based evidence - overcoming insecure attachments. *Educational Psychology in Practice*, *27*(4), 325–335. https://doi.org/10.1080/02667363.2011.615299

Geller, E. (2022). The dissemination challenge: Practical solutions to make a difference. *Behavior and Social Issues, 31*(1), 54-70. https://doi.org/10.1007/s42822-022-00110-5

Guldberg, K. (2017). Evidence-based practice in autism educational research: can we bridge the research and practice gap? *Oxford Review of Education*, *43*(2), 149–161. https://doi.org/10.1080/03054985.2016.1248818

Happe, F., & Frith, U. (2020). Annual Research Review : Looking back to look forward – changes in the concept of autism and implications for future research. *The Journal of Child Psychology and Psychiatry*. https://doi.org/10.1111/jcpp.13176

Harmsworth, S., & Turpin, S. (2000). Creating an effective dissemination strategy: An expanded interactive workbook for educational development projects. *TQEF National Co-ordination Team,* 1-33. https://ajpp-online.org./resources/downloads/06-CreatingAnEffectiveDisseminationStrategy-AnExpandedWorkbook.pdf

Health Care and Professions Council. (2015). *Standards of Proficiency: Practitioner psychologists.* Health Care and Professions Council. https://www.hcpc-uk.org/standards/standards-of-proficiency/practioner-psychologists/

Humphrey, N., Barlow, A., & Ledrum, A. (2018). Quality matters: Implementation moderates student outcomes in the PATHS curriculum. *Prevention Science, 19,* 197-208. https://doi.org/10.1007/s11121-017-0802-4

Ibrahim, A. M., Lillemoe, K. D., Klingensmith, M. E., & Dimick, J. B. (2017). Visual abstracts to disseminate research on social media: A prospective, case-control crossover study. *Annals of Surgery*, *266*(6), e46–e48. https://doi.org/10.1097/SLA.0000000000002277

Kearney, C. A. (2002). Identifying the function of school refusal behavior: A revision of the School Refusal Assessment Scale. *Journal of Psychopathology and Behavioral Assessment*, *24*(4), 235–245. https://doi.org/10.1023/A:1020774932043

Khatter, A., Naughton, M., Dambha-Miller, H., & Redmond, P. (2021). Is rapid scientific publication also high quality? Bibliometric analysis of highly disseminated COVID-19 research papers. *Learned Publishing*, *34*(4), 568-577. https://doi.org/10.1002/leap.1403

Kovacs, R. J. (2015). Using practice-based evidence to reduce disparities in care: A virtuous cycle turns. *Journal of the American College of Cardiology*, *66*(11), 1234–1235. https://doi.org/10.1016/j.jacc.2015.07.046

Kratochwill, T. R., Hoagwood, K. E., Kazak, A. E., Weisz, J. R., Hood, K., Vargas, L. A., & Banez, G. A. (2012). Practice-Based evidence for children and adolescents: Advancing the research agenda in schools. *School Psychology Review*, *41*(2), 215–235. https://doi.org/10.1080/02796015.2012.12087521

Lai, M. C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., Szatmari, P., & Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. *The Lancet Psychiatry*, *6*(10), 819–829. https://doi.org/10.1016/S2215-0366(19)30289-5

Lincoln, Y., & Guba, E. (1985). *Naturalistic Inquiry*. SAGE.

Locke, J., Rotheram-Fuller, E., Harker, C., Kasari, C., & Mandell, D. S. (2019). Comparing a practice-based model with a research-based model of social skills interventions for children with autism in schools. *Research in Autism Spectrum Disorders*, *62*, 10–17. https://doi.org/10.1016/j.rasd.2019.02.002

McNeill, J. (2019). Social validity and teachers' use of evidence-based practices for autism. *Journal of Autism and Developmental Disorders*, *49*(11), 4585–4594. https://doi.org/10.1007/s10803-019-04190-y

Milton, D. (2014). So what exactly are autism interventions intervening with? *Good Autism Practice*, *15*(2), 6–14. http://kar.kent.ac.uk/contact.html%0Ahttp://kar.kent.ac.uk/62631/

National Autistic Society (NAS). (2021). *School Report 2021.* Retrieved March 30, 2023, from https://s2.chorus-mk.thirdlight.com/file/24/0HTGORW0HHJnx_c0HWpWc/NAS-Education-Report-2021-A4%20%281%29.pdf

National Health Service. (2020, March 10). *Autism Statistics, April 2019 to December 2021*. Retrieved March 23, 2023, from https://digital.nhs.uk/data-and-information/publications/statistical/autism-statistics/april-2019-to-december-2020#

Parsons, S., Charman, T., Faulkner, R., Ragan, J., Wallace, S., & Wittemeyer, K. (2013). Commentary - Bridging the research and practice gap in autism: The importance of creating research partnerships with schools. *Autism*, *17*(3), 268–280. https://doi.org/10.1177/1362361312472068

Parsons, S., & Kasari, C. (2013). Schools at the centre of educational research in autism: Possibilities, practices and promises. *Autism*, *17*(3), 251–253. https://doi.org/10.1177/1362361313483624

Pellicano, E., & den Houting, J. (2022). Annual Research Review: Shifting from 'normal science' to neurodiversity in autism science. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, *63*(4), 381–396. https://doi.org/10.1111/jcpp.13534

Penfield, T., Baker, M. J., Scoble, R., & Wykes, M. C. (2014). Assessment, evaluations, and definitions of research impact: A review. *Research Evaluation*, *23*(1), 21–32. https://doi.org/10.1093/reseval/rvt021

Reed, M. S., Ferré, M., Martin-Ortega, J., Blanche, R., Lawford-Rolfe, R., Dallimer, M., & Holden, J. (2021). Evaluating impact from research: A methodological framework. *Research Policy*, *50*(4). https://doi.org/10.1016/j.respol.2020.104147

Robinson, L., & Bond, C. (2017). A cross-national review of evidence-based psychosocial treatments for children and adolescents with autistic spectrum disorders in the United Kingdom, Ireland, and United States. *Psychology in the Schools*, *54*(9), 1160–1175. https://doi.org/10.1002/pits.22051

Robinson, L., Bond, C., & Oldfield, J. (2018). A UK and Ireland survey of educational psychologists' intervention practices for students with autism spectrum disorder. *Educational Psychology in Practice*, *34*(1), 58–72. https://doi.org/10.1080/02667363.2017.1391066

Ross-Hellauer, T., Tennant, J. P., Banelytė, V., Gorogh, E., Luzi, D., Kraker, P., Pisacane, L., Ruggieri, R., Sifacaki, E., & Vignoli, M. (2020). Ten simple rules for innovative dissemination of research. *PLoS Computational Biology*, *16*(4), 1–12. https://doi.org/10.1371/journal.pcbi.1007704

Scott-Barrett, J., Cebula, K., & Florian, L. (2022). The experiences and views of autistic children participating in multimodal view-seeking research. *International Journal of Research and Method in Education*, 1–32. https://doi.org/10.1080/1743727X.2022.2149728

Sedgwick, A., & Stothard, J. (2021). Educational Psychology and the Dissemination of Evidence to Professional Practice. *Educational Psychology Research and Practice*, *7*(1), 2021.

Silveira-Zaldivar, T., & Curtis, H. (2019). Im not trained for this!" and other barriers to evidence-based social skills interventions for elementary students with high functioning autism in inclusion. *International Electronic Journal of Elementary Education*, *12*(1), 53–66. https://doi.org/10.26822/iejee.2019155337

Sordé Martí, T., Flecha, R., Rodríguez, J. A., & Bosch, J. L. C. (2020). Qualitative inquiry: A key element for assessing the social impact of research. *Qualitative Inquiry*, *26*(8–9), 948–954. https://doi.org/10.1177/1077800420938117

Stewart-Brown, S., Anthony, R., Wilson, L., Winstanley, S., Stallard, N., Snooks, H., & Simkiss, D. (2011). Should randomised controlled trials be the "'gold standard'" for research on preventive interventions for children? *Journal of Children's Services*, *6*(4), 228–236. https://doi.org/10.1108/17466661111190929

Tonge, B. J., & Silverman, W. K. (2019). Reflections on the field of school attendance problems: For the times they are a-changing? *Cognitive and Behavioral Practice*, *26*(1), 119–126. https://doi.org/10.1016/j.cbpra.2018.12.004

Totsika, V., Hastings, R. P., Dutton, Y., Worsley, A., Melvin, G., Gray, K., Tonge, B., & Heyne, D. (2020). Types and correlates of school non- attendance in students with autism spectrum disorders. *Autism*, *27*(7), 16399–1649.

https://doi.org/10.1177/1362361320916967

Wilkinson, C. (2019). Evidencing impact: A case study of UK academic perspectives on evidencing research impact. *Studies in Higher Education*, *44*(1), 72–85. https://doi.org/10.1080/03075079.2017.1339028

Wilson, P. M., Petticrew, M., Calnan, M. W., & Nazareth, I. (2010). Disseminating research findings: What should researchers do? A systematic scoping review of conceptual frameworks. *Implementation Science*, *5*(1), 1–16. https://doi.org/10.1186/1748-5908-5-91

Wong, C., Odom, S. L., Hume, K. A., Cox, A. W., Fettig, A., Kucharczyk, S., Brock, M. E., Plavnick, J. B., Fleury, V. P., & Schultz, T. R. (2015). Evidence-based practices for children, youth, and young adults with autism spectrum disorder: A comprehensive review. *Journal of Autism and Developmental Disorders*, *45*(7), 1951–1966. https://doi.org/10.1007/s10803-014-2351-z

Appendices

Appendix 1: Research in Autism Spectrum Disorders journal guidelines

MANUSCRIPT PREPARATION & SUBMISSION

Use of word processing software

Files must be saved in the native format of the word processor and the text should be in 10-point Arial font, single-column format, double spaced, with standard 1 inch page margins (2.54 cm). Please keep the layout of the text as simple as possible, as most formatting codes will be replaced on processing the article. In particular, do not use the options to justify text or hyphenate words. However, do use bold face, italics, subscripts, superscripts etc. Note that source files of figures and text graphics will be required whether or not you embed them in the text. See also the section on Electronic artwork below for details on preparing figures and graphics.

Language (usage and editing services)

Please write your text in good English (American or British usage is accepted, but not a mixture of these). Authors who feel they require support in editing to eliminate possible grammatical or spelling errors and to conform to correct scientific English may wish to use the English Language Editing service available from Elsevier's WebShop (https://webshop.elsevier.com/language-editing-services/language-editing/).

In relation to terminology, we ask that authors carefully consider their choice of wording when describing the patterns of strengths and difficulties that are associated with autism. Specifically, based on a paper by Kenny et al., (2015; http://aut.sagepub.com/content/early/2015/06/10/1362361315588200.abstract) we ask authors not to describe participants as 'low-functioning' or 'high-functioning' but to provide precise information about participants' abilities and areas of difficulty instead, ideally as assessed using relevant standardised tools. Autism should also not be described as a 'disease' or 'illness'. Finally, authors are encouraged to avoid language that inappropriately pathologizes certain characteristics or behaviours of autistic individuals (e.g., 'abnormality', 'impairment', 'deficit' etc) choosing less laden descriptions instead (e.g., 'difference'; 'tendency', 'preference', etc) - we note, however, that there are contexts where it may be appropriate to describe certain characteristics as, for example, an impairment (e.g., language impairment).

Types of Articles

Research in Autism Spectrum Disorders publishes the following types of manuscripts:

Brief reports: Papers of no more than 2,500 words that report an original piece of research of limited scope and/or that serves as proof-of principle for larger-scale studies.

Regular Articles: Papers of up to 6,000 words that report a substantive piece of research that makes a significant contribution and has clear implications for practice. Manuscripts reporting the results of randomized trials or interventions must demonstrate adherence to the CONSORT guidelines (http:// www.consort-statement.org/) and include the relevant flow diagram and completed checklist.

Reviews: Papers of up to 10,000 words that provide a comprehensive overview of a significant area of research. Quantitative (e.g., meta-analyses) and qualitative reviews are welcome as long as they go beyond a mere description of the available literature and synthesise new knowledge with clear implications for future directions and practice. For systematic reviews and meta-analyses, authors must demonstrate adherence to the PRISMA guidelines (www.prisma-statement.org) and include the relevant flow diagram and checklist. Commentaries: We welcome brief commentaries of no more than 1,000 words that offer new insights on papers published in RASD or elsewhere.

Commentaries on government policy and/or items in the media are also welcome.

Registered Reports: Registered reports are a form of empirical article in which the rationale, methods, and proposed analyses are pre-registered and reviewed prior to research being conducted. This format seeks to neutralise a variety of unhelpful research practices and biases that contribute to the many inconsistencies in findings that currently exist in the autism and wider literature. This format is suitable for novel as well as replication studies and we particularly welcome submissions describing proposed studies involving under-represented groups in research such as the elderly, minority groups and individuals with complex support needs. For further details please click RASD Registered Reports Author Guidelines)

NOTE: Word limits do not include the title page, abstract, figure legends, tables and reference list.

Submission

Our online submission system guides authors stepwise through the submission process. The system converts article files to a single PDF file used in the peer–review process. Editable files (e.g., Word, LaTeX) are required to typeset your article for final publication. All correspondence, including notification of the Editor's decision and requests for revision, is sent by e–mail. Elsevier accepts electronic supplementary material such as supporting applications, high resolution images, background datasets, sound clips and more. These will be published online alongside the electronic version of your article in Elsevier Web products, including ScienceDirect: http:// www.sciencedirect.com. For further information, please visit our artwork instruction pages at https:// www.elsevier.com/artworkinstructions To increase the transparency of editorial information within the framework of single/ double blind peer review , RASD displays the number of unique reviewer reports received in the first round of review with each published article. This policy will be in place for original research articles submitted from 1 January 2016 that are accepted for publication.

Queries

For questions about the editorial process (including the status of manuscripts under review) or for technical support on submissions, please visit our Support Center.

Manuscript Format

All manuscripts must include a Title, Abstract and Highlights on separate pages, followed by the main manuscript text. The main manuscript text of brief reports, regular articles and quantitative reviews should include subsections carrying the headings Introduction, Methods, Results, Discussion & Implications. Reviews may deviate from this structure but must include a methods section that provides details on how the relevant literature was searched. The structure of commentaries is at the discretion of authors.

Essential Title Page Information

Title: Titles must be concise and informative and should have no more than 20 words. Titles are often used in information–retrieval systems. Avoid abbreviations and formulae where possible.

Author names and affiliations: Please clearly indicate the given name(s) and family name(s) of each author and check that all names are accurately spelled. Present the author's affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lowercase superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e–mail address of each author.

Corresponding author: Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. Ensure that the e–mail address is given and that contact details are kept up to date by the corresponding author.

Present/permanent address: If an author has moved since the work described in the article was done, or was visiting at the time, a 'Present address' (or 'Permanent address') may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main affiliation address. Superscript Arabic numerals are used for such footnotes.

Abstract & Keywords

The abstract page must include a structured abstract of no more than 250 words that includes the following subsections:

Background: A brief summary of the research question and rationale for the study.

Method: A concise description of the methods employed to test the stated hypotheses, including details of the participants where relevant.

Results: A brief description of the main findings.

Conclusions: This section must include a clear statement about the implications of the findings for practice. Immediately after the abstract, a maximum of 6 keywords should be provided, avoiding general and plural terms and multiple concepts (for example, avoid 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible (e.g., ADOS, ASD, etc). These keywords will be used for indexing purposes.

Graphical Abstract

Graphical abstracts are optional but encouraged to draw more attention to the online article. The graphical abstract should summarize the contents of the article in a concise, pictorial form designed to capture the attention of a wide readership. Graphical abstracts should be submitted as a separate file in the online submission system. Please provide an image with a minimum of 531 X 1328 pixels (h X w) or proportionally more. The image should be readable at a size of 5 X13 cm using a regular screen resolution of 96 dpi. Preferred file types include TIFF, EPS, PDF or MS Office files. See https://www.elsevier.com/graphicalabstracts for examples. Authors can make use of Elsevier's Illustration and Enhancement service to ensure the best presentation of their images. https://webshop.elsevier.com/illustrationservices/

Introduction

The introduction should develop a clear rationale for the presented work on the basis of a concise overview of the relevant literature. Detailed literature reviews should be avoided.

Methods This section will typically include sub–headings for a description of the Participants, Materials & Design, Procedures and Analysis. However, alternative sub–headings may be used to suit particular research approaches (e.g., case–studies, meta–analyses, imaging studies etc.)

The participants section should provide demographic information (age, sex, ethnicity, socio–economic status, etc.), and include details on where and how participants were recruited and how relevant clinical diagnoses were verified. Additional clinical information (e.g., intellectual functioning, co– morbidities, use of medication etc.) is desired and may be necessary for some research designs. Sample sizes should be justified by suitable power calculations although it is appreciated that it is not always feasible to obtain desired numbers of participants.

The materials, design and procedures must be described in sufficient detail for the work to be replicable. Authors must also include a statement confirming that the work was carried out in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Declaration of Helsinki as revised in 2000. In this context confirmation should also be given that participant or guardian informed consent was obtained where appropriate.

The analysis section should provide details of the statistical methods used including information on the significance thresholds and the methods used to correct for multiple comparisons where necessary. Information on inter–rater reliability and any data filtering / transformation that was applied should also be included here.

Results

The results should be set out transparently and in full and should conform to the formatting style of the American Psychological Association (http://www.apastyle.org/). Effect sizes must be reported for all significant and non–significant effects, and sufficient descriptive statistics must be provided for the effect size calculations to be replicated.

Tables

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. The formatting of tables should conform to APA guidelines (http://www.apastyle.org/).

Figures & Artwork

General points

- Make sure you use uniform lettering and sizing of your original artwork.
- Embed the used fonts if the application provides that option.
- Aim to use the following fonts in your illustrations: Arial, Courier, Times New Roman, Symbol, or use similar fonts.
- Number the illustrations according to their sequence in the text.
- Use a logical naming convention for your artwork files.
- Provide captions to illustrations separately.
- Size the illustrations close to the desired dimensions of the published version.
- Submit each illustration as a separate file. For Vector drawings, the recommended file format is EPS or PDF (embed all used fonts). For all other artwork, please use TIFF or JPEG file formats with the following resolutions:
- Colour or grayscale photographs (halftones): 300 dpi
- Pure black & white line drawings: 1000 dpi
- Combination halftone and black & white: 500dpi

Please do not:

- Supply files that are optimized for screen use (e.g., GIF, BMP, PICT, WPG)
- Supply files that are too low in resolution;
- Submit graphics that are disproportionately large for the content. If, together with your accepted article, you submit usable colour figures, Elsevier will ensure, at no additional charge, that these figures will appear in colour online (e.g., ScienceDirect and other sites) regardless of whether or not these illustrations are reproduced in colour in the printed version. For colour reproduction in print, you will receive information regarding the costs from Elsevier after receipt of your accepted article. Please indicate your preference for colour: in print or online only. For further information please see https://www.elsevier.com/artworkinstructions.

Video Data

Elsevier accepts video material and animation sequences to support and enhance presentation of your scientific research. Authors who have video or animation files that they wish to submit with their article are strongly encouraged to include links to these within the body of the article. This can be done in the same way as a figure or table by referring to the video or animation content and noting in the body text where it should be placed. All submitted files should be properly labelled so that they directly relate to the video file's content. In order to ensure that your video or animation material is directly usable, please provide the files in one of our recommended file formats with a preferred maximum size of 150 MB. Video and animation files will be published online in the electronic version of your article in Elsevier Web products, including ScienceDirect: http://www.sciencedirect.com. Please supply 'stills' with your files; you can choose any frame from the video or animation or make a separate image. These will be used instead of standard icons and will personalize the link to your video data. For more detailed instructions, please visit our video instruction pages at https:// www.elsevier.com/artworkinstructions. Note: since video and animation cannot be embedded in the print version of the journal, please provide text for both the electronic and the print version for the portions of the article that refer to this content.

3D neuroimaging

You can enrich your online articles by providing 3D neuroimaging data in NIfTI format. This will be visualized for readers using the interactive viewer embedded within your article, and will enable them to: browse through available neuroimaging datasets; zoom, rotate and pan the 3D brain reconstruction; cut through the volume; change opacity and colour mapping; switch between 3D and 2D projected views; and download the data. The viewer supports both single (.nii) and dual (.hdr and .img) NIfTI file formats. Recommended size of a single uncompressed dataset is maximum 150 MB. Multiple datasets can be submitted. Each dataset will have to be zipped and uploaded to the online submission system via the '3D neuroimaging data' submission category. Please provide a short informative description for each dataset by filling in the 'Description' field when uploading a dataset. Note: all datasets will be available for downloading from the online article on ScienceDirect. If you have concerns about your data being downloadable, please provide a video instead. For more information see: https://www.elsevier.com/3DNeuroimaging.

Discussion and Implications

The discussion section should draw together the findings and must end with a clear indication of the implications of the findings for practice under a separate subheading (Implications).

Acknowledgements

Collate acknowledgements in a separate section at the end of the main manuscript text and before the references. List here any sources of funding (including grant numbers where relevant) and briefly describe the role of the sponsor(s), if any, in study design; the collection, analysis or interpretation of data; the writing of the report; and the decision to submit the article for publication. If the funding source(s) had no such involvement then this should be stated.

Conflict of interest

At the end of the main manuscript text and before the references, authors must disclose any actual or potential conflict of interest including any financial, personal or other relationships with other people or organizations within three years of beginning the submitted work that could inappropriately influence, or be perceived to influence, their work. If no such conflict of interest exists, this must be clearly stated. For further information and examples of conflict of interest statements please visit the following: https://www.elsevier.com/conflictsofinterest https://service.elsevier.com/ app/answers/detail/a_id/286/supporthub/publishing A decision may be made by the Journal not to publish on the basis of the declared conflict.

References

In-text citations should conform to the formatting style of the American Psychological Association. Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full

References in a special issue

Please ensure that the words 'this issue' are added to any references in the list (and any citations in the text) to other articles in the same Special Issue.

Reference management software

Most Elsevier journals have a standard template available in key reference management packages. This covers packages using the Citation Style Language, such as Mendeley and also others like EndNote) and Reference Manager.

[dataset] Oguro, M., Imahiro, S., Saito, S., Nakashizuka, T. (2015). Mortality data for Japanese oak wilt disease and surrounding forest compositions. Mendeley Data, v1. http://dx.doi.org/10.17632/ xwj98nb39r.1. Examples Reference to a journal publication: Van der Geer, J., Hanraads, J. A. J., & Lupton, R. A. (2010). The art of writing a scientific article. Journal of Scientific Communications, 163, 51-59.

Reference to a book:

Strunk, W., Jr., &White, E. B. (2000). The elements of style. (4th ed.). New York: Longman, (Chapter4).

Reference to a chapter in an edited book:

Mettam, G. R., & Adams, L. B. (2009). How to prepare an electronic version of your article. In B. S. Jones, & R. Z. Smith (Eds.), Introduction to the electronic age (pp. 281-304). New York: E–Publishing Inc

Cover Letter

All submissions must be accompanied by a cover letter to confirm that the work described has not been published previously (except in the form of an abstract or as part of a published lecture or academic thesis or as an electronic preprint, see https://www.elsevier.com/sharingpolicy), that it is not under consideration for publication elsewhere, that its publication is approved by all authors and tacitly or explicitly by the responsible authorities where the work was carried out, and that, if accepted, it will not be published elsewhere in the same form, in English or in any other language, including electronically, without the written consent of the copyright–holder. To verify originality, your article may be checked by the originality detection service CrossCheck https://www.elsevier.com/ editors/plagdetect

If a submission is to be considered for a special issue, authors are asked to indicate this also in their cover letter.

Submission checklist

The following list will be useful during the final checking of an article prior to sending it to the journal for consideration. Please refer to relevant sections above for guidance if you are not yet in a position to confirm all of the following points.

Ensure that the following items are present:

• The title page is complete, one author has been designated as the corresponding author and contact details are provided (e-mail; full postal address)

• All necessary files have been uploaded and include all necessary sections

• All figures have been uploaded and figure captions are provided separately • All tables are clear and include relevant captions and footnotes

• The manuscript has been 'spell&checked' and 'grammar–checked' References are in the correct format.

- All references mentioned in the Reference list are cited in the text, and vice versa
- Permission has been obtained for use of copyrighted material from other sources (including the Internet)
- All sources of funding have been acknowledged and the authors have either declared conflicts of interest or confirmed that none exist
- The manuscript gives due consideration to the practical implications of the work, which are clearly stated in the abstract and thoroughly considered in a final section of the discussion

For any further information please visit our customer support site at https://service.elsevier.com.

Highlights

Highlights are optional yet highly encouraged for this journal, as they increase the discoverability of your article via search engines. They consist of a short collection of bullet points that capture the novel results of your research as well as new methods that were used during the study (if any). Please have a look at the examples here: example Highlights. Highlights should be submitted in a separate editable file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point).

Data references

This journal encourages you to cite underlying or relevant datasets in your manuscript by citing them in your text and including a data reference in your Reference List. Data references should include the following elements: author name(s), dataset title, data repository, version (where available), year, and global persistent identifier. Add [dataset] immediately before the reference so we can properly identify it as a data reference. The [dataset] identifier will not appear in your published article.

Preprint references

Where a preprint has subsequently become available as a peer-reviewed publication, the formal publication should be used as the reference. If there are preprints that are central to your work or that cover crucial developments in the topic, but are not yet formally published, these may be referenced. Preprints should be clearly marked as such, for example by including the word preprint, or the name of the preprint server, as part of the reference. The preprint DOI should also be provided.

Data visualization

Include interactive data visualizations in your publication and let your readers interact and engage more closely with your research. Follow the instructions here to find out about available data visualization options and how to include them with your article.

Research data

This journal encourages and enables you to share data that supports your research publication where appropriate, and enables you to interlink the data with your published articles. Research data refers to the results of observations or experimentation that validate research findings. To facilitate reproducibility and data reuse, this journal also encourages you to share your software, code, models, algorithms, protocols, methods and other useful materials related to the project. Below are a number of ways in which you can associate data with your article or make a statement about the availability of your data when submitting your manuscript. If you are sharing data in one of these ways, you are encouraged to cite the data in your manuscript and reference list. Please refer to the "References" section for more information about data citation. For more information on depositing, sharing and using research data and other relevant research materials, visit the research data page.

Data linking

If you have made your research data available in a data repository, you can link your article directly to the dataset. Elsevier collaborates with a number of repositories to link articles on ScienceDirect with relevant repositories, giving readers access to underlying data that gives them a better understanding of the research described. There are different ways to link your datasets to your article. When available, you can directly link your dataset to your article by providing the relevant information in the submission system. For more information, visit the database linking page. For supported data repositories a repository banner will automatically appear next to your published article on ScienceDirect. In addition, you can link to relevant data or entities through identifiers within the text of your manuscript, using the following format: Database: xxxx (e.g., TAIR: AT1G01020; CCDC: 734053; PDB: 1XFN).

Data statement

To foster transparency, we encourage you to state the availability of your data in your submission. This may be a requirement of your funding body or institution. If your data is unavailable to access or unsuitable to post, you will have the opportunity to indicate why during the submission process, for example by stating that the research data is confidential. The statement will appear with your published article on ScienceDirect. For more information, visit the Data Statement page.

Appendix 2: Table showing excluded studies from 29 reports sought for retrieval

Reference	**Reason for exclusion**
Ashburner et al., (2019)	Theme of anxiety too peripheral - main focus of study on bullying
Berkovits et al., (2020)	Focus of article on diagnosis
Cheak-Zamora et al., (2015)	Focus of article on transition and participants outside age range for inclusion
Crane et al., (2019)	Participants outside age range for inclusion
Ferenc et al., (2021)	Focus of article too broad around wellbeing
Halim et al., (2018)	Participants outside age range for inclusion
Hebron & Humphrey (2014)	Focus of article too broad around mental health and school
Hill, L. (2014)	Focus of article too broad about school experiences
Montaque et al., (2018)	Focus of article on parental experiences
Reyes et al., (2022)	Parental and school staff perspectives and some participants outside age range for inclusion
Scott & Sedgewick (2021)	Participants outside age range for inclusion
Simpson et al., (2019)	Unable to locate article or abstract
Tarver et al., (2021)	Focus of article on parental experiences and management of anxiety
Trembath et al., (2021)	Participants outside age range for inclusion
Vincent (2019)	Participants outside age range for inclusion
Vincent et al., (2017)	Participants outside age range for inclusion
Ward & Webster (2018)	Participants outside age range for inclusion
Ward & Webster (2018)	Duplicate study

Appendix 3: Critical appraisal frameworks

Qualitative Research Framework

Author(s):

Title:

Journal Reference:

Criterion/ score		R1	R2	Agree %	R1	R2	Agree %	Comment
Clear aim of research *e.g. aim/ goal/ question of the research clearly stated, importance/ utility justified*	**1** **0**							
Appropriateness of the research design *e.g. rationale vis-à-vis aims, links to previous approaches, limitations*	**1** **0**							
Clear sampling rationale *e.g. description, justification; attrition evaluated*	**1** **0**							
Appropriateness of data collection method *e.g. methods link to research aims, rationale for method provided*	**1** **0**							
Well executed data collection *e.g. clear details of who, what, where, how; intended/ actual (if modified) effect of execution on*	**2** **1** **0**							

data quality; data saturation considered								
Analysis close to the data, *e.g. researcher can evaluate fit between categories/ themes and data, participant ‘voice’ evident*	**2** **1** **0**							
Evidence of explicit reflexivity *e.g.* - *impact of researcher (vis-à-vis cultural/ theoretical position; researcher-participant relationship)* - *limitations identified* - *data validation (e.g. inter-coder checks/ peer moderation/ consultation)* - *researcher philosophy/ stance evaluated* - *conflict of interest statement included*	**4** **3** **2** **1** **0**							
Negative case analysis, *e.g. e.g. contrasts/ contradictions/ outliers within data; categories/ themes as dimensional; diversity of perspectives.*	**1** **0**							
Evidence of researcher-participant negotiation of meanings, *e.g. member checking, methods to empower participants.*	**1** **0**							
Valid conclusions drawn *e.g. data presented support the findings which in turn support the conclusions*	**1** **0**							

Emergent theory related to the problem, *e.g. links to previous findings/ explanation of changes or differences/ abstraction from categories/ themes to model/ explanation.*	**1** **0**							
Transferable conclusions *e.g. contextualised findings; limitations of scope identified.*	**1** **0**							
Evidence of attention to ethical issues *e.g. presentation, sensitivity, minimising harm, feedback*	**1** **0**							
Comprehensiveness of documentation *e.g. schedules, transcripts, thematic maps, paper trail for external audit*	**1** **0**							
Clarity and coherence of the reporting *e.g. clear structure, clear account linked to aims, key points highlighted*	**1** **0**							
Total	*Max* 20			Mean % agree			Mean % agree	

Quantitative Research Framework

Author(s):

Title:

Journal Reference:

Criterion	Score	R 1	R 2	Agree %	R 1	R 2	Agree %	Comment
Design (evaluation studies only)								
Use of a randomised group design	**2 1 0**							
(i) Comparison with treatment-as-usual or placebo, **OR**	**2 1 0**							
(ii) Comparison with standard control group/ single case experiment design	**1 0**							
Use of manuals/ protocols for intervention/ training for intervention	**2 1 0**							
Fidelity checking/ supervision of intervention	**2 1 0**							
Data gathering								
Clear research question or hypothesis *e.g. well-defined, measureable constituent elements*	**1 0**							
Appropriate participant sampling *e.g. fit to research question, representativeness.*	**1 0**							
Appropriate measurement instrumentation. *e.g. sensitivity/ specificity/ reliability/ validity*	**2 1 0**							

Use of multiple measures	**2 1 0**							
Comprehensive data gathering *e.g. context of measurement recorded (e.g. when at school vs at home)*	**1 0**							
Appropriate data gathering method used *e.g. soundness of administration*	**1 0**							
Reduction of bias within participant recruitment/ instrumentation/ administration *e.g. harder-to-reach facilitation; accessibility of instrumentation*	**1 0**							
Response rate/ completion maximised *e.g. response rate specified; piloting; access options*	**1 0**							
Population subgroup data collected *e.g. participant gender; age; location*	**1 0**							
Data analysis								
Missing data analysis *e.g. Level and treatment specified*	**1 0**							
Time trends identified *e.g. year on year changes*	**1 0**							
Geographic considerations *e.g. regional or subgroup analyses*	**1 0**							
Appropriate statistical analyses (descriptive or inferential)	**2 1 0**							

e.g. coherent approach specified; sample size justification/ sample size adequacy								
Multi-level or inter-group analyses present *e.g. comparison between participant groups by <u>relevant</u> location or characteristics*	**1 0**							
Data interpretation								
Clear criteria for rating of findings *e.g. benchmarked/ justified evaluation of found quantitative facts*	**1 0**							
Limitations of the research considered in relation to initial aims *e.g. critique of method; generalizability estimate*	**1 0**							
Implications of findings linked to rationale of research question *e.g. implications for theory, practice or future research*	**1 0**							
	Total score			Mean % agree			Mean % agree	
Total (investigation studies) (max=20)								
Total (evaluation studies) (max=28)								

Appendix 3: Example of inter-rated critical appraisal framework

Author(s): Acker et al. (2018)

Title: Are they just gonna reject me?

Journal Reference: Research in Autism Spectrum Disorders

Criterion/ score		**R1**	**R2**	**Agree %**	**R1**	**R2**	**Agree %**	**Comment**
Clear aim of research *e.g. aim/ goal/ question of the research clearly stated, importance/ utility justified*	**1** **0**	1	1	100%	1	1	100%	Clear gap; need to capture lived exp discussed
Appropriateness of the research design *e.g. rationale vis-à-vis aims, links to previous approaches, limitations*	**1** **0**	.75	1	75%	.75	.75	75%	use of IPA to capture lived exp discussed; limitations previous research p.10 just before method
Clear sampling rationale *e.g. description, justification; attrition evaluated*	**1** **0**	.75	0.5	67%	.5	.5	100%	Opportunistic but clear inclusion criteria.
Appropriateness of data collection method *e.g. methods link to research aims, rationale for method provided*	**1** **0**	1	1	100%	1	1	100%	Focus on anxiety; adapted SSI for autistic YP; use of standardised measures for inclusion.
Well executed data collection *e.g. clear details of who, what, where, how; intended/ actual (if modified) effect of execution on data quality; data saturation considered*	**2** **1** **0**	1.75	1.5	86%	1.75	1.5	86%	Procedure outlined p.11; dev with autistic people, pilot. Modifications, execution effects

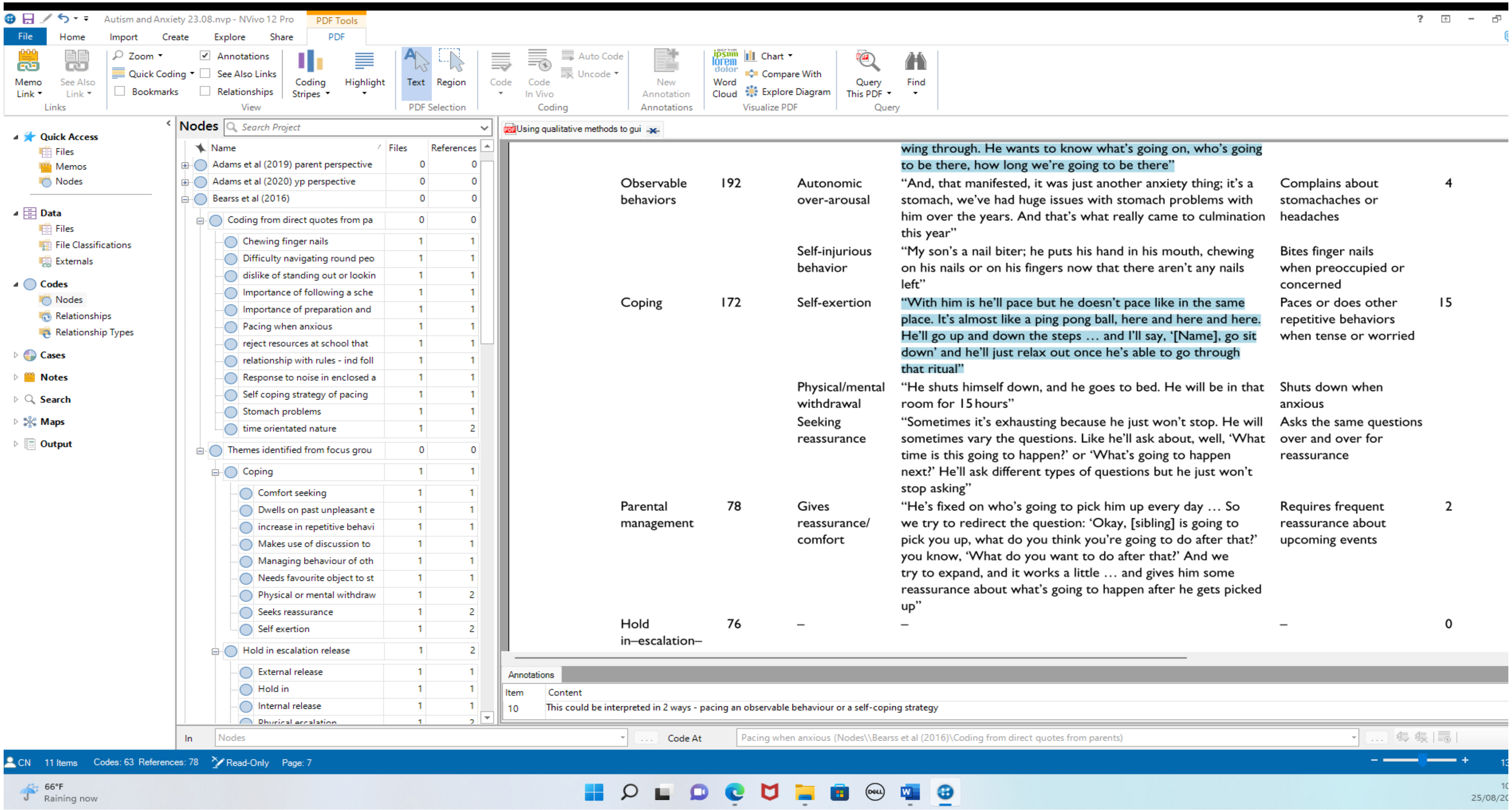
								and saturation not discussed.
Analysis close to the data, *e.g. researcher can evaluate fit between categories/ themes and data, participant ‘voice’ evident*	**2** **1** **0**	2	2	100%	2	2	100%	p.12 Clear outline of analysis process; thematic map and quotes.
Evidence of explicit reflexivity *e.g.* • *impact of researcher (vis-à-vis cultural/ theoretical position; researcher-participant relationship)* • *limitations identified* • *data validation (e.g. inter-coder checks/ peer moderation/ consultation)* • *researcher philosophy/ stance evaluated* • *conflict of interest statement included*	**4** **3** **2** **1** **0**	3	3	100%	3	3	100%	Reflexivity considered p.11; p.11 consulted with autistic people; p.12 bracketing used and inter coder checks; CofI statement Limitations discussed, less evaluation of stance. Assumption of their own cultural perspective
Negative case analysis, *e.g. e.g. contrasts/ contradictions/ outliers within data; categories/ themes as dimensional; diversity of perspectives.*	**1** **0**	.75	1	75%	.75	1	75%	Contradictions explored e.g. relationship to help; steady vs meltdown
Evidence of researcher-participant negotiation of meanings, *e.g. member checking, methods to empower participants.*	**1** **0**	.5	0.25	50%	.25	.25	100%	Developed schedule with autistic people but not involved in data analysis
Valid conclusions drawn		1	1	100%	1	1	100%	

e.g. data presented support the findings which in turn support the conclusions	**10**							
Emergent theory related to the problem, *e.g. links to previous findings/ explanation of changes or differences/ abstraction from categories/ themes to model/ explanation.*	**10**	.75	1	75%	.75	.75	100%	Links to other theories explored e.g. Wood & Gaddow, Gilbert p.13; Green p.15. Revisited in discussion - implications.
Transferable conclusions *e.g. contextualised findings; limitations of scope identified.*	**10**	1	1	100%	1	1	100%	Limitations of sample and generalisability discussed
Evidence of attention to ethical issues *e.g. presentation, sensitivity, minimising harm, feedback*	**10**	.5	1	50%	.5	.75	67%	p.11 ethical approval gained; consent checked regularly and clear right to withdraw
Comprehensiveness of documentation *e.g. schedules, transcripts, thematic maps, paper trail for external audit*	**10**	.5	1	50%	.75	1	75%	Schedule in app, recurrence table and thematic map
Clarity and coherence of the reporting *e.g. clear structure, clear account linked to aims, key points highlighted*	**10**	1	1	100%	1	1	100%	Clearly explained.

Total	*Max* 20	16.75	17.25	Mean 97% agree	16	16.5	Mean 97% agree	

Appendix 5: Example of NVIVO coding

Stage 1 & 2:



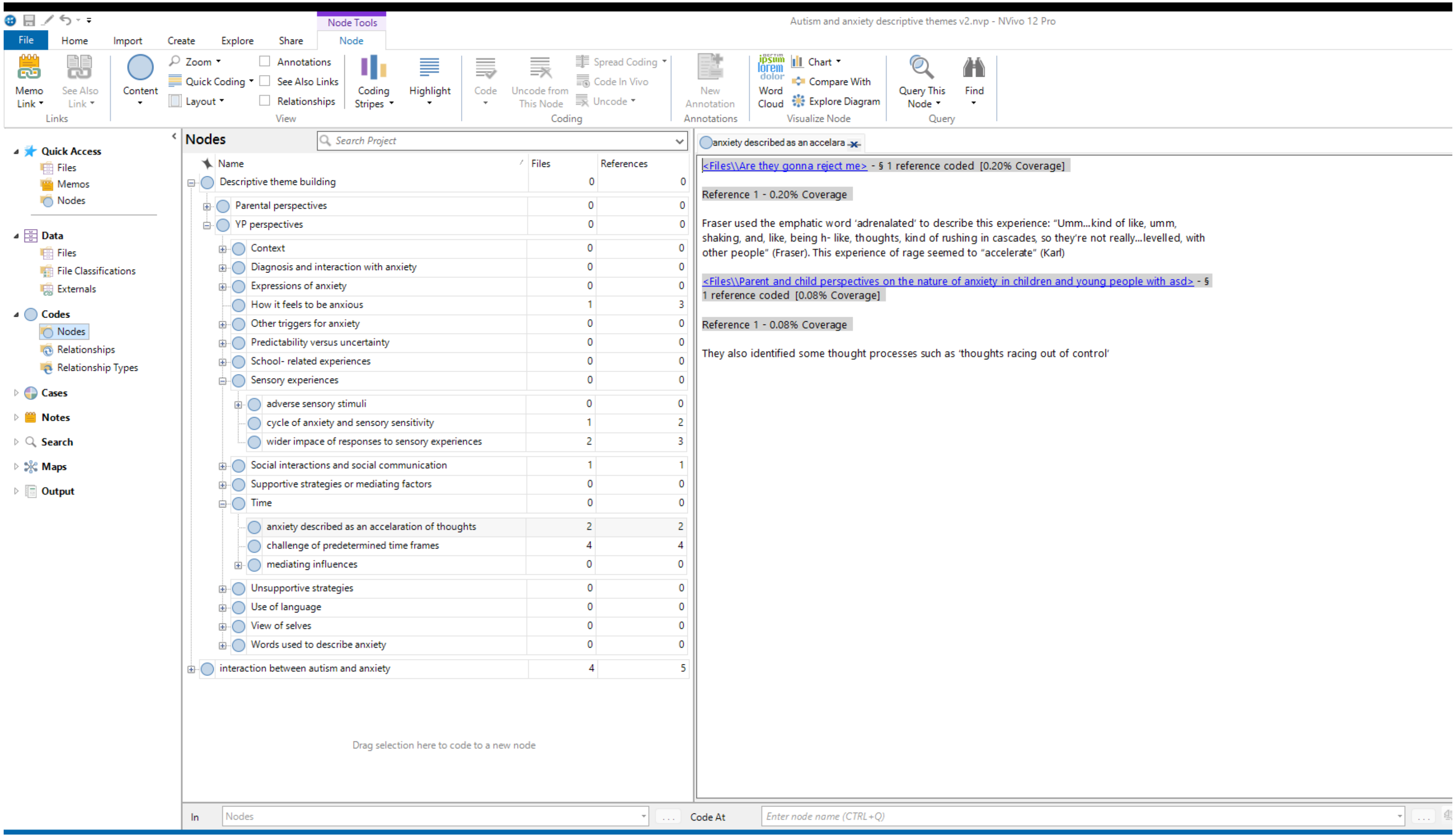
Name	Files	References
Adams et al (2019) parent perspective	0	0
Adams et al (2020) yp perspective	0	0
Bearss et al (2016)	0	0
Coding from direct quotes from pa	0	0
Chewing finger nails	1	1
Difficulty navigating round peo	1	1
dislike of standing out or lookin	1	1
Importance of following a sche	1	1
Importance of preparation and	1	1
Pacing when anxious	1	1
reject resources at school that	1	1
relationship with rules - ind foll	1	1
Response to noise in enclosed a	1	1
Self coping strategy of pacing	1	1
Stomach problems	1	1
time orientated nature	1	2
Themes identified from focus grou	0	0
Coping	1	1
Comfort seeking	1	1
Dwells on past unpleasant e	1	1
increase in repetitive behavi	1	1
Makes use of discussion to	1	1
Managing behaviour of oth	1	1
Needs favourite object to st	1	1
Physical or mental withdraw	1	2
Seeks reassurance	1	2
Self exertion	1	2
Hold in escalation release	1	2
External release	1	1
Hold in	1	1
Internal release	1	1
Physical escalation	1	2

			wing through. He wants to know what's going on, who's going to be there, how long we're going to be there"		
Observable behaviors	192	Autonomic over-arousal	"And, that manifested, it was just another anxiety thing; it's a stomach, we've had huge issues with stomach problems with him over the years. And that's what really came to culmination this year"	Complains about stomachaches or headaches	4
		Self-injurious behavior	"My son's a nail biter; he puts his hand in his mouth, chewing on his nails or on his fingers now that there aren't any nails left"	Bites finger nails when preoccupied or concerned	
Coping	172	Self-exertion	"With him is he'll pace but he doesn't pace like in the same place. It's almost like a ping pong ball, here and here and here. He'll go up and down the steps … and I'll say, '[Name], go sit down' and he'll just relax out once he's able to go through that ritual"	Paces or does other repetitive behaviors when tense or worried	15
		Physical/mental withdrawal	"He shuts himself down, and he goes to bed. He will be in that room for 15 hours"	Shuts down when anxious	
		Seeking reassurance	"Sometimes it's exhausting because he just won't stop. He will sometimes vary the questions. Like he'll ask about, well, 'What time is this going to happen?' or 'What's going to happen next?' He'll ask different types of questions but he just won't stop asking"	Asks the same questions over and over for reassurance	
Parental management	78	Gives reassurance/ comfort	"He's fixed on who's going to pick him up every day … So we try to redirect the question: 'Okay, [sibling] is going to pick you up, what do you think you're going to do after that?' you know, 'What do you want to do after that?' And we try to expand, and it works a little … and gives him some reassurance about what's going to happen after he gets picked up"	Requires frequent reassurance about upcoming events	2
Hold in–escalation–	76	–	–	–	0

Item	Content
10	This could be interpreted in 2 ways - pacing an observable behaviour or a self-coping strategy

Code At: Pacing when anxious (Nodes\\Bearss et al (2016)\Coding from direct quotes from parents)

Stage 3:



Name	Files	References
Descriptive theme building	0	0
Parental perspectives	0	0
YP perspectives	0	0
Context	0	0
Diagnosis and interaction with anxiety	0	0
Expressions of anxiety	0	0
How it feels to be anxious	1	3
Other triggers for anxiety	0	0
Predictability versus uncertainty	0	0
School- related experiences	0	0
Sensory experiences	0	0
adverse sensory stimuli	0	0
cycle of anxiety and sensory sensitivity	1	2
wider impact of responses to sensory experiences	2	3
Social interactions and social communication	1	1
Supportive strategies or mediating factors	0	0
Time	0	0
anxiety described as an accelaration of thoughts	2	2
challenge of predetermined time frames	4	4
mediating influences	0	0
Unsupportive strategies	0	0
Use of language	0	0
View of selves	0	0
Words used to describe anxiety	0	0
interaction between autism and anxiety	4	5

<Files\\Are they gonna reject me> - § 1 reference coded [0.20% Coverage]

Reference 1 - 0.20% Coverage

Fraser used the emphatic word 'adrenalated' to describe this experience: "Umm...kind of like, umm, shaking, and, like, being h- like, thoughts, kind of rushing in cascades, so they're not really...levelled, with other people" (Fraser). This experience of rage seemed to "accelerate" (Karl)

<Files\\Parent and child perspectives on the nature of anxiety in children and young people with asd> - § 1 reference coded [0.08% Coverage]

Reference 1 - 0.08% Coverage

They also identified some thought processes such as 'thoughts racing out of control'

Appendix 6: JORSEN guidelines

Author Guidelines

The *Journal of Research in Special Educational Needs* publishes scholarly papers based on original research as well as critical reviews and theoretical essays. This includes submissions from a range of colleagues within the SEN field and across the disability community. Authors are asked to be sensitive to the diverse international audience of the *Journal of Research in Special Educational Needs* and explain the use of terms that might be meaningful or have a specific meaning in a particular national context. The use of jargon should be avoided and technical terms defined. Standard stylistic conventions based on British spelling and form should be followed.

Sections

1. Submission and Peer Review Process
2. Article Types
3. After Acceptance

1. Submission and Peer Review Process

New submissions should be made via the Research Exchange submission portal at the following web address **https://wiley.atyponrex.com/journal/JORSEN**. Should your manuscript proceed to the revision stage, you will be directed to make your revisions via the same submission portal. You may check the status of your submission at any time by logging on to submission.wiley.com and clicking the "My Submissions" button. For technical help with the submission system, please review our **FAQs** or contact **submissionhelp@wiley.com**.

By submitting a manuscript to or reviewing for this publication, your name, email address, and affiliation, and other contact details the publication might require, will be used for the regular operations of the publication, including, when necessary, sharing with the publisher (Wiley) and partners for production and publication. The publication and the publisher recognize the importance of protecting the personal information collected from users in the operation of these services and have practices in place to ensure that steps are taken to maintain the security, integrity, and privacy of the personal data collected and processed. You can learn more at **https://authorservices.wiley.com/statements/data-protection-policy.html**.

Article Preparation Support
Wiley Editing Services offers expert help with English Language Editing, as well as translation, manuscript formatting, figure illustration, figure formatting, and graphical abstract design – so you can submit your manuscript with confidence. Also, check out our resources for **Preparing Your Article** for general guidance about writing and preparing

your manuscript. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

Free format submission

The *Journal of Research in Special Educational Needs* now offers **Free Format submission** for a simplified and streamlined submission process.

Before you submit, you will need:

Your manuscript: this should be an editable file including text, figures, and tables, or separate files—whichever you prefer. All required sections should be contained in your manuscript, including abstract, introduction, methods, results, and conclusions. Figures and tables should have legends. Figures should be uploaded in the highest resolution possible. If the figures are not of sufficiently high quality your manuscript may be delayed. References may be submitted in any style or format, as long as it is consistent throughout the manuscript. Supporting information should be submitted in separate files. If the manuscript, figures or tables are difficult for you to read, they will also be difficult for the editors and reviewers, and the editorial office will send it back to you for revision. Your manuscript may also be sent back to you for revision if the quality of English language is poor.

An ORCID ID, freely available at **https://orcid.org**. *(Why is this important? Your article, if accepted and published, will be attached to your ORCID profile. Institutions and funders are increasingly requiring authors to have ORCID IDs.)*

The title page of the manuscript, including:

- Your co-author details, including affiliation and email address. *(Why is this important? We need to keep all co-authors informed of the outcome of the peer review process.)*
- Statements relating to our ethics and integrity policies, which may include any of the following *(Why are these important? We need to uphold rigorous ethical standards for the research we consider for publication)*:
    - data availability statement
    - funding statement
    - conflict of interest disclosure
    - ethics approval statement
    - patient consent statement
    - permission to reproduce material from other sources
    - clinical trial registration

Important: the journal operates a double-anonymized peer review policy. Please anonymize your manuscript and supply a separate title page file.

To submit, login at **https://wiley.atyponrex.com/journal/JORSEN** and create a new submission. Follow the submission steps as required and submit the manuscript.

Authorship

All listed authors should have contributed to the manuscript substantially and have agreed to the final submitted version. Review **editorial standards** and scroll down for a description of authorship criteria.

Funding
You should list all funding sources in the Acknowledgments section. You are responsible for the accuracy of their funder designation. If in doubt, please check the **Open Funder Registry** for the correct nomenclature.

Reproduction of Copyright Material
If excerpts from copyrighted works owned by third parties are included, credit must be shown in the contribution. It is your responsibility to also obtain written permission for reproduction from the copyright owners. For more information visit **Wiley's Copyright Terms & Conditions** FAQ.

The corresponding author is responsible for obtaining written permission to reproduce the material "in print and other media" from the publisher of the original source, and for supplying Wiley with that permission upon submission.

The Journal of Research in Special Educational Needs requires the submitting author (only) to provide an ORCID iD when submitting a manuscript.

This journal does not charge submission fees.

Refer and Transfer Program
Wiley believes that no valuable research should go unshared. This journal participates in Wiley's **Refer & Transfer program**. If your manuscript is not accepted, you may receive a recommendation to transfer your manuscript to another suitable journal within the **Wiley Special Education Publishing Network**, either through a referral from the journal's editor or through our Transfer Desk Assistant. Authors decide whether to accept the referral, with the option to transfer their paper with or without revisions. Once the referral is accepted, submission happens automatically, along with any previous reviewer reports, thereby relieving pressure on the peer review process. While a transfer does not guarantee acceptance, it is more likely to lead to a successful outcome for authors by helping them to find a route to publication quickly and easily.

Guidelines on Publishing and Research Ethics in Journal Articles
The journal requires that you include in the manuscript details IRB approvals, ethical treatment of human and animal research participants, and gathering of informed consent, as appropriate. You will be expected to declare all conflicts of interest, or none, on submission. Please review Wiley's policies surrounding **human studies, animal studies, clinical trial registration, biosecurity, and research reporting guidelines**. This journal follows the core practices of the **Committee on Publication Ethics (COPE)** and handles cases of research and publication misconduct accordingly (**https://publicationethics.org/core-practices**).

Peer Review

This journal operates under a **double anonymized** peer review model. Except where otherwise stated, manuscripts are peer reviewed by at least two anonymous reviewers and an Associate or Assistant Editor. Papers will only be sent to review if the Editor-in-Chief determines that the paper meets the appropriate quality and relevance requirements. In-house submissions, i.e. papers authored by Editors or Editorial Board members of the title, will be sent to Editors unaffiliated with the author or institution and monitored carefully to ensure there is no peer review bias. Wiley's policy on the confidentiality of the review process is available **here**.

Preprint policy:
Please find the Wiley preprint policy **here**.

2. Article Types

Article Types	Descriptions	Word Count
Original Article	Reports of original research, with methods, findings and conclusions.	Articles should normally be between 6,000 and 8,000 words, excluding the title page, references and figures/tables.
Editorial	To convey an opinion, or overview of an issue, by the Editor or someone invited by the editor	
Media Review	Short review on the usefulness/quality of one or more books or other media, to aid readers in decision-making	
SENCO Policy Paper	Public statement of what a representative group of experts agree to be evidence-based and state-of-the-art knowledge on an aspect of practice/policy.	
SEN Policy Research Forum	Public statement of what a representative group of experts agree to be evidence-based and state-of-the-art knowledge on an aspect of practice/policy.	

References: References should be listed in full at the end of the paper in alphabetical order of authors' names, set out as below:

Book:
Kornblum, W. & Smith, C. K. (eds) (2004) Social Problems in Schools. (5th edn). Milton Keynes: Open University Press.

Chapter in book:
Roof, C. (ed.) (2000) ‘Behavioural difficulties in children.’ In R. Davies & D. Galway (eds), Listening to Children, pp. 108–20. London: Fulton.

Journal:
Hadaway, C. (1981) ‘The English school environment: proposed changes.’ Cambridge Journal of Education, 20 (1), pp. 77–89.

Electronic resources:
Belson, K. C. (2005) ‘Auditory training for autistic children.’ Paediatrics, 102, pp. 41–3. <<a href='http://www.aap.org/policy.html'>http://www.aap.org/policy.html> (accessed 18 January 2005).

Others:
Firth, G. (2004) Developmental Process in Mental Handicap: A Generative Structure Approach. Unpublished PhD dissertation, Department of Education, Brunel University.

Clark, G. N. (1983) Intensive Interaction: Changing Views and Relationships (draft final report). Leeds Mental health NHS Trust: Learning Disability Psychology Services.

Illustrations, tables and figures should be numbered consecutively (e.g. Figure 1, Table 1, Table 2, etc.) and submitted on separate sheets. The approximate position of tables and figures should be indicated in the manuscript.

Manuscripts are subject to an anonymous peer review process, and authors should take care to identify themselves **only on the title page or cover letter**. Please give your affiliation and full contact details, including email. The cover letter should confirm that the manuscript is original work, not under consideration or published elsewhere. Each article should be accompanied by a **150-250** word abstract and a list of up to **7** keywords on a separate sheet. The main body format should be as follows: **introduction**, **methods**, **results**, and **discussion**.

A PDF proof will be sent to the author to allow for essential corrections. In view of the cost and time involved in correcting we have to insist that changes be kept to a minimum. They should be corrected on the hard copy and returned to the editor within one week.

A PDF offprint will be supplied to all contributors signed up to Author Services, on publication in the journal.

Data sharing, Data Availability Statements, and Data Citation

Data sharing

The *Journal of Research in Special Educational Needs* has adopted **Wiley's 'Expect' data sharing policy**. Where appropriate and reasonable, authors who are reporting on original data (including code, models, algorithms, methods, etc.) are expected to archive the data underpinning their paper in a public repository. We understand that it may not be appropriate for all researchers to archive their data in a public repository due to ethical or legal requirements and/or resource implications. Authors are not required to archive or share their data in order to publish with The *Journal of Research in Special Educational Needs.* The **FAIR principles** and the **registry of research data repositories** are useful resources.

Data availability statement

Authors reporting original research are required to provide a data availability statement, which describes where, and under what conditions, data underpinning a publication can be accessed. By this we mean the dataset needed to interpret, replicate and/or build on the methods or findings reported in the article. If you cannot share the data described in your manuscript, for example for legal or ethical reasons, or do not intend to share the data, then you must still provide an appropriate data availability statement. Data sharing is not required in order to publish with the *Journal of Research in Special Educational Needs*. Data availability statements should be included within the title page and will be included in the final version of accepted articles. **Sample statements are available here**. If published, all statements will be placed in the metadata of your manuscript. Please note that data availability statements are required by some funding bodies and institutions.

Data citation

Authors are encouraged to cite underlying or relevant datasets in the manuscript by citing them in-text and in the reference list. Data references should include the following elements: name(s) of data creator; publication year; dataset title; version (where available); data repository/publisher; and global persistent identifier. For example:

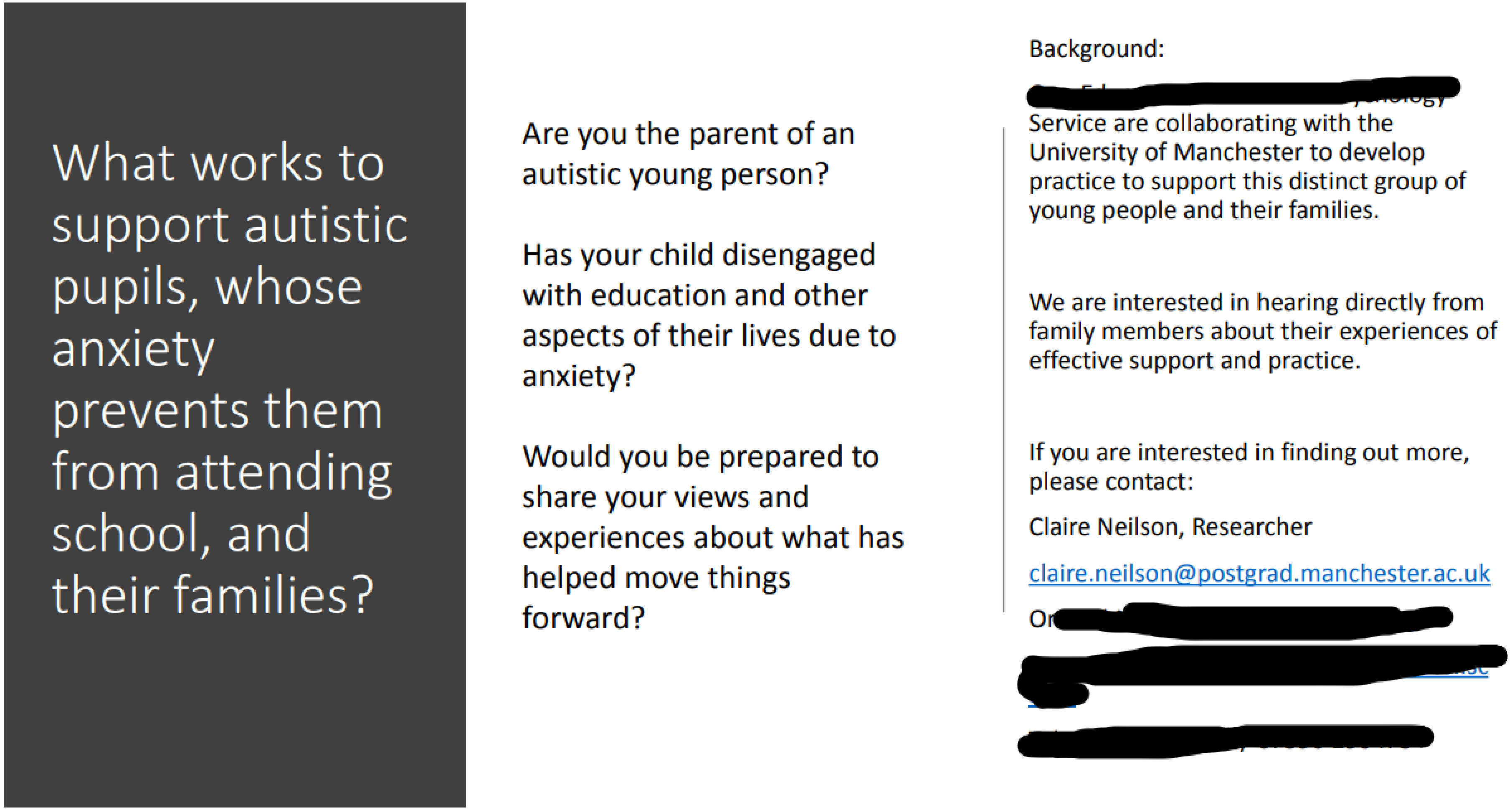
Endfield, G.H., Veale, L., Royer, M., Bowen, J.P., Davies, S., Macdonald, N., Naylor, S., Jones, C., & Tyler-Jones, R. (2017) Extreme weather in the UK: past, present and future - event details from the TEMPEST database. Centre for Environmental Data Analysis **doi:10.5285/d2cfd2af036b4d788d8eddf8ddf86707.**

Best practice guidance about data citation is available via **DataCite**.

Preprint Policy

This journal will consider for review articles previously available as preprints. Authors may also post the submitted version of a manuscript to a preprint server at any time. Authors are requested to update any pre-publication versions with a link to the final published article.

Appendix 7: Parental recruitment flyer



What works to support autistic pupils, whose anxiety prevents them from attending school, and their families?

Are you the parent of an autistic young person?

Has your child disengaged with education and other aspects of their lives due to anxiety?

Would you be prepared to share your views and experiences about what has helped move things forward?

Background:

[redacted] Service are collaborating with the University of Manchester to develop practice to support this distinct group of young people and their families.

We are interested in hearing directly from family members about their experiences of effective support and practice.

If you are interested in finding out more, please contact:

Claire Neilson, Researcher

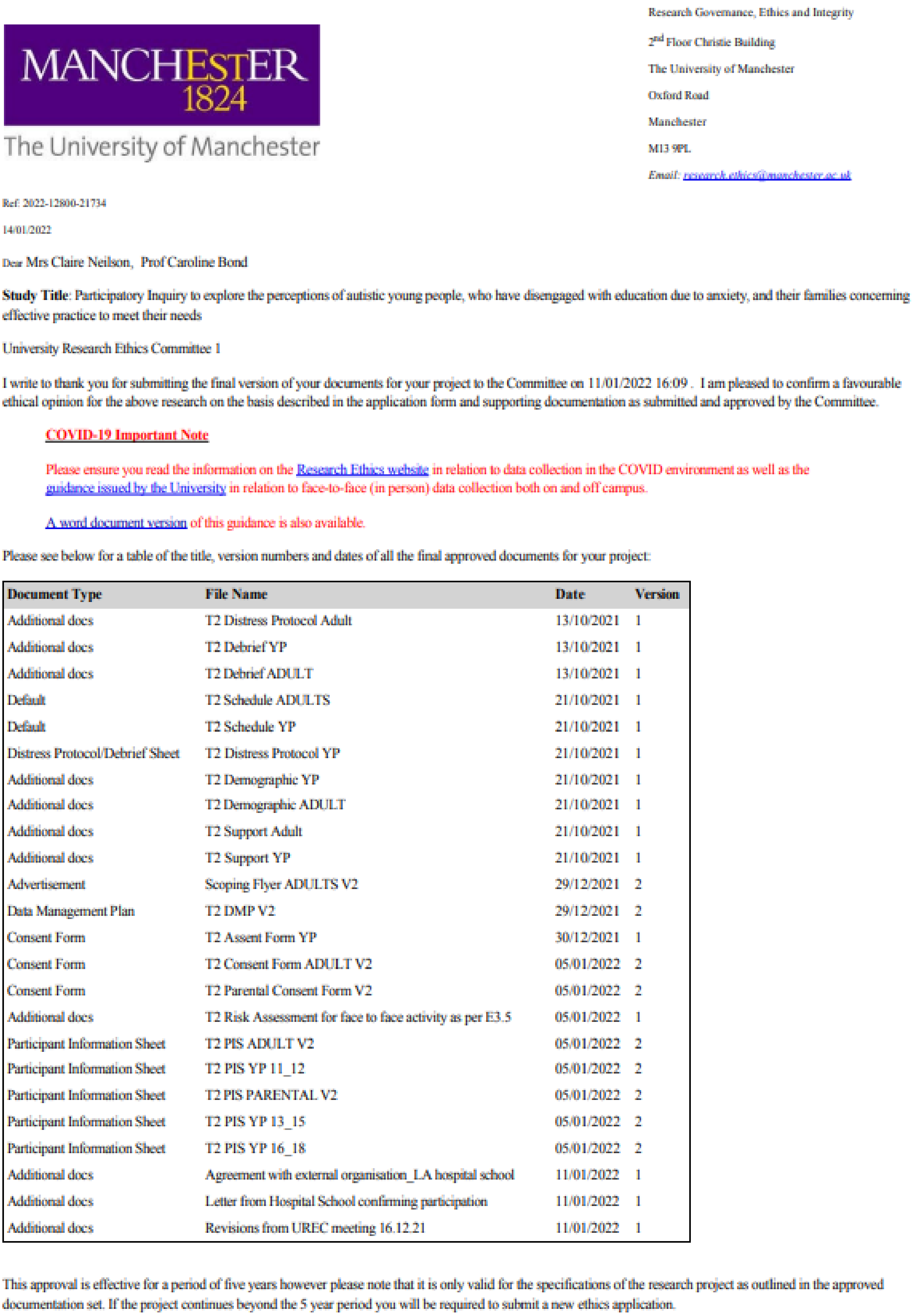
claire.neilson@postgrad.manchester.ac.uk

Or [redacted]

[redacted]

[redacted]

Appendix 8: Ethical approval letter



Research Governance, Ethics and Integrity
2nd Floor Christie Building
The University of Manchester
Oxford Road
Manchester
M13 9PL
Email: research.ethics@manchester.ac.uk

Ref: 2022-12800-21734

14/01/2022

Dear Mrs Claire Neilson, Prof Caroline Bond

Study Title: Participatory Inquiry to explore the perceptions of autistic young people, who have disengaged with education due to anxiety, and their families concerning effective practice to meet their needs

University Research Ethics Committee 1

I write to thank you for submitting the final version of your documents for your project to the Committee on 11/01/2022 16:09 . I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form and supporting documentation as submitted and approved by the Committee.

COVID-19 Important Note

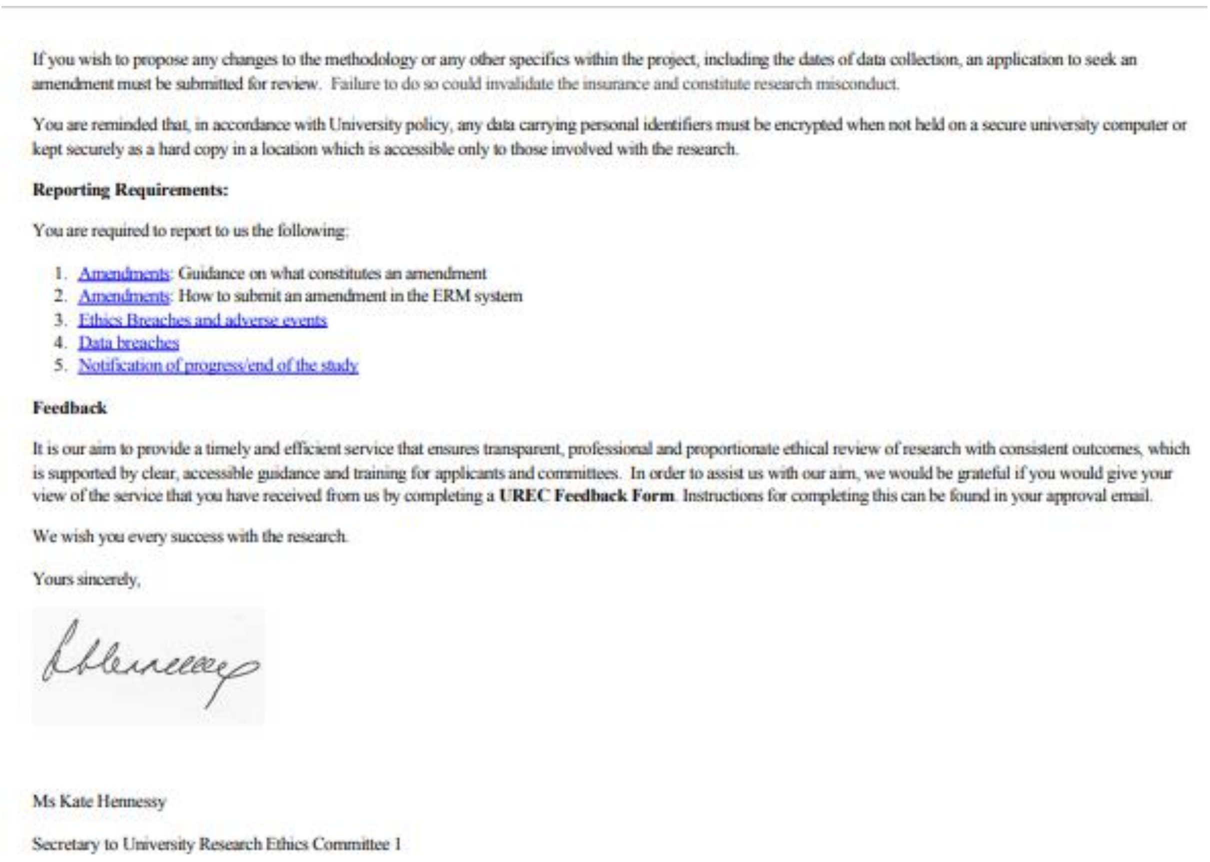
Please ensure you read the information on the Research Ethics website in relation to data collection in the COVID environment as well as the guidance issued by the University in relation to face-to-face (in person) data collection both on and off campus.

A word document version of this guidance is also available.

Please see below for a table of the title, version numbers and dates of all the final approved documents for your project:

Document Type	File Name	Date	Version
Additional docs	T2 Distress Protocol Adult	13/10/2021	1
Additional docs	T2 Debrief YP	13/10/2021	1
Additional docs	T2 Debrief ADULT	13/10/2021	1
Default	T2 Schedule ADULTS	21/10/2021	1
Default	T2 Schedule YP	21/10/2021	1
Distress Protocol/Debrief Sheet	T2 Distress Protocol YP	21/10/2021	1
Additional docs	T2 Demographic YP	21/10/2021	1
Additional docs	T2 Demographic ADULT	21/10/2021	1
Additional docs	T2 Support Adult	21/10/2021	1
Additional docs	T2 Support YP	21/10/2021	1
Advertisement	Scoping Flyer ADULTS V2	29/12/2021	2
Data Management Plan	T2 DMP V2	29/12/2021	2
Consent Form	T2 Assent Form YP	30/12/2021	1
Consent Form	T2 Consent Form ADULT V2	05/01/2022	2
Consent Form	T2 Parental Consent Form V2	05/01/2022	2
Additional docs	T2 Risk Assessment for face to face activity as per E3.5	05/01/2022	1
Participant Information Sheet	T2 PIS ADULT V2	05/01/2022	2
Participant Information Sheet	T2 PIS YP 11_12	05/01/2022	2
Participant Information Sheet	T2 PIS PARENTAL V2	05/01/2022	2
Participant Information Sheet	T2 PIS YP 13_15	05/01/2022	2
Participant Information Sheet	T2 PIS YP 16_18	05/01/2022	2
Additional docs	Agreement with external organisation_LA hospital school	11/01/2022	1
Additional docs	Letter from Hospital School confirming participation	11/01/2022	1
Additional docs	Revisions from UREC meeting 16.12.21	11/01/2022	1

This approval is effective for a period of five years however please note that it is only valid for the specifications of the research project as outlined in the approved documentation set. If the project continues beyond the 5 year period you will be required to submit a new ethics application.



If you wish to propose any changes to the methodology or any other specifics within the project, including the dates of data collection, an application to seek an amendment must be submitted for review. Failure to do so could invalidate the insurance and constitute research misconduct.

You are reminded that, in accordance with University policy, any data carrying personal identifiers must be encrypted when not held on a secure university computer or kept securely as a hard copy in a location which is accessible only to those involved with the research.

Reporting Requirements:

You are required to report to us the following:

1. Amendments: Guidance on what constitutes an amendment
2. Amendments: How to submit an amendment in the ERM system
3. Ethics Breaches and adverse events
4. Data breaches
5. Notification of progress/end of the study

Feedback

It is our aim to provide a timely and efficient service that ensures transparent, professional and proportionate ethical review of research with consistent outcomes, which is supported by clear, accessible guidance and training for applicants and committees. In order to assist us with our aim, we would be grateful if you would give your view of the service that you have received from us by completing a **UREC Feedback Form**. Instructions for completing this can be found in your approval email.

We wish you every success with the research.

Yours sincerely,

Ms Kate Hennessy

Secretary to University Research Ethics Committee 1

Appendix 9: Consent documentation

A participatory inquiry to explore the perceptions of autistic young people, who have disengaged with mainstream education due to anxiety, and their families concerning effective practice to meet their needs.

PARENTAL CONSENT FORM

If you are happy for your child to participate in the research study, please complete and sign the consent form below:

	Activities	Initials
1	I confirm that I have read the attached Parental Information Sheet (Version 2; Date 12/2021) for the above study and have had the opportunity to consider the information and ask questions and had these answered satisfactorily.	
2	I understand that my child's participation in the study is voluntary and that they are free to withdraw assent at any time without giving a reason and without detriment to themselves. I understand that it will not be possible to remove your child's data from the project once it has been anonymised and forms part of the data set. I understand that after initial consent, verbal assent will be collected (from yourself and your child) to progress to each subsequent stage of the research. This will ensure my child can withdraw consent at any time. I agree for my child to take part on this basis.	
3	I agree to the sessions being audio recorded.	
4	I agree that any data collected may be included in anonymous form in thesis/publications/conference presentations.	
5	I understand that data collected during the study may be looked at by individuals from The University of Manchester or regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.	
6	I understand that there may be instances where during the course of the research information is revealed which means the researchers will be obliged to break confidentiality and this has been explained in more detail in the information sheet.	

7	I agree for my child/ward to take part in this study.	

The following activities are optional, your child may participate in the research without agreeing to the following:

8	I agree that the researcher may read confidential documents containing personal data from their school setting (individual risk assessment and pupil profile) to ensure the researcher understands your child's needs and how best to support.	
9	I agree that any anonymised data collected may be made available to other researchers.	
10	I agree that the researchers may retain my contact details in order to provide my child with a summary of the findings for this study.	

Data Protection

The personal information we collect and use to conduct this research will be processed in accordance with UK data protection law as explained in the Participant Information Sheet and the Privacy Notice for Research Participants.

____
Name of Participant (child's name)

____________________________ ____________________________ ______________
Name of Parent Signature Date

____________________________ ____________________________ ______________
Name of the person taking consent Signature Date

[copy for the participant, 1 copy for the research team (original)]

This Project Has Been Approved by the University of Manchester Research Ethics Committee

[Ref: 2022-12800-21734]

A participatory inquiry to explore the perceptions of autistic young people, who have disengaged with mainstream education due to anxiety, and their families concerning effective practice to meet their needs.

Parental information sheet

I would like to invite your child to take part in a research study to develop improved understanding of effective practice and support to meet the needs of autistic young people who have disengaged with mainstream education due to anxiety; together with their families. This study will form part of the Lead Researcher's thesis for the Doctorate in Educational and Child Psychology programme.

Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully before deciding whether you would like to give consent for your child to take part. It is important that you discuss the study with your child. If you provide consent, they will also be asked for consent to participate in the study. Hence, your child will be provided with a young person's version of the Participant Information Sheet and they will be asked to sign an Assent Form. Please ask if there is anything that is not clear either for you or your child or if both or either of you would like more information.

Thank you for taking the time to read this.

About the research

- **Who will conduct the research?**

Lead Researcher: Claire Neilson, Trainee Educational Psychologist, School of Education, Environment and Development, University of Manchester

Academic Supervisor: Professor Caroline Bond, FBPsS, Deputy Head of Manchester Institute of Education and Professional Placement Director, Doctorate in Educational and Child Psychology, Ellen Wilkinson Building, University of Manchester.

The research has been commissioned by **What is the purpose of the research?**

Nonattendance from school is associated with a range of immediate and long-term adverse outcomes. School nonattendance is an umbrella term however this study relates to Anxiety-Based School Avoidance. Existing literature suggests students with autism have a higher prevalence and severity of nonattendance and there is currently a lack of research into this area. The lead researcher's previous research identified a need to develop practice with autistic students whose anxiety has led to long-term avoidance of school and other areas of their life.

This thesis study will take the form of Participatory Inquiry and intends to explore the views of young people with autism who have experience of long-term avoidance from school due to anxiety around best practice to support their needs. The research also aims to gain the views of their parents in order that findings represent a range of perspectives.

The longer-term aim of this research is to provide multi-agency professionals who support young people and their families with an improved understanding of what works. In order that, practice and guidance may be developed to meet needs more effectively.

Your child has been invited to participate in this study because staff at their school believe they would be able to share their views around effective practice. We hope to work with a total of 4-8 autistic young people.

➢ **Will the outcomes of the research be published?**

This research will contribute to the Lead Researcher's thesis for the Doctorate in Educational and Child Psychology.

It is intended that the findings will be published in a relevant academic journal and may be presented at a conference.

The findings will be widely shared in different settings across the Local Authority which may include Educational Psychology service, schools, health, social care and/or attendance teams. Your child will be consulted regarding who would benefit from understanding the findings.

Participants will be provided with a copy of the findings and the full thesis/journal article will be available if required.

➢ **Disclosure and Barring Service (DBS) Check**

The Lead Researcher who will have access to children and young people has undergone an Enhanced DBS check, which was obtained through the University of Manchester.

➢ **Who has reviewed the research project?**

The project has been reviewed by the University of Manchester Research Ethics Committee on 14th January 2022 [Ref: 2022-12800-21734].

What would my child/ward's involvement be?

➢ **What would your child be asked to do if they took part?**

It is envisaged that your child will take part in between 1 and 8 research sessions which will not last for longer than 1 hour at your child's school setting. The Lead Researcher (Claire Neilson) has extensive experience delivering creative, participatory workshops with young people, including those with autism.

- Sessions 1-2 will support the young people to become acquainted with the researcher and explore how the young people would prefer to contribute their views. This may be through interview, a written document, drawings, games, a creative medium or another method of the young people's choice.

- Sessions 3-6 will explore the young people's views and experiences through their chosen medium.
  The views shared will be positive experiences around the support that has enable your child to progress from complete school withdrawal to attendance at the school setting. Possible themes to explore in the sessions:
  - ➢ Positive changes during this period of time
  - ➢ What helped with the journey: Key moments, people, best practice and helpful services/professional involvement
  - ➢ What is helpful and best practice at the setting
  - ➢ What they would like to tell the professionals/services who work with them to make practice even better

- Sessions 7-8 will enable the young people to evaluate the experience of taking part in the process.

Your child (along with yourself) may choose the number of sessions they wish to attend and they will also be invited to feedback their views to a group of parents who will also be interviewed.

It is envisaged that the researcher will lead sessions at your child's school setting, however the ongoing COVID-19 pandemic may result in a remote platform (Zoom or TEAMs) being more appropriate.

Participatory Inquiry is an empowering method of research, and the researcher hopes that the young people will gain personal benefit from participating and sharing their views and experiences. The focus of the inquiry is on positive experiences of support and practice however it is recognised that the experiences your child has gone through may bring up difficult memories and emotions. To support this, an atmosphere of mutual respect will be always fostered, and sessions will be stopped if emotional distress is experienced by participants. A member of staff who knows the young people will also support with the research process.

Please see the accompanying Support Protocol, which outlines the support and guidance which is provided to your child to ensure participation in this study is a positive experience and reduces the risk of any potential distress.

➢ **Will I or my child/ward be compensated for taking part?**

There will not be any compensation offered for taking part in this study.

➢ **What happens if I do not want my child/ward to take part or if I change my mind?**

It is up to you to decide whether you want your child to take part. If you are interested in your child taking part, please email claire.neilson@postgrad.manchester.ac.uk.

If you decide to provide consent, you will be given this Information Sheet to keep and will be asked to sign a Consent Form. The Lead Researcher will then invite your child to participate in the study by meeting them at their school setting. Time will be taken with this process to ensure your child feels comfortable and fully understands the purpose of the research and what it will involve. If your child wishes to participate, they will be asked to sign an Assent Form.

You can both back out at any time, without giving a reason, before the first session at the setting. However, it will not be possible to remove their data once the sessions have begun. This does not affect your data protection rights.

If you decide not to take part, you do not need to do anything further.

Audio recording of sessions may take place to support the research process and if recording occurs will be transcribed verbatim, however any identifying information removed or changed.

Your child will be asked for verbal assent to continue with the research study after each set of sessions. There will be no detriment to the individual or research study if they chose not to continue to be involved.

Data Protection and Confidentiality

➢ **What information will you collect about my child?**

In order to participate in this research study we will need to collect information about your child that could identify them, called “personal identifiable information”. We will need to collect:

- Their forename and surname
- Gender
- Age
- Length of time out of school

For audio recordings we will need to collect:

- Voice only

In addition, the researcher will request consent to read confidential school documents containing personal data, such as individual risk assessment and pupil profile. This is to ensure the researcher has a comprehensive understanding of your child’s needs and how best to support. This information will not be retained by the researcher.

➢ **Under what legal basis are you collecting this information?**

We are collecting and storing this personal identifiable information in accordance with UK data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is “a public interest task” and “a process necessary for research purposes”.

➢ **What are my rights in relation to the information you will collect about my child/ward?**

You have a number of rights under data protection law regarding your personal information. For example, you can request a copy of the information we hold about your child, including anonymised transcripts.

If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our Privacy Notice for Research.

- **Will my child/ward's participation in the study be confidential and their personal identifiable information be protected?**

The researcher will work closely with school staff to ensure that pupils not involved in the research study do not know your child has taken part. The sessions will take place in a room that is private and inaccessible to other pupils during the research.

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your child's personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way:

- Each participant will be allocated a pseudonym known only to the research team (Claire Neilson and Caroline Bond).
- Any audio recordings will be transcribed verbatim by a University of Manchester's recommended transcriber, who is aware of the University's confidentiality policy. Any identifiable information shared in the interview will be anonymised or changed to protect their identity. The original recording will be deleted after transcription.
- All Consent/Assent Forms and Participant Demographic Sheets will be retained electronically on a secure, encrypted server and any paper (hard) original copies will be stored in a lockable cabinet.
- All electronic data will be anonymised, encrypted and stored securely for a period of 5 years and hard copies will be securely disposed of at the end of the study

Potential disclosures which may result in individuals outside of the research team being provided with details about your child/ward's involvement in the study:

- They disclose information that leads to me having concerns about their safety or the safety of others
- They disclose information about misconduct/poor practice, we have a professional obligation to report this
- They disclose information about any current or future illegal activities, we have a legal obligation to report this

Please also note that individuals from The University of Manchester or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. This may involve looking at identifiable data. All individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant.

Additional information in relation to COVID-19

Due to the current COVID-19 pandemic, we have made some adjustments to the way in which this research study will be conducted that ensures we are adhering to the latest government advice in relation to social distancing as well as taking all reasonable precautions in terms of limiting the spread of the virus. You should carefully consider all of the information provided below before deciding if you still want to your child to take part in this research study. If you choose not to take part, you need to inform research team. If you have any additional queries about any of the information provided, please speak with a member of the research team.

For remote participation

If, your child's participation in this research will be recorded in Teams or Zoom and their personal data will be processed by Microsoft or Zoom respectively. This may mean that their personal data is transferred to a country outside of the European Economic Area, some of which have not yet been determined by the European Commission to have an adequate level of data protection. Appropriate legal mechanisms to ensure these transfers are compliant with the UK General Data Protection Regulation are in place. The recordings will be removed from the above third party platform and stored on University of Manchester managed file storage as soon as possible following the completion of data collection.

If using Zoom, please also consult the FAQs for more information on recordings - http://documents.manchester.ac.uk/display.aspx?DocID=48888

For face-to-face participation:

Are there any additional considerations that my child and I need to know about before deciding whether my child should take part?

- Contact with other research participants during sessions
- Possible infection through data collection activities.

You should not take part in any research activities if your child is in a vulnerable group or if they have symptoms

What additional steps will you take to keep my child safe while they take part?

- Tables and chairs will be disinfected prior and after each use
- A well-ventilated room will be used for research activities
- Researcher will ensure one metre plus distance from and between participants at all times
- Researcher has three vaccines and carries out twice weekly lateral flow testing
- Researcher will provide single use equipment (ie. pens, post-its etc)

Is there any additional information that my child and I need to know?

- Researcher and your child will follow school COVID-19 guidance at all times
- Your child will be asked to arrive on time to avoid waiting time before research activities
- Researcher and your child will be asked to use hand sanitiser when entering and exiting the room

Additional data use

- Please note you may have to provide contact details to NHS Track and Trace if it becomes necessary.

What if the Government Guidance changes?

- Participation in the project may be postponed
- The project may be reorganised to remote working

What if I have additional queries?

Please contact a member of the research team

Claire Neilson – claire.neilson@postgrad.manchester.ac.uk

Caroline Bond – caroline.bond@manchester.ac.uk

What if I have a complaint?

If you have a complaint that you wish to direct to members of the research team, please contact:

Prof. Caroline Bond (Deputy Head of Manchester Institute of Education and Professional Placement Director)

caroline.bond@manchester.ac.uk
0161 275 3686

If you wish to make a formal complaint to someone independent of the research team or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact:

The Research Ethics Manager, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL,

Email: research.complaints@manchester.ac.uk

Telephoning: 0161 306 8089.

If you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building, The University of Manchester, Oxford Road, M13 9PL at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the Information Commissioner's Office about complaints relating to your personal identifiable information Tel 0303 123 1113

Contact Details

If you have any queries about the study or if you are interested in taking part, please contact the researcher.

Claire Neilson (Trainee Educational Psychologist)
claire.neilson@postgrad.manchester.ac.uk

This project has been approved by the University of Manchester Research Ethics Committee

[Ref: 2022-12800-21734]

MANCHESTER
1824
The University of Manchester

A participatory inquiry to explore the perceptions of autistic young people, who have disengaged with mainstream education due to anxiety, and their families concerning effective practice to meet their needs.

ASSENT FORM

Tell us if you want to take part by circling all that you agree with:

	Activities	**Yes/No**
1	Do you understand what the study is about?	Yes/No
2	Have you asked all the questions you want to ask about the study?	Yes/No
3	Did you understand the answers to your questions?	Yes/No
4	Do you understand you can stop the study at any time without giving a reason?	Yes/No
5	Are you happy that things you tell the researcher will be used in the articles and reports they write?	Yes/No
6	Are you happy that things you say in the study will be looked at by people at the University of Manchester or other people who help to make sure that you are kept safe?	Yes/No
7	Are you happy that things you say in the study are shared with researchers at other places?	Yes/No
8	Do you understand that the researcher may have to tell your parents/carers/teachers things you said in the study if they are worried about you?	Yes/No
9	Are you happy to take part in the study?	Yes/No

If you don't want to take part, don't sign your name!

If you do want to take part, you can write your name below

___________________________	___________________________	_____________
Name of Young Person	Signature	Date
___________________________	___________________________	_____________
Name of the person taking assent	Signature	Date

1 copy will be given to you to keep and 1 copy will be kept by the research team.

This Project Has Been Approved by the University of Manchester Research Ethics Committee

[Ref: 2022-12800-21734]

MANCHESTER
1824
The University of Manchester

A participatory inquiry to explore the perceptions of autistic young people, who have disengaged with mainstream education due to anxiety, and their families concerning effective practice to meet their needs.

Who is Conducting the Research?

Hi, my name is Claire.
I am a student researcher at the University of Manchester. I would like to invite you to take part in our research study. The study is about what is helpful if an autistic young person is unable to go to school because they are feeling anxious.

Before you decide if you wish to take part, please make sure that you understand:

1. Why the research is being done

2. What your involvement in the project will be

Take your time to read through this information sheet before you decide if you wish to take part. Ask as many questions as you wish.

What is the Purpose of the Research?

What is school avoidance due to anxiety?

Young people who feel unable to attend school due to emotional reasons. Feeling anxious about aspects of school or leaving the house may be at the heart of these difficulties.

What is the link between autism and school avoidance?

Research suggests that autistic young people experience more severe and long-term nonattendance from school. Some of these young people may spend a lot of time at home and avoiding lots of different parts of their lives.

What helps?

I did some previous research and adults told me what they think helps autistic young people with these feelings to return to school.

I think it is important to hear from you, as a person who knows the most about it.

Why Are We Doing Our Research?

The aim of this research is to explore the views of autistic young people in a way they are comfortable with.

Firstly, I will ask you how you would like to contribute to the study. This may be through interview, writing, drawings, games, a creative activity like Lego building or a method of your choice.

Secondly, I will use your chosen method to explore what that has helped you to engage with education at times when going to school was difficult.

I am also asking similar questions to a group of parents.

Finally, I will write a report to share with the types of adults who support you. To make sure they know what young people think is helpful.

There hasn't been a lot of research published yet. I think it's important that changes.

Why Have I Been Asked to Take Part?

We have asked you to take part because you are an autistic young person with experience of not attending school due to anxiety. Your teachers suggested that you would be able to share with me what has helped you.

We will only be talking about positive approaches and support that has helped.

I would like to learn from you.

How Long is the Study?

The study will be across 3 sets of sessions. Each session will be no longer than an hour.

You can choose to take part in any number of these sessions. **You do not have to take part in them all.** You can tell me which parts you are interested in during the study.

In total you can choose to take part in between 1 & 8 sessions.

What Would I Be Asked to Do if I Take Part?

If you want to take part, we will ask that you volunteer to take part in the following activities across the 3 sets of sessions:

- Set 1 – Give me ideas about how you would like to share your views.
  Set 1 will be between 1 & 2 sessions.
- Set 2 – These sessions will be guided by you. I will ask you to share your views about positive support and experiences that has helped you attend school.
  Set 2 will be between 1 & 4 sessions.
- Set 3 – Reflect on the ideas you shared with me - you may choose to help me to feed this back to others. Tell me about the experience of taking part in this research.
  Set 3 will be between 1 & 2 sessions.

Where will the Study Take Place?

The study will take place at your school.

Will other people know I have taken part in this study?

No!
I will make sure that no one knows you have chosen to take part in the study. I will work with staff from your school to make sure that other pupils from your school do not know you have chosen to take part in the study. Sessions will take place in a room that will be kept private.

Information you have given to us is kept confidential. To do this we will use a process called anonymising, which means that we will generate a code for your information. We will make sure that your name is stored in a different place to the rest of the information you give us. We will keep the information you give us for 5 years and then it will be safely destroyed.

In order to take part in the research we will need to know your name, age, gender, length of time not attending school.

Only myself and my supervisor (Caroline Bond) will have access to your information, and we will ensure it is kept safe and secure.

We are keeping this information safe and following data protection law.

The University of Manchester is the Data Controller, which means that we will protect the information about you. All researchers have received training to do this and we will make sure that they keep your information safe.

There are a few occasions when I might have to tell your parent, or teacher things you have said if we are worried about you. For example, if you talked about something that puts yourself or someone else at risk of harm or illegal activity.

You have a number of rights under data protection law, including the right to see any of the information you have shared with us. If you would like to know more about your rights or find out the legal reason we collect and use your information, please read through the Privacy Notice for Research or discuss it with your parent/guardian.

Do I Have to Take Part?

No!
It is completely up to you if you wish to take part in the study. Make sure you think carefully and consider all the information contained in this sheet before you decide.

After you have decided you will be asked to sign an assent form that shows you understand and agree to take part in the research.

Your parent will also sign a consent form if they agree for you to take part in the study. It is important that you discuss this with your parent and that you both agree.

What if I Change my Mind?

That's fine!
You are free to withdraw from the study at any point without having to give a reason.

This type of research is called Participatory Inquiry. It means the research will be guided by you. You will have the option of taking part in everything or just certain parts. You will be able to tell me how you would like to share ideas.

You are the expert! I will be learning from you!

Who is Organising and Approving the Research?

The research is being organised by the University of Manchester along with One Education, Educational Psychology Service.

The research has also been approved by the University of Manchester Research Ethics Committee. This is a group of people who work to protect your safety, rights, wellbeing and dignity.

What Do I Do Now?

If you have any questions relating to the information contained in this sheet, please let me know:

Researcher: Claire Neilson – claire.neilson@postgrad.manchester.ac.uk

Research Supervisor: Caroline Bond – caroline.bond@manchester.ac.uk

Thank you for reading this!

This project has been approved by the University of Manchester Research Ethics Committee

[Ref: 2022-12800-21734]

MANCHESTER
1824
The University of Manchester

A participatory inquiry to explore the perceptions of autistic young people, who have disengaged with mainstream education due to anxiety, and their families concerning effective practice to meet their needs.

PARTICIPANT DEMOGRAPHIC SHEET – YOUNG PERSON

1. Gender:

2. Age:

3. Length of time out of school

This Project Has Been Approved by the University of Manchester Research Ethics Committee

[Ref: 2022-12800-21734]

MANCHESTER
1824
The University of Manchester

A participatory inquiry to explore the perceptions of autistic young people, who have disengaged with mainstream education due to anxiety, and their families concerning effective practice to meet their needs.

CONSENT FORM

If you are happy to participate, please complete and sign the consent form below:

	Activities	Initials
1	I confirm that I have read the attached information sheet (Version 2; Date 12/2021) for the above study and have had the opportunity to consider the information and ask questions and had these answered satisfactorily.	
2	I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving a reason and without detriment to myself. I understand that it will not be possible to remove my data from the project once it has been anonymised and forms part of the data set. I understand that after initial consent, verbal assent will be collected to progress to each subsequent stage of the research. This will ensure I can withdraw consent throughout the process to no detriment to myself or the research study. I agree to take part on this basis.	
3	I agree to interviews/focus groups being audio recorded.	
4	I agree that any data collected may be included in anonymous form in thesis/publications/conference presentations.	
5	I understand that data collected during the study may be looked at by individuals from The University of Manchester or regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.	
6	I understand that there may be instances where during the course of the research information is revealed which means the researchers will be obliged to break confidentiality and this has been explained in more detail in the information sheet.	
7	I agree to take part in this study.	

The following activities are optional, you may participate in the research without agreeing to the following:

8	I agree that any anonymised data collected may be made available to other researchers.	
9	I agree that the researchers may retain my contact details in order to provide me with a summary of the findings for this study.	

Data Protection

The personal information we collect and use to conduct this research will be processed in accordance with UK data protection law as explained in the Participant Information Sheet and the Privacy Notice for Research Participants.

____________________________ ____________________________ ______________

Name of Participant Signature Date

Name of the person taking consent Signature Date

[copy for the participant, 1 copy for the research team (original)]

This Project Has Been Approved by the University of Manchester Research Ethics Committee

[Ref: 2022-12800-21734]

A participatory inquiry to explore the perceptions of autistic young people, who have disengaged with mainstream education due to anxiety, and their families concerning effective practice to meet their needs.

Participant Information Sheet

You are being invited to take part in a research study to develop understanding of effective practice and support to meet the needs of autistic young people, who have disengaged with mainstream education due to anxiety, and their families. This study will form part of the Lead Researcher's thesis for the Doctorate in Educational and Child Psychology programme.

Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully before deciding whether to take part and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information.

Thank you for taking the time to read this.

About the research

- **Who will conduct the research?**

Lead Researcher: Claire Neilson, Trainee Educational Psychologist, School of Education, Environment and Development, University of Manchester

Academic Supervisor: Professor Caroline Bond, FBPsS, Deputy Head of Manchester Institute of Education and Professional Placement Director, Doctorate in Educational and Child Psychology, Ellen Wilkinson Building, University of Manchester.

The research has been commissioned by XX

- **What is the purpose of the research?**

Nonattendance from school is associated with a range of immediate and long-term adverse outcomes. School nonattendance is an umbrella term however this study relates to Anxiety-Based School Avoidance. Existing literature suggests students with autism have a higher prevalence and severity of nonattendance and there is currently a lack of research into this area. The Lead Researcher's previous research identified a need to develop practice with autistic students whose anxiety has led to long-term avoidance of school and other areas of their life.

This thesis study will take the form of Participatory Inquiry and intends to explore- the views of parents around best practice to support both their children and the needs of the wider family. The research also aims to gain the views of autistic young people who have experience of long-term avoidance from school due to anxiety in order that findings represent a range of perspectives.

The longer-term aim of this research is to provide multi-agency professionals who support young people and their families with an improved understanding of what works. In order that, practice and guidance may be developed to meet needs more effectively.

You have been invited to participate in this study because you have a child who attends the XX school and have experience and knowledge relevant to the area of study. We hope to engage a total of 4-8 parents.

- **Will the outcomes of the research be published?**

This research will contribute to the Lead Researcher's thesis for the Doctorate in Educational and Child Psychology.

It is intended that the findings will be published in a relevant academic journal and may be presented at a conference.

The findings will be widely shared in different settings across the Local Authority which may include Educational Psychology service, schools, health, social care and/or attendance teams. You will be consulted regarding who would benefit from understanding the findings.

Participants will be provided with a copy of the findings and the full thesis/journal article will be available if required.

- **Disclosure and Barring Service (DBS) Check**

The Lead Researcher who will have access to children and young people has undergone an Enhanced DBS check, which was obtained through the University of Manchester.

- **Who has reviewed the research project?**

The project has been reviewed by the University of Manchester Research Ethics Committee on 14th January 2022 [Ref: 2022-12800-21734].

What would my involvement be?

- **What would I be asked to do if I took part?**

If you are interested in taking part in the research, we will email you a Consent Form and Participant Demographic Sheet for completion before the interview. The Participant Demographic Sheet will provide contextual information which will be anonymised in the thesis/journal article. This will take less than 10 minutes to complete.

If you provide consent, you will be invited to participate in 3 research sessions:

1. A focus group with the other parent participants to share your perspectives on the research area (if an individual interview would be preferred this may be arranged). The views invited to be shared will be positive experiences of best practice around the following themes –
    - The support and practice that has enabled your child to progress from complete school withdrawal to attendance at the hospital school

- The support and best practice that has helped the wider family with their own needs and with those of their child

2. A follow-up individual interview to provide more detail of your experiences and best practice and support for your distinct family's needs.

3. A final focus group which will provisionally include the following reflective and evaluation activities –
   - Themes drawn out of the first 2 research sessions will be shared with you. This process is called member checking and ensures participants agree the themes reflect their contributions and provides an opportunity for comment.
   - Themes from sessions with young people will be presented to you and there will be the opportunity for comment.
   - Opportunity to contribute to decisions around the dissemination of findings
   - Invitation to evaluate the experience of taking part in the research study.

It is entirely optional whether you continue to participate in the research study after the initial focus group.

It is envisaged that the focus groups/interviews will take place at your child's school setting, however the ongoing COVID-19 pandemic may result in a remote platform (Zoom or TEAMs) being more appropriate.

The focus groups will last for no longer than 1.5 hours and individual interviews will last for no longer than 1 hour. The timings will be arranged to be convenient to all participants.

Participatory Inquiry is an empowering method of research, and we hope that participants will gain personal benefit from participating and sharing their views and experiences. The focus of the inquiry is on positive experiences of support and practice however it is recognised that the experiences your children and wider family have gone through have the potential to include difficult memories and emotions. To support this, an atmosphere of mutual respect will be always fostered, and interviews/focus groups will be stopped by the researcher if emotional distress is experienced by participants.

Please see the accompanying **Support Protocol**, which outlines the support and guidance which is provided to you to ensure participation in this study is a positive experience and reduces the risk of any potential distress.

- **Will I be compensated for taking part?**

There will not be any compensation offered for taking part in this study.

- **What happens if I do not want to take part or if I change my mind?**

It is up to you to decide whether to take part. If you are interested, please email claire.neilson@postgrad.manchester.ac.uk. If you do decide to take part, will be given this Participant Information Sheet to keep and will be asked to sign a Consent Form prior to the date of the first interview/focus group. If you decide to take part, you are still free to withdraw at any time before the interview/focus group without giving a reason and without detriment to yourself.

However, it will not be possible to remove your data from the project once it has been anonymised as we will not be able to identify your specific data. This does not affect your data protection rights.

If you decide not to take part, you do not need to do anything further.

Audio recording of interview/focus group will be essential for the study and will be transcribed verbatim, however any identifying information removed or changed.

Each participant will be asked for verbal assent to attend stage 2 and 3 of the research study. There will be no detriment to the individual or research if you chose not to continue to be involved after the initial focus group.

Data Protection and Confidentiality

➢ What information will you collect about me?

In order to participate in this research project we will need to collect information that could identify you, called "personal identifiable information". We will need to collect:

- Your forename and surname
- Relationship to autistic young person who has experienced time out of school due to anxiety-based school avoidance
- Age of young person
- Gender of young person
- Length of time out of school

For audio recordings we will need to collect:

- Voice only

➢ Under what legal basis are you collecting this information?

We are collecting and storing this personal identifiable information in accordance with UK data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is "a public interest task" and "a process necessary for research purposes".

➢ What are my rights in relation to the information you will collect about me?

You have a number of rights under data protection law regarding your personal information. For example you can request a copy of the information we hold about you, including anonymised transcripts.

If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our Privacy Notice for Research.

- **Will my participation in the study be confidential and my personal identifiable information be protected?**

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way:

- Each participant will be allocated a pseudonym known only to the research team (Claire Neilson and Caroline Bond).
- The meeting data will be transcribed verbatim by a University of Manchester's recommended transcriber, who is aware of the University's confidentiality policy. Any identifiable information shared in the interview will be anonymised or changed to protect your identity. The original recording will be deleted after transcription.
- All Consent/Assent Forms and Participant Demographic Sheets will be retained electronically on a secure, encrypted server and any paper (hard) original copies will be stored in a lockable cabinet
- All electronic data will be anonymised, encrypted and stored securely for a period of 5 years and hard copies will be securely disposed of at the end of the study.

Potential disclosures which may result in individuals outside of the research team being provided with details about your involvement in the study:

- You disclose information that leads to me having concerns about your safety or the safety of others
- You disclose information about misconduct/poor practice, we have a professional obligation to report this
- You disclose information about any current or future illegal activities, we have a legal obligation to report this

Additional information in relation to COVID-19

Due to the current COVID-19 pandemic, we have made some adjustments to the way in which this research study will be conducted that ensures we are adhering to the latest government advice in relation to social distancing as well as taking all reasonable precautions in terms of limiting the spread of the virus. You should carefully consider all of the information provided below before deciding if you still want to take part in this research study. If you choose not to take part, you need to inform research team. If you have any additional queries about any of the information provided, please speak with a member of the research team.

For remote participation:

If remote, your participation in this research will be recorded in Teams or Zoom and your personal data will be processed by Microsoft or Zoom respectively. This may mean that your personal data is transferred to a country outside of the European Economic Area, some of which have not yet been determined by the European Commission to have an adequate level of data protection. Appropriate legal mechanisms to ensure these transfers are compliant with the UK General Data Protection Regulation are in place. The recordings will be removed from the above third party platform and stored on University of Manchester managed file storage as soon as possible following the completion of data collection.

If using Zoom, please also consult the FAQs for more information on recordings - http://documents.manchester.ac.uk/display.aspx?DocID=48888

For face-to-face participation:

Are there any additional considerations that I need to know about before deciding whether I should take part?

- Possible infection travelling to and from the venue
- Contact with other research participants during focus groups
- Possible infection through data collection activities.

You should not take part in any research activities if you are in a vulnerable group or if you have symptoms

What additional steps will you take to keep me safe while I take part?

- Tables and chairs will be disinfected prior and after each use
- A well-ventilated room will be used for research activities
- Researcher will ensure one metre plus distance from and between participants at all times
- Researcher has three vaccines and carries out twice weekly lateral flow testing
- Researcher will provide single use equipment (ie. pens, post-its etc)

Is there any additional information that I need to know?

- Researcher and all participants will wear a mask at all times unless exempt
- Please arrive on time to avoid waiting time before research activities
- Researcher and participants to use hand sanitiser when entering and exiting the venue

Additional data use

- Please note you may have to provide contact details to NHS Track and Trace if it becomes necessary.

What if the Government Guidance changes?

- Participation in the project may be postponed
- The project may be reorganised to remote working

What if I have additional queries?

Please contact a member of the research team

Claire Neilson – claire.neilson@postgrad.manchester.ac.uk

Caroline Bond – caroline.bond@manchester.ac.uk

Please also note that individuals from The University of Manchester or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. This may involve looking at identifiable data. All individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant.

What if I have a complaint?

If you have a complaint that you wish to direct to members of the research team, please contact:

PROF. CAROLINE BOND (DEPUTY HEAD OF MANCHESTER INSTITUTE OF EDUCATION AND PROFESSIONAL PLACEMENT DIRECTOR)
Email: caroline.bond@manchester.ac.uk
Telephone: 0161 275 3686

If you wish to make a formal complaint to someone independent of the research team or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact:

The Research Ethics Manager, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL.

Email: research.complaints@manchester.ac.uk

Telephone: 0161 306 8089.

If you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie

Building, The University of Manchester, Oxford Road, M13 9PL at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the Information Commissioner's Office about complaints relating to your personal identifiable information Tel 0303 123 1113

Contact Details

If you have any queries about the study or if you are interested in taking part, please contact the researcher.

CLAIRE NEILSON (TRAINEE EDUCATIONAL PSYCHOLOGIST)
Email: **claire.neilson@postgrad.manchester.ac.uk**

This Project Has Been Approved by the University of Manchester Research Ethics Committee

[Ref: 2022-12800-21734]

MANCHESTER
1824
The University of Manchester

A participatory inquiry to explore the perceptions of autistic young people, who have disengaged with mainstream education due to anxiety, and their families concerning effective practice to meet their needs.

PARTICIPANT DEMOGRAPHIC SHEET - ADULT

4. Relationship to autistic young person who has experienced time out of school due to anxiety-based school avoidance:
5. Age of young person:
6. Gender of young person:
7. Length of time out of school:

This Project Has Been Approved by the University of Manchester Research Ethics Committee

[Ref: 2022-12800-21734]

Appendix 10: Additional documentation for protocols to minimise risk

MANCHESTER
1824
The University of Manchester

A participatory inquiry to explore the perceptions of autistic young people, who have disengaged with mainstream education due to anxiety, and their families concerning effective practice to meet their needs.

YOUNG PERSON DEBRIEF INFORMATION SHEET

Thank you very much for taking part in this part of the research study and I hope that you have found it interesting. If you have found anything discussed has caused distress and you wish to discuss it further there are a range of people you can contact.

The researcher or her supervisor:

Researcher: Claire Neilson
claire.neilson@postgrad.manchester.ac.uk

Supervisor: Caroline Bond
caroline.bond@manchester.ac.uk

Manchester Institute of Education
School of Environment, Education and Development
Ellen Wilkinson Building
The University of Manchester
Oxford Road
M13 9PL

The XX to arrange a drop-in session:

Name of school link
Email address

There are also a number of organisations listed below that you can contact:

Organisations	Contact
The Samaritans	Call: 116 123 Email: jo@samaritans.org
Child Line	Call: 0800 1111 childline.org.uk
Hub of Hope (Search for charities in your local area)	hubofhope.co.uk

SUPPORT PROTOCOL FOR YOUNG PEOPLE PARTICIPANTS

Support: This protocol has been developed to ensure the appropriate level of support and guidance is given to participants to ensure participation in the study is a positive experience and reduce the risk of potential distress caused by research sessions.

Proactive Supports:

- The research questions are strengths-based and will explore positive experiences of support and best practice.
- The researcher will meet the young people on at least one occasion to gain their trust to ensure they provide informed assent to participation in the study.
- The initial session with young people will start with a discussion of expectations in relation to participation and confidentiality and a group contract will be developed.
- The researcher is an experienced facilitator of groups and will ensure an atmosphere of mutual trust and respect is always fostered.
- The young people will be given the opportunity to express their preference in relation to how they participate in the study and method of sharing their views.
- There will be no pressure or expectation to continue with the research sessions. The young people will be asked each session if they wish to continue participating in the study.
- The sessions will take place at the school setting and considerations will be made with regards to the timings of the sessions. All attempts will be made to ensure the research sessions will be held at a time and place convenient for all participants.
- A member of staff from the school will attend all sessions to support with the research activities.
- The sessions will end with relaxation time to debrief and supporting Debrief Information Sheet will be provided to participants.
- Drop-in support will be offered to the young person by the setting's XX should they need it to further debrief after a session.
- No identifying information relating to your child will be available in the researcher's thesis/publication.

DISTRESS PROTOCOL FOR YOUNG PEOPLE PARTICIPANTS

Distress: Participant shows signs that they are experiencing distress or exhibits behaviours associated with distress such as crying. This might suggest that the questions asked caused stress to the participants or that the responses given have triggered personal or traumatic memories.

Prior to study:

Prior to commencement of the study, the participants will be given a participant information sheet with details of who to contact if they experience distress (Claire Neilson, Lead Researcher) and these details will be reiterated again with the participant at the conclusion of each data gathering session.

Prior to data gathering sessions, researcher will read individual risk assessments and pupil profiles to ensure an individualised understanding of need.

All participants will also be provided with a Debrief Information Sheet at the end of each session.

Should a participant become distressed during the interview/focus group the subsequent steps will be followed:

Step 1 (all steps will be supported by the member of staff from the setting):

- Researcher offers immediate emotional support.
- Researcher asks the participant how they are feeling, listens with empathy and offers support.
- Researcher suggests to the participant if they would like to take a break, pause, or leave the session, have a drink of water, or go into a separate room.
- Researcher asks participant if they would like to withdraw consent from participating in the study.

Step 2:

- If the participant would like to continue, the researcher/member of staff will offer continued support and reiterate that the participant can leave the session at any time to take a break.
- If the participant would like to stop or appears highly distressed (continuing to cry, evidence of low mood), follow the actions in **Step 3.**

Step 3:

- Pause the session and escort individual out of the room.
- **Mild distress**: Member of staff from the setting will support the young person and their parent will be contacted to either collect them from school or to let them know they are feeling some distress. Session to continue with other young people.
- **Moderate distress:** Member of staff from the setting will support the young person and their parent will be immediately informed and asked to collect them from school. The researcher will cancel the remainder of the session with other young people.
- **High distress:** Member of staff from the setting will support the young person and their parent will be immediately informed. The researcher will phone the relevant emergency services for assistance and remain with the participant until they arrive. The protocols at the setting will also be followed. The researcher will cancel the remainder of the session with the other young people.
- **In all instances the researcher will seek support from their supervisor.**

Follow-up actions:

- Offer to follow participant up with a parental phone call the following day.
- Offer the participant the opportunity to withdraw from the study and for their data to be destroyed.
- Recommend the participant contacts their GP or appropriate mental health services, if they continue to feel distressed.
- Offer a drop-in session with the setting's Wellbeing Manager.

The researcher will act in accordance with the following guidance *Keeping children safe in education* (2021), *Working together to safeguard children* (2018) & BPS *Practice Guidelines* (2018).

Risk: Participant discloses information which implies risk to themselves or to another person.

Should a participant disclose information that implied a risk to the participant or someone else the following steps would be taken:

- The educational setting's safeguarding protocols will be followed and the Designated Safeguard Lead will be informed immediately.

- Any concerns would be discussed with the individual and they will be informed that the researcher will be sharing information to respect confidentiality
- If action is felt to be required the researcher will immediately report these concerns to the most appropriate child safeguarding team.
- All actions will be completed with priority and at the researcher's earliest opportunity.
- The researcher will keep a clear written record of the concern and all steps taken to deal with the matter, for example who the concern has been raised with and on what date.
- **In all instances the researcher will seek support from their supervisor.**

MANCHESTER
1824
The University of Manchester

A participatory inquiry to explore the perceptions of autistic young people, who have disengaged with mainstream education due to anxiety, and their families concerning effective practice to meet their needs.

PARTICIPANT DEBRIEF INFORMATION SHEET

Thank you very much for taking part in this part of the research study and I hope that you have found it interesting. If you have found anything discussed has caused distress and you wish to discuss it further there are a range of people you can contact.

The researcher or her supervisor:

Researcher: Claire Neilson
claire.neilson@postgrad.manchester.ac.uk

Supervisor: Caroline Bond
caroline.bond@manchester.ac.uk

Manchester Institute of Education
School of Environment, Education and Development
Ellen Wilkinson Building
The University of Manchester
Oxford Road
M13 9PL

There are also a number of organisations listed below that you can contact:

Organisations	Contact
The Samaritans	Call: 116 123 Email: jo@samaritans.org
Mind	Call: 0300 123 3393 Email: info@mind.org.uk
Hub of Hope (Search for charities in your local area)	hubofhope.co.uk

MANCHESTER
1824
The University of Manchester

SUPPORT PROTOCOL

Support: This protocol has been developed to ensure the appropriate level of support and guidance is given to participants to ensure participation in the study is a positive experience and reduce the risk of potential distress caused by focus groups/interviews.

Proactive Supports:

- The research questions are strengths-based and will explore positive experiences of support and best practice.
- Participants will be given the opportunity to choose whether they wish to participate in an initial focus group or individual interview.
- Focus group will start with a discussion of expectations in relation to participation and confidentiality and a group contract will be developed.
- The Lead Researcher is an experienced facilitator of groups and will ensure an atmosphere of mutual trust and respect is always fostered.
- There will be no pressure or expectation to continue with the research sessions after the initial focus group/interview.
- The initial focus group will start with a discussion of expectations and a group contract will be developed to ensure mutual respect and confidentiality within the group.
- The sessions will ideally take place at their child’s school setting and considerations will be made with regards to the timings of the sessions. All attempts will be made to ensure the research sessions will be held at a time and place convenient for all participants.
- The sessions will end with time to debrief and supporting Debrief Information Sheet will be provided to participants.
- No identifying information relating to participants, their child attending the school or wider family will be available in the researcher’s thesis/publication.

DISTRESS PROTOCOL FOR ADULT PARTICIPANTS

Distress: Participant shows signs that they are experiencing distress or exhibits behaviours associated with distress such as crying. This might suggest that the questions asked caused stress to the participants or that the responses given have triggered personal or traumatic memories.

Prior to study:

Prior to commencement of the study, the participants will be given a participant information sheet with details of who to contact if they experience distress (Claire Neilson, Lead Researcher) and these details will be reiterated again with the participant at the conclusion of the interview/focus group.

Should a participant become distressed during the interview/focus group the subsequent steps will be followed: RED INDICATES ADAPTATIONS SHOULD INTERVIEWS/FOCUS GROUPS BE CARRIED OUT REMOTELY

Step 1:

- Researcher offers immediate emotional support.
- Researcher asks the participant how they are feeling, listens with empathy and offers support.
- Researcher suggests to the participant if they would like to take a break, pause, or stop the interview, have a drink of water, or go into a separate room. BREAK OUT ROOMS WILL BE USED TO SEPARATE DISTRESSED PARTICIPANT FROM OTHERS IF REQUIRED.

Step 2:

- If the participant would like to continue, the researcher will offer continued support and reiterate that the participant can stop the interview at any time to take a break.
- If the participant would like to stop or appears highly distressed (continuing to cry, evidence of low mood), follow the actions in **Step 3.**

Step 3:

- Stop the interview/focus group and escort individual out of the room. OTHER PARTICIPANTS IN FOCUS GROUP TO LEAVE THE MEETING.
- **Mild distress**: Ask participant if there is anyone you can call to come and meet the participant or to let them know they are feeling some distress. STAY ON THE CALL UNTIL DISTRESS HAS ABATED OR A FRIEND/FAMILY MEMBER ARRIVES TO SUPPORT.
- **Moderate distress:** Immediately inform a family member or friend of the participant, ask them to collect the participant and stay with the participant until they arrive. STAY ON THE CALL UNTIL A FRIEND/FAMILY MEMBER ARRIVES TO SUPPORT.
- **High distress:** Researcher will phone the relevant emergency services for assistance but remain with the participant until they arrive. STAY ON THE CALL UNTIL THE RELEVANT EMERGENCY SERVICE ARRIVES.
- **In all instances the researcher will seek support from their supervisor.**

Follow-up actions:

- Offer to follow participant up with a phone call the following day.
- Offer the participant the opportunity to withdraw from the study and for their data to be destroyed.
- Recommend the participant contacts their GP if they continue to feel distressed.

The researcher will act in accordance with the following guidance *Keeping children safe in education* (2021), *Working together to safeguard children* (2018) & BPS *Practice Guidelines* (2018).

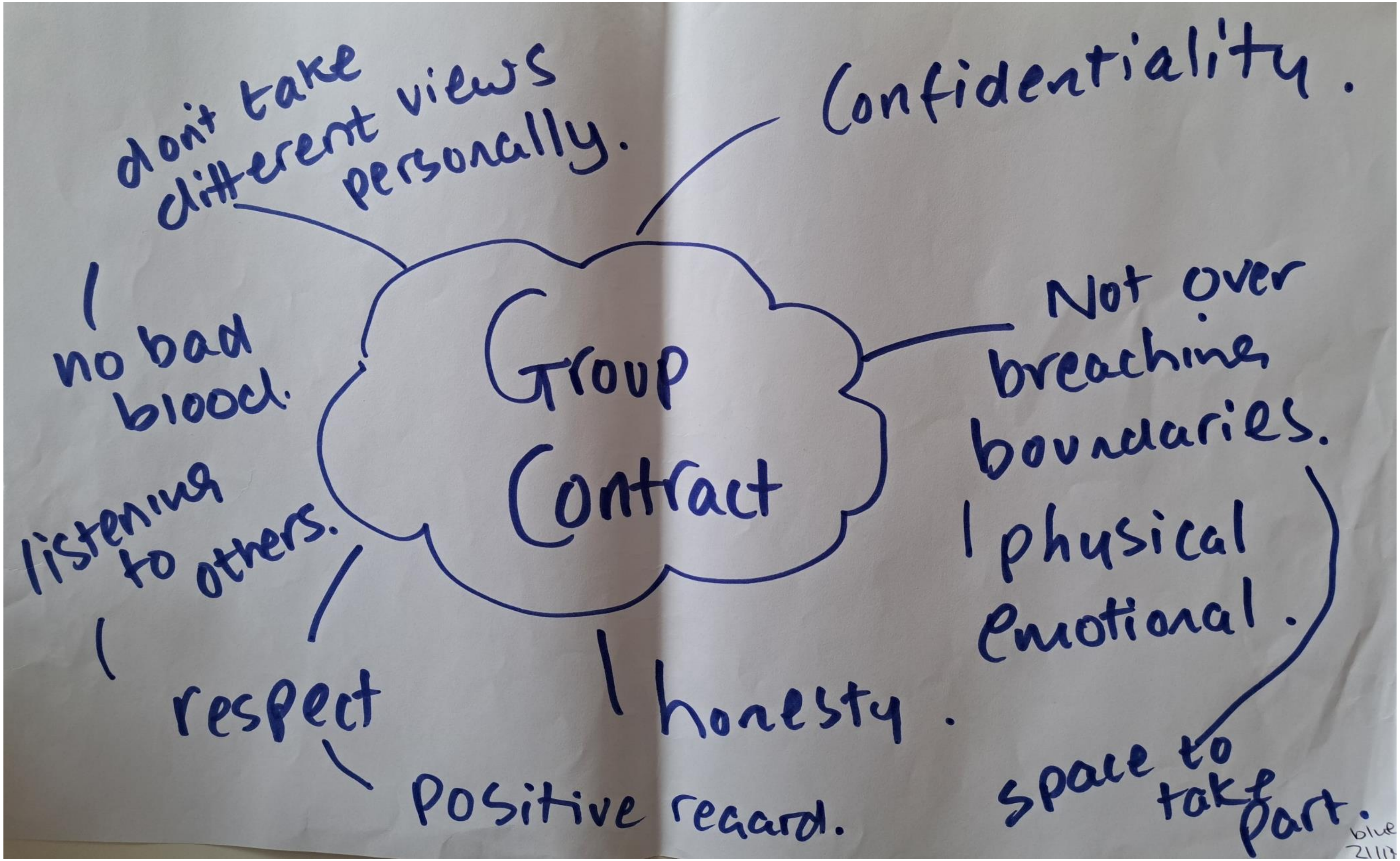
Risk: Participant discloses information which implies risk to themselves or to another person.

Should a participant disclose information that implied a risk to the participant or someone else the following steps would be taken:

- The educational setting's safeguarding protocols will be followed and the Designated Safeguard Lead will be informed immediately.
- Any concerns would be discussed with the individual and they will be informed that the researcher will be sharing information to respect confidentiality
- If action is felt to be required the researcher will immediately report these concerns to the most appropriate child safeguarding team.

- All actions will be completed with priority and at the researcher's earliest opportunity.
- The researcher will keep a clear written record of the concern and all steps taken to deal with the matter, for example who the concern has been raised with and on what date.
- **In all instances the researcher will seek support from their supervisor.**

Appendix 11: Group Contract



Appendix 12: Parental interview guide

MANCHESTER
1824
The University of Manchester

A participatory inquiry to explore the perceptions of autistic young people, who have disengaged with mainstream education due to anxiety, and their families concerning effective practice to meet their needs.

DATA GATHERING SCHEDULE WITH PARENTAL PARTICIPANTS

Research session 1:

Format:

It is envisaged this will be a focus group however individual interviews may be arranged if requested by participants.

Opening:

- Welcome – thank you for agreeing to participate and outline timings for the session.
- Recap of consent protocol – right to withdraw without consequence – will be audio recording and may make some notes.
- Introductions to myself (Lead Researcher), and participants.
- Confidentiality, participation and ethical protocol – introduce expectations and develop a group contract with contributions from participants.

Content:

Participants will be invited to share positive experiences of best practice around the following themes –

- The support and practice that has enabled their child to progress from complete school withdrawal to attendance at the hospital school
- The support and best practice that has helped the wider family with their own needs and with those of their child

Prompts:

- What positive changes have seen in young people (broader than just education)? What supported these changes?
- What does best practice look like? People, activities, relationships, services
- Your child’s identity as an individual with autism – what impact has that had on their journey and effective practice?
- What are the positive aspects about the specialist setting?
- What would your advice be to other families and professionals?
- What has supported the wider family? With their own needs? To support your child?
- On reflection, anything that could have been improved, done differently, happened at a different time, involvement with a different service/activity?

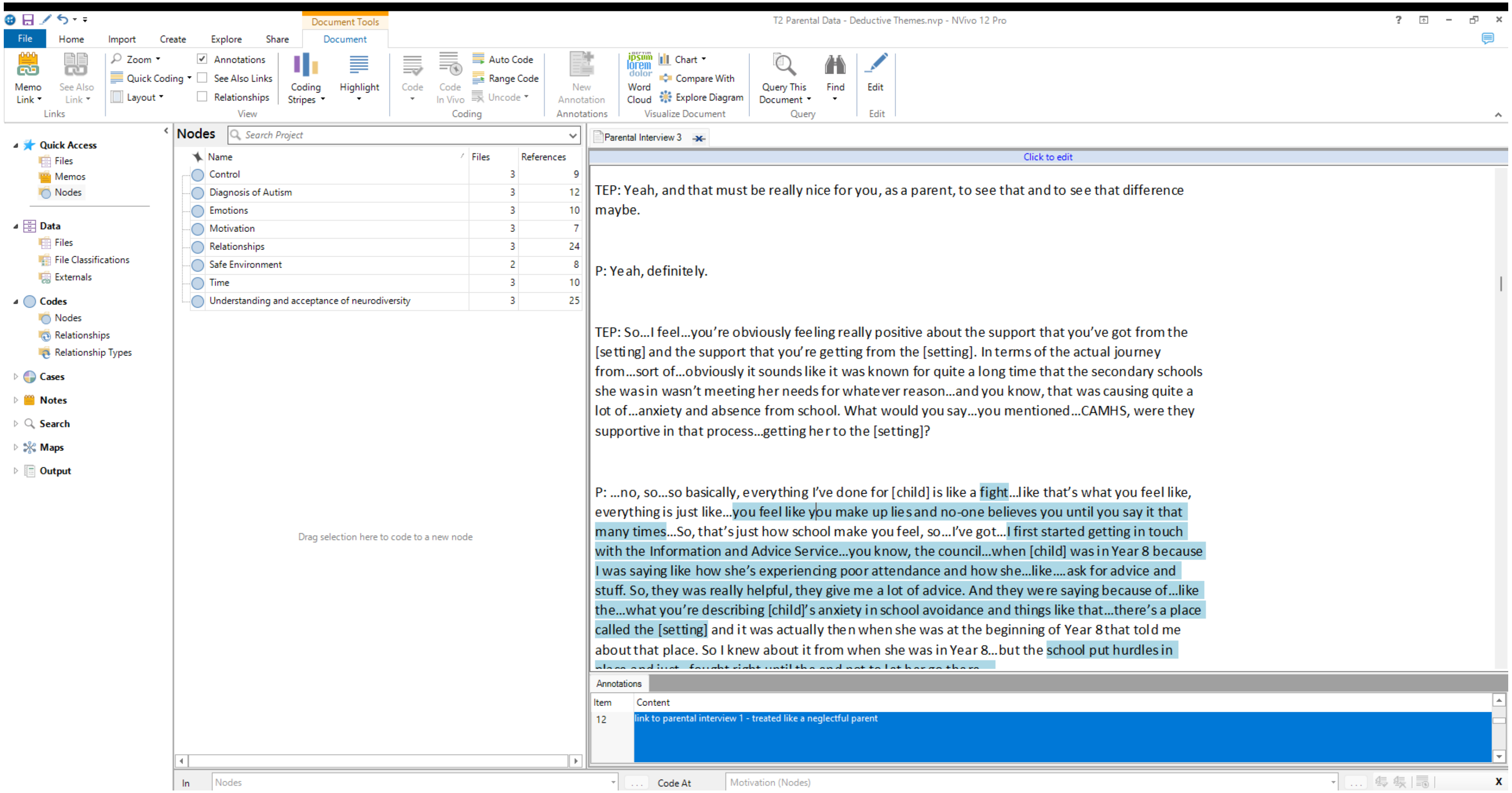
Dependent on the engagement of the participant and perspectives shared activities may include -

- Golden moment – individuals will be invited to share a golden moment in the young person or family’s journey
- Timeline activity – placing different ideas shared onto a timeline for best practice
- Mind-map activity – explore concepts introduced by participants by expanding through a mind-map. For example, if a participant mentioned “Effective communication” – mind-map this concept in more depth – what does that mean, what does it look like in practice?
- Ranking activity – use of post-it notes to rank in order supportive practice

Debrief:

- Mind-map – key points from the Focus Group
- Debrief Information Sheet to be provided to each participant

Appendix 13: Example of NVIVO coding of parental data



Name	Files	References
Control	3	9
Diagnosis of Autism	3	12
Emotions	3	10
Motivation	3	7
Relationships	3	24
Safe Environment	2	8
Time	3	10
Understanding and acceptance of neurodiversity	3	25

TEP: Yeah, and that must be really nice for you, as a parent, to see that and to see that difference maybe.

P: Yeah, definitely.

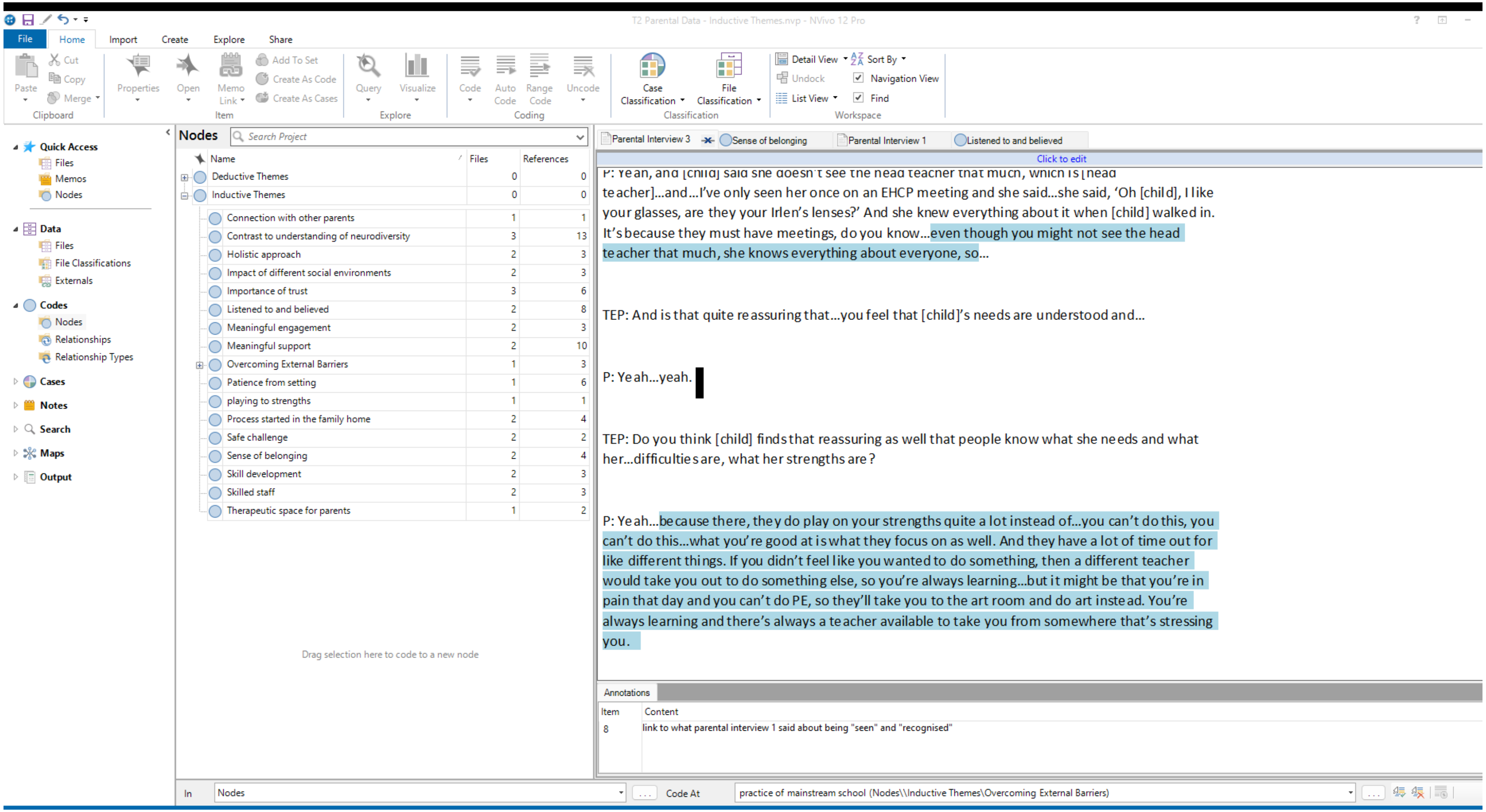
TEP: So…I feel…you're obviously feeling really positive about the support that you've got from the [setting] and the support that you're getting from the [setting]. In terms of the actual journey from…sort of…obviously it sounds like it was known for quite a long time that the secondary schools she was in wasn't meeting her needs for whatever reason…and you know, that was causing quite a lot of…anxiety and absence from school. What would you say…you mentioned…CAMHS, were they supportive in that process…getting her to the [setting]?

P: …no, so…so basically, everything I've done for [child] is like a fight…like that's what you feel like, everything is just like…you feel like you make up lies and no-one believes you until you say it that many times…So, that's just how school make you feel, so…I've got…I first started getting in touch with the Information and Advice Service…you know, the council…when [child] was in Year 8 because I was saying like how she's experiencing poor attendance and how she…like….ask for advice and stuff. So, they was really helpful, they give me a lot of advice. And they were saying because of…like the…what you're describing [child]'s anxiety in school avoidance and things like that…there's a place called the [setting] and it was actually then when she was at the beginning of Year 8 that told me about that place. So I knew about it from when she was in Year 8…but the school put hurdles in

Annotations

Item	Content
12	link to parental interview 1 - treated like a neglectful parent

Stage 1 – Deductive themes. Notes – additional content and links to other interviews



Name	Files	References
Deductive Themes	0	0
Inductive Themes	0	0
Connection with other parents	1	1
Contrast to understanding of neurodiversity	3	13
Holistic approach	2	3
Impact of different social environments	2	3
Importance of trust	3	6
Listened to and believed	2	8
Meaningful engagement	2	3
Meaningful support	2	10
Overcoming External Barriers	1	3
Patience from setting	1	6
playing to strengths	1	1
Process started in the family home	2	4
Safe challenge	2	2
Sense of belonging	2	4
Skill development	2	3
Skilled staff	2	3
Therapeutic space for parents	1	2

P: Yeah, and [child] said she doesn't see the head teacher that much, which is [head teacher]…and…I've only seen her once on an EHCP meeting and she said…she said, 'Oh [child], I like your glasses, are they your Irlen's lenses?' And she knew everything about it when [child] walked in. It's because they must have meetings, do you know…even though you might not see the head teacher that much, she knows everything about everyone, so…

TEP: And is that quite reassuring that…you feel that [child]'s needs are understood and…

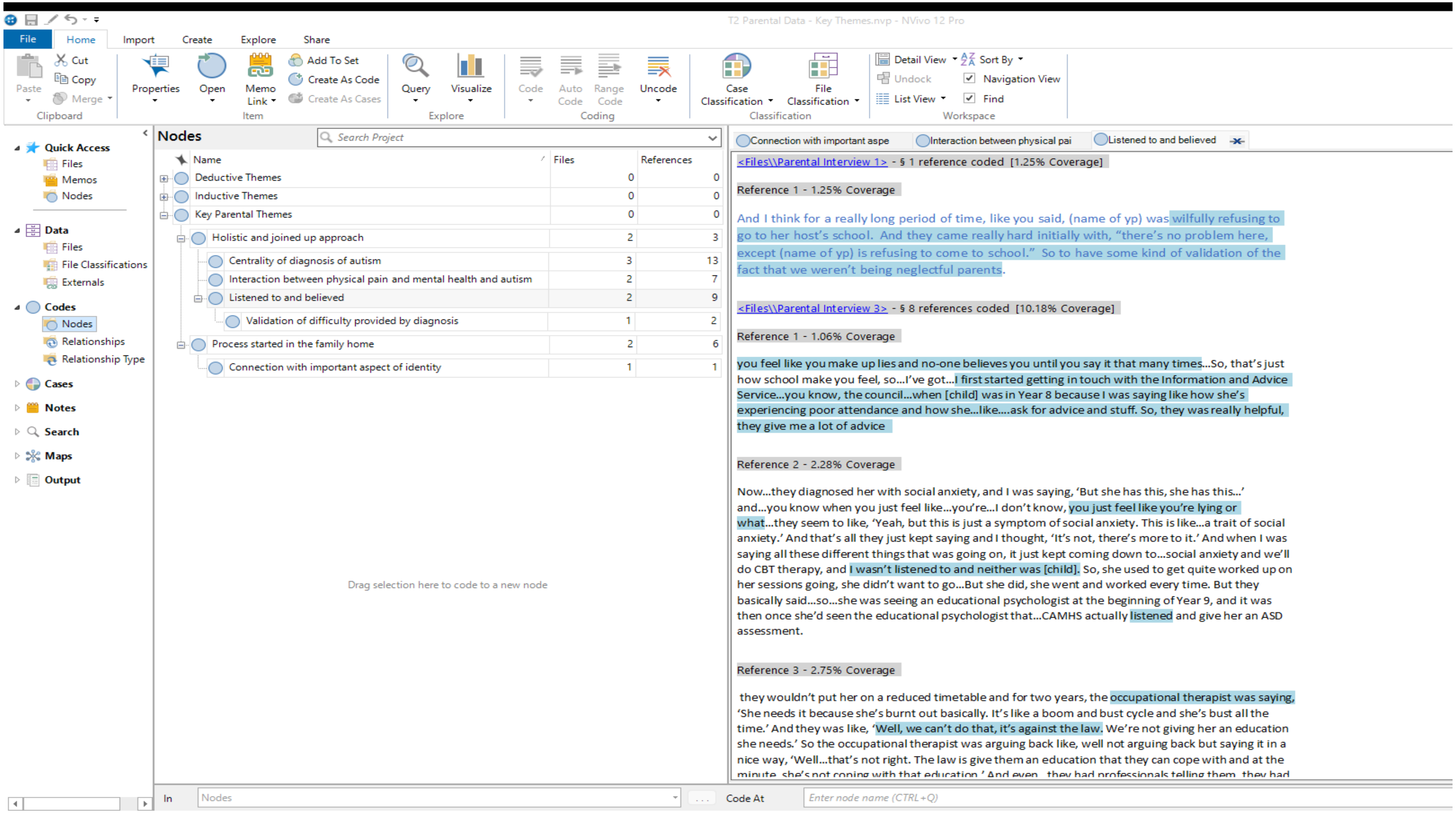
P: Yeah…yeah.

TEP: Do you think [child] finds that reassuring as well that people know what she needs and what her…difficulties are, what her strengths are?

P: Yeah…because there, they do play on your strengths quite a lot instead of…you can't do this, you can't do this…what you're good at is what they focus on as well. And they have a lot of time out for like different things. If you didn't feel like you wanted to do something, then a different teacher would take you out to do something else, so you're always learning…but it might be that you're in pain that day and you can't do PE, so they'll take you to the art room and do art instead. You're always learning and there's always a teacher available to take you from somewhere that's stressing you.

Item	Content
8	link to what parental interview 1 said about being "seen" and "recognised"

Step 2 – Inductive coding – building up codes from across parental interviews



Nodes

Name	Files	References
Deductive Themes	0	0
Inductive Themes	0	0
Key Parental Themes	0	0
Holistic and joined up approach	2	3
Centrality of diagnosis of autism	3	13
Interaction between physical pain and mental health and autism	2	7
Listened to and believed	2	9
Validation of difficulty provided by diagnosis	1	2
Process started in the family home	2	6
Connection with important aspect of identity	1	1

<Files\\Parental Interview 1> - § 1 reference coded [1.25% Coverage]

Reference 1 - 1.25% Coverage

And I think for a really long period of time, like you said, (name of yp) was wilfully refusing to go to her host's school. And they came really hard initially with, "there's no problem here, except (name of yp) is refusing to come to school." So to have some kind of validation of the fact that we weren't being neglectful parents.

<Files\\Parental Interview 3> - § 8 references coded [10.18% Coverage]

Reference 1 - 1.06% Coverage

you feel like you make up lies and no-one believes you until you say it that many times...So, that's just how school make you feel, so...I've got...I first started getting in touch with the Information and Advice Service...you know, the council...when [child] was in Year 8 because I was saying like how she's experiencing poor attendance and how she...like....ask for advice and stuff. So, they was really helpful, they give me a lot of advice

Reference 2 - 2.28% Coverage

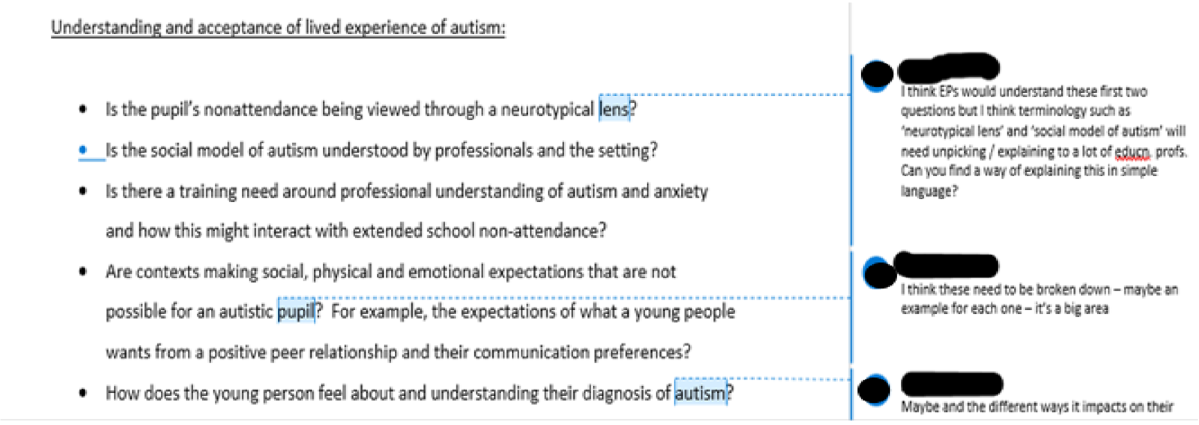
Now...they diagnosed her with social anxiety, and I was saying, 'But she has this, she has this...' and...you know when you just feel like...you're...I don't know, you just feel like you're lying or what...they seem to like, 'Yeah, but this is just a symptom of social anxiety. This is like...a trait of social anxiety.' And that's all they just kept saying and I thought, 'It's not, there's more to it.' And when I was saying all these different things that was going on, it just kept coming down to...social anxiety and we'll do CBT therapy, and I wasn't listened to and neither was [child]. So, she used to get quite worked up on her sessions going, she didn't want to go...But she did, she went and worked every time. But they basically said...so...she was seeing an educational psychologist at the beginning of Year 9, and it was then once she'd seen the educational psychologist that...CAMHS actually listened and give her an ASD assessment.

Reference 3 - 2.75% Coverage

they wouldn't put her on a reduced timetable and for two years, the occupational therapist was saying, 'She needs it because she's burnt out basically. It's like a boom and bust cycle and she's bust all the time.' And they was like, 'Well, we can't do that, it's against the law. We're not giving her an education she needs.' So the occupational therapist was arguing back like, well not arguing back but saying it in a nice way, 'Well...that's not right. The law is give them an education that they can cope with and at the minute, she's not coping with that education.' And even...they had professionals telling them, they had

Step 3: Development of themes – key themes to synthesise – to include pertinent individual contributions

Appendix 14: Extracts of feedback from stakeholders



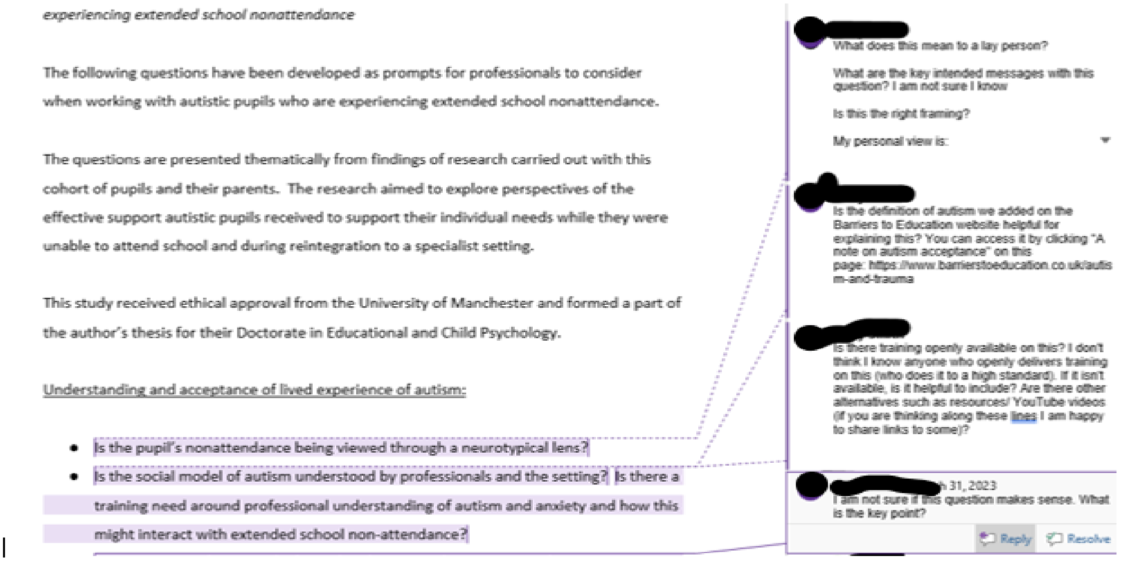
Understanding and acceptance of lived experience of autism:

- Is the pupil's nonattendance being viewed through a neurotypical lens?
- Is the social model of autism understood by professionals and the setting?
- Is there a training need around professional understanding of autism and anxiety and how this might interact with extended school non-attendance?
- Are contexts making social, physical and emotional expectations that are not possible for an autistic pupil? For example, the expectations of what a young people wants from a positive peer relationship and their communication preferences?
- How does the young person feel about and understanding their diagnosis of autism?

[redacted]
I think EPs would understand these first two questions but I think terminology such as 'neurotypical lens' and 'social model of autism' will need unpicking / explaining to a lot of educn. profs. Can you find a way of explaining this in simple language?

[redacted]
I think these need to be broken down – maybe an example for each one – it's a big area

[redacted]
Maybe and the different ways it impacts on their



experiencing extended school nonattendance

The following questions have been developed as prompts for professionals to consider when working with autistic pupils who are experiencing extended school nonattendance.

The questions are presented thematically from findings of research carried out with this cohort of pupils and their parents. The research aimed to explore perspectives of the effective support autistic pupils received to support their individual needs while they were unable to attend school and during reintegration to a specialist setting.

This study received ethical approval from the University of Manchester and formed a part of the author's thesis for their Doctorate in Educational and Child Psychology.

Understanding and acceptance of lived experience of autism:

- Is the pupil's nonattendance being viewed through a neurotypical lens?
- Is the social model of autism understood by professionals and the setting? Is there a training need around professional understanding of autism and anxiety and how this might interact with extended school non-attendance?

[redacted]
What does this mean to a lay person?

What are the key intended messages with this question? I am not sure I know

Is this the right framing?

My personal view is:

[redacted]
Is the definition of autism we added on the Barriers to Education website helpful for explaining this? You can access it by clicking "A note on autism acceptance" on this page: https://www.barrierstoeducation.co.uk/autism-and-trauma

[redacted]
Is there training openly available on this? I don't think I know anyone who openly delivers training on this (who does it to a high standard). If it isn't available, is it helpful to include? Are there other alternatives such as resources/ YouTube videos (if you are thinking along these lines I am happy to share links to some)?

[redacted] h 31, 2023
I am not sure if this question makes sense. What is the key point?

Extract from email received from key adult at research site:

I have read the information this morning - really helpful. I am going to share this with our SENCO and assistant SENCO - hopefully this will help with transition to our setting for young, autistic people.
I really like alot of the questions - the first question about non-attendance being looked at through a neurotypical lense is a really important one and something I know that I sometimes have not considered. From working with mainstream schools I know this is something, sadly, they do not think about it either. There is so much pressure on schools to have as close to 100% attendance due to OFSTED.
I know from the work that I completed with you - something that I have taken away is the idea of control. I sometimes think that professionals so often think they know what is best for the young person, due to them being the adult. This is often not the case. I think if we are willing to share control with the young person, we would see some more success.
I also think that relationships are key for having successful re-integration. Knowing your young people, making them not feel judged. Knowing they have someone to support them.

Appendix 15: Document to feedback themes to participants

Thank you so much for contributing to my research.

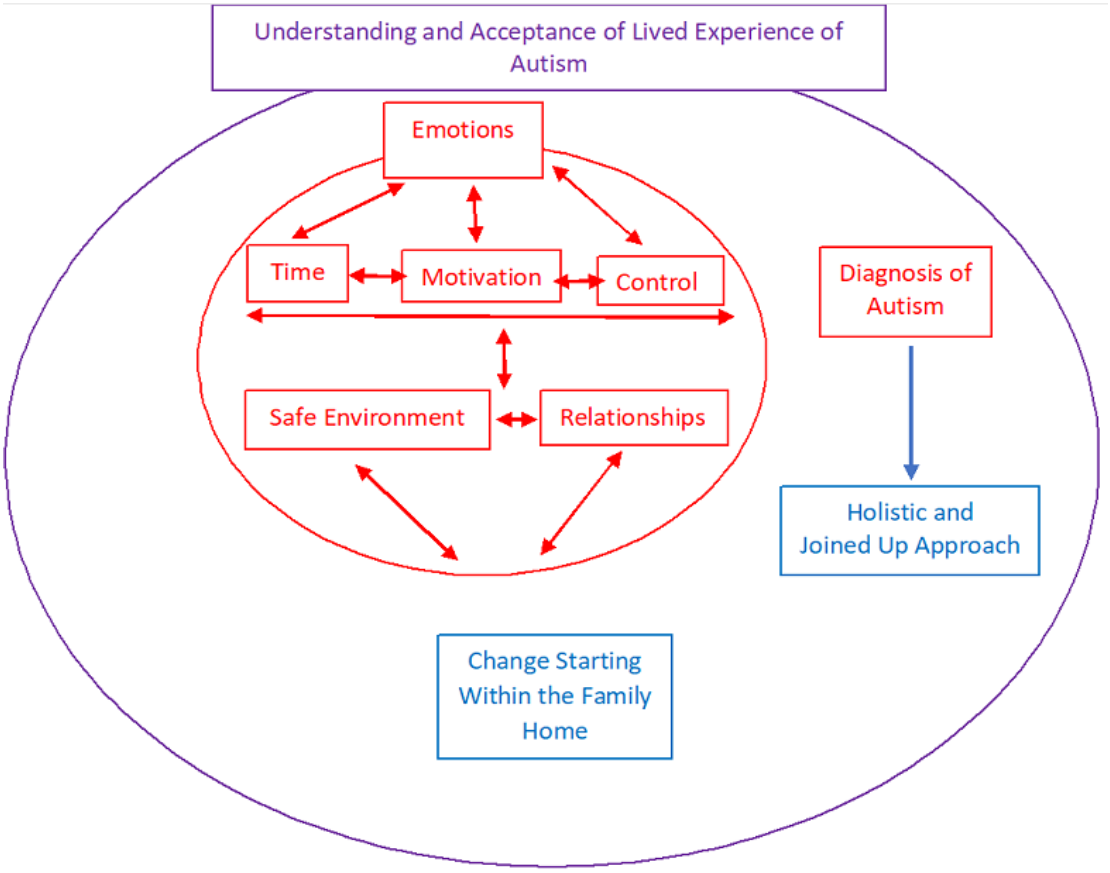
I have produced a document that outlines the themes that were developed with the young people and those I developed from the parental interviews. I have merged ideas together and I hope you feel your views are represented throughout the findings. I have also developed a theme, which appears to bring everything together around understanding and acceptance of individual lived experiences of autism.

Research Question:

How do autistic YP who have experienced extended school nonattendance describe effective support to meet their needs?

Findings:

Thematic map to show the way the themes developed by young people, parents and researcher relate to each other.



Key:

🟥 = Young people’s themes

🟦 = Parental themes

🟪 = Researcher theme

Young people's themes

a. Time

This was identified as most important for the young people.

- Time that was allowed away from school over the school holidays and starting a new school at the start of a new school year.
- Being given the right amount of time to start to engage with school, complete work and build relationships. This was compared to the negative impact of time-constraints being imposed by school.
- Fast pace of mainstream school lead to school nonattendance. The only way of stopping the fast pace was by not going into school.

b. Motivation

This was ranked of second most importance and closely related to a lack of time-constraints and freedom with homework.

- The source of motivation varied between participants: aspirations for the future and attending college and looking forward to a particular interest (eg. computer game).
- Motivation has a great impact upon emotions and de-motivation is a particularly negative feeling and linked with depression and not going outside.

c. Control

This theme was ranked joint first importance for one young person and closely supported time and motivation.

- Control around school work was important and highlighted as supportive when work was completed in their own time rather than being forced upon them. It was also discussed as helpful when there is flexibility around the content of a curriculum.
- Control was also discussed in relation to being able to say 'no' in different environments.
- Being involved in the planning of dates and times of visits to a new school and their timetable.

- Control at school more generally was discussed as supportive for autistic pupils and this was compared to when you loose control and can feel negative emotions like anxiety.

d. Safe Environment

This theme was closely related to Relationships. In school, an environment being safe meant the young people felt a degree of control.

- A school needs to feel safe to be able to attend. This was compared to previous mainstream settings which felt ‘hectic.’
- A key attribute of a safe environment was one that celebrates individual difference so pupils do not have to conform to ‘societal norms.’
- Safe environments have a positive effect on emotions.
- It helped when trusted professionals supported pupils in new environments by attending meetings with them.

e. Relationships

This theme was discussed as important by young people but friendships were not straightforward.

- Positive relationships were described as possible within a safe environment which felt like a ‘family’ and this was different to the mainstream secondary school.
- Young people discussed that it was supportive when they didn’t feel pressure to talk to others and conform to social expectations, however this could make peer friendships challenging.
- Good relationships with professionals were described as possible if you were given space to talk about yourself and time to build trust. Furthermore, when they felt listened to and what they described actually happened.

f. Emotions

Positive and negative impact upon emotions was described in conjunction with all the previous themes. The young people emphasised that attending a school that met their needs improved their mental health.

g. Diagnosis of Autism

The impact of a diagnosis of autism appeared to be more important if it occurred during the period of nonattendance from school.

- Diagnosis provides others with ‘physical proof’ of difficulties and resulted in people being more accommodating.
- Resulted in a greater understanding of why pupils might struggle to attend school.

Parental themes

The perspectives shared by parents overlapped with all the young people’s themes. Safe Environment and Relationships appeared most important to the parents.

- Relationships forged within the specialist setting was also described by a parent like a ‘family.’
- Positive interactions between their children and all staff members from headteacher to receptionist.
- Important that children felt seen, heard and understood.
- Opportunity to spend time with other people other than a parent at home.

h. Holistic and Joined Up Approach

The theme I named Holistic and Joined Up Approach was represented across all parents’ interviews and related to the young people’s theme of Diagnosis of Autism.

- Importance that professionals were working together. In contrast to when parents felt they were managing the situation on their own or different professionals were supporting different areas of difficulty.
- A holistic and joined up approach was particularly important for children who experienced medical difficulties and there was an interaction between physical pain or illness, anxiety and autism.
- Formality of an autism diagnosis was important for difficulties to be recognised and supported. The diagnosis also reduced stressors on the family such as fines and

practice from previous settings that was described as ‘bullying’. It also validated that nonattendance was not due to neglectful parenting.

i. Change Starting Within the Family Home

The second parental theme brought together views about the impact of support that took place for the family and within their home.

- Positive impact of parents receiving family therapy. This supported them to respond to their child’s difficulties differently, which resulted in the start of returning to the ‘social world.’
- Specialist setting providing outreach support within the family home. A home tutor providing a ‘stepping stone’ towards greater engagement as the work is individually tailored and introduced routine. Work provided to a child at home enabled a ‘reconnect’ with a love of learning. It should be noted that frustration is experienced when barriers are hit to progressing from home learning to finding a suitable school placement.

Researcher theme

j. Understanding and Acceptance of Individual Lived Experience of Autism

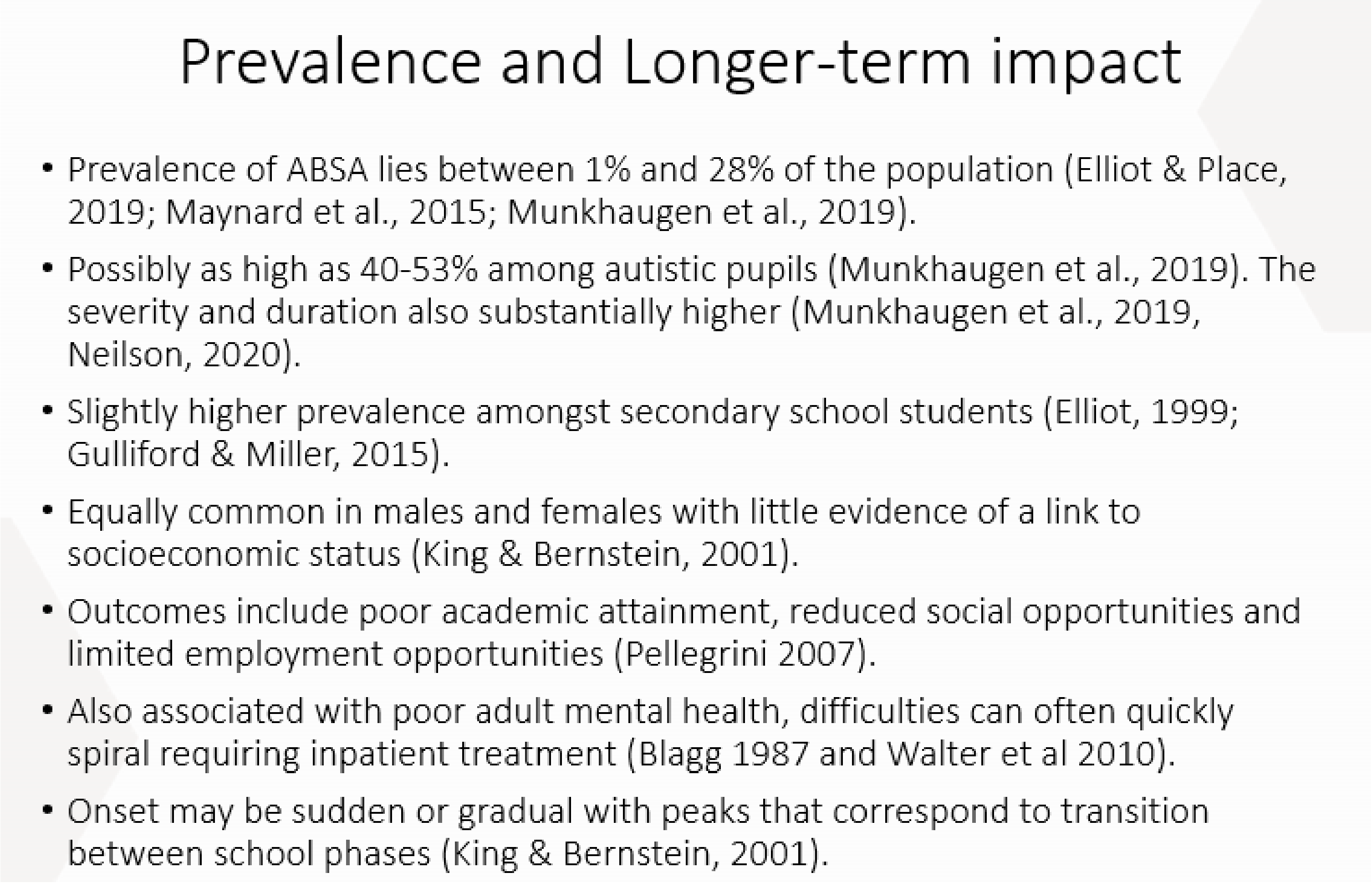
I developed this theme after reflecting upon the themes developed by the young people and parental perspectives.

- Young people described effective support offered by individuals and in different contexts in contrast to mainstream school that had neurotypical expectations.
- One young person agreed that if the link between autism and school nonattendance had been made earlier, progress might have been quicker. They also described that when they personally understood the link - they experienced a shift of understanding. From self-blame and shame about their nonattendance, to an understanding that it was not their fault and how it was ‘an actual thing’ that needed ‘proper support.’
- Parental perspectives described professional practice and settings that did not meet their children’s needs and all used the term ‘fight’. In particular, ‘fighting with a

system that is ableist,’ which they described to blame the autistic pupil for their difficulties and believed they should learn to ‘cope’.

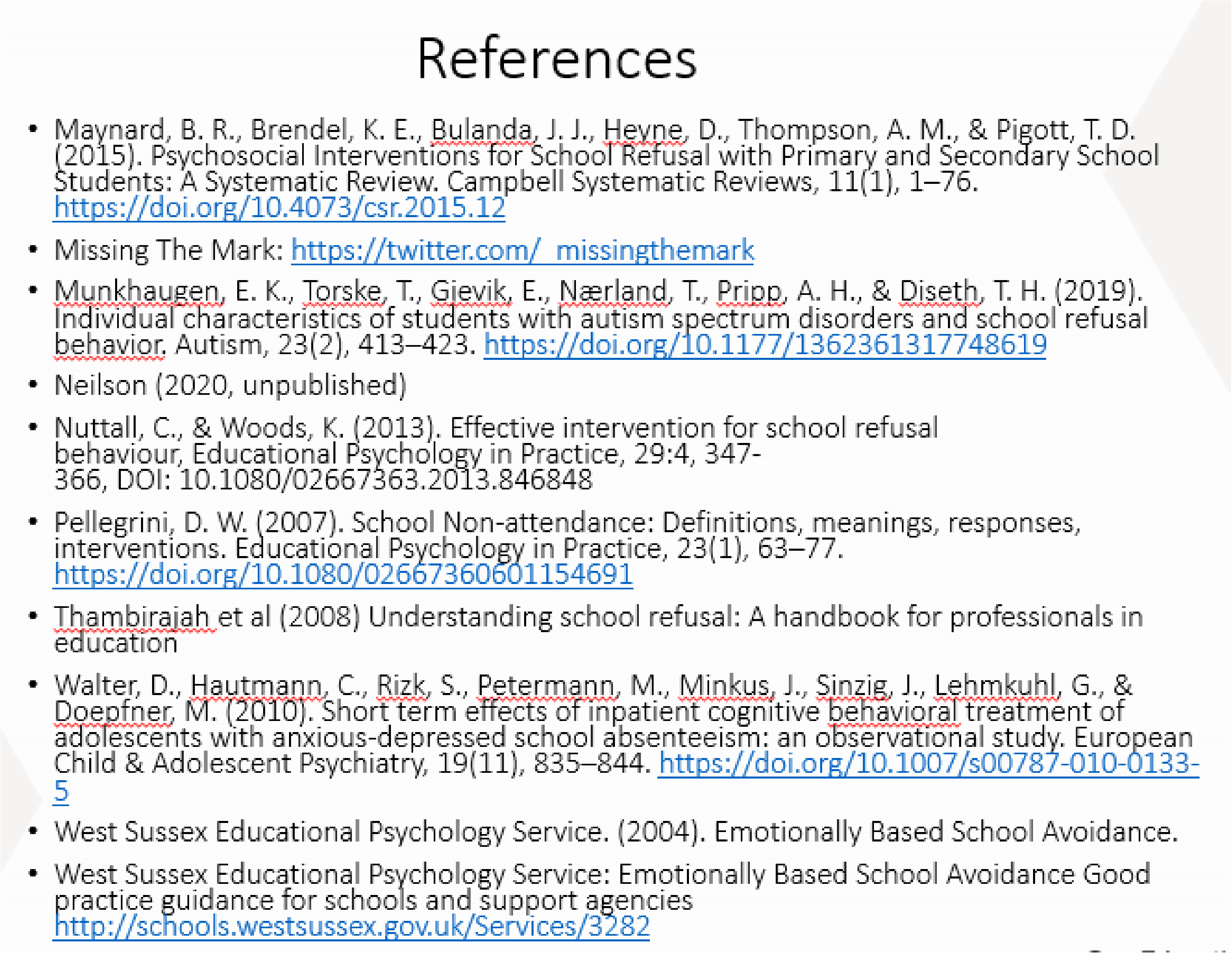
- In contrast, effective practice that accommodated and understood their child’s needs was described as showing patience, flexibility and allowed for ‘lots of plans’ and ‘lots of refusals.’

Appendix 16: Extracts from attendance presentation



Prevalence and Longer-term impact

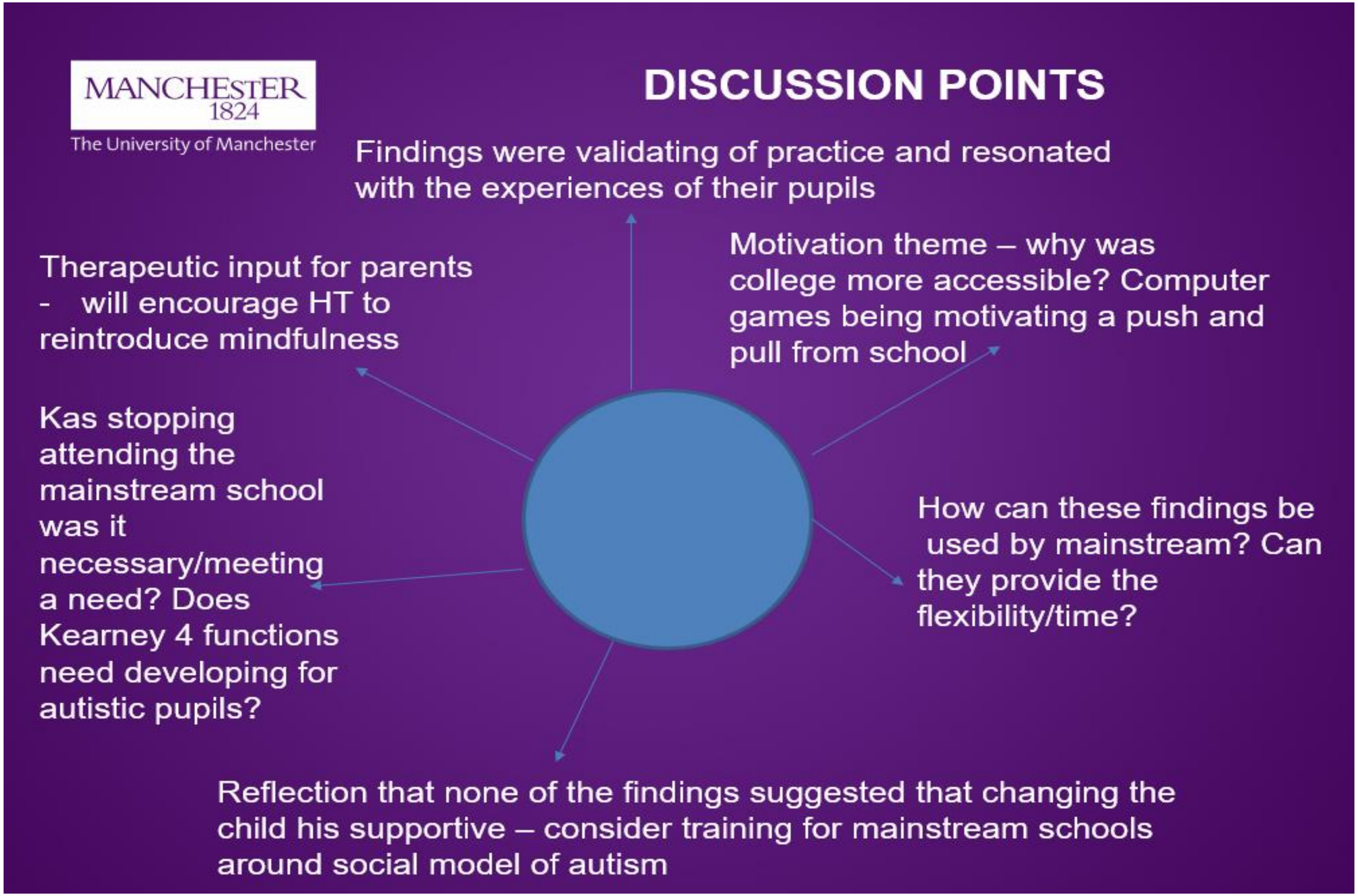
- Prevalence of ABSA lies between 1% and 28% of the population (Elliot & Place, 2019; Maynard et al., 2015; Munkhaugen et al., 2019).
- Possibly as high as 40-53% among autistic pupils (Munkhaugen et al., 2019). The severity and duration also substantially higher (Munkhaugen et al., 2019, Neilson, 2020).
- Slightly higher prevalence amongst secondary school students (Elliot, 1999; Gulliford & Miller, 2015).
- Equally common in males and females with little evidence of a link to socioeconomic status (King & Bernstein, 2001).
- Outcomes include poor academic attainment, reduced social opportunities and limited employment opportunities (Pellegrini 2007).
- Also associated with poor adult mental health, difficulties can often quickly spiral requiring inpatient treatment (Blagg 1987 and Walter et al 2010).
- Onset may be sudden or gradual with peaks that correspond to transition between school phases (King & Bernstein, 2001).



References

- Maynard, B. R., Brendel, K. E., Bulanda, J. J., Heyne, D., Thompson, A. M., & Pigott, T. D. (2015). Psychosocial Interventions for School Refusal with Primary and Secondary School Students: A Systematic Review. Campbell Systematic Reviews, 11(1), 1–76. https://doi.org/10.4073/csr.2015.12
- Missing The Mark: https://twitter.com/_missingthemark
- Munkhaugen, E. K., Torske, T., Gjevik, E., Nærland, T., Pripp, A. H., & Diseth, T. H. (2019). Individual characteristics of students with autism spectrum disorders and school refusal behavior. Autism, 23(2), 413–423. https://doi.org/10.1177/1362361317748619
- Neilson (2020, unpublished)
- Nuttall, C., & Woods, K. (2013). Effective intervention for school refusal behaviour, Educational Psychology in Practice, 29:4, 347-366, DOI: 10.1080/02667363.2013.846848
- Pellegrini, D. W. (2007). School Non-attendance: Definitions, meanings, responses, interventions. Educational Psychology in Practice, 23(1), 63–77. https://doi.org/10.1080/02667360601154691
- Thambirajah et al (2008) Understanding school refusal: A handbook for professionals in education
- Walter, D., Hautmann, C., Rizk, S., Petermann, M., Minkus, J., Sinzig, J., Lehmkuhl, G., & Doepfner, M. (2010). Short term effects of inpatient cognitive behavioral treatment of adolescents with anxious-depressed school absenteeism: an observational study. European Child & Adolescent Psychiatry, 19(11), 835–844. https://doi.org/10.1007/s00787-010-0133-5
- West Sussex Educational Psychology Service. (2004). Emotionally Based School Avoidance.
- West Sussex Educational Psychology Service: Emotionally Based School Avoidance Good practice guidance for schools and support agencies http://schools.westsussex.gov.uk/Services/3282

Appendix 17: Discussion points from reflective questions



MANCHESTER
1824
The University of Manchester

DISCUSSION POINTS

Findings were validating of practice and resonated with the experiences of their pupils

Motivation theme – why was college more accessible? Computer games being motivating a push and pull from school

Therapeutic input for parents
- will encourage HT to reintroduce mindfulness

Kas stopping attending the mainstream school was it necessary/meeting a need? Does Kearney 4 functions need developing for autistic pupils?

How can these findings be used by mainstream? Can they provide the flexibility/time?

Reflection that none of the findings suggested that changing the child his supportive – consider training for mainstream schools around social model of autism

Appendix 18: DECP cross-cohort day presentation

AUTISM AND LONG-TERM NONATTENDANCE FROM SCHOOL

Claire Neilson

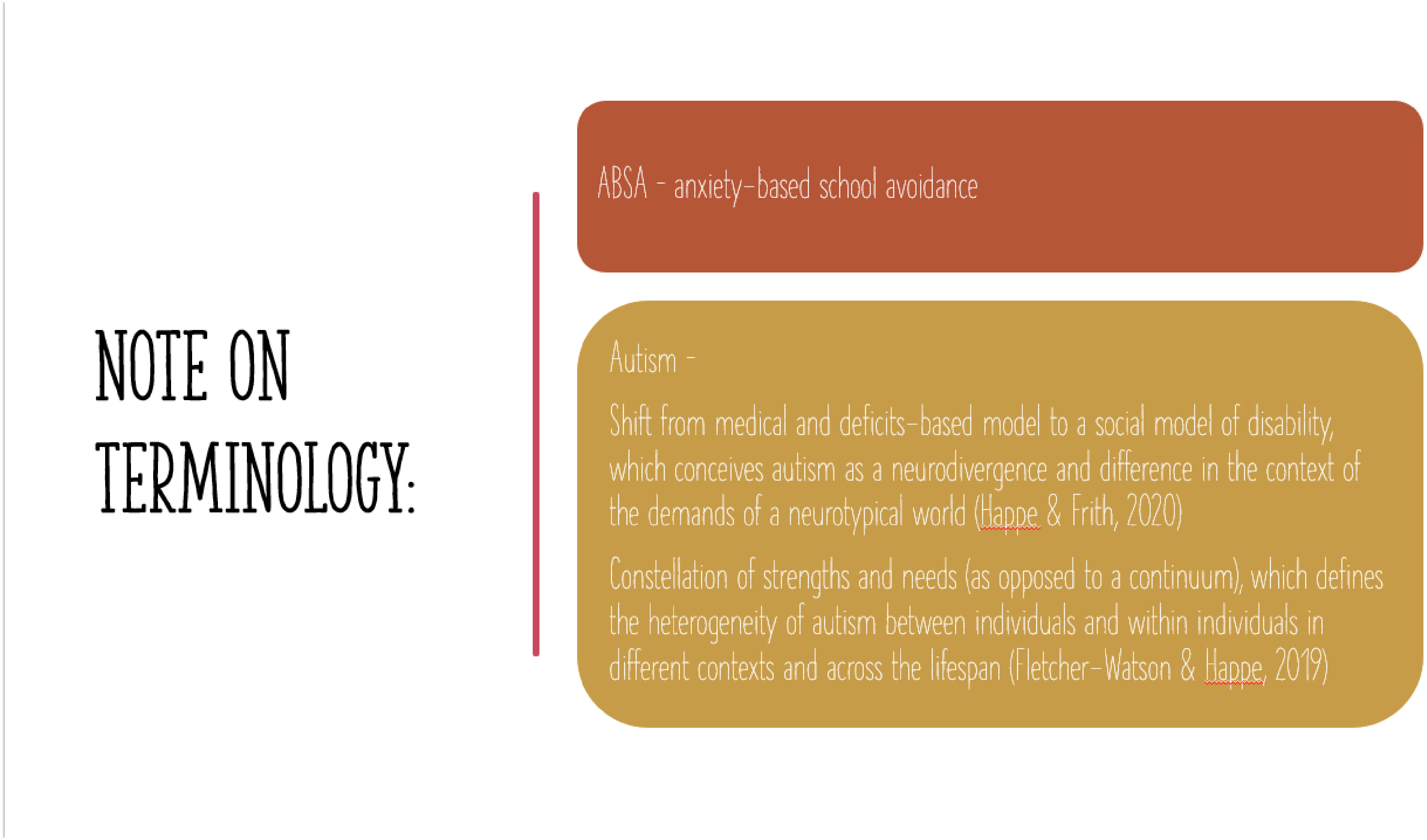
claire.neilson@postgrad.manchester.ac.uk

RATIONALE:

- My thesis commission was from XX who had been concerned about the reengagement of autistic pupils with persistent non-attendance due to anxiety.
- LA ABSA document for school contains a general section around autism and ABSA.
- They are closely affiliated to the Local Authority's XX school who also wish to develop their provision.

LITERATURE:

- International literature suggests that the prevalence of ABSA lies between 1% and 28% of the population (Elliot & Place, 2019; Maynard et al., 2015; Munkhaugen et al., 2019). However, this is reported to rise to 40-53% among autistic pupils (Munkhaugen et al., 2019) and the severity and duration of nonattendance from school is also reported to be substantially higher (Munkhaugen et al., 2019).
- Existing studies around profiles and needs of autistic pupils experiencing ABSA are quantitative.
- To date there are only two published papers around the lived experience of how autistic pupils with long-term nonattendance due to anxiety can be supported to re-engage with school (Brouwer-Borghuis et al., 2019; Preece & Howley, 2018) plus a previous thesis study.



NOTE ON TERMINOLOGY:

ABSA – anxiety-based school avoidance

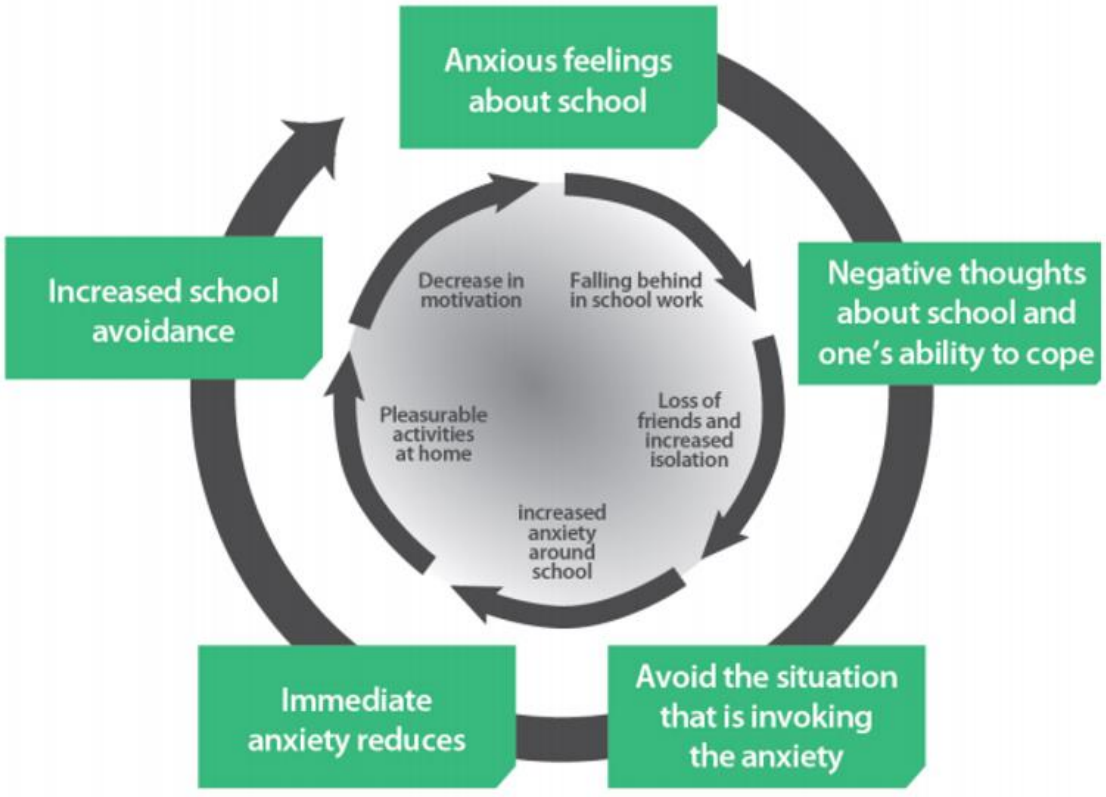
Autism –

Shift from medical and deficits-based model to a social model of disability, which conceives autism as a neurodivergence and difference in the context of the demands of a neurotypical world (Happe & Frith, 2020)

Constellation of strengths and needs (as opposed to a continuum), which defines the heterogeneity of autism between individuals and within individuals in different contexts and across the lifespan (Fletcher-Watson & Happe, 2019)

MAINTENANCE CYCLE OF ANXIETY

INITIAL ANXIETY CAUSING NON-ATTENDANCE AND SECONDARY MAINTENANCE FACTORS



Anxious feelings about school

Negative thoughts about school and one's ability to cope

Avoid the situation that is invoking the anxiety

Immediate anxiety reduces

Increased school avoidance

Decrease in motivation

Falling behind in school work

Loss of friends and increased isolation

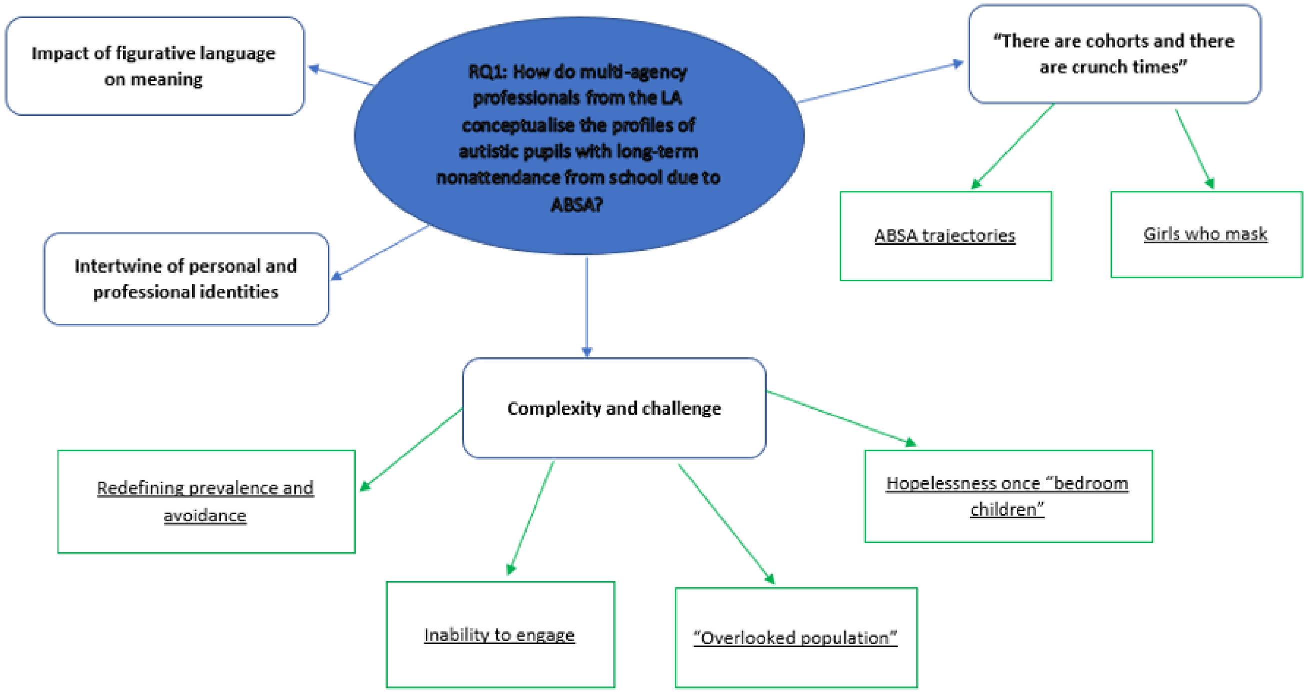
increased anxiety around school

Pleasurable activities at home

ASSIGNMENT 1

- Title - "These kids that are pendulums if you challenge them too far you break them". An exploratory study of how professionals from one local authority perceive the needs of autistic pupils with long-term nonattendance from school due to ABSA are met to support re-engagement with education.
- Aim - Explore the perceptions of professionals working within the LA, with regards to how the needs of autistic pupils with long-term non attendance due to ABSA are met to support reengagement with education
- Research Questions:
- 1. How do multi-agency professionals from the local authority conceptualise the profiles of autistic pupils with long-term nonattendance due to ABSA?
- 2. How is effective practice supporting this group of pupils to re-engage with education described across the LA?

FINDINGS - RQ1



RQ1: How do multi-agency professionals from the LA conceptualise the profiles of autistic pupils with long-term nonattendance from school due to ABSA?

Impact of figurative language on meaning

Intertwine of personal and professional identities

"There are cohorts and there are crunch times"

ABSA trajectories

Girls who mask

Complexity and challenge

Redefining prevalence and avoidance

Inability to engage

"Overlooked population"

Hopelessness once "bedroom children"

INTERTWINE OF PERSONAL AND PROFESSIONAL IDENTITIES

- "personal project"
- "suffered massive anxiety ad starting truanting at secondary school"
- "the most gutting thing to see your child fall to pieces"
- "that started a whole, sort of thing for me. That's what helped me get into special and then that' why raising anxiety and unmet need and social com […] Especially in girls. It's become a bit of a passion for me […] very close to my heart"

IMPACT OF FIGURATIVE LANGUAGE ON MEANING

- "thin veneer of coping"
- "the sort of shadow of a person"
- "these kids that are pendulums if you challenge them too far you break them. And then you'll swing back to a position where they are not coping, or they'll withdraw"

COMPLEXITY AND CHALLENGE – "YOUR MOST COMPLEX CHILDREN WITH AUTISM"

- Redefining prevalence and avoidance: "more about the significant impact that it has on the individual and their family. Because I think [...] that is really important actually. It has such a catastrophic impact on them and their situation"; "young people are not just avoidant of school, they are avoidant of every aspect of their life"; "bedroom children"; "there's a lot more attached to that it just being you can get them back into school for a day and they'll be fine".
- Inability to engage: "an implication of choice"; "we as professionals need to understand [...] it's an inability to engage rather than a refusal to engage"

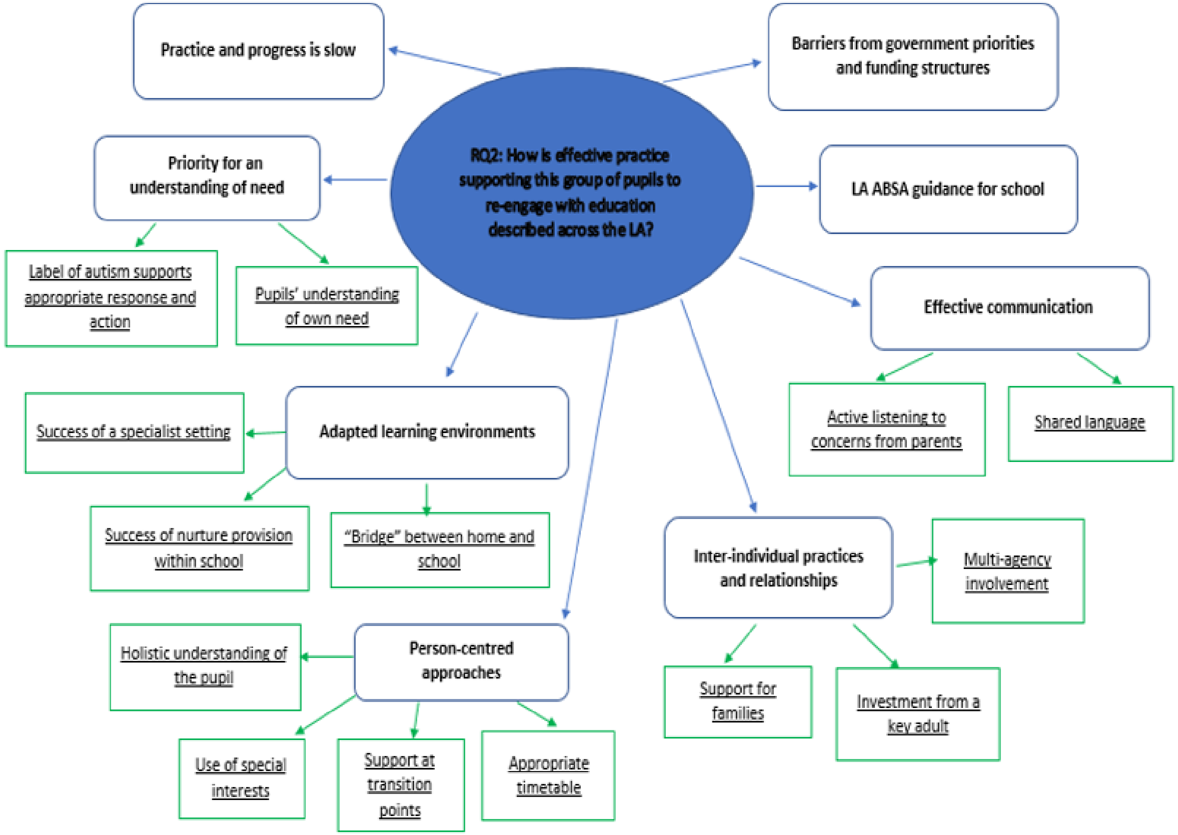
COMPLEXITY AND CHALLENGE

- "Overlooked population": "kids with anxiety, that's severe and that impacts them in many ways, are a hugely overlooked population""; "common pattern really, that the difficulty is that the young people's needs aren't perceived as a special need"; "they're never prioritised because they don't' cause a fuss. They are just not there"
- Hopelessness once "bedroom children": "the hardest group of people, children to work with and I can count on the fingers on one hand the success stories"; "I'm going to sound a little negative here [...] But it's rare that you get a child who's been out for an extended period of time and you can successfully re-establish them to [...] full-time successful reengagement at school"; "really very, very stuck, very stuck"

"THERE ARE COHORTS AND CRUNCH TIMES"

- ABSA trajectories: "crunch points where different kids fall out"; "who never manage to come into school at all"; Year group transitions - 3&4, 7, 9, 11, 6th form
- Girls who mask: "girls [...] who sort of take on this persona as a survival instinct and who appear articulate and sociable"; "The bedroom girls, the ones who, where the ABSA starts, becomes really entrenched in Year 7, Year 8, those girls by and large are not diagnosed before their school non-attendance"

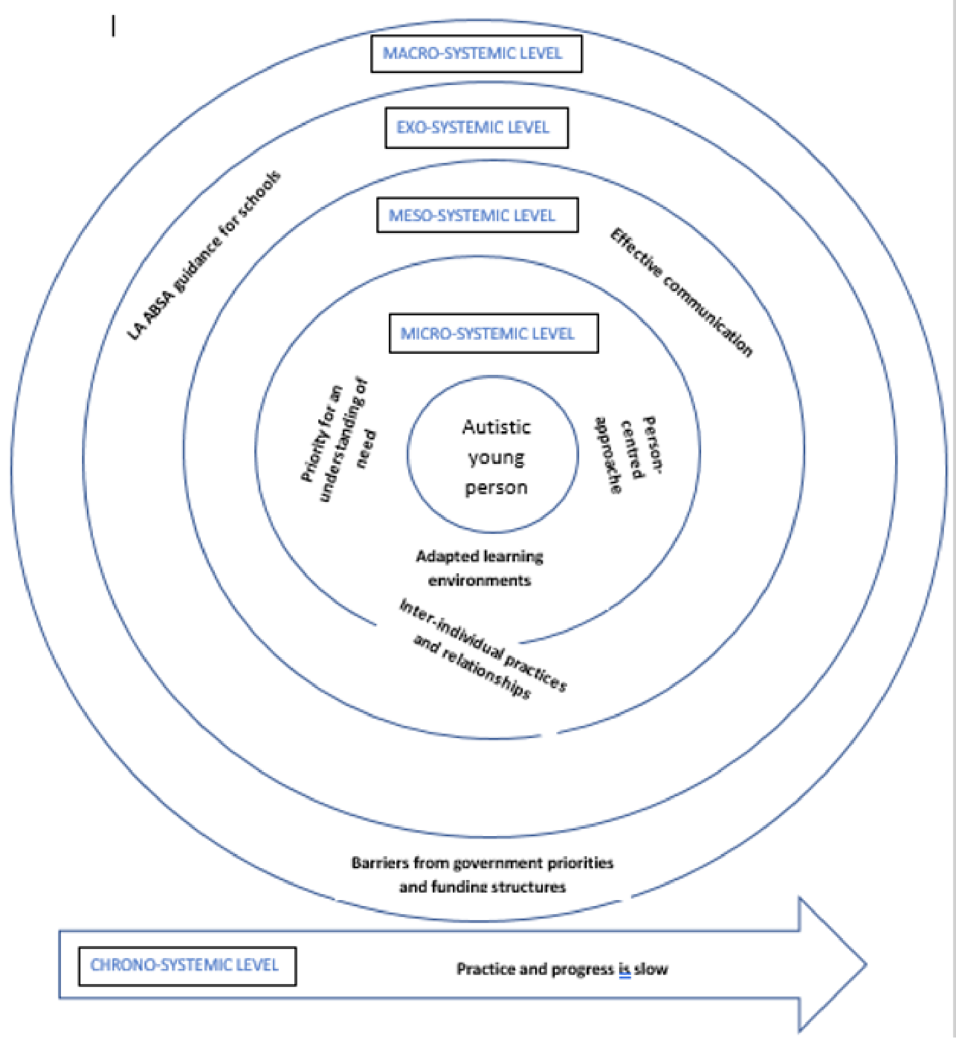
FINDINGS - RQ2



RQ2: How is effective practice supporting this group of pupils to re-engage with education described across the LA?

- Practice and progress is slow
- Barriers from government priorities and funding structures
- LA ABSA guidance for school
- Priority for an understanding of need
  - Label of autism supports appropriate response and action
  - Pupils' understanding of own need
- Effective communication
  - Active listening to concerns from parents
  - Shared language
- Adapted learning environments
  - Success of a specialist setting
  - Success of nurture provision within school
  - "Bridge" between home and school
- Inter-individual practices and relationships
  - Multi-agency involvement
  - Support for families
  - Investment from a key adult
- Person-centred approaches
  - Holistic understanding of the pupil
  - Use of special interests
  - Support at transition points
  - Appropriate timetable

APPLIED TO BIO-ECOSYSTEM MODEL OF HUMAN DEVELOPMENT (BRONFENBRENNER & MORRIS, 2007)



MACRO-SYSTEMIC LEVEL

EXO-SYSTEMIC LEVEL

LA ABSA guidance for schools

MESO-SYSTEMIC LEVEL

Effective communication

MICRO-SYSTEMIC LEVEL

Priority for an understanding of need

Autistic young person

Person-centred approache

Adapted learning environments

Inter-individual practices and relationships

Barriers from government priorities and funding structures

CHRONO-SYSTEMIC LEVEL

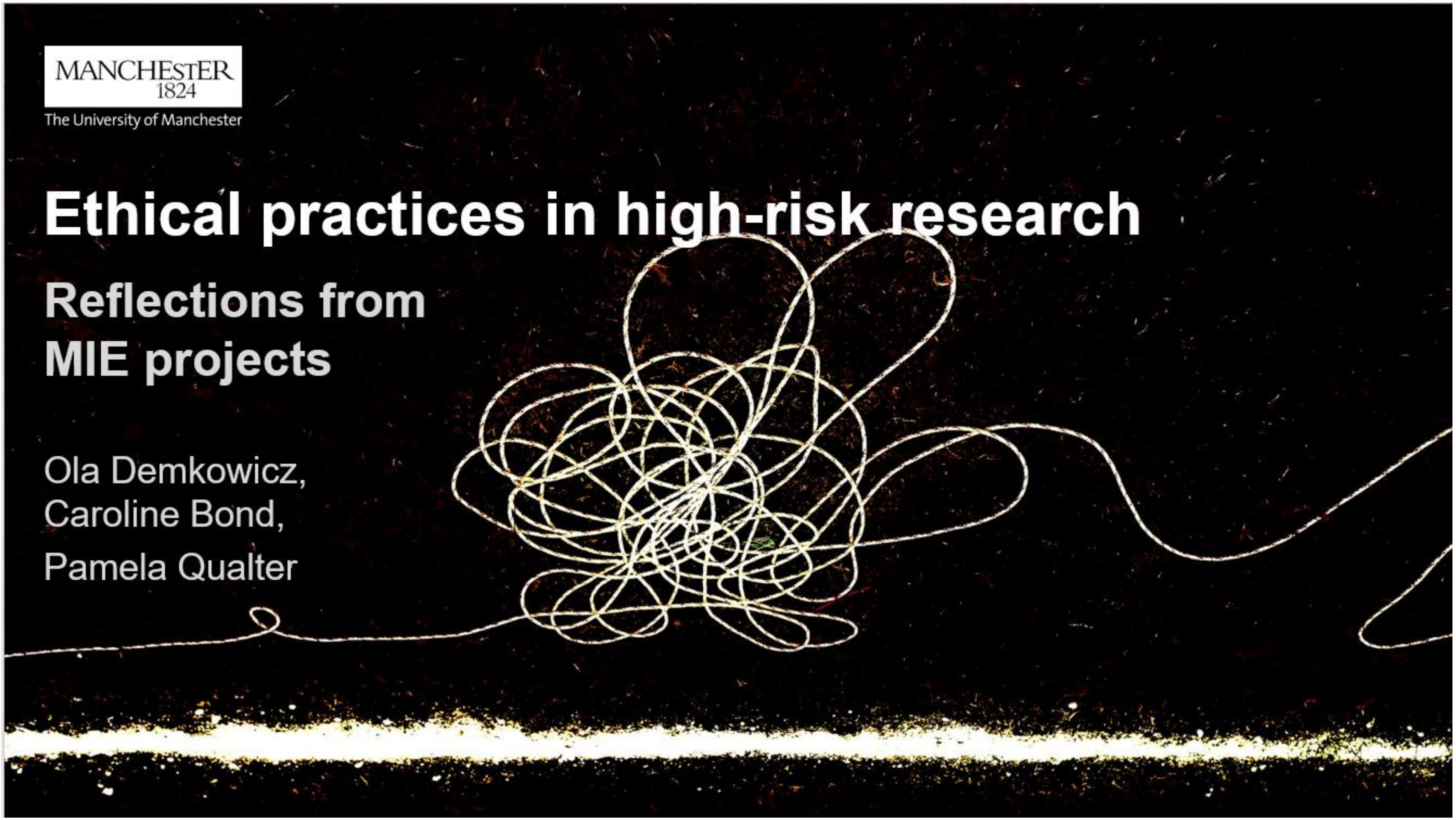
Practice and progress is slow

WHAT NEXT?

T1 – autism and anxiety – lived experience from the perspective of school aged children and their parents

T2 – A participatory inquiry to explore the perceptions of young people, who have disengaged with mainstream education due to anxiety, and their families concerning effective practice to meet their needs.

Appendix 19: Extracts from high-risk research presentation

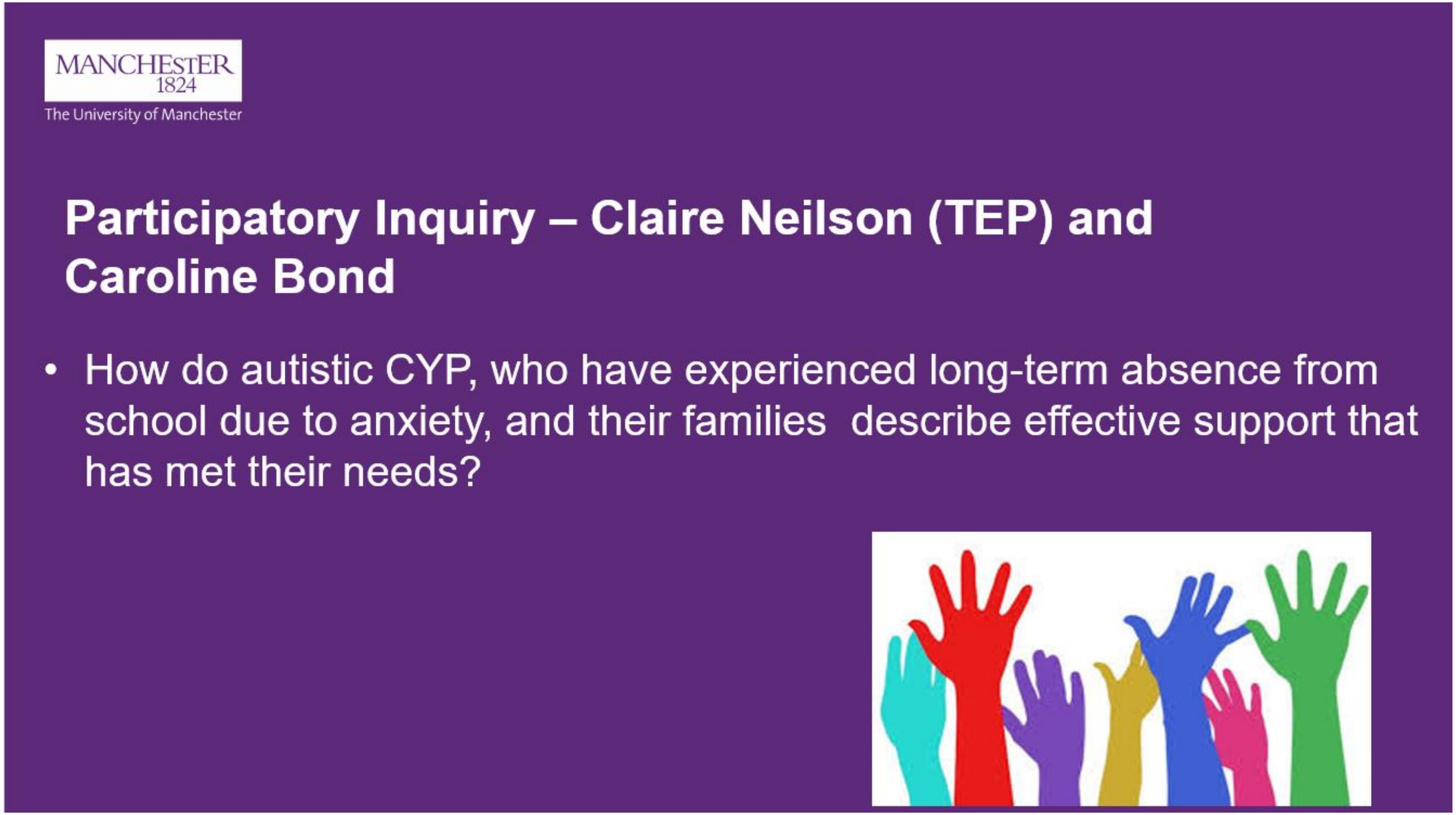


MANCHESTER
1824
The University of Manchester

Ethical practices in high-risk research

Reflections from MIE projects

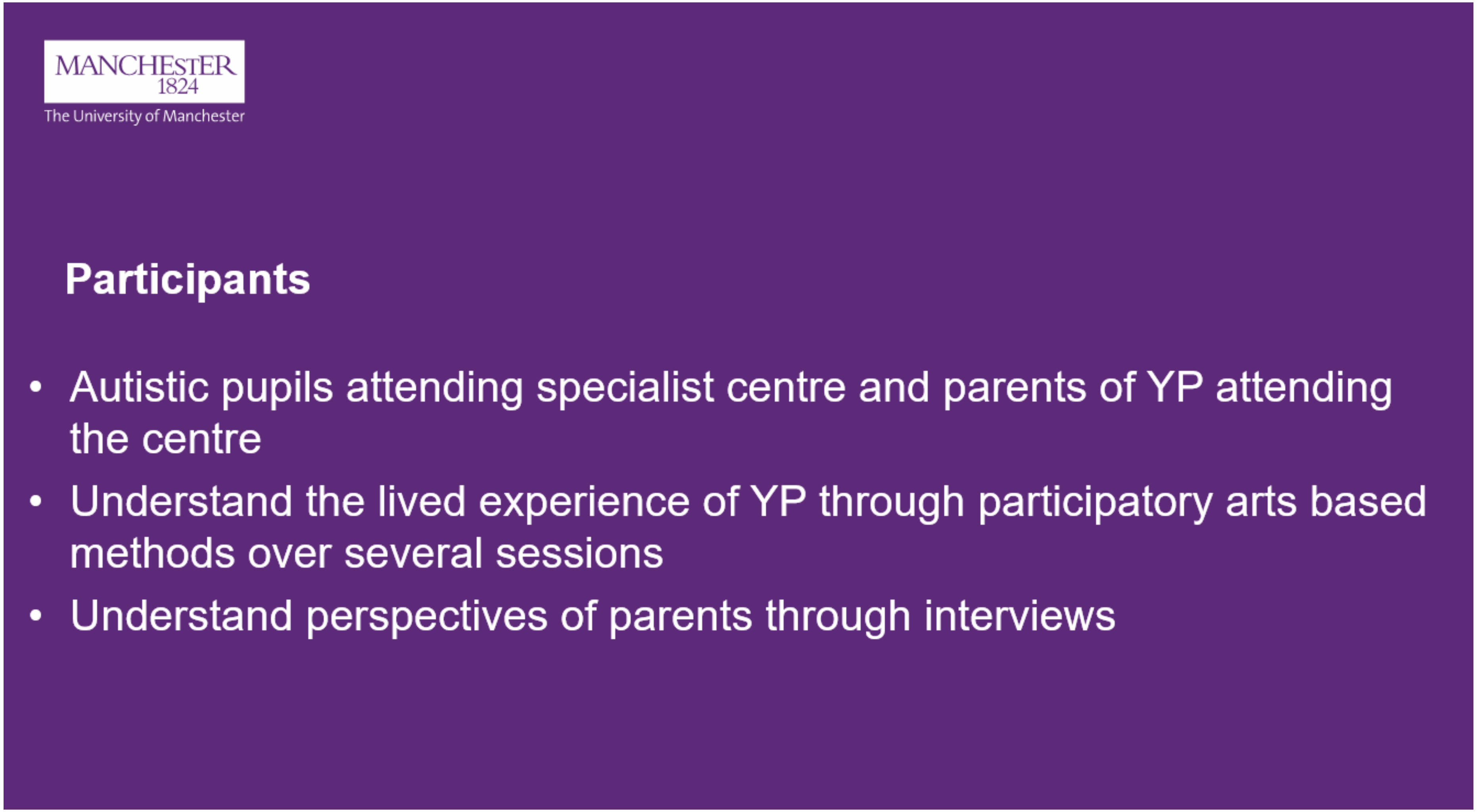
Ola Demkowicz,
Caroline Bond,
Pamela Qualter



MANCHESTER
1824
The University of Manchester

Participatory Inquiry – Claire Neilson (TEP) and Caroline Bond

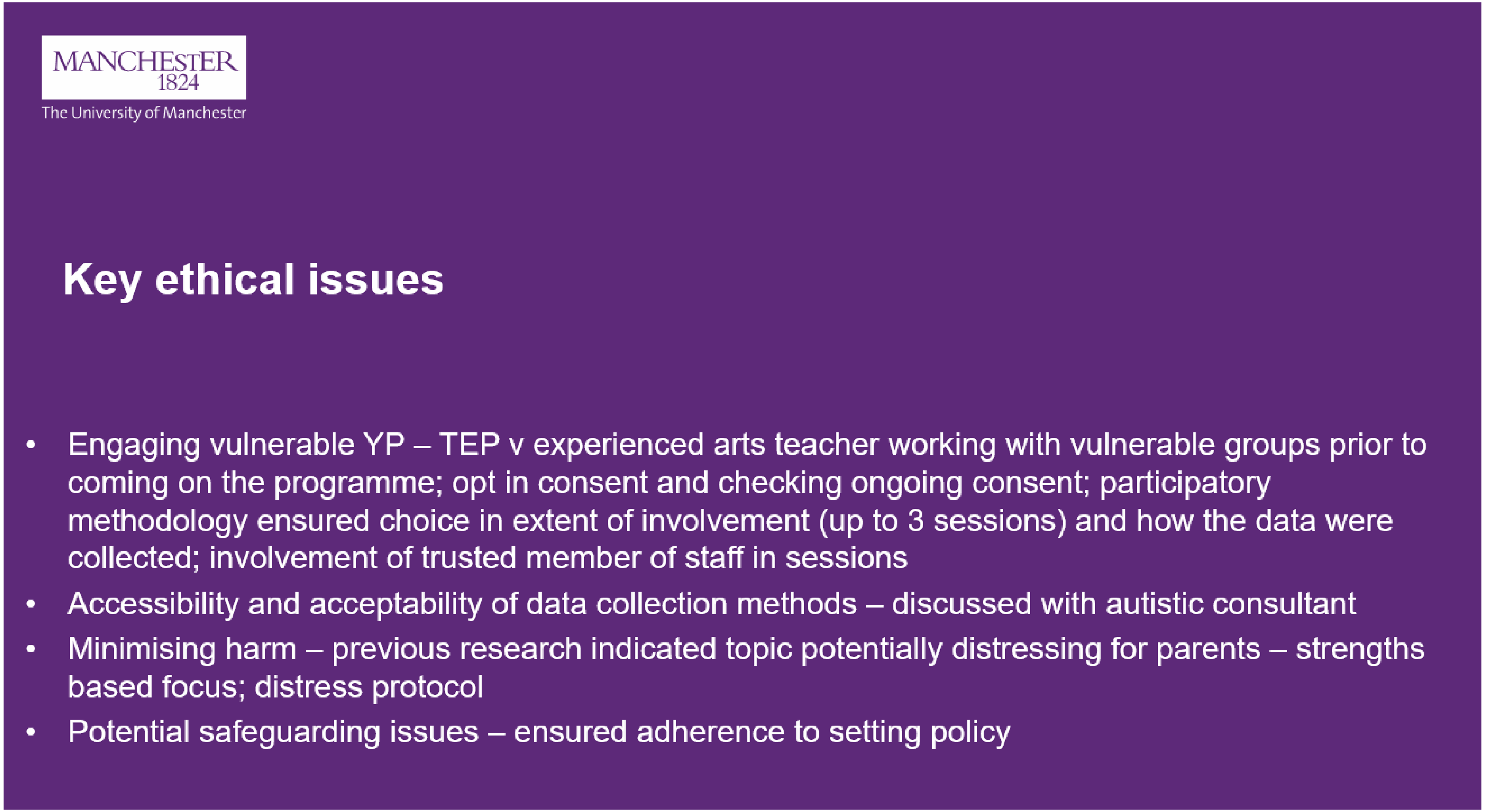
- How do autistic CYP, who have experienced long-term absence from school due to anxiety, and their families describe effective support that has met their needs?



MANCHESTER
1824
The University of Manchester

Participants

- Autistic pupils attending specialist centre and parents of YP attending the centre
- Understand the lived experience of YP through participatory arts based methods over several sessions
- Understand perspectives of parents through interviews



MANCHESTER
1824
The University of Manchester

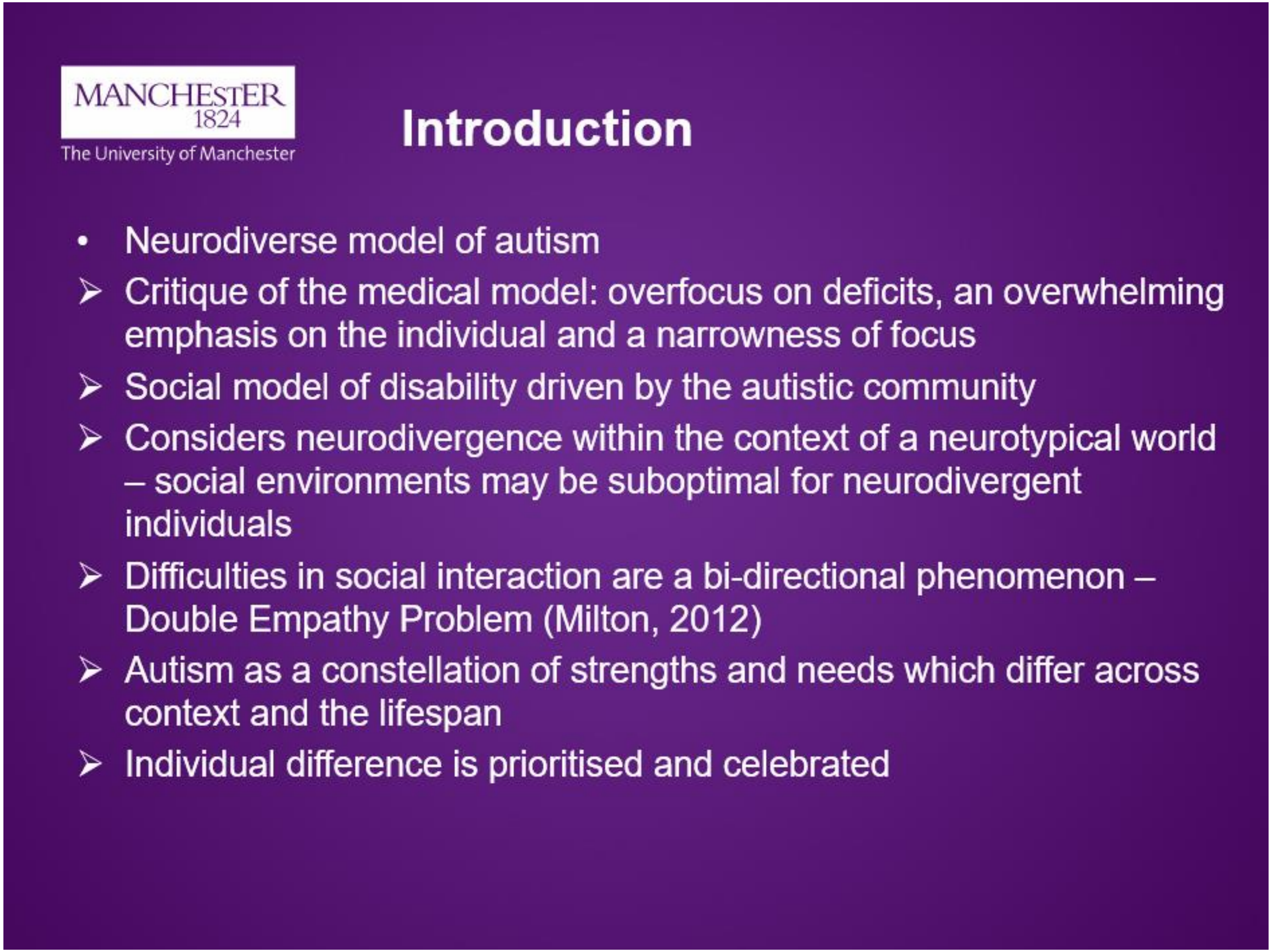
Key ethical issues

- Engaging vulnerable YP – TEP v experienced arts teacher working with vulnerable groups prior to coming on the programme; opt in consent and checking ongoing consent; participatory methodology ensured choice in extent of involvement (up to 3 sessions) and how the data were collected; involvement of trusted member of staff in sessions
- Accessibility and acceptability of data collection methods – discussed with autistic consultant
- Minimising harm – previous research indicated topic potentially distressing for parents – strengths based focus; distress protocol
- Potential safeguarding issues – ensured adherence to setting policy

Appendix 20: Presentation for EP CPD at practice placement EPS

MANCHESTER
1824
The University of Manchester

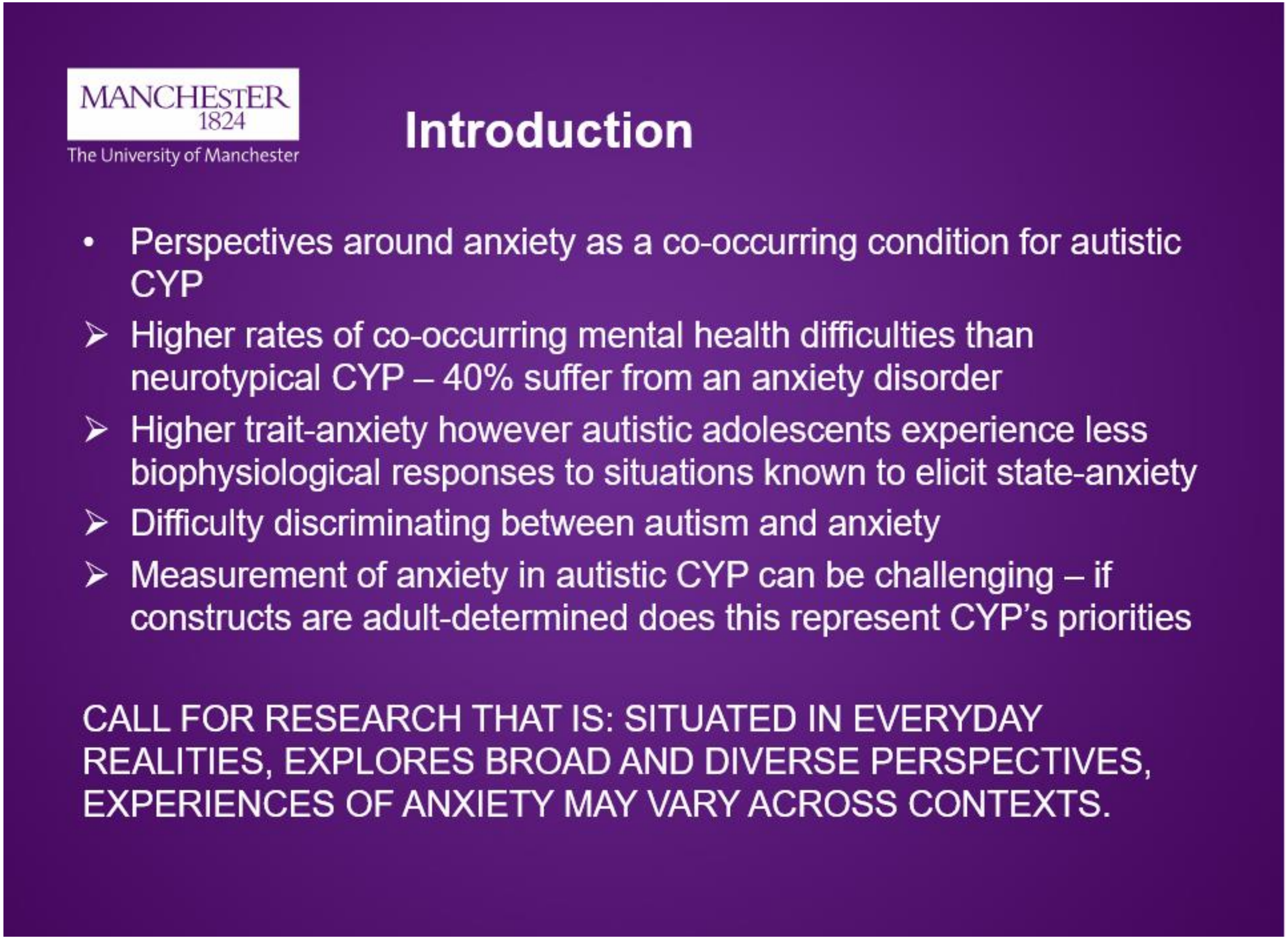
The experience of anxiety for autistic children and young people: A thematic synthesis review



MANCHESTER
1824
The University of Manchester

Introduction

- Neurodiverse model of autism
- ➢ Critique of the medical model: overfocus on deficits, an overwhelming emphasis on the individual and a narrowness of focus
- ➢ Social model of disability driven by the autistic community
- ➢ Considers neurodivergence within the context of a neurotypical world – social environments may be suboptimal for neurodivergent individuals
- ➢ Difficulties in social interaction are a bi-directional phenomenon – Double Empathy Problem (Milton, 2012)
- ➢ Autism as a constellation of strengths and needs which differ across context and the lifespan
- ➢ Individual difference is prioritised and celebrated

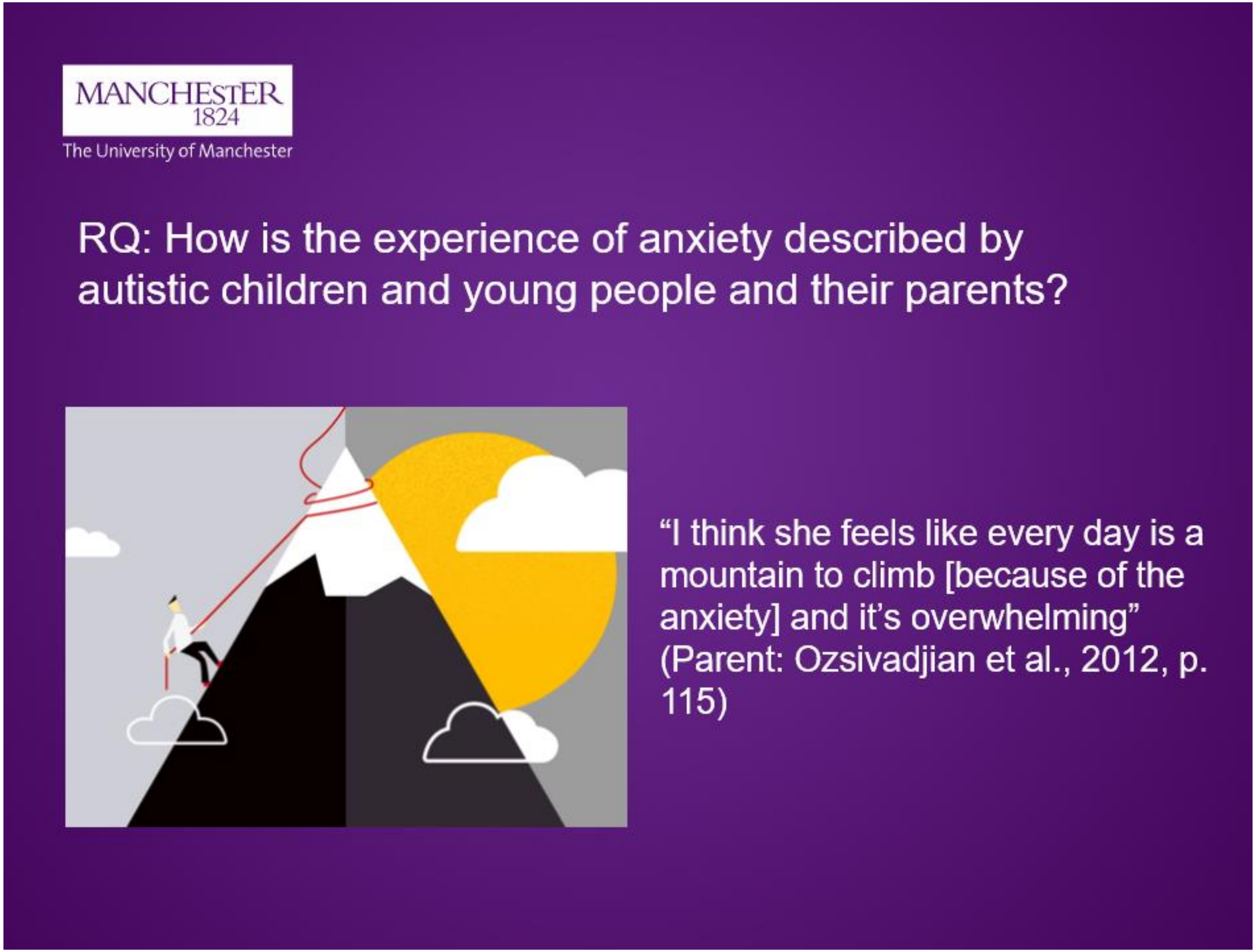


MANCHESTER
1824
The University of Manchester

Introduction

- Perspectives around anxiety as a co-occurring condition for autistic CYP
- ➢ Higher rates of co-occurring mental health difficulties than neurotypical CYP – 40% suffer from an anxiety disorder
- ➢ Higher trait-anxiety however autistic adolescents experience less biophysiological responses to situations known to elicit state-anxiety
- ➢ Difficulty discriminating between autism and anxiety
- ➢ Measurement of anxiety in autistic CYP can be challenging – if constructs are adult-determined does this represent CYP's priorities

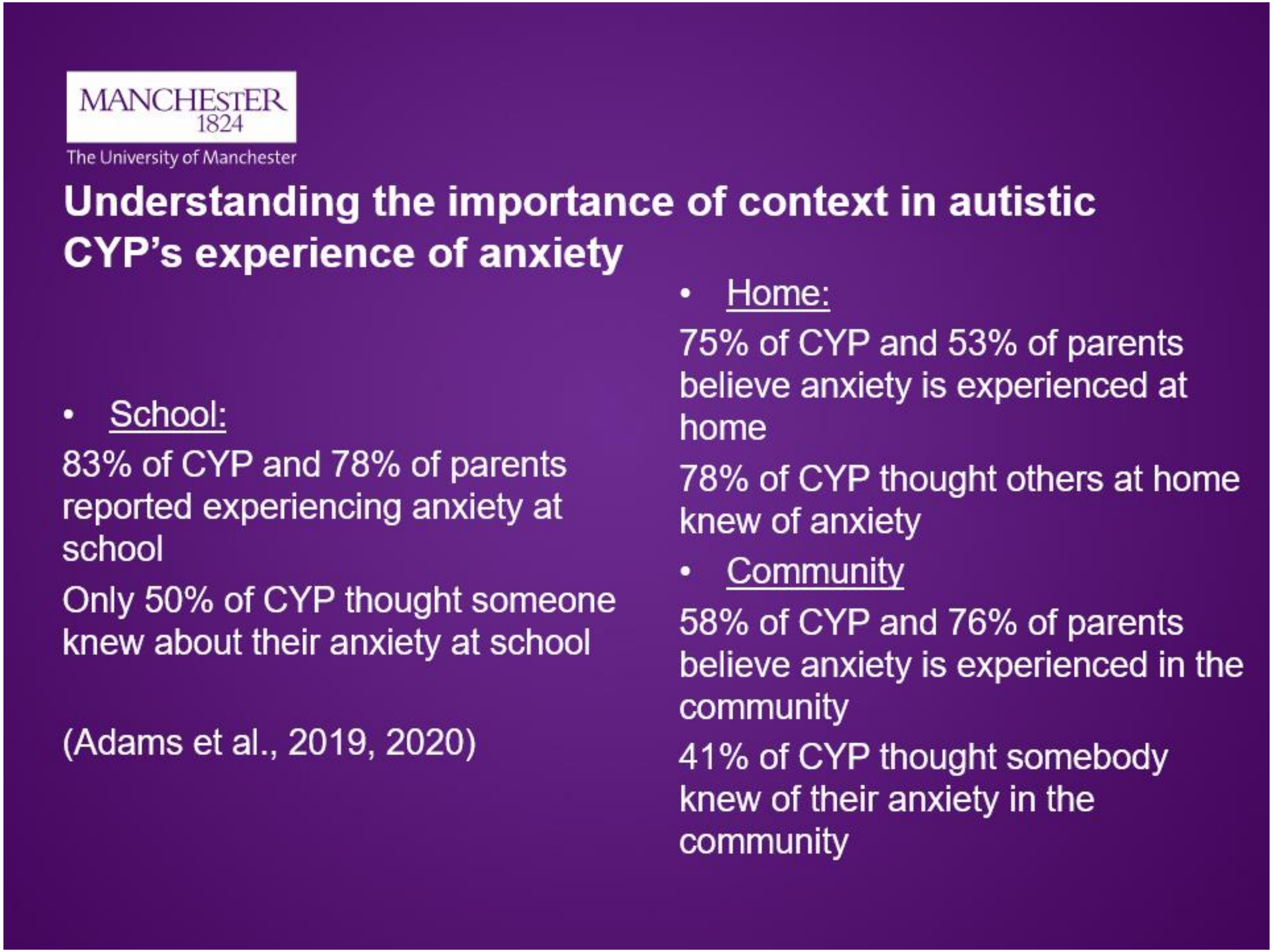
CALL FOR RESEARCH THAT IS: SITUATED IN EVERYDAY REALITIES, EXPLORES BROAD AND DIVERSE PERSPECTIVES, EXPERIENCES OF ANXIETY MAY VARY ACROSS CONTEXTS.



MANCHESTER
1824
The University of Manchester

RQ: How is the experience of anxiety described by autistic children and young people and their parents?

“I think she feels like every day is a mountain to climb [because of the anxiety] and it’s overwhelming” (Parent: Ozsivadjian et al., 2012, p. 115)



MANCHESTER
1824
The University of Manchester

Understanding the importance of context in autistic CYP's experience of anxiety

- School:

83% of CYP and 78% of parents reported experiencing anxiety at school

Only 50% of CYP thought someone knew about their anxiety at school

(Adams et al., 2019, 2020)

- Home:

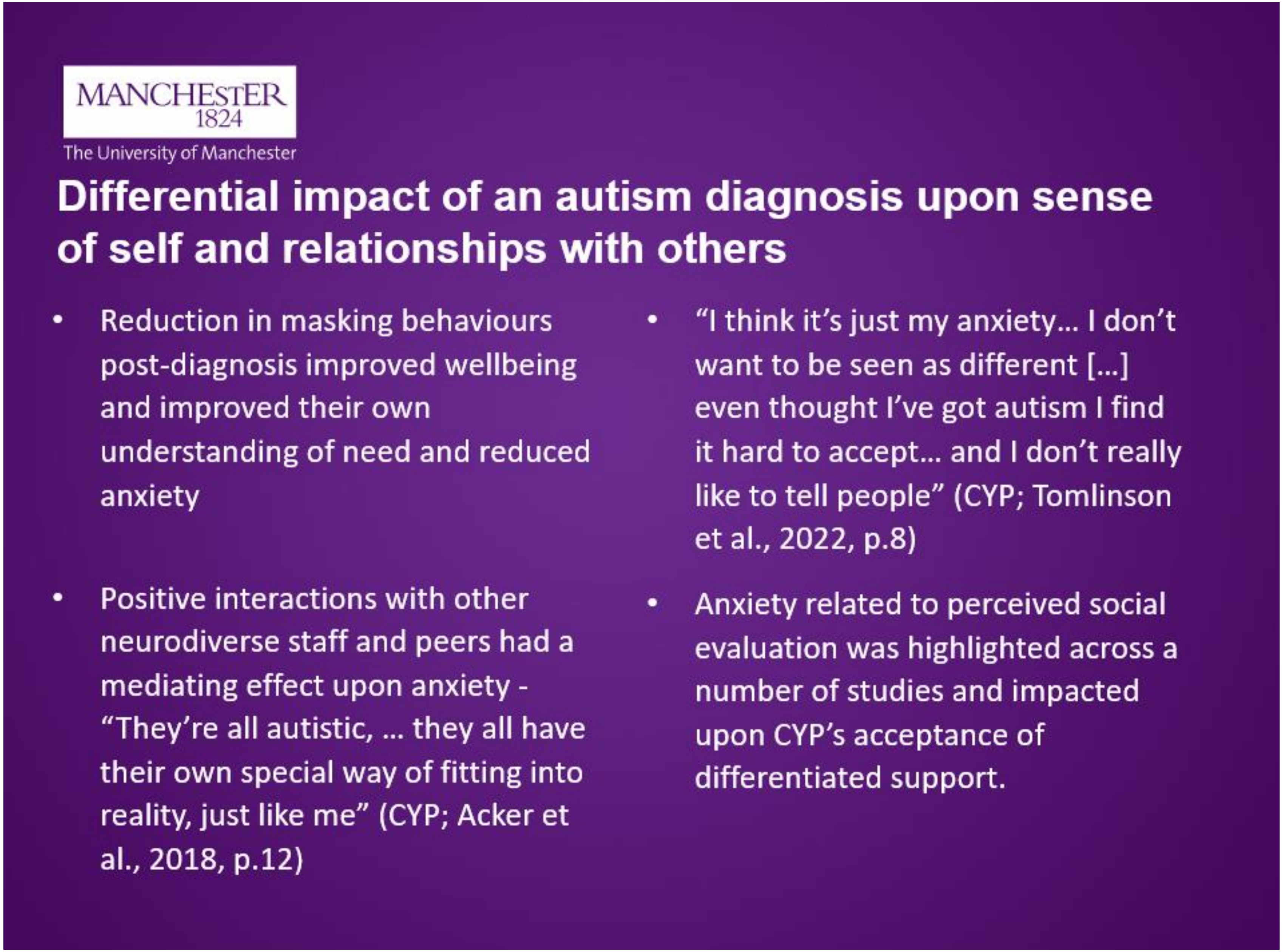
75% of CYP and 53% of parents believe anxiety is experienced at home

78% of CYP thought others at home knew of anxiety

- Community

58% of CYP and 76% of parents believe anxiety is experienced in the community

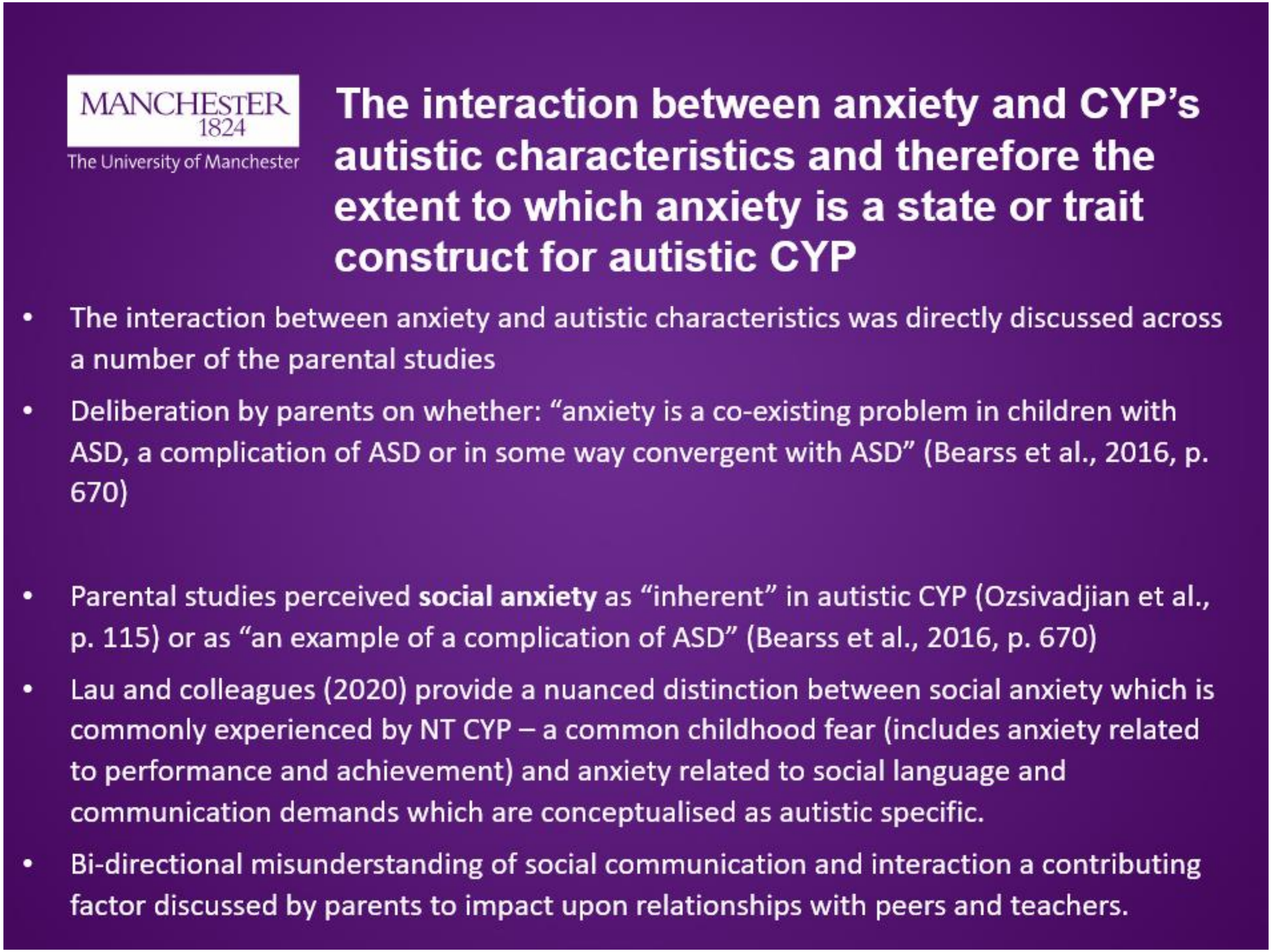
41% of CYP thought somebody knew of their anxiety in the community



MANCHESTER
1824
The University of Manchester

Differential impact of an autism diagnosis upon sense of self and relationships with others

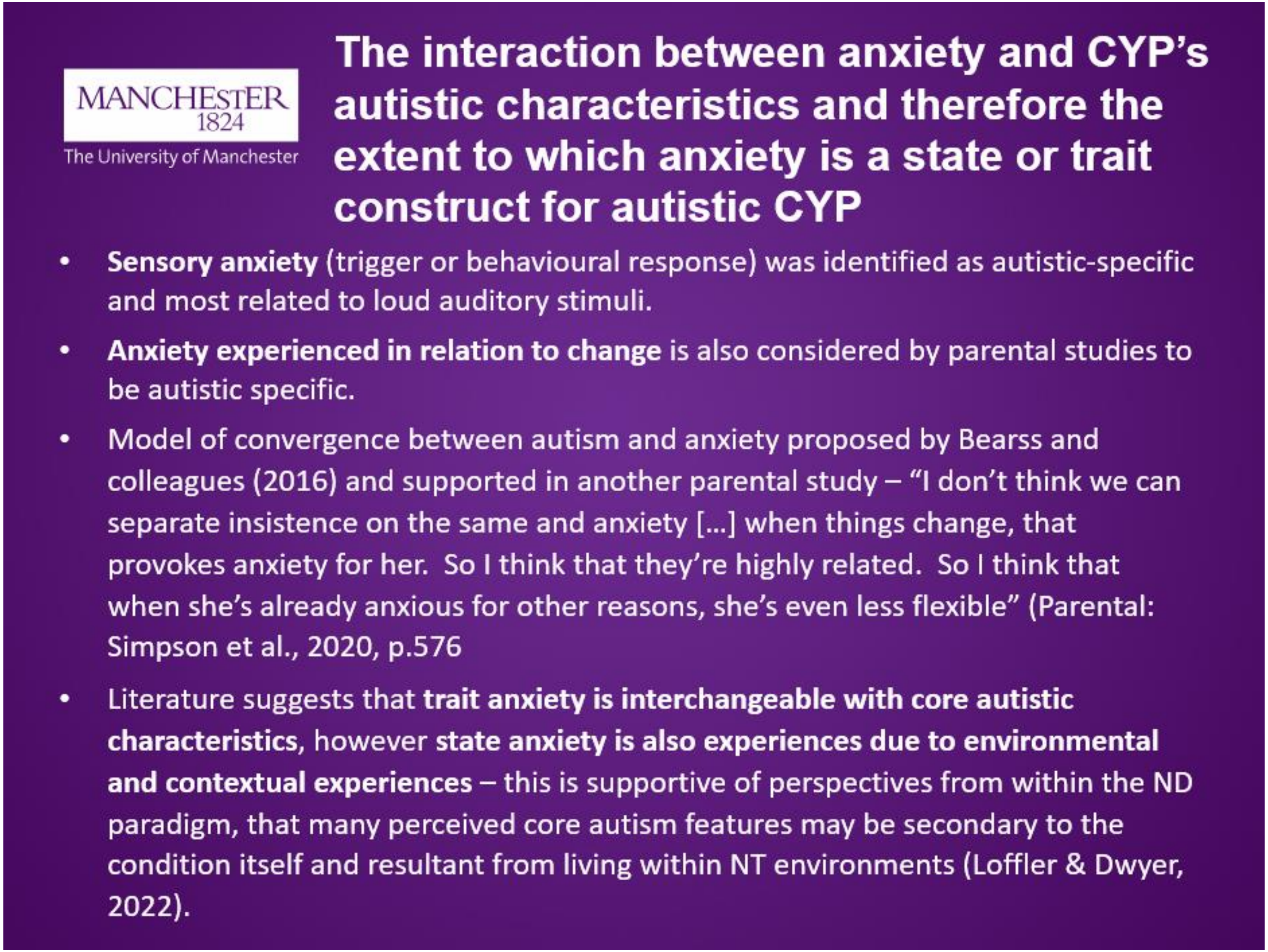
- Reduction in masking behaviours post-diagnosis improved wellbeing and improved their own understanding of need and reduced anxiety
- Positive interactions with other neurodiverse staff and peers had a mediating effect upon anxiety - “They’re all autistic, … they all have their own special way of fitting into reality, just like me” (CYP; Acker et al., 2018, p.12)
- “I think it’s just my anxiety… I don’t want to be seen as different […] even thought I’ve got autism I find it hard to accept… and I don’t really like to tell people” (CYP; Tomlinson et al., 2022, p.8)
- Anxiety related to perceived social evaluation was highlighted across a number of studies and impacted upon CYP’s acceptance of differentiated support.



The interaction between anxiety and CYP's autistic characteristics and therefore the extent to which anxiety is a state or trait construct for autistic CYP

- The interaction between anxiety and autistic characteristics was directly discussed across a number of the parental studies
- Deliberation by parents on whether: "anxiety is a co-existing problem in children with ASD, a complication of ASD or in some way convergent with ASD" (Bearss et al., 2016, p. 670)

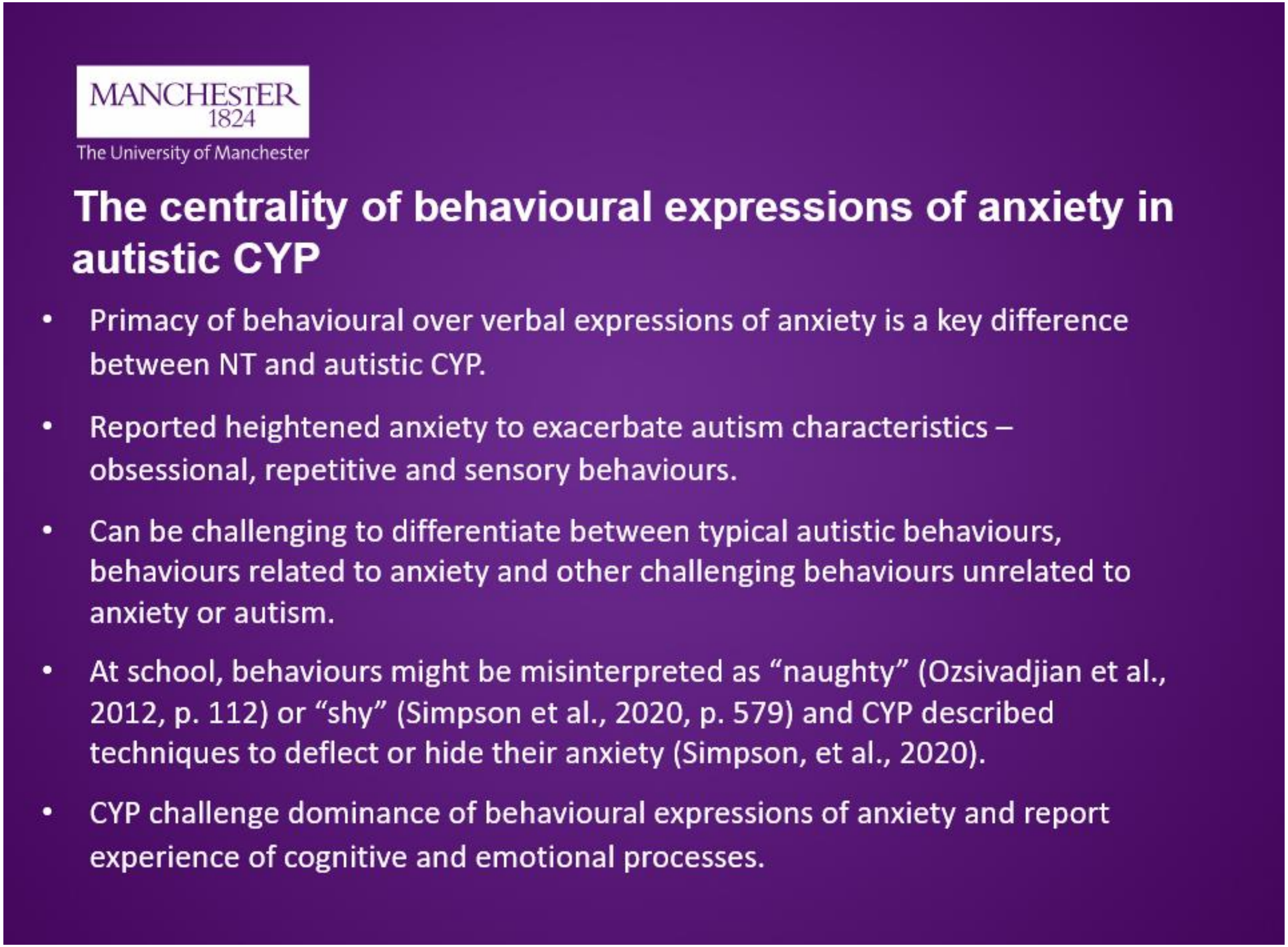
- Parental studies perceived **social anxiety** as "inherent" in autistic CYP (Ozsivadjian et al., p. 115) or as "an example of a complication of ASD" (Bearss et al., 2016, p. 670)
- Lau and colleagues (2020) provide a nuanced distinction between social anxiety which is commonly experienced by NT CYP – a common childhood fear (includes anxiety related to performance and achievement) and anxiety related to social language and communication demands which are conceptualised as autistic specific.
- Bi-directional misunderstanding of social communication and interaction a contributing factor discussed by parents to impact upon relationships with peers and teachers.



MANCHESTER
1824
The University of Manchester

The interaction between anxiety and CYP's autistic characteristics and therefore the extent to which anxiety is a state or trait construct for autistic CYP

- **Sensory anxiety** (trigger or behavioural response) was identified as autistic-specific and most related to loud auditory stimuli.
- **Anxiety experienced in relation to change** is also considered by parental studies to be autistic specific.
- Model of convergence between autism and anxiety proposed by Bearss and colleagues (2016) and supported in another parental study – "I don't think we can separate insistence on the same and anxiety […] when things change, that provokes anxiety for her. So I think that they're highly related. So I think that when she's already anxious for other reasons, she's even less flexible" (Parental: Simpson et al., 2020, p.576
- Literature suggests that **trait anxiety is interchangeable with core autistic characteristics**, however **state anxiety is also experiences due to environmental and contextual experiences** – this is supportive of perspectives from within the ND paradigm, that many perceived core autism features may be secondary to the condition itself and resultant from living within NT environments (Loffler & Dwyer, 2022).



MANCHESTER
1824
The University of Manchester

The centrality of behavioural expressions of anxiety in autistic CYP

- Primacy of behavioural over verbal expressions of anxiety is a key difference between NT and autistic CYP.
- Reported heightened anxiety to exacerbate autism characteristics – obsessional, repetitive and sensory behaviours.
- Can be challenging to differentiate between typical autistic behaviours, behaviours related to anxiety and other challenging behaviours unrelated to anxiety or autism.
- At school, behaviours might be misinterpreted as “naughty” (Ozsivadjian et al., 2012, p. 112) or “shy” (Simpson et al., 2020, p. 579) and CYP described techniques to deflect or hide their anxiety (Simpson, et al., 2020).
- CYP challenge dominance of behavioural expressions of anxiety and report experience of cognitive and emotional processes.

MANCHESTER
1824
The University of Manchester

Distinct contribution of time

- A time delay between an event and expression of anxiety – “A 2-3 week delay between something happening and me being able to tell and by the end it’s so embedded that you’ve got to disentangle the whole thing before you get to the point” (Parent: Ozsivadjian et al,. 2012, p. 114)

- Concentrating across the whole school day was difficulty to manage and imposed time-frames for task completion were a trigger for anxiety.

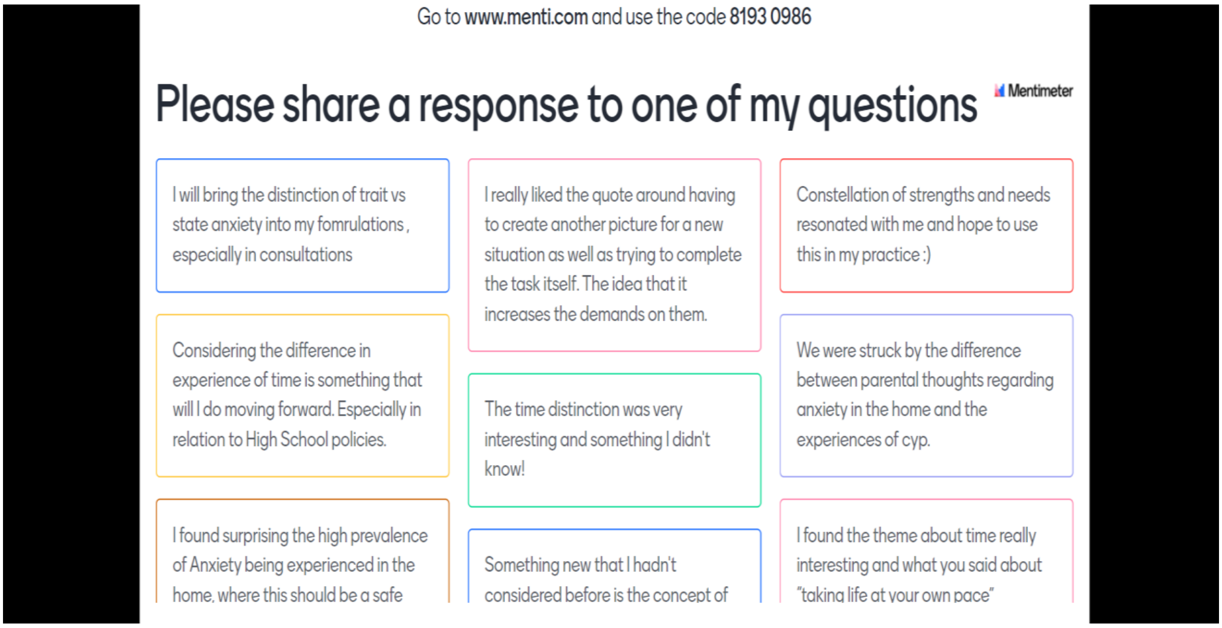
- Consistent mediating influences on anxiety was support regulated the experience of time: to enhance organisational skills, support time-management or take life at a self-directed pace

MANCHESTER
1824
The University of Manchester

The experience of anxiety for autistic children and young people: A thematic synthesis review

- Is there anything that surprised you/was new thinking from the findings?
- How do the themes resonate with your practice?
- What will you take away from today?
- Is there anything you intend to try out in professional practice?

Appendix 21: Feedback about EP CPD



Go to **www.menti.com** and use the code **8193 0986**

Please share a response to one of my questions

I will bring the distinction of trait vs state anxiety into my fomrulations , especially in consultations

Considering the difference in experience of time is something that will I do moving forward. Especially in relation to High School policies.

I found surprising the high prevalence of Anxiety being experienced in the home, where this should be a safe

I really liked the quote around having to create another picture for a new situation as well as trying to complete the task itself. The idea that it increases the demands on them.

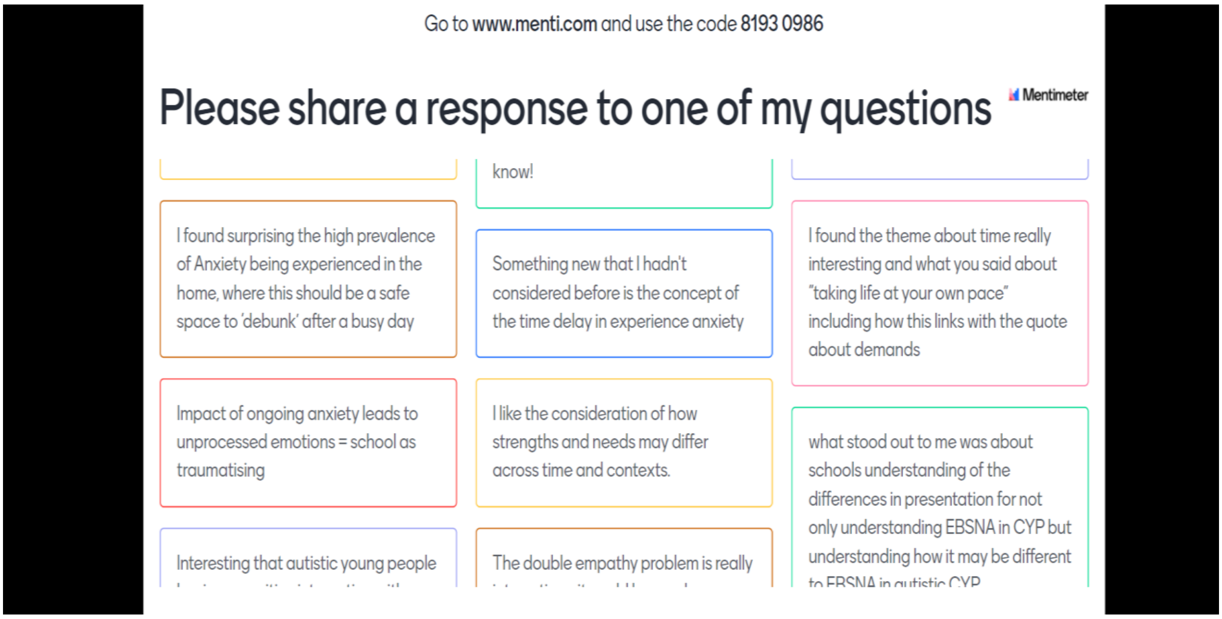
The time distinction was very interesting and something I didn't know!

Something new that I hadn't considered before is the concept of

Constellation of strengths and needs resonated with me and hope to use this in my practice :)

We were struck by the difference between parental thoughts regarding anxiety in the home and the experiences of cyp.

I found the theme about time really interesting and what you said about "taking life at your own pace"



Go to **www.menti.com** and use the code **8193 0986**

Please share a response to one of my questions

know!

I found surprising the high prevalence of Anxiety being experienced in the home, where this should be a safe space to 'debunk' after a busy day

Impact of ongoing anxiety leads to unprocessed emotions = school as traumatising

Interesting that autistic young people

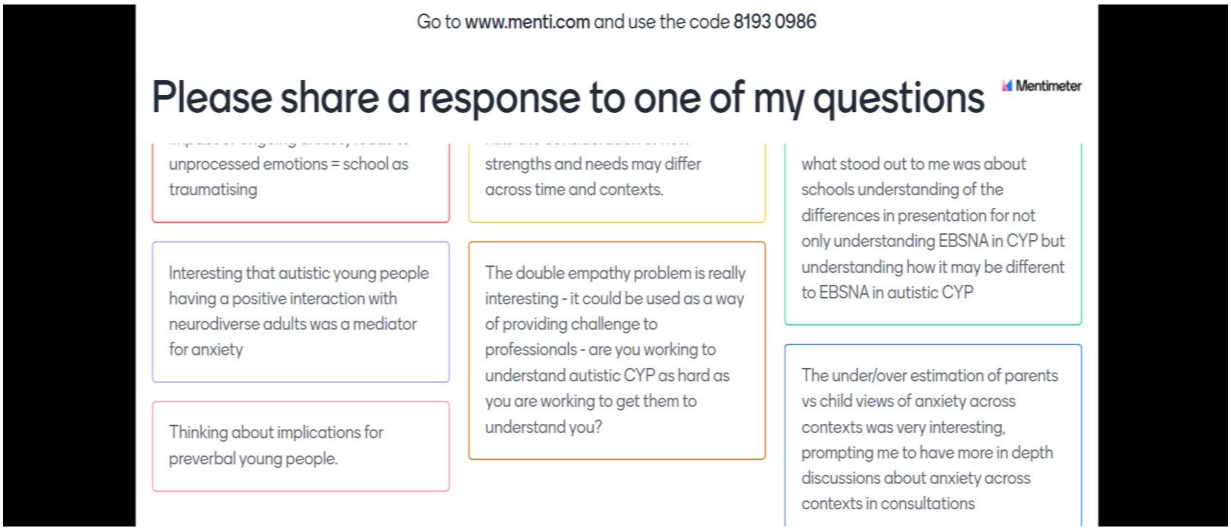
Something new that I hadn't considered before is the concept of the time delay in experience anxiety

I like the consideration of how strengths and needs may differ across time and contexts.

The double empathy problem is really

I found the theme about time really interesting and what you said about "taking life at your own pace" including how this links with the quote about demands

what stood out to me was about schools understanding of the differences in presentation for not only understanding EBSNA in CYP but understanding how it may be different to EBSNA in autistic CYP



Go to **www.menti.com** and use the code **8193 0986**

Please share a response to one of my questions

unprocessed emotions = school as traumatising

Interesting that autistic young people having a positive interaction with neurodiverse adults was a mediator for anxiety

Thinking about implications for preverbal young people.

strengths and needs may differ across time and contexts.

The double empathy problem is really interesting - it could be used as a way of providing challenge to professionals - are you working to understand autistic CYP as hard as you are working to get them to understand you?

what stood out to me was about schools understanding of the differences in presentation for not only understanding EBSNA in CYP but understanding how it may be different to EBSNA in autistic CYP

The under/over estimation of parents vs child views of anxiety across contexts was very interesting, prompting me to have more in depth discussions about anxiety across contexts in consultations

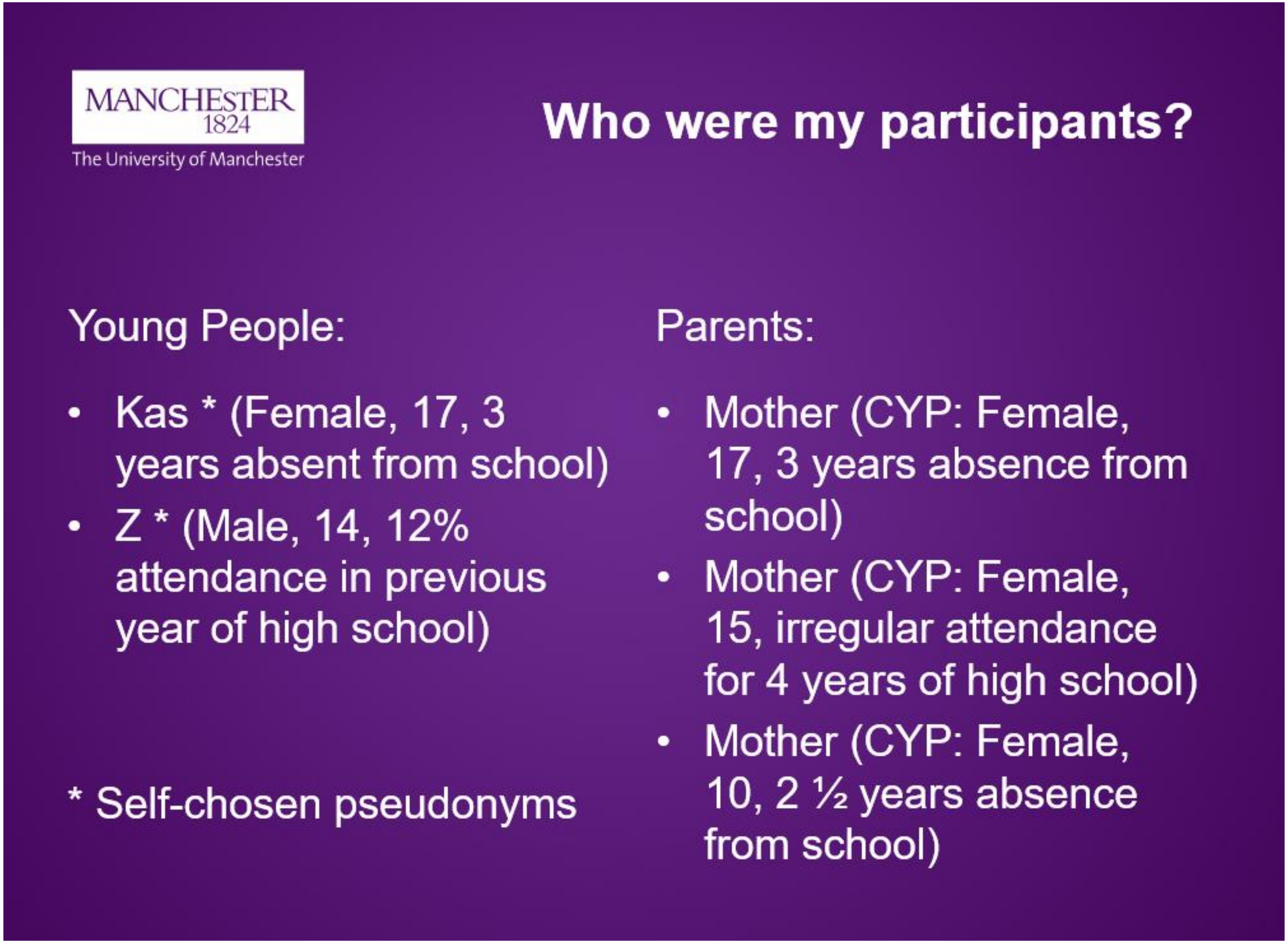
Appendix 22: Presentation for NW CPD Day (also slides 4-10 from Appendix 19)

MANCHESTER
1824
The University of Manchester

Research Project – Participatory Inquiry

Research Aim:

1. How do autistic CYP who have experienced extended school nonattendance describe effective support to meet their needs?



MANCHESTER
1824
The University of Manchester

Who were my participants?

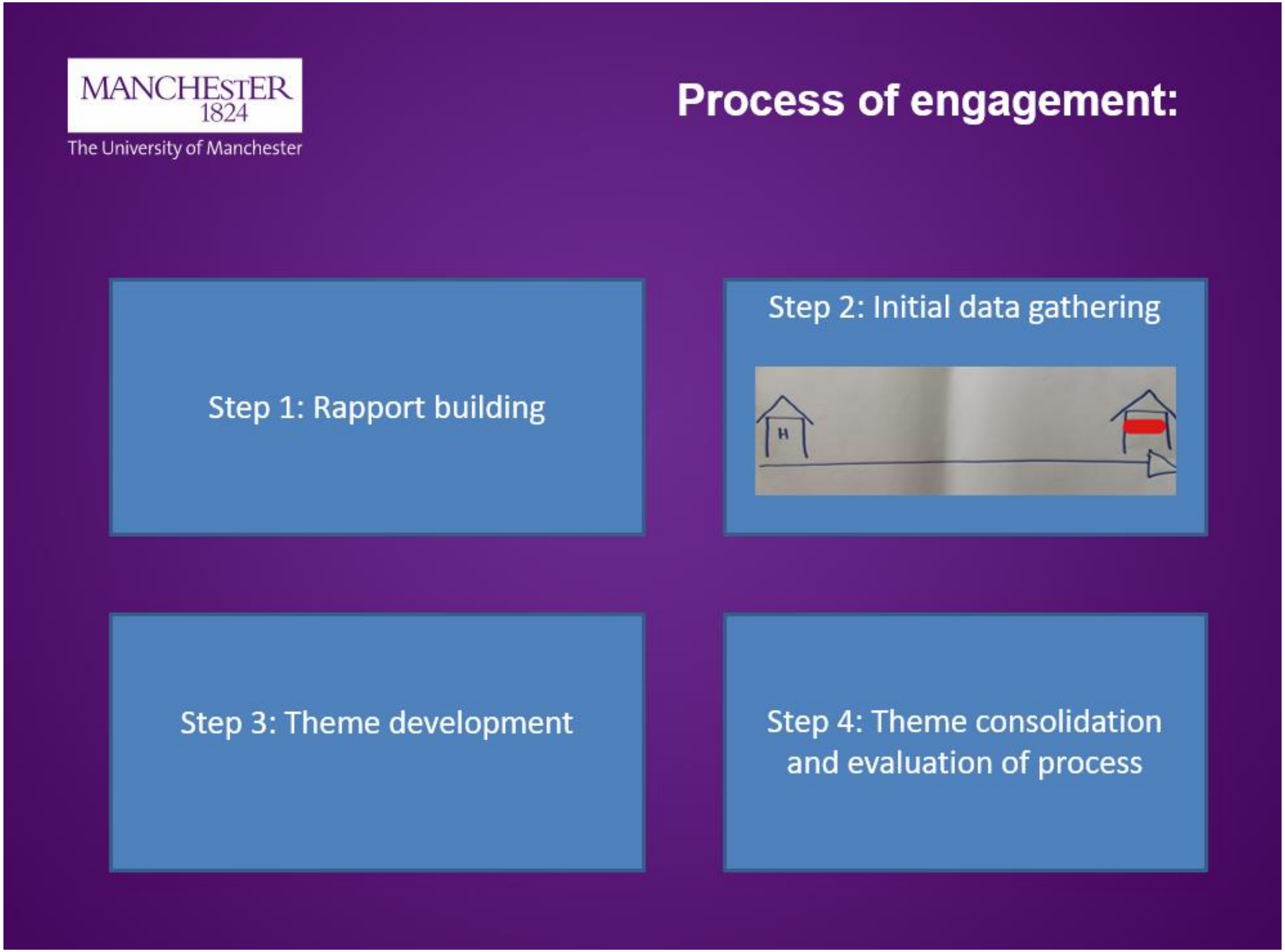
Young People:

- Kas * (Female, 17, 3 years absent from school)
- Z * (Male, 14, 12% attendance in previous year of high school)

* Self-chosen pseudonyms

Parents:

- Mother (CYP: Female, 17, 3 years absence from school)
- Mother (CYP: Female, 15, irregular attendance for 4 years of high school)
- Mother (CYP: Female, 10, 2 ½ years absence from school)



MANCHESTER
1824
The University of Manchester

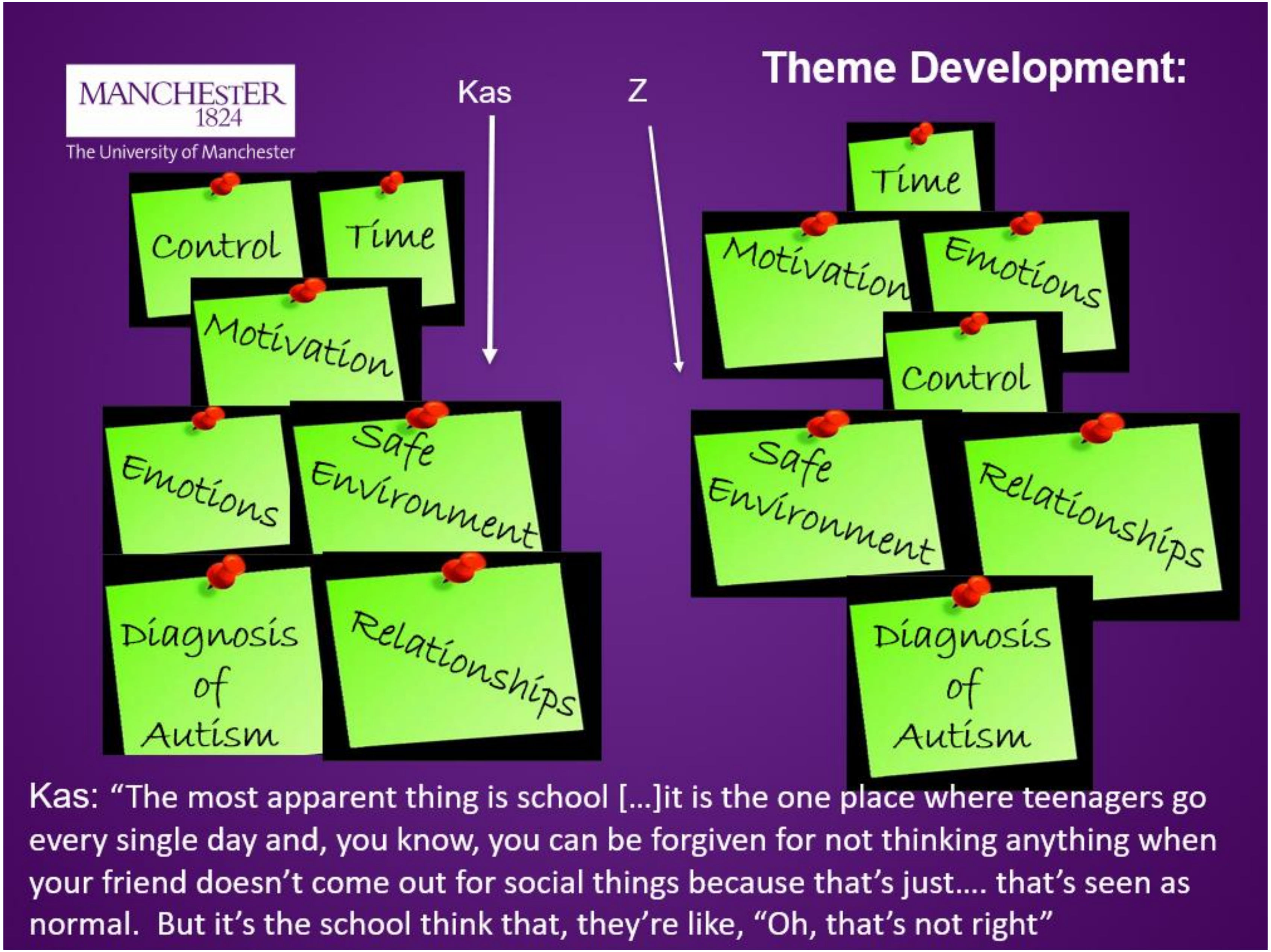
Process of engagement:

Step 1: Rapport building

Step 2: Initial data gathering

Step 3: Theme development

Step 4: Theme consolidation and evaluation of process



Theme Development:

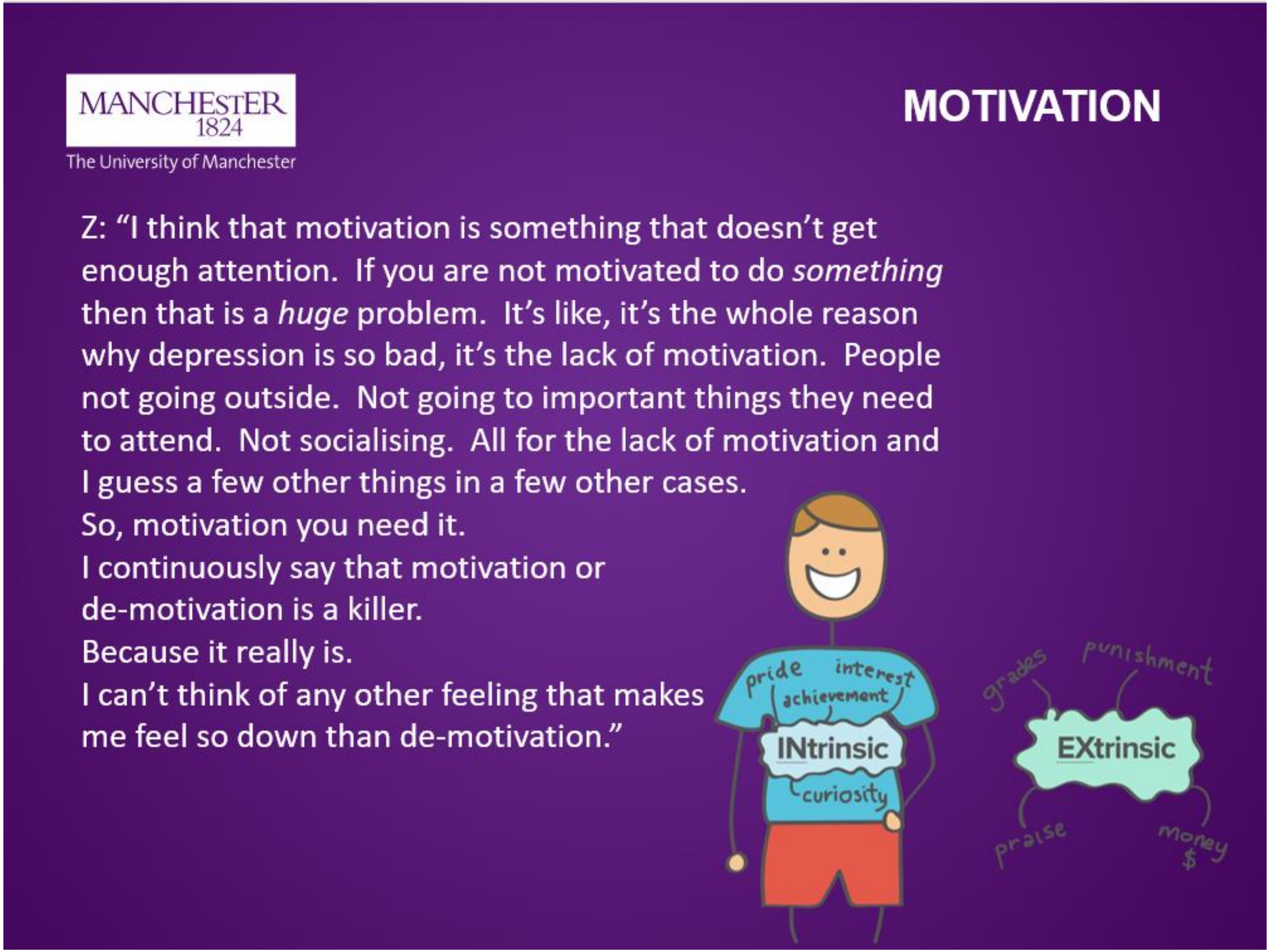
Kas: "The most apparent thing is school […]it is the one place where teenagers go every single day and, you know, you can be forgiven for not thinking anything when your friend doesn't come out for social things because that's just…. that's seen as normal. But it's the school think that, they're like, "Oh, that's not right"

MANCHESTER
1824
The University of Manchester

TIME

Z:"I think it might have been the 6-weeks holiday – since I was off before I was off with the context that I wasn't meant to be off. The 6 week – I had all that time to myself. I didn't have to worry – I was calming down. […] It allowed me to contemplate things […] there was no pressure to take all the time I needed"

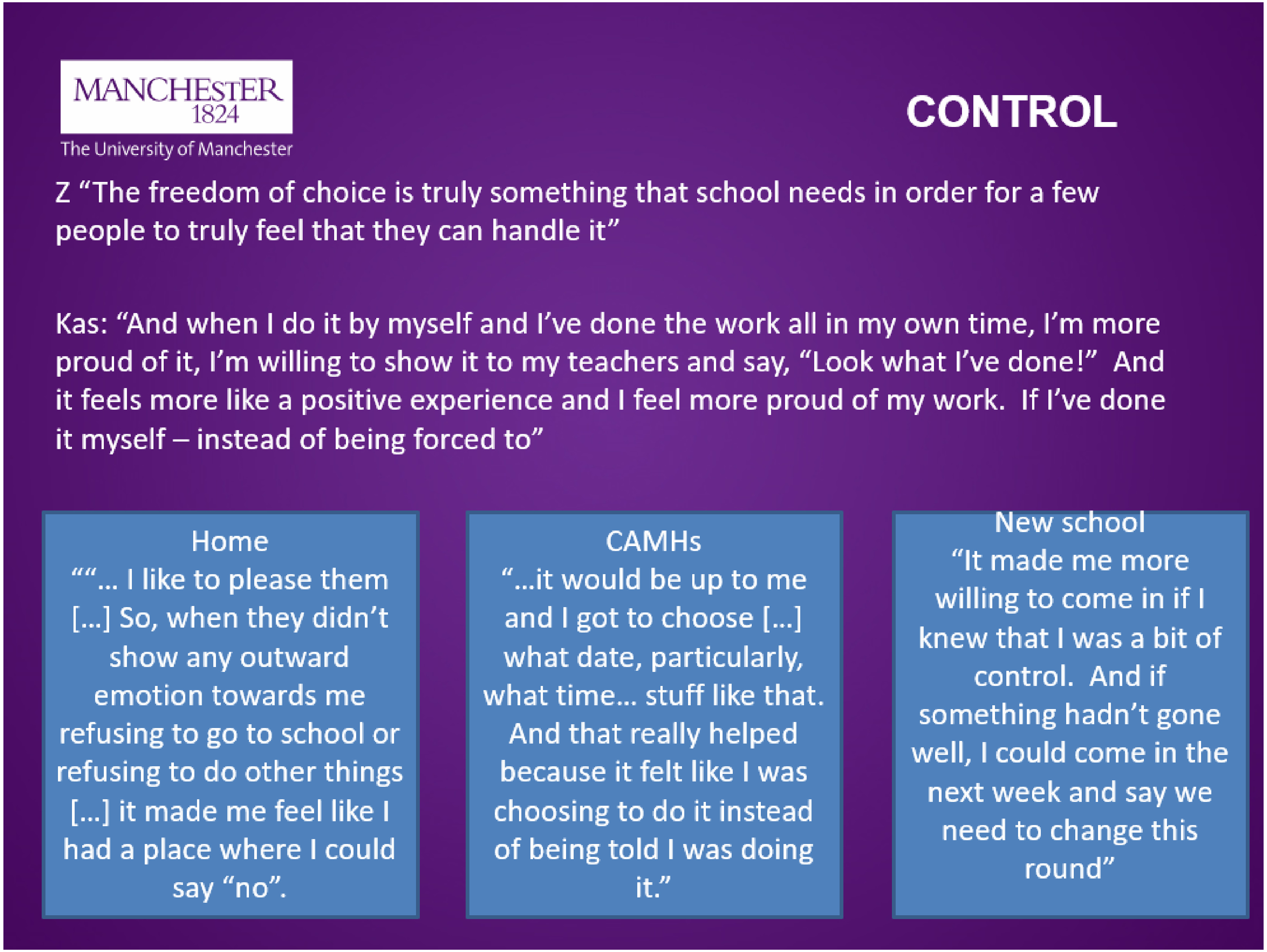
Kas: "If I'm given a time constraint and someone says, [….]. I tend to not do it […] and it stresses me out during that whole time. Whereas, if someone says, "Hey I'd like you to do this as soon as possible but if not that's ok – like you can take the time you need". I'm a lot more willing to do it in my own time and
I can go at my pace"



MANCHESTER
1824
The University of Manchester

MOTIVATION

Z: “I think that motivation is something that doesn’t get enough attention. If you are not motivated to do *something* then that is a *huge* problem. It’s like, it’s the whole reason why depression is so bad, it’s the lack of motivation. People not going outside. Not going to important things they need to attend. Not socialising. All for the lack of motivation and I guess a few other things in a few other cases.
So, motivation you need it.
I continuously say that motivation or de-motivation is a killer.
Because it really is.
I can’t think of any other feeling that makes me feel so down than de-motivation.”



MANCHESTER
1824
The University of Manchester

CONTROL

Z “The freedom of choice is truly something that school needs in order for a few people to truly feel that they can handle it”

Kas: “And when I do it by myself and I’ve done the work all in my own time, I’m more proud of it, I’m willing to show it to my teachers and say, “Look what I’ve done!” And it feels more like a positive experience and I feel more proud of my work. If I’ve done it myself – instead of being forced to”

Home
““… I like to please them […] So, when they didn’t show any outward emotion towards me refusing to go to school or refusing to do other things […] it made me feel like I had a place where I could say “no”.

CAMHs
“…it would be up to me and I got to choose […] what date, particularly, what time… stuff like that. And that really helped because it felt like I was choosing to do it instead of being told I was doing it.”

New school
“It made me more willing to come in if I knew that I was a bit of control. And if something hadn’t gone well, I could come in the next week and say we need to change this round”

MANCHESTER
1824
The University of Manchester

SAFE ENVIRONMENT

Kas: “If I didn’t have a safe environment I wouldn’t be in school”

Z: “Here we support people […] we accept them because that is what we should do […] . You kind of have to confirm less to, let’s call it societal norms in school terms, I suppose you could say.”

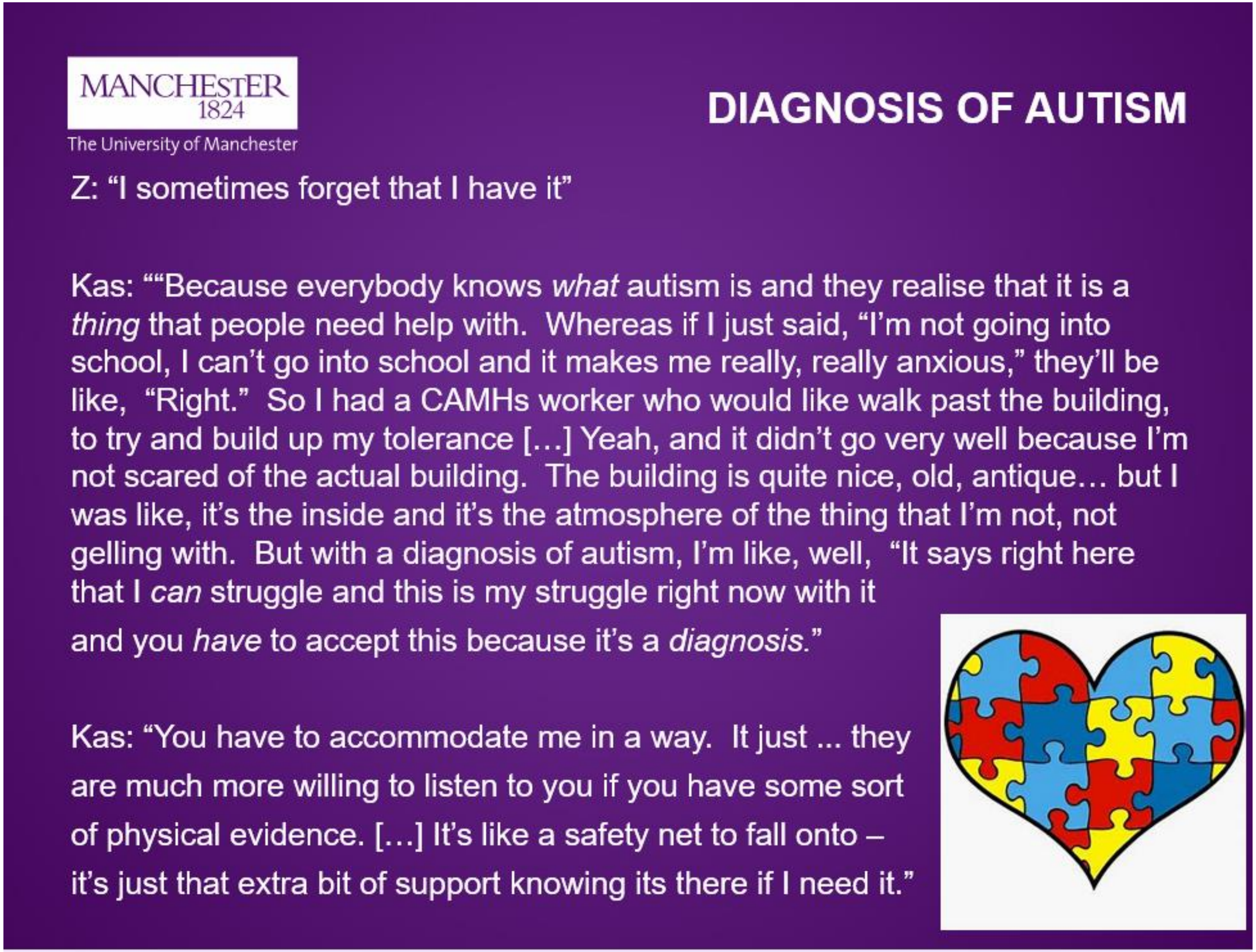
Kas: “…we can sit down and talk about what you want.
It might not be about school, it might be something stupid, as it often is. It’s just nice, especially that it is in school… it’s like, you know, ok normal conversations can happen in school and you know that every time I’m here it isn’t just kind of, head down, work! It can be a, you know, calm place; instead of a hectic running down corridors trying to get to your next lesson place.”

MANCHESTER
1824
The University of Manchester

RELATIONSHIPS

Z: “I’ve grown close to quite a lot of people here and it feels like a safe environment. A safe environment to socialise in but I still.. I just don’t want to people to talk to me […] It’s more nuanced than please don’t talk to me though – it’s also a matter of pressure. […] it’s not exactly peer pressure but it’s pressure from yourself. It’s a sort of guilt perhaps”.

Kas: “To be a socially acceptable person, who communicates with people how you’re *meant to*. I very much prefer my own company, if someone doesn’t forcibly talk to me, I will not talk to them. […] But then coming here it was a big shock because I hadn’t spoken to anyone my age in a long while […] and then I realised everyone else kind of felt the same way. They were all like, “Oh, I don’t want to talk to you either.” “I don’t want to talk to you as well but we can sit next to each other in silence!” And that’s what I really enjoyed, just knowing that someone understands that I’m not talking to them, at all.”



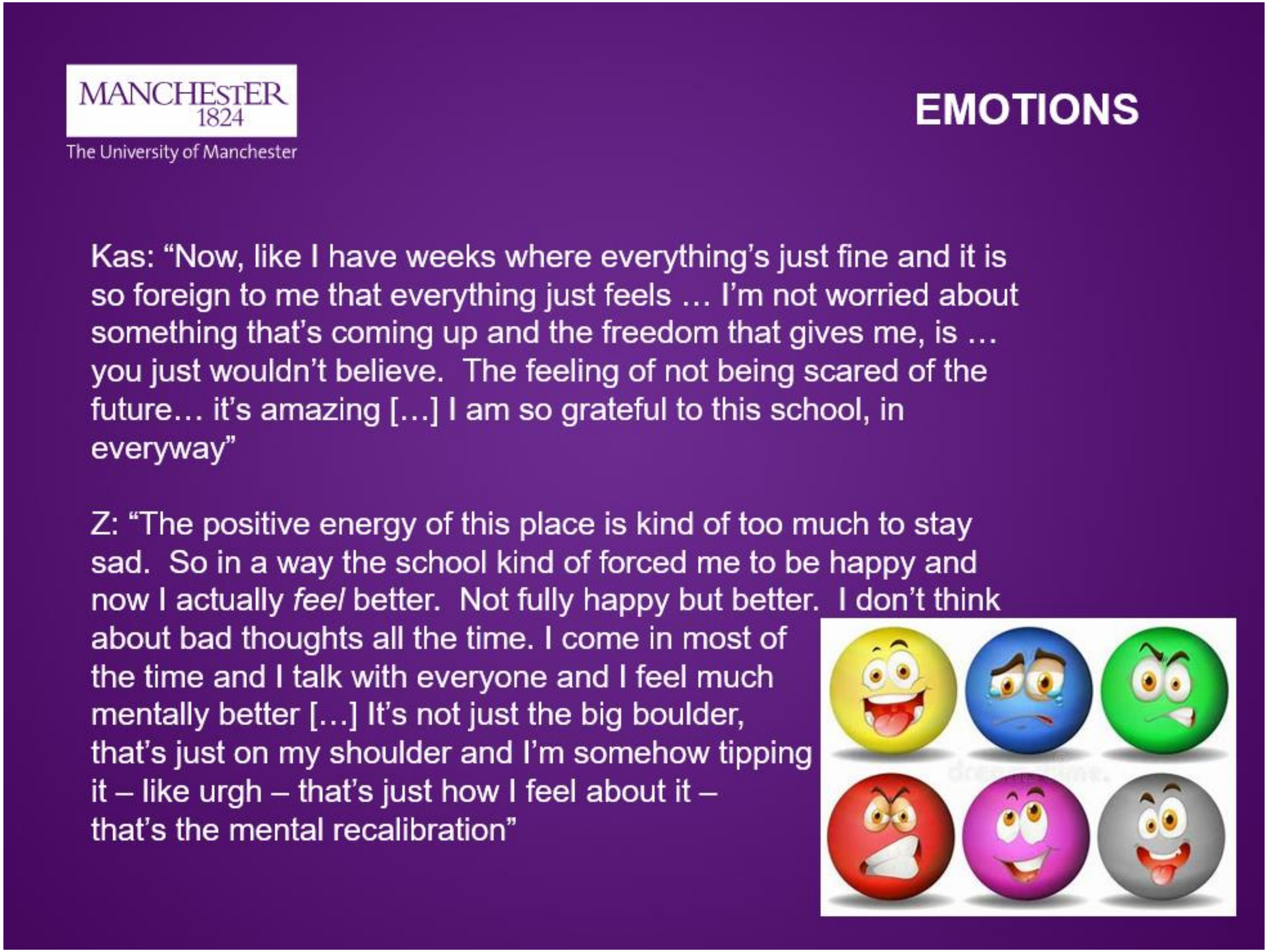
MANCHESTER
1824
The University of Manchester

DIAGNOSIS OF AUTISM

Z: “I sometimes forget that I have it”

Kas: ““Because everybody knows *what* autism is and they realise that it is a *thing* that people need help with. Whereas if I just said, “I’m not going into school, I can’t go into school and it makes me really, really anxious,” they’ll be like, “Right.” So I had a CAMHs worker who would like walk past the building, to try and build up my tolerance […] Yeah, and it didn’t go very well because I’m not scared of the actual building. The building is quite nice, old, antique… but I was like, it’s the inside and it’s the atmosphere of the thing that I’m not, not gelling with. But with a diagnosis of autism, I’m like, well, “It says right here that I *can* struggle and this is my struggle right now with it and you *have* to accept this because it’s a *diagnosis*.”

Kas: “You have to accommodate me in a way. It just ... they are much more willing to listen to you if you have some sort of physical evidence. […] It’s like a safety net to fall onto – it’s just that extra bit of support knowing its there if I need it.”

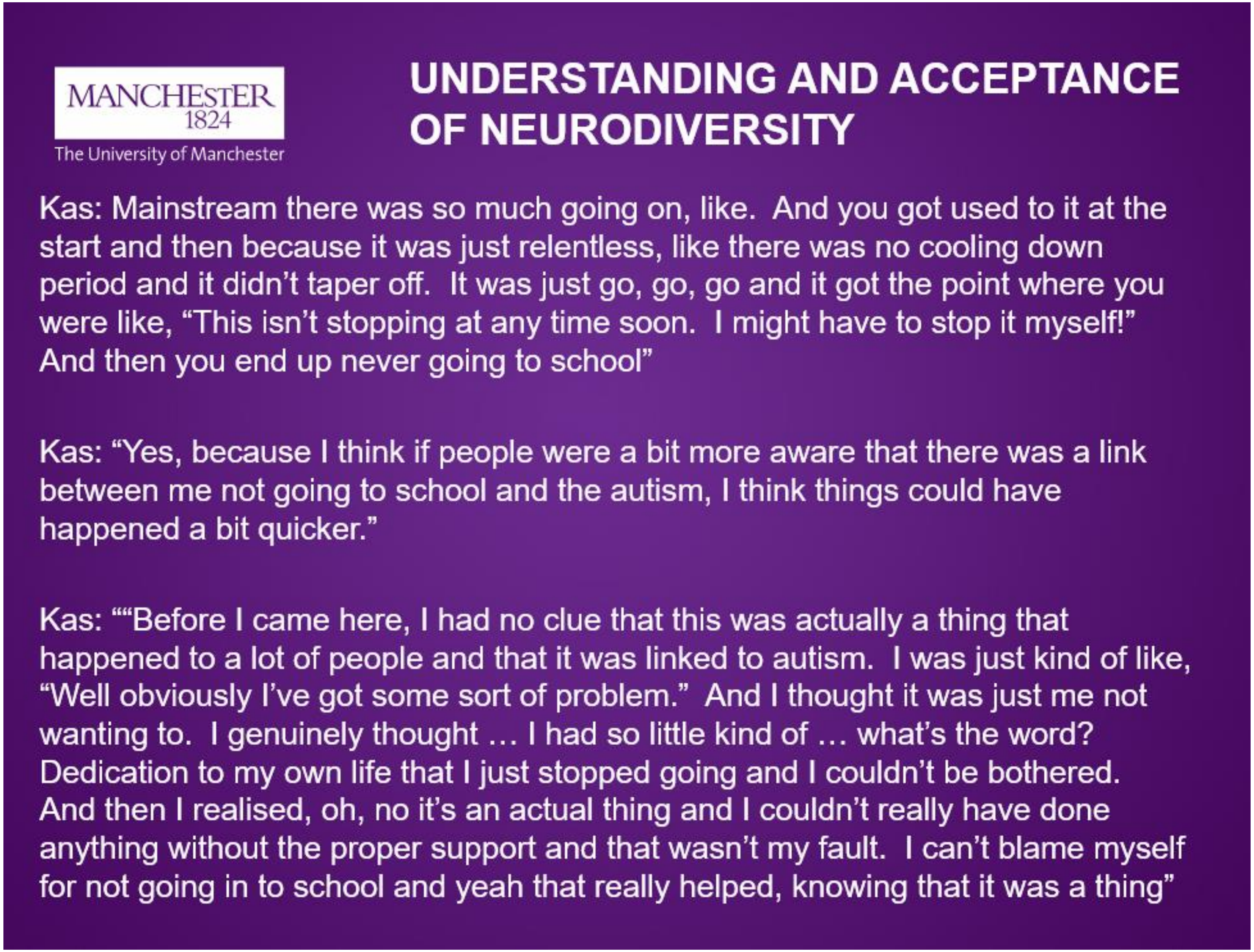


MANCHESTER
1824
The University of Manchester

EMOTIONS

Kas: “Now, like I have weeks where everything’s just fine and it is so foreign to me that everything just feels … I’m not worried about something that’s coming up and the freedom that gives me, is … you just wouldn’t believe. The feeling of not being scared of the future… it’s amazing […] I am so grateful to this school, in everyway”

Z: “The positive energy of this place is kind of too much to stay sad. So in a way the school kind of forced me to be happy and now I actually *feel* better. Not fully happy but better. I don’t think about bad thoughts all the time. I come in most of the time and I talk with everyone and I feel much mentally better […] It’s not just the big boulder, that’s just on my shoulder and I’m somehow tipping it – like urgh – that’s just how I feel about it – that’s the mental recalibration”



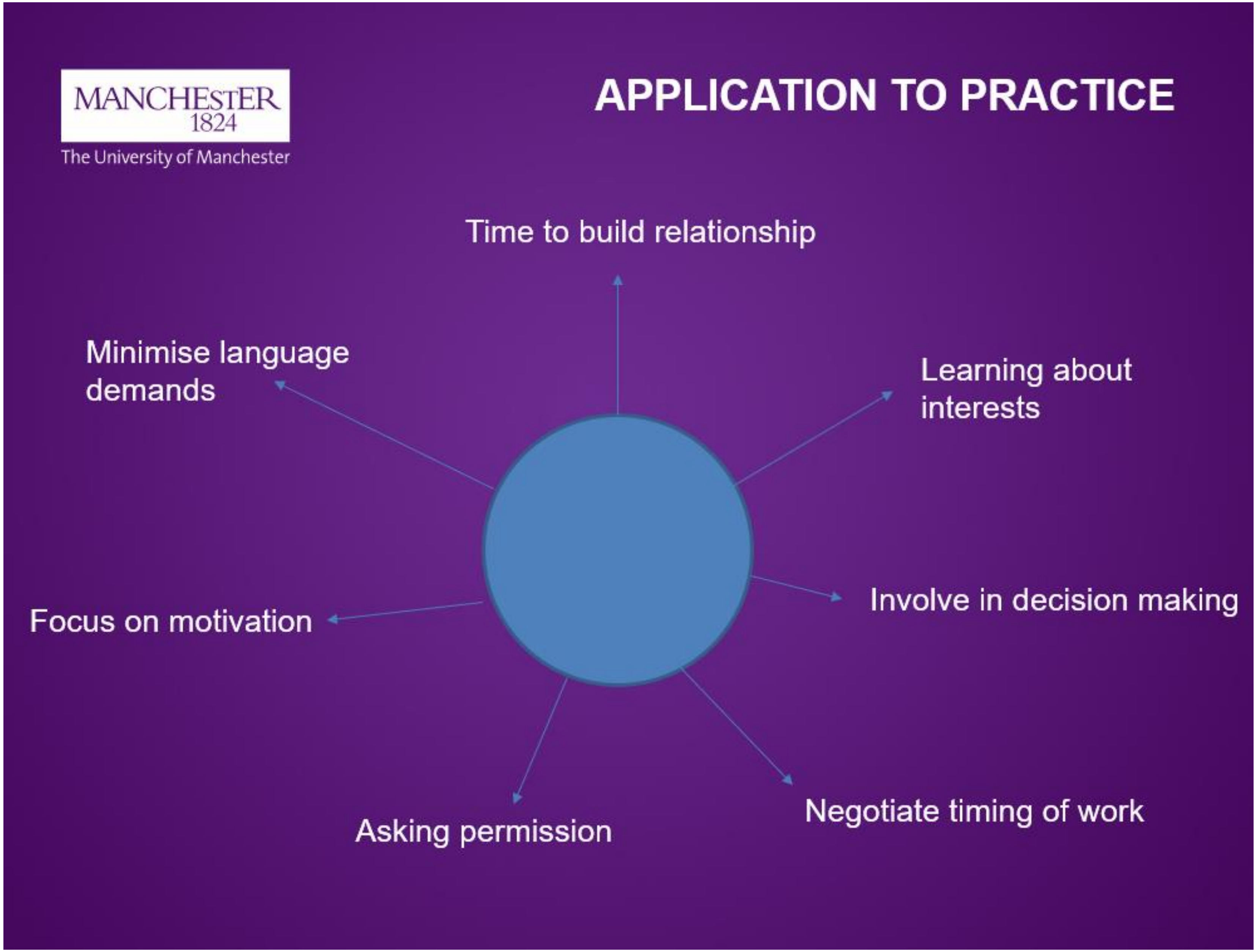
MANCHESTER
1824
The University of Manchester

UNDERSTANDING AND ACCEPTANCE OF NEURODIVERSITY

Kas: Mainstream there was so much going on, like. And you got used to it at the start and then because it was just relentless, like there was no cooling down period and it didn't taper off. It was just go, go, go and it got the point where you were like, "This isn't stopping at any time soon. I might have to stop it myself!" And then you end up never going to school"

Kas: "Yes, because I think if people were a bit more aware that there was a link between me not going to school and the autism, I think things could have happened a bit quicker."

Kas: ""Before I came here, I had no clue that this was actually a thing that happened to a lot of people and that it was linked to autism. I was just kind of like, "Well obviously I've got some sort of problem." And I thought it was just me not wanting to. I genuinely thought … I had so little kind of … what's the word? Dedication to my own life that I just stopped going and I couldn't be bothered. And then I realised, oh, no it's an actual thing and I couldn't really have done anything without the proper support and that wasn't my fault. I can't blame myself for not going in to school and yeah that really helped, knowing that it was a thing"



MANCHESTER
1824
The University of Manchester

APPLICATION TO PRACTICE

Time to build relationship

Learning about interests

Involve in decision making

Negotiate timing of work

Asking permission

Focus on motivation

Minimise language demands

Appendix 23: Evaluation of NW EP conference

NW EP Networking and CPD event 2022 – Feedback Evaluation

2022	Number of delegates in attendance	144	Number of evaluation survey responses	45
2021 (virtual)		103		39

1. Overall ratings of 2022 conference

		Percentage of overall response	
	Number of responses	In 2022	In 2021
Excellent	37	89%	74%
Good	8	11%	26%
Average	0	-	-
Fair	0	-	-
Poor	0	-	-

5. Morning seminars: number of responses

	Excellent	Good	Average	Fair	Poor
1. Enhanced Case Management [redacted]	6	0			
2. Alternative Provision ([redacted] [redacted])	2	3			
3. Lancashire EBSA Strategy [redacted] [redacted]	12	1			
4. Identity: Therapeutic Tools [redacted] [redacted]					
5. Post 14 Development [redacted] [redacted]	7	2			
6. Systemic Barriers (Claire Neilson, [redacted] & [redacted]	4	3			