Bridging research and Educational Psychology practice on restricted and repetitive behaviours and interests in autism

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I, Katerina Avramides, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Abstract

Aim: Restricted and Repetitive Behaviours and Interests (RRBIs) are a diagnostic feature of Autism Spectrum Disorder (ASD). The literature on RRBIs interventions has been critiqued for focusing on symptom reduction instead of broader outcomes which are meaningful to autistic Children and Young People (CYP). Given the ecosystemic and CYP-centred framework within which most EPs practice, the extent to which EP practice and research can inform each other is unclear. The aim of this research was to bridge research and practice on RRBIs, using Bronfenbrenner's bioecological model as a framework for discussion.

Method: *Part 1:* A systematic scoping review (SSR) of RRBI intervention design that examined how outcomes are defined, by whom, and whether interventions are effective in achieving broader outcomes. The SSR included 564 studies. *Part 2:* Focus groups with 7 EPs and 3 Trainee EPs to elicit their views on how they practice with regard to RRBIs.

Findings: The SSR indicated that the reasons for intervention were not clearly reported, and the intended broader outcomes were not consistently measured. CYP views were rarely reported. Parent/caregiver and teacher views on RRBIs were largely summarised in short statements of negative impact. There were few reports of collaborative approaches to setting outcomes. A discussion of a subset of studies that defined and measured reasons for intervention suggested that changes in RRBIs sometimes, but not always, are associated with changes in broader outcomes. The EP focus groups emphasised understanding the meaning / function of behaviour and advocating against normalisation. EPs suggested that they avoid the RRBI term because it implies deficit and because of its limitations in understanding behaviour.

Conclusion: Current intervention literature is limited in informing when and for what purpose intervention on RRBIs may be effective. Barriers to meaningful collaboration between research and practice are discussed. EPs can contribute

to reframing RRBI research with a focus on meaningful outcomes for autistic CYP and their families.

Impact statement

The context of this research was an apparent lack of alignment between Educational Psychology (EP) practice and the research literature on interventions for Restricted and Repetitive Behaviours and Interests (RRBI). While EPs mostly practice within an ecosystemic, child-centred framework, the research literature on RRBI interventions has been criticised for an emphasis on deficit and symptom reduction. This is likely to impact on whether EPs can contribute their professional expertise to research, but also whether the research literature on RRBI interventions is accessed and used by EPs.

The findings from this research contribute to bridging research and practice in several ways. They highlight the need to review the framework within which RRBI intervention research is designed and reported. The current design of interventions is limited in the extent to which it can inform when and for what purpose RRBI interventions are effective in achieving broader outcomes for autistic CYP. There is a need to clearly report the reasons for targeting RRBIs and to measure intervention effectiveness with respect to the reasons for intervention. It also highlights a lack of collaborative involvement by autistic CYP and stakeholders in defining outcomes. A discussion of RRBI intervention effectiveness, in a subset of studies that did specify and measure a reason for intervention, suggests that a change in RRBIs is sometimes, but not always, associated with changes in broader outcome. However, the lack of participation from autistic CYP and collaboration with stakeholders is a concern in interpreting these findings. Some of the literature that was reviewed (which included practitioner research) was conducted within a broader framework of CYP developmental needs. However, it appears that the findings are still reported in terms of RRBI reduction. This can have broader implications in terms of perpetuating a focus on RRBI reduction and hindering access to the research literature by practitioners who may not consider this body of knowledge to be relevant to their practice.

EPs could play a key role in working with the research community to reframe how research is conducted with regard to behaviours that are currently defined under the RRBI diagnostic term. The findings highlighted that EP practice focuses on understanding behaviour in specific contexts, understanding the meaning and function of behaviour for autistic CYP, and that EPs work to advocate for CYP rights. This way of working addresses many concerns about current research on RRBIs, and autism more generally. The findings suggest that EPs avoid the RRBI diagnostic term, and consequently would not engage with the body of research literature on RRBI interventions. However, by contributing to research, EPs could have a significant impact. In order to achieve this, collaborative research processes need to be in place, as has been noted in the literature. However, the findings from this thesis suggest that there also exist barriers to establishing joint discourse with others within the research community. Significant commitment may be required to engage with and reframe RRBI-related terms and definitions of behaviour.

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List of abbreviations

ASD – Autism Spectrum Disorder

CYP – Children and Young People

EBP – Evidence based practice

EP – Educational Psychologist

PPCT – Process-Person-Context-Time model

PRISMA - Preferred Reporting Items for Systematic Reviews and Meta-Analysis

RRBIs – Restricted and repetitive behaviours and interests

SR – Systematic Review

SSR – Systematic Scoping Review

TEP – Trainee Educational Psychologist

List of tables and figures

Chapter 1. Introduction

In a recent survey, Educational Psychologists (EPs) in the UK reported that, on average, 30% of their caseload related to supporting children and young people (CYP) with a diagnosis of Autism Spectrum Disorder (ASD) (Robinson et al., 2018). ASD is a neurodevelopmental condition that is characterised by difficulties in social communication and interaction and restricted and / or repetitive behaviours and interests (RRBIs) (American Psychiatric Association, 2013). The prevalence of ASD in the UK is estimated to be around 1 in 100, with a higher prevalence in males (2%) than females (0.3%) (Baird et al., 2006; Brugha et al., 2012). Individual expression of ASD varies considerably in terms of behavioural and cognitive profiles (Wozniak et al., 2017). ASD also has high co-occurrence with other conditions, such as Attention-Deficit / Hyperactivity Disorder, gastrointestinal symptoms, and sleep problems (Mannion & Leader, 2013; Supekar et al., 2017).

RRBIs cover a range of behaviours. Before defining these, it is noted that the diagnostic language has been criticised for implying deficit and pathologising behaviour, as will be explored later in this thesis. The diagnostic definition of RRBIs includes repetitive and stereotyped movements, inflexibility in routines, highly fixated and perseverative interests which are atypical in intensity, and unusual interests in sensory aspects of the environment (American Psychiatric Association, 2013). A distinction that is generally accepted in the literature, and will be used in this thesis, is that made between low-level and high-level RRBIs. Low-level RRBIs involve a repetitive movement and have a sensory element, such as rocking, spinning or repetition of words. High-level RRBIs include difficulty with changes in routine, intense focus on specific interests, and object attachments (Bishop et al., 2013; Raulston & Machalicek, 2018).

A focus on a diagnostic feature of ASD may prompt the criticism that this thesis follows a 'medical model' of understanding CYP need. In other words, a framing of development in terms of deficit or functional impairment. The criticism of the

medical model has been that it aims to normalise behaviour and achieve symptom reduction without consideration of the function of behaviour or the role of environmental factors (Kapp et al., 2013). In reaction to the medical model, proponents of the neurodiversity movement have argued for an acceptance of ASD as a natural variation in human development and to recognise autistic differences (both challenges and strengths) as part of autistic identity (Leadbitter et al., 2021). It should be noted that concerns have been expressed about misconceptions of the neurodiversity movement (den Houting, 2019). Neurodiversity proponents acknowledge disability related to ASD. However, they advocate for respect for autistic ways of being and acceptance of these in society, rather than intervention that aims to reduce ASD characteristics (den Houting, 2019). Intervention should aim to support individual well-being and consider how the environment can be adapted. However, intervention does not preclude help to build skills (Kapp, 2020; Leadbitter et al., 2021).

The position taken in this thesis is that assuming a dichotomy between a medical model and the neurodiversity movement does not address the complexity of defining when and for what purpose autistic CYP should be supported through intervention. This dichotomy overlooks variation within, and overlap between, medical and neurodiversity positions (Kapp, 2020; Kapp et al., 2013), the complexity and contextual sensitivity of defining what behaviour is harmful or places CYP 'at risk' (Akhtar & Jaswal, 2013), and the balance between supporting development and changing the autistic characteristics of a person (particularly for young children) (Leadbitter et al., 2021). Some of the ethical questions regarding intervention are clear. For example, the thesis rejects a view of intervention that frames need as within-child deficit and aims to normalise behaviour in order to fit neurotypical norms. Instead, this work follows a bioecological model of development (Bronfenbrenner, 2005) which requires understanding of child-context *interaction* (Bronfenbrenner's bioecological model is described later in this chapter). However, it is acknowledged that there is complexity in identifying meaningful developmental outcomes and understanding how to support them. For example, society needs to recognise

and respect autistic differences, but many parents may also believe that supporting the development of skills in social interaction can contribute to greater individual well-being for autistic CYP.

The reason for using the term RRBIs, and the diagnostic definition of behaviour, in this thesis it that it currently constitutes a criterion for identifying CYP need and is used with reference to diagnosis. It also aligns with the current research literature (Fletcher-Watson & Happé, 2019). It is acknowledged that this language can be seen as pathologising behaviour. The thesis was prompted by concern about a deficit view of RRBIs within the research literature and the question of whether and how EPs engage with this literature. Therefore, the RRBI term is used to discuss these issues. Use of the diagnostic term does not imply that the thesis is aligned with a deficit view of behaviour or that the focus of intervention should be the autistic individual. Examining how these behaviours are understood and whether (and how) intervention can be helpful is a focus of this research.

RRBIs are not unique to ASD. Some research suggests that they exist independently in other atypical populations, sometimes with the same intensity (Brunsdon & Happé, 2014; Honey et al., 2012). However, there is also evidence that incidence and intensity of RRBIs tends to be greater in ASD populations (Richler et al., 2007; Turner-Brown et al., 2011). Further, the display of RRBIs in autistic people has been linked to autistic differences in perception and information-processing, for example, longer visual inspection (Mottron, 2017). Therefore, this thesis focuses specifically on ASD.

'ASD' is used throughout this thesis as it is consistent with the current diagnostic term in DSM-5 and ICD-11 (American Psychiatric Association, 2013; World Health Organization, 2018). However, concerns about the use of the term 'disorder' to describe variations in development are acknowledged (Baron-Cohen, 2017). Identity-first language (i.e., autistic CYP) is used in this thesis, as it did not involve direct work with participants who may have expressed a

preference for person-first language (i.e., CYP with autism). Identity-first language is associated with a model of disability that portrays it as neutral or positive, and a natural human characteristic (Bottema-Beutel et al., 2021; Dunn & Andrews, 2015; Vivanti, 2020). Throughout this thesis, the term 'broader outcomes' will be used to refer to outcomes that are meaningful to autistic CYP and their families, as discussed in the following section.

1.1. Practice and research on RRBIs

EP practice

A search at the outset of this thesis using RRBI-related terms found no published literature on EP practice. The reasons for this are unclear and will be explored, in part, in this research. However, there are general principles and frameworks that underpin EP training and practice that may broadly suggest how RRBIs are understood and supported by EPs. This includes an ecosystemic / bio-ecological approach (Bronfenbrenner, 1979, 2005) to understanding and supporting CYP development (British Psychological Society, 2017; 2019), practice that is centred on CYP views, and a consultative process of working with families and other stakeholders that is non-hierarchical and based on professional expertise in facilitating collaboration (Wagner, 2016). The CYP and family-centred principles of practice are recognised in the legislative framework within which EPs work (Department for Education, 2015). EP practice is discussed further in Chapter 3.

RRBI interventions in the research literature

There is a growing body of research literature on RRBIs that has evaluated educational, developmental, pharmacological and behavioural interventions (Boyd et al., 2012; Leekam et al., 2011; Ninci et al., 2020; Patterson et al., 2010; Yu et al., 2020). The effectiveness of RRBI interventions tends to be summarised in these systematic reviews and meta-analyses in terms of whether they result in a reduction in RRBIs. Some reviews have also synthesised

research on how RRBIs can motivate engagement with other activities, such as reading comprehension and play with peers (Harrop et al., 2019).

Concerns have been voiced that outcomes for RRBI interventions are focused on symptom reduction without a clear understanding of the meaning of the behaviour for the autistic individual (Kapp et al., 2019). This is particularly pertinent to an ASD population because the function of their behaviour can and has often been misunderstood (Jaswal & Akhtar, 2019). This is both an ethical point and a question of effectiveness. If interventions are focused on symptom reduction, does this necessarily translate to meaningful outcomes for autistic CYP? Further, if interventions are focused on reducing RRBIs as a means to achieving broad outcomes for CYP, is intervention effectiveness evaluated in terms of achievement of these outcomes? The research literature on RRBI interventions is further discussed in Chapter 2.

Research-practice gap

The concerns around RRBI intervention design echo broader concerns about research on ASD, with calls to focus on issues that more directly impact on autistic people's lives (Frazier et al., 2018; Roche et al., 2021). For example, Roche et al. (2021) conducted a systematic review of studies that reported on stakeholders' priorities for research. The findings emphasised the importance of outcomes that reflect meaningful changes in the lives of autistic people and a need for including stakeholder views in identifying priorities for research.

The definition of outcomes for autistic people has also been criticised as too narrow, as it is often measured in terms of meeting diagnostic criteria or standard scores of 'adaptive' behaviours, and are judged by clinicians or researchers (Bal et al., 2018; Georgiades & Kasari, 2018). Bal et al. (2018) summarise several considerations when defining meaningful outcomes. This included understanding the outcome in relation to the person's context, broadening the scope of outcome measurement to include subjective well-being, and the need for development of new assessment tools. Lounds Taylor

(2017) emphasises the need for defining and measuring outcomes longitudinally. McConachie et al. (2018) report similar perspectives from parents on the importance of outcomes that are relevant to everyday life.

Within the ongoing discussion of research priorities and the focus on broader outcomes, many have argued that disagreement and conflict is inevitable, as there is also variation in the views that are expressed by autistic people and their families (Pellicano & Stears, 2011). Further, there are challenges in engaging with stakeholders during the research process. These must be recognised, and appropriate methods used to overcome them, if the research output is to be relevant, applicable, and socially valid (Callahan et al., 2017; Elsabbagh et al., 2014; Nicolaidis et al., 2019). However, there is a broad consensus that research must include greater and more democratic collaboration with autistic people, their families, practitioners, and other stakeholders (Parsons, 2021; Roche et al., 2021; Zuber & Webber, 2019). EPs are one such stakeholder for many autistic CYP.

1.2. Summary of problem

There is concern that research on RRBI interventions (and ASD more broadly) is framed within a deficit-model of CYP need. This is coupled with a lack of clarity on whether and how EPs engage with this research literature. If the published research is not aligned, or is perceived not to be aligned, with the way EPs practice, do EPs contribute to it and is it accessed and used by them?

The problem is, therefore, a possible gap between the research literature and EP practice which would hinder the development of shared knowledge. It may mean that EPs are not contributing their professional expertise to shaping the research literature, when there are significant concerns about autism research. Further, EPs must adhere to professional standards of proficiency, which includes evidence-informed practice (Health and Care Professions Council, 2015). However, it is unclear whether research is designed in a way that can

inform EP practice. Although the RRBI intervention literature (and ASD literature more broadly) has been criticised for framing RRBIs as deficits and focusing on symptom reduction, no review has been carried out to systematically describe the design of RRBI interventions. Consequently, it is not known how the research literature *can* inform practice given the ecosystemic, collaborative, and CYP-centred framework within which most EPs practice.

1.3. Thesis rationale: systematic scoping review and empirical work

The thesis involved two parts, a systematic scoping review (SSR) and empirical work with EPs. SSRs and systematic reviews (SRs) have a different focus (as discussed in Chapter 2). Scoping reviews have a focus on describing the literature and do not typically aim to evaluate the effectiveness of interventions, but both follow a rigorous search process. Given that the primary concern was the way that research is designed, the SSR was carried out first. The design of the SSR was guided by the general principles and frameworks of EP practice that place advocacy for CYP and their families at the centre, as well as the ethical and pragmatic concerns about research into RRBIs and ASD more broadly. The SSR, therefore, examined how outcomes are defined for RRBI interventions and by whom. It also aimed to examine the extent to which broader outcomes are achieved (beyond reduction in autistic behaviours). The SSR is reported in Chapter 2. The second part of the thesis involved empirical work with EPs to explore practice with regard to RRBIs. The findings of the SSR were used to guide discussion with EPs, as no existing literature on practice was found using RRBI-related terms. The empirical work is reported in Chapter 3.

Framework for synthesis: Bronfenbrenner's model
This thesis tried to bridge two areas that are potentially very different: research on RRBI interventions and EP practice that may not use the term RRBIs. Bronfenbrenner's Process-Person-Context-Time (PPCT) model (Figure 1), which underlies much of EP practice (as discussed in Chapter 3), was used as

an overarching framework to discuss the factors that may shape how the need for intervention is understood for autistic CYP.

Figure 1

Bronfenbrenner's Process-Person-Context-Time (PCCT) model
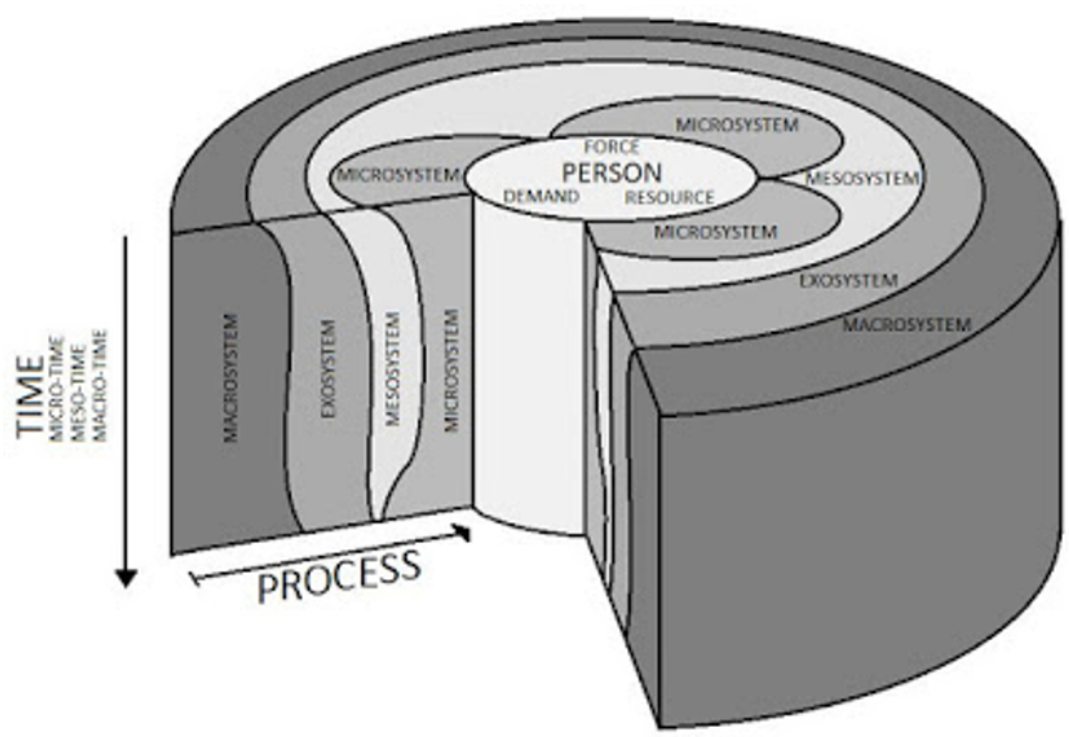
Bronfenbrenner's PCCT model

Bronfenbrenner conceptualised development in terms of the accommodation between an active, growing human and a changing context (Bronfenbrenner, 2005). Perhaps the most cited element of his theory is the definition of context in terms of multiple nested systems (defined as microsystem, mesosystem, exosystem and macrosystem). The microsystem relates to the child's immediate environment. The definition of the mesosystem (the relationships between the child's microsystems) emphasises the need to study development beyond a single context (for example, school and family and how the two interrelate). The definition of wider context in terms of nested systems (exosystem and macrosystem) encourages practitioners to explore how wider contexts, which are more distant to the child, nevertheless impact on the child's

development. For example, the policy decisions that determine day care arrangements, or the experiences of particular groups of people, such as socioeconomic or religious groups. Bronfenbrenner later added a fifth system (the chronosystem), which recognises the influence of time on development.

An important element of Bronfenbrenner's theory is a phenomenological analysis of context. In other words, an analysis of how each person perceives their context and the people and objects within it. His thinking is thus in line with social constructionism (Burr, 2015) and emphasises the use of methodology that aims to understand the subjective experience of CYP. In Bronfenbrenner's later work he became more concerned with developmental processes and paid much more attention to the role of individual CYP, including biological factors. In the bioecological model, proximal processes are interactions between CYP and context that endure over time and are the mechanism through which development occurs (Bronfenbrenner, 2005). Bronfenbrenner eventually formulated his work into the Process-Person-Context-Time model (PPCT model). In the PPCT proximal processes are influenced by the characteristics of the person and context, and vary over time. Broadly speaking, Bronfenbrenner conceptualised CYP's influence with an emphasis on their behavioural dispositions (such as motivation and persistence) their mental, emotional and material resources (such as skills, material objects and access to a responsive caregiver), and qualities that influence how others respond to CYP (such as attractiveness and calmness) (Hayes et al., 2017; Tudge et al., 2009). These individual factors influence how CYP interact with their context and the people within it, which in turn impacts on the contextual influences on CYP. Thus the developmental process is one of increasingly more complex interactions as CYP develop.

It is important to highlight the social constructionist nature of Bronfenbrenner's model. CYP's experience and view of the world is at the centre of the developmental process. Accessing and understanding their view is, therefore, a fundamental part of understanding how their development can be supported. At

the centre of social constructionism is the belief that knowledge is socially constructed using language and building on existing experiences (Burr, 2015). Therefore, behaviour must always be understood as an interaction between the person and their context and requires consideration of the subjective experiences that are created by that interaction. This is in contrast with the historical 'medical model' which emphasises factors that exist within the person, are fixed, and can be identified or measured by an objective observer. Intervention (in the medical model) then follows from the correct 'diagnosis' of these within-person characteristics.

1.4. Significance of research

The findings of this research contribute to understanding barriers between research and practice and how they may be bridged. Concerns are expressed about the deficit focus of RRBI intervention research and there have been calls for greater participation of autistic CYP in research, as well as greater collaboration with stakeholders, such as EPs. The thesis contributes with an analysis of the research literature and how study design can be improved to better meet the needs of autistic CYP and their families. It also explores possible barriers to EP engagement with the research literature. EPs may have a significant role to play in reframing the way that RRBI intervention research is conducted. However, this may be hindered by working in different ways. In addition to participatory research processes, the development of joint discourse may require significant commitment from all stakeholders to find common ground.

1.5. Personal research journey

Through the professional doctorate I have become more aware of the neurodiversity movement and the challenges and ethical issues in supporting CYP who follow atypical development pathways. I have also worked with families who have expressed concern about the impact of RRBIs on CYP's well-being, their siblings and family life.

I first began reflecting on RRBIs when I was employed as a teaching assistant working with young autistic children. For example, Ben (pseudonym), who attended a mainstream primary school, was very interested in water bottles. While we felt we understood that Ben's interest brought him enjoyment, it was not clear how we should be responding across different contexts. Should we block access to engage him in structured learning activities, even if he was initially distressed? How should we prevent him from using other children's bottles (for hygiene reasons), which were easily accessible as they were kept outside each classroom? In retrospect there were many questions that link to the issues that have arisen in this thesis in terms of whether intervention was needed and what this might involve.

During the first year of the doctorate, I carried out a small-scale project with 48 participants that explored teachers' and teaching assistants' perceptions of RRBIs. A questionnaire was disseminated to any teaching staff working with autistic CYP, including SENCOs, teachers, teaching assistants, and tutors. This included both mainstream and specialist schools. The findings suggested that the participants often took an adult-centred view of the function of RRBIs. For example, they reported that CYP avoided social interaction rather than having an intrinsic interest. Some participants did not consider the function of the RRBI for the CYP at all, even when asked explicitly. Instead, they responded from a teacher's perspective in terms of the interest being positive because it enabled them to teach the curriculum. I also found that the perceived impact of RRBIs and the perceived impact of difficulties in social communication and interaction were often not separated when setting targets for autistic CYP. This prompted me to reflect further on how outcomes are set with regard to RRBIs and possible assumptions that may be made about their association with social communication skills.

Having worked in academic research for many years I was open to engaging with the research literature, despite the apparently significant gap between

research and practice. The projects that I was involved with as a researcher were mostly applied to the development of learning experiences (through technology) and involved collaboration between multiple disciplines, as well as teachers, school leadership, and other stakeholders. I was aware that the different frameworks within which researchers and practitioners had developed their expertise meant that, even with the best intentions, an extended period of time was needed to create common ground before engaging in any research.

Having completed this thesis I believe that there is some literature that is published with reference to RRBIs which can inform my practice as an EP. However, this was not easily accessible largely because of the way that it is reported. I also feel that it is important that EPs (and other practitioners) contribute to the ongoing research literature, in order to bring about significant change. There appears to be a need for different language and definition of behaviour to the diagnostic term. However, it seems that significant commitment may be needed, from all sides, to move forward in a way that informs how to best support autistic CYP and their families.

Chapter 2. Systematic scoping review on RRBI interventions

2.1. RRBI interventions

The effectiveness of interventions that focus on RRBIs has been reviewed in terms of reduction of what are considered to be inappropriate or dysfunctional behaviours, such as repetitive motor behaviours and difficulty with changes in routine (Akers et al., 2020; Boyd et al., 2012; Leekam et al., 2011; Mulligan et al., 2014; Patterson et al., 2010; Tarr et al., 2020; Yu et al., 2020; Zarafshan et al., 2017). Individual reports of RRBI interventions often introduce their work by citing studies of the negative impact of RRBIs, such as a negative impact on socialisation, engagement in academic activities, social stigma, acquisition of skills and general functioning in daily life (Grahame et al., 2015; Lin & Koegel, 2018; Verriden & Roscoe, 2019). RRBIs have also been highlighted as a significant factor hindering the inclusion of many autistic CYP, particularly in mainstream classrooms (Gunn & Delafield-Butt, 2016). Further, literature is cited that RRBIs can create challenges for parents of autistic people in daily life (Bishop et al., 2007; Gabriels et al., 2005; South et al., 2005). Intervention for high-level RRBIs, specifically, has been based on their association with heightened anxiety. For example, there is evidence that 'insistence on sameness' can in some cases be described as a coping response to anxiety which in fact does not result in the desired reduction in anxiety (Lidstone et al., 2014; Rodgers et al., 2012). Distress and aggression prompted by interruption of RRBIs is also cited as a reason to intervene (Eilers & Hayes, 2015; Fisher et al., 2019).

Because RRBIs are reported to have a severe negative impact on daily life, reducing these behaviours is seen as a way of mitigating their impact, leading to 'adaptive' outcomes. However, there are several issues with this view of RRBIs, as discussed in this section, that have implications for the design of intervention studies and, consequently, for the application of research evidence to practice.

This view of RRBIs could be described as placing a focus on fixed, within-child characteristics that, irrespective of contextual factors, create difficulties for autistic CYP and those around them. In reference to the PCCT model, therefore, the relative emphasis is on within-child characteristics in the absence of consideration of child-context interaction. Further, the subjective experiences of autistic CYP (from a social constructionist perspective), and the meaning of the behaviour for the individual, appear to be missing.

Contextual variation

Although much of the literature on RRBI interventions cites the 'problematic' nature of RRBIs as a reason to reduce these behaviours, some argue for intervention only in specific contexts or for specific aspects of RRBIs. For example, some behavioural interventions aim to reduce RRBIs at times when it has a perceived negative impact, such as during instruction, but do not intervene at other times (Brusa & Richman, 2008; Falligant & Dommestrup, 2020; Tiger et al., 2017).

Boyd et al. (2011) discuss the uncertainty that parents express about their children's RRBIs in whether and how to intervene. Parents perceive some aspects of RRBIs as strengths and can be surprised by their children's mastery, such as their factual knowledge in certain areas. However, at the same time parents are concerned about the extent of their children's difficulties in other areas, such as social interaction, as well as the distress and aggressive behaviour that results from interrupting engagement in RRBIs. Parents' concern in some cases is, therefore, related to the perceived rigidity of their children's behaviour, and the impact that this has on their family, rather than a desire to reduce certain behaviours.

Uncertainty about the impact of RRBIs

Recently, J. L. Cook & Rapp (2020) questioned the robustness of the evidence-base that stereotypy (a type of RRBI) interferes with learning, as the literature

that is often cited to support intervention mostly includes studies that were conducted four decades ago. They implemented a series of interventions, which involved a progressively greater degree of intervention. They only blocked behaviour when other interventions had not been effective at increasing engagement. The results suggested that stereotypy does not always need to be reduced to support autistic CYP's engagement.

However, it is noted that even 3 – 4 decades ago, some researchers expressed uncertainty over whether RRBIs can be said to interfere. An alternative hypothesis, they argued, would be that CYP are not able to engage in the desired alternative behaviour, and that the RRBI is an alternative, perhaps incompatible, response but not one that is the cause of the lack of engagement (Cohen et al., 1980; E. H. Cook et al., 1992). It is noted that the authors' state this in terms of 'ability' to engage, but it may be more appropriate to understand this in terms of interest. There are also early studies, not often cited, that suggest that RRBIs can occur without interfering (Chock & Glahn, 1983; Hargrave & Swisher, 1975; Klier & Harris, 1977). Within a behaviourist intervention approach, RRBIs had also successfully been used as reinforcers for engagement in learning activities (Charlop et al., 1990; Wolery, 1978). This literature, which may not align with the PPCT model but does question a universal need to reduce RRBIs, is not often cited.

Further, some of the reported difficulties with RRBIs relate to a negative impact on the CYP's social interaction and communication. There appears to have been an assumption until recently that RRBIs result from a more fundamental 'deficit' in social communication and interaction (Richler et al., 2010). Although there may be an association between RRBIs and social interaction, it is not clear that this is causal. Recent evidence on the link between the two core features of ASD, in terms of aetiology, is unclear. Although the two core features of ASD co-occur at above chance rate, there is evidence that there is no single underlying cause. Fletcher-Watson and Happé (2019) summarise evidence from several sources to support this conclusion: a) genetic studies

suggest that separate genes contribute to each ASD feature, b) evidence of different developmental trajectories of each ASD feature, and c) at the cognitive level, accounts of ASD have not been able to propose a 'primary' explanation that can account for autistic characteristics across social communication and interaction, and RRBIs. Although research on aetiology does not automatically translate to evidence of the efficacy of interventions, the above findings question any assumption that interventions targeting RRBIs will necessarily impact on social communication and vice versa.

Learning through RRBIs

Another approach to intervention which questions a negative view of RRBIs has tried to embed them in learning environments in order to increase motivation to engage in other activities. The intrinsic motivational value of RRBIs can, therefore, be seen as a strength not only for the positive impact that they have for the individual in terms of interest, but also from the perspective of supporting their involvement in other activities.

The findings from reviews of these interventions have been mixed. Evaluation of interventions that embed RRBIs into learning environments have led to both positive (Harrop et al., 2019) and negative (Ninci et al., 2020) results. Ninci et al. (2020) suggest that, as with interventions that aim to modify RRBIs, one critical factor may be the degree of flexibility in CYP's behaviour. They argue that if CYP show a low degree of flexibility then embedding the RRBI in a learning environment might have a negative impact on learning, as it may not lead to engagement with other aspects of the activity. The separation of flexibility from other aspects of RRBIs is backed up by research findings that have supported the definition of 'insistence on sameness' as a separate sub-type of RRBIs (Bishop et al., 2013; Honey et al., 2012).

Variation in types of interest might also be relevant. For example, an intense interest in a TV character could range from memorising lines from TV shows to being interested in reading stories around that character. The latter may be

easier to embed in a learning activity. Some researchers have tried to categorise intense interests, but this has proven difficult. Categories derived from one study (Baron-Cohen & Wheelwright, 1999) could not be reliably applied to behaviours described in other research (Klin et al., 2007). Intense interests can be placed in multiple categories, such as categories related to content (for example, physics), type of information (for example, memorising trivia), or the type of activity that the CYP enjoys (for example, drawing or collecting objects). Describing (and understanding) an RRBI thus requires the 'assessor' to collect detailed information about the CYP's behaviour and interests (Klin et al., 2007).

It should be noted that the value of an intense interest to the individual does not need to be defined in terms of how it supports engagement in structured learning. Caution is needed, because embedding an intense interest in structured learning may not necessarily recognise its meaning for the individual. It could just be seen as a tool to support learning. For example, understanding the meaning of the interest from the perspective of autistic CYP may require understanding the intensity as representing degree of interest rather than how 'repetitive' or 'restricted' interests are (Murray, 2019). The issue of understanding autistic perspectives is explored next.

Neurotypical vs autistic perspectives guiding intervention

The above research questions a default view of RRBIs as having a negative impact. However, these studies do not necessarily involve an understanding of autistic CYP's subjective experiences of RRBIs. Even when RRBIs (such as intense interests) are used to support learning in other areas, there is not always a focus on the meaning of these interests to the individual or their contribution to the development of their identity. The following research has tried to address this.

Some researchers (including autistic researchers) have tried to counter the dominant negative view of RRBIs by emphasising their positive aspects

(Dawson et al., 2008; Kapp et al., 2019; Mottron, 2017). RRBIs often demonstrate unexpected strengths in individuals, are linked to strong positive emotions, and the pursuit of these interests can be seen as intrinsically motivating for CYP (Klin et al., 2007; Mercier et al., 2000; Winter-Messiers, 2007; Winter-Messiers et al., 2007). Mercier et al. (2000) were concerned about the lack of studies on the subjective experiences of individuals with ASD and attempted to explore RRBIs in terms of their meaning for the individual. The authors interviewed six verbally and cognitively able individuals, their parents and / or siblings. The participants had a diagnosis of autism and communication skills that enabled them to participate in the interview. Although participants acknowledged the potential negative impact of RRBIs they also reported that they can be a source of intense positive emotion. Similarly, Winter-Messiers (2007) conducted interviews with 23 autistic CYP, and surveys with 18 caregivers. They reported that RRBIs can be inseparable from individuals' self-image and that CYP can have a much more positive view of themselves when they are engaged in their RRBIs or related activities. However, it was still acknowledged that some rigidity and pervasiveness of these behaviours could be a significant challenge to daily functioning for the individual and their families. More recently, Wood (2021) described a study of the participation of autistic CYP in school. She reported many positive educational and affective responses for CYP to enabling access to intense interests at school. As in the previous studies, intense interests also created some barriers to learning, socialisation and inclusion in school activities.

Some theoretical accounts of RRBIs also offer an understanding of the meaning and function that RRBIs can have for autistic individuals that recognises difference but does not frame this as deficit. Monotropic theory states that the intense focus that is apparent in RRBIs is the primary difference between autistic and non-autistic people (Murray et al., 2005; Murray, 2018). This difference arises from atypicality in the way that attention is allocated. All people have limited attention. Some tend to distribute it among many interests ('polytropic tendency') whereas others tend to focus on a few ('monotropic

tendency'). At the far end of this variation are autistic people who focus all their available attention on a few highly motivating interests. Social difficulties may then arise for autistic people because social interaction requires broadly distributed attention. RRBIs have also been associated with a state of 'flow', understood as a deep state of well-being (Csikszentmihalyi, 1990; McDonnell & Milton, 2014). Wood (2021) describes observing a young child who, when in this state of flow, required little or no adult prompting and appeared to be purposely engaged and content. These theoretical accounts illustrate the intense positive feelings that autistic individuals can experience from behaviours that are defined as RRBIs. They also offer an alternative understanding of RRBIs to the deficit-based medical model.

As discussed in Chapter 1 with reference to the neurodiversity movement, deciding whether a behaviour is 'problematic' involves a judgement of what constitutes a 'good' outcome and there is an ethical issue in who decides. This is particularly true when the desired outcome is defined in terms of fitting in with neurotypical behavioural norms. However, this is not just an ethical point. Autistic CYP often follow atypical developmental pathways. Our 'neurotypical' perceptions may lead us to make misguided assumptions about how CYP learn. For example, atypical eye contact and interaction towards others is assumed to show evidence of a lack of social motivation (Chevallier et al., 2012). However, this is contrary to what many autistic people themselves have expressed (Jaswal & Akhtar, 2019; Mottron, 2017). Similarly, while it has often been stated that motor stereotypies are non-functional (Barry et al., 2011), reports of adults with a diagnosis of autism suggest that they can have an important self-regulatory function (Kapp et al., 2019). There is a question, therefore, over the frameworks used to assess the function of RRBIs, particularly when autistic CYP experience difficulties communicating their needs.

<u>A note on social validity measures</u>
It is important to emphasise that understanding the subjective experiences of autistic CYP requires their participation. Chapter 1 discussed calls for greater,

more democratic, participation of autistic CYP and stakeholders in research. It is noted that this is different to measures of social validity that are employed in some research, although even social validity is not often reported (Callahan et al., 2017). Social validity measures can help understand the "acceptability, feasibility, and contextual alignment of interventions in practice" (McNeill, 2019). Efforts have been made to develop measures that can be accessed by CYP who have communication difficulties (Hanley et al., 2005). However, social validity measures do not involve collaborative participation prior to intervention. Collaboration is necessary to understand behaviour for individual CYP before intervention is designed. Further, studies that have involved families from the start report that they value the process of shared decision-making on treatment outcomes (McLay et al., 2019).

Existing systematic reviews on RRBIs

SRs of RRBI interventions to date largely evaluate their effectiveness in terms of the extent to which the target RRBIs were reduced (Akers et al., 2020; Boyd et al., 2012; Leekam et al., 2011; Mulligan et al., 2014; Patterson et al., 2010; Tarr et al., 2020; Yu et al., 2020; Zarafshan et al., 2017). In a limited number of cases, it may be desirable to focus on reducing a behaviour (if, for example, that behaviour poses danger to someone). However, as illustrated in the above discussion, in the majority of cases we cannot assume either that RRBIs are by definition undesirable, nor that reducing them will automatically translate into desired broader outcomes.

There have been calls for a greater focus on broader outcomes in RRBI interventions (Boyd et al., 2012; Leekam et al., 2011). Boyd et al. (2012) argue that research may need to a) consider the function of the behaviour for the CYP, and b) focus more broadly "on strategies that could impact the overall level of behavioral flexibility and adaptability to promote optimal child and family outcomes" (ibid. p. 1244). The emphasis here does not appear to recognise the meaning of the behaviour for autistic CYP. However, they do argue against reducing RRBIs as an aim of intervention in itself. Although the function of

RRBIs has been considered in the design of some interventions and has been the subject of two reviews (Mulligan et al., 2014; Patterson et al., 2010), the focus was still on behaviour reduction. For example, Patterson et al. (2010) report 'collateral' increases in desirable behaviours. These reviews are now a decade old and it is unclear how research on RRBI interventions may have changed to address this concern. Further, there is no information in these reviews on whether the views of CYP, and those of their parents/caregivers or teachers, were taken into account to either understand the meaning of the behaviour or to decide on outcomes.

Therefore, the gap in the literature that this SSR addressed is threefold. First, an overview of how outcomes are defined in RRBI interventions and, second, by whom. The SSR specifically analysed whether or not the views of CYP, their parents/caregivers, and/or teachers have been sought in setting outcomes, since parents/caregivers and teachers are significant stakeholders for autistic CYP. Third, an evaluation of the effectiveness of interventions that target RRBIs in achieving broader outcomes for CYP, beyond a narrow focus on the reduction of the target RRBIs. An initial scoping review, that was carried out prior to defining the protocol for this SSR, identified increases in social communication skills, engagement in learning and positive academic performance as possible broader outcomes (Gunn & Delafield-Butt, 2016; Harrop et al., 2019; Lanovaz et al., 2013).

The only systematic review that evaluates the effectiveness of interventions beyond a narrow measure of reduction in target RRBIs is by Lanovaz et al. (2013). They conducted a systematic review of intervention studies that measured not only changes in the target RRBIs but also any changes in other RRBIs and/or social communication skills (Lanovaz et al., 2013). However, this only looked at vocal and motor stereotypies (a sub-type of RRBIs) and it included studies of not only CYP with an ASD diagnosis but also other developmental conditions. Given the evidence that RRBIs are more intense in CYP with ASD (Richler et al., 2007; Turner-Brown et al., 2011), it is unclear

whether the conclusions of this review can be applied to an ASD population specifically.

A couple of systematic reviews have focused on intense interests (a sub-type of RRBIs) and examined whether embedding these in learning environments led to positive outcomes (Harrop et al., 2019; Ninci et al., 2020). However, neither of these reviews focus on the function/impact of intense interests prior to the intervention and whether/how this changed along with other outcomes. Ninci et al. (2020) analysed whether other variables mediated the effects of the intervention, such as severity of ASD (categorised into three groups: severe autism, autism and high-functioning autism; measured by a combination of language delay, intellectual ability, IQ and adaptive behaviour/age-equivalent scores). For CYP in the group with less severe symptoms embedding their interests increased their engagement, whereas for other CYP it was distracting. Further, there was no information on CYP views in either of these reviews. Another systematic review focussed on parent-mediated interventions and RRBIs (Harrop, 2015). Harrop (2015) found that few studies explicitly targeted RRBIs or measured changes in these behaviours. She recommended a greater focus on the measurement of RRBs pre- and post-intervention for parent-mediated interventions. However, the focus of this review was on the design of parent-mediated interventions more generally, as opposed to RRBI interventions specifically.

It is worth noting that a recent systematic review looked at RRBIs in females with an ASD diagnosis, in order to explore differences between the male and female phenotype (Allely, 2019). Only 19 studies were retrieved, and the results were mixed, making it difficult to draw clear conclusions about differences between males and females. However, the author highlighted suggestions that clinicians are less likely to identify RRBIs in females as these behaviours might differ from the behaviours commonly associated with ASD. Gender differences in ASD presentation are an important area of research but were beyond the scope of this thesis.

2.2. Systematic scoping review rationale and aims

The SSR component of this thesis aimed to address the current gap in the literature with regard to how RRBI intervention studies have defined outcomes. Specifically, it addressed this in terms of three related areas: 1) How outcomes have been defined in RRBI intervention studies, 2) Who has defined them, and 3) What the evidence is of the effectiveness of RRBI interventions in studies that have defined and measured broader outcomes (i.e. beyond the reduction of RRBIs).

1) How outcomes have been defined

Several reviews of RRBI interventions have discussed their effectiveness in reducing behaviours. In some cases, such as when a behaviour causes harm, behaviour reduction can lead to an immediate desirable outcome (the prevention of harm). However, as discussed, reduction in RRBIs might not necessarily lead to broader outcomes that are meaningful for autistic CYP. It is unknown to what extent RRBI interventions have been evaluated beyond a measurement of reduction in behaviours. The SSR, therefore, aimed to describe the literature in terms of how outcomes have been defined.

2) CYP, parent/caregiver, teacher views on RRBIs

There is a need to consider the perspective of autistic individuals to understand behaviour that is atypical. Chapter 1 also discussed this in broader terms with regard to autism research and the need to involve stakeholders in the research process. Therefore, the SSR aimed to describe who has defined outcomes in RRBI intervention studies. The SSR specifically considered whether the perspectives of parents/caregivers, or teachers have been included in the definition of outcomes, as they are significant stakeholders for autistic CYP.

3) Effectiveness of interventions with regard to broader outcomes

Having described how broader outcomes are defined, the SSR aimed to synthesise the findings of those studies that have evaluated broader outcomes.

The aim was to examine whether reducing RRBIs in those studies also led to broader outcomes for CYP.

Changes in the last decade

Although there were no date restrictions for the overall SSR, the SSR also aimed to group studies that have been published in the last decade (2011 – May 2021, when the final searches for the SSR were conducted). The purpose was to examine any changes in how research has been designed more recently.

Research questions

These research questions focus on the research literature as whole (and included any published work by EPs) and, therefore, do not specifically reference EP work.

RQ1: How have outcomes in restricted and repetitive interests and behaviours and interests (RRBI) interventions been defined?
- What proportion of intervention studies have sought solely to reduce RRBIs and what proportion have defined broader outcomes?
- In those latter studies, how have broader outcomes been defined?

RQ2: Have the views of the children and young people (CYP), parents/caregivers, or teachers been sought in setting outcomes for RRBI interventions?
- If so, what are their views? Are they aligned with each other?

RQ3: Have RRBI interventions been effective in achieving outcomes beyond a reduction in the target RRBI?
- If so, which interventions have been used and how are the outcomes defined?

2.3. Method

Theoretical perspective

The SSR aims to contribute to understanding the design of the research literature in the context of evidence-based practice (EBP) with regard to RRBIs and is underpinned by a particular theoretical perspective on EBP. While RRBIs are a component of a medical diagnosis of ASD, the outcomes that are defined regarding these behaviours do not automatically follow from the diagnosis. This is in contrast to a 'medical' EBP approach – from which the drive for EBP originated – which is based on a notion of practice in which practice follows from a correct diagnosis of a condition (Eraut, 2004). The perspective on EBP taken in this thesis is that while EBP is important to certain aspects of education it can become reductionist if applied to educational practice as a whole (Biesta, 2010; Kvernbekk, 2016). The EBP approach can inform practice with regard to specific, well-defined aspects of instruction, such as reading instruction and the use of specific instructional strategies (e.g. providing feedback). However, educational practice is a complex system within which a range of actors interact with a range of values and norms. This system is open, with actors and norms from 'outside' impacting on interventions and actions within any educational setting (Kvernbekk, 2016). These values and norms are reflected in the development and evaluation of interventions and understanding them are an integral part of understanding the evidence base. Therefore, the SSR aims to describe this wider framework within which RRBI interventions are studied.

Further, the SSR focuses on understanding how stakeholders are involved in defining outcomes. This is underpinned by a perspective that understanding how individuals make sense of the world, in alignment with a social constructionist approach (Robson & McCartan, 2019), forms an important part of developing educational practice that is relevant and valuable to those it impacts (Biesta, 2007). There is a danger when stakeholders are excluded from setting educational outcomes that the outcomes do not serve their interests.

Research design and methodology

Research questions 1 – 3 focus on understanding the evidence base of RRBI interventions in terms of a) their design (RQ 1 & 2) and b) their outcomes (RQ 3). In order to address these questions, it is necessary to adopt procedures that will identify, appraise and synthesise all relevant research evidence. Therefore, a systematic search process is most appropriate. This thesis primarily focuses on describing the literature in terms of the design of interventions rather than aiming to synthesise and evaluate their effectiveness, which is the aim of a SR (systematic review). RQ3 does address effectiveness, but whether and how this would be feasible was not known at the start of the review process. Therefore, the thesis is best described as a SSR (systematic *scoping* review).

SSRs differ from SRs in that their aim is to map out and clarify key concepts within an area of research rather than focussing on effectiveness of interventions (Munn et al., 2018). They can be particularly useful when there is emerging evidence, and in order to examine the way research has been conducted (M. Peters et al., 2015). The synthesis of research evidence is not typically undertaken in an SSR. SSRs can also identify aspects of a topic on which not enough is known and thus help shape future research (Davies, 2004; M. Peters et al., 2015).

Systematic approaches to reviewing the literature involve a specific process that aims to minimise bias by ensuring that all relevant research evidence is identified, appraised and synthesised (Petticrew & Roberts, 2006). This is the same for SSRs and SRs but has been discussed in the literature with reference to SRs. Traditional literature reviews do not usually search the literature in a systematic way and may be based on a small number of studies that are selected by the author (Uman, 2011). Further, the use of "explicit, accountable rigorous research methods" (Gough et al., 2017, p.5) in SRs enables the process to be reproduced and minimises risk of bias. SRs had an initial focus on the evaluation of treatments/interventions through Randomised Control Trials and became defined by the rules set out by the Cochrane collaboration

(Robson & McCartan, 2019). However, SRs have since been expanded to cover other areas of research and alternative study designs (Davies, 2004; Higgins & Wells, 2011), as well as answering more complex research questions in areas such as social science (Pawson, 2006). The methods involved in scoping reviews have received less attention (Arksey & O'Malley, 2005). However, the searching process used in SSRs is identical to that of SRs (M. Peters et al., 2015).

Given the likely variation in study design and the broad scope of the SSR, the process recommended by Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) (Moher et al., 2009) was followed. This allows for a range of study designs. Existing SRs indicated that educational RRBI interventions were likely to include primarily single case design studies for educational and developmental interventions (Harrop et al., 2019; Lanovaz et al., 2013; Leekam et al., 2011; Ninci et al., 2020; Patterson et al., 2010) and Randomised Control Trials for behavioural and pharmacological interventions (Boyd et al., 2012; Leekam et al., 2011; Yu et al., 2020). Moreover, RQ2 is concerned with stakeholder views, which was likely to involve qualitative or mixed method study designs.

SSRs are usually conducted by teams of researchers, both because the process is time-consuming and in order to minimise bias (M. Peters et al., 2015). This SSR was undertaken as part of doctoral research but did involve second coders to ensure rigour in the analysis.

Review protocol

The review protocol was prospectively registered with the PROSPERO database (https://www.crd.york.ac.uk/prospero/) developed by the Centre for Research and Dissemination at the University of York (www.york.ac.uk/inst/crd). The protocol, as defined before the review was undertaken, is included in Appendix A.1. Any changes to this, as well as elaboration on the process, is made explicit in the following sections.

Sources

The search was restricted to publications written in English. Conference abstracts were excluded, as there would be insufficient detail on study design. Master's theses were excluded due to their limited scope, unless they were subsequently published in a peer-reviewed journal. There were no date restrictions.

<u>Databases</u>

A range of databases were searched that covered peer-reviewed and grey literature in the areas of education, social sciences, and health sciences. The databases were selected based on existing SRs. Further, EThOS, OpenDOAR and OpenGrey were searched for additional grey literature. Searching grey literature can help minimise publication bias, as negative results tend not to be published. Google Scholar was searched for any unindexed publications.

The following databases were searched: *PubMed, MEDLINE (Ovid version - including In-Process and Other Non-Indexed Citations), CINAHL, EMBASE, CENTRAL (Cochrane Central Register of Controlled Trials), AMED (Allied and Complementary Medicine), PsycINFO, PsycARTICLES Full Text, PsycEXTRA, Child Development & Adolescent Studies, ERIC, Web of Science (Core collection, BIOSIS Previews), Scopus, ProQuest Central (includes psychology and education), ProQuest Dissertations and Theses Full Text, EThOS.; OpenDOAR, OpenGrey, Google Scholar.*

<u>Handsearching</u>

The following journals were searched. These were selected because of their specific focus on autism research: *Journal of Autism and Developmental Disorders, Autism, Research in Autism Spectrum Disorders, Autism Research, Journal of Developmental Disabilities, Focus on Autism and Other Developmental Disabilities.*

Search strategy

The search strategy was developed from three concepts: 1) Autism Spectrum Disorder, 2) Restricted and Repetitive Behaviours and Interests, and 3) interventions. The search terms used were developed from key concepts and existing SRs and refined based on initial scoping searches. The main search terms for each concept included:

> 1) Asperger, autism, kanner, "pervasive developmental disorder", "semantic-pragmatic disorder"
>
> 2) "special interest", "circumscribed interest", "restricted interest", "restricted activities", "focused interest", "intense interest", "object preoccupation", "pattern of interest", "preferred interest", "preferred object", "perseverative interest", RRBIs, "repetitive behaviour", "repetitive pattern", "restricted pattern", "repetitive movement", stereotypy, "motor behaviour", "sensorimotor behaviour", "stereotyped behaviour", "stereotyped movement", "self-stimulation", "ritualistic behaviour", "compulsive behaviour", "obsessive behaviour", "self-restricted behaviour", "repetitive use", "insistence on sameness", "repetitive speech", echolalia, monotropism , rocking, "hand flapping", stimming, resistance to change
>
> 3) treatment, intervention, therapy, modification, reinforcement, clinical trial

These were expanded to cover possible variations, and subsequently translated to truncated keywords. For example, 'autism' and 'autistic' could be combined into 'autis*'. The full search strategy is included in Appendix 2.

The search terms were restricted to RRBIs, rather than including broader concepts such as 'challenging behaviour' and 'aberrant behaviour'. Even though some studies use these terms to describe RRBIs (e.g. Machalicek et al., 2009), scoping searches indicated that the search results would contain many false positives. There is a balance in any SSR between increasing the breadth of the search to locate all relevant records and reducing the number of false positives that would make the screening process unmanageable. The impact of the choice of search terms on the findings of the SSR is discussed in section 2.5 on study limitations.

The specific search strategy for each database was built based on database guides and, where available, included MeSH (Medical Subject Headings) terms

and other, database-specific, controlled vocabulary. Certain types of resources that fell outside the inclusion criteria were excluded using filters if these were available for each database. This included publications not written in English, SRs and meta-analyses, animal studies, and any news items, textbooks, or other teaching resources. The exact search strategy used for each database is detailed in Appendix A.2, in line with the PRISMA-S guidance on reporting literature searches (Rethlefsen et al., 2021).

Inclusion/Exclusion criteria

<u>Participants</u>

- A diagnosis of ASD, based on a validated ASD diagnostic tool
- Restricted, repetitive patterns of behaviour, interests or activities, as identified by a diagnostic tool, interviews with parents/participants or researcher observations
- Between 0 - 24 years, to include children and young people (based on the World Health Organisation's definition of young people: 10 - 24 years)
- All genders

<u>Interventions</u>

Interventions were included that target RRBIs either in isolation or within a broader intervention that targets ASD symptomatology. This included behavioural, developmental, educational or pharmacological interventions.

<u>Study design</u>

There were no restrictions on the types of study design eligible for inclusion. Both quantitative and qualitative studies were included.

<u>Screening</u>

Studies were screened according to the following criteria:

- include at least one participant, between the ages of 0 and 24, with an ASD diagnosis,
- evaluate an intervention that targets at least one behaviour that is defined in the study as an RRBI (as identified by a diagnostic tool, interviews with parents/participants or researcher observations) OR evaluate an intervention that targets RRBIs as part of broader interventions on ASD symptomatology,
- includes an outcome measure that relates to at least one behaviour that is defined in the study as an RRBI OR includes an outcome measure that incorporates RRBIs (for example, broader measures on ASD symptomatology).

'Self-injurious' behaviour is not included in the diagnostic criterion of RRBIs and, therefore, was excluded. There may be some ambiguity in the definition of behaviour as repetitive or self-injurious. For example, hand biting may be defined as repetitive behaviour if the skin is not broken, but self-injurious if it is. The authors' definition of behaviour was accepted. The impact of this in terms of the findings of this review are discussed in section 2.5 on study limitations.

A diagnosis of ASD was accepted based on the criteria that were current at the time of the study. The following syndromes were excluded, unless a diagnosis of ASD was also reported: Fragile X, Rett syndrome, Prader Willi syndrome, Phelan McDermid syndrome, Rubinstein-Taybi syndrome, Downs syndrome.

Master's theses and conference abstracts were excluded. If a master's thesis resulted in publication, this was included. If doctoral dissertations were also published, only the published record was included. If multiple articles reported on the same study (focussing, for example, in more depth on different outcomes), only the record that provided the greatest amount of detail on RRBIs was included. If only a subset of participants or studies (published in the same record) met the inclusion criteria, only those that did were included in the review.

Elaboration on the application of inclusion/exclusion criteria during screening

Following the screening of the full text, the inclusion/exclusion criteria were further clarified from the initial definition in the study protocol:

- A significant number of research articles did not report the diagnostic tool that was used to confirm an ASD diagnosis, particularly in the Applied Behaviour Analysis literature. Therefore, studies were included as long as it was clearly stated that the participant had a diagnosis of ASD, even when the process of diagnosis was not reported. However, studies that defined CYP's behaviour as 'autistic-like' but did not confirm diagnosis were excluded (e.g. Tomporowski, 1983).

- Studies that did not explicitly target RRBIs for intervention were excluded. Studies that explored associations or measured 'collateral' effects on behaviour were not designed as interventions and, therefore, fell outside the scope of this SSR. For example, this included:
    - Studies that measured repetitive behaviours as side-effects of medication but did not target them for intervention (e.g., Groden et al., 1987).
    - Studies that examined how RRBIs varied in association with environmental factors, such as lighting (e.g. Colman et al., 1976).
    - Studies that explored the association between RRBIs and other behaviours (e.g. Boyd et al., 2007).
    - Studies that examined specific aspects of RRBI intervention procedures, such as selection of preferred items (e.g. McDonald et al., 2012), but were not written with a focus on targeting the RRBI.

- Short (a page long) conference papers and letters were excluded. It was decided that there would be insufficient space to fully report the study design, which was the focus of this SSR.

- When not all participants met the inclusion criteria (ASD diagnosis, age between 0 and 24 years, or presence of RRBIs) and it was not possible to separate the results for each participant (e.g. Simpson et al., 1980), the following applied: a) for RQ 1 and 2, these studies were included if the same

study design applied to all participants, b) for RQ3, these studies were excluded as it was not possible to extract findings with regard to the participants who met the inclusion criteria.

Risk of bias assessment

Study quality in SRs is assessed in terms of the measures that have been taken in the design, conduct and analysis of the study to minimise error and bias (Boland et al., 2017). This is important in order to assess the trustworthiness, validity and reliability of the findings when synthesising the literature. There exist a number of quality assessment tools, for different study designs, to assist reviewers in assessing quality (Boland et al., 2017; Gough et al., 2017). Based on existing SRs and an initial scoping review, it was anticipated that the present SSR would include primarily single case designs and randomised control trials with regard to evaluating RRBI interventions, but also qualitative and mixed method study designs with regard to researching stakeholder views on RRBIs. Therefore, the Mixed Methods Appraisal Tool (Hong et al., 2018) was selected to assess risk of bias. This tool can appraise five categories of study designs (a) qualitative, (b) randomised controlled trial, (c) non-randomised, (d) quantitative descriptive and (e) mixed methods studies. Five criteria are used for each type of design. For example, for qualitative studies this includes the appropriateness of the study approach to the research question, the adequacy of the data collection methods, how the findings have been derived from the data, the substantiation of the results in the data, and the coherence of the data sources, collection, analysis and interpretation.

At the start of the SSR it was unclear whether it would be possible to synthesise intervention studies for RQ3 and, therefore, whether studies would need to be included based on quality. Given the variability in how broader outcomes have been defined, a synthesis was not possible. Therefore, study quality was only assessed in order to describe the included studies.

Data extraction

The specific data that was extracted for each research question is discussed in the following sections. This included:

- participant information (number of participants, age, diagnostic category and how diagnosis was confirmed/verified),
- intervention outcomes (primary outcomes, secondary outcomes),
- who participated in defining the outcomes (researcher, child/young person, parent, teacher, other),
- study design,
- intervention design (intervention delivery, whether part of broader intervention approach, procedure),
- outcome measures (definition, measurement),
- results (changes in each outcome variable, maintenance of change over time).
- publication date

Data recording

All results were imported into EndNote for the screening process and the review of full text for eligibility. The suitability of EndNote's functionality has been described in the context of conducting SRs (M. Peters, 2017). Data from included studies was extracted into an Excel spreadsheet. The content analysis (which is discussed later in this section) was carried out in Excel.

Search dates

Database searches were completed on 29 and 30 July 2020. Database alerts were set at this time and reviewed in May 2021. Additional grey literature searches were completed on 1 January 2021, and updated in May 2021. Handsearching included volumes up to and including May 2021. Google Scholar was search for unindexed publications in May 2021.

Second coding

The broad scope of this SSR and the fact that it was carried out as doctoral research meant that there were limited resources for a second researcher to screen and code the records. Therefore, a percentage of results were randomly selected, a process also adopted in Harrop (2015). Part of the initial screening was done by a trainee EP. The remainder of the initial screening and all other coding was done by a doctoral researcher whose research also focused on ASD.

Table 1 summarises the second coding process at the different stages of the SSR. During the initial screening, 20% of results were coded. The second coders were blinded to the first coder's decisions. Typically, in a SR at least two researchers screen the title/abstract and the results are compared before retrieving the full text. The process is then repeated once all records have been retrieved. However, the large number of records included in RQ1 and RQ2 and the limited resources for second coding meant that this was not feasible. Therefore, the screening phase involved looking at the titles and abstracts, but also accessing the full text when a decision could not be made based on the abstract alone. Disagreements were resolved through discussion[1].

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[1] During the screening stage, for one paper, which reported on trichotillomania (Ghaziuddin et al., 1991), the researcher's supervisors were consulted on whether to include a behaviour as an RRBI. The authors had defined it as self-injurious behaviour in the Methods section but as an RRBI elsewhere. A decision was made based on definition of behaviour that was stated in the Methods section and, therefore, the study was excluded.

Table 1

Systematic Scoping Review Second Coding Process

SSR stage	% of records that were second coded	% agreement before discussion	Whether blinded to first coder's decisions
Screening	20%	96%	Yes
Full text eligibility	20%	100%	No
RQ1 content analysis	10%	90%	Yes
RQ2 content analysis	10%	96%	Yes
RQ3 data extraction & quality assessment	20%	100%	Yes

The next stage, which involved retrieving the full text for all records and applying the inclusion criteria to these, was done by the first coder. At the end of this process, the second coder checked 20% of *excluded* studies that required a judgement (i.e. not those excluded as duplicate records, short papers, or master theses). The second coder was, therefore, not blinded to the first coder's decision. There were no disagreements at this stage.

During the content analysis for RQ1 and 2, 10% of records were initially second coded. The second coder was blinded to the first coder's decisions. The first coder had coded all papers three times during the development and application of the content analysis frameworks for RQ1 and 2, adding to the consistency of the analysis. Had there been a low level of agreement further checks would have been made. However, this was not warranted as agreement was high. During the content analysis for RQ1, all disagreement resulted from the second coder applying the criteria more strictly.

A subset of papers was included in RQ3, and data extraction and quality assessment of 20% of these were second coded. The second coder was

blinded to the first coder's decisions. There were no disagreements at this stage.

Strategy for data synthesis

<u>Research question 1: How have outcomes in RRBI interventions been defined?</u>
Content analysis was used to analyse how outcomes have been defined. The findings were further grouped by date, to establish changes in the past decade. Robson and McCartan (2019) describe content analysis as akin to structured observation, which requires a clear research question to guide the process. The development of the framework for carrying out the content analysis is described in the following section.

<u>Research question 2: Have the views of the CYP, parents/caregivers, or teachers been sought in setting outcomes for RRBI interventions?</u>
Studies were categorised based on whether outcomes have been defined with contribution from CYP, parent/caregiver, teachers. For studies that had sought such views, the intention was to analyse them using thematic analysis. The alignment between stakeholder views was also going to be analysed. However, there was not enough information to warrant the use of thematic analysis. Therefore, content analysis was also used for RQ2. The development of the framework for carrying out the content analysis is described in the following section.

<u>Research question 3: Have RRBI interventions been effective in achieving outcomes beyond a reduction in the target RRBIs?</u>
Only studies that had found a reduction in RRBIs and had also measured one or more corresponding outcomes were included (the meaning of this is explained further in the discussion of the content analysis framework for RQ1). Based on a scoping review, a range of metrics for non-RRBI outcomes and study designs was anticipated. Vote counting based on directional effect (i.e. counting an effect irrespective of statistical significance) was, therefore, the planned method for synthesis. However, the heterogeneity of the studies in

terms of types of outcomes, coupled with lack of clarity with regard to whether and how the RRBI was expected to impact on the broader outcomes, meant that the included studies could not be synthesised meaningfully with a vote counting method. Therefore, the studies were broadly grouped based on the type of outcome (learning, social, etc) and a subset of them was described.

Development of content analysis frameworks (RQ1 & 2)

<u>Framework for RQ1</u>

As discussed in section 2.1, the premise of this research is that a reduction in RRBIs cannot be assumed to lead to broader outcomes and, therefore, the broader outcome for the CYP that is expected to result from intervention needs to be empirically evaluated. The purpose, therefore, of this analysis was to describe whether and how the literature has defined broader outcomes for CYP in the context of RRBI interventions. All the included studies were clearly framed as interventions, not studies of association (see section 2.3 for the *Inclusion/Exclusion criteria*).

The content analysis framework was not defined at the start of the SSR but was formulated from an analysis of the literature. Although an initial scoping review had identified a lack of clarity in the definition of outcomes for RRBI interventions, it was unclear how to systematically analyse this. It is noted that an analysis of how outcomes have been defined could not be based solely on a collation of outcome measures, because these may or may not have been linked to the targeted RRBI by the researchers. In other words, a study may have been exploring multiple outcomes without any theoretically or empirically based hypothesis that change in the RRBI would mediate any change in the other outcomes.

The process of developing the analysis framework involved three steps:

Step 1, involved reading all included papers from the database searches in order to gain an overview of the literature. The following data was extracted to an Excel spreadsheet:

- Publication information (authors, date, title, journal)
- Participant information: ASD diagnosis, number of participants, age range, any inclusion/exclusion criteria
- Study design
- Intervention
- Type of RRBI targeted (as defined by the authors)
- RRBI outcome measure(s) and any other outcome measure(s)
- Whether the function of the RRBI was assessed
- A short summary of how RRBIs were framed in the introduction, including whether an empirical/theoretical account was given of RRBIs
- A short summary of whether the RRBIs were described as having a specific impact on the participants' functioning and whether (and if so, how) this was linked by the authors to any outcomes that were measured

This initial process highlighted the following variation in how outcomes are defined:

Reasons for targeting RRBIs. Some studies defined a reason for targeting RRBIs that was specific to the participant(s), some cited reasons from existing literature (for example, that RRBIs can interfere with learning, as discussed in section 2.1), while other studies did not give any reason for intervening. Further, in other papers the reason for intervening was implied in how the behaviours were defined. For example, they measured 'disruptive' behaviours of which stereotypy (a sub-type of RRBI) was one.

Link between reasons for targeting RRBIs and outcome measures. Some studies that defined reasons for targeting RRBIs (either for the study

participants or based on literature) measured corresponding outcomes for at least one of the reasons given. However, many studies stated a reason for intervening but did not measure a corresponding outcome. For example, they stated that the RRBI interfered with socialisation but did not include a measure of socialisation as an outcome for the evaluation of the intervention. Many studies measured multiple outcomes (other than RRBIs) but did not explicitly report that the RRBIs were thought to potentially mediate changes in these outcomes. Further, other studies measured non-RRBI outcomes as a measure of the 'educational value' of the intervention but without reference to the specific needs of the participants. In other words, they did not explicitly report this non-RRBI outcome as a reason for intervening for the study participants.

RRBIs as interfering or lack of skill. Some interventions directly targeted RRBIs to reduce them whereas others aimed to increase another behaviour (or both). So, for example, if a participant engaged in object stereotypy instead of variably playing with toys, then some studies tried to reduce object stereotypy whereas others tried to increase non-stereotypic engagement with objects, or both. The underlying difference is important, because stereotypy is either seen as an interfering behaviour that needs to be reduced before other types of engagement can develop, or a consequence of a lack of skill (whereby increasing the skill will result in reduction of stereotypy without it being directly targeted).

Targeting RRBI or using them to motivate. Some interventions targeted RRBIs for intervention and others used RRBIs to motivate engagement in other activities.

Whether RRBIs are a primary or secondary measure. It was not clearly reported across the literature whether the RRBI was targeted as a primary or secondary outcome. Drug trials mostly made this explicit, but in many papers that measured multiple outcomes it was not explicitly stated. Therefore, this information could not be reliably extracted.

<u>Where information is reported</u>**.** The initial analysis also highlighted the need to be specific in the analysis framework about where the information would be located. In most papers the information on outcomes and reasons for intervening for the participant(s) was located in the Methods section, with the exception of case reports that do not tend to follow this reporting structure. However, a few papers anecdotally discussed the impact of RRBI reduction on classroom behaviour in the Discussion but did not report a measure of it in the Methods section.

<u>Implicit approaches</u>**.** A further issue was that some authors who publish in journals that are associated with specific approaches, such as Applied Behaviour Analysis, may report their research within a framework that is implicit in the overarching approach or the specific journal, but is not made explicit to the reader. For example, they may frame their research by citing other papers but not explicitly discuss the reasoning behind the design. It is noted that the SSR can only describe what is explicitly reported by the authors, as discussed in section 2.5.

Step 2, involved formulating the categories for the analysis framework. The challenge was to simplify the complexity in a meaningful way to address the research question. The simplification inherent in synthesising studies in a SSR can be a limitation of this methodology (as discussed in section 2.5). Synthesising the different approaches and designs, as well as the explicit (and implicit) frameworks in the conceptualisation of RRBIs within different areas of study, was a significantly complex task.

As discussed above, the initial analysis (in Step 1) identified that the reasons for which RRBIs were targeted for intervention were not often communicated clearly in relation to the needs of the participant(s). Defining a reason for targeting participants' RRBIs is an essential aspect of defining a broader outcome for the intervention. If the end point of an intervention is not just to

reduce RRBIs but to achieve a broader outcome (such as increased engagement in learning) then there has to be a reason why the RRBI is targeted to achieve this broader outcome. Note that this SSR only included studies that are framed as evaluations of the effectiveness of *interventions*, not studies whose stated aim is to explore possible relationships between RRBIs and other variables.

Based on the findings from Step 1, the following framework was developed. One category included those studies that had defined a reason based on *the specific needs of the study participants*. For example, that the teacher had identified RRBIs as interfering with learning. In the remaining studies, one category included studies that had defined a reason for intervening based on the research literature (citing, for example, studies of RRBI impact discussed in section 2.1 on the negative impact of RRBIs for autistic CYP). The remaining category included those studies that did not report any reason for targeting participants' RRBIs. The reasons for intervening, when specified for the study participants, could then be extracted and summarised.

Not all studies that defined a reason for intervening measured a corresponding outcome that linked to the reason. For example, if the reason for intervening was that the RRBI interfered with academic engagement, the impact of the intervention on academic engagement was not necessarily measured. Therefore, whether a corresponding outcome was measured or not was included as a category in the analysis framework.

Evidence from the research literature that RRBI reduction is linked to a broader outcome, such as increased academic engagement, is a questionable basis for intervention because the impact of RRBIs is not the same across all autistic CYP (as discussed in section 2.1). However, it was informative to separate the studies that based their design on the research literature from those that did not make any theoretically or empirically based link between reduction in RRBIs and positive changes in the non-RRBI outcomes that they may have measured.

A final distinction was made between the studies that targeted RRBIs in order to reduce them and those that used RRBIs to motivate engagement in other activities. The latter did not target changes to RRBIs, but it was informative to describe the types of outcomes that have been targeted through the motivational value of RRBIs.

In summary, the analysis framework was designed to:

- Separate the papers that (1) aimed to reduce RRBIs from (2) those that used RRBIs to motivate engagement.
- For (1) – also summarised in Figure 2
  - (a) whether one or more reasons were given for targeting the RRBI *for the study participant(s),* and, if so, (b) what the reason was and (c) whether a corresponding outcome was measured.
  - If a reason for targeting the RRBI is not given OR a reason is given but no corresponding outcome is measured, then (d) whether other outcomes were measured and, if so, (e) what were these outcomes, and (f) whether the authors reasoned that these outcomes were potentially linked to a reduction in RRBIs based on research with autistic CYP.
- For (2) what where the other outcomes that the motivating value of the RRBI was used to achieve

Figure 2

Content Analysis Framework Summary for RQ1
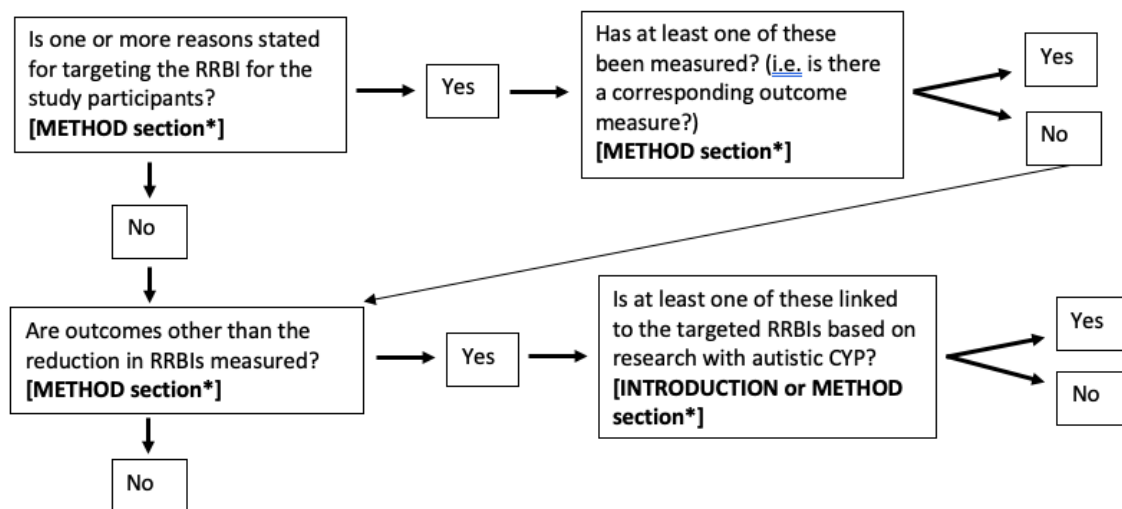
*Unless a case report

Both the reasons for which an RRBI was targeted and the outcome measures were only coded if they were defined in the Methods section and formally measured, unless the record was a case report that did not have this structure.

Step 3, defined codes for categorising *(a)* the type of reason given for intervening, *(b)* whether a corresponding outcome was measured, and *(c)* the type of non-RRBI outcome that was measured.

The 200 papers that had been identified in Step 1 as defining a reason for targeting RRBIs, linking RRBIs and other outcomes based on literature, or using RRBIs to motivate engagement in other activities, were reviewed again. Data was extracted in free text relating to the reasons given for targeting the RRBIs *(point 'a' above)*, whether and how the outcome corresponded to the reason for intervening *(point 'b' above)*, and outcomes measured *(point 'c' above)*. A short textual entry sufficed to summarise this information. Multiple reasons for intervening could be coded for each record. For example, if multiple reasons for intervening were given for one participant or if a study included multiple participants with different reasons for intervening. For studies that used RRBIs

to motivate engagement in other activities it was only relevant to extract the type of non-RRBI outcome that was measured.

The codes for 'a' and 'c' are defined in Tables 2 and 4. The codes for 'b' (in Table 3) are defined below.

Yes. This was defined loosely, as long as the reason for intervening and outcome measure related to the same area of development or functioning, for example, learning, social interaction, or daily activities.

No. No corresponding outcome is measured. This included those interventions that reinforced an alternative response as part of the intervention procedure but this was not specified as the reason for intervening for a participant. For example, certain behaviourist interventions concurrently block an RRBI and reinforce an alternative response (such as Response Interruption and Redirection). The alternative response may be 'appropriate vocalisations' whereas the reason for intervening may be that vocal stereotypy is disruptive in the classroom. In these studies, the outcome that is measured does not correspond to the reason given for intervening.

No, but the outcome is the same as reduction. The reason given for targeting the RRBI informs the intended (if not, measured) broader outcomes of the intervention. However, some reasons might not necessarily warrant an outcome measure. For example, if an RRBI results in a) harm to self or others, or property destruction, b) there are strong reasons for a behaviour to be considered socially inappropriate, such as inappropriate sexual behaviour, or c) a behaviour seen as a symptom of anxiety and, therefore, is targeted as an indication of changes in underlying anxiety. In these studies, it could be argued that the reason for intervening does not require confirmation from an outcome measure but is evidenced by a reduction in the behaviour. In the case of anxiety, the RRBI would in essence be a measure of anxiety.

Table 2.

Codes for Reasons for Intervening (RQ1)

Reasons for intervening

1. No detail for individual participants
    - It is stated that a reason was identified for each participant but no detail is reported for individual participants because, for example, it is a group study
2. General interference
    - A general statement is made, such as "in all areas" or it is stated that there was a negative impact but no detail is given about what this impact was
3. Interferes with learning or vocational work
    - Any aspect of structured learning: academic goals, school day, skill acquisition, participation in educational activities, group activities, on-task, appropriate play, responding to instruction, etc
4. Interferes with social interaction
    - engaging socially with others, being isolated, communication, use of communication device, etc
5. Interferes with daily activities or routines
    - life skills, daily functioning, etc
6. Interferes with leisure time
    - Outside structured learning settings, e.g. free play, choice of activity
7. Causes distress or anxiety to CYP for any reason
    - For example, distress when interrupted, distress from changes in routines, etc.
8. Disruptive to others
    - in class, community, public settings, etc
9. Is socially inappropriate behaviour
    - code ONLY for: sexual behaviour, touching others or behaviour that impacts on hygiene. DO NOT code if the behaviour is labelled inappropriate but is not described.
10. Stigma
    - General statement of perceived stigma, described as unwanted behaviour, looks different, teased by peers, called names, described as inappropriate, etc
11. Harmful to self, harmful to others, dangerous, causes property destruction
12. Impact on inclusion
    - in classroom or school
13. Indication of anxiety
    - When RRBIs are targeted as a measure of anxiety

Table 3

Codes for Corresponding Measures (RQ1)

For each reason given for intervening, whether there was a corresponding outcome measure
• Yes
• No
• No, but the outcome is the same as reduction (ONLY for codes: 9 or 11 or 13 in Table 2)

Table 4

Codes for non-RRBI Outcome Measures (RQ1)

Non-RRBI Outcomes Measured
1. Appropriate play
o For example, play with toys in a way that matches their design
2. Appropriate vocalisations
o For example, responding to questions
3. Elements of social interaction
o For example, initiation, turn-taking
4. Engagement in learning
o For example, task performance, completion, engagement
5. Cognitive flexibility
o As measured by specific tests
6. Affect
o With reference to CYP's response to intervention, for example, whether they were distressed or appeared happy
7. Challenging / problem behaviours
o For example, aggressive behaviour
8. Sleep
9. Motor skill development
10. RRBIs
o In the context of using intense interests to motivate engagement in other activities, measuring impact on RRBIs such as stereotypy or repetitive object manipulation

Framework for RQ2

RQ2 focused on the involvement of CYP and stakeholders in the design of the
intervention through their views on the RRBIs that are being targeted. This goes
beyond being involved in identifying or defining behaviour for a participant. It is
also different to collecting data on stakeholder views *after* the implementation of
the intervention, such as including measures of 'social validity' (McNeill, 2019).

Initially, it was unclear how stakeholder views on RRBIs might be collected or reported. Therefore, all included papers from the database searches were read and information was extracted in free text on whether CYP, parent/caregiver or teacher views on the RRBIs were reported. This was conducted at the same time as Step 1 in the development of the analysis framework for RQ1.

This initial analysis identified that most studies did not report CYP, parent/caregiver or teacher views. Barriers to accessing views were also not stated. In a few studies CYP had been interviewed about their RRBIs, but details were not reported. In the studies that reported stakeholder views this was brief. It mostly involved a short reference to parent/caregiver or teacher views on the negative impact of RRBIs, as a reason for targeting them for intervention. Therefore, to capture this variation, the analysis framework included three codes (Table 5). As with RQ1, the information had to be stated in the Methods section, that is as part of the study design, rather than retrospectively discussed in the Discussion.

Table 5

Codes for categorising stakeholder views (RQ2)

Codes for categorising stakeholder views
• Collaborative definition of outcomes regarding RRBIs
o When stakeholders were involved in defining the focus of the intervention
• Some positive impact stated OR stated as no negative impact
o When stakeholders reported some positive impact of RRBIs or no negative impact, even if they also reported some negative impact
• Short statement of negative impact
o A short statement on the negative impact of the RRBI with no reported positive or neutral impact

Interventions that were implemented by parents/caregivers were not coded as reporting their views simply because they were participating in the delivery of the intervention, but only when parent/caregiver views were explicitly reported. When parents/caregivers were collaboratively involved in setting outcomes, this was coded even if the outcomes that were identified in this way did not include

RRBIs. In other words, the study measured RRBIs (and was therefore included in the SSR), but this was not the result of collaboration with parents/caregivers.

In some papers, a 'functional assessment' was carried out (to assess the function of the behaviour), using specific questionnaires or interviews. When it was reported that either parents/caregivers or teachers were involved in carrying out a functional assessment this was not coded as collaboration or them expressing their views, unless specific views were explicitly reported. However, when parents/caregivers or teachers rated the 'severity' of the behaviour through standard measures as a reason for intervention, this was coded as the study reporting a parental or teacher view of negative impact.

Views about RRBIs were also not coded if it was unclear who was expressing the view. For example, the reason for intervening was often expressed in a passive voice (e.g. "Stereotypy impacted on…." or "the child was referred to the clinic because…"). Further, therapist views (for example, ABA therapists or hospital staff) were not coded, as they would most likely be involved in the intervention, and the focus of this SSR was on the collaborative involvement of other stakeholders. The implications of this in terms of the study limitations are examined in the discussion.

Trustworthiness, credibility and transferability

SSRs are typically carried out by teams of researchers, partly in order to minimise bias (Robson & McCartan, 2019). Although it was not feasible for the present review process to be carried out independently by a second researcher, a random selection of studies was second coded by another doctoral student. The results of this process are reported in Table 1.

The quality of SRs depends on the quality of the studies that are included. A SSR does not usually exclude studies. However, it can be useful to describe study quality. This is assessed through tools that explore the risk of bias related to study design (MacMillan et al., 2019). RQ1 was concerned with the design of

RRBI interventions rather than their effectiveness. The number of studies included in this part of the review was large (over 500 records) and, therefore, assessment of study quality was not feasible. An indication of the study quality of the research literature would be desirable but is not essential to addressing RQ1 which focuses on how outcomes are defined. For RQ2, it was anticipated that study quality on exploring stakeholder views would be assessed. However, the amount of data on stakeholder views was minimal and the methods of collecting it were rarely reported. Therefore, an assessment of study quality in terms of how these views was collected was not possible either. Study quality was, however, assessed for RQ3.

The inclusion criteria of SSRs are factors that will influence the conclusion. This may also be influenced by the professional experience of those undertaking the review (Gough et al., 2017). As discussed in Chapter 1, this thesis was carried out as part of doctoral training in Educational Psychology. The researcher's perspective on RRBI intervention was that it should be centred on outcomes that are meaningful to autistic CYP and their families and should involve them in a collaborative process. The researcher's perspective aligns with a neurodiversity model, which emphasises societal acceptance but also understanding of need as child-context interaction. Every effort was made to make explicit the context in which this research was carried out and the perspectives that underlie it. Further, the process of the SSR has been made explicit in order to allow it to be replicated. A PRISMA diagram (Moher et al., 2009) is used to show how the references found in the searches have been accounted for (Appendix A.3).

The introduction discussed the need to include the voice of CYP, parents/caregivers and teachers in setting outcomes for RRBI interventions. It would have been desirable to involve these stakeholders in the SSR process, but this was not feasible given the scope of the doctoral thesis and the communicative challenges in such a process (Rees & Oliver, 2017). However,

the results of the review may contribute to the discourse about the involvement of stakeholders in how RRBI interventions are designed.

Systematic approaches to reviewing the literature are not without critics. This process of reviewing the research literature, or perhaps its central role in current evidence-based approaches to shaping education policy (Oakley, 2003), have been criticised for reducing a wealth of literature on complex issues to a handful of studies (MacLure, 2005).Therefore, clarity has been provided as to the purpose of the present SSR and how it aims to contribute to a broader context of practice (as also examined in the discussion of the perspective on evidence based practice that underlies this research).

Ethical issues

The ethical approval for the work described in this chapter is included in Appendix A.4. No significant ethical issues were identified. It is possible that some individuals, particularly autistic CYP or adults and their caregivers, may be affected by the questions asked in this research. Therefore, the findings need to be disseminated with a clear acknowledgement that there is an ongoing discussion around neurodiversity and how best to support autistic CYP.

2.4. Findings

A detailed PRISMA diagram for reporting the results of a SSR is included in Appendix A.3. Figure 3 shows a summary diagram. In total, 564 studies were included. Of these, 523 were found through database searches, 25 through handsearching journals, 5 from trial registries (the study protocol was found through databases), 10 through database alerts (subsequent to the searches) and 1 from Google Scholar.

Figure 3

Search Results (summary PRISMA diagram)
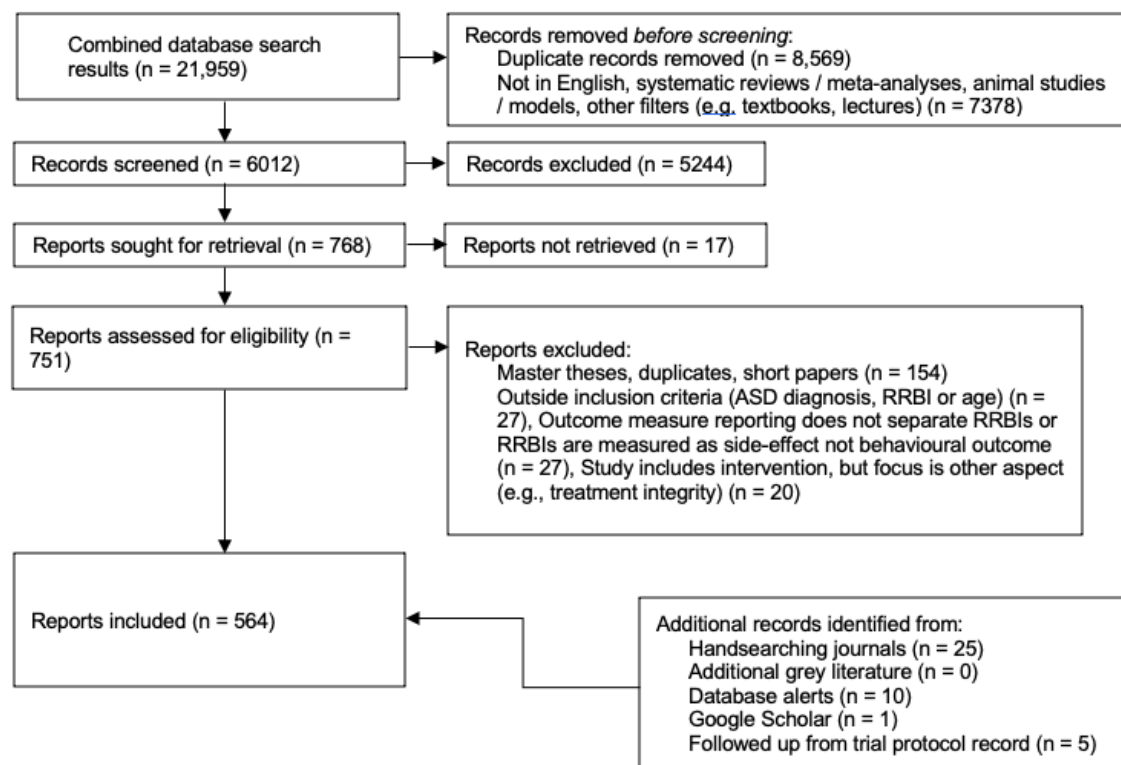
The way the content analysis was carried out for RQ1 and RQ2 is illustrated in Appendix A.5 which includes a screenshot of the excel coding sheet that was used.

RQ 1: Outcome definition in RRBI interventions

How have outcomes in restricted and repetitive interests and behaviours and interests (RRBI) interventions been defined?

- *What proportion of intervention studies have sought solely to reduce RRBIs and what proportion have defined broader outcomes?*
- *In those latter studies, how have broader outcomes been defined?*

A summary of the content analysis findings is shown in Table 6. The total number of included studies was 564, of which 29 used RRBIs to motivate

engagement in other activities, leaving 535 that targeted RRBIs. These two
groups were separated.

Table 6

Summary of RQ1 Findings

Studies included in RQ1	Number (Percentage)	*For 2011 – May 2021*
Whether a reason for intervening was defined		
Total number of studies	564	*313*
Studies that used RRBIs to motivate engagement in other activities	29	*17*
Studies that targeted RRBI for intervention	535	*296*
Of which, studies that stated a reason for intervening for the study participants	136 (25%)	*82 (28%)*
Whether a corresponding outcome was measured		
Total number of studies that stated reasons for intervening for which an outcome measure was warranted [i.e. excluding those that ONLY defined reasons within categories 9 (harm / property destruction), 11 (socially inappropriate behaviour) and 13 (RRBI is measure of anxiety) in Table 2 (n = 13 overall, and n = 8 between 2011 – May 2021)]	123	74
Of which,		
studies that included a corresponding outcome measure for at least one of the reasons	53 (43%)	*34 (46%)*
studies that did not include any corresponding outcome measures	70 (57%)	*40 (54%)*
Of which, studies that measured other outcomes that were linked to the RRBI based on research with autistic CYP (but not the reason that they defined for intervening)	14 (20%)	*11 (28%)*
Whether an outcome was measured based on the ASD literature		
Studies that did not state a reason for intervening for the study participants	399 (75%)	*214 (72%)*
Of which, studies that included other outcome measures (other than the targeted RRBIs), which were linked to RRBIs based on research with autistic CYP	78 (20%)	*38 (18%)*

Defining a reason for intervening

The total number of studies that targeted RRBIs for intervention were 535. A quarter of these (n = 136, 25%) defined a reason for intervening for the study participants.

When reasons were defined for intervening, this included a short statement. For example, "Mark's teachers expressed concern that he engaged in stereotypy when directed to select independent leisure activities and therefore could not play appropriately by himself during free time" (Slaton & Hanley, 2016, p.931).

Types of reason for intervening

Table 7 shows the types of reason given for intervening. More than one reason could be given in each study (either multiple for a single participant or different reasons for each participant). Therefore, these figures do not add up to the total number of studies.

The majority (n = 82) were related to structured learning or vocational work. For example, 'interfering with participation in academic activities', 'interfered with her ability to obtain vocational employment', or 'the behaviour made it difficult for teachers to complete academic work with him'.

Table 7

Reasons for Intervening and Corresponding outcomes (RQ1)

Reasons stated for intervening for the study participants	Number stating as reason* (of which a corresponding outcome was measured)
No detail or general interference	
No detail for each participant because it is a group study	3 (3)
General interference ("in all areas" or no detail given)	6 (0)
Reasons where relevant to measure outcomes	
Interferes with learning or vocational work - anything that is structured learning (academic goals, school day, skill acquisition, participation in educational activities, group activities, therapy, on-task, appropriate play, responding to instruction, etc)	82 (29)
Interferes with social interaction (engaging socially with others, being isolated, communication, use of communication device, etc)	29 (5)
Disruptive to others (in class, community, public settings, etc)	20 (0)
Interferes with daily activities or routines (life skills, daily functioning, adaptive behaviour, etc)	14 (6)
Causes distress or anxiety to CYP for any reason (when interrupted, changes in routines, waiting, etc)	13 (11)
Stigma (parents perceive stigma, parent say it's unwanted behaviour, looks different, teased by peers, called names, etc)	11 (0)
Impact on inclusion (in classroom or school)	5 (1)
Interferes with leisure time (e.g. free play, choice of activity)	3 (1)
Reasons where outcome measurement may not be necessary	
Harmful to self, harmful to others, potentially dangerous, aggressive behaviour (or has potential to cause), causes property destruction	16 (n/a)
Is socially inappropriate behaviour (code ONLY for: touching others, sexual behaviour)	6 (n/a)
Indication of anxiety	3 (n/a)

Note: *Multiple reasons could be given within each study, therefore, the numbers will add up to more than the total number of studies

The following are examples of the other types of outcomes:

- No detail for each participant because it is a group study: 'parents identified a problematic RRBI to work on during the group' [in context of group study]

- General interference: 'Results of the Repetitive Behavior Scale–Revised completed by the participant's parent or teacher indicated that these 5 participants had at least moderate problems with restricted or sameness behaviour.' [no further detail although individual results were presented]

- Interferes with social interaction: 'frequently engaged in these behaviours, especially in social settings (e.g., restaurants). Parents were concerned that her stereotypy affected social interactions'

- Disruptive to others: 'the teacher had to continuously prompt the child to stop engaging in this behaviour that was disruptive to her teaching'

- Interferes with daily activities or routines: "interfered with the child's participation in everyday activities or routines"

- Causes distress or anxiety to CYP for any reason: 'participants reliably engaged in problem behaviour (e.g. aggression, screaming) when asked to change specific aspects of their routine'

- Impact on inclusion: 'stereotypy was intrusive to the point of impacting participation in group academics and inclusion in assembly, resulting in removal so as to avoid disturbing other students'

- Interferes with leisure time: 'preventing him from engaging with leisure items or participating in activities in his home and community'

- Stigma: 'Conspicuous stereotypic behaviour reported to be stigmatizing in public places'

- Harmful to self, harmful to others, causes property destruction: 'repetitive behaviour in the form of pulling her eyelashes, eyebrows, and hair'

- Is socially inappropriate behaviour: 'scratching using peers' fingers'

- Indication of anxiety: 'Physical perseveration had clear correlation to child's anxiety'

Measuring a corresponding outcome

Table 6 shows that out of those studies that defined a reason for intervening, less than half measured a corresponding outcome (n = 53, 43%). This excludes the studies in which the reasons for intervening *only* included one of the following: harm or property destruction, inappropriate social behaviour, and measures of RRBIs as an indication of anxiety. As discussed previously, this is because for these categories of behaviour it could be argued that an outcome measure is not warranted to confirm that a change in the RRBI has also addressed the reason for intervening.

Table 7 shows how frequently a corresponding outcome was measured by type of reason for intervening. Reasons related to structured learning or vocational work were measured in 29 studies, distress to CYP was measured in 11 studies, social interaction was measured in 5 studies, daily activities in 6 studies, and impact on school inclusion and leisure time in 1 study, respectively. No studies measured outcomes related to stigma or disruption to others.

Measuring outcomes based on ASD literature

A subset of studies that did not define a reason for intervening for the study participants, or defined a reason but did not measure a corresponding outcome, made a connection between RRBIs and other outcomes based on research with autistic CYP. Table 8 shows the categories of outcomes that were measured in these studies. The majority focus on learning (n = 43) and social interaction (n = 22). Example learning outcomes included performance measures, engagement, and task completion. Example social interaction outcomes included increasing conversational responses, language development and social engagement.

Table 8

Outcome Measures Which Are Linked to ASD Literature (RQ1)

Outcome measures that were linked to research with autistic CYP (but no reason given for intervening OR no measure linked to the reason for intervening)	Number of studies measuring this category of outcome
Engagement in learning (task performance, completion, engagement)	43
Elements of social interaction (initiation, appropriate responses)	22
Appropriate play	15
Appropriate vocalisations	14
Cognitive flexibility	1
Challenging / problem behaviours	1
Sleep	1

Outcomes when RRBIs are used to motivate

Finally, Table 9 shows the types of outcomes in studies that used RRBIs (i.e. intense interests) to motivate engagement in other activities. The majority focus on learning (n = 17) and social interaction (n = 15). Example learning outcomes included on-task behaviour, following directions, and reading comprehension. Example social interaction outcomes included turn-taking and socialisation with peers.

Table 9

Outcome Measures in Studies Using RRBIs to Motivate (RQ1)

Outcome measures that were linked to research with autistic CYP (but no reason given for intervening OR no measure linked to the reason for intervening)	Number of studies measuring this category of outcome
Elements of social interaction (initiation, appropriate responses)	17
Engagement in learning (task performance, completion, engagement)	15
Challenging / problem behaviours	4
RRBIs	4
Affect	2
Motor skill development	1
Appropriate play	1

Results for last decade

The findings for RQ1 that were separated by date do not differ much when the results are restricted to publications from 2011 to May 2021. A similar proportion of studies specify a reason for intervention (28% in the last decade versus 25% overall). A similar proportion of studies that did not specify a reason for intervention measured non-RRBI outcomes that the authors linked to RRBIs based on research with autistic CYP (18% in the last decade versus 20% overall). This suggests that other (non-RRBI) outcomes are measured but still without a clear underlying reasoning about how they might relate to RRBIs. One difference is in the number of studies that use RRBIs to motivate engagement in other activities, which is proportionally larger for the last decade (17 of a total of 313 in the last decade, compared with 29 of a total of 564 overall).

In summary, the findings from the analysis for RQ1 suggested that there is a lack of clarity in the reporting of RRBI interventions with regard to the reasons why RRBIs are targeted. Even when reasons were specified, corresponding outcomes were not necessarily measured. Therefore, the interventions were not evaluated in reference to the reasons for targeting RRBIs. With respect to the types of outcomes that are measured (both when reasons are given for study participants and when outcomes are measured based on ASD literature), most focus on structured learning and vocational work, and to a lesser extent on social interaction. Interventions that use RRBIs to motivate engagement in other activities appear to focus equally on learning and social interaction.

RQ 2: Who has defined RRBI outcomes

Have the views of the children and young people (CYP), parents/caregivers, or teachers been sought in setting outcomes for RRBI interventions?

- *If so, what are their views? Are they aligned with each other?*

The same studies were included in both RQ1 and RQ2. The findings from the content analysis are summarised in Table 10.

Table 10

Summary of RQ2 Findings

	CYP	Parent/caregiver	Teacher	Either CYP, parent/car., or teacher view
Number of studies that reported views on RRBIs	**2**	**64**	**54**	**94**
Collaborative definition of outcomes	0	8	0	-
Some positive or neutral impact stated (with or without some reported negative impact)	1	2	2	-
Short statement of negative impact (with no reported positive or neutral impact)	1	54	52	-

This analysis examined whether the studies reported CYP, parents/caregivers or teachers views on the RRBIs that were targeted for intervention. It should be acknowledged that the participants may not have been living with their parents or attending school. It was not possible to reliably extract this information in order to only include the studies where this was the case. Therefore, this analysis cannot identify the proportion of studies that involved parents/caregivers or teachers out of the number of studies for which this would be relevant. However, the analysis does identify the nature of this involvement in those studies that reported parent/caregiver and teacher views.

The total number of studies that reported either CYP, parent/caregiver or teacher views were 94. Two studies reported CYP views out of all the studies that were reviewed. Of these, one involved CYP in identifying the negative impact (severity) of behaviour and another included report of some positive function. Vause et al. (2017) sought CYP views jointly with their parent views on the impact of compulsive behaviours. Bruhn et al. (2015) interviewed the participant about his behaviour. The participant reported that he was aware that he was engaging in the behaviour, that he tended to engage in it when he was nervous, and that it helped him to feel good and calm down. It is possible that CYP views may not have been accessed in many studies because of barriers in communication. However, there were no reports of such barriers. Thus the number of studies in which there were barriers to accessing CYP views is unclear, as this information was not reported by the authors.

Parent/caregiver views were reported in 64 studies, the majority of which included a short statement of the negative impact (see the examples given in RQ1 of negative impact on learning or other types of outcomes). Two studies reported that parents recognised a positive function for RRBIs in some contexts. For example, that RRBIs were an independent play behaviour. Teachers' views were reported in 54 studies. Similarly, this involved short statements of negative impact. A small number of studies (n = 2) reported some positive or neutral

impact of RRBIs. For example, the authors reported that teachers did not identify RRBIs as having a negative impact.

There were a few examples (n = 8) of collaboration with parents/caregivers to inform the intervention, but none with teachers. In some studies parents identified targets in collaboration with a clinician, in addition to other measures of behaviour. One noteworthy example is the behaviour vignettes used by Arnold et al., (2003), because it was used within a randomised control trial study design. Parent discussed the behaviour with a clinician, including the behaviour duration, impact and possible triggers and functions. The assessment processes involved quantified behaviour ratings of parent reports. The target behaviours were first categorised by type of RRBI and then each pair of vignettes were rated on a nine-point scale of improvement / deterioration. Arnold et al. (2003) compared these rating with those of a panel of blinded autism researchers and found that the measures converged.

RQ 3: Effectiveness of interventions for broader outcomes

Have RRBI interventions been effective in achieving outcomes beyond a reduction in the target RRBI?

- *If so, which interventions have been used and how are the outcomes defined?*

The original aim of the SSR was to synthesise those studies that had defined broader outcomes using vote counting. However, the findings from such a synthesis would be limited because the reasons for targeting RRBIs were often stated in one sentence without further detail as to how this was established. Further, other studies that measured non-RRBI outcomes and did not report a reason for intervening, did not clearly state that the impact of RRBIs was unknown. Therefore, the inclusion criteria for RQ3 (specifying a reason and measuring a corresponding outcome) are not robust enough to either include the studies that have evidenced that RRBIs had a negative impact that

warranted intervention or to exclude those that did not. It is unclear how such inclusion criteria might be reliably defined, given that reasons for intervening are mostly not reported and studies are not often designed to establish the mediating role of RRBIs.

Although a synthesis would not be reliable, a discussion of the range of findings can still be informative. The studies were grouped into categories based on the reasons given for intervention in RQ1. Given time limitations in completing this thesis, the discussion will focus on the largest group which included an outcome related to structured learning or vocational tasks (n = 29, see Table 7). The other groups included fewer studies: measuring distress to CYP (n = 11), interference with daily activities (n = 6), social interaction (n = 5), school inclusion (n = 1), and leisure time (n = 1). Following a summary of the quality assessment, the effectiveness of interventions in achieving broader outcomes is discussed. The discussion is structured by type of intervention, because of the similarities between studies that adopt similar approaches to intervention.

<u>Quality assessment</u>

The studies were single case designs or case reports. Therefore, a comment cannot be made about the representativeness of the participants in terms of their sampling process. There is large individual variability with regard to RRBIs (as discussed in section 2.1), which impacts on the generalisability of the findings. In the studies with more than one participant a multiple baseline design was used, which helps to identify the impact of confounding variables on the findings. Measurements were appropriate to the outcome variables and reported inter-observer reliability when observational methods were used. The interventions were administered by the researchers or under their supervision, therefore, intervention integrity was not measured. One study was a case report and did not involve formal data collection, but instead included informal parental reports.

Effectiveness on RRBIs and broader outcomes

Durand & Carr (1987) reframed a behaviour that was seen as problematic to understanding it as a communicative behaviour. Therefore, this study is separated from the rest. Even though the reason for the study was originally framed in terms of interference with learning, the interventions subsequently successfully used communication training to replace RRBIs.

Educational interventions

Some studies found a positive impact on learning with an associated change in RRBIs. One participant in Cheney (1984) engaged in echolalia which appeared to interfere with instruction. Cheney found that some response techniques were more effective at reducing echolalia and concurrently increasing task performance. Interestingly, Cheney (Cheney, 1984) found that 2 weeks after the intervention echolalia had increased (after it was reduced during the intervention), but accurate responding remained high. A self-monitoring technological device evaluated by Rosenbloom et al. (2019) was also effective at reducing echolalia with an associated increase in on-task behaviour and task completion.

However, Symons and Davis (1994) found that while stereotypy decreased with instructional prompts, there was no effect on rate of task completion. Similarly, Roxburgh and Carbone (2013) found that faster instructional presentation rates decreased stereotypy, but there was no effect on correct responding (though the authors suggested a possible ceiling effect).

Exercise and sensory-based interventions

Many of these studies report individual differences between participants in the same study. In J. Lee et al. (2018), for one participant an increase in task engagement was associated with a *decrease* in stereotypy, whereas for a second participant it was associated with an *increase* in stereotypy. For the third participant, there was an observed ceiling effect for task engagement. A study comparing a weighted vest, a compression vest, and antecedent exercise

(Losinski et al., 2017) found some reduction in stereotypy but no change in attention to task. Pokorski et al. (2019) made two comparisons, using antecedent interventions: a) headphones vs no headphones and b) gross motor exercise vs sensory based intervention vs seated work. They did not report a clear covariation between engagement and stereotypy, though certain interventions impacted on engagement and stereotypy separately (without impact on the other outcome).

Behavioural interventions
The studies taking a behavioural approach all targeted stereotypy. They included a range of interventions that varied in whether stereotypy was blocked or alternative behaviour was reinforced, or both. Some compared interventions with and without a blocking component.

Conroy et al. (2005), Longano and Greer (2006), and Slaton and Hanley (2016) used stimulus pairing procedures to indicate when stereotypy was not permitted. While all reported a reduction in stereotypy with the procedure, Slaton and Hanley (2016) and Longano and Greer (2006) also reported greater engagement, whereas Conroy et al., (2005) found no change in engagement.

Anderson and Le (2011), J. L. Cook and Rapp (2020), and Verriden and Roscoe (2019) compared interventions with and without a blocking component. Verriden and Roscoe (2019), and Anderson and Le (2011) reported that a component that blocked behaviour was necessary to reduce stereotypy and this also increased engagement. In contrast, J. L. Cook and Rapp (2020) found that blocking stereotypy was only necessary for one participant. They implemented a series of interventions that were progressively more intensive and only the last one involved blocking behaviour.

Edwards et al. (2018), Gibbs et al. (2018), Greenberg et al. (2010), Long (2015), and Cicero (2008) implemented blocking with reinforcement (though using different procedures). They all found reduced stereotypy and increased

engagement. Specifically, this included leisure play that generalised to new toys (Edwards et al., 2018), increased on-task behaviour (Greenberg et al., 2010 and Gibbs et al., 2018), and increased and faster task completion (Long, 2015). However, the study by Long (2015) studied the impact of intervention at a two-week follow-up and found no maintenance of the changes. Cicero (2008) also found only a slight increase in appropriate object engagement in association with a decrease in stereotypy.

Lerman et al. (2003), L. C. Peters and Thompson (2013), Wells, Forehand and Hickey (1977), and Wells, Forehand, Hickey and Green (1977) only implemented an intervention with a behaviour blocking component. Peters and Thompson (2013) reported that it reduced stereotypy for all three participants, but only increased engagement for two. Similarly, Wells, Forehand and Hickey (1977) and Lerman et al. (2003) found inconsistent results, with at least one of the participants showing decreased targeted stereotypy but increased untargeted stereotypy and either reduced or no effect on engagement. Wells, Forehand, Hickey and Green (1977) similarly found that a decrease in stereotypy was associated with an increase in appropriate play for only one of the two participants.

Behavioural interventions without a blocking component also reported mixed findings (these intervention included a procedure for reinforcing alternative behaviour). Haring and Kennedy (1990), and Haring et al. (1986) reported that for the participants whose stereotypy decreased with reinforcement of alternative behaviour, task performance increased only for some (though they report a possible ceiling effect). Hedquist and Roscoe (2019), who also used a behaviour reinforcement procedure, reported an increase in item engagement with a decrease in stereotypy.

Pharmacological
A case report by Wink et al. (2011) included a parental report, but no formal measurement of changes in behaviour. Parents reported that a decrease in

repetitive movements was associated with increased ability to participate in activities at school.

Intervention comparisons

Two studies compared different types of intervention, and both reported changes in learning outcomes associated with changes in RRBIs. Ellis-Hervey (2011) compared a weighted vest and behavioural intervention. They reported that stereotypy decreased and attention to task increased more during the behavioural intervention for all participants. Zimmerman et al. (2019) found greater task engagement with structured work boxes compared with a weighted vest intervention. In this case the data collection included stereotypy as instances of un-engagement, therefore, an increase in task engagement was interpreted as a decrease in stereotypy.

2.5. Discussion

The aim of this SSR was to describe the design of intervention studies on RRBIs in terms of how outcomes are defined (RQ1) and by whom (RQ2), and whether interventions have been effective in achieving broader outcomes (beyond reduction in behaviours) (RQ3). This research was prompted by a dominant view of RRBIs as having a negative impact, with studies that have reported a negative impact being emphasised in the literature. Content analysis frameworks were used to address RQ1 and 2. These were developed after several steps of analysis. A synthesis of the literature was not possible to address RQ3, because of the lack of clarity in reporting the basis of intervention. However, a discussion of a subset of these studies (which focused on learning/vocational outcomes) reported approaches to intervention and range of findings.

Research questions 1 and 2

The findings from the content analyses addressing RQ1 and 2 suggest that there is a lack of clarity about why RRBIs are targeted for intervention and the

broader outcomes that changes in RRBIs are intended to achieve. A majority of studies do not state the reason for targeting RRBIs for the study participants. Less than half of those that do, do not measure a corresponding outcome in order to evaluate whether the intervention had any effect on the reason for targeting the RRBIs. Further, CYP involvement in understanding their RRBIs is rarely reported. This may be due to barriers in communication. However, the reasons behind the lack of CYP participation are not acknowledged. Where there has been parent/caregiver or teacher involvement their view is succinctly reported, most often in terms of the necessity for intervention with no elaboration as to how this was ascertained. There were few examples of reported collaboration between researchers/clinicians and parents/caregivers.

It is interesting to note that the results for RQ1 are very similar when limited to the last decade (2011 – May 2021). A similar proportion of studies specify a reason for intervening and of those that do, a similar proportion measure a corresponding outcome. However, querying the impact of RRBIs, and whether (and in what contexts) they should be directly targeted, is not a new discussion. For example, Woods (1983) argues for intervention only in certain contexts because RRBIs do not always have a negative impact. Powers and Crowel (1985) discuss intervention in terms of the educational outcomes of reducing RRBIs. Further, there are examples of earlier studies that consider RRBIs in terms of more holistic functioning, such as parent-child interaction and the impact of RRBIs on functioning (e.g. Marchant et al., 1974). Even within the pharmacological literature that tends to focus on symptom reduction there have been questions over whether changes in observed behaviour translate to meaningful developmental outcomes (Buitelaar et al., 1990). However, much of the current literature still appears to be framed on the basis that RRBI reduction in itself indicates developmental progress.

These findings reinforce calls for research to focus on outcomes that are meaningful for autistic CYP and their families, as discussed in Chapter 1 (e.g. Frazier et al., 2018; Lounds Taylor, 2017; McConachie et al., 2018; Roche et

al., 2021). Even aside from the question of whether intervention is needed for RRBIs, a fundamental issue is that the reason for targeting RRBIs should be reported and be part of the evaluation. Further, the literature reflects a narrow focus on certain categories of outcome. When a reason is given, there seems to be a greater focus on structured learning/vocational outcomes, though a small number of studies do focus on other aspects, such as distress caused to CYP. This may reflect the fact that educational settings are the contexts in which RRBI-related behaviours are more likely to be seen as barriers. However, focusing on outcomes that are meaningful for autistic CYP and their families should include a more holistic consideration of CYP functioning, beyond engagement in structured learning/vocational activities. This is recognised in legislation that identifies "cognition and learning" as one area that must be understood in conjunction with other aspects of development, such as communication, emotional well-being and mental health (SEND Code of Practice, Department for Education, 2015). It is also noted that even when autistic CYP have exceptional ability in some domains, a narrow focus on academic ability may negatively impact on their well-being, as it is often accompanied by significant variation in ability across domains (Courchesne et al., 2015).

It is also important to note that certain reasons for intervention were less likely to be measured, or not at all. For example, disruption to others and stigma appear to be assumed, rather than measured. Given that there is concern regarding normalisation of atypical development, it would be helpful to measure perceived disruption and stigma to better establish whether certain assumptions about behaviour underlie these perceptions. Consequently, other interventions (for example, peer interventions or family support) may be more appropriate to meeting the needs of autistic CYP.

The reason why the views of autistic CYP were not reported could be because of barriers in communication. However, authors could have included a discussion of CYP needs that created barriers to communication, what methods

had been used to facilitate communication, and what the implications of not accessing CYP views may have been for the study. As a first step it is important to report when interventions have been carried out without accessing CYP views. Further, to report any specific barriers that have hindered accessing CYP views, as well as what methods may have been used (successfully or not). The rights of CYP to participate in decision that affect them are enshrined in the UN Convention of the Rights of the Child in Article 12, and with specific reference to children with SEND in Article 23 (United Nations, 1989). They are also recognised in UK legislation (SEND Code of Practice, Department for Education, 2015; Children and Families Act, 2014).

There were only a few examples of researchers (practitioners or clinicians) working in collaboration with parents to identify targets for intervention. Succinctly reporting parents/caregivers concerns about a behaviour is different to involving them in a collaborative process, as recommended in autism practice (Guldberg et al., 2019). Collaborative practice is also emphasised in legislation that promotes multi-disciplinary working between professionals, and recognises the rights of families to be involved in decision-making (SEND Code of Practice, Department for Education, 2015; Children and Families Act, 2014). A collaborative process means that common understanding is being developed about CYP needs more broadly, and that the professionals who are involved can contribute their own expertise to designing a meaningful intervention. For example, parents/caregivers may seek treatment for a specific behaviour but, through collaborative working, a practitioner may identify that what is of most concern is parental confidence in knowing how to respond to the behaviour. For example, Harrop (2015) found that an intervention that focused on supporting caregiver-CYP interactions helped caregivers to redirect RRBIs that may have otherwise hindered engagement in dyadic interactions and play routines. This did not lead to a change in RRBIs but may have increased caregivers' ability and confidence in how to respond to these behaviours. Finally, if CYP are attending an educational setting then a collaborative process that involves all adults who are close to them (including EPs) would be a step towards ensuring

that their needs are understood across various contexts. Consequently, interventions would be better designed to address those needs.

Another reason to work with parents/caregivers is evidence that their reports can differ from clinician and teacher reports (Guastella et al., 2015; Jones et al., 2017; Reed & Osborne, 2013; Schwartzman et al., 2021; Stratis & Lecavalier, 2017). A study by Guastella et al. (2015) illustrated a 'placebo' effect in parent ratings. Parents reported greater symptom reduction when they believed their child was receiving treatment, compared with those who believed their child was receiving a placebo. However, these beliefs did not correspond with actual drug assignment. These finding do not undermine the value of parental perspectives or question the 'reliability' of evaluation measures, but they do point to a need for a collaborative approach to intervention that leads to joint understanding.

Research question 3

A formal synthesis of the evidence was not possible for RQ3. However, an informal discussion of a subset of studies suggested mixed findings on the effectiveness of RRBI interventions on learning outcomes. There was some evidence of an association between a decrease in RRBIs and an increase in learning outcomes. But there was also evidence that a decrease in RRBIs did not lead to an increase in learning outcomes. The mixed findings suggest that even when RRBIs appear to interfere with learning (as a basis for intervention), interventions that are effective in decreasing RRBIs may not necessarily lead to the desired learning outcomes. Further, the lack of reporting on participation of autistic CYP and stakeholders is of concern in interpreting these findings.

Factors that may be perpetuating a focus on RRBI reduction

The methodology used in this review cannot address the question of why there is a lack of clarity in the reasons for targeting RRBIs. This is because the researchers' reasoning is not reported in the literature. The findings from the SSR could be understood in the context of a historical focus on deficit and a view of intervention in terms of autistic symptom reduction, as discussed with

reference to the 'medical model' in Chapter 1. There has been less focus on alternative theoretical accounts of RRBIs that frame these behaviours in terms of difference and not deficit, such as monotropism (Murray et al., 2005; Murray, 2018) and flow (McDonnell & Milton, 2014), as discussed in section 2.1. The following discussion aims to identify possible factors that may be perpetuating this focus in the RRBI intervention literature.

An overarching framework of symptom reduction

Intervention may be defined in terms of the presence of a behaviour (invariability or repetitiveness) or the absence of a behaviour (variability or communicative skill). From a practitioner perspective, the RRBI behaviour may be perceived to be a behaviour that is occurring instead of an alternative one that would lead to broader developmental outcomes, such as engagement in play, language skill development or coping with unpredictability. However, even if those developmental outcomes are accepted as desirable, does the behaviour that is currently occurring need to be defined and targeted as part of the intervention? Or is it sufficient to define and support the alternative behaviour? For example, interventions that support the development of conversational skills may include participants who engage in echolalia or perseverative speech, but the intervention may not be framed in terms of changing these behaviours. Instead, the intervention is framed in terms of supporting development of language (Charlop & Milstein, 1989). Similarly, studies may evaluate interventions that aim to increase variability in play behaviour but not frame this in terms of reducing repetitive play (Contreras, 2017). Additionally, studies that implement interventions to increase skill or variability frame them in terms of RRBI reduction, though they do not necessarily directly try to reduce RRBIs (Choi, 2000; Dib & Sturmey, 2007; Napolitano et al., 2010; Nuzzolo-Gomez et al., 2002; Stasolla et al., 2014; 2016). For example, Stasolla et al. (2014; 2016) employed an educational intervention to increase engagement and also report reduction in stereotypy. The primary aim may have been to increase engagement, but this was also framed as an intervention that targeted RRBIs.

It is interesting to note, therefore, that there are factors that shape the *reporting* of research in terms of RRBI reduction when interventions do not necessarily focus on this as a primary aim. This would relate to the macrosystemic level of the PPCT model. Even if researchers (which includes education practitioners who contribute to the research literature) work within an ecosystemic framework, they may be required (or perceive the requirement) to report their work in terms of symptom reduction.

It may be argued that the way a study is framed is not important because it is in any case helpful to understand how RRBIs covary with environmental factors, other behaviours, or developmental outcomes. The argument may be that this research can contribute to a better understanding of the function of behaviours for autistic CYP and the factors impacting on their behaviour and development. However, when a study is framed as an intervention it implies that RRBIs have a negative impact and their reduction is a positive thing. This will add to a body of literature on 'RRBI interventions' and will perpetuate the focus on RRBIs as behaviours that needs to be reduced (shaping the macrosystemic level that impacts on how the need for intervention for autistic CYP is framed). Further, if a study is designed based on the assumption that a reduction in RRBIs is positive, and it is not acknowledged that the impact of RRBIs is unknown, then it is unlikely to be designed to explore the mechanisms between any covariation in RRBIs and other outcomes. This is of concern when there appears to be some degree of assumption in the research literature that RRBIs have a negative impact as a starting point for intervention (see section 2.1). There is enough evidence to show that RRBIs are not necessarily negative (as discussed in section 2.1) and there is some indication that changing them does not necessarily translate to broader outcomes (as reviewed for RQ3). An assumption that RRBIs require intervention may also arise from the dominance of theoretical accounts of RRBIs that frame them as deficit. Alternative accounts, such as monotropism (Murray, 2018) or flow (McDonnell and Milton, 2014), which provide a different framework for understanding RRBIs, are not as

widely used. In these accounts, the starting point for intervention is not a notion of behaviour as deficit, but behaviour as having a function and meaning for the autistic individual.

Separate literatures

Part of the problem may also be that studies of the impact of RRBIs and intervention studies largely constitute separate literatures, and this hinders the development of understanding of both. It should be emphasised that behaviours defined as RRBIs need to be understood before any intervention is deemed relevant. However, even if it is thought that intervention is needed, intervention studies must include robust designs that can inform understanding of the impact of RRBIs *for the study participants*. Using evidence that RRBIs have a negative impact for other autistic CYP cannot be a basis of intervention, because behaviour varies between individuals and between contexts.

Understanding the function of behaviour

A related issue to how intervention is framed is how the behaviour is understood. There has been an increased focus on assessing the function of RRBIs, and this has been emphasised in SRs (Boyd et al., 2012; Leekam et al., 2011; Patterson et al., 2010). However, function tends to be defined within a behaviourist approach and mostly assessed in a systematic way (though less so for high-level RRBIs, Rodriguez et al., 2012). Such systematic approaches distinguish between social and non-social function in the context of interventions (Iwata et al., 1993; Rapp & Vollmer, 2005), but do not necessarily try to understand the meaning of the behaviour for the individual. For example, the behaviour may have a regulatory function, which would require meeting the underlying need in a different way. It may also represent an interest that defines CYP's identity. Leadbitter (2021) emphasises the need to understand the drivers behind the behaviour as part of understanding whether intervention is needed, and how it may best serve the needs of autistic CYP, while respecting their autistic identity. This aligns with the social constructionist perspective of the PPCT model, in which CYP are the drivers behind development and their

subjective experiences is essential to understanding the developmental process.

In summary, the discussion has explored the limitations with the way that the RRBI intervention literature is currently defined. A few factors that may be contributing to this were also identified. This includes an overarching framework for reporting research (at the macrosystemic level), which appears to emphasise intervention in terms of symptom reduction. The discussion also highlighted a lack of recognition for the right of CYP to participate in decisions that affect their lives, and a limited framework for understanding the subjective experiences of CYP in terms of the function / meaning of their behaviour. Finally, there is a need for the development of joint understanding between parents/caregivers, teachers (where applicable) and professionals, such as EPs in the design and implementation of interventions for autistic CYP. This will be discussed further in Chapter 3.

Study limitations

The SSR aimed to describe the design of RRBI interventions and, therefore, uses the language used in the research literature. As discussed in Chapter 1, it is acknowledged that this language frames behaviour in terms of deficit and pathologises behaviour that serves a function for autistic CYP.

The synthesis of research in systematic reviews has been criticised for reducing the complexity of research (MacLure, 2005). The analysis in the current SSR is constrained by certain parameters. Diagnosis of ASD was based on author report, as was identification of RRBIs. RRBIs are complex to define and the authors' definition was accepted. Further, there exist a wide range of measurement tools in the study of RRBIs (Berry et al., 2018; Honey et al., 2012). These are mainly questionnaires and diagnostic interviews, with few structured observational methods, or methods for understanding autistic CYP views. The focus of this research was on the diagnostic term (as discussed in

Chapter 1) and this has shaped the literature that was discussed. The work with EPs (discussed in Chapter 3) may provide a different perspective and way of understanding behaviour that is defined as RRBIs. However, the methodology chosen was deemed appropriate for the research questions. The findings have been presented with acknowledgement of the limitations in the conclusions that can be drawn.

The SSR can only describe what is reported by authors. Because the analysis coded the absence of information from reports, care was taken in the definition of the inclusion criteria. For example, short papers were excluded, as there may not have been enough space to report on design details. Publications that included an intervention but were primarily reporting on intervention *process* were excluded. Studies that were framed as testing a hypothesis rather than reporting an intervention were also excluded.

The significant variation within an ASD diagnosis has implications for the generalisability of the findings. One way of addressing this would have been to add CYP profile as an additional parameter to the analysis. However, the variation in how this is defined meant that it would have required too much time to define meaningful categories.

As noted earlier, RRBIs are not specific to ASD. There is growing evidence that RRBIs occur across typical as well as atypical populations. Several authors have expressed concern that there are CYP with additional needs who do not meet the full criteria for ASD diagnosis but have high levels of need with respect to RRBIs and, consequently, require but are not receiving additional support (Happé et al., 2006). This research was limited in terms of its focus on ASD. However, the findings of the SSR apply more generally to study design for research on RRBIs.

This and other reviews have used search terms for RRBIs and their subtypes. However, this assumes that behaviour that falls under the definition of RRBIs

will be labelled as such in the literature. Terms such as 'challenging' or 'aberrant' behaviour have been used to include RRBIs (Machalicek et al., 2009). Although this means that some studies will have not been included, this would be a small proportion of studies. Further, as discussed, there is a more important question in how behaviour is conceptualised based on diagnosis, which may impact not only on how interventions are reported but also on how the need for intervention is conceptualised.

Future research

This SSR aimed to examine the design of any research that included an RRBI intervention. Given this broad focus, details about specific behaviour may have been overlooked. Further, because of the large number of studies and limited timeframe, more detailed analysis that examined different parameters within the literature, such as type of intervention or CYP profile, was not possible. Future research could carry out a more focused review that would enable such an analysis. This, for example, could serve to identify practice within specific research fields.

RQ3 aimed to synthesis evidence on the impact of RRBI interventions on broader outcomes. This was not possible due to the lack of clarity in the reasons for intervening and the range of outcome measures. Further research is needed to examine when and for what purpose RRBI interventions are necessary and effective. This may require a reframing of how behaviour is defined. Practitioners, such as EPs, may be able to play a key role in this. This is because they tend to work within a collaborative framework of practice and focus on broad developmental outcomes that are meaningful to CYP and their families. The following chapter reports on a study with EPs that explored their practice specifically with regard to RRBIs.

Chapter 3. Empirical work: EP practice

3.1. RRBIs in EP practice

A search of professional literature on EP practice with regard to RRBIs (using RRBI-related terms) did not identify any publications. Informal conversations with the author's colleagues suggested that, while RRBIs might be labelled as such with regard to diagnosis, this definition of behaviour is not the conceptual framework or the language used in professional EP practice to inform assessment and intervention. Instead, the behaviours that are defined under RRBIs may be considered without reference to the diagnostic category, but in terms of their function within specific contexts. The term and definition of RRBIs may appear to EPs to be more aligned with a 'within-child', deficit-based approach to understanding CYP needs that is based on an 'expert' professional view. The diagnostic approach does not define behaviour based on its meaning to the autistic individual or the role of context in the function of that behaviour (as discussed in Chapters 1 and 2). The following literature review discusses principles and frameworks underlying EP training and practice that can help frame the empirical work.

Ecosystemic approach

Bronfenbrenner's ecological systems theory (Bronfenbrenner, 1979) played a central role in a shift to a holistic understanding of CYP which takes into account interaction with their surrounding environment (Hayes et al., 2017; Wicks, 2013). Bronfenbrenner described development in terms of a dynamic process of accommodation between the CYP (an active, growing human) and a context that is also changing. He defined context in terms of multiple nested systems. This work was later developed into the Process-Person-Context-Time model (Bronfenbrenner, 2005). In Bronfenbrenner's work, the immediate environment of the child is being influenced by processes that occur in the wider contexts that surround it. In adopting Bronfenbrenner's model, the role of the EP became one of *problem-solver*. Involvement and evaluation over time

and across multiple setting, became key to developing an understanding of CYP (British Psychological Society, 2017; 2019). This framework and way of working was a move away from a 'medical model' that focuses on assessment that leads to diagnosis. The medical model has historically emphasised the identification and labelling of CYP deficits in relation to an 'average' that represents a notion of typical development. The focus is on the atypicality of CYP's characteristics, rather than a consideration of the 'match' between CYP and their environment.

Practicing within an ecological approach requires a longer and more dynamic process of assessment and individualised intervention formulation (Wicks, 2013). The role of the EP is defined as that of a problem-solver within an ecosystemic approach by the EP profession (British Psychological Society, 2017; 2019). However, it is important to note that there are factors that may constrain how EPs work in practice. Legislation currently stipulates that EPs are involved in the assessment of special educational needs and disabilities (SEND). This potentially narrows down EPs' roles, leaving less capacity to work within an ecological problem-solving approach which requires longer-term involvement. School and teacher expectations of the role of EPs are additional factors that impact on EP practice. Schools have tended to view EP roles more narrowly in terms of advice and assessment (K. Lee & Woods, 2017). The impact of such attitudes perhaps becomes greater in the context of traded services where schools are paying clients (Fallon, 2018).

Children and Young People's voice

A central part of the EP role is one of advocate for CYP (Greig et al., 2014). Enabling CYP participation in decision-making is a central principle of the psychological theories that underpin EP training. For example, an important element of Bronfenbrenner's theory is a phenomenological analysis of context (Bronfenbrenner, 1977, 1979, 2005). In other words, an analysis of how each person perceives their context and the people and objects within it. His framework thus emphasises the use of methodology that aims to understand

subjective experiences. The participation of CYP with SEND in the decisions that impact on them, as well as that of their parents, is recognised in legislation (SEND Code of Practice, Department for Education, 2015). It is also recognised in the UN Convention of the Rights of the Child in Article 12, and with specific reference to children with SEND in Article 23 (United Nations, 1989). Children have the right to express their views, feelings and wishes in all matters that affect them and for these to be taken into consideration when making decisions that impact on their lives. They should also not face discrimination and be able to join in with activities, without their disability stopping them from taking part.

Professional expertise has been highlighted as an important factor in accessing the voice of CYP with complex communication needs (Hill et al., 2016; Palikara et al., 2009). Franklin and Sloper (2009) identified autistic CYP as one group that may be seen to be particularly 'hard to reach'. Professional experience can contribute to finding creative ways in which participation methods can be adapted to CYP's needs. But the role of professionals, such as EPs, is also important in advocating for systemic changes. Facilitating CYP participation may require cultural changes within an organisation, as well as additional time for staff to prepare materials, understand CYP's communication needs, and prepare CYP over more than one meeting to enable them to express their views (Franklin & Sloper, 2009).

Consultation: an overarching framework for practice

Consultation is a common way of working in UK EP services (Farrell & Woods, 2015). Consultation is an overarching, whole service approach to EP practice that is characterised by a collaborative, non-hierarchical process (Wagner, 2016). It acknowledges the role and impact that others have on CYP's development and engages the parent/caregiver as someone who has expert knowledge of their child (Kennedy et al., 2008). Consultation is compatible with the PPCT model, for example, because it allows EPs to build an understanding of the interactions between CYP and their context.

EPs support consultation through expertise in the *process*. Consultation is more than a conversation and requires structured approaches and skills in order to explore a situation and open up possibilities for change (Newell & Newell, 2011; Wagner, 2016). For example, collaborative participation is necessary for the effectiveness of consultation in terms of achieving change (Erchul & Martens, 2010), but may require skill to achieve. Interpersonal flexibility is needed to adapt to different people and situations (Farrell & Woods, 2015). Skill is also needed to overcome barriers, such as expectations of the EP to take an expert role (Larney, 2013).

The comprehensive and recursive nature of consultation is key to its effectiveness. Once CYP's behaviour is framed in terms of the relationship between them and their contexts, it becomes necessary for the EP to work at a systemic level. It is also necessary for this process to be recursive, because EPs are not applying a known remedy to a fixed diagnosis. EPs are supporting change in a bi-directional relationship between CYP and their contexts, and it is not possible to predict how changes in one will impact on the other (Bronfenbrenner, 2005; Bronfenbrenner & Ceci, 1994). Further, it is necessary to focus on strengths as well as needs and consider both when identifying desired outcomes and what they would look like in practice. This may involve a process of 'reformulation' in terms of how the 'problem' is perceived, particularly when the 'problem' is initially identified 'within' CYP (Nolan & Moreland, 2014). Facilitating collaboration with parents/caregivers and teachers may be particularly challenging with regard to RRBIs, given that such behaviours may negatively impact on family life and create challenges for the inclusion of CYP in the classroom (as discussed in Chapter 2).

In summary, although no published information was found on how EPs practice when searching with RRBIs-related terms, Bronfenbrenner's conceptual model and the consultation model of service delivery provide insights into the key principles and frameworks which underpin EP practice. These suggest that

RRBIs would be understood within a broader bioecological framework of development, which involves understanding the interaction between CYP and their contexts, rather than seeing them as within-child deficits that need to be reduced. EPs are likely to seek to understand the meaning of behaviour for CYP, to access CYP views, and to work in a collaborative way with parents and other stakeholders to identify desired outcomes. This process requires skill in order to create the space for equal participation and a shared understanding of CYP need in terms of their interaction with their context.

3.2. Rationale for empirical work

The starting point of this thesis was a perceived gap between EP practice and research on RRBI interventions, within a broader context of discussion on neurodiversity and autism research (as discussed Chapter 1). The frameworks that underlie EP training and practice (as discussed above) suggested a bioecological and collaborative way of working which may not align with the very definition of RRBIs, which is a deficit-based diagnostic criterion. Therefore, the purpose of the empirical work was to outline an initial description of how EPs practice with regard to RRBIs, which could inform whether and how they contribute to or are informed by the research literature on RRBIs.

EPs currently practice within a framework of assessment and intervention, drawing their professional knowledge and experience. For example, Fallon et al. (2010) define EPs as "scientist-practitioners who utilise, for the benefit of children and young people (CYP), psychological skills, knowledge and understanding through the functions of consultation, assessment, intervention, research and training, at organisational, group or individual level across educational, community and care settings, with a variety of role partners" (ibid, p.4). The research questions focused specifically on a) whether the term RRBIs is used in EP practice, and more broadly on b) how EPs practice with regard to RRBIs (including assessment, defining outcomes and identifying interventions). As discussed in Chapter 1, this work is framed around the RRBI diagnostic

criterion because it is the current framework for identifying need and aligns with the research literature.

3.3. Research questions

This research aimed to examine the following research questions:

1. Is the term RRBIs used by EPs?
2. How do EPs practice with regard to RRBIs, including assessment, defining outcomes, identifying intervention?

3.4. Method

Theoretical perspective

The theoretical perspective regarding evidence-based practice (EBP) described in Chapter 2 also applies to the empirical work described in this chapter. EBP is important to certain aspects of education but it can become reductionist if applied to educational practice as a whole (Biesta, 2010; Kvernbekk, 2016). Educational practice is a complex system within which a range of actors interact with a range of values and norms. This system is open, with actors and norms from 'outside' impacting on interventions and actions within any educational setting (Kvernbekk, 2016). These values and norms are reflected in the development and evaluation of interventions and understanding them are an integral part of understanding the evidence base. Therefore, this empirical study aims to understand how EPs practice within this complex system and bridge the divide between the different systems and contexts in which EBP evolves and is then implemented. The research literature on RRBI interventions is but one feature of these diverse influences. Additionally, it is noted that this research is undertaken in the context of professional training. This training is based on a perspective of professional knowledge that emphasises the role of both academic knowledge in evidence-based practice, in terms of informing professionals about 'what works', and also the professional judgements that are

made based on knowledge built through practice and professional supervision (Hill et al., 2015).

From a perspective of social constructionism, the empirical data that will be collected in these focus groups will be generated in interaction with the author and, therefore, is a joint produce rather than 'pure' information (Huberman & Miles, 2002). As the interviewer will be a Trainee EP (TEP) they will, to some extent, share a language and conceptual model and experience with the interviewees (Willig, 2013) and this will shape the results.

Research design and methodology

As discussed, no publications were found in the professional EP literature when searching using RRBI-related terms. Further, informal conversations between the author and colleagues suggested that EPs do not typically consider behaviours in reference to RRBIs when conducting assessments or identifying outcomes and interventions. It would, therefore, be difficult to design a questionnaire, as it would be unclear how to formulate questions on practice when the term RRBIs may not align with how EPs define behaviour, or reflect the language that is used to develop psychological formulations. Individual interviews would allow greater flexibility. However, it was decided that focus groups would have the advantage of stimulating discussion between participants.

Robson and McCartan (2019) define focus groups as 'group interviews' that can have varied levels of structure and commonly have a mixture of discussion and interview-posed questions. Group dynamics within a focus group "help in focusing on the most important topics and it is fairly easy to assess the extent to which there is a consistent and shared view" (Robson & McCartan, 2019, p. 299). An additional advantage that was considered important was that if the recruitment advert mentioned RRBIs, EPs who do not use or are uncomfortable with this term may have been more reluctant to participate in an individual interview. However, they may be more comfortable in a group setting as well as

interested to listen to what other EPs may have to say. Given that there was no existing literature that could be identified through specific reference to RRBIs, the primary aim of the research was to identify initial themes. Moreover, the focus of this study was on individual EP perceptions of EP practice as a whole rather than detail of individual practice. Hence the advantages of focus groups were outweighed by disadvantages, such as limitations on the number of questions that can be covered and a difficulty in following up individual responses (Robson & McCartan, 2019).

Three focus groups were carried out, two with seven qualified EPs and one with three TEPs. The focus groups were unstructured but were guided by the researcher to address the research questions. The type of questions used are discussed later in this section.

Sampling strategy and participants

The focus groups included Trainee, Maingrade, Senior and Principal EPs. The participants for each focus group were recruited in different ways to increase the diversity of the sample: (a) an EP special interest group on ASD, (b) a mailing list for EP professionals (email included in Appendix A.6), and (c) a convenience sample of TEPs from the researcher's contacts. The number of participants in each group were 4, 3 and 3, respectively. An additional three participants dropped out because of work commitments. Across all participants seven EP Services were represented in the sample. This included regions within England (specifically, North West, East, South East, and Greater London). EPs in groups (a) and (c) knew each other, while those in group (b) did not. The consent forms and information sheet are included in Appendix A.4.

TEPs were recruited in order to explore how RRBIs are considered in training. TEPs are also perhaps most recently familiar with the theoretical frameworks that underpin EP practice, as well as being required to frequently review the research literature for their assessed work. It was emphasised during recruitment that the focus of this research was not on expertise. However, there

was concern that, particularly among trainees who have limited experience, the dynamic between participants who did not know each other might create barriers to discussion. Therefore, the TEPs were recruited from a group who knew each other. This was less of a concern for qualified EPs.

Materials

The focus groups were unstructured but followed discussion of key issues and were guided by the researcher. All focus groups started with the question of whether participants used the term RRBIs in their practice. None of the participants used this term and, therefore, across all focus groups the follow-up questions explored why the term RRBI was not used. Within this discussion the researcher also prompted further elaboration. For example, if participants discussed that the diagnostic criteria did not take into account contextual factors, the researcher asked them to elaborate on whether, and if so how, within-child factors may also be relevant to consider and whether the research literature could inform this aspect of understanding behaviour. Similarly, if participants discussed the term RRBIs as promoting a deficit view, the researcher followed up with a question on whether RRBI interventions are necessarily designed to target within-child deficit or may also target contextual factors. Another example of a follow-up question was clarification of discourse around not setting RRBI outcomes because the participants were against normalisation of behaviour. The researcher asked how outcomes for autistic CYP were determined, that is, whether and, if so how, there is a balance to be struck between developing skills to function within a neurotypical society and respecting autistic characteristics.

The focus groups did not include questions that directly corresponded to RQ2. For example, the researcher did not ask 'how do you assess RRBIs?' or 'how do you define outcomes with regard to RRBIs?'. This was because participants did not define behaviour in terms RRBIs in their practice. Instead, when participants mentioned specific cases or specific examples of behaviour, the researcher followed-up with questions to clarify processes of assessment,

identifying outcomes and interventions. For example, a participant mentioned the case of a young person engaged in repetitive behaviour in the classroom. The researcher followed-up with questions on how the way that EPs practice helps them to understand the meaning and impact of this behaviour.

The researcher also presented a summary of the scope of the SSR and overarching findings during the focus groups. Only an overview was given in order to prompt discussion. This included the overall proportion of studies that a) defined a reason for intervening and b) reported CYP and stakeholder views, as well as the reasons for intervening (Table 7 in section 2.4). In the first group these were presented at the start using PowerPoint. However, on reflection the researcher felt that this brought up too many issues at once. Therefore, in the subsequent focus groups the review findings were presented during the discussion, when it felt most relevant to the discussion.

Procedure

All focus groups were carried out remotely via video call and lasted for 1 hour for both EP groups, and 45 minutes for the TEP group. The discussion was recorded on an audio recorder.

The first focus group began with a short summary of the findings from the systematic review. The second and third focus groups began with a discussion, and the SSR findings were presented during the discussion, as described in the previous section. All focus groups started with the question of whether participants used the term RRBIs in their practice.

The researcher intentionally did not focus on specific types of RRBIs or approaches to understanding RRBIs. The reason for this was not to impose specific constructs or definitions, and to allow the participants to guide the discussion based on their professional perspectives and experience.

Data analysis

The interviews were transcribed in full and analysed following the six steps defined in thematic analysis (Braun & Clarke, 2006, 2019, 2020). Reflexive thematic analysis was used because the data analysis required finding patterns of meaning which related to EP practice. Willig (2013) highlights the difficulty in defining what a theme is and, given the theoretical flexibility of the method, argues that the researcher must define what the themes represent. As discussed in the Rationale for this work, the research questions were formulated based on the processes within current EP practice (assessment, defining outcomes and identifying interventions). However, the themes qualitatively describe how EPs practice, rather than, for example, summarising processes. The approach to generating themes was predominantly inductive (determined by the data).

In the familiarisation phase (Step 1), the transcripts that had been automatically generated were checked against the audio recording. This step was completed shortly after each focus group, and initial notes were made. In the coding phase (Step 2), the transcripts were analysed using the qualitative data analysis software NVivo. This allowed the collation of data into groups based on initial codes. An interview segment could be coded in relation to more than one code if multiple meanings were being conveyed. For example, a single interview segment included a code on 'frustration with the medical model' and a separate code on 'rejection of the medical model'.

In the theme generation phase (Step 3), themes were generated from the codes. Although the nature of focus groups does not allow an analysis of individual viewpoints, it was possible to identify codes that were reflected in more than one participant's views within each group, and some that were not. In other words, whether the same view was repeated or elaborated on by others in the same focus group. Therefore, it was noted when a view was limited to one participant in each focus group, and not acknowledged or elaborated on in the group. This was not intended as a quantitative measure of whether there was

agreement within the group. Instead, it was interpreted as an indication of the emphasis within the group discussion. It was also noted when a view was only discussed in one of the focus groups. For example, only the TEPs discussed confidence in their practice.

The themes were reviewed (Step 4) for consistency within the data. Several themes were merged and split in this phase. For example, there were several themes that related to the limitations of the RRBI diagnostic term, which were merged into a single theme. The themes were then defined and named (step 5) and described (Step 6).

Trustworthiness, credibility and transferability

As discussed above, focus groups were selected as an appropriate method for the aim of the study, which was to explore EP practice. This description of EP practice is not intended to be exhaustive. Generalisability, which is noted as a limitation of focus groups (Robson & McCartan, 2019), was not an aim on the thematic analysis (Braun & Clarke, 2020).

Further, as with other interview-based methods, the data from focus groups stemmed from the specific context. In the present study, this will include the researcher, who is a TEP carrying out their doctoral research, how the research is framed by the researcher's questions, the views expressed by participants as a whole, the group dynamic, current debates with regard to ASD, as well as current discourse within the EP profession. The focus group discussion, and the data analysis, were guided by the researcher to address the research questions. However, the participants did not all interpret the questions in the same way and their responses often explored their own experience of practice.

Ethical issues

The ethical approval for the work described in this chapter is included in Appendix A.4. No significant ethical issues were identified. There was a minor

concern that participants may have felt that their knowledge was being tested, especially if they were still in training and had not had much experience working with RRBIs. There was clear written guidance that there were no right or wrong answers and the research was framed in terms of understanding participants' own practice and personal views. It was also possible that some participants may have given identifying information about a specific child or school. Any responses that contained such information were anonymised during analysis to reduce the risk of identification.

3.5. Findings

Table 11 shows the themes and subthemes that were generated during analysis of the focus group transcripts (also represented diagrammatically in Figure 4).

Table 11

Themes and labels from EP focus groups

Note: the subthemes are underlined

Theme 1: The function and implications of language in EP practice.
Outlines the importance of language / terminology used by EPs and the
reasons behind it. Diagnostic terms are used in communication about
diagnosis, for example, with paediatricians. In practice, positive or neutral
language is preferred (such as 'passions' or 'enthusiasms') as opposed to
diagnostic terms that imply deficit.

Theme 2: 'Understanding behaviour' as a description of what EPs do.
Outlines how EPs described what they do in practice when working with
RRBIs. This primarily involves <u>understanding the role of context</u> in shaping
behaviour and <u>understanding the function of behaviour</u> for CYP. One
participant in each of two focus groups mentioned within-child factors. TEPs
discussed their confidence in understanding autistic behaviour.

Theme 3: Limitations of diagnosis in EP practice. Outlines that EPs did
not feel that diagnostic terms were helpful to understanding CYP's behaviour.
The reason was primarily the <u>complexity and variability of behaviour</u> in terms
of the factors that underlie it. Diagnosis was limited in understanding the
contextual factors that shape behaviour and its emergence over time.

***Theme 4: Questioning the goal of / need for intervention for autistic
CYP.*** Focuses on the questions that EPs raised about the need for
intervention. The emphasis was on a strong <u>rejection of the normalisation of
behaviour</u>, considering <u>outcomes across all areas of development</u> rather than
isolated behaviour, and <u>reframing the meaning / function of CYP's behaviour</u>
for adults around CYP. This theme also included discussion of the views of
adults around CYP, such as teachers and parents/caregivers, who may see
the behaviour as problematic. One participant mentioned challenges in
communicating the EP approach of understanding behaviour effectively.

Theme 5: CYP participation in EP practice. Focuses on the importance of
including CYP in EP practice. EPs discussed the rights of CYP to be involved
in decisions that affect them, taking into account CYP views in order to
understand their behaviour, and considering CYP's ability to make choices
about outcomes and interventions. Distress to CYP from interventions was
considered in discussions about whether and how to intervene.

Figure 4

Diagram of themes and subthemes from EP focus groups
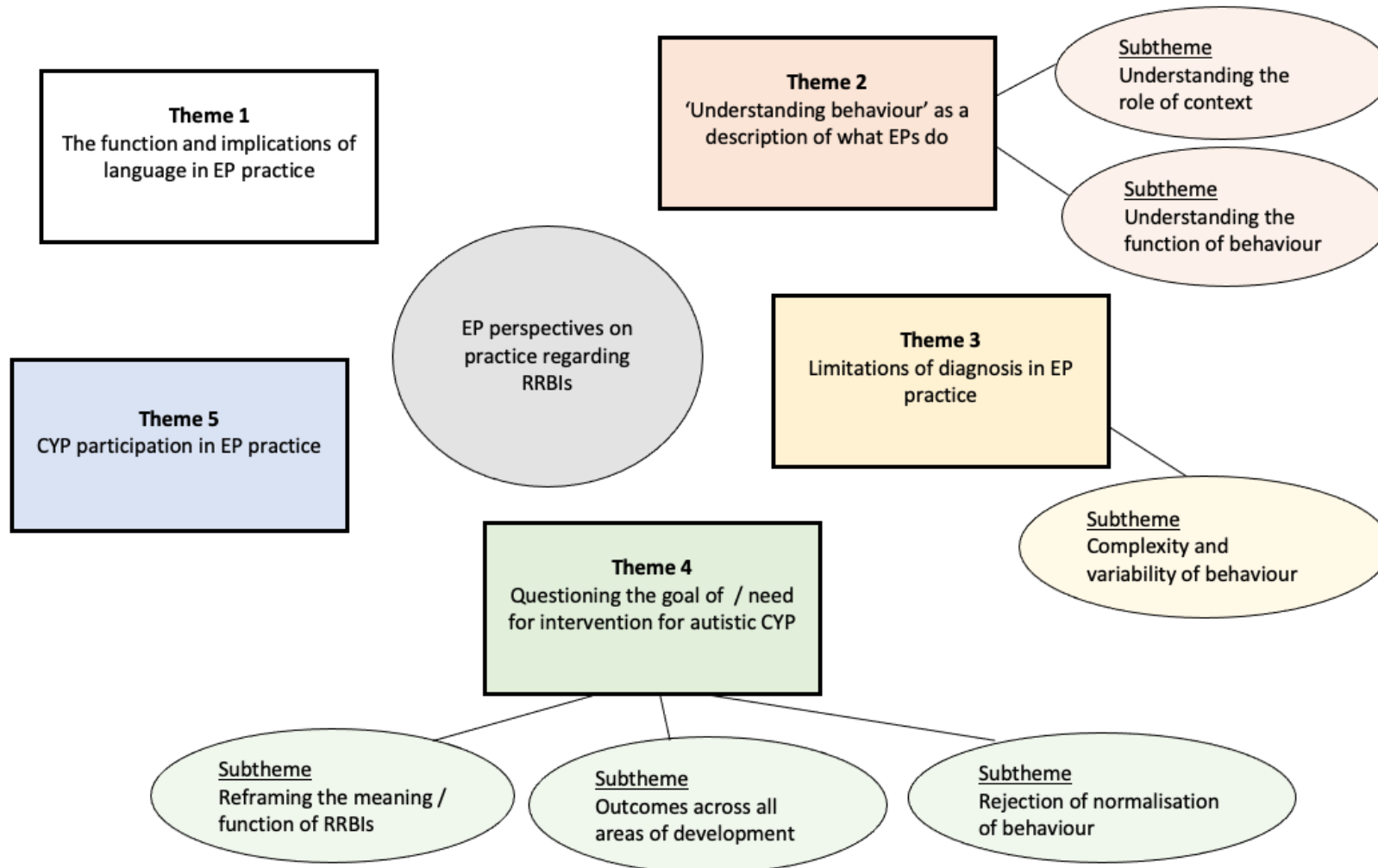
The themes and subthemes, with example quotes, are discussed in this section. The findings and discussion are separated, because the themes offer a better description of EP practice as a whole than as individual aspects of practice. Brackets […] are used to indicate where part of quotes have been omitted for brevity, when participants rephrased their thoughts as they were speaking. Repeated words, that are characteristic of spoken language, have been removed. The subthemes are underlined in Table 11 and in the subsequent discussion.

Theme 1: The function and implications of language in EP practice

There was acceptance of the term RRBIs in terms of context-specific language use, mainly with regard to diagnosis. Some participants reported that the term was also used when working with other professionals, for example with paediatricians, or when delivering training about ASD with other organisations. However, there was agreement that the term was never used in any other context of practice. For example, one participant stated:

> *"So I acknowledge that it's a medical term, it's part of the diagnosis, so I accept it as that. […] So I suppose I don't object to the term per say, I understand that it's medicalised language, but I certainly wouldn't use it in my practice"*

Participants reported that they use neutral or positive language, such as 'communicating behaviours', 'enthusiasms', 'passions' or 'interests'. The reason that EPs preferred this language over the diagnostic terms was that they wanted to avoid language that is negative and implies deficit.

Theme 2: 'Understanding behaviour' as a description of what EPs do

EPs described what they do in terms of 'understanding behaviour'. Participants did not refer to specific processes, frameworks or tools that they use in practice. However, there were several elements of practice that were discussed.

One key element of understanding behaviour was <u>understanding the function of behaviour</u> for CYP. This was defined in terms of the meaning that it has for CYP and what they gain from it. For example:

> *"it goes back, doesn't it to how we think about lots of things - what is that repetitive behaviour – or, especially, what purpose is that serving for that child?"*

<u>Understanding the role of context</u> was also emphasised in several ways. For example, participants emphasised differences in behaviour between contexts:

> *"individuals are motivated or driven by different things and probably different contexts. It will often depend upon where they are and what they're doing and with whom."*

There was also discussion of how autistic behaviours vary. In other words, CYP's behaviour would be defined as more or less autistic depending on the context in which they were observed:

> *"in some situations children will demonstrate more autistic type behaviours than others. It's not a constant, so that within-child impulsive behaviour is not a constant. And if you could, and it's the environment that actually is a key factor here."*

Context was also linked to the emergence of behaviour:

> *"What is natural or unnatural about these [behaviours]? We can find natural reasons for them. Perhaps if we go back far enough - and then it becomes an environmental issue again, obviously there's some elements of social communication disorder here, but then there's also the environmental impact on the child and restricting them and changing the way they are. So, you know, just sort of saying it's just down to something in it - just purely biological would not be…"* [the participants' thoughts trailed off at this point]

EPs' discussion of contextual factors did not explicitly explore what CYP bring to the child-context interaction. Only two participants (in separate focus groups)

more explicitly mentioned within-child factors. One referred to within-child factors as an aspect of child-context interaction:

> "It's always a gene environment interaction for me. You know, we all have some predisposition for certain things, and then the gene environment interaction kind of takes place so within-child is not a bad thing. You know it's part of your holistic assessment"

Another participant, in the TEP focus group, discussed a perceived reluctance by EPs to consider within-child factors:

> "I mean, when we're supposed to take a holistic view - and if you look at things like the Interactive factors framework and a truly holistic perspective - some EPs would be quite averse to looking at any biological factors and I don't necessarily agree with that. I'm not saying that they are the definitive cause, because they're not, and that's very ignorant to think so. But that doesn't mean you should just disregard them. And I think sometimes - I've observed consultations where there's no conversation at all around family history or genetics or biology. Or you know what might have happened during pregnancy, and I do think there is a role for biology there. I think we have a responsibility to emphasise it is not the only contributing factor. Of course the environment plays a massive role."

The question of confidence in terms of knowledge of ASD was mentioned in the TEP focus group. They reflected on the fact that they work with many autistic CYP and, therefore, may get complacent in researching about this condition in comparison to others that are rarer. For example:

> "I think it probably makes me question [knowledge] a little bit - because for my own practice, probably because autism comes up a lot. However, if I came across a sort of slightly, something I've not heard of before, my immediate reaction would be to look into it and then I find out about it and that would be my first step - whereas when I come across anything related to autism I don't really tend to do that. Not that I know everything about it, but just I come across it quite a lot now, so I think perhaps I then get a bit complacent with my understanding of that and perhaps don't always go back to literature - like those nuanced parts of it"

Theme 3: Limitations of diagnosis in EP practice

A principal reason for the limitations of diagnosis to EP practice (that is, to understanding behaviour) was the complexity and variability of behaviour, which meant that the same behaviour can be shaped by different underlying factors. This also meant that definition of behaviour in terms of RRBIs was not seen as useful to understanding it. Because the diagnostic term covers such a wide range of behaviours, participants felt that using this term to describe behaviour risks limiting their understanding of it. For example, one participant emphasised the individual differences in RRBIs:

> *"[…] let's imagine there's a population with repetitive behaviours or interests. They'll be so much variance within that population, and so much difference - like [X] said about them – in the contextual function. And then you can get really confused with the types and subtypes. For me it's much better to really think about it in a very contextualized way, and what that response serves […]. The variety of examples that could fall into that broader category would be so huge that actually it almost becomes meaningless, I think, for me."*

Another participant reflected on the difficulty of discussing how they practice with regard to RRBIs because of individual differences in behaviours:

> *"it's because probably a lot of the work that we do tends to be with individual children with autism. You cannot - it's so difficult. We're thinking of examples. We're thinking of how it applies in certain individual children rather than a general thing. Which is why - it may be why the results are coming out so - because you can't, there isn't - there isn't a sort of a catch all."*

There was reference to the variability in CYP's developmental profile, for example, their cognitive profile, as a factor that impacts on RRBIs. This is not highlighted in the diagnostic term. The interpretation of the same behaviour (as defined by diagnosis) would vary depending on CYP's profile. For example:

"And there's something particular about cognitive profile and whether or not you're talking about children and young people who have, kind of, more significant cognitive difficulties as opposed to more sophisticated, able young people who will have a different type of rigidities"

Another reason for considering diagnosis to be limited in its application to practice was because it does not recognise contextual factors and the reasons for the emergence of behaviour. For example, one participant highlighted the limitation of diagnosis in terms of not providing a holistic understanding of CYP:

"[…] So you hold that in one sense, you know, you've got this idea of the child comes with the autism, but then we also, we're looking at everything else that impacts on the child as well. So it's not that we would see RRBIs as purely an autism function in themselves either. This is something that you know, it's something that may come out of other factors in that child's life, in their environment, etc. So we do this, you know, all our kind of problem solving and everything else is done in a systemic way. It's not just a within-child, oh, they've got autism, so this is related to that and that's it sort of way, so, you know, we use lots of different methods in terms of exploring those systems."

Another participant commented on how they approach understanding need of autistic CYP within an ecosystemic framework, which the diagnostic criteria do not:

"always when I'm asked to go look at any sort of ASD need, I'm asking those questions of it: is it something more ecosystemic? But I think that the way restricted behaviours are conceptualized in the criteria doesn't make that very clear"

The concept of RRBIs was seen as 'not workable' because of the above limitations:

"it worries me that our thinking has restricted us to, you know, a very narrow concept, and I'm not sure that that is workable - you know, in the long term - in terms of understanding what RRBIs are, why they're there"

Theme 4: Questioning the goal of / need for intervention for autistic CYP

Much of the discussion was focused on questioning what the goal of intervention might be for RRBIs, and whether intervention is needed. There were three key elements (defined as subthemes) within this discussion. All focus groups emphasised the rejection of normalisation of behaviour and that this should not be the basis for defining outcomes*.* The following quote is an example of the question EPs raised about setting outcomes based on normalisation of behaviour:

> *"And how other people might interpret behaviour - and it's the motivation behind suppressing these behaviours to normalize to make them look normal like the rest, like a neurotypical - that's not OK, and actually we need to accept that some of these restricted repetitive behaviours, all of them actually, you know that those are self-regulating anyway, those that have a regulatory function are absolutely fine and we need to kind of educate peers and staff around the function and acceptance and encouragement of those."*

There was also broader discussion of outcomes across all areas of development rather than focusing on only specific areas such as academic learning. Behaviour was considered within a holistic assessment of development. For example:

> *"Schools come with concerns around not making progress in, say, cognition and learning, primarily so when they're talking about progress, often they're conflating that with academic progress or using it synonymously, […], and as [X] said, if we can evidence OK, well, fair enough, they might not have made progress in English […] however, we can see that socially they've made progress in this way […]"*

Within the context of defining developmental outcomes, there was discussion of identifying the alternative behaviour that is desirable when implementing interventions, rather than focusing on reducing behaviours (RRBI) per se. For example:

"Not necessarily how can we reduce that behaviour, but how can we enhance the other thing that we want to see? […] and actually if they're doing this, what are they not getting? What are the opportunities that they're missing and […] reframing it that way?"

The process of <u>reframing the meaning / function of RRBIs</u> was also emphasised as part of EP practice. This focused on identifying for whom and in what context behaviour is considered to be problematic, to challenge views that are based on normalisations of behaviour and to advocate for CYP views. Working with adult views around CYP was discussed specifically in the context of reframing how adults understand a behaviour and why they might see it as problematic:

"I think it's important when an educational psychologist is doing their assessment to look at the attitudes to the RRBI from different members of staff, parents and so on. Who does it affect? Who's feeling negative about it and why, you know? And is there a sense in which, you know, you might be able to reframe that for, you know, for all the adults around the child."

Concern of the acceptance of this way of working was mentioned by one participant. The participant reflected on the challenges that EPs may fact when communicating the EP approach to intervention, in contrast to other approaches:

"I've always been fascinated why parents like ABA and it's kind of because it seems to come with an easy cookbook as opposed to what we might come up with."

Theme 5: CYP participation in EP practice

EPs emphasised the inclusion of CYP in their practice. There was discussion about taking into account CYP views, and the rights of CYP to participate in decisions that affect them. For example:

"[…] Should we be the ones determining that that's an outcome? That he should stop doing that? And then clearly, you know he's quite happy in himself and whose decision is that? He hasn't expressed himself that he

wants to change this […] We had that conversation with the school that just because you're perceiving this to be problematic doesn't mean it is for the young person"

CYP rights and views were not necessarily discussed in terms of CYP's ability to decide and make a choice. There was broader emphasis on adults' responsibility to try to communicate with CYP to understand their perspective. However, there was also a related discussion about CYP's ability to make a choice. Participants made a distinction between CYP who could make a choice about changing their behaviour and may need support to achieve this. For example:

"I guess in my mind I think about it - where's the child experience in - child voice in this? That, you know, if a child's saying: this is causing me grief, it's getting in the way of me living, you know, a happy connected social life, I want some help - that's very different I think to, kind of, it being a problem for the adults around them"

An important factor in defining intervention was also the level of distress to CYP. For example, one participant discussed the distress that may be caused to CYP from interventions that aim to change behaviour in the short-term, rather than supporting gradual development:

"The pain of growth is different to the pain of trauma, and that's, kind of, if this, you know, like X said, if it's sort of a short-term bit of pain to sort of get everything in the world moving a bit better. That's to me a very, very different set of circumstances than something where it is just: right this will be done for your own good sort of thing."

3.6. Discussion

This study aimed to explore EP practice with regard to RRBIs. The research questions focused on whether the term RRBI is used in practice (RQ1), as well describing how EPs practice with regard to RRBIs (RQ2), including specific aspects of current EP practice: including assessment, defining outcomes and identifying interventions. RQ1 linked to Themes 1 and 3, and RQ2 linked to all themes.

RQ1. Is the term RRBIs used by EPs?
EPs only used the term RRBIs in specific contexts, such as when communicating with paediatricians or delivering training. The diagnostic term was accepted as part of the framework of diagnosis that is currently used, but not used in practice. There was a strong preference for neutral or positive language, which does not imply deficit. Additionally, the limitations of diagnosis in understanding the behaviour that is defined under the term RRBIs meant that the term was not seen as helpful to EP practice. Given these limitations, the term RRBIs was used in EP practice in a very limited way, specifically when discussing ASD diagnosis.

2. How do EPs practice with regard to RRBIs, including assessment, defining outcomes, identifying intervention?
EPs described their practice in terms of understanding the behaviour of autistic CYP. There were two elements that were strongly related to this. Because each behaviour varies based on contextual factors, identifying contextual factors that shape RRBIs were central to understanding that behaviour. The second element was understanding the function of behaviour for CYP. Function was defined in terms of the meaning of the behaviour and what CYP gained from it. For example, understanding its regulatory function or the expression of intrinsic interest. Only two participants referred to within-child factors, as one aspect of understanding behaviour. There was also a question of confidence which was only raised in the TEP group with regard to their understanding of autistic behaviours. TEPs wondered whether they spend enough time researching

autism because they work with so many autistic CYP that it feels familiar compared with rarer diagnoses.

The participants perceived significant limitations with the diagnostic term, which impacted on whether it was used in EP assessment and psychological formulation. The complexity and variability of behaviour was highlighted throughout the discussion. Each behaviour is shaped by different factors and, therefore, needs to be understood separately. EPs were particularly concerned with understanding the impact of contextual factors. The diagnosis was not seen as adding to this contextual understanding. EPs also discussed differences in behaviour in terms of its emergence. In other words, the behaviour would be shaped over time by contextual factors. It was difficult to draw meaningful comparisons between types of behaviours (i.e. types of RRBIs), because the same behaviour could be interpreted differently for each CYP, and across different contexts.

There was strong emphasis on CYP participation in EP practice. Discussion of the rights of CYP / CYP views emphasised in relation to understanding what the behaviour meant for CYP. There was no description of how CYP views are accessed, particularly when there are communication barriers. CYP views were discussed in terms of understanding how they may differ from those of the adults around them. There was particular concern with identifying whether the request for EP assessment was about behaviour not aligning with social norms.

The participants mostly questioned the need for outcomes to be set with regard to RRBIs. They were concerned with defining outcomes across all areas of development when discussing CYP needs, not isolated behaviours. As mentioned above, EPs were also concerned that the purpose of outcomes may be normalisation of behaviour, and that a behaviour that is perceived as problematic by adults around CYP is not necessarily problematic for CYP themselves. In other words, the outcome may be for the benefit of others not CYP themselves. The findings highlighted a strong ethical position in EP

practice, which emphasised the rights of CYP and advocacy against outcomes that essentially mean fitting in with neurotypical norms.

Intervention was mostly discussed in terms of encouraging an alternative behaviour, rather than trying to change an RRBI. Intervention was also discussed in terms of the process of 'reframing'. EPs saw their role as one of advocating for CYP in a context where adults around them may measure negative impact in terms of behaviour norms. In such cases they saw their role as engaging with the notion of normalisation and 'reframing' how the behaviour is understood by emphasising its meaning and function for CYP. There was also concern about intervention causing distress to CYP, if the intervention blocks behaviour or forces an alternative. Instead, intervention was defined in terms of gradual development. Finally, there was a consideration of CYP's ability to make choices as a prerequisite for intervention. This links to the emphasis on CYP rights to participate in decisions that affect them and the responsibility of EPs to access CYP views.

<u>Implications</u>

EPs are an important stakeholder for many CYP and, based on the above findings, their practice aligns with many of the arguments in the neurodiversity movement which call for an acceptance of autistic identity and understanding the meaning of behaviour for autistic CYP (as discussed in Chapter 1). The findings also align with the legislative context and bioecological framework for practice, that recognise the necessity of collaboration with families, understanding and respecting CYP views, and working within a holistic understanding of development. EPs could, therefore, play a key role in addressing current concerns about the research literature, including those voiced about ASD research more generally (as discussed in Chapter 1) but also the limitations identified in the SSR reported in Chapter 2.

The fact that there is continued emphasis on symptom reduction within the research literature suggests that any change may not be easily made.

Collaborative participation is essential and in order to achieve this there is a need for shared discourse and conceptualisation of behaviour. The research-practice gap in autism research has been highlighted by many (Parsons, 2021; Roche et al., 2021; Zuber & Webber, 2019). Parsons (2021) discusses several factors that need to be considered to address this. She cites longstanding arguments that there needs to be an equal sharing of power in education research if it is to be truly transformative. If research is to make an impact on practice then it must be inclusive. The research-practice gap is not about a lack of 'transfer of knowledge' from research to practice, but a more fundamental absence of practitioners and autistic individuals from the co-construction of knowledge. The framework of social constructionism is also relevant here. The subjective reality of autistic CYP is central to any understanding of their development. It is only through valuing their experience that research will be relevant to their lives.

Parsons et al. (2013) argue for school-based collaboration to address the (well-recognised) research-practice gap in autism education and research. They report that the perspective of many researchers to address this gap is that better quality research and better dissemination to practitioners is needed. The findings of the SSR reported in Chapter 2, suggest that the former may well be a significant factor in RRBI intervention research. But the SSR findings suggested that perhaps the quality of the research is not about the rigour of the methodology but about the conceptualisation of the intended outcomes. The underlying assumption in the RRBI intervention literature largely seems to be that RRBI reduction will lead to broader outcomes, rather than understanding what the need is for the specific participants (in specific contexts). Parsons et al. (2013) also note that the research-practice gap may be better addressed by focusing on individual needs, because this is the way that school practitioners work to support autistic CYP. Practitioners take a holistic view and do not focus specifically on one aspect of behaviour. The importance of focusing on need (rather than assuming need and intervention based on diagnosis) has also been made in reference to the support that CYP receive in the UK education system

(Dockrell et al., 2019). Changes in legislation were intended to move away from providing support based on diagnosis, because of variation in need between CYP with the same diagnosis. However, Dockrell et al. (2019) found that provision for CYP with developmental language disorder and ASD continue to be driven by diagnostic categories. In this case, autistic CYP were more likely to receive support that those with developmental language disorder, irrespective of their individual level of need.

Parsons et al. (2013) report an example of working in partnership with schools, which provided opportunities for better understanding between research and practice. However, they reflect that even with those participatory processes in place, they felt that it was difficult to change the researcher-led and data-driven nature of the research activity. This points to the challenge of establishing inclusive research practices, but their project also highlights the possibilities when participatory processes are adopted.

In the context of RRBI research, the research-practice gap may be difficult to bridge because of the different approaches to defining behaviour. Based on the findings from the focus groups, the avoidance or even 'rejection' of the term (and definition of behaviour as) RRBIs by EPs appeared to be more than just discomfort with the use a diagnostic term or its association with medical models of practice. Rather, the discussions suggested that the concept behind the term RRBIs is not useful to practice. There was a strong emphasis on the complexity and variability of behaviours that fall under the definition of RRBIs, which made its use difficult. Further, the term RRBIs was seen as limited in terms of the assessment that EPs do, which was largely discussed in terms of understanding the function of the behaviour for CYP and the role of contextual factors in shaping behaviour. These issues will be discussed further to explore what they might mean for the research-practice gap in relation to RRBIs.

Defining behaviour

From the perspective of the research literature, it is generally recognised that RRBIs are not easily categorised and putting behaviours into the same category risks obscuring differences (Kim & Lord, 2010; Turner, 1999). However, researchers may point to some agreement in their definition. A generally accepted distinction is that between low-level behaviours that involve a repetitive movement and have a sensory element, such as rocking, spinning or repetition of words, and higher-level behaviours, such as difficulty with changes in routine, excessive focus on specific interests, and object attachments (Bishop et al., 2013; Turner, 1999). Further, although the number of sub-categories of RRBIs that have been derived from diagnostic and assessment tools varies, there is some consistency. For example, factor analysis using the Repetitive Behaviour Scale Revised (RBS-R) has resulted in a five-factor structure: ritualistic/sameness behavior, stereotypic behavior, self-injurious behavior, compulsive behavior, and restricted interests (Lam & Aman, 2007). Other studies using the Autism Diagnostic Interview-Revised (ADI-R) have found two or three factors: sensory/motor behaviours, insistence on sameness and circumscribed interests, with the latter two being combined in a two-factor solution (Cuccaro et al., 2003; Smith et al., 2009; Szatmari et al., 2006). These categories of behaviour are reflected in the structure of the research literature.

However, there are issues with these categories of behaviour beyond their complexity and variability. EPs were uncomfortable with the language used, because it pathologises behaviour that serves a function for autistic CYP. Following a social constructionist perspective, where knowledge and experience is created through language, it is important for all stakeholders to understand how the language used shapes subjective perceptions of behaviour. This applies both to how neurotypicals understand autistic behaviour, as well as how autistic CYP think of themselves. Autistic diagnosis and whether to disclose is complex for many individuals and shaped by their everyday experiences (Leven, 2020; Mogensen & Mason, 2015). The language used in the diagnosis will be an important part of the development of their identity. While the

diagnostic language is well-established and may be hard to change, it is perhaps an essential part of developing a collaborative approach to research. The participation of autistic CYP to understand their experience of diagnosis would be essential to the development of joint discourse around behaviours that are currently termed RRBIs. Murray (2019), for example, who describes himself as an autist, argues that focused interests (what are termed as repetitive or restricted in diagnosis) are passions. He points out that all strong interests are repetitive in nature and this needs to be recognised rather than pathologising autistic interests.

While the dominant view of RRBIs may frame them as deficit, there exist alternative frameworks, as discussed in Chapter 2. EPs may be able to use such theoretical accounts, for example, monotropism (Murray et al., 2005; Murray, 2018) and flow (McDonnell & Milton, 2014), to frame the way that they work with RRBIs and through this to challenge the dominant, deficit-based discourse. Currently, alternative theoretical accounts are not as widely accepted. Fletcher-Watson and Happé (2019), for example, include monotropism in their discussion with the note that it "awaits empirical testing" (p.169). As discussed with reference to the findings of the SSR in Chapter 2, there are questions about the empirical basis of a deficit view of RRBIs, but nonetheless it is the dominant framework. This creates an additional challenge to EPs. However, alternative theoretical accounts can provide the framework (and language) within which examples from practice can be reported in a way that recognises autistic differences. For example, the interest-based interpretation of autism (Murray, 2018) explains the 'pull' towards an intense focus in a way that emphasises the positive feelings that arise from it. This contrasts with a deficit view of RRBIs, which frame the same behaviour in terms of a 'deficit' that prevents CYP from engaging in other behaviour that is considered more meaningful to a neurotypical observer. Murray (2018) explains how 'redirection', to shift attention, may be needed. However, the disturbance that this causes must be recognised, for example, by providing sufficient recovery time. This way of understanding RRBIs creates a space for positive or

neutral language and starts with describing the behaviour in terms of its function and meaning for the autistic individual, not the atypicality of it in reference to neurotypical norms.

Child-context interaction

The PPCT model defines development as interaction between a child and their context. This interaction is driven by the child and shaped by both within-child and contextual factors, over time. The research literature reviewed in Chapter 2 was criticised for emphasising within-child (diagnosis-based) factors. EPs, on the other hand, emphasised the role of contextual factors on shaping behaviour with only one participant in each of two focus groups referencing within-child factors at all. This area may be one where collaboration between different professionals (as well as participation of autistic CYP) may be helpful towards developing an understanding of atypical development. Both within-child factors and context are important in the PPCT model, even if intervention is focused on context. In other words, understanding within-child factors does not imply that intervention should focus on changing the person.

Some examples of within-child factors that may shape behaviour include differences in executive function (Brunsdon & Happé, 2014; Turner, 1999), atypical ways of detecting and processing changes in environmental stimuli (Fletcher-Watson & Happé, 2019), differences in physiological arousal (Lidstone et al., 2014), or intense interests that strongly 'pull' an individual's attention (Murray, 2019). It should be noted that these factors are complex and it is thought that various factors interact (Fletcher-Watson & Happé, 2019). It is not suggested that within-child factors could be considered outside of context. But they may inform psychological formulation. Working with this complexity would involve understanding how within-child factors (as experienced by autistic CYP) may shape child-context interaction.

It is interesting to note here that the relative emphasis on context in practice has been discussed in reference to the application of Bronfenbrenner's ecosystemic

model. Bronfenbrenner's work is often cited as a theory of the influence of context on development, with no reference to the active role of the child (Darling, 2007; Tudge et al., 2009). In Bronfenbrenner's later work, in particular, he paid significant attention to the role of the individual CYP, including biological factors (Bronfenbrenner, 2005; Bronfenbrenner & Ceci, 1994; Rosa & Tudge, 2013; Tudge et al., 2009). It may, therefore, be relevant to consider why EPs may have emphasised contextual factors and not discussed any within-child factors that inform their understanding of behaviour. Given the limitations of this study in terms of time and the nature of group discussion, the fact that EPs did not discuss within-child factors should not be interpreted as evidence that they do not consider them in their practice. However, it does suggest that they may at least have chosen to emphasise contextual factors.

One reason may be related to EP's confidence in their area of expertise. EPs develop expertise in applied psychology, including research skills. The importance of research skills and a research mindset inherent in a role as "scientist-practitioner" is reflected in the curriculum of training programmes (British Psychological Society, 2019; Eodanable & Lauchlan, 2009). However, an understanding of within-child factors may also require knowledge of other disciplines, such as cognitive psychology and neuroscience. This reflects a need for multi-disciplinary collaboration with equal participation from both practitioners, such as EPs, and other professionals.

Another reason why EPs may have emphasised contextual factors may be the perceived (or actual) dominance of a view of RRBIs in terms of symptom reduction (as highlighted in the findings of the SSR reported in Chapter 2). Within-child approaches to supporting development persist. For example, there are still pressures to treat 'within-child' factors for challenging behaviour with medication (Hill & Turner, 2016). The emphasis of EP discourse on context may reflect cautiousness from EPs to discuss within-child factors for fear of this being oversimplified as support for within-child *intervention*.

Perhaps, therefore, a necessary prerequisite for collaboration is building trust about the nature of the research outcomes. For example, there may be assumptions from practitioners about researchers' view on intervention being focused on CYP (not context). These may be well-founded given an existing emphasis on autistic symptom reduction. It may, therefore, help to include an initial process of developing shared ethical principles about intervention.

Accessing CYP views

The question of how to understand atypical development is important, even when categorically rejecting the normalisation of behaviour as a goal for intervention. As discussed in Chapter 1, there are differences in what is considered to be a desirable outcome by autistic people and their families. While the focus groups gave a clear description of EPs as problem-solvers within an ecosystemic and CYP-centred approach, further information about how autistic CYP views are understood would help to share best practice. In other words, what processes do (neurotypical) EPs use to understand atypical behaviour? This is noted in the 'double empathy problem', that is the barriers that both autistic and non-autistic individuals face in understanding each other (Milton et al., 2018). Appropriate methods may be necessary to overcome difficulties when engaging with autistic CYP and stakeholders, because of barriers to communication (Callahan et al., 2017; Elsabbagh et al., 2014; Nicolaidis et al., 2019). Palikara et al. (2018) have noted that despite changes in legislation to support CYP's active involvement in decisions that involve them, there is scarce empirical evidence of what happens in practice. It may, therefore, be important both for EP and wider practice, as well as for research, to try to define and share specific approaches and interventions that are successfully used in EP practice to access the views of autistic CYP that may be harder to reach.

Working with adults around CYP

The role of EPs in 'reframing' behaviour was highlighted, but only one participant noted potential challenges in achieving this. It has been noted that

the 'medical model' has persisted over a long period of time (Fallon et al., 2010), suggesting that 'reframing' views may be challenging to achieve. The medical model persists even though it is widely recognised that the diagnostic criteria are behaviour-based and the same behaviour can be shaped by different underlying factors (Fletcher-Watson & Happé, 2019). Given the persistence of the 'medical model', EPs could contribute to shaping research by exploring the barriers that they have experienced in their work with adults around RRBIs. There may be multiple factors contributing to how families perceive CYP's behaviour, such as their experience of stigma and the impact of RRBIs on family life, and, therefore, families may require longer-term support. Further, Gunn & Delafield-Butt (2016) argue that mainstream teachers may be acting on negative assumptions about RRBIs. Even though teachers may be focused on identifying strengths in CYP, the assumptions that they may hold about the function of RRBIs will affect whether these are seen as strengths or difficulties. Therefore, 'reframing' may require changing assumptions that teachers may not have had the opportunity to reflect on. This can happen through the process of consultation, which EPs use in their practice.

In summary, the reports of EP practice that were generated through the focus groups suggest that the way that EPs practice addresses the concerns of the neurodiversity movement and is aligned with legislation that recognises the rights of autistic CYP and their families to be involved in decisions that affect them. The research-practice gap is well-recognised but there are still significant challenges in addressing it. Systemic changes are needed to facilitate inclusive research practices, that value and respect the contribution of autistic CYP, practitioners and researchers equally. The discussion of the findings from the focus groups identifies some specific barriers to bridging the research-practice gap with respect to RRBIs. This included the language used to define behaviour, building trust about the ethical principles of intervention, shared understanding that within-child factors need to be understood in interaction with CYP's context, shared understanding of best practice on accessing the views of

autistic CYP, and an understanding of working with the adults around autistic CYP and providing them with the support that they need.

Study limitations

The empirical work was carried out in conjunction with SSR, but this combination of work also created limitations in terms of time constraints for further focus groups or follow-up surveys and interviews. The findings are, therefore, limited by the small number of participants and the fact that the participants were self-selected. The small number of participants in each focus group allowed time for everyone to contribute and the researcher did not identify reluctance from participants to express their view. However, the group dynamics may have hindered the expression of differences in opinion.

The focus groups were designed to be open-ended because there was little existing information to build on and the researcher did not want to impose a particular definition or framework of RRBIs. However, as discussed in the Methods section, this may have impacted on the depth of the discussion as it may have taken time to establish common ground. Further, as Robson and McCartan (2019) note, the focus group moderator influences data collection. The researcher will have influenced the discussion in the way that questions were presented, and the discussion was facilitated. The fact that the researcher was a TEP would also have potentially impacted on the dynamics of the discussion, both in groups with maingrade and senior EPs and in the group with TEPs. For example, it is possible that expression of uncertainty in EP practice only emerged in the TEP group because of the researcher's familiarity with the participants.

Focus groups are appropriate to "explore collective phenomena, not individual ones" (Robson & McCartan, 2019, p.202) and, therefore, the findings are interpreted in broad terms with regard to EP practice. Further research is needed to understand specific aspects of individual EPs' practice.

Finally, this research was undertaken as part of doctoral training in Educational Psychology. Consequently, the empirical work focuses on EP practice and the thesis is more generally shaped by the principles and frameworks that underpin EP training. Other professionals are also involved in supporting autistic CYP and may have provided different perspectives. Research with autistic CYP and their families would also have contributed a different perspective both on RRBIs and their experience of working with different professionals.

Future research

The focus groups helped identify questions for further research that focus on the details of EPs practice, which could ultimately help share best practice and influence how research is conducted. Individual interviews may be helpful in enabling more detailed analysis. This may be best achieved through discussion of individual CYP that EPs have been involved with. The role of EPs means that they frequently work with families and schools, as well as other professionals. It may, therefore, be possible to explore multiple perspectives on individual CYP needs, including CYP, parent, and teacher views, as well as the approaches used by other professionals (as detailed either interviews or through EPs' access to their reports). Focusing on the needs of individual CYP may help to ground the discussion.

The aim of future research may be best conceptualised in terms of setting up frameworks of collaboration with other professionals. In other words, to identify how the way that EPs practice can inform more meaningful research for autistic CYP and their families, but also how research can inform practice. As discussed in Chapter 1, there have been many calls for better alignment between research priorities and those of the people it intends to serve.

Chapter 4: Conclusion

The research reported in this thesis consisted of a SSR and empirical work with EPs. Each part had a different focus, but an overarching aim of this work was also to provide some insight into the relationship between published research on RRBI interventions and EP practice. The starting point for this research was an apparent dominance of a negative view of RRBIs in the research literature, which has raised concern from a neurodiversity perspective. This negative focus also appears to be contrary to the bioecological and CYP-centred frameworks and principles of EP practice. The apparent discrepancy between research and EP practice prompted the question of whether EPs contribute to the research evidence-base on interventions, and whether differences in approach meant that there are significant barriers to how the research literature can inform practice.

There have been many calls for autistic research to involve participation of autistic CYP and stakeholders in order to better serve their needs. The findings of the SSR reinforce these calls. As a whole, the research literature on RRBI interventions tends to be based on the assumption that RRBI reduction will correspond with broader developmental outcomes. The reason for intervention is largely assumed and not formulated with respect to the needs of the study participants. Further, the literature reflects a dominant focus on learning/vocational outcomes, rather than more meaningful outcomes such as individual well-being. CYP views are largely missing from this research, as is meaningful collaboration with parents/caregivers and teachers. While stakeholder views were often succinctly reported, there was no evidence of the kind of collaboration that would lead to joint understanding. There was no report of holistic problem-solving through consideration of the multiple contextual factors that impact on CYP behaviour.

The impact of the SSR part of this thesis pertains more to the design of research rather than practice, although this includes practitioner-reported

interventions. Dissemination of the findings from the SSR in a research publication may help to highlight the need to be clear about why RRBIs are targeted in intervention and to promote the involvement of CYP and stakeholders in a collaborative process. The SSR describes the bigger picture of RRBI intervention research, and this may lead to research that is better designed to understand for what purpose intervention may be necessary. This is not just an ethical point, but also a question of effectiveness. The findings form the SSR also add to existing calls for research to focus on achieving outcomes that are meaningful to CYP and their families.

In contrast to the findings of the SSR, the discussion of EP practice within the focus groups aligned with an acceptance of autistic identity and understanding the meaning of behaviour for CYP. EP practice also aligned with the current legislative context that recognises CYP and family rights to be involved in decision-making. Reports of EP practice also fitted the bioecological framework for practice which defines development in terms of child-context interaction. EPs described the difference between their practice and RRBI terminology as fundamental, stemming from the very definition of behaviour in terms of the diagnostic term. They reported that this definition of behaviour is not helpful to their practice, because it does not help to understand behaviour. Given the current differences between research and EP practice, it is unlikely that EPs contribute to this literature or that they are access it to inform their practice.

Implications for practice

EPs could play a key role in shaping the research literature, given their experience of working with autistic CYP and their families. However, the fact that there is continued emphasis on symptom reduction within the research literature suggests that any change may not be easily made. Collaborative participation requires some common ground. At the very least, there is a need to develop shared discourse and conceptualisation of behaviour. Given that there are significant differences from the very start, in the use of the term RRBIs, it appears that significant commitment may be needed from all sides to

find a common language. As discussed in Chapter 2, theoretical accounts exist that provide an alternative to the more dominant deficit-based language and frameworks.

There are some positive indications that a shift in the focus of RRBI intervention research may be feasible for part of it. In Chapter 2, it was noted that some research does report and measure reasons for intervening. The consideration of the needs of autistic CYP may be quite limited, focusing largely on barriers to structed learning. However, this does signal an intention to achieve broader outcomes, not just a reduction in symptoms. Further, as discussed in Chapter 2, while many studies are reported in terms of RRBI reduction, the intervention design is primarily focused on motivating engagement in alternative behaviour for the purpose of achieving broader outcomes. These interventions evaluate adjustment of contextual factors such as instructional approaches and sensory interventions. This research is still lacking in terms of participation and a holistic understanding of the needs of autistic CYP. But perhaps a shift in the underlying view of RRBIs may not be as fundamental as it would appear given the use of the diagnostic term. For this subset of research literature, the limitation may be more about the framework for reporting research in terms of symptom reduction rather than the researchers aiming to achieve this as a primary target. With the contribution of practitioners, such as EPs, this research could evolve into identifying more holistic and meaningful outcomes.

Significant change cannot happen without change in systemic factors that shape how research is carried out. There has to be equal participation if collaboration is to be effective, and a genuine desire to respect and listen to the expertise of all participants. However, as an initial step it may be helpful to share a different way of working. Currently, the research that is published with reference to RRBIs will not be linked to other research that takes a more holistic view of the needs of autistic CYP, because of a difference in the terms used. Perhaps contributing to the research literature with examples of EP practice (referencing and reframing the RRBI diagnostic term) may help to introduce a

different way of working and reporting research. There are specific reasons why EPs may be well placed to contribute. They work with multiple stakeholders and are skilled at accessing CYP views. They also work at a systemic level and can understand the bigger picture of what meaningful and equal collaboration needs to involve. EPs have research skills that are developed through doctoral level training. This places them in a position where they can be both critical consumers of research but also active participants in the research community. Achieving change at a systemic level will be challenging but in terms of impact would be a very significant step towards supporting the needs of autistic CYP and their families.

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Appendices

A.1. Systematic Scoping Review Protocol

Systematic review

This record cannot be edited because it is being assessed by the editorial team

1. * Review title.

Give the working title of the review, for example the one used for obtaining funding. Ideally the title should state succinctly the interventions or exposures being reviewed and the associated health or social problems. Where appropriate, the title should use the PI(E)COS structure to contain information on the Participants, Intervention (or Exposure) and Comparison groups, the Outcomes to be measured and Study designs to be included.

How have outcomes of interventions for restricted and repetitive interests and behaviours in autism been defined and by whom? Have interventions been effective beyond a reduction in the target behaviours?

2. Original language title.

For reviews in languages other than English, this field should be used to enter the title in the language of the review. This will be displayed together with the English language title.

3. * Anticipated or actual start date.

Give the date when the systematic review commenced, or is expected to commence.

01/06/2020

4. * Anticipated completion date.

Give the date by which the review is expected to be completed.

31/05/2021

5. * Stage of review at time of this submission.

Indicate the stage of progress of the review by ticking the relevant Started and Completed boxes. Additional information may be added in the free text box provided.

Please note: Reviews that have progressed beyond the point of completing data extraction at the time of initial registration are not eligible for inclusion in PROSPERO. Should evidence of incorrect status and/or completion date being supplied at the time of submission come to light, the content of the PROSPERO record will be removed leaving only the title and named contact details and a statement that inaccuracies in the stage of the review date had been identified.

This field should be updated when any amendments are made to a published record and on completion and publication of the review. If this field was pre-populated from the initial screening questions then you are not able to edit it until the record is published.

The review has not yet started: Yes

Review stage	Started	Completed
Preliminary searches	No	No
Piloting of the study selection process	No	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

Provide any other relevant information about the stage of the review here (e.g. Funded proposal, protocol not yet finalised).

6. * Named contact.

The named contact acts as the guarantor for the accuracy of the information presented in the register record.

Dr Katerina Avramides

Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:
Katerina

7. * Named contact email.

Give the electronic mail address of the named contact.

katerina.avramides@ucl.ac.uk

8. Named contact address

PLEASE NOTE this information will be published in the PROSPERO record so please do not enter private information

Give the full postal address for the named contact.

9. Named contact phone number.

Give the telephone number for the named contact, including international dialling code.

10. * Organisational affiliation of the review.

Full title of the organisational affiliations for this review and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

UCL Institute of Education

Organisation web address:
https://www.ucl.ac.uk/ioe/

11. * Review team members and their organisational affiliations.

Give the personal details and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong. **NOTE: email and country are now mandatory fields for each person.**

Dr Katerina Avramides. UCL Institute of Education
Dr Laura Crane. UCL Institute of Education
Vivian Hill. UCL Institute of Education

12. * Funding sources/sponsors.

Give details of the individuals, organizations, groups or other legal entities who take responsibility for initiating, managing, sponsoring and/or financing the review. Include any unique identification numbers assigned to the review by the individuals or bodies listed.

None

Grant number(s)

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13. * Conflicts of interest.

List any conditions that could lead to actual or perceived undue influence on judgements concerning the main topic investigated in the review.

None

14. Collaborators.

Give the name and affiliation of any individuals or organisations who are working on the review but who are not listed as review team members. **NOTE: email and country are now mandatory fields for each person.**

15. * Review question.

State the question(s) to be addressed by the review, clearly and precisely. Review questions may be specific or broad. It may be appropriate to break very broad questions down into a series of related more specific questions. Questions may be framed or refined using PI(E)COS where relevant.

1) How have outcomes in restricted and repetitive interests and behaviours and interests (RRBI) interventions been defined?

• What proportion of intervention studies have sought solely to reduce RRBIs and what proportion have defined broader outcomes?

• In those latter studies, how have broader outcomes been defined?

2) Have the views of the children and young people (CYP), parents/caregivers, or teachers been sought in setting outcomes for RRBI interventions?

• If so, what are their views? Are they aligned with each other?

3) Have RRBI interventions been effective in achieving outcomes beyond a reduction in the target RRBIs?

• If so, which interventions have been used and how are the outcomes defined?

16. * Searches.

State the sources that will be searched. Give the search dates, and any restrictions (e.g. language or publication period). Do NOT enter the full search strategy (it may be provided as a link or attachment.)

PubMed, MEDLINE (Ovid version - including In-Process and Other Non-Indexed Citations), CINAHL, EMBASE, CENTRAL (Cochrane Central Register of Controlled Trials), AMED (Allied and Complementary Medicine), PsycINFO, PsycARTICLES Full Text, PsycEXTRA, Child Development & Adolescent Studies, ERIC, Web of Science (Core collection, BIOSIS Previews), Scopus, Google Scholar, ProQuest Central (includes psychology and education), ProQuest Dissertations and Theses Full Text, eTHOS

Grey literature: Open DOAR, OpenGrey

Conference abstracts and Masters Theses will be excluded

Publications written in English

No date restrictions

17. URL to search strategy.

Give a link to a published pdf/word document detailing either the search strategy or an example of a search strategy for a specific database if available (including the keywords that will be used in the search strategies), or upload your search strategy.

Do NOT provide links to your search results.

https://www.crd.york.ac.uk/PROSPEROFILES/171910_STRATEGY_20200511.pdf

18. * Condition or domain being studied.

Give a short description of the disease, condition or healthcare domain being studied. This could include health and wellbeing outcomes.

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition. Restricted and/or repetitive behaviours and interests (RRBIs) are a core feature of ASD. RRBIs cover a range of behaviours, including repetitive and stereotyped movements, inflexibility in routines, highly fixated and perseverative interests which are abnormal in intensity, and unusual interests in sensory aspects of the environment.

19. * Participants/population.

Give summary criteria for the participants or populations being studied by the review. The preferred format includes details of both inclusion and exclusion criteria.

Inclusion criteria
- A diagnosis of Autism Spectrum Disorder, based on a validated ASD diagnostic tool
- A Restricted and/or Repetitive Behaviour or Interest, as identified by a diagnostic tool, interviews with parents/participants or researcher observations
- Between 0 - 24 years, to include children and young people (based on the World Health Organisation's definition of young people: 10 - 24 years)
- All genders.

20. * Intervention(s), exposure(s).

Give full and clear descriptions or definitions of the nature of the interventions or the exposures to be reviewed.

Any intervention that targets restricted and/or repetitive behaviours or interests either in isolation or within a broader intervention that targets ASD symptomatology.

This includes behavioural, developmental, educational or pharmacological interventions.

21. * Comparator(s)/control.

Where relevant, give details of the alternatives against which the main subject/topic of the review will be compared (e.g. another intervention or a non-exposed control group). The preferred format includes details of both inclusion and exclusion criteria.

Not applicable.

22. * Types of study to be included.

Give details of the types of study (study designs) eligible for inclusion in the review. If there are no restrictions on the types of study design eligible for inclusion, or certain study types are excluded, this should be stated. The preferred format includes details of both inclusion and exclusion criteria.

No restrictions on the types of study design eligible for inclusion.

Both quantitative and qualitative studies will be included.

23. Context.

Give summary details of the setting and other relevant characteristics which help define the inclusion or exclusion criteria.

24. * Main outcome(s).

Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is defined and measured and when these measurement are made, if these are part of the review inclusion criteria.

To determine how the outcomes of interventions on RRBIs have been defined and by whom.

Specific categories of outcomes will emerge from the review. These could be defined solely in terms of reduction of RRBIs, with regard to another outcome (such as social communication), a combination of both the above, or RRBIs could be

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targeted as part of broader ASD symptomatology. The review will determine what proportion of interventions fall into each category and whether this has changed in the last decade of research (as recommended in previous reviews).

As part of the above, to determine whether the views of the individual, their parents/caregivers and/or teachers have been taken into account in defining the outcomes of RRBI interventions.

* Measures of effect
Not applicable.

25. * Additional outcome(s).

List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main outcomes. Where there are no additional outcomes please state 'None' or 'Not applicable' as appropriate to the review

- Where the views of children and young people, their parents/caregivers and/or teachers have been sought in setting outcomes for RRBIs, to determine what their views are, and whether their views are aligned.

- Where the outcomes of RRBI interventions include broader outcomes (not solely the reduction of RRBIs), to determine whether the interventions have been effective and how the outcomes have been defined.

* Measures of effect
Not applicable.

26. * Data extraction (selection and coding).

Describe how studies will be selected for inclusion. State what data will be extracted or obtained. State how this will be done and recorded.

Studies will be screened through titles and abstracts according to the following criteria:

a) include at least one participant, between the ages of 0 and 24, with an ASD diagnosis,

b) evaluate an intervention that targets at least one behaviour that is defined in the study as an RRBI (as identified by a diagnostic tool, interviews with parents/participants or researcher observations)

OR evaluate an intervention that targets RRBIs as part of broader interventions on ASD symptomatology,

c) includes an outcome measure that relates to at least one behaviour that is defined in the study as an RRBI

OR includes an outcome measure that incorporates RRBIs (for example, broader measures on ASD symptomatology)

Study selection: one reviewer will review studies for inclusion, another reviewer (who will be blinded to the first reviewer's decisions) will review decisions on 20% of studies that will be randomly selected (a process also adopted in Harrop, C. (2015). Evidence-based [...]. Autism, 19(6), 662-672). Disagreements will be resolved through discussion.

The following data will be extracted from study documents:

a) participant information (number of participants, age, diagnostic category and how diagnosis was confirmed/verified),

b) intervention outcomes (primary outcomes, secondary outcomes),

c) who participated in defining the outcomes (researcher, child/young person, parent, teacher, other),

d) study design,

e) intervention design (intervention delivery, whether part of broader intervention approach, procedure),

f) outcome measures (definition, measurement),

g) results (changes in each outcome variable, maintenance of change over time).

h) publication date

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One reviewer will extract the data on all studies. A second reviewer will extract data on 20% of randomly selected studies; disagreements will be resolved through discussion.

Study authors will be contacted for missing data where possible.

Data will be recorded in an Excel spreadsheet.

27. * Risk of bias (quality) assessment.

Describe the method of assessing risk of bias or quality assessment. State which characteristics of the studies will be assessed and any formal risk of bias tools that will be used.

With regard to research question (1) all studies will be included in examining how outcomes of interventions are set as this pertains to the design of interventions. With regard to research question (2), an assessment of quality will be made in studies where the views of CYP, parents/caregivers or teachers has been sought. With regard to research question (3) studies will be included based on the quality of study designs. A range of study designs is expected.

The Mixed Methods Appraisal Tool (MMAT), which can appraise five categories of study designs (a) qualitative, (b) randomised controlled trial, (c) non randomised, (d) quantitative descriptive and (e) mixed methods studies. Five criteria are assessed for each type of study design. For example, for qualitative studies this includes appropriateness of the study approach to the research question, adequacy of the data collection methods, how the findings have been derived from the data, substantiation of the results in the data, and coherence of the data sources, collection, analysis and interpretation.

One reviewer will assess quality, another reviewer (who will be blinded to the first reviewer's decisions) will check decisions on 20% of randomly selected studies. Disagreements will be resolved through discussion.

28. * Strategy for data synthesis.

Provide details of the planned synthesis including a rationale for the methods selected. This **must not be generic text** but should be **specific to your review** and describe how the proposed analysis will be applied to your data.

Research question 1: How have outcomes in RRBI interventions been defined?

Content analysis will be used to categorise outcomes. Intervention studies will be further grouped by date, to establish changes in the past decade. Research question 1 is concerned with study design and not effectiveness.

Research question 2: Have the views of the CYP, parents/caregivers, or teachers been sought in setting outcomes for RRBI interventions?

Intervention studies will be categorised based on whether outcomes have been defined with contribution from CYP, parent/caregiver, teachers. For studies that have sought such views, thematic coding will be used to synthesise the data on the views that have been expressed separately from CYP, parents/caregivers, or teachers. Where the views of more than one individual have been sought, the alignment of these views within studies will be synthesised using thematic coding to identify areas of agreement or disagreement.

Research question 3: Have RRBI interventions been effective in achieving outcomes beyond a reduction in the target RRBIs?

Only studies that have found a reduction in RRBIs and have measured one or more non-RRBI outcome will be included. Based on a scoping review, a range of metrics for non-RRBI outcomes and study designs is anticipated. Vote counting based on directional effect will be used for synthesis. Studies will be grouped according to type of intervention, type of non-RRBI outcome, and type of RRBI. A detailed framework for grouping will emerge from analysis - at the highest level it will include: educational, behavioural, developmental, pharmacological (type of interventions); low and high level RRBIs (type of RRBI). Types of non-RRBI outcome will emerge from RQ1. Effect direction will be defined in terms of benefit or harm, depending on outcome definition (benefit could be defined as an increase in communication or a decrease in disruptive behaviour). Effect estimates will be reported where available.

29. * Analysis of subgroups or subsets.

State any planned investigation of 'subgroups'. Be clear and specific about which type of study or participant will be included in each group or covariate investigated. State the planned analytic approach.

None.

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30. * Type and method of review.

Select the type of review and the review method from the lists below. Select the health area(s) of interest for your review.

Type of review

Cost effectiveness	No
Diagnostic	No
Epidemiologic	No
Individual patient data (IPD) meta-analysis	No
Intervention	Yes
Meta-analysis	No
Methodology	No
Narrative synthesis	Yes
Network meta-analysis	No
Pre-clinical	No
Prevention	No
Prognostic	No
Prospective meta-analysis (PMA)	No
Review of reviews	No
Service delivery	No
Synthesis of qualitative studies	No
Systematic review	Yes
Other	No

Health area of the review

Alcohol/substance misuse/abuse	No
Blood and immune system	No
Cancer	No
Cardiovascular	No
Care of the elderly	No
Child health	No
Complementary therapies	No
COVID-19	No

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Crime and justice	No
Dental	No
Digestive system	No
Ear, nose and throat	No
Education	Yes
Endocrine and metabolic disorders	No
Eye disorders	No
General interest	No
Genetics	No
Health inequalities/health equity	No
Infections and infestations	No
International development	No
Mental health and behavioural conditions	Yes
Musculoskeletal	No
Neurological	No
Nursing	No
Obstetrics and gynaecology	No
Oral health	No
Palliative care	No
Perioperative care	No
Physiotherapy	No
Pregnancy and childbirth	No
Public health (including social determinants of health)	No
Rehabilitation	No
Respiratory disorders	No
Service delivery	No
Skin disorders	No
Social care	No
Surgery	No

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Tropical Medicine	No
Urological	No
Wounds, injuries and accidents	No
Violence and abuse	No

31. Language.

Select each language individually to add it to the list below, use the bin icon to remove any added in error.

English

There is not an English language summary

32. * Country.

Select the country in which the review is being carried out from the drop down list. For multi-national collaborations select all the countries involved.

England

33. Other registration details.

Give the name of any organisation where the systematic review title or protocol is registered (such as with The Campbell Collaboration, or The Joanna Briggs Institute) together with any unique identification number assigned. (N.B. Registration details for Cochrane protocols will be automatically entered). If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.

34. Reference and/or URL for published protocol.

Give the citation and link for the published protocol, if there is one

No I do not make this file publicly available until the review is complete

35. Dissemination plans.

Give brief details of plans for communicating essential messages from the review to the appropriate audiences.

A paper will be submitted to a leading journal in this field.

Do you intend to publish the review on completion?

Yes

36. Keywords.

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords will help users find the review in the Register (the words do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.

Autism Spectrum Disorder; Repetitive and restricted behaviours and interests; Intervention

37. Details of any existing review of the same topic by the same authors.

Give details of earlier versions of the systematic review if an update of an existing review is being registered, including full bibliographic reference if possible.

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38. * Current review status.

Review status should be updated when the review is completed and when it is published. For newregistrations the review must be Ongoing.

Review_Ongoing

39. Any additional information.

Provide any other information the review team feel is relevant to the registration of the review.

Following your feedback, I have added information in section 28 on how data will be synthesised.

40. Details of final report/publication(s) or preprints if available.

This field should be left empty until details of the completed review are available OR you have a link to a preprint.

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A.2. Search strategy

Overview of search concepts and sources

PICO concepts	DATABASES	Additional grey literature
Autism Spectrum Disorder Restricted and repetitive behaviours and interests Interventions	**Medicine/Health** PubMed Medline (Ovid version - including In-Process and Other Non-Indexed Citations) CINHAL EMBASE CENTRAL (Cochrane Central Register of Controlled Trials) AMED (Allied and Complementary Medicine) **Psychology** PsychINFO PsycARTICLES Full Text PsycEXTRA **Social science** Child Development & Adolescent Studies **Education** ERIC **Multi-disciplinary** Web of Science Core collection Web of Science BIOSIS Previews Scopus Google Scholar ProQuest Central (includes psychology and education) ProQuest Dissertations and Theses Full Text	Open DOAR OpenGrey Theses and dissertations that may not be published in EThOS https://ethos.bl.uk?

Handsearching journals	Journal of Autism and Developmental Disorders
	Autism
	Research in Autism Spectrum Disorders
	Autism Research
	International Journal of Developmental Disabilities
	Focus on Autism and Other Developmental Disabilities
Exclude	Conference abstracts and Masters Theses will be excluded
	Literature reviews, systematic reviews, meta-analyses will be excluded
	Animal studies will be excluded

Search concepts

	Concept 1		
Main concepts	Autism Spectrum Disorder		
Controlled vocabulary	<u>MeSH</u> Child Development Disorders, Pervasive [sub-terms: Autism Spectrum Disorder → Aspergers Syndrome & Autistic Disorder]		
Free text	**Keyword**	**Synonyms (alternate spelling, word)**	**Truncation* and Wilcard?**
	asperger	asperger asperger's aspergers	asperger*
	autism	autism autistic	autis* ["autis* spectrum disorder*/condition*"] kanner*
	kanner	kanner kanner's kanners	
	"pervasive developmental disorder"	"pervasive developmental disorder" "pervasive developmental disorders" "pervasive child developmental disorders" "pervasive development disorder" "pervasive development disorders"	"pervasive development* disorder*" "pervasive child development* disorder*"

		"pervasive child development disorders" "semantic-pragmatic disorder"	
	"semantic-pragmatic disorder"		
Excluded concepts	Review, systematic review, meta-analysis Animal studies, animal models		
Limit by:	English language, Human, No time limit, [0 – 24 years old]		

	Concept 2		
Main concepts	Restricted and repetitive behaviours and interests		
Controlled vocabulary	<u>MeSH</u> Echolalia Stereotyped behaviour		
Free text	**Keyword**	**Synonyms (alternate spelling, word)**	**Truncation* and Wilcard?**
	"special interest"	"special interest" "special interests"	"special interest*"
	"circumscribed interest"	"circumscribed interest" "circumscribed interests"	"circumscribed interest*"
	"restricted interest"	"restricted interest" "restricted interests"	"restricted interest*"
	"restricted activities"	"restricted activities"	
	"focused interest"	"focused interest" "focused interests" "focussed interest" "focussed interests"	"focus* interest*"
	"intense interest"	"intense interest" "intense interests"	"intense interest*"
	"object preoccupation"	"object preoccupation"	
	"pattern of interest"	"pattern of interest"	"pattern* of interest"

	"patterns of interest"	
"preferred interest"	"preferred interest"	"preferred interest*"
	"preferred interests"	
"preferred object"	"preferred object"	"preferred object*"
	"preferred objects"	
"perseverative interest"	"perseverative interest"	"perseverative interest*"
	"perseverative interests"	
RRBIs	RRBIs	
	RRBs	
"repetitive behaviour"	"repetitive behaviour"	"repetitive behavio*"
	" repetitive behaviours"	
	" repetitive behavior"	
	" repetitive behaviors"	
"repetitive pattern"	"repetitive pattern"	"repetitive pattern*"
	"repetitive patterns"	
"restricted pattern"	"restricted pattern"	"restricted pattern*"
	"restricted patterns"	
"repetitive movement"	"repetitive movement"	"repetitive movement*"
	"repetitive movements"	
stereotypy	stereotypy	stereotyp*
	stereotypies	
"motor behaviour"	"motor behaviour"	"motor behavio*"
	"motor behaviours"	
	"motor behavior"	
	"motor behaviors"	
"sensorimotor behaviour"	"sensorimotor behaviour"	"sensorimotor behavio*"
	"sensorimotor behaviours"	
	"sensorimotor behavior"	
	"sensorimotor behaviors"	
"stereotyped behaviour"	"stereotyped behaviour"	(included above in stereotyp*)
	"stereotyped behaviours"	
	"stereotyped behavior"	
	"stereotyped behaviors"	
	"stereotypic behaviour"	
	"stereotypic behaviours"	

		"stereotypic behavior" "stereotypic behaviors"	
	"stereotyped movement"	"stereotyped movement" "stereotypic movement"	(included above in stereotyp*)
	"self-stimulation"	"self-stimulation" "self-stimulatory"	"self-stimulat*"
	"ritualistic behaviour"	"ritualistic behaviour" "ritualistic behaviours" "ritualistic behavior" "ritualistic behaviors"	"ritualistic behavio*"
	"compulsive behaviour"	"compulsive behaviour" "compulsive behaviours" "compulsive behavior" "compulsive behaviors"	"compulsive behavio*"
	"obsessive behaviour"	"obsessive behaviour" "obsessive behaviours" "obsessive behavior" "obsessive behaviors"	"obsessive behavio*"
	"self-restricted behaviour"	"self-restricted behaviour" "self-restricted behaviours" "self-restricted behavior" "self-restricted behaviors"	"self-restricted behavio*"
	"repetitive use" "insistence on sameness" "repetitive speech" echolalia monotropism rocking "hand flapping" stimming resistance to change	"repetitive use" "insistence on sameness" "repetitive speech" echolalia monotropism rocking "hand flapping" stimming resistance to change	
Excluded concepts	As for Concept 1		
Limit by:	As for Concept 1		

	Concept 3		
Main concepts	Interventions		
Controlled vocabulary	<u>MeSH</u> Therapeutics Early intervention, Educational Behavior therapy [sub-term Applied Behavior Analysis] Clinical Trials, As Topic Drug Therapy		
Free text	**Keyword**	**Synonyms (alternate spelling, word)**	**Truncation* and Wilcard?**
	treatment	treatment treatments	treatment*
	intervention	intervention interventions	intervention*
	therapy	therapy therapies therapeutic	therap*
	modification	modification	
	reinforcement	reinforcement	
	clinical trial	trial trials clinical trial clinical trials	trial* "clinical trial*"
Excluded concepts	As for Concept 1		
Limit by:	As for Concept 1		

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Search strings

'Concept 1 search string':
> asperger* OR autis* OR kanner* OR "pervasive development* disorder*" OR "pervasive child development* disorder*" OR "semantic-pragmatic disorder"

'Concept 2 search string':
> "special interest*" OR "circumscribed interest*" OR "restricted interest*" OR "restricted activities" OR "focus* interest*" OR "intense interest*" OR "object preoccupation" OR "pattern* of interest" OR "preferred interest*" OR "preferred object*" OR "perseverative interest*" OR RRBs OR RRBIs OR "repetitive behavio*" OR "repetitive pattern*" OR "restricted pattern*" OR "repetitive movement*" OR stereotyp* OR "motor behavio*" OR "sensorimotor behavio*" OR "self-stimulat*" OR "ritualistic behavio*" OR "compulsive behavio*" OR "obsessive behavio*" OR "self-restricted behavio*" OR "repetitive use" OR "insistence on sameness" OR "repetitive speech" OR echolalia OR monotropism OR rocking OR "hand flapping" OR stimming OR "resistance to change"

'Concept 3 search string':
> treatment* OR intervention* OR therap* OR modification OR reinforcement OR trial* OR "clinical trial*"

'Title search to exclude systematic reviews/meta-analyses':
> "systematic review" OR "meta-analysis"

'Title search to exclude animal studies / animal models':
> mouse OR mice OR rat OR rats OR macaque OR macaques OR monkey OR monkeys OR mink OR minks OR parrot OR parrots OR rodent OR rodents OR murine OR "animal model*"

Database search strategies

Database search template

Steps in search strategy	Comment
1. Search in [database fields] for: ('Concept 1 search string' OR [concept 1 controlled vocabulary]) AND ('Concept 2 search string' OR [concept 2 controlled vocabulary]) AND ('Concept 3 search string OR [concept 3 controlled vocabulary])	Search for the 3 concepts (referred to below as the 'main search')
2. Limit (1) by English language (if available)	Only keep results that are written in English
3. Limit (2) by systematic reviews/meta-analyses (if available)	Limit the 'main search' results to those that are tagged as systematic reviews/meta-analyses
4. 'Title search to exclude systematic reviews/meta-analyses'	Database title search for systematic reviews/meta-analyses
5. (4) AND (2)	Title search for systematic reviews/meta-analyses in the 'main search' results
6. (3) OR (5)	All the results from the 'main search' that are systematic reviews/meta-analyses (either tagged or from the title search)
7. (2) NOT (6)	Remove the systematic reviews/meta-analyses from the 'main search' results
8. Limit (7) by animal studies (if available)	Limit the 'main search' results to those that are tagged as animal studies
9. Limit (7) by human (if available)	Limit the 'main search' results to those that are tagged as human
10. (8) NOT (9)	Remove the human results from the animal study results (i.e. those that are tagged as both animal and human, for example, interventions with animals)
11. 'Title search to exclude animal studies / animal models'	Database title search for animal studies/models
12. (11) AND (2)	Title search for animal studies/models title in the results of the 'main search'
13. (10) OR (12)	All the results from the 'main search' that are animal studies/models (either tagged or from the title search)
14. (7) NOT (13)	Remove the animal studies/models from the 'main search' results
15. Limit (14) by other filters (if applicable)	Limit the 'main search' results to other types of resources that are not applicable (for example, textbooks, lectures, audio-visual material, etc)
16. (14) NOT (15)	Remove other filters from the search results

Search parameters for each database

Database	Fields	Controlled vocabulary	Limits used				Other limits applied
			English	Reviews/Meta-analyses	Animal / Human	Other	
PubMed	Abstract/Title	MeSH	Yes	Yes	Yes	n/a	
MEDLINE Ovid	Abstract, Title, Keyword Heading Word	MeSH	Yes	Yes	Yes	n/a	
CINAUL	Abstract/Title/Subject	Yes	Yes	n/a	n/a	n/a	
EMBASE Ovid	Abstract, Title, Keyword Heading Word	MeSH	Yes	Yes	Yes	n/a	
Cochrane	Abstract, Title, Keyword	MeSH	n/a	Yes	n/a	n/a	
AMED	Abstract, Title, Keyword Heading Word	MeSH	n/a	Yes	n/a	n/a	
PsycInfo Ovid	Abstract, Title, Keyword	MeSH	Yes	Yes	Yes	Yes	review-book, review media, review software, encyclopaedia entry, obituary, poetry, classic book, handbook manual, reference book, textbook/study guide, authored book, edited book, encyclopaedia
PsycArticles Ovid	Abstract, Title, Keyword	n/a	n/a	Yes	n/a	n/a	
PsycExtra	Abstract, Title, Keyword	MeSH	n/a	n/a	n/a	Yes	brochure/fact sheet, monograph, periodical, speech/interview, standard/guideline
Child and Adolescent studies	Abstract, Title, Keyword, author supplied keyword	n/a	n/a	n/a	n/a	n/a	

ERIC EBSCO	Abstract, Title, Keyword	n/a	n/a	n/a	n/a	n/a	
WOS Core collection	Abstract, Title, Author Keywords, and Keywords Plus (TS - TOPIC)	n/a	Yes	Yes	n/a	Yes	Meeting abstract, book, news item, editorial material
WOS Biosis	Abstract, Title, Author Keywords, and Keywords Plus (TS - TOPIC)	n/a	Yes	Yes	Animal only	n/a	
Scopus	Abstract, Title, Keyword (TITLE-ABS-KEY)	n/a	Yes	Yes	Animal only	n/a	
ProQuest Central	Abstract, Title, Main subject headings	n/a	Yes	Yes	n/a	Yes	General information, commentary, correspondence, editorial, transcript, letter to the editor, book
ProQuest Dissertations	Abstract, Title, ALL subjects and indexing	n/a	Yes	n/a	n/a	Yes	Doctoral thesis only

MeSH terms or controlled vocabulary used

Database name	Concept 1	Concept 2	Concept 3
PubMed	child development disorders, pervasive [MeSH Term]	echolalia [MeSH Term] OR stereotyped behavior [MeSH Term]	therapeutics [MeSH Term] OR early intervention, educational [MeSH Term] OR behavior therapy [MeSH Term] OR clinical trials, as topic [MeSH Term] OR drug therapy [MeSH Term]

MEDLINE Ovid	exp Child Development Disorders, Pervasive/	exp Echolalia/ OR exp Stereotyped behavior/	exp Therapeutics/ OR exp Early intervention, Educational/ OR exp Behavior therapy/ OR exp Clinical Trials, As Topic/ OR exp Drug Therapy/
CINAUL	MH "Child Development Disorders, Pervasive+"	MH "Disruptive Behavior" (no subheadings) OR MH "Stereotyping" (no subheadings) (not in database) Echolalia/ (not in database) Stereotyped behavior	(MH "Behavior Therapy+") OR (MH "Therapeutics+") OR (MH "Clinical Trials+") OR (MH "Disciplines, Tests, Therapy, Services+") OR (MH "Behavioral Changes") (no subheadings)
EMBASE Ovid	exp autism/	exp Echolalia/ OR exp Stereotypy/ (instead of Stereotyped behavior/)	exp Therapy/ (instead of Therapeutics/) OR exp Early Childhood intervention/ (instead of Early intervention, Educational/) OR exp Behavior therapy/ OR exp Clinical trial (instead of Clinical Trials, As Topic/) OR exp Drug Therapy/
Cochrane	Child Development Disorders, Pervasive [mh]	Echolalia [mh] OR Stereotyped behavior [mh]	Therapeutics [mh] OR Early intervention, Educational [mh] OR Behavior therapy [mh] OR Clinical Trial [mh] OR Drug Therapy [mh]
AMED	exp autistic disorder/	exp Stereotyped behavior/	exp therapeutics/ OR exp Behavior therapy/ OR exp Clinical trials/ OR exp treatment outcome/ OR exp Drug Therapy/ OR exp Pharmacology/ OR exp Program evaluation/ OR exp Education/
PsycInfo Ovid	exp Autism spectrum disorders/	exp Echolalia/ OR exp Stereotyped behavior/	exp Negative Therapeutic Reaction/ OR exp Therapeutic Community/

			OR exp Therapeutic Environment/ OR exp Therapeutic Processes/ OR exp Therapeutic Social Clubs OR exp Early Intervention/ OR exp School based intervention/ OR exp Educational programs/ OR exp Intervention/ OR exp Special Education/ OR exp Behavior therapy/ OR exp Clinical Trials/ OR exp Experimentation/ OR exp Clinical practice/ OR exp Treatment Outcome/ OR exp Treatment effectiveness evaluation/ OR exp Drug Therapy/ OR exp Treatment/
PsycExtra	exp autistic disorders/	exp Echolalia/ OR exp Stereotyped behavior/	exp Negative Therapeutic Reaction/ OR exp Therapeutic Community/ OR exp Therapeutic Environment/ OR exp Therapeutic Processes/ OR exp Therapeutic Social Clubs/ OR exp Intervention/ OR exp Behavior therapy/ OR exp Experimentation/ OR exp Clinical Trials/ OR exp Treatment Outcome/ OR exp Treatment effectiveness evaluation/ OR exp Clinical practice/ OR exp Drug Therapy/ OR exp Treatment/

Additional searches (Grey literature and Google Scholar)

EThOS search

Limit of 6 search terms.
Searched permutations of concept 1 and 3, because of the limit on number of search terms:
- pervasive developmental disorder OR kanner OR asperger OR autism OR autistic
- with each of treatment OR intervention OR therapy OR modification OR reinforcement OR trial OR clinical trial

OpenDOAR

Searched for repositories by subject: Health and Medicine; Education; Psychology
Types of documents: Conference and workshop papers
Repositories search results: Queensland University of Technology ePrints Archive, Scholars Commons @ Laurier, KOPS, RDI.UCSG, Repositorio Institucional de la Universidad de Oviedo, HAL-HCL, HAL-Rennes 1, HAL Université de Savoie, HAL, OAR@UM, UMS Institutional Repository, Theses & Dissertations, Federal University Oye Ekiti Repository, Tilburg University Repository, Norwegian Institute of Public Health Open Repository, COPELABS Scientific commons, ScholarBank@NUS, The Open University of Tanzania Institutional Repository, Borys Grinchenko Kyiv University Institutional repository, Taurida National V.I. Vernadsky University Repository, Hamilton Digital Commons, D-Scholarship@Pitt, DigitalCommons@Lesley, Digital Commons @ EMUI, Kenyon College: Digital Kenyon - Research, Scholarship, and Creative Exchange, Digital Commons@Carleton College.

When there were limits on number of search terms, searched permutations of concept 1 and 3:
- pervasive developmental disorder OR kanner OR asperger OR autism OR autistic
- with each of treatment OR intervention OR therapy OR modification OR reinforcement OR trial OR clinical trial

OpenGrey & Google Scholar

A search for a combination of the 3 concepts was carried out.

A.3. Search results

Database name	Search dates	Concept 1 and 2 and 3 search results	Limit 1 applied (English)	*Limit 1 total removed*	Limit 2 applied (Systematic reviews and meta-analyses)	*Limit 2 total removed*	Limit 3 applied (animal)	*Limit 3 total removed*	Limit 4 applied (other)	*Limit 4 total removed*	Total results
PubMed	30/07/2020	1941	1850	91	1378	472	1092	286	0	0	**1092**
MEDLINE Ovid	29/07/2020	1949	1858	91	1382	476	1096	286	0	0	**1096**
CINAUL	30/07/2020	1019	1006	13	964	42	954	10	0	0	**954**
EMBASE Ovid	29/07/2020	3341	3189	152	2586	603	2153	433	0	0	**2153**
Cochrane	30/07/2020	240	0	0	233	7	0	0	0	0	**233**
AMED	29/07/2020	75	75	0	70	5	69	1	0	0	**69**
PsycInfo Ovid	29/07/2020	2252	2069	183	1965	104	1776	189	1542	234	**1542**
PsycArticles Ovid	29/07/2020	26	26	0	23	3	22	1	0	0	**22**
PsycExtra	29/07/2020	50	50	0	50	0	50	0	41	9	**41**
Child and Adolescent studies	30/07/2020	200	200	0	193	7	0	0	0	0	**193**
ERIC EBSCO	30/07/2020	341	341	0	325	16	324	1	0	0	**324**
WOS Core collection	29/07/2020	2373	2267	106	1805	462	1547	258	1505	42	**1505**
WOS Biosis	29/07/2020	2651	2587	64	2263	324	1858	405	0	0	**1858**
Scopus	30/07/2020	3142	2935	207	2343	592	1969	374	0	0	**1969**
ProQuest Central	30/07/2020	1809	1796	13	1689	107	1564	125	1017	547	**1017**
ProQuest Dissertations	30/07/2020	550	537	13	531	6	513	18	365	0	**513**

PRISMA diagram

Identification of studies via databases and registers

Identification

Records identified from:
PubMed (n = 1941), MEDLINE Ovid (n = 1949), CINAUL (n = 1019), EMBASE Ovid (n = 3341), Cochrane (n = 240), AMED (n = 75), PsycInfo Ovid (n = 2252), PsycArticles Ovid (n = 26), PsycExtra (n = 50). Child and Adolescent studies (n = 200). ERIC EBSCO (n = 341). WOS Core collection (n = 2373). WOS Biosis (n = 2651). Scopus (n = 3142). ProQuest Central (n = 1809). ProQuest Dissertations (n = 550)
TOTAL (n = 21,959)

Records removed *before screening*:
Duplicate records removed (n = 8,569)
Records removed, not in English (with duplicates n = 933; duplicates removed n = 471)
Records removed, reviews/meta-analyses (with duplicates n = 3,226; duplicates removed n = 814)
Records removed, animal studies/models (with duplicates n = 2,387; duplicates removed n = 614)
Records removed, other reasons (with duplicates n = 832; duplicates removed n = 707)

Screening

Records screened (n = 6012)

Records excluded (n = 5244)

Reports sought for retrieval (n = 768)

Reports not retrieved - Total n = 17 [book section (n = 1); report/journal (n = 7); thesis (n = 9)

Reports assessed for eligibility (n = 751)

Reports excluded:
Master theses (n = 65); Duplicate records of same study, e.g. thesis/journal article (n = 23); Short papers (n = 65); Incorrect citation (n = 1) Outside inclusion criteria (ASD diagnosis, RRBI or age) (n = 27), Outcome measure reporting does not separate RRBIs or RRBIs are measured as side-effect not behavioural outcome (n = 27), Study includes intervention but focus is other aspect (e.g. treatment integrity) (n = 20)

Reports included in the development of a content analysis framework (n = 523)

Included

Reports included (n = 564)

Identification of studies via other methods

Additional records identified from:
Handsearching journals (n = 25)
Additional grey literature (n = 0)
Alerts (n = 10)
Google Scholar (n = 1)
Followed up from trial protocol record (n = 5)

The full text of all records could be retrieved. Records were checked for duplicates with database searches, retrieved and assessed for eligibility at the time of the search.

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A.4. Ethical approval

Subject: Ethical approval granted for 18146038 / Katerina Avramides
Date: Monday, 11 May 2020 at 16:28:45 British Summer Time
From: IOE.Doctorate In Educational Psychology
To: Avramides, Katerina
CC: Baines, Ed, Hill, Vivian, Crane, Laura

Dear Katerina,

I am very pleased to inform you that your research project **'How have outcomes of interventions for restricted and repetitive interests and behaviours in autism been defined and by whom? Have interventions been effective beyond a reduction in the target behaviours?'** for the year 2 research project on the Doctorate in Professional Educational, Child and Adolescent Psychology, has been given ethical approval. If you have any further queries in this regard, please contact your supervisor.

Please note that if your proposed study and methodology changes markedly from what you have outlined in your ethics review application, you may need to complete and submit a new or revised application. Should this possibility arise, please discuss with your supervisor in the first instance before you proceed with a new/revised application.

Your ethical approval form has been logged and will be uploaded to the UCL IOE database.

Very best of luck with your data collection!

Many thanks,

Will

Will Matthews
Programme Administrator

Doctorate in Professional Educational, Child and Adolescent Psychology
UCL Institute of Education
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✉ ioe.DEdPsy@ucl.ac.uk

DEdPsy Programme Webpage

Participant Information Sheet For Educational Psychologists

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of Study:
How have outcomes of interventions for restricted and repetitive interests and behaviours in autism been defined and by whom? Have interventions been effective beyond a reduction in the target behaviours?

Department:
Psychology and Human Development, UCL Institute of Education

Name and Contact Details of the Researcher:
Katerina Avramides, katerina.avramides@ucl.ac.uk

Name and Contact Details of the Research Supervisors:
Laura Crane, l.crane@ucl.ac.uk
Vivian Hill, v.hill@ucl.ac.uk

1. About me and my research
I am a Trainee Educational Psychologist and you are being asked to take part in a focus group as part of my doctoral research project. Participation is voluntary. Before you decide whether you wish to take part it is important for you to understand why the research is being done and what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

2. What is the project's purpose?
The purpose of this project is to better understand how to support children and young people with a diagnosis of autism who display restrictive and/or repetitive behaviours and interests. The first part of this project involved a systematic review of the literature. The second part involves a questionnaire and focus groups on Educational Psychology practice. You are being asked to participate in the focus group.

3. Why have I been chosen?
You have been asked to participate because you are a qualified or trainee Educational Psychologist. We will run 2 focus groups, with 5-6 participants in each.

4. Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. You can withdraw at any time without giving a reason and without it affecting any benefits that you are entitled to. if you decide to withdraw

you will be asked what you wish to happen to the data you have provided up to that point.

5. What will happen to me if I take part?
You will participate in one focus group that will last up to 45 minutes about your practice with children and young people who have an autism diagnosis.

6. Will I be recorded and how will the recorded media be used?
The focus group will be audio or video recorded solely for the purpose of transcription and stored on an encrypted laptop. The audio/video recording will be destroyed immediately after transcription is completed.

7. What are the possible disadvantages and risks of taking part?
There are no right or wrong answers, but it is possible that you may feel that you are not giving the 'best' answer. The focus group will focus on a complex issue, on which there are no definitive answers. The purpose of this research is to understand your personal experience and practice of how to best support children and young people with an autism diagnosis.

8. What are the possible benefits of taking part?
Whilst there are no immediate benefits for those people participating in the project, it is hoped that this work will inform practice for Educational Psychologists, as well as other professionals working with children and young people with an autism diagnosis.

9. What if something goes wrong?
If, for any reason, you would like to complain about your participation in this research in the first instance please contact my supervisors, Laura Crane (l.crane@ucl.ac.uk) or Vivian Hill (v.hill@ucl.ac.uk). If you feel your complaint has not been handled to your satisfaction please contact the UCL Institute of Education Research Ethics Committee on ioe.researchethics@ucl.ac.uk

10. Will my taking part in this project be kept confidential?
All the information that we collect about you during the course of the research will be kept strictly confidential. Any personal identifiable information from the interviews will not be transcribed and the audio recordings will be destroyed immediately after transcription. The researcher will complete all the transcriptions.

You will not be able to be identified in any ensuing reports or publications.

11. Limits to confidentiality
Confidentiality will be respected unless there are compelling and legitimate reasons for this to be breached. If this was the case we would inform you of any decisions that might limit your confidentiality.

12. What will happen to the results of the research project?

The results of this research will be published within a doctoral thesis, in research articles and at conferences. The research data will be stored for a minimum of ten years.

13. Local Data Protection Privacy Notice
The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in research studies, please visit https://www.ucl.ac.uk/legal-services/privacy/ucl-general-research-participant-privacy-notice

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The lawful basis that would be used to process your *personal data* will be performance of a task in the public interest.

We will collect your name for the purpose of obtaining consent for your participation. However, your name will not be linked to the interview.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

14. Contact for further information
If you would like further information about this project please contact the researcher Katerina Avramides (katerina.avramides@ucl.ac.uk) or research supervisors: Laura Crane (l.crane@ucl.ac.uk) or Vivian Hill (v.hill@ucl.ac.uk).

This project has been reviewed and approved by the UCL IOE Research Ethics Committee.

If you have any questions about the above research project, wish to exercise your rights as a research participant, or wish to make a complaint, please send an email with details to the UCL Institute of Education Research Ethics Committee on ioe.researchethics@ucl.ac.uk so that we can look into the issue and respond to you. You can also contact the UCL Institute of Education Research Ethics Committee by telephoning +44 (0)20 79115449

You will be given a copy of this information sheet and a signed consent form to keep.

Thank you for reading this information sheet and for considering to take part in this research study.

CONSENT FORM

Title of research:

How have outcomes of interventions for restricted and repetitive interests and behaviours in autism been defined and by whom? Have interventions been effective beyond a reduction in the target behaviours?

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by ticking/initialling each box below I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

		Tick Box
1.	I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction and would like to take part in a focus group.	
2.	I understand that I will be able to withdraw my data up to 2 weeks after the focus group. As this is a group discussion, only your contributions will be withdrawn.	
3.	I consent to participate in the study. I understand that my personal information, i.e. my name, will be used for the purposes explained to me. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing.	

4.	**Use of the information for this project only** I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified. I understand that my data gathered in this study will be stored anonymously and securely. It will not be possible to identify me in any publications.	
5.	I understand that my information may be subject to review by responsible individuals from the University for monitoring and audit purposes.	
6.	I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason. I understand that if I decide to withdraw, any personal data I have provided up to that point will be deleted unless I agree otherwise.	
7.	I understand the potential risks of participating and the support that will be available to me should I become distressed during the course of the research.	
8.	I understand the direct/indirect benefits of participating.	
9.	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.	
10.	I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future.	
11.	I understand that the information I have submitted will be published as a report and I wish to receive a copy of it. Yes/No	
12.	I consent to my interview will be conducted remotely and will being audio or video recorded using UCL-approved software. I understand that the recording will be stored on an encrypted laptop and destroyed immediately following transcription.	
13.	I hereby confirm that I understand the inclusion criteria as detailed in the Information Sheet and explained to me by the researcher.	
14.	I hereby confirm that:	

	(a) I understand the exclusion criteria as detailed in the Information Sheet and explained to me by the researcher; and (b) I do not fall under the exclusion criteria.	
15	I am aware of who I should contact if I wish to lodge a complaint.	
16	I voluntarily agree to take part in this study.	
17	Use of information for this project and beyond I would be happy for the transcription of the interview I provide to be archived for 5 years. I understand that other authenticated researchers will have access to my anonymised data.	

_____ _____

Name of participant Date   Signature

_____ _____

Researcher   Date   Signature

Katerina Avramides

UCL Institute of Education
Department of Psychology and Human Development
katerina.avramides@ucl.ac.uk

Research supervisors
Laura Crane (l.crane@ucl.ac.uk), Vivian Hill (v.hill@ucl.ac.uk)

This study has been approved via the Department of Psychology and Human Development at UCL Institute of Education

A.5. Example screenshot of excel coding sheet for RQ1 and RQ2

A Reference number	B Authors	C Year	D Title	E Were CYP views sought on their RRBIs?	F Summarise what CYP views were (free text)	G Were parents views sought on RRBIs?	H Summarise what parent views were (free text)	I Were teacher views sought on RRBIs?	J Summarise what teacher views were (free text)	K Is one or more broader outcomes stated for targeting the RRBI(s)? For the specific participant(s)	L What is the broader outcome (category)? - 1	M Is there a corresponding outcome measured?	N What is the broader outcome (category)? - 2	O Is there a corresponding outcome measured?	P What is the broader outcome (category)? - 3	Q Is there a corresponding outcome measured?	R What is the broader outcome (category)? - 4	S Is there a corresponding outcome measured?	T Are other outcomes measured?	U Are the measured outcomes a reason for intervening re RRBIs for the ASD population (based on literature)?	V Outcome measure - 1 (additional outcome - not RRBI)	W Outcome measure - 2 (additional outcome - not RRBI)	X Outcome measure - 3 (additional outcome - not RRBI)
50	Boris, M., Goldblatt, A. and	2005	Improvement in children	Not reported		Not reported		Not reported		No - go to next white									Yes - answer blue	No			
51	Boris, M., Kaiser, C. C.,	2007	Effect of pioglitazone	Not reported		Not reported		Not reported		No - go to next white									Yes - answer blue	No			
52	Bova Toms, S., Janke, M. C., Loy,	2019	Research in Recreation	Not reported		Not reported		Not reported		No - go to next white									No				
53	Boyd, B. A., Hume, K., McBee, M.	2014	Comparative efficacy of LEAP,	Not reported		Not reported		Not reported		No - go to next white									Yes - answer blue	No			
54	Boyd, B. A., Woodard, C. R. and	2011	Modified exposure and	Not reported		Not reported		Yes	Completed interview (Interview	Yes - answer orange	Causes distress or anxiety to	Yes											
55	Boyd, B. A., Woodard, C. R. and	2013	Feasibility of exposure	Not reported		Not reported		Yes	Completed interview (Interview	No - go to next white									Yes - answer blue	Yes - answer green (as	Engagement in learning	Engagement in co-occuring	
56	Boyd, B., McDonough, S., Rupp,	2011	Effects of a Family-Implement	Not reported		Yes	Interefered with everyday	Not reported		Yes - answer orange	Interfers with daily activities or	Yes											
57	Boyle, M. A., Ortman, M. E.,	2018	Functional communication	Not reported		Not reported		Not reported		Yes - answer orange	Causes property destruction,	Yes											
58	The effects of multi-sensory	2014	The effects of multi-	Not reported		Not reported		Not reported		No - go to next white									Yes - answer blue	No			
59	Brogan, K. M., Rapp, J. T., Sennott,	2018	Further Analysis of the	Not reported		Not reported		Not reported		No - go to next white									No				
60	Bruhn, A. L., Balint-Langel, K.,	2015	Assessing and Treating	Yes	Interviewed (Student Functional	Not reported		Not reported	Interviewed (Preliminary	Yes - answer orange	Is socially inappropriate behaviour	No, but the outcome is essentially								No			
61	Brusa, E. and Richman, D.	2008	Developing stimulus control for	Not reported		Not reported		Not reported		Yes - answer orange	Interfers with learning or vocational	No								No			

Column A: record number; Columns B – D: publication details; Columns E - J: views for each stakeholder (Yes / Not reported), if yes what views were reported; Column K: was a reason for intervention specified; Columns L – S: If yes, what type and was a corresponding outcome measured; Column T: were outcomes other than RRBIs measured; Column U: If yes, were these linked to the literature on autism; Column V - X: if yes, what types of other outcomes were measured

A.6. Participant recruitment email

Dear all

I'm running two focus groups for my research and I would hugely appreciate your contribution.

The only criteria for participation are that you work as an Educational Psychologist in the UK, and that your practice includes work with children or young people who have a diagnosis of autism.

About my research

My research focuses on one of the two core features of autism, Restricted and/or Repetitive Behaviours and Interests (RRBIs). RRBIs include a range of behaviours, such as stimming, sensory motor movements, insistence on routines, difficulty coping with interruptions, intense interests, perseverative speech, etc.

RRBIs can have a significant impact on children and young people and their families. There is some evidence that they can interfere with learning and social interactions, but more recently RRBIs have also been described in positive terms.

I have completed a (comprehensive!) systematic review of the literature on RRBI interventions. The review has explored how outcomes of RRBI interventions have been defined, who has defined these outcomes for the CYP, and how effective the interventions are in terms of CYP functioning (not just a reduction in RRBIs – which is what has been reported in the literature to date).

About the focus group

I'm interested in how EPs think about RRBIs and how we formulate needs and outcomes that are relevant to such behaviours (though we may not use the term RRBIs).

The purpose of the focus groups is to discuss personal experience – I am not looking for expertise. I will share a short summary of my findings from the review at the start of the focus group. I will also have a few themes to feed into the discussion if needed, but I won't be rigid about what we discuss.

You don't need to have any particular expertise or experience to participate. You may not think of CYP's needs in terms of RRBIs. Perhaps using the term RRBIs seems too much like a medicalised approach. I would still like to hear from you.

Dates for focus groups

The focus group will last up to 45 minutes (depending on number of participants). It will be run remotely via Teams.

If you would like to participate and can make one of the following dates, please email me and I will send you more detailed information, the consent form, and Teams link.

I'm looking for up to 6 participants in each group (I will fill the places as I received responses).

1 – 1.45pm on Monday 15th March

OR

2 – 2.45pm on Friday 19th March

My email is: katerina.avramides@ucl.ac.uk

Thank you for reading this and I hope to hear from you.

Katerina

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