A personalised, co-produced sleep intervention: The impact of a personalised, co-produced sleep intervention on autistic children's sleep quality and mental health

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Abstract

The systematic literature review examined the relationship between autistic children's sleep and mental health. Thirteen studies met the inclusion criteria for the final review. Gough's Weight of Evidence framework was used to assess the studies' quality and relevance, while the AXIS checklist was used for assessing the methodological quality. This led to 13 studies receiving a 'medium' weight of evidence rating and 1 study receiving a 'high' rating. A significant positive relationship between sleep and mental health was found in the majority of studies, suggesting poor sleep can negatively impact autistic children's mental health. Implications and further research needed is discussed.

The empirical paper examined the effectiveness of a personalised sleep intervention on autistic children's sleep quality and mental health. A mixed-methods approach was employed, using a multiple baseline single case experimental design and semi-structured interviews. Six autistic children participated in the sleep intervention and 3 autistic children and 4 parents in the interviews. Pre-intervention, post-intervention and follow up data was collected for all 6 participants. However due to research constraints only 3 participants participated in the single case experimental design where visual analysis, Tau-U and PEM analysis were employed. A significant weighted average Tau-U small effect size was found, demonstrating the intervention had a positive effect on sleep quality on average across all 3 participants. However, individual analysis found a significant improvement in sleep quality for only 1 participant. Reliable Change Index analysis showed significant

improvements in sleep quality pre- to post-intervention for 1 of 6 participants and in mental health for 4 of 6 participants. The interviews shed light on participants' views of the sleep intervention and the relationship between sleep and mental health. Themes emerged, such as improved sleep outcomes, the child-led nature, enjoyment and accessibility of the routine, helping to inform development of future sleep interventions.

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Chapter 1: Introduction

1.1 Rationale for Topic

This thesis explores the relationship between autistic children's sleep and mental health in Chapter Two and Chapter Three evaluates the effectiveness of a personalised sleep intervention on autistic children's sleep quality and mental health. Finding appropriate sleep interventions for autistic children is the overarching theme for this thesis, considering the importance of sleep for daily functioning and mental health. This chapter will outline the rationale for the topic selection, epistemological and theoretical perspectives informing the methodological approach and research and end with an outline of the thesis organisation.

1.1.1 Autism

Autism Spectrum Condition (ASC) is a neurodevelopmental condition, characterised by the Diagnostic and Statistical Manual (DSM-5) by repetitive, restrictive patterns of behaviour, interests or activities and persistent social communication and interaction difficulties (American Psychiatric Association [APA], 2013). However, Autism diagnosis and language has often focused on a 'deficit-based' medical model. This model does not consider the strengths of autistic individuals (Ferreira et al., 2024). This is changing with the neurodiversity discourse shifting focus of autism to neurological differences rather than deficits. This has led to neurodiversity-affirmative language which captures heterogeneity, appreciates diversity and recognises

strengths. For example, having superior visual processing and attention skills (Black et al., 2023).

Prevalence rates of autism diagnosis have increased in recent years. In 2018, 2.94% of 10-14-year olds had a diagnosis of autism compared to 0.02% of adults over the age of 70 (O'Nions et al., 2023). Research suggests that there might be approximately 750,000 people over the age of 20 with undiagnosed autism. This increase is suggested to be related to increasing awareness, broadening diagnostic criteria and improved access to diagnostic services (Russell et al., 2022). Therefore, considering the needs of autistic individuals and appropriate support is becoming increasingly important.

1.1.2 The Importance of Sleep

Sleep is a basic human need, important for mental health, learning and physical health (Schlieber & Han, 2021). Sleep has two main processes: rapid eye movement (REM) sleep and non-rapid eye movement sleep (NREM). NREM consists of four stages related to varying levels of depth of sleep. The deeper sleep stage is proposed to be important for synaptic plasticity, essential for memory consolidation. The deepest NREM sleep stage is important for physical growth and strengthening the immune system. REM sleep is when dreaming occurs (Patel et al., 2024). The amount of sleep needed changes throughout the lifespan with younger children typically

needing more sleep than adults (Turnbull et al., 2013). The National Sleep Foundation recommends 9 to 11 hours sleep for school aged children (age 6-13), 8 to 10 hours for teenagers (age 14-17) and 7 to 9 hours for adults (age > 18) (Hirshkowitz et al., 2015). However, sleep difficulties are prevalent among children and young people with these difficulties changing with age. NHS statistics showed over 7 nights, 34% of children aged 7 to 16 years old had sleep problems (NHS, 2022).

1.1.2.1 Sleep and Autism

Functional MRI studies have shown key physiological benefits of sleep for emotional brain functioning. This includes the importance of sleep for regulating and expressing emotions, restoring next day emotion reactivity, processing and consolidating emotional memories (Goldstein & Walker, 2014). For example, one study found one night of sleep deprivation triggered a 60% amplification in reactivity of the amygdala, following being shown negative pictures, compared to a normal night's sleep (Yoo et al., 2007). Although this research was not specific to the autistic population, multiple studies have found a relationship between sleep quality and mental health for autistic children. This includes an association between sleep and anxiety (May et al., 2015; Mazurek et al., 2019; Mazurek & Petroski, 2015), sleep and depression (Martinez-Cayuelas et al., 2023; Phung et al., 2019) and general internalising and externalising difficulties (Bianca et al., 2024; Goldman et al., 2011; Kang et al., 2020; Park et al., 2012). Studies have found these difficulties persist through childhood and adolescence (Goldman

et al., 2011; Mazurek et al., 2019, 2019; Schreck, 2021). However, the relationship between sleep and mental health is proposed to be bi-directional with sleep affecting mental health and vice versa (Scott et al., 2021).

There are different types of sleep problems and disorders. The main sleep disorders are defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (APA, 2013). Compared to neurotypical children, sleep difficulties are prevalent among autistic children with research suggesting 50-80% of autistic children experience sleep problems (Veatch et al., 2015). Symptoms of insomnia (deficient sleep quality or quantity) are suggested to be the most prevalent sleep problem among autistic children, particularly sleep onset, maintenance and duration difficulties (Richdale & Schreck, 2009). It is suggested that inappropriate bedtime routines, bedtime associations and anxiety are associated with settling and night waking problems. It is proposed that variables can affect the circadian rhythm, such as decreased sensitivity to social cues and due to light sensitivity potential misalignment between circadian phase and light/dark cycles (Cohen et al., 2014). Research has found significantly lower melatonin production in day and night time in autistic individuals compared to typically developing controls (Tordjman et al., 2012). However, other studies have found a variance in melatonin production with some autistic individuals having normal melatonin profiles, highlighting the heterogeneity between autistic individuals. Alternative theories suggest that sleep problems are caused by co-occurring psychiatric and medical conditions that autistic children commonly have, such as gastrointestinal disorders leading to induced toilet awakenings in the night (Mannion & Leader, 2016). Nevertheless, it is suggested that the difference

in sleep schedules and behaviours among autistic children might be influenced by melatonin and altered rhythms (Cohen et al., 2014).

1.1.3 Sleep Interventions and Educational Psychology Practice

Behavioural sleep interventions are proposed to support autistic children's sleep quality, including sleep hygiene, environmental adaptions and parent training (Carnett et al., 2020; Kirkpatrick et al., 2019). This aligns with the National Institute for Health and Care excellence [NICE] (2013) guidelines, first using a behavioural approach alongside parents/carers to improve sleep quality. However, limited research to date has explored children's views on interventions and strategies they find helpful for sleeping, leading to a limited number of appropriate sleep interventions for autistic children (Pavlopoulou, 2020). Moreover, no research to date has examined the effectiveness of personalised, co-produced sleep interventions on autistic children's sleep quality and mental health.

Considering the important functions of sleep, relationship with mental health and prevalence of sleep difficulties among autistic children, finding appropriate sleep interventions is crucial. A meta-analysis, examining the effect of 72 interventions, found improving sleep quality had a medium-sized effect on mental health, reducing stress, anxiety and depression (Scott et al., 2021). Research suggests supporting children's sleep holistically is

important, considering environmental and personal factors (Pavlopoulou, 2020). Therefore, working with autistic children, parents, schools and professionals is key to supporting autistic children's sleep.

Educational psychologists (EP) support children's mental health and wellbeing, working directly with children and systemically (Rydzkowski et al., 2016). Rydzkowski et al. (2016) argues EPs have the training and skills to support children's sleep, considering the specific, holistic needs of children and the psychological components of interventions to support mental health and sleep. Therefore, EPs are in an ideal position to support autistic children's sleep through gathering children's views, delivering sleep interventions and supporting parents, schools and other professionals through consultations and training.

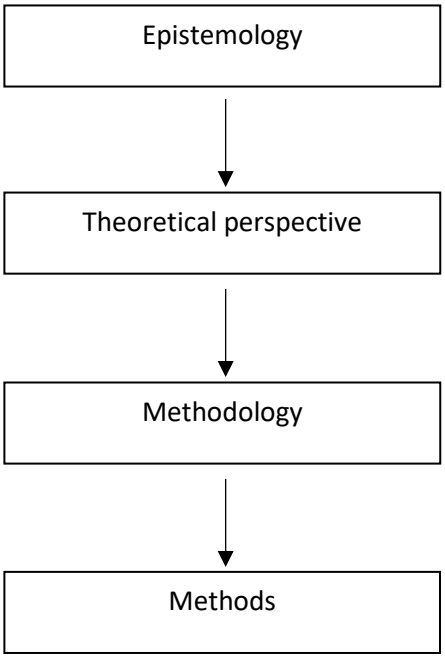
1.2 Epistemological Position

1.2.1 Epistemology

When conducting research, researchers need to consider their epistemological position with this position informing the methodological approach and methods. Epistemology is the "theory of knowledge" which describes how we come to know, understand and explain what we know (Barker et al., 2002; Crotty, 1998). Epistemology is proposed to inform the researcher's theoretical perspective which informs the methodology in the research questions, subsequently informing the choice and use of methods (Crotty, 1998). This is outlined in Figure 1.1, taken from Crotty (1998).

Figure 1.1

Four elements informing the research project (Crotty, 1998, p.4)



Alongside epistemology sits ontology, which considers the ‘study of being’, ‘what is’ and the ‘nature of existence’ (Crotty, 1998). Ontology also informs the theoretical perspective with each theoretical perspective helping to understand ‘what is’ (ontology), alongside understanding ‘what it means to know’ (epistemology).

There are argued to be three key epistemological positions which guide how we come to know things; objectivism, constructivism and subjectivism (Crotty, 1998). Objectivism is an epistemological view that things exist independently of our thoughts, feelings or experiences and instead objects exist independently with their own truth and meaning (Crotty, 1998). This view is more common in traditional scientific and quantitative research. Contrasting to this view, the epistemological subjectivism view believes meaning is created and shaped through individual’ minds and culture. This

view aligns more with qualitative research instead of quantitative research. Lastly, epistemological constructionism posits that meaning is constructed through people, built through individual experiences and our engagement with the world. Therefore, meaning can be constructed by different people in different ways (Crotty, 1998). Epistemological constructionism can align with both quantitative and qualitative psychological research.

This research aimed to understand the effects of a personalised sleep intervention, considering the effects for each individual participant, and the participants' views and experience of the sleep intervention. Therefore, this research's epistemological position was constructionist. Although single case experimental design examines individual behaviour in a controlled way, the design understands the interaction with and influence of environmental and contextual factors, fitting with the constructionist rather than subjectivist or objectivist views. Moreover, interview data was gathered through dialogue between the researcher and participant, with the meaning of the data being constructed, interpreted and understood through both the researcher and participants' context and experience.

1.2.2 Theoretical Position

This research is underpinned by a pragmatist theoretical position which believes knowledge is created from practical activity and the consequences (Cornish & Gillespie, 2009). Knowledge is viewed as a tool for action, constructing knowledge through action, considering methods and insights of modern science (Cornish & Gillespie, 2009; Riga, 2020). This means knowledge is created through processes and actions, resolving problems to

create new knowledge (Riga, 2020). Pragmatism recognises the importance of the natural, physical world alongside the psychological and social word, believing knowledge is both constructed and based on the reality of the world we experience and live in (Johnson & Onwuegbuzie, 2004). Dewey, the founder of pragmatism, applied pragmatic methods in educational practice to develop the philosophy, arguing the importance of considering practical and empirical consequences (Riga, 2020). It is also often used in psychology in relation to creating and evaluating interventions (Cornish & Gillespie, 2009). This is relevant to this research which explores the effects of a sleep intervention through implementing the intervention and evaluating the effects of it and participants' views to develop new knowledge and understanding.

1.2.3 Methodological Approach and Methods

The methodological approach informs the research questions and choice of methods. The methodology is informed by the epistemology and theoretical perspective. This research takes a mixed methods approach, combining both quantitative and qualitative research methods. Mixed methods is proposed to be a third research movement, using multiple methods to answer research questions, instead of restricting the researcher's options (Johnson & Onwuegbuzie, 2004). This enables the researcher to gather information to better answer the research question. This fits with the epistemological constructionist view and pragmatic approach, using quantitative and qualitative methods to answer the research questions.

This research employed a concurrent multiple baseline single case experimental design alongside using interviews to answer the research

questions. This enabled the researcher to analyse the effectiveness of the sleep intervention through quantitative methods and understand participant views about the sleep intervention through interviews. This aligns with the pragmatism approach, testing what works in the real world alongside providing a deeper understanding about participants' experience of the intervention to help understand the effectiveness and feasibility of the intervention. Moreover, the sleep intervention took place in the participants' natural home environment, helping to understand how the intervention works in real life practice.

1.3 Overview of Thesis

This introductory chapter has provided a rationale and background for the thesis topic, alongside explaining the epistemological and theoretical views informing the thesis. An overview of the other three chapters is provided below.

Chapter 2: Review Paper

The review paper involved a systematic literature review examining the relationship between autistic children's sleep and mental health. Prior to investigating the effects of a personalised sleep intervention on sleep and mental health, this review paper helped to understand the relationship between autistic children's sleep and mental health. In total, 14 peer reviewed studies which met the inclusion criteria were included in the final review. The quality and relevance of the studies were assessed using the Weight of Evidence Framework (Gough, 2007) and the methodological quality through the Axis Checklist (Downes et al., 2016) (see appendix D).

Significant positive relationships between sleep problems and mental health difficulties were found among the majority of studies, with effect sizes ranging from small to large. Where possible the relationship between particular mental health variables and sleep variables were considered, alongside developmental differences across ages, and differences between typically developing participants and autistic participants in relation to sleep and mental health. Implications for practice were considered.

Chapter 3: Empirical Paper

The Empirical Paper aims to investigate the effectiveness of a personalised co-produced sleep intervention on autistic children's sleep quality and mental health. Parental and child views on the relationship between sleep and mental health after the intervention were also explored, linking to Chapter Two. A mixed methods approach was chosen, using a multiple baseline single case experimental design and semi-structured interviews. Six autistic children participated in the sleep intervention and four of the parents and three of the children participated in the interviews. Pre-intervention, post-intervention and follow up sleep data was collected for all six participants (children). However, single case experimental design data was only collected for three of these participants due to research constraints. A weighted average significant Tau-U small effect size was found between baseline and intervention, demonstrating an overall positive effect of the sleep intervention on average across all three participants. However, only one participant had a significant Tau-U effect size from baseline to intervention, alongside an effective PEM effect size. One participant had a very effective PEM effect

size but non-significant Tau-U effect size and the third participant a questionable PEM effect size and non-significant small Tau-U effect size. The Reliable Change Index showed significantly reliable improvements in sleep quality for one of the six participants pre-post intervention and two participants pre-intervention to follow up. Reliably significant improvements were shown in mental health for four participants pre-post intervention and three participants pre-intervention to follow-up. Interview data suggests the sleep intervention led to improvements in sleep quality and shed light on the beneficial impact of the sleep routine, including its accessibility, flexibility, child-led nature and enjoyment of the routine. Interviews highlighted autistic children and parents' views on the relationship between sleep and mental health. Findings suggest sleep is important for wellbeing and resilience, impacting on emotional regulation, energy levels, mood, coping mechanisms and managing environmental demands. Further research is needed to extend understanding about the impact of personalised sleep interventions and to generalise the findings.

Chapter 4: Dissemination

In Chapter Four, a critical review of evidence-based practice and practice-based evidence is provided. The positioning of Chapter Two and Three in relation to these concepts is discussed, alongside the role of Educational Psychologists in evidence-based practice and practice-based evidence. The academic, societal, economic and political impact of Chapter Two and Chapter Three is considered. Following this, pathways to impact and dissemination strategies are outlined, considering how to disseminate

findings to academic and non-academic audiences. This includes publication to journals, presenting at research conferences, sharing findings with charities, professionals and other organisations. Draft abstract and titles of the two proposed papers are included for journal publication. At the end, a Gantt Chart illustrates the proposed timeline for the dissemination strategy.

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Chapter Two: Review Paper

What is the Relationship Between Autistic Children's Sleep and Mental Health?

2.1 Abstract

Sleep is a basic human function which is suggested to be important for daily functioning, child development and mental health. This systematic literature review examined the relationship between autistic children's sleep and mental health, from age 0 to 18. A systematic search on three databases (Web of Science, Psycinfo, Medline) identified 14 correlational studies for the final review. The studies quality and relevance were assessed through using Gough's (2007) Weight of Evidence Framework and the methodological quality through the Axis Checklist (Downes et al., 2016). The majority of studies received an overall 'medium' weight of evidence rating, considering the studies' methodological quality and relevance and topic relevance. The majority of studies demonstrated a significant positive relationship between sleep and mental health, with effect sizes ranging from small to large. This suggests poor sleep can negatively impact children's mental health. Although more research is needed in this area, examination of the relationship between specific mental health and sleep variables, developmental differences and comparisons with typically developing peers helped to better understand the relationship. This review highlights the importance of considering the impact sleep has on autistic children's mental health. Implications are discussed, including the need for educational psychologists and other professionals to assess and support children's sleep. Further research into developmental differences, sleep facilitating factors and appropriate sleep interventions for autistic children will be beneficial.

2.2 Introduction

2.2.1 Autism

Autism Spectrum Condition (ASC) is a neurodevelopmental condition, characterised by two broad areas of needs in social communication and interaction and restricted, repetitive patterns of behaviour, interests or activities (American Psychiatric Association [APA], 2013). ASC stems from early altered brain development and neural reorganisation (Lord et al., 2018). To be diagnosed with autism, individuals need to show evidence of difficulties in each of the three social communication domains; social-emotional reciprocity, non-verbal communicative behaviour, and deficits in developing, maintaining and understanding relationships. Alongside this, individuals must show difficulties in two of the four restricted repetitive sensory-motor behaviours including; stereotyped or repetitive motor movements, use of objects of speech; insistence on sameness, inflexible adherence to routines or ritualised patterns of non-verbal and verbal behaviour; highly restricted, fixated interests that are highly intense or focused; hyperactivity or hyporeactivity to sensory input or different interests in sensory aspects of the environment (Lord et al., 2018).

‘Autism Spectrum Condition’ is an umbrella term, including autism and related medical diagnosis, including Asperger’s disorder and pervasive developmental disorder. Autism is very heterogeneous and is viewed as a ‘spectrum’, ranging from mild to severe (Lord et al., 2018). There are varied views on the way autism is and should be described. Research from a study investigating the preferred terminology within the autistic community found that the most highly endorsed terms were ‘autism’, ‘on the autism spectrum’

and to a lesser extent ‘autism spectrum disorder’ (Kenny et al., 2016). Therefore, for the purpose of this review, the term ‘autism’ will be used.

2.2.2 Mental Health

Mental health difficulties have increased from 2017 to 2021, from 11.6% to 17.4% in 6 to 16 year olds and from 10.1% to 17.4% in 17 to 19 year olds (NHS Digital, 2021). Mental health difficulties are particularly prevalent among autistic children and adolescents. A meta-analysis found the prevalence of depression is four times higher in autistic children and adolescents, under the age of 18, compared to typically developing peers (Hudson et al., 2019). Moreover, anxiety disorders are suggested to be more than two times higher in autistic children compared to typically developing peers (Costello et al., 2005). A systematic review of 31 studies including participants all aged under 18 years old, found 39.6% of autistic individuals had at least one anxiety disorder with a specific phobia being the most common (29.8%), followed by OCD (17.4%), social anxiety disorder (16.6%), agoraphobia (16.6%), generalised anxiety disorder (15.4%), separation anxiety disorder (9%) and panic disorder (1.8%) (van Steensel et al., 2011). However, it is argued that due to the overlap between autistic features and anxiety symptoms, such as social difficulties and avoidance, it can be difficult to assess anxiety in autistic individuals (Kerns & Kendall, 2014). This is suggested to potentially lead to under-diagnosis (anxiety symptoms viewed as autistic symptoms) or over-diagnosis where autistic symptoms are viewed as symptoms of anxiety. Nevertheless, mental health difficulties appear to be prevalent among autistic children and adolescents.

2.2.3 Sleep

Sleep is proposed to be crucial for child development, being important for physical health, cognitive functioning and socioemotional functioning (Schlieber & Han, 2021). Younger children typically need more sleep than older children and adults and the required amount of sleep decreases throughout childhood (Schlieber & Han, 2021). Children aged 6-12 years are recommended to need 9-12 hours of sleep a night and adolescents, aged 13-18, require 8-10 hours of sleep a night (Great Ormond Street Hospital for Children, 2020). However, many children and young people are not getting the required amount of sleep with 28.7% of 6 to 10-year olds, 38.4% of 11 to 16 year olds and 57.1% of 17 to 23 year olds experiencing problems with sleep on three or more nights. These statistics were higher among all age groups of individuals with a probable mental health disorder (respectively 59.5%, 74.2%, 86.7%) (NHS Digital, 2021).

Sleep problems are particularly prevalent among autistic children with 50-80% experiencing sleep problems, mainly related to sleep onset or maintenance (Veatch et al., 2015). Comparatively, 11-37% of typically developing children experience sleep problems. Sleep problems experienced by autistic children are suggested to be caused by neurobiological, medical or behavioural factors. Additionally, there is a high prevalence of mental health difficulties, particularly anxiety and depression, among autistic individuals. Insomnia has been associated with anxiety and depression and therefore might be linked to sleep difficulties among autistic individuals (Richdale & Schreck, 2009).

The main sleep disorders for all children, including autistic children, are outlined by the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (APA, 2013). These disorders include: insomnia disorder (deficient quantity or quality of sleep); hypersomnolence disorder (excessive daytime sleepiness), including narcolepsy (periods of excessive daytime sleepiness often alongside muscle weakness); breathing-related sleep disorders including obstructive sleep apnea hyponea (blood oxygen desaturation caused by respiratory obstruction during sleep), circadian rhythm sleep-wake disorders (disruption of alignment between endogenous and exogenous sleep/wake rhythm); parasomnias (non-epileptic paroxysmal events during sleep) including non-rapid eye movement sleep arousal disorders, nightmare disorders and rapid eye movement sleep behaviour disorder; restless legs syndrome (urge to move the legs or other body parts with an uncomfortable sensation).

Subjective sleep parameters, deduced from interviews, sleep diaries and questionnaires enable clinicians to estimate subjective sleep items. These sleep parameters include; bedtime resistance, sleep-onset difficulties, night awakenings, sleep duration, difficulties with morning awakenings, daytime sleepiness, sleep-disordered breathing, restless sleep and parasomnias (Cortese et al., 2020). Objective sleep parameters are derived from methods such as actigraphy (a wearable sleep device that tracks sleep activity) and polysomnography (a test that measures brain and body activity while sleeping). These parameters include; sleep-onset latency (the amount of time it takes to fall asleep), number of stage shifts in total sleep time, number of stage shifts/ hours sleep, percentage of stage 1 sleep, percentage of stage 2

sleep, percentage of slow-wave sleep (deep sleep), rapid eye movement (REM) sleep latency, percentage of REM, sleep efficiency assessed with polysomnography, sleep efficiency assessed with actigraphy, true sleep on actigraphy, night wakings on actigraphy, average time to fall asleep at multiple sleep latency test and Apnea-Hypopnea Index (quantifies the severity of sleep apnea, a condition where breathing stops while sleeping) (Cortese et al., 2020).

The most commonly found sleep problems among autistic children are proposed to be symptoms of insomnia, including sleep onset and maintenance problems and sleep duration (Richdale & Schreck, 2009). A systematic review with a meta-analysis examining sleep problems in autistic children found autistic children compared to typically developing controls, scored significantly higher on bedtime resistance, sleep onset delay, sleep anxiety, parasomnias, night awakenings, sleep disordered breathing, sleep onset latency, daytime sleepiness, restorative value of sleep, general sleep problems and lower sleep duration. However, autistic children compared to control individuals did not significantly differ in sleep quality, sleep efficiency or sleep duration (in minutes). For objective measures, autistic children had a significantly lower total sleep time, higher time spent in stage 1 sleep, lower sleep efficiency, lower time of rapid eye movement (REM) sleep and higher time awake after sleep onset (Díaz-Román et al., 2018).

2.2.4 Relevance to Educational Psychology Practice

Sleep is important for children's mental and physical health and cognition and learning (Stores, 2009). It is argued that poor sleep can negatively impact

memory, concentration, decision-making and general learning. A review evaluating the association between sleep and memory in typically developing children and adolescents, found most studies supported the hypothesis that sleep is important for the working memory and memory consolidation (Kopasz et al., 2010). Findings demonstrated that higher brain functions, which are needed in abstract and complex tasks, declined after sleep deprivation. Similarly, a review found sleep problems in autistic individuals negatively affected multiple cognitive functions, including memory consolidation, declarative memory, spatial memory, selective attention, memory recall, impaired intelligence and verbal skills (Shaw et al., 2022).

In relation to mental health, a review found associations in typically developing children and adolescents between sleep and anxiety, depression and behavioural problems (Gregory & Sadeh, 2012). Similarly, one review examined the relationship between sleep and behaviour in autistic children and found sleep disruption to be associated with emotional and behavioural difficulties, including internalising and externalising symptoms (Cohen et al., 2014). For example, studies found sleep difficulties were associated with aggression, non-compliance, overactivity and affective problems which can all affect daytime functioning. However, no reviews to date have examined the association between sleep and mental health in autistic children and adolescents. Therefore, more understanding is needed about the association between sleep and mental health in autistic children and adolescents.

The SEND Code of Practice (Department for Education & Department of Health and Social Care, 2015), the government guidance on ‘mental health

and behaviour in schools' (Department for Education, 2018) and the 'transforming children and young people's mental health provision' green paper (Department for Education & Department of Health and Social Care, 2017), all highlight the importance of schools, Educational Psychologists (EP) and other professionals identifying and supporting children's mental health. With increasing prevalence of mental health and sleep difficulties among autistic children and adolescents, developing the understanding of the association between sleep and mental health is important. This could help EPs and other professionals understand the consequences of poor sleep on autistic children' and adolescents' mental health.

Therefore, this review aims to address the following question:

What is the relationship between sleep and mental health in autistic children and adolescents?

The review will outline the systematic literature search strategy, followed by critical appraisals of the identified studies, including examining participants, measures, research design and analysis and the study findings and effect sizes. The review will end with the conclusion and recommendations for future research.

2.3 Critical Review of the Evidence Base

2.3.1 Systematic Literature Search

The systematic literature review was conducted in July 2023 and August 2024, using the following databases: Medline, Web of Science and PsycInfo. Medline and PsycInfo were searched through OVID. These databases cover

medical, psychological and health literature. The search terms used are outlined in Table 2.1.

The initial search identified 1120 papers in total across the three databases, with 44 found on Medline, 906 on Web of Science and 170 on PsycInfo. Following removing 12 duplicates, the titles and abstracts of 1108 studies were screened, using the inclusion and exclusion criteria, outlined in Table 2.2. This led to 1071 studies being excluded and 37 articles being full-text screened, resulting in 12 studies meeting the inclusion criteria for the review

Through using the same databases and search terms, an additional search was conducted on 6th August 2024 (Appendix A). To identify all articles published between the original search date and August 2024, the date range was modified. This search produced 23 studies on PsycInfo, 32 studies on Medline, and 163 on Web of Science. These studies were screened by title and abstract. Following removing two duplicates, full text screening was carried out on 17 articles and 2 met the inclusion criteria to be included in the final review. This resulted in 14 studies being included in the final review. This search process is outlined in Figure 2.1, using the PRISMA (2020) flow diagram template, and excluded studies are referenced, with reasons, in Appendix B.

Table 2.1

Search Terms

Search Criteria	Databases		
	Medline	Web of Science	PsycInfo
Autism	Autis* OR ASC OR ASD	Autis* OR ASC OR ASD	Autis* OR ASC OR ASD
AND			
Sleep	Sleep	Sleep	Sleep
AND			
Mental health	mental health OR well*being or anxiety or depressi* or behaviour or behavior	mental health OR well*being or anxiety or depressi* or behaviour or behavior	'mental health' OR wellbeing or anxiety or depressi* or behavi*
Child	Child* or adolescen*	Child* or adolescen*	Child* or adolescen*

Table 2.2

Inclusion and Exclusion Criteria

Study Feature	Inclusion Criteria	Exclusion Criteria	Rationale
1. Type of publication	Study published in a peer-reviewed journal	Study is not from a peer-reviewed journal	Peer-reviewed journals are of a high academic and scientific standard, having been evaluated by expert reviewers
2. Participants	Must include autistic children between the age of 0-18	Sample does not include autistic children between the age of 0-18	This review is evaluating the relationship between sleep and mental health in autistic

Study Feature	Inclusion Criteria	Exclusion Criteria	Rationale
			children and adolescents
	Participants who are not treated with medication or therapy as part of the study	Participants who are being treated with medication (e.g. melatonin) or therapy as part of the study	Medication, such as sleep or mental health medication, or therapy could influence the mental health and sleep relationship.
3. Diagnosis	Children must have a diagnosis of autism	Children without a diagnosis of autism	This review is evaluating evidence related to autistic children and adolescents
4. Outcomes	One or more outcome measures that measure both sleep and internalising mental health difficulties (e.g. anxiety, depression)	Outcome measures that do not measure sleep and internalising mental health difficulties (e.g. anxiety, depression)	This review is examining the relationship between sleep and mental health
	Must measure the relationship between sleep and mental health specifically among autistic participants	Does not measure the relationship between sleep and mental health and does not measure this relationship specifically among autistic participants (e.g. if typically developing peer control group is also included in	

Study Feature	Inclusion Criteria	Exclusion Criteria	Rationale
		the analysis and not separated)	
5. Study Design	The study uses a correlational design, examining the relationship between two variables without manipulating them. Studies using the following common analytic methods will be included: bivariate correlation, partial correlation, regression, path analysis and structural equation modelling.	The study is not a correlational design and includes analytic methods different to bivariate correlation, partial correlation, regression, path analysis and structural equation modelling.	This review seeks to understand the relationship between mental health and sleep and therefore a correlational design best fits this question. This is because correlation analysis examines the association between two variables, helping to understand how change in one variable predicts change in another variable.
6. Language	The study is published in English	The study is not published in English	The author's first language is English. Therefore, this ensures the article can be fully understood and evaluated.

Figure 2.1

PRISMA (2020) Literature search process

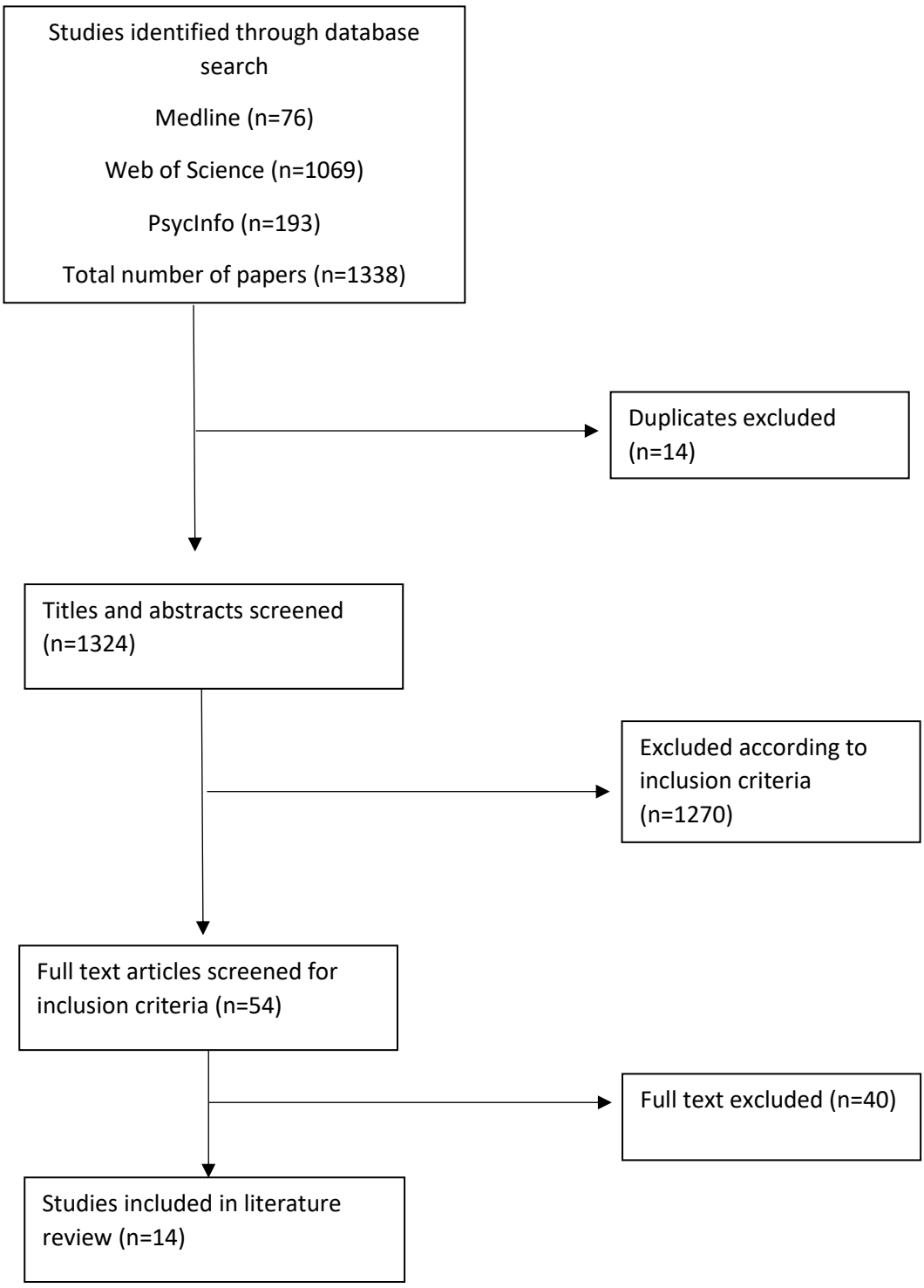

Table 2.3

Included studies

Included Studies
Bianca, B., Silvia, G., Elisa, F., Deny, M., Giovanni, V., Lino, N., & Stefano, V. (2024). Insomnia in Children with Autism Spectrum Disorder: A Cross-Sectional Study on Clinical Correlates and Parental Stress. *Journal of Autism and Developmental Disorders*, *54*(1), 46–55. https://doi.org/10.1007/s10803-022-05793-8
Goldman, S. E., McGrew, S., Johnson, K. P., Richdale, A. L., Clemons, T., & Malow, B. A. (2011). Sleep is associated with problem behaviors in children and adolescents with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders*, *5*(3), 1223–1229. https://doi.org/10.1016/j.rasd.2011.01.010
Kang, Y., Song, X., Wang, G., Su, Y., Li, P., & Zhang, X. (2020). Sleep Problems Influence Emotional/Behavioral Symptoms and Repetitive Behavior in Preschool-Aged Children With Autism Spectrum Disorder in the Unique Social Context of China. *Frontiers in Psychiatry, 11, 273*. https://doi.org/10.3389/fpsyt.2020.00273
Martinez-Cayuelas, E., Gavela-Perez, T., Rodrigo-Moreno, M., Pozo, R., Moreno-Vinues, B., Garces, C., & Soriano-Guillen, L. (2023). Sleep Problems, Circadian Rhythms, and Their Relation to Behavioral Difficulties in Children and Adolescents with Autism Spectrum Disorder. *Journal of autism and Developmental Disorders*, 54, 1712-1726. https://doi.org/10.1007/s10803-023-05934-7
May, T., Cornish, K., Conduit, R., Rajaratnam, S. M. W., & Rinehart, N. J. (2015). Sleep in high-functioning children with autism: Longitudinal developmental change and associations with behavior problems. *Behavioral Sleep Medicine*, *13*(1), 2–18. https://doi.org/10.1080/15402002.2013.829064
Mazurek, M., Dovgan, K., Neumeyer, A., & Malow, B. (2019). Course and Predictors of Sleep and Co-occurring Problems in Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *49*(5), 2101–2115. https://doi.org/10.1007/s10803-019-03894-5
Mazurek, M. O., & Petroski, G. F. (2015). Sleep problems in children with autism spectrum disorder: Examining the contributions of sensory over-responsivity and anxiety. *Sleep Medicine*, *16*(2), 270–279. https://doi.org/10.1016/j.sleep.2014.11.006
Park, S., Cho, S.-C., Cho, I. H., Kim, B.N., Kim, J.W., Shin, M.S., Chung, U.S., Park, T.W., Son, J.W., & Yoo, H. J. (2012). Sleep problems and their correlates and comorbid psychopathology of children with autism

Included Studies
spectrum disorders. *Research in Autism Spectrum Disorders*, *6*(3), 1068–1072. https://doi.org/10.1016/j.rasd.2012.02.004
Phung, J. N., Abdullah, M. M., & Goldberg, W. A. (2019). Poor sleep quality among adolescents with ASD is associated with depressive symptoms, problem behaviors, and conflicted family relationships. *Focus on Autism and Other Developmental Disabilities*, *34*(3), 173–182. https://doi.org/10.1177/1088357618794916
Richdale, A., Baker, E., Short, M., & Gradisar, M. (2014). The role of insomnia, pre-sleep arousal and psychopathology symptoms in daytime impairment in adolescents with high-functioning autism spectrum disorder. *Sleep Medicine*, *15*(9), 1082–1088. https://doi.org/10.1016/j.sleep.2014.05.005
Richdale, A. L., & Baglin, C. L. (2015). Self-report and caregiver-report of sleep and psychopathology in children with high-functioning autism spectrum disorder: A pilot study. *Developmental Neurorehabilitation*, *18*(4), 272–279. https://doi.org/10.3109/17518423.2013.829534
Schreck, K. (2021). Sleep quantity and quality as predictors of behavior and mental health issues for children and adolescents with autism. *Research in Autism Spectrum Disorders*, *84*. https://doi.org/10.1016/j.rasd.2021.101767
Sommers, L., Papadopoulos, N., Fuller-Tyszkiewicz, M., Sciberras, E., McGillivray, J., Howlin, P., & Rinehart, N. (2024). The Connection Between Sleep Problems and Emotional and Behavioural Difficulties in Autistic Children: A Network Analysis. *Journal of Autism and Developmental Disorders, 55, 1159-1171*. https://doi.org/10.1007/s10803-024-06298-2
Zaidman-Zait, A., Zwaigenbaum, L., Duku, E., Bennett, T., Szatmari, P., Mirenda, P., Smith, I., Vaillancourt, T., Volden, J., Waddell, C., Kerns, C., Elsabbagh, M., Georgiades, S., Ungar, W. J., Fombonne, E., & Roberts, W. (2020). Factor analysis of the children's sleep habits questionnaire among preschool children with autism spectrum disorder. *Research in Developmental Disabilities*, 97. https://doi.org/10.1016/j.ridd.2019.103548

2.3.2 Weight of Evidence

The 14 studies were critically appraised for quality and relevance through using Gough's (2007) Weight of Evidence (WoE) framework. There are three core components in the WoE framework; assessing methodological quality (WoE A), methodological relevance (WoE B) and relevance of the topic to the review question (WoE C).

Methodological Quality (WoE A)

The methodological quality of each study (WoE A) was assessed through using the Axis Checklist (Downes et al., 2016). The AXIS critical appraisal tool (see appendix D) was chosen because it assesses methodological quality of a study through addressing each individual aspect of study design to produce an overall assessment of the quality of the study. The National Institute for Health and Care Excellence (2014) guidelines recommend the AXIS checklist for cross sectional studies which is relevant to this review.

Although the longitudinal studies in this review measured sleep and mental health over a period of time, the studies were correlational and similar in design to the cross-sectional studies. Therefore, the AXIS checklist was deemed appropriate for assessing the methodological quality of the longitudinal, correlational studies. The AXIS checklist provides an opportunity to assess each individual aspect of study design for an overall assessment of study quality. Moreover, the longitudinal design was taken into consideration in WoE B.

Typology of Correlational Analysis (WoE B)

WoE B considers the appropriateness of the study design and analysis for the review question (Gough, 2007). For methodological relevance, all studies used a form of quantitative correlational analysis and therefore WoE B was determined by appraising the type of correlational analysis and whether the study used a longitudinal design. This hierarchy was created by the

researcher, considering the research on different types of correlation analysis and longitudinal research designs (see research and justification in ratings below).

High: Studies that employed both a longitudinal design and Structural Equation Modelling (SEM), path analyses or regression, received a 'high' rating. This is because these are more advanced statistical techniques that consider more independent variables. SEM is proposed to have the closest approximation to a causal relationship between the predictor and outcome variable. SEM is able to test whether two latent constructs (X and Y) correlate or covary, whether X causes Y, Y causes X or both reciprocally cause each other (Thompson et al., 2005). Path analyses is a form of SEM. Longitudinal studies are proposed to be useful for establishing evidence of causality through taking measurements at two or more time points (Johnson, 2001).

Medium: Studies that utilised either a longitudinal study design or Structural Equation Modelling (SEM), path analyses or regression, received a medium WoE B rating.

Low: Studies that employed bivariate correlation, such as Pearsons for parametric data or Spearman's rho for non-parametric data, received the lowest WoE B rating. This is because bivariate analysis does not take into account other variables which might affect the relationship between the two variables being assessed (Field, 2018).

Relevance of the Topic to the Review Question (WoE C)

For WoE C, the weighting is a review specific judgement about the relevance of the focus of the evidence for the review question. Studies were rated based on the following criteria; participant diagnosis, participant age range, sleep outcome measures and mental health outcome measures. Details of the ranking can be found in Appendix C.

Weight of Evidence D

The overall rating for each study (WoE D) was calculated through equally combining the three weightings. For this review, weight of evidence ratings between 1-1.6 are considered “low”, “medium” for 1.7-2.3 and “high” for 2.4-3. The ratings for each study are outlined in Table 2.4.

Table 2.4

Weight of evidence ratings

Study	WoE A: Methodological quality	WoE B: Methodological relevance	WoE C: Topic relevance	WoE D: Overall weight of evidence	Descriptor
Bianca et al. (2024)	2.25 (medium)	1 (low)	2 (medium)	1.75	Medium
Goldman et al. (2011)	1.8 (medium)	2 (medium)	2.3 (medium)	2	Medium
Kang et al. (2020)	2.1(medium)	2 (medium)	1.8 (medium)	2	Medium
Martinez-Cayuelas et al. (2023)	2.1 (medium)	1 (low)	2.5 (high)	1.9	Medium

Study	WoE A: Methodological quality	WoE B: Methodological relevance	WoE C: Topic relevance	WoE D: Overall weight of evidence	Descriptor
May et al. (2015)	1.8 (medium)	3 (high)	2 (medium)	2.3	Medium
Mazurek et al. (2019)	2.4 (high)	3 (high)	1.8 (medium)	2.4	High
Mazurek & Petroski (2015)	2 (medium)	2 (medium)	2.3 (medium)	2.1	Medium
Park et al. (2012)	2 (medium)	2 (medium)	2.3 (medium)	2.1	Medium
Phung et al. (2019)	2.1 (medium)	2 (medium)	2.8 (high)	2.3	Medium
Richdale et al. (2014)	2.4 (high)	2 (medium)	2.3 (medium)	2.2	Medium
Richdale & Baglin (2015)	2.3 (medium)	1 (low)	2.5 (high)	1.9	Medium
Schreck (2021)	2 (medium)	2 (medium)	1.8 (medium)	1.9	Medium
Sommers et al. (2024)	1.95 (medium)	1 (low)	2.25 (medium)	1.73	Medium
Zaidman-Zait	1.7 (medium)	2 (medium)	2 (medium)	1.9	Medium

Study	WoE A: Methodological quality	WoE B: Methodological relevance	WoE C: Topic relevance	WoE D: Overall weight of evidence	Descriptor
et al. (2020)					

Note 1-1.6=low, 1.7-2.3=medium, 2.4-3 =high

2. 3.3 Mapping the Field

The 14 studies included in this review all examined the relationship between sleep and mental health in autistic children and adolescents. Quantitative measures were used to measure sleep and mental health. The studies were all observational and employed a cross-sectional or longitudinal correlation design. The key features of each study are outlined in Table 2.5.

Table 2.5

Mapping the Field

Study	Country	Research Aims	Participants	Study Design	Sleep Measure	Mental Health Measure	Key Findings
Bianca et al. (2024)	Italy	Firstly, to assess the prevalence of a co-occurring diagnosis of insomnia in autistic children. Secondly, to investigate the relationship between insomnia symptoms and the severity of core autism symptoms, age, cognitive development, adaptive behaviour, parental stress and behavioural and emotional problems.	270 autistic children aged between 1.8 years and 9.6 years	Cross-sectional	Paediatric Sleep Clinical Global Impression Scale (S-CGI)	Child Behaviour Checklist (CBCL)	One-third of children had insomnia which was related to emotional and behavioural problems. A significant positive correlation was found between emotional and behavioural symptoms and S-CGI scores. This indicated higher CBCL scores are related to higher S-CGI scores.
Goldman et al. (2011).	United States	To determine whether parent reported sleep problems relate to problematic daytime behaviour in autistic children across the age span; to assess the relative risk and variability of poor sleepers having a behavioural difficulty and to identify differences in the sleep-behaviour paradigm across the age span	1784 autistic children, aged 2-18	Cross-sectional study	CSHQ Parental Concerns Questionnaire (PCQ)	PCQ	There was a higher percentage of behavioural problems on all PCQ scales for poor sleepers compared to good sleepers The association between sleep problems and behavioural problems, including anxiety, persisted from early childhood through adolescence.
Kang et al. (2020)	China	To compare and evaluate sleep disturbances in preschool aged autistic and typically developing children	252 autistic children and 223 age-matched typically developing children, aged 3-6 years old (pre-school children)	Cross-sectional study	CSHQ	Strengths and Difficulties Questionnaire (SDQ)	81.7% of parents reported that their autistic child had sleep problems compared to 61% of typically developing children. Significant correlations were found between the total CSHQ and emotional symptoms, hyperactivity and total SDQ score for autistic participants. Sleep onset delay explained 17.3% of the variance in the total SDQ score of autistic children.

Study	Country	Research Aims	Participants	Study Design	Sleep Measure	Mental Health Measure	Key Findings
Martinez-Cayuelas et al. (2023)	Spain	To study the relationship between behavioural difficulties, sleep and circadian parameters (temperature, motor activity, time in movement and light exposure)	Children and adolescents between age 5 and 18.45 autistic children and 24 typically developing children.	Cross sectional exploratory study	Ambulatory Circadian Monitoring device	CBCL The Repetitive Behaviour Scale-Revised The General Health Questionnaire	Sleep onset difficulties were associated with anxiety, depression and withdrawal. Sleep fragmentation was associated with somatic complaints and self-injury. Sleep efficiency was associated with self-injury.
May et al. (2015)	Australia	To understand changes in sleep difficulties for autistic children and to determine if this differed from typical development or gender; to understand longitudinal predictive associations, in both directions, between sleep disturbance and behavioural/emotional problems; to investigate the relationship between developmental change in sleep and behavioural problems.	46 autistic children and 38 typically developing children, aged 7 to 12 years	Longitudinal correlational study	CSHQ	The Spence Children's Anxiety Scale (SCAS)	Sleep problems were higher for autistic children compared to typically developing peers. Sleep disturbance at baseline predicted later anxiety. Sleep disturbances for autistic children reduced over the year. However, 65.2% of autistic children still scored above the clinical cut off on the CSHQ compared to 78.1% at Time 1, suggesting sleep difficulties may continue to be a problem across childhood.
Mazurek et al. (2019)	United States	To examine the chronicity of sleep disturbance and the longitudinal relations among sleep problems and co-occurring symptoms in autistic children and adolescents.	437 autistic children, aged 2-3 and 4-10 years old.	Longitudinal, correlational study	CSHQ	CBCL Aberrant Behavior Checklist	Sleep problems were significantly positively associated to anxiety with a medium effect size for autistic children (age 4-10) at baseline and follow-up. For younger children (Age 2-3), significant positive relationship with a large effect size was found between sleep problems and anxiety at baseline but this relationship was not significant at follow-up. No differences in sleep problems were found between younger and older children at baseline or follow-up.

Study	Country	Research Aims	Participants	Study Design	Sleep Measure	Mental Health Measure	Key Findings
Mazurek & Petroski (2015)	Columbia	To examine the interrelations between sensory problems, anxiety and sleep problems.	1347 autistic children and adolescents aged 2-17.6 years	Cross-sectional	CSHQ	CBCL	Anxiety for both age groups (age 2-5 and 6-18) was significantly positively associated with each CSHQ subscale. The effect sizes ranged from small to medium for both age groups.
Park et al. (2012)	Korea	To compare the prevalence of sleep problem variables among autistic children and their typically developing siblings and to determine the correlated and comorbid psychopathology of sleep problems.	166 autistic children and 111 non autistic siblings, aged 4 to 15 years	Cross-sectional	Parent reported sleep questionnaire	Koran CBCL	Sleep problems were associated with internalising and externalising problems among autistic children. Autistic children were more likely to have insomnia, bedtime resistance and daytime sleepiness compared to their typically developing siblings.
Phung et al. (2019)	United States	To examine differences between autistic and typically developing groups in sleep quality, psychological wellbeing, adaptive and problem behaviours and mother-adolescent relationship quality. Additionally, to examine the relationship between sleep quality in and adolescents' psychological wellbeing, adaptive and problem behaviours and mother-adolescent relationship quality within both groups.	28 mother-adolescent dyads with autistic adolescents, aged 12-18 and 27 mother-adolescent dyads with TD adolescents, aged 12-17 years.	Cross-sectional	The Center for Epidemiological Studies Depression Scale (CES-D) CBCL	CSHQ The Sleep Habits Survey (SHS)	For autistic children, more daytime sleepiness was associated with more depressive symptoms and in the typically developing sample, more sleep-wake problems were associated with more depressive symptoms.
Richdale et al. (2014)	Australia	To investigate the relationship between sleep disturbance, psychopathology symptoms and daytime functioning in adolescents with high-functioning autism compared to typically developing peers	27 autistic adolescents and 27 typically developing adolescents with a mean age of 15.5 years	Cross-sectional	Depressed mood: CES-D Anxiety: The anxiety subscale of the Depression,	Modified Sleep Habits Survey (mSHS) 7 day sleep/wake diary	In the autistic group, compared to the typically developing group, more significant correlations were found between sleep variables and psychopathology variables and sleep variables and daytime functioning.

Study	Country	Research Aims	Participants	Study Design	Sleep Measure	Mental Health Measure	Key Findings
					Anxiety and Stress Scale (DASS-21) Pre-sleep arousal: Sleep Anticipatory Anxiety Questionnaire (SAAQ)	Actigraphy device The Chronic Sleep Reduction Questionnaire (CSRQ)	
Richdale & Baglin (2015)	Australia	To examine relationships between psychological and sleep problems in high-functioning autistic children (HFASD) and TD children.	17 HFASD (mean age =10.03) and 15 TD children (mean age =9.99 years) Three children had a co-morbid diagnosis of ADHD, one a diagnosis of asthma and one sleep apnoea.	Cross-sectional	CSHQ (parent report) Sleep Self Report (SSR) questionnaire (child report)	CBCL (parent report) Screen for Childhood Anxiety Related Emotional Disorders (SCARED) (child report) Children's Depressive Inventory – Short Form (CDI) (child report)	HFASD children had poorer sleep than TD children. Caregiver reported psychopathology and self-reported anxiety were higher for HFASD children. Poor sleep was associated with anxiety in both groups, particularly Somatic-pain for HFASD children.
Schreck (2021)	United States	To investigate the interrelationship between daytime behaviours (externalising), anxiety and depression (internalising), sleep quality and sleep quantity	446 autistic children (age 16 months – 18 years old)	Cross-sectional	The Behavioural Evaluation of Disorders of Sleep (BEDS)	CBCL	Children and adolescents internalising behaviour was related to their sleep quality and quantity. Participants who experienced sleep quality and quantity disruptions were more likely to have internalising problems during the day, despite their age

Study	Country	Research Aims	Participants	Study Design	Sleep Measure	Mental Health Measure	Key Findings
Sommers et al. (2024)	Australia	To investigate the interconnections between autism symptoms, sleep problems and emotional and behavioural difficulties in autistic children with moderate to severe sleep difficulties	240 autistic children (age 5-13) with moderate to severe sleep problems	Cross-sectional	CSHQ	Developmental Behaviour Checklist – Primary Carer Version	Network analysis found depression, anxiety and behaviour difficulties were the most central variables of the network model. The results indicate interconnectedness between sleep problems and emotional and behavioural difficulties for autistic children.
Zaidman-Zait et al. (2020)	Canada	To examine the factor structure of the CSHQ in preschool autistic children and relationships between factors of the CSHQ and children's emotional, cognitive and behavioural dysregulation.	281 autistic children, aged 4 to 5 years	Cross-sectional	CSHQ	CBCL	Sleep problems were associated with aggression, anxiety/depression and attention problems

2.4 Critical Review of the Evidence

2.4.1 Participants

Sample Size

Sample sizes varied across the studies from 32 participants (Richdale & Baglin, 2015) to the largest sample of 1784 participants (Goldman et al., 2011). However, no studies justified their sample size through statistical analysis. Although the size of a sample needed will differ for different designs, a larger sample size reduces type II error (incorrectly concluding no effect when one exists) and therefore increases test power. Power calculations are helpful to include to decide the appropriate sample size (Button et al., 2013).

Diagnosis

As outlined in the inclusion criteria, all participants had a diagnosis of autism. Eight of the 14 studies (Bianca et al., 2024; May et al., 2015; Park et al., 2012; Phung et al., 2019; Richdale et al., 2014; Richdale & Baglin, 2015; Sommers et al., 2024; Zaidman-Zait et al., 2020) included participants with a clinical diagnosis of autism and conducted a study based screening to confirm the diagnosis. This contributed to a higher WoE C rating. Five of the studies (Goldman et al., 2011; Kang et al., 2020; Martinez-Cayuelas et al., 2023; M. Mazurek et al., 2019; M. O. Mazurek & Petroski, 2015) included participants with a clinical diagnosis of autism but did not conduct a study based screening. One study (Schreck, 2021) did not specify the details of the participants' autism diagnosis, contributing to a lower WoE C rating.

Age of Participants

The age range in the studies varied from 1 to 18 years. Two of the studies (Kang et al., 2020; Zaidman-Zait et al., 2020) had an age range of less than one quarter of the target age range (4.5 year range), with Kang et al. (2020) including participants aged 3 to 6 years and aged 4 to 5 years in Zaidman-Zait et al.'s (2020) study. Additionally, two of the studies gave a mean age of 15.5 (Richdale et al., 2014) and 10.03 years (Richdale & Baglin, 2015) but did not specify the age range. Therefore, these studies received lower WoE C ratings for the age range criterion. This is because the smaller age range makes it difficult to generalise these findings to other age groups across childhood. However, Kang et al. (2020) did analyse age differences in sleep for 3 to 6-year olds, finding sleep disturbances were not significantly associated with age in preschool children. This might be due to the comparison among a narrow age range and similar development stage of 3 to 6-year olds.

Five of the studies (Bianca et al., 2024; May et al., 2015; Mazurek et al., 2019; Phung et al., 2019; Sommers et al., 2024) covered an age range of between a quarter to half the target age range (4.5-9 year range). Bianca et al. (2024) included participants aged 1.8 to 9.6 years old, Sommers et al. (2024) aged 5 to 13 years, May et al. (2015) included participants aged 7 to 12 years, Mazurek et al. (2019) age 2 to 10 years and Phung et al. (2019) age 12 to 18 years. These studies received a medium WoE C rating for the age range criterion. Although these studies had a 'medium weighting' age range, age analysis was completed for three of the studies (Bianca et al.,

2024; May et al., 2015; Mazurek et al., 2019). May et al. (2015) found a significant reduction in sleeping difficulties over a 1-year period for autistic children but not typically developing peers, suggesting sleep difficulties reduce with age for autistic children. Contrastingly, Mazurek et al. (2019) found there were no differences in sleep problems between younger and older children at baseline and follow up. Similarly, Bianca et al. (2024) found sleep problems were similar among children younger and older than 6 years. Bianca et al. (2024) and Mazurek et al.'s (2019) studies suggest sleep difficulties persist over time for autistic children and these children might not experience the same age-related changes in sleep as typically developing peers. Although more research regarding developmental sleep differences is needed, these differences between studies might be related to the different ages of participants and follow up periods with the follow up period being longer in Mazurek et al.'s (2019) study (3.8 years) compared to May et al.'s (2015) study (1 year).

Five studies (Goldman et al., 2011; Martinez-Cayuelas et al., 2023; Mazurek & Petroski, 2015; Park et al., 2012; Schreck, 2021) covered at least half of the target age range (9-18 year range). Goldman et al. (2011) included participants aged 2 to 18 years old, Mazurek and Petroski (2015) age 2 to 17.6 years, Schreck (2021) age 16 months to 18 years old, Martinex-Cavuelas et al. (2023) age 5 to 18 and Park et al. (2012) age 4 to 15 years. The studies with wider age ranges received higher WoE C ratings due to this review question assessing the relationship between sleep and mental health across childhood and adolescence and therefore a wider age range increasing generalisability of the findings. The findings from these studies

with a wide age range indicate that the relationship and problems with sleep and mental health might be present across childhood. For example, Mazurek and Petroski (2015) found for both age groups (ages 2-5 and 6-18) anxiety was significantly associated with sleep problems across each CSHQ subscale. Similarly, Goldman et al. (2011) and Schreck (2021) reported an association between sleep problems and mental health difficulties throughout childhood. Park et al. (2012) and Martinex-Cavuelas et al. (2023) did not report on developmental differences in the relationship between sleep and mental health but due to their wide age range of participants and findings, it indicates the relationship might persist throughout childhood.

Selection and Sampling

One of the thirteen studies (Richdale et al., 2014) reported using random sampling with Richdale et al. (2014) randomly selecting identification codes for the actigraphy component of the study. This contributed to a higher WoE A rating due to randomisation ensuring each participant in the sampling frame has an equal chance of being included in the sample, creating an unbiased representation of the population (Downes, 2016). The other 13 studies provided limited information on their selection and sampling procedure, making replication difficult, contributing to a lower WoE A weighting.

Non Response Bias

Information on non-responders was provided by three studies (Mazurek et al., 2019; Richdale et al., 2014; Richdale & Baglin, 2015). Mazurek et al. (2019) reported missing data of 44 participants at baseline and 18 at follow

up. Information was provided on the missing data, stating that incomplete cases did not differ from complete cases on gender, IQ or caregiver education. Reporting this information is important to ensure non-responders are not from a specific group which could lead to results that do not represent the target population (Downes et al., 2016). Richdale et al. (2014) outlined the number of missing responses and non-responders. Richdale et al. (2014) stated that responders were removed if there were two or more items missing from the questionnaires, resulting in one participant being excluded for missing two questions and one excluded for not completing the questionnaire. However, no information on these excluded participants was provided. Richdale and Baglin (2015) reported a 63% response rate with useable data for 32 participants, raising concerns about non-response bias. Information was provided on the participants who responded but not the non-responders. Due to the assumptions of normality being violated for most variables and the sample size being <30 for each group, non-parametric tests were used. The other 11 studies (Bianca et al., 2024; Goldman et al., 2011; Kang et al., 2020; Martinez-Cayuelas et al., 2023; May et al., 2015; Mazurek & Petroski, 2015; Park et al., 2012; Phung et al., 2019; Schreck, 2021; Sommers et al., 2024; Zaidman-Zait et al., 2020) did not provide information about non-responders, contributing to a lower WoE A score.

2.4.2 Measures

2.4.2.1 Sleep Outcome Measures

Two of the studies used gold standard objective sleep measures (Martinez-Cayuelas et al., 2023; Richdale et al., 2014) . This included actigraphy devices (ambulatory circadian monitoring devices), alongside a 7-day

sleep/wake diary. Objective sleep measures, including actigraphy devices, are viewed as gold standard measures (Lujan et al., 2021). This is because subjectivity is reduced, resulting in a more accurate reflection of sleep quality (Hughes et al., 2018) Therefore, this contributed to a higher WoE A weighting.

Richdale and Baglin (2015) and Phung et al. (2019) received a high WoE A rating due to having two sources for sleep measures, increasing reliability. Having multiple sources increases the rigour of research through triangulating perspectives and countering threats to validity (Robson & McCartan, 2016). In both studies, the Children's Sleep Habits Questionnaire (CSHQ) was completed by parents. In Richdale and Baglin's (2014) study, the children completed the Sleep Self Report Questionnaire (SSR) and in Phung et al.'s (2019) study the Sleep Habits Survey (SHS). Both reported that the CSHQ has been used extensively in previous research with autistic children, indicating the appropriateness and reliability of the measures. Richdale and Baglin (2015) reported satisfactory internal consistency of the CSHQ (α=0.68 and 0.78, respectively) and Phung et al. (2018) reported Chronback's α to equal .77 for higher scores indicating poorer nocturnal sleep quality. For the SHS, scores were summed and higher scores indicated greater daytime sleepiness (Cronbach's α = .70) (Phung et al., 2019). Richdale and Baglin (2014) reported good reliability and validity of the SSR with an internal consistency coefficient of α=0.88. The reliability and validity of the sleep measures used contributed to a higher WoE A score and a higher WoE C score for using two sources of sleep measures.

Ten of the studies employed one self- or parent-report sleep measure, contributing to a lower WoE C score (Bianca et al., 2024; Goldman et al., 2011; Kang et al., 2020; May et al., 2015; Mazurek et al., 2019; Mazurek & Petroski, 2015; Park et al., 2012; Schreck, 2021; Sommers et al., 2024; Zaidman-Zait et al., 2020) . Six of these studies utilised the CSHQ (Kang et al., 2020; May et al., 2015; Mazurek et al., 2019; Mazurek & Petroski, 2015; Sommers et al., 2024; Zaidman-Zait et al., 2020). Kang et al. (2020) reported Chronbach's alpha coefficient to be 0.86 for the full scale CSHQ and for the subscales it ranged from 0.38 (sleep disordered breathing) to 0.70 (sleep duration). May (2015) argued acceptable reliability and validity for the CSHQ, including test-retest reliability (range 0.62-0.79). Mazurek (2019) examined the Total Sleep Disturbance score in the CSHQ as an index of overall sleep problems and found Cronbach's alpha for the CSHQ to be .626 at baseline and .697 at follow-up. Sommers et al. (2024) reported good to acceptable internal consistency in the study: sleep anxiety/co-sleeping (α = 0.83), daytime alertness (α = 0.82), total score (α = 0.76), night waking/parasomnias (α = 0.70) and sleep initiation and duration (α = 0.63). Schreck (2021) used the Behavioural Evaluation of Sleep Disorders (BEDS) questionnaire. Schreck (2021) reported reliability coefficients, reporting that the total BEDS score and four factors within it yielded adequate internal consistency: Apnea (α=.60), Disorientated Awakenings (α=.65), Sensitivity to the Environment (α=.65), Expressive Awakening (α=.85) and Total (α=.82). Reporting reliability coefficients indicated reliability of the measures, contributing to a higher WoE A score. Bianca et al. (2024) employed the Paediatric Sleep Clinical Global Impression Scale (S-CGI). Although

reliability of the S-CGI was not conducted, they reported good convergent validity of S-CGI with CSHQ for overall score alongside significant associations between the S-CGI and sleep onset delay of the actigraphy. Goldman et al. (2011) used the Sleep Composite Measure and Park et al. (2012) employed a parent reported sleep questionnaire but did not state the name of the questionnaire. These two studies did not report reliability coefficients, contributing to a lower WoE A score.

2.4.2.2 Mental Health Outcome Measures

Two studies (Phung et al., 2019; Richdale & Baglin, 2015) included parent and child self-report measures, contributing to a higher WoE C mental health outcome criterion score. Children completed the Screen for Childhood Anxiety Related Emotional Disorders (SCARED) to assess anxiety in Richdale and Baglin's (2015) study. Internal consistency of the SCARED (α = 0.88) and use of the measure with autistic children aged 8 to 14 was reported in the study, indicating reliability of the measure. In Phung et al.'s (2019) study, children completed the Center for Epidemiological Studies Depression Scale (CES-D) to assess depressive symptoms. Chronbach's alpha was reported for the CES-D for the current sample to be α= .89, indicating good reliability. In both studies, parents completed the Child Behaviour Checklist (CBCL) to assess their child's behavioural and emotional difficulties. Phung et al. (2019) stated that the CBCL has good reliability but did not provide reliability coefficients. Richdale and Baglin (2015) used three of the CBCL DSM-IV scales (Affective, Anxiety and ADHD problems), outlining good reliability of these scales with internal consistency coefficients ranging from α= 0.71 to 0.89 and reported previous use of the CBCL with autistic children.

Reporting reliability coefficients indicated reliability of the measures which contributed to a higher WoE A score.

The other 12 studies used one source to assess children's mental health, contributing to a lower WoE C mental health outcome criterion score. Seven of the studies assessed children's mental health through parents completing the CBCL (Bianca et al., 2024; Martinez-Cayuelas et al., 2023; Mazurek et al., 2019; Mazurek & Petroski, 2015; Park et al., 2012; K. Schreck, 2021; Zaidman-Zait et al., 2020) but did not employ child self-report measures. Martinez-Cayuelas (2023) also included the General Health Questionnaire (GHQ-28) which assessed somatic symptoms, anxiety and insomnia, social dysfunction and depression, to understand the impact on the families. Although most of these studies (Martinez-Cayuelas et al., 2023; Mazurek & Petroski, 2015; Zaidman-Zait et al., 2020) commented on the CBCL being validated in children previously, only Bianca et al. (2024) gave the manuals test-retest reliability score (0.95) which is indicative of good reliability of the measure. Similarly, no reliability or validity information was provided for the GHQ-28 in Martinez-Cayuelas et al.'s (2023) study. Not providing reliability or validity information negatively affected the WoE A score. Sommers et al. (2024) utilised the Developmental Behaviour Checklist – Primary Carer Version (DBC-P) to assess emotional and behavioural difficulties. Internal consistency scores were reported, ranging from excellent to satisfactory: total score ($\alpha = 0.94$), disruptive and antisocial behaviour subscale ($\alpha = 0.90$), hyperactivity ($\alpha = 0.80$), anxiety ($\alpha = 0.70$) and depression ($\alpha = 0.66$). This positively contributed to the WoE A score.

Richdale et al. (2014) assessed depression through self-reports, using the CES-D to assess depressive symptoms and reporting a reliability coefficient of the scale for the HFASD group to be excellent (α=.89) and good for the typically developing group (α=.74). Anxiety was assessed through the anxiety subscale of the Depression, Anxiety and Stress Scale (DASS-21) with reliability of the scale for the HFASD being excellent (α=0.86) and moderate for the typically developing group (α=0.54). In May et al's (2015) study, the Spence Children's Anxiety Scale (SCAS) was completed by parents to assess children's anxiety which was described to have satisfactory test-retest reliability. The Chinese version of the Strengths and Difficulties Questionnaire (SDQ) was used in Kang et al.'s (2020) study to assess children's behavioural and emotional difficulties. The Chinese version was reported to have good reliability and validity with Chronbach's alpha coefficient of 0.641 for the total difficulties scale. Parents completed the Parental Concerns Questionnaire (PCQ) in Goldman et al.'s (2011) study to assess emotional and behavioural problems. However, no reliability or validity information was provided, negatively affecting the WoE A score. Overall, two studies (Phung et al., 2019; Richdale & Baglin, 2015) which included multiple sources for questionnaire data received a higher WoE C mental health criterion rating due to increasing the reliability of the data. The WoE A rating increased for five of the studies (Bianca et al., 2024; Kang et al., 2020; Richdale et al., 2014; Richdale & Baglin, 2015; Sommers et al., 2024) that provided reliability and validity information about the mental health questionnaires.

2.4.3 Research Design and Analysis

A correlational cross sectional (collecting data at a single point in time) or longitudinal research design (collecting data at more than one point in time) was employed in all 14 studies. Correlational studies examine the relationship between two or more variables to investigate the association between the variables (Barker et al., 2016). The different types of correlation design are outlined in WoE B and include bivariate correlation, regression, path analysis and structural equation modelling.

Two of the 14 studies (May et al., 2015; Mazurek et al., 2019) employed a longitudinal design. Longitudinal studies are proposed to be particularly useful for establishing evidence of causality through taking measurements at two or more time points (Johnson, 2001). Therefore, due to also using regression (May et al., 2015) or path analyses (Mazurek et al., 2019) these studies received a high WoE B rating. This is because regression and path analysis can control for more independent variables when examining the change in the dependent variable (Robson & McCartan, 2016). Path analysis is a form of structural equation modelling which is proposed to have the closest approximation to a causal relationship between the predictor and outcome variable. It can also indicate whether two latent constructs covary or correlate and can indicate the direction of the two variables (Thompson et al., 2005). All the other studies collected data at one time point and therefore received a medium or low WoE B rating, dependent on the correlational analysis employed in the study. Regression was used in eight of the studies (Goldman et al., 2011; Kang et al., 2020; May et al., 2015; Park et al., 2012; Phung et al., 2019; Richdale et al., 2014; Schreck, 2021; Zaidman-Zait et al., 2020) and path analysis, a form of multiple regression, was used in two of the

studies (Mazurek et al., 2019; Mazurek & Petroski, 2015). Therefore, the studies using regression or path analysis with a longitudinal design received a high WoE B rating, while those with a cross-sectional design, received a medium weighting.

Four of the studies (Bianca et al., 2024; Martinez-Cayuelas et al., 2023; Richdale & Baglin, 2015; Sommers et al., 2024) received the lowest WoE B rating due to using bivariate correlations. This is because bivariate correlation only takes into account two variables and does not consider other variables which might affect the relationship between sleep and mental health (Field, 2018) . Martinez-Cavuelas et al. (2023) used parametric or nonparametric statistical tests, based on the Shapiro-Wilk normality test. However, they did not specify the type of correlational analysis used. Sommers et al. (2024) used network analysis, utilising partial correlation to measure the relationship between emotional-behavioural difficulties and sleep. Richdale and Baglin (2015) analysed data using non-parametric tests (Chi-square analyses and Spearman's correlations) due to the assumption of normality being violated for most variables and the same size being less than 30. Similarly, Bianca et al. (2024) used Spearman's rank correlation coefficient to measure the relationship between CBCL (emotional/behavioural) and S-CGI (sleep) scores.

In the correlation analysis, 12 of the studies (Bianca et al., 2024; Goldman et al., 2011; Kang et al., 2020; Martinez-Cayuelas et al., 2023; May et al., 2015; Mazurek & Petroski, 2015; Phung et al., 2019; Richdale et al., 2014; Richdale & Baglin, 2015; Schreck, 2021; Sommers et al., 2024; Zaidman-Zait et al.,

2020) included the sleep measure subscales and 10 of the studies (Goldman et al., 2011; Kang et al., 2020; Martinez-Cayuelas et al., 2023; Mazurek & Petroski, 2015; Park et al., 2012; Phung et al., 2019; Richdale et al., 2014; Richdale & Baglin, 2015; Sommers et al., 2024; Zaidman-Zait et al., 2020) included the mental health measure subscales. This was helpful for understanding particular sleep (e.g. sleep duration, bedtime resistance) or mental health factors (e.g. anxious, depressed) that might have been influencing the relationship between sleep and mental health. This positively affected the WoE C rating.

In the correlation analysis between sleep and mental health, three studies (May et al., 2015; Mazurek et al., 2019; Park et al., 2012) did not complete subscale-level analysis for sleep measures and two studies (May et al., 2015; Schreck, 2021) did not perform subscale-level analysis for mental health measures. However, Mazurek et al. (2019) did include descriptive statistics of the sleep subscales and a correlation between sleep problems at baseline and follow up. Similarly, May et al. (2015) included a correlation between sleep subscales, age and IQ in the typically developing and autistic group. Park et al. (2012) included descriptive statistics of the sleep subscales, comparing the autistic group with the typically developing group. For the CBCL, Schreck (2021) and Bianca (2024) included an internalising scale (anxious/depressed, somatic complaints and withdrawn-depressed) and an externalising scale (rule-breaking, attention, aggressive behaviour, destructive) but did not include each subscale in the analysis. However, including the internalising total score was helpful for understanding the relationship between internalising factors and sleep. For example, Schreck

(2021) found sleep quantity and quality predicted daytime anxiety and depression (i.e. internalising) and Bianca et al. (2024) found a positive correlation between all sleep subscales (except night waking) and the internalising score. Due to not including all subscales, these studies received a low WoE C rating for either the sleep or mental health measure criteria. This is because including the subscales in the correlation analysis gives a more detailed analysis of specific factors affecting the relationship between sleep and mental health.

All studies, except for Sommers et al. (2024), included p-values to determine statistical significance which was clearly shown in the analysis. The p-values are useful for testing hypothesis, deciding whether to reject the null hypothesis, showing statistical significance (Schober et al., 2018). This contributed to the methodological quality rating of the studies. Three of the studies (Goldman et al., 2011; Mazurek & Petroski, 2015; Park et al., 2012) included a 95% confidence interval and Zaidman-Zait et al. (2020) included a 90% confidence interval for the primary variables of interest. Confidence Intervals (CI) show the range of values that the population parameter will fall between (Schober et al., 2018). Therefore, for a 95% CI, there is a 95% probability that the true values fall within the range provided. This is helpful for interpreting the reliability of the results and contributed to the WoE A rating

2.5 Study Findings and Effect Sizes

All studies employed correlational designs and included effect sizes (size of association), shown in Table 2.7. Twelve of the studies provided effect sizes

in the ‘r’ value. Goldman et al. (2011) and Park et al. (2012) provided odds ratios and Zaidman-Zait et al. (2020) provided beta values. These effect sizes were converted into ‘r’, using the psychometrica website (Lenhard & Lenhard, 2022), to enable comparison across the studies. To compare effect sizes, Cohen’s (1998) criteria was used, outlined in Table 2.6 (Cohen, 1988, 1992).

Table 2.6

Interpretation of effect sizes

r value (+/-)	Negligible	Small	Medium	Large
Cohen’s criteria	0-0.1	0.1-0.3	0.3-0.5	0.5+

Table 2.7

Study findings and effect sizes

Study	Sample Size	Sleep Measure	Mental Health Measure	Effect Size (r) (autistic participants)	Descriptor (using Cohen's criteria)	Effect Size (typically developing participants	Descriptor (using Cohen's criteria)
Bianca et al. (2024)	270 participants	Paediatric Sleep Clinical Global Impression Scale (S-CGI):	Child Behaviour Checklist (CBCL):				
		Bedtime resistance	Internalising problems	r=0.272***	Small	-	-
		Sleep onset delay	Internalising problems	r=0,276***	Small	-	-
		Night waking	Internalising problems	r=0.146*	Small	-	-
		Parent satisfied	Internalising problems	r=0.316***	Medium	-	-
		Family affected	Internalising problems	r=0.282***	Small	-	-
		Overall S-CGI	Internalising problems	r=0.311***	Medium	-	-
Goldman et al. (2011)	1784 participants	Parental Concerns Questionnaire (sleep subscales to compare 'good' and 'poor' sleepers):	Parental Concerns Questionnaire (anxiety)	r=0.11 (RR=1.5)	Small	-	-
		Bedtime Resistance	Anxiety	r=0.03 (OR=0.9)	Negligible	-	-
		Sleep delay	Anxiety	r=0.05 (OR=1.2)	Negligible	-	-
		Sleep anxiety	Anxiety	r=0.07 (OR=1.3)	Negligible	-	-
		Parasomnias	Anxiety	r= 0.05 (OR=1.2)	Negligible	-	-

Study	Sample Size	Sleep Measure	Mental Health Measure	Effect Size (r) (autistic participants)	Descriptor (using Cohen's criteria)	Effect Size (typically developing participants	Descriptor (using Cohen's criteria)
Kang et al. (2020)		Total CSHQ	Total SDQ	r=0.324***	Medium	-	-
		Total CSHQ	Emotional Symptoms	r=0.408***	Medium	-	-
		Bedtime resistance	Total SDQ	r=0.196*	Medium	-	-
		Sleep anxiety	Total SDQ	r=0.312**	Medium	-	-
		Sleep duration	Total SDQ	r=0.126	Small	-	-
		Sleep disordered breathing	Total SDQ	r=0.033	Negligible	-	-
		Parasomnias	Total SDQ	r=0.185*	Small	-	-
		Daytime sleepiness	Total SDQ	r=0.128	Small	-	-
		Night wakings	Total SDQ	r=0.231*)	Small	-	-
		Sleep onset delay	Total SDQ	r=0.350***	Medium	-	-
Martinez-Cayuelas et al. (2023)		Ambulatory Circadian Monitoring (ACM):	CBCL:				
		Awakenings per hour	Somatic complaints	r=0.357**	Medium	-	-
		Wake after sleep onset	Somatic complaints	r=0.417**	Medium	-	-
		Sleep onset latency	Withdrawn	r=0.347*	Medium	-	-
		Sleep efficiency	Withdrawn	r=-0.328*	Medium	-	-
		Sleep onset latency	Anxious/depressed	r=0.381**	Medium	-	-
		Sleep efficiency	Anxious/depressed	r=-0.303*	Medium	-	-
May et al. (2015)		Time 1 CSHQ	Time 1 SCAS	r=.653**	Large	-	-
		Time 2 CSHQ	Time 2 SCAS	r=.515**	Large	-	-

Study	Sample Size	Sleep Measure	Mental Health Measure	Effect Size (r) (autistic participants)	Descriptor (using Cohen's criteria)	Effect Size (typically developing participants	Descriptor (using Cohen's criteria)
Mazurek et al. (2019)		Baseline: CSHQ (sleep problems)	Baseline: Anxiety Scale (CBCL)	4-10 year olds: r=.446* 2-3 year olds: r=.582*	Medium Large	- -	- -
		Follow-up: CSHQ (sleep problems)	Follow-up: Anxiety Scale (CBCL)	4-10 year old: r=.390** 2-3 year olds: r =.174	Medium Small	- -	- -
Mazurek & Petroski (2015)		CHSQ: Bedtime Resistance	Anxiety Scale (CBCL)	r=0.30*** (age 2-5) r=0.24*** (age 6-18)	Medium Small	- -	- -
		Sleep Onset Delay	Anxiety Scale (CBCL)	r=0.21*** (age 2-5) r=0.15***	Small Small	- -	- -
		Sleep Duration	Anxiety Scale (CBCL)	r=0.28*** (age 2-5) r=0.23*** (age 6-18)	Small Small	- -	- -
		Sleep Anxiety	Anxiety Scale (CBCL)	r=0.42*** (age 2-5) r=0.36*** (age 6-18)	Medium Medium	- -	- -
		Night Wakings	Anxiety Scale (CBCL)	r=0.29*** (age 2-5) r=0.14***(age 6-18)	Small Small	- -	- -

Study	Sample Size	Sleep Measure	Mental Health Measure	Effect Size (r) (autistic participants)	Descriptor (using Cohen's criteria)	Effect Size (typically developing participants	Descriptor (using Cohen's criteria)
Park et al. (2012)		Total Sleep problems (parent reported sleep questionnaire)	K-CBCL:				
			Total behavioural problems	r=0.3112***	Medium	-	-
			Internalizing problems	r=0.4105***	Medium	-	-
			Anxious/depressed	r=0.28	Small	-	-
			Withdrawal	r=0.31**	Medium	-	-
			Somatization	r=0.52*	Large	-	-
Phung et al. (2019)		Poor sleep quality (CSHQ)	Depressive symptoms (CES-D)	r=.20	Small	r=.26	Small
		Poor sleep quality (CSHQ)	Affective problems (CBCL)	r=.42*	Medium	r=-.09	Negligible
		Poor sleep quality (CSHQ)	Anxiety problems (CBCL)	r=.32	Medium	r=-.15	Small
		Sleep-wake problems (SHS)	Depressive symptoms (CES-D)	r=.26	Small	r=.57**	Large
		Sleep-wake problems (SHS)	Affective problems (CBCL)	r=.01	Negligible	r=-.26	Small
		Sleep-wake problems (SHS)	Anxiety problems (CBCL)	r=.18	Small	r=-.22	Small
		Daytime sleepiness (SHS)	Depressive symptoms (CES-D)	r=.53**	Large	r=.45*	Medium
		Daytime sleepiness (SHS)	Affective problems (CBCL)	r=.04	Negligible	r=-.18	Small
		Daytime sleepiness (SHS)	Anxiety problems (CBCL)	r=.26	Small	r=-.31	Medium
Richdale et al. (2014)		Chronic Sleep Reduction Questionnaire (CSRQ)	Depression (CES-D)	r=0.71***	Large	r=0.30	Medium
			Anxiety (DASS-21)	r=0.60***	Large	r=0.49**	Medium
		Reporting a sleep problem	Anxiety (DASS-21)	r=0.54**	Large	r=-0.12	Medium
			Depression (CES-D)	r=-0.48**	Medium	r=-0.38*	Medium
		Insomnia (mSHS)	Anxiety	r=-0.46*	Medium	r=-0.46*	Medium
			Depression (CES-D)	r=-0.42*	Medium	r=-0.31	Medium
		Sleep diary variables:					
		Bedtime	Depression (CES-D)Anxiety (DASS-21)	r=0.28 r=0.18	Medium Small	r=0.16 r=0.03	Small Negligible
		Wake time	Depression (CES-D)	r=0.40	Medium	r=0.34	Medium
			Anxiety (DASS-21)	r=0.17	Small	r=0.23	Small

Study	Sample Size	Sleep Measure	Mental Health Measure	Effect Size (r) (autistic participants)	Descriptor (using Cohen's criteria)	Effect Size (typically developing participants	Descriptor (using Cohen's criteria)
		Total Sleep	Depression (CES-D)	r=-0.27	Small	r=0.04	Negligible
			Anxiety (DASS-21)	r=-0.37	Medium	r=0.15	Small
		Sleep efficiency	Depression (CES-D)	r=-0.43*	Medium	r=0.12	Small
			Anxiety	r=-0.46*	Medium	r=-0.03	Negligible
		Sleep latency	Depression (CES-D)	r=0.51*	Large	r=-0.10	Small
			Anxiety (DASS-21)	r=0.59**	Large	r=0.01	Negligible
		Wake after sleep onset	Depression (CES-D)	r=0.06	Negligible	r=-0.09	Negligible
			Anxiety (DASS-21)	r=-0.01	Negligible	r=0.05	Negligible
		Actigraphy Variables:					
		Sleep onset time	Depression (CES-D)	r=0.54*	Large	r=0.20	Small
			Anxiety (DASS-21	r=0.22	Small	r=0.05	Negligible
		Wake time	Depression (CES-D)	r=0.41	Medium	r=0.17	Small
			Anxiety (DASS-21	r=0.24	Small	r=0.23	Small
		Sleep length	Depression (CES-D)	r=-0.43	Medium	r=-0.05	Negligible
			Anxiety (DASS-21	r=-0.04	Negligible	r=0.05	Negligible
		Sleep latency	Depression (CES-D)	r=0.35	Medium	r=0.09	Negligible
			Anxiety (DASS-21	r=0.17	Small	r=0.28	Negligible

Study	Sample Size	Sleep Measure	Mental Health Measure	Effect Size (r) (autistic participants)	Descriptor (using Cohen's criteria)	Effect Size (typically developing participants	Descriptor (using Cohen's criteria)
Richdale & Baglin (2015)		Sleep Problem (CSHQ – parent report)	Affective Problems (CBCL)	r_s=-0.64***	Large	r_s =-0.56*	Large
			Somatic-panic (SCARED)	r_s =-0.57*	Large	-	-
		Sleep Problem (SSR – self report)	Anxiety Problems (CBCL)	r=-0.75***	Large	-	-
				r_s =0.60**			
		SSR total score	Affective Problems (CBCL)	r_s =0.50*	Large	-	-
			Somatic-panic (SCARED)		Large	-	-
		CSHQ total score	Somatic-panic (SCARED)	r_s =0.60**	Large	-	-
Schreck, K. (2021)		Hours slept per night	Total CBCL score	r=.30**	Medium	-	-
			Internalising	r=-.26**	Small	-	-
		BEDS Expressive Sleep Disturbances	Total CBCL score	r=.34**	Medium	-	-
			Internalising	r=.31	Medium	-	-
		BEDS Sensitivity to Environment	Total CBCL	r=.34**	Medium	-	-
			Internalising	r=.36**	Medium	-	-
		BEDS Disorientated Wakening	Total CBCL	r=.34**	Medium	-	-
			Internalising	r-=.33**	Medium	-	-
		Apnea	Total CBCL	r=.14*	Small	-	-
			Internalising	r=.11*	Small	-	-

Study	Sample Size	Sleep Measure	Mental Health Measure	Effect Size (r) (autistic participants)	Descriptor (using Cohen's criteria)	Effect Size (typically developing participants	Descriptor (using Cohen's criteria)
Sommers et al. (2024)		Sleep initiation and duration	Anxiety	r=.00	No association	-	-
			Depression	r=.18	Small	-	-
		Sleep anxiety/co-sleeping	Anxiety	r=.28	Small	-	-
			Depression	r=.36	Medium	-	-
		Night waking/parasomnias	Anxiety	r=.36	Medium	-	-
			Depression	r=.00	No association	-	-
		Daytime alertness	Anxiety	r=.00	No association	-	-
			Depression	r=.31	Medium	-	-
Zaidman-Zait et al. (2020)		CSHQ:	CBCL:				
		Bedtime Routine	Anxiety/Depression	rs =0.25**	Small	-	-
		Sleep Onset & Duration	Anxiety/Depression	rs =.26**	Small	-	-
		Night Wakes	Anxiety/Depression	r=.23**	Small	-	-
		Sleep Disordered Breathing	Anxiety/Depression	r=.15**	Small	-	-
		Morning Wakening	Anxiety/Depression	r=.29**	Small	-	-

P <0.05, **P <0.01, ***P<0.001

Associations between sleep and mental health were found in all studies with 12 of the 14 studies (Bianca et al., 2024; Kang et al., 2020; Martinez-Cayuelas et al., 2023; May et al., 2015; Mazurek et al., 2019; Mazurek & Petroski, 2015; Park et al., 2012; Phung et al., 2019; Richdale et al., 2014; Richdale & Baglin, 2015; Schreck, 2021; Zaidman-Zait et al., 2020), reporting significant associations, indicating a positive relationship between sleep problems and mental health difficulties. However, effect sizes and variables differed across these studies

Bianca et al. (2024) found small and medium positive associations between internalising problems and the sleep problem subscales, with a medium sized, positive association (r=0.311***) between overall sleep problem score (S-CGI) and internalising problems (CBCL). This indicates high sleep problem scores relate to high internalising problem scores. Sleep problems were similar in children younger and older than age 6, highlighting persistence of sleep problems over time. Moreover, a third of participants met ICSD-3 criteria for the diagnosis of chronic insomnia, suggesting high prevalence of sleep problems among autistic children.

Goldman et al. (2011) found a small sized, positive association (r=0.11) between sleep problems and anxiety problems. Relative risk (RR) findings indicate poor sleepers have a 15% higher chance of having problems with anxiety (RR=1.5) and 19% higher likelihood of having mood swings (RR=1.9). Stepwise logistic regression indicated that for a one unit increase in bedtime resistance, sleep delay, sleep anxiety and parasomnia, increased the odds of a parent reporting an anxiety problem by 9%, 12%, 13% and 12%

respectively. However, the size of association was ‘negligible’ for the CSHQ subscales and anxiety. Moreover, significance values were not reported, which made it difficult to understand the significance of these relationships.

Furthermore, Kang et al. (2020) found a statistically significant positive relationship with a medium effect size ($r=0.324$, $p<0.001$) between total CSHQ score and total SDQ score for pre-school aged children. In particular, sleep onset delay had the greatest ability to explain the variance in the total SDQ score, explaining 17.3% of the variance ($R^2=0.173$). Multiple regression, showed that sleep problems (total CSHQ score) could explain 20.7% ($R^2=0.207$) of the variance in total SDQ score. Additionally, they found the prevalence of sleep problems was higher in pre-school aged autistic children (81.7%) compared to typically developing pre-school aged children (61%).

Through collecting objective sleep data, Martinez-Cayuelas (2023) found a significant positive relationship, with a medium effect size, between somatic complaints and awakenings per hour ($r=0.36$, $p=0.01$) and wake after sleep onset ($r=0.42$, $p=0.005$). Positive associations, with a medium effect size, were found between withdrawal and sleep onset latency ($r=0.347$, $p=0.02$) and sleep efficiency ($r=-0.328$, $p=0.03$). Furthermore, anxious/depressed symptoms positively correlated, with a significant medium effect size, with sleep onset latency ($r=0.381$, $p=0.01$) and sleep efficiency ($r=-0.303$, $p=0.04$). Sleep fragmentation (higher time in movement) was associated with somatic complaints. This indicates that autistic children who experience various types of sleep problems are more likely to experience mental health difficulties.

However, the directionality of this relationship or causality cannot be established.

In May et al.'s (2015) longitudinal study, they found sleep disturbance predicted anxiety 1 year later in both typically developing and autistic children. A significant positive relationship with a large effect size was found between sleep problems (total CSHQ) and anxiety (CBCL scale) at time-1 ($r=.652$, $p<.01$) and time-2 ($r=.515$, $p<.01$). They found sleep difficulties reduced for autistic children over the 1-year period which was not associated with medications or interventions. However, 65.2% of children still scored above the CSHQ cut off at Time 2, compared to 78.1% at Time 1. Sleep problems were higher among autistic children compared to typically developing children, experiencing more difficulties in sleep onset delay, bedtime resistance, sleep anxiety, sleep duration, daytime sleepiness and parasomnias. Sleep disordered breathing and night wakings did not differ between the typically developing and autistic children, suggesting certain sleep problems are more prevalent among autistic children relative to typically developing peers.

In Mazurek et al.'s (2019) study, sleep problems were significantly, positively related to anxiety (CBCL scale), with a medium effect size, for autistic older children (age 4-10) at baseline ($r=.446$ ($p<.01$) and follow-up ($r=.390$, $p<.01$). For autistic younger children (age 2-3), a significant positive relationship, with a large effect size, was found between sleep problems and anxiety at baseline ($r=.582$, $p<.01$). However, the relationship was not significant, with a small effect size at follow-up ($r=.174$). No differences in sleep problems were

found between younger and older children at baseline or follow-up. Although a significant cross-sectional correlation between anxiety and sleep was found for both age groups at baseline, the longitudinal analysis did not indicate a significant predictive relationship between anxiety and sleep, after accounting for covariates. This more in-depth analysis reflects the studies higher WoE D rating.

Using bivariate correlations and multivariate path analyses, Mazurek and Petroski (2015) found in both age groups (age 2-5 and age 6-18), a positive significant relationship, with small to medium effect sizes, between anxiety and all types of sleep problems (sleep-onset delay, bedtime resistance, sleep anxiety, sleep duration and night wakings) on the CSHQ. This suggests higher sleep problem scores relate to higher mental health problem scores.

In Park et al.'s (2012) study, autistic children with sleep problems, compared to those without sleep problems, were significantly more likely to have somatising problems ($r=0.52$, $p=0.041$), internalising problems ($r=0.41$, $p=0.008$), withdrawal problems ($r=0.31$, $p=0.006$) and total behavioural problems ($r=0.3112$, $p=0.006$). These effect sizes varied from small to large. This suggests an increase in sleep problems relates to an increase in mental health difficulties for autistic children. They also found autistic children, compared to their typically developing siblings, were significantly more likely to have insomnia, bedtime resistance and daytime sleepiness. Sleep disordered breathing and parasomnia did not differ between groups, suggesting certain sleep problems are more prevalent among autistic children compared to neurotypical children.

Phung et al. (2019) found a significant positive association, with a large effect, between daytime sleepiness and depressive symptoms (r=.53, $p<0.01$) for autistic adolescents. Significant associations with a medium effect size were found between poor sleep quality (CSHQ) and affective problems (CBCL). The regression model, adjusted for IQ and income, showed a significant positive relationship between sleep quality and self-reported depressive symptoms (CES-D), explaining 23% ($R^2=0.23$) of the variance. However, no significant relationship was found between sleep quality and parent-reported affective and anxiety problems, measured on the CBCL.

Richdale et al.'s (2014) found, in the autistic group compared to the typically developing group, significant positive correlations between sleep variables and psychopathology variables and sleep variables and daytime functioning. There were significant positive correlations with large effect sizes between sleep onset time (measured by actigraphy device) and depression ($r=0.54$, $p<0.05$), sleep problems (CSRQ) and depression ($r=0.60$, $p<0.001$) and sleep problems (CSRQ) and anxiety ($r=0.54$, $p<0.001$). No significant associations on the sleep diary variables were found between the bedtime, wake time, total sleep or wake after sleep onset and anxiety or depression. However, a significant positive correlation with a large effect size was found between sleep latency and depression ($r=0.51$, $p <0.05$) and sleep latency and anxiety ($r=0.59$, $p<0.01$) Similarly, a significant positive association with a medium effect size was found between sleep efficiency and depression ($r=0.43$, $p<0.05$) and anxiety ($r=0.46$, $p<0.05$). This suggests certain sleep

problems are positively related to mental health difficulties, with an increase in sleep problems associated with an increase in mental health difficulties.

Richdale and Baglin (2015) reported their correlation findings in the text but this data was not presented in tables. This made it difficult to analyse the findings in more depth. In the autistic group, a significant positive association, with a large effect, was found between self-reported sleep problems (SSR) and Affective Problems (r=0.60, p=0.01), as well as between somatic panic (SCARED) and both total CSHQ score (r=0.50, p=0.04) and SSR total score (r=0.60, p=0.01). Interestingly, sleep problems (SSR) were significantly negatively associated, with a large effect size, with Anxiety Problems (CBCL) (r=-0.75, p=0.001). A caregiver reported sleep problem (CSHQ) was significantly negatively associated with Affective Problems (CBCL) (r=-0.64, p=0.006) and Somatic-panic (SCARED) (r=-0.57, p=0.02). This would indicate as sleep problems increase, mental health problems decrease. However, the negative association was not commented on in the study and due to not including tables with the data in, it is difficult to understand this relationship. This reflects the low WoE B rating with less in-depth analysis making it difficult to understand the relationship between sleep and mental health.

Schreck (2021) found sleep quantity and quality (BEDS), predicted internalising behaviour (anxiety and depression) in autistic children and adolescents, regardless of age. They found significant small to medium positive correlations between hours slept per night (r=.30, p<0.01), expressive sleep disturbances (r=.34, p<0.01), Sensitivity to Environment (r-

.34, p<0.01), Disorientated Wakening (r=.32, p<0.01), Apnea (r=.14, p<0.05) and total CBCL score. Stepwise multiple regression showed that participants who were sensitive to environmental changes, experienced disorientated awakening, slept fewer hours per night and awoke during the night screaming were more likely to have internalising problems during the day, accounting for 19.5% (R^2=.195, p<0.001) of the variance.

Sommers et all. (2024) found a positive relationship with small and medium effects sizes between sleep initiation and duration and depression (r=.18), sleep anxiety and co-sleeping and depression (r=.36) and anxiety (r=.28), night waking/parasomnias (r=.36) and daytime alertness and depression (r=.31). However, no association was found between sleep initiation and duration and anxiety (r=.00), night waking/parasomnias and depression (r=.00) and daytime alertness and anxiety (r=.00).

Zaidman-Zait et al. (2020) found significant positive associations, with small effect sizes, between all sleep variables (CSHQ; Bedtime Routine, Sleep Onset and Duration, Night Wake, Sleep Disordered Breathing and Morning Wakening) and anxiety/depression (CBCL). The CSHQ subscales could explain 13% of the variance in anxiety/depressed symptoms and the overall model accounted for 18% of the total variance in children's internalising behaviour.

2.6 Conclusion and Recommendations

The aim of this review was to consider whether studies support the relationship between autistic children's sleep quality and mental health, exploring whether there is an association between sleep problems and

mental health problems. All studies received a medium WoE D rating, except one study (Phung et al., 2019) which had a high WoE D rating. The review included non-UK, international studies (United States, Italy, Spain, Australia, Columbia and Korea) with children from different ethnic backgrounds, increasing generalisability and relevance to all children and adolescents.

The majority of studies found significant positive relationships between sleep problems and mental health difficulties, with effect sizes ranging from small to large. This suggests an increase in sleep problems relates to an increase in mental health problems. However, two studies (Goldman et al., 2011; Sommers et al., 2024) did not include significance values, making it difficult to conclude whether their results were statistically significant. Including subscale analysis, helped to understand the relationship between particular sleep variables and mental health variables. Future research should explore these relationships in more depth. . As shown in Whelan et al.'s (2022) systematic literature review, few studies have used qualitative research to explore the relationship between autistic children's sleep and mental health. Qualitative methods could help understand autistic children's view on the relationship between their sleep and their mental health. For example, how sleep affects mental health (e.g. anxiety, emotional regulation, sensory processing etc.), other influencing factors (e.g. environmental, social, sensory factors) and the nuances between participants.

The studies included autistic children and young people from age 0 to 18, making the findings more generalisable to all autistic children and young people. Age analysis was reported in six of the studies (Bianca et al., 2024;

Goldman et al., 2011; May et al., 2015; Mazurek et al., 2019; Mazurek & Petroski, 2015; Schreck, 2021). This helped to understand developmental differences in sleep and mental health across childhood. The majority of studies found sleep problems persisted across childhood for autistic children. This is suggested to be different to age-related changes in sleep for neurotypical children (Iglowstein et al., 2003; Ohayon et al., 2004). However, further research is needed to examine developmental changes in the relationship between sleep and mental health across childhood. More longitudinal research could develop the understanding of age-related changes in sleep and mental health.

A few studies included a typically developing participant group. Sleep problems and mental health difficulties were found to differ between groups (Phung et al., 2019; Richdale et al., 2014; Richdale & Baglin, 2015). For example, Richdale et al. (2014) found more significant correlations between sleep variables and psychopathology variables for autistic participants compared to typically developing participants. Although descriptive statistics were provided for differences in sleep problems, few studies compared the relationship between sleep and mental health for autistic and typically developing children. Therefore, more research is needed to explore these relational differences.

This review highlights the association between sleep problems and mental health difficulties. Therefore, it will be important for educational psychologists and other professionals working with children, to assess and support children's sleep and mental health, considering the interaction between the

two variables. Educational psychologists could address these needs during direct work with children and in consultations with school, parents and other professionals. The relationship between sleep and mental health should be considered when providing educational psychology recommendations to schools and parents/carers. Due to most children sleeping away from school, communication between school and parents about sleep problems will be key.

Considering the relationship between sleep and mental health, more research will be needed into appropriate sleep interventions for autistic children to improve sleep quality and mental health. Research has found that sleep facilitating factors for autistic adolescents are in direct contrast to mainstream sleep hygiene recommendations (Pavlopoulou, 2020). Considering this gap in research, a personalised sleep intervention for autistic children will be explored in the empirical paper.

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Chapter Three Empirical Paper

The impact of a personalised, co-produced sleep intervention on autistic children's sleep quality and mental health

3.1 Abstract

This study investigated the effectiveness of a personalised, co-produced sleep intervention on autistic children's sleep quality and mental health. This study addressed three research questions to explore the effectiveness of the sleep intervention, alongside parent and child views on the intervention and relationship between sleep and mental health.

The study used a mixed methods approach, employing a multiple baseline concurrent single case experimental design and a qualitative element, interviewing parents and children. Six autistic children and their parents participated in this study with pre-intervention, post-intervention and follow-up data collected for all six participants. Single case experimental design data was collected for three of the six participants due to research constraints. To examine the impact of the intervention, visual analysis, Percentage of Data exceeding the Median (PEM) effect sizes and Tau-U statistics were employed. Reliable Change Index was used for measuring the change in sleep quality pre-intervention to post-intervention and pre-intervention to follow up.

From baseline to intervention, a significant weighted average Tau-U small effect size across all three participants was found, suggestive of the sleep intervention being effective on average across all three participants. However, individual between phase analysis showed significant improvements in sleep quality for only one of three participants. The Reliable Change Index found reliably significant improvements in sleep for one of six

participants pre-post intervention and two participants pre-intervention to follow up. Reliably significant improvements in mental health were found for four of the six participants pre to post intervention and three participants pre-intervention to follow-up, demonstrating the longer-term positive impact of the sleep intervention on mental health. The interviews provided a more extensive understanding of parental and child views on the relationship between sleep and mental health and views of the sleep intervention. Themes were identified, such as the child-led nature, accessibility and adaptability, improved sleep outcomes and enjoyment of the routine, helping to inform future sleep interventions for autistic children.

This is the first study to investigate the effects of a personalised, co-produced sleep routine, adding new research to the field. The findings of this research show there is some effectiveness of a personalised sleep intervention on sleep quality and mental health. Factors such as the child-led nature, accessibility and enjoyment of the sleep routine appear important to children and parents. Further research will be needed to extend the knowledge and understanding of the impact of personalised sleep interventions.

3.2 Introduction

3.2.1 Autism

Autism Spectrum Condition (ASC) is a neurodevelopmental condition. As outlined in the DSM-5 diagnostic manual, autism is reportedly characterised by persistent social communication and interaction difficulties and restricted, repetitive patterns of behaviour, activities or interests (American Psychiatric Association, 2013). It is argued that autism language and diagnostic criteria portrays a 'deficit model', not capturing the strengths of autistic individuals (Ferreira et al., 2024). However, this is changing with the neurodiversity discourse changing to neurological differences instead of deficits, capturing the heterogeneity and strengths of autistic individuals. Views vary in how to describe autism with research investigating preferred terminology within the autistic community, finding 'autism' and 'on the autism spectrum' to be the preferred terminology (Kenny et al., 2016). Therefore, this research will use the term 'autism'.

3.2.2 Importance of Sleep

Defining sleep problems is challenging due to lack of consensus around how to assess and define sleep problems (Gregory & Sadeh, 2012). This is due to various reasons, including having different diagnostic classification systems, with the Diagnostic and Statistical Manual for Mental Disorders and the International Classification of Sleep Disorders. Moreover, there is a lack of agreement over what constitutes a 'sleep problem' with differences in assessment methods (subjective and objective methods). It is also important to be mindful that family and societal expectations and culture can influence what constitutes the ideal sleep pattern (Wiggs, 2007).

Healthy sleep has been defined as adequate sleep quality, sleep duration, appropriate sleep timings and no sleep disorders (Dutil et al., 2018). Sleep is regulated by two main neurobiological processes, the circadian system and sleep/wake homeostasis process (Bathory & Tomopoulos, 2017). The circadian system involves cyclic changes in the body of biological rhythms over the 24-hour period. This includes the sleep/wake cycle, blood pressure regulation, body temperature cycle, alertness and hormonal secretions (e.g. cortisol and melatonin). The circadian clock fuels the circadian process, driven by environmental cues known as zeitgebers with light being the most powerful zeitgeber, activating secretion of melatonin (sleep hormone). Other examples of environmental cues are meals and alarm clocks (Bathory & Tomopoulos, 2017). The homeostatic system is the biological drive for maintaining equilibrium between sleep and waking. Waking hours increase sleep promoting substances, creating a ‘sleep drive’ over time whereas during sleep these substances reduce, leading to a decreasing drive to sleep (Bathory & Tomopoulos, 2017).

There are different stages of sleep, including rapid eye movement (REM) sleep which is suggested to be important for memory consolidation and is when dreaming occurs (Peever & Fuller, 2017). Non rapid eye movement sleep (NREM) has three stages with differing levels of sleep depth and functions, supporting physical growth and memory consolidation (Patel et al., 2024). Sleep is also important for emotional regulation, with functional MRI studies showing the physiological benefits of sleep in emotional reactivity, processing and consolidating emotional memories (Goldstein & Walker, 2014). Relationships between sleep and mental health have been found in

multiple studies, including sleep and depression (Martinez-Cayuelas et al., 2023; Phung et al., 2019) and sleep and anxiety (May et al., 2015; Mazurek et al., 2019; Mazurek & Petroski, 2015). This is suggested to be a bi-directional relationship with sleep affecting mental health and vice versa (Scott et al., 2021). Therefore, sleep is important for children for learning, growth and development and socioemotional functioning (Schlieber & Han, 2021).

3.2.3 Sleep and autism

The prevalence of sleep problems is higher among autistic children compared to neurotypical children with estimations of 50-80% of autistic children experiencing sleep problems. Relatively, the estimation of sleep problems among neurotypical children is 11-37% (Veatch et al., 2015). Although the reasons for this are unclear, the higher prevalence is suggested to be related to behavioural, neurobiological or medical reasons. For example, features of autism, such as higher sensitivity to the sleeping environment or attachment to routines, might lead to bedtime resistance or settling difficulties (Richdale & Schreck, 2009; Schreck et al., 2004).

All children can experience different sleep difficulties, including bedtime resistance, night awakenings, sleep duration, sleep onset difficulties, daytime sleepiness, difficulties waking in the morning, restless sleep, sleep disordered breathing and parasomnias (Cortese et al., 2020). Although every autistic individual may experience different sleep problems, findings suggest the most prevalent sleep problems for autistic children are sleep onset delay and sleep duration (Malow et al., 2006). Similarly, another study found the

most frequent sleep problems for autistic children were difficulties falling asleep and restlessness during the night (Mayes & Calhoun, 2009).

3.2.4 Sleep interventions

Findings suggest that for autistic children, behavioural interventions, underpinned by behavioural theory, including sleep hygiene, parent training, extinction, gradual extinction, reinforcement and environmental changes can significantly reduce sleep problems (Carnett et al., 2020; Kirkpatrick et al., 2019; Rigney et al., 2018). Behavioural interventions encourage initiation and maintenance of sleep through increasing frequency of behaviours that improve sleep and reducing behaviours that adversely affect sleep (Kirkpatrick et al., 2019). The NICE (2013) guidelines advises a behavioural approach for improving autistic children's sleep first, working with the parents or carers to address the sleep problem and to establish a regular night-time sleep pattern.

Involving parents in their child's sleep intervention equips parents with the support, knowledge and appropriate training on how to support their child's bedtime behaviours (Kirkpatrick et al., 2019). This aligns with Bronfenbrenner's bio-ecological systems theory, viewing child development within a complex system of relationships, influenced by different levels of the environment, with the immediate environment, named the microsystem (e.g. family and school), being the most influential on a child's development (Bronfenbrenner, 1989). Furthermore, it is suggested that sleep-related parental self-efficacy, which is the parental belief in being capable of dealing with difficult sleep situations, leads to positive parenting behaviour which

positively influences children's sleep (Werner et al., 2022). Studies suggest that parental training of children's sleep behaviour can increase their self-efficacy (Werner et al., 2022; Wolfson et al., 1992).

Additionally, it is important to ensure children are involved in sharing their views and making decisions. This relates to self-determination theory which highlights the importance of an individual's own ability to manage themselves, think on their own and make confident choices. Self-determination can increase independence and positively impact on motivation (Deci & Ryan, 1994). For example, findings suggest that co-participatory practices can have a positive impact on children's lives and promote sense of agency to improve socio-emotional wellbeing (Kumpulainen et al., 2014). Moreover, Pavlopoulou's (2020) research found sense of agency during the daytime was important for autistic adolescent's sleep quality, ensuring they had choice and control on how to spend their time at school and home, increasing positive feelings. Therefore, involving children in the creation and implementation of sleep interventions is important.

3.2.5 Rationale for this study

This research project aims to investigate the effects of a personalised sleep intervention on autistic children's sleep quality and mental health. This project is important due to the high prevalence of sleep problems among autistic children, impacting on mental health and daytime functioning. With long CAMHS waiting lists for mental health and sleep support, more accessible, appropriate interventions are needed for autistic children.

Although a few studies have explored the effects of sleep interventions on autistic children's sleep quality (Cuomo et al., 2017; Vriend et al., 2011), much of this research has used parent reported sleep measures and limited research has explored children's views on strategies that support their sleep (Pavlopoulou, 2020). This is particularly important considering the heterogeneity of the autistic population. Pavlopoulou's participatory qualitative research found autistic children's sleep facilitating factors are in direct contrast to mainstream sleep hygiene recommendations. Pavlopoulou's (2020) research sheds light on four key areas which might improve adolescents' sleep, based on adolescents' views. This includes physical activity, focused interests, sense of agency during daytime and sensory autonomy during bedtime. All of these factors, are personal to the individual and therefore differ to mainstream sleep hygiene recommendations which give less consideration to personal sleep facilitating factors. For example, some autistic children might find having a television in their room supports their sleep (e.g. soothing sounds) which mainstream recommendations, such as NICE guidelines (2013) advise against. Therefore, it is important to consider sleep hygiene interventions that focus on the individual's experiences of sleep facilitating factors, considering environmental and personal factors that affect each autistic individual (Pavlopoulou, 2020).

No studies to date have investigated the effects of a personalised, co-produced sleep intervention on autistic children's sleep and mental health with many sleep interventions having a pharmacological and behavioural (with no personalisation) focus (Beresford et al., 2018). As outlined in the

Special Educational Needs Code of Practice (2015), gathering children's views is key when providing support for children and families. This aligns with person centred planning (PCP) and positive psychology theory, tailoring services around the individual, considering strengths and interests, rather than assuming 'one size fits all' (Ratti et al., 2016). PCP approaches have been included within government regulations and agency policy in the UK (Department of Health, 2009). Therefore, understanding the impact of a personalised, co-produced sleep intervention, considering environmental and personal factors affecting each individual, is important.

3.2.6 Research questions

Considering previous research theory and evidence, this study aimed to explore the effectiveness of a personalised, co-produced sleep intervention on autistic children's sleep quality and mental health. The following research questions (RQ) were examined:

RQ1. What is the effectiveness of a personalised co-produced sleep intervention on autistic children's sleep quality and mental health?

RQ2. What is the relationship between autistic children's sleep and mental health?

RQ3. What are parents' and children's views on a personalised sleep intervention?

3.3 Methods

3.3.1 Design

This study employed an explanatory sequential mixed-methods design (Creswell & Creswell, 2023) which begins with collecting quantitative data,

followed by a qualitative phase to gather an in-depth understanding of quantitative results. The quantitative phase provides a general understanding of the research problem whilst the qualitative phase helps explain the results through exploring participant views (Creswell & Creswell, 2023; Ivankova et al., 2006). When using quantitative and qualitative research in combination, it allows for a more comprehensive analysis, allowing the researcher to develop a better understanding of the research problem (Ivankova et al., 2006).

For RQ1, a single-case concurrent multiple baseline design was employed. The multiple baseline design establishes experimental control by staggering the introduction of the intervention with increasing baseline lengths for each participant across staggered times of the intervention (Kratochwill et al., 2010). Multiple baseline designs are appropriate for interventions which cause lasting changes in an individual's ability, making a return to baseline performance and reversal design less feasible (Lobo et al., 2017). Participants were allocated to different baseline lengths within an 8-day period. This ensured the intervention would finish before the school holidays started. In a sleep intervention, there are many confounding variables (e.g. day of the week, general health, school activities, weather etc.) which are difficult to control for. However, steps were taken to control for confounding variables as much as possible, including ensuring the intervention took place during the school term from start to finish.

All six children participated in the sleep intervention for 4 weeks, with the support of their parents. The independent variable was the personalised

sleep intervention and the dependent variables were sleep quality and mental health. Mental health and sleep quality were measured for all six participants, pre- and post- intervention and at 1 month follow up through the Child Sleep Habits Questionnaire (CSHQ) (Owens et al., 2000) and Revised Child Anxiety Depression Scale Parent Version (RCADS-P) (Chorpita et al., 2005). Due to time and recruitment constraints, alongside trying to control for confounding variables, it was only possible to collect baseline data for three of the six child participants (see Appendix T). Therefore, due to not collecting baseline data for three of the participants, they could not be included in the staggered multiple baseline single case experimental design (SCED). With consideration of research ethics and robustness of the data, these participants were still included in the pre-post design, using their CSHQ and RCADS-P pre-, post-intervention and follow-up data. Excluding data from these participants would have been unethical, considering their decision to participate and time they had invested. However, including their data in the SCED would have compromised the validity of the analysis which would have also been unethical. Therefore, a hybrid design, as shown in figure 3.1 and 3.2 was chosen, including their valuable pre-, post-intervention and follow-up RCADS-P and CSHQ data and adhering to the SCED requirements. Figure 3.1 shows what the pre-post design is, without the multiple baseline design, for three of the participants (Gabz, Participant 2 and Harry). Figure 3.2 shows the multiple baseline design for Harrison, Peter and Bob12_8 which also included pre-post and follow up measures.

Figure 3.1

Diagrammatic representation of pre-post intervention design

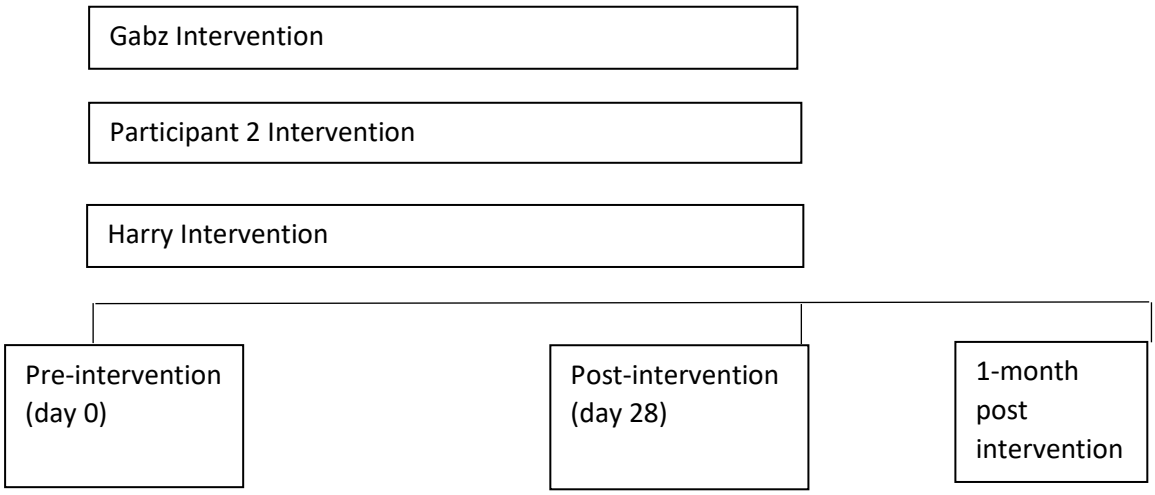
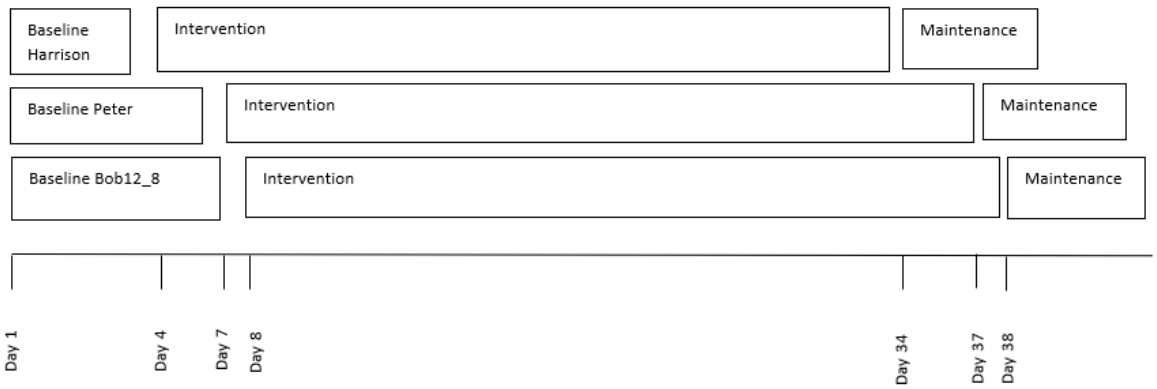


Figure 3.2

Diagrammatic representation of multiple baseline design



Horner et al. (2005) propose that experimental control is shown when the design has at least three demonstrations of the experimental effect at three different time points (within-subject replication) with a single participant or across different participants (inter-participant replication). An ABC multiple baseline design was utilised with three participants with a pre-intervention

(A), intervention (B) and maintenance (C) stage. Maintenance data was collected for three to five nights, after the intervention finished. Experimental control is demonstrated here through covariation between change in behaviour patterns and introduction of the intervention within three different participants at three different time points (Horner et al., 2005)

This design was chosen because it is a practical methodology for assessing the effects of interventions, being useful for establishing evidence-based practice and defining practices at the level of the individual. It aims to record a causal or functional relationship between independent and dependent variables (Horner et al., 2005). Within- and between-subjects comparisons are made, to control for threats of internal validity and to enhance external validity (Horner et al., 2005) Single-case designs are suitable for heterogeneous populations due to the focus on the individual participant who serve as their own control (Tate et al., 2013). This is relevant for this study given the heterogeneity of the autistic population, with each child having individual differences and different home contexts.

In the second qualitative phase, for answering RQs 2 and 3, semi-structured interviews were employed. Qualitative methods allow access to individual's subjective worlds and meanings, including marginalised and often invisible groups within western psychology (Braun & Clarke, 2006). Few studies have used interviews to explore autistic children and parent's views of sleep interventions and sleep facilitating factors. Therefore, it is hoped interviews will provide a more in depth understanding of effective components of sleep interventions and sleep facilitating factors.

3.3.2 Participants

Participants, in the intervention, were six year 4, 5 and 6 students (age 9-11), attending a mainstream primary school in London and Medway, and their parents. Single-case designs can involve only one participant but usually include three to eight participants with the individual participant serving as his/her/their own control (Horner et al., 2005). It is suggested that replicating findings with a minimum of three participants is necessary to indicate a pattern of behaviour and experimental effect (Kratochwill & Levin, 2010; Riley-Tillman & Burns, 2009). The control for Type 1 error (belief that a treatment effect is significant when it is not) increases as the number of baselines increase (Ferron & Jones, 2006). Therefore, due to needing to increase the baseline length for each participant and time constraints, needing to complete the 4-week intervention by the end of the school term, only three participants were included in the single case multiple baseline design.

This age range (9-11 years old) was chosen because it is the pre-adolescent period. There is limited research of sleep problems within this age range. Sleep problems appear to be particularly prevalent during adolescence for autistic young people, consistent with typically developing peers (van Deurs et al., 2021). This is suggested to be due to environmental factors (e.g. increased responsibilities at school, increased internet use), physiological changes (e.g. changes in circadian phases), schedule changes and increased autonomy (Loring et al., 2016). Therefore, intervening at an early stage is crucial to prevent sleep problems from escalating.

Participants were recruited through non-probability, purposive sampling methods due to the inclusion criteria and accessibility of participants. To be eligible for participation in the intervention, participants needed to meet the criteria outlined in table 3.1. All participants had a diagnosis of autism and were experiencing sleep problems, both confirmed by their parents. Due to the self-reflective and cognitive nature of the sleep intervention materials, participants needed to be able to understand and engage with the verbal, written materials. This was checked through explaining to the SENCo and parents the nature of the sleep materials and whether they thought the child would be able to understand and engage with the sleep intervention. Information about the child's sleep difficulties was gathered from the researcher speaking to parents and pre-intervention CSHQ data.

Table 3.1

Participant inclusion criteria

Criteria	Description
Diagnosis	Have a diagnosis of autism, as confirmed by parents
Sleep	The child will need to be experiencing sleep difficulties, confirmed by their parent
Cognitive ability	Due to the cognitive nature of the sleep intervention, participants needed to be able to engage with the verbal, written materials
Age	9 to 11 years old

Criteria	Description
	Year 4, 5 and 6
Intervention	Not receiving any other targeted mental health intervention or sleep intervention (e.g. CBT)

For answering RQ 2 and 3, participants and their parents were invited to partake in the interviews. In the case of the children's interviews, parents were present to support the interview process. There were no additional inclusion criteria for this part of the study. All participants' parents, who were all mothers, supported their child during the intervention through supporting the creation of the routine and ensuring the intervention was implemented effectively. Therefore, gathering parental views on the implementation and efficacy of the intervention was important. Full participant criteria, alongside parental involvement throughout the research, is outlined in Table 3.2.

Table 3.2.

Participant description

	Gabz	Participant 2	Harry	Harrison	Peter	Bob12_8
Parent interview	Yes	Yes	Yes	No	Yes	No
Child interview	Yes	Yes	No	No	Yes	No
Age	11	10	9	9	10	9
Year Group	6	5	4	5	5	5
Gender	Male	Female	Male	Male	Male	Male
Sleep difficulty	Want to improve sleep routine, sleeping in parent's bed	Difficulty falling asleep, sleep talks, sleep walks	Struggles to settle at bedtime, difficulty falling asleep	Difficulty falling asleep, waking in night and sleeping in parent's bed	Difficulty falling asleep, waking in night and sleeping in parent's bed	Want a more consistent night's sleep and routine, sleepwalks

3.3.3 Ethical Considerations

3.3.3.1 Ethical approval

Ethical approval for this project was obtained from the University College London's (UCL) Ethics committee (Appendix J). Alongside this, the Principal Educational Psychologist of the local authority who gave verbal approval to conduct this project in the schools. Further ethical approval was agreed by UCL, following changes that were made to the recruitment strategies (Appendix K).

3.3.3.2 Informed Consent

Given the age of the participants, initial written informed consent was sought from their parents, aligning with the British Psychological Society (2021) Code of Ethics and the Health and Care Professions Council (2016) standard of conduct, performance and ethics. The parents were provided with accessible, comprehensive information sheets and consent forms (Appendix L). Subsequently, the researcher organised a meeting in school or a phone call to speak with the child participants, explaining the study's objectives, procedures and implications of participating. This facilitated an opportunity to seek clarification and ask questions. Verbal and written informed consent was acquired from all participants (children and parents) (Appendix M).

3.3.3.3 Confidentiality and Right to Withdraw

All participants' data was anonymised to ensure confidentiality. Participants (children) chose a pseudonym for themselves, except for participant 2. Participants were informed that confidentiality would only be breached if

there were concerns about their safety or safety of others. Participants were informed of their right to withdraw at any point throughout the intervention.

3.3.3.4 Debrief

Following the intervention, the researcher arranged a phone call with each child participant's parent to discuss next steps and any questions or concerns they had. This included signposting to sleep and mental health services, if they needed support in the future. The results of the research were shared with the parents of the participants for both the children and parents.

3.3.3.5 Data Protection

Data was collected and stored on the researcher's password protected UCL laptop in password protected files. Interviews were transcribed, removing identifiable information, and saved in a password protected file on One Drive. Once interview recordings were transcribed and analysed, they were deleted from the researcher's laptop. Data was only stored until completion of the study.

3.3.3.6 Trustworthiness

To establish trustworthiness of the qualitative data, four factors were considered; credibility (preference to internal validity), transferability (preference to generalisation/external validity), dependability (preference to reliability) and confirmability (preference to objectivity) (Shenton, 2004).

3.3.3.6.1 Credibility

Credibility was ensured by following guidelines for semi-structured interviews and reflexive thematic analysis, alongside discussing the analysis with my research supervisor throughout the process. Erlandson et al. (1993) argue

the importance of developing a relationship of trust and understanding with participants. I developed an understanding and relationship of trust with participants through having a phone call to ensure informed consent before the intervention and interviews, alongside regular check in phone calls throughout the intervention. Furthermore, triangulation is proposed to be important for compensating for individual limitations of different methods (Guba, 1981). Parent and child interviews, sleep diaries and questionnaire data were triangulated to increase credibility. Lastly, although peer checks of the interview data were not able to be carried out due to time constraints, regular debriefing sessions between the researcher and research supervisor occurred, helping to provide alternative views and constructive criticism.

3.3.3.6.2 Transferability

Transferability relates to the extent to which the findings of one study can apply to another situation (Merriam, 1998). However, it is important to note that with qualitative research, results need to be understood within the context of particular participant or organisation characteristics (Shenton, 2004). To ensure transferability, participant details were described (see Table 3.2) and data collection methods.

3.3.3.6.3 Dependability

To address dependability, processes within the research need to be outlined in detail to allow future research to repeat the work (Shenton, 2004). Adhering to this, information on the research design and implementation was described, including examples of the reflexive thematic analysis (Appendix

H), interview questions (Appendix I) and reflexive thematic analysis stages (Table 3.3).

3.3.3.6.4 Confirmability

To ensure confirmability, findings need to reflect the participants' ideas and experiences rather than the researcher's ideas (Shenton, 2004). Audio recordings and transcripts were regularly referred back to when developing codes, subthemes and themes to ensure participant experiences were reflected in the themes. Moreover, direct quotes were included in the results to increase confirmability. The researcher used a research diary to record reflections, decisions and analysis throughout the process (Appendix T).

3.3.4 Procedure

3.3.4.1 Participant Recruitment

Eight autistic students from four mainstream primary schools in London and Medway were identified to participate in the research. Parents were involved in supporting their child with creating and implementing the intervention and four parents participated in the second interview stage of the research. Schools, within the London borough that the Trainee Educational Psychologist (TEP) was on placement and schools in Medway, were emailed. This email included a summary of the research project and the parent information sheet, outlining further information. Subsequent meetings were held with the Special Educational Needs Coordinator (SENCo) from the schools. During the meetings with the SENCo, details about the project, including the intervention, logistics and benefits of participating were

discussed. The SENCo had the opportunity to ask questions during these meetings.

Following these meetings, eight children and their parents were identified as potential participants and the parent information and consent forms were emailed to the parents of these potential participants who met the inclusion criteria. Parents returned the consent forms to the SENCo who emailed them to the TEP. Once parental consent was gained, the TEP called the parents to provide an opportunity for questions and gaining informed consent. The TEP then spoke with child participants at school or via telephone to ascertain their interest in the programme. They were given information sheets and consent forms and given the opportunity to ask any questions, to ensure informed consent was gained. Seven out of eight participants agreed to take part in the research and provided written consent. One participant started the intervention and dropped out after a week due to starting new medication. Their data was not included in the analysis. This resulted in six children participating in the sleep intervention from schools within London and Medway. Three of these children and four parents participated in the interviews.

3.3.4.2 Phase 1: Quantitative Data.

Baseline (A). As required by single case designs, a baseline was established before the intervention was introduced. This baseline was staggered for three participants. Baseline data was collected through a sleep diary, with a self-reported sleep rating each night (Appendix E) from three participants over a staggered period of four to eight nights. All six parents

were administered the Revised Child Anxiety Depression Scale – Parent version (RCADS-P) (Appendix F) to measure their child's anxiety and depressive symptoms and the Child Sleep Habits Questionnaire (CSHQ) (Appendix G) to measure their child's sleep quality pre-intervention.

Intervention (B). Following the baseline stage, the intervention was introduced. This involved all six children, supported by their parents and researcher, creating a personalised sleep routine, and following this every night for 4 weeks. Three of the children who were included in the multiple baseline design recorded their quality of sleep each night in the sleep diary. The researcher called each parent each week to troubleshoot any difficulties they were experiencing.

Maintenance (C) At the end of the four-week intervention, three of the participants continued to record information in the sleep diary for four nights. The post-intervention RCADS-P and CSHQ were re-administered to all six parents. At this stage, the researcher stopped playing an active role in the intervention.

Follow up. One month after the intervention phase, follow-up measures were taken to assess sleep quality and mental health, re-administering the CSHQ and RCADS-P to all six participants' parents.

3.3.4.3 Phase 2: Qualitative Data.

Semi-Structured Interviews

To answer RQ2 and 3, all participants (children and their parents) were given the option to participate in the interview stage to gather their views on the personalised sleep intervention and how sleep affected their mental health.

Three children and four parents consented to partake in the interview. This was in the format of semi-structured Microsoft Teams interviews (see appendix H).

3.3.5 Intervention

This intervention stemmed from insights of Pavlopoulou's (2020) research, finding that sleep-facilitating factors for autistic children often contrast from the mainstream sleep hygiene recommendations. Pavlopoulou (2020) highlighted the importance of treating sleep individually for each autistic child in relation to environmental and personal factors. The sleep hygiene materials were developed by North East London Foundation Trust (NELFT) Mental Health Support Team (MHST), based on findings from Pavlopoulou's (2020) research, thereby ensuring their relevance in addressing the specific needs of autistic children.

The intervention involved participants (children and their parents) attending a training session on the functions and benefits of sleep, sleep problems and sleep hygiene information (Appendix N). The researcher delivered this training five times, individually with four child participants and their mothers, and jointly with two child participants and their mothers. A separate parent training video was sent to all parents which had more of a focus on sleep and autism, helping parents understand difficulties autistic individuals might experience with sleep and reasons for this (Appendix O). The child-parent training did not focus on the autism diagnosis due to not wanting to make children feel stigmatised socially. At the end of the training session, participants, supported by their parents and the researcher, created a

personal sleep routine, using the sleep hygiene materials (Appendix P). The researcher individually supported each participant to create their routine, including during the joint session, sitting individually with each participant to support the creation of their routine. The researcher used their training in psychological consultation skills, using active listening and problem-solving skills. This included asking participants questions, including Socratic questions and a mix of open ended and closed questions about their interests and what they find relaxing to support the creation of the personal sleep routine (see Appendix P). The participants followed this personalised sleep routine for 4 weeks, supported by their parents.

Due to the personalised nature of the sleep intervention, children with the support of their parents, were able to tailor the implementation according to their preferences. Throughout the intervention, the researcher maintained regular communication with the parents of the children, through a weekly phone call check in, to address any challenges and troubleshoot as needed. This helped to also increase implementation fidelity.

3.3.6 Measures

3.3.6.1 Quantitative Data

Parent measures were chosen for assessing sleep and mental health due to the validity and reliability of the measures, age of the children and communication needs. Findings indicate weak correlations between self-report and parental reports for autistic children, including the RCADS-Child and RCADS-Parent (Khalfe et al., 2023). This difference is suggested to be affected by verbal ability and metacognitive skills (Blakeley-Smith et al.,

2012). Therefore, parental measures were chosen instead of self-reports. However, the views of the child participants were gathered through the sleep diary and semi-structured interviews.

3.3.6.1.1 Sleep Diary

For the single case experimental design (SCED), three of the six participants (Harrison, Bob12_8 and Peter) who had baseline sleep data and therefore could be included in the SCED, recorded how well they slept each night in a sleep diary. This included rating sleep quality on a scale of 0 (worst night's sleep) to 100 (best night's sleep), recording the time they went to sleep, wake time and a box to note down anything that affected their sleep (Appendix E). SCEDs often involve using your own outcome measures related to the measurable behaviour which are short to administer due to needing to repetitively record information (Krasny-Pacini & Evans, 2018). Sleep diaries are argued to be cost-efficient and allow the participant to self-assess their sleep (Ibáñez et al., 2018). The sleep diary also enabled collection of parental and child views about factors affecting sleep each night. Through children and parents sharing their perspectives on sleep quality, this can increase reliability of the data.

3.3.6.1.2 The Children's Sleep Habits Questionnaire

The Children's Sleep Habits Questionnaire (CSHQ) (Owens et al., 2000) was administered at baseline, at the end of the intervention and at 1 month follow-up. The CSHQ is a 35-item parent questionnaire that measures a range of children's sleep behaviours and has been found to demonstrate adequate internal consistency and test-retest reliability. The CSHQ is proposed to be

the most widely used standardised assessment tool for autistic children (Owens et al., 2000). It includes insomnia-related dimensions, such as bedtime resistance, sleep anxiety, sleep onset delay, sleep duration, night waking, sleep disordered breathing, parasomnias and sleep onset delay (Malow et al., 2009). The CSHQ has been validated in children age 4-10 years and has been used with autistic children and children of other ages (Goldman et al., 2011; Lewandowski et al., 2011; Malow et al., 2009). The test-retest reliability coefficient of the CSHQ has been found to be acceptable (range 0.62 to 0.79) within the community and clinical sample (Owens et al., 2000). Within a sample of autistic children, the CSHQ has been found to have modest internal consistency (a = .68) between items in the eight subscales (Johnson et al., 2012). This supports the reliability and validity of the use of the CSHQ for sleep problems in autistic children.

3.3.6.1.3 Revised Child Anxiety Depression Scale-Parent version

The Revised Child Anxiety Depression Scale-Parent version (RCADS-P) (Chorpita et al., 2005) was administered pre-intervention, post-intervention and at follow-up. The RCADS-P assesses youth anxiety and depressive symptoms. It can be completed by parents of children, aged 8 to 18. The RCADS-P is a 47-item parent-report measure with subscales, including: separation anxiety disorder, social phobia, generalized anxiety disorder, panic disorder, obsessive compulsive disorder and low mood. It has good reliability and robust internal consistency reliability in different assessment settings, countries and languages (Chorpita et al., 2005).

It is suggested that the RCADS is too developmentally advanced for young people with learning disabilities to engage with but has been found to be useful for some children with mild learning difficulties (Law & Wolpert, 2014). Among a group of autistic children (age 6-14 years) with anxiety, the RCADS-P total anxiety scores demonstrated strong internal consistency (α =.91) and the six subscales acceptable-to-good internal consistency (social phobia: α=0.87; panic disorder:, α=0.71; major depression:, α=0.67; separation anxiety: α=0.79; generalized anxiety: α=0.84; obsessive-compulsive: α= 0.74) (Khalfe et al., 2023). For a sample of autistic children, test-retest reliability of the RCADS-P was found to be excellent across all subscales of the RCADS-P (ICC>0.75), including the total anxiety (ICC=.82, p<.001) and total anxiety and depression (ICC=.84, p<.001) (Kaat & Lecavalier, 2015). Therefore, this suggests the RCADS-P is reliable, valid measures for internalising symptoms in autistic children.

3.3.6.2 Qualitative Data

3.3.6.2.1 Semi-Structured Interviews.

Following the last week of the intervention, the views of three children (Gabz, participant 2 and Peter), their mothers and Harry's mother were gathered through semi-structured Microsoft Teams interviews with the researcher. The interview included five questions, designed to gather the children's and parents' views on the intervention and the impact of it on their sleep and mental health (Appendix I). The interviews were recorded, using the video recorder on Microsoft Teams on the researcher's university laptop and then transcribed verbatim for analysis.

3.3.7 Analysis

3.3.7.1 Phase One Analysis

3.3.7.1.1 Visual Analysis

Visual analysis is argued to be a key method for interpreting effects of an intervention in single case experimental designs (Lane & Gast, 2014) . Visual analysis involves plotting data on a graph with the different time points of experimental design (Horner & Swoboda, 2014). Therefore, the SCED data for three participants (Harrison, Bob12_8 and Peter) was visually analysed to assess the level of functional relation between the independent and dependent variables (Parsonson & Baer, 1986). Effect sizes were calculated through the percentage of data exceeding the median (PEM) between each stage (Ma, 2006).

3.3.7.1.2 Tau-U

To analyse the single-case design for three participants (Harrison, Bob12_8 and Peter), standardised mean difference effect sizes were calculated, evaluating the mean difference between pre-intervention, intervention and maintenance scores. Tau-U was calculated to provide effect size estimates, ranging from 0 to 1 (Parker et al., 2011). Brossart et al. (2018) argue Tau-U can provide useful descriptive and inferential insights about data through examining within-phase and across-phase differences separately (Brossart et al., 2018). Therefore, Tau-U was employed to analyse this data.

3.3.7.1.3 Reliable Change Index

To further address RQ1, reliable change index (RCI; Jacobson & Truax, 1991) was used to examine pre, post and follow up intervention changes in

sleep quality and mental health for all six participants. The RCI examines change at the individual level and is therefore appropriate for studies involving a small sample size and with a focus on the individual which is relevant to this research (Zahra & Hedge, 2010). The RCI assesses statistical reliability of changes in scores from pre-intervention to post-intervention with scores above 1.96 considered statistically significant (Jacobson & Truax, 1991). RCI can determine whether there has been changes in functioning that exceeds the probable range of measurement error and indicates whether a change in score is due to real change or chance variation (Ferguson et al., 2002; Hawley, 1995).

3.3.7.2 Phase 2: Analysis

3.3.7.2.1 Reflexive Thematic Analysis

To address RQ2 and 3, the interview transcripts were analysed through using Reflexive Thematic Analysis (Braun et al., 2019). This method allowed the researcher to identify themes and patterns across the qualitative data. This particular qualitative approach was chosen due to the flexibility it provides, allowing the researcher to play an active role in the analysis, using an iterative approach, creating codes which can evolve throughout the data analysis process (Braun et al., 2019). Reflexive Thematic Analysis utilises a systematic six phases approach, outlined in Table 3.3.

Table 3.3

Reflexive Thematic Analysis Stages

Phase	Process undertaken
Phase 1: Familiarisation with the data	Read the interview transcripts multiple times to become familiar with the data.
Phase 2: Generating initial codes	The data was made sense of through systemically identifying meaning throughout the data and organising the data into codes.
Phase 3: Constructing themes	Grouped together and organised the codes into potential themes and subthemes which captured meaningful patterns from the dataset.
Phase 4: Reviewing themes	The themes were reviewed and refined, using a thematic map to show links between the themes and evaluation questions.
Phase 5: Defining and naming themes	Themes were clearly defined to reflect the content of the data.
Phase 6: Producing the report	The final stage involved presenting the analysis in the thesis. The RQs and coding notes were revisited to ensure the themes remained close to the data and answered the RQs.

Reflexivity is important during Reflexive Thematic Analysis, reflecting on oneself to recognise one's own position, identity, values, choices and practices during the research process and the influence of these on the participants and knowledge created (Braun and Clarke, 2022). This included personal reflexivity (how the researcher's values shape their research and

knowledge), functional reflexivity (how methods and design aspects shape the research and knowledge) and disciplinary reflexivity (how academic disciplines shape knowledge) (Braun and Clarke, 2022). For example, considering the researcher's views on what constitutes 'good sleep' and past experience of supporting children's sleep. This was considered in relation to how this might impact on the questions asked during the interviews and during the analysis. Outlining quotes in the write up, helped capture participants' voices. A reflexive journal was kept throughout the process to help become self-aware and reflect on decisions and choices (Appendix T).

Interviews were recorded on Microsoft Teams and transcribed by the researcher, using Microsoft Word transcription software. The researcher listened to each recording twice to check the transcription was accurate and to become familiar with the data. NVivo Qualitative Data Analysis software was used and tables on Microsoft Word to analyse the data, helping to systemically organise the data (Appendix H). Through analysing the data, codes were created and subsequently grouped into themes to capture meaningful patterns from the dataset (Braun et al., 2019).

3.4 Results

3.4.1 RQ1. What is the effectiveness of a personalised, co-produced parent-led sleep intervention on autistic children's sleep quality and mental health?

Recommended techniques for single case experimental designs (Kratochwill et al., 2010) were used to examine the effectiveness of the personalised sleep intervention on autistic children's sleep quality. This included visual

analysis, calculation of effect sizes using percentage of data exceeding the median (PEM) (Ma, 2006) and Tau-U (Parker et al., 2011). Alongside this, the Reliable Change Index (RCI) was used to assess the effectiveness of the sleep intervention on both sleep quality and mental health pre-intervention, post- intervention and at follow-up.

3.4.1.1 Effect Sizes

Ma (2006) defines PEM as “the number of data points exceeding the baseline median line.” PEM was chosen rather than percentage of non-overlapping data (PND) due to the effect not being influenced by extreme outliers which can have a detrimental effect on the PND score, causing type II error (i.e. accepting the false null hypothesis) (Ma, 2006). Moreover, PEM can reflect the effect size with the presence of a ceiling effect, which was present with one participant in this study, whereas PND cannot. Rakap’s (2015) interpretation of PEM effect sizes was used to assess the effect, outlined in table 3.4.

Table 3.4

Interpretation of PEM effect size (Rakap, 2015)

Method	Score range	Ineffective	Questionable	Effective	Very effective
PEM	0-100	x≤50	50<x≤70	70≤x<90	X ≥90

Compared to any other non-overlap index, Tau-U is relatively new and considered the strongest overlap index with higher statistical power. Parker

et al. (2011) propose Tau-U addresses the limitations of both regression-based and simpler dominance-based (non-overlap) models. Tau-U combines Phase AB nonoverlap with Phase B trend. Tau-U controls for an undesirable baseline (Phase A) trend and is unlikely to produce a 100% ceiling effect. Therefore, Tau-U helped to overcome the limitations of PEM. Parker et al.'s (2011) interpretation of Tau-U effect sizes was used in this analysis (0-0.65=small effect size, 0.66-0.92=medium effect size, 0.93-1.0= large effect size).

3.4.1.2 Visual Analysis

Visual analysis of graphic displays of data is a core component of single-case designs. Guidance from Kratochwill et al. (2010) and Lane and Gast (2014) was followed. This involved assessing the level, trend, variability, immediacy of effect, overlap and consistency of data in similar phases (see table 3.5). These features were examined individually and collectively to assess whether results demonstrate a causal relation between an independent variable and outcome variable (Kratochwill et al., 2010). Three demonstrations of experimental effect across three different participants (inter-participant replication) or at three different time points with a single participant (within subject replication) need to be shown to indicate a causal relation (Kratochwill et al., 2010). PEM and Tau-U effect sizes are outlined in table 3.8 and 3.9.

Table 3.5

Factors in Visual Analysis from Lane and Gast (2014) and Horner et al. (2022)

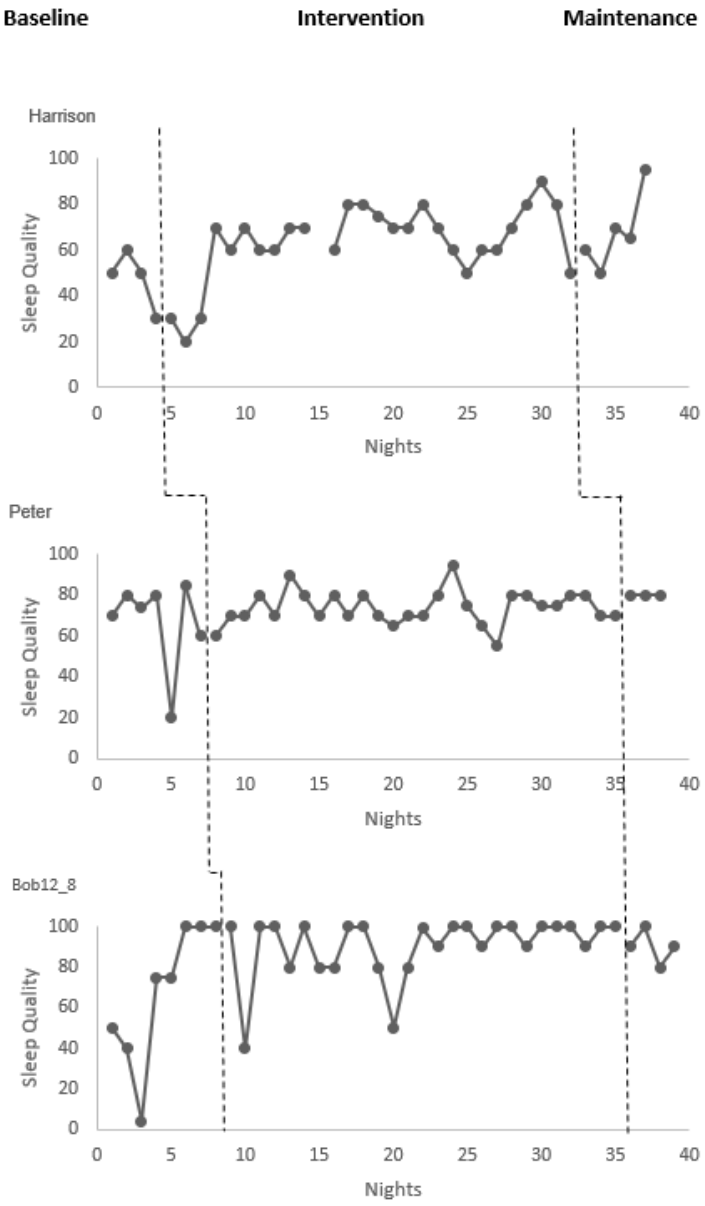
Factor	Description	Process
Level	The mean score of data within a phase	The median was used to calculate the level of change in a phase, to avoid any outlier scores having an influence on the level (Lane & Gast, 2014).
Trend	The slope of best-fit straight line for the data within a phase	The direction of the trend (upwards of downwards) was examined through analysing the slope of the best fit linear line for each stage.
Variability	The range or standard deviation of data about the best-fit straight line	A stability envelope was created from the median with the percentage of data points within ± 25% of the median. Stability was determined if 80% of data points were within the stability envelope (Lane & Gast, 2014).
Immediacy of effect	The level of change between the last three data points in one phase and first three data points of the next. The more immediate the change, the more likely the change is caused by manipulation of the independent variable.	Through visual analysis of the last three data points of the baseline phase and first three data points in the intervention phase.
Overlap	The proportion of overlapping data between phases	The PEM calculation and Tau-U were used to determine overlap between baseline and intervention phases.
Consistency	Consistency of data in similar phases	This involves examining the consistency of data in similar phases (all ‘baseline’,

Factor	Description	Process
		'intervention' and 'maintenance' phases). The greater the consistency, the more likely a causal relationship (Kratochwill et al., 2010).

Figure 3.3 shows a summary of self-reported sleep quality for all three participants recorded each night, on a scale of 0-100 (0=worst night's sleep, 100=best night's sleep). This was recorded during the baseline, intervention and maintenance stage.

Figure 3.3

Graphic display of participants' nightly sleep quality rating



Descriptive statistics of the median and means of each stage are outlined in table 3.6. The mean score increased from baseline to intervention for all three participants and continued to increase into the maintenance stage for two of the three participants (Harrison and Peter). This indicates improvements in sleep quality for all three participants between the baseline and intervention stage. However, the median scores increased from baseline to intervention for Harrison and Bob12_8 but not for Peter. This might be related to outlier scores affecting the mean.

Table 3.6

Descriptive statistics of means and medians of each stage

	Baseline	Intervention	Maintenance
Harrison			
Median	50	70	65
Mean	47.5	63.9	68
Peter			
Median	74	72.5	80
Mean	67	74	80
Bob12_8			
Median	75	100	90
Mean	68	90.7	90

The within level analysis is outlined in table 3.7, showing an increasing relative level change within the intervention stage for all three participants, indicating improvements in sleep quality from the beginning to end stage of the intervention. However, due to not having a stable baseline, Bob12_8's baseline period also showed increasing within level sleep quality. This

variability could be due to confounding variables at the time of the intervention, such as the hot weather. Further analysis is reported for each participant below.

Table 3.7

Within Level Analysis

	Phase A	Phase B	Phase C
Harrison			
Median of 1st half	55	60	55
Median of 2nd half	40	70	80
Relative level change	-15 (Deteriorating)	+10 (Increasing)	+25 (Increasing)
First value	50	30	60
Last value	30	50	95
Absolute level change	-20 (Deteriorating)	+20 (Increasing)	+35 (Increasing)
Peter			
Median of 1st half	74	70	80
Median of 2nd half	60	75	80
Relative level change	-14 (deteriorating)	+5 (increasing)	0 (constant)
First value	70	60	80
Last value	60	70	80
Absolute level change	-10 (deteriorating)	+10 (increasing)	0 (constant)
Bob12_8			
Median of 1st half	45	80	95
Median of 2nd half	100	100	85
Relative level change	+55 (increasing)	+20 (increasing)	-10 (decreasing)
First value	50	100	90
Last value	100	100	90

	Phase A	Phase B	Phase C
Absolute level change	+50 (increasing)	0 (constant)	0 (constant)

3.4.1.3 Harrison

3.4.1.3.1 Within Phase

Harrison recorded his sleep quality, with parent support, for 4 days before starting the sleep intervention for 28 days. Harrison's baseline (100% stability envelope), intervention (81% stability envelope) and maintenance data (80% stability envelope) were stable. There was a downward trend in the baseline data with sleep quality reducing at the relative (-15) and absolute level (-20). During the intervention phase, there was an upward trend with sleep quality improving at the relative (+10) and absolute level (+20). An upwards trend was also found during maintenance with sleep quality increasing at the relative (+20) and absolute (+35) level. This suggests there were improvements in sleep quality during the intervention and maintenance stages.

3.4.1.3.2 Between phases

Through visually examining the last three data points of baseline and first three of the intervention, there was a delayed immediacy of effect between baseline and intervention. This suggests the intervention did not have an immediate effect. As shown in table 3.6, the mean and median scores increased from baseline to intervention and from intervention to maintenance. There was a change in trend from downward-decelerating trend in baseline to accelerating-improving during intervention and accelerating-improving in maintenance. This indicates improvements in sleep quality.

The PEM scores demonstrated the intervention was effective (70≤ x < 90) on sleep quality from baseline to intervention (81%), showing 81% of the data points during the intervention exceeded the median for the baseline phase. This aligned with the Tau-U score, indicating a significant change from baseline to intervention with a medium effect size (Tau-U=0.66, p=0.0365). Moreover, the PEM score demonstrated the intervention was effective from baseline to maintenance (80%), suggesting the positive effects were maintained after intervention. However, for Tau-U, a non-significant, medium effect size (Tau=0.75, p=0.0662) was found between baseline to maintenance. This demonstrates an observable improvement at maintenance but without statistical significance.

3.4.1.4 Peter

3.4.1.4.1 Within phase

Peter recorded his sleep quality, with parent support, for 7 days before starting the intervention. Peter's baseline (85.7% stability envelope), intervention (96.4% stability envelope) and maintenance data (100% stability envelope) were stable. There was a downward trend in the baseline data with sleep quality reducing at the relative (-14) and absolute (-10) level. During the intervention phase there was a slightly increasing trend with sleep quality increasing at the relative (+5) and absolute (+10) level, indicating improved sleep quality during intervention. The maintenance trend was constant (0) for both absolute and relative levels, suggestive of sleep quality remaining stable.

3.4.1.4.2 Between phase

Through visually examining the last three data points of baseline and first three of the intervention, there was an immediate effect of the intervention on sleep quality. This suggests the sleep intervention had an immediate effect from baseline to intervention. As shown in table 3.6, the mean score increased from baseline to intervention and from intervention to maintenance. The median score decreased slightly from baseline to intervention but increased from intervention to maintenance. There was a change in trend from downward-decelerating trend in baseline to accelerating-improving during intervention and constant in maintenance. This indicates improvements in sleep quality.

However, the PEM score (50%) indicated questionable effects ($50 \leq x < 70$) on sleep quality from baseline to intervention. This shows 50% of data points during the intervention exceeded the median for the baseline phase. Similarly, there was a non-significant small effect size from baseline to intervention (TAU=0.0459, p=0.8528). Nevertheless, from baseline to maintenance, the PEM score (100%) indicated that the sleep intervention was very effective at the maintenance stage. This might be related to the intervention taking time to have an effect. However, the Tau-U score (Tau-U=0.4286, p=0.3051) demonstrated a non-significant small effect size. This shows there were observable but non-significant improvements at maintenance.

3.4.1.5 Bob12_8

3.4.1.5.1 Within phase

Bob12_8 recorded his sleep quality, with parent support, for 8 days before starting the intervention. Although Bob12_8's intervention (92.6% stability envelope) and maintenance data (100% stability envelope) were stable, the baseline data was not stable (25% stability envelope). This is likely due to confounding variables, such as the hot weather at the time during the baseline and intervention period. There was an upwards trend in both the baseline and intervention sleep quality data and a slightly downward trend in maintenance data. The within level change for baseline was +55 at the relative level and +50 at the absolute level. There was an increase in intervention level change at the relative level (+20) and constant at the absolute level (0). For maintenance there was a decreasing level change at the relative level (-10) and constant absolute level change (0). The unstable baseline trend makes it difficult to decipher whether the change in sleep quality from baseline to intervention was related to the introduction of the intervention or other factors (Parker et al., 2006). However, it is often difficult to secure a stable baseline trend, such as in this study where there were time constraints. Nevertheless, statistical analysis is able to control for undesirable baseline effects which is outlined in the next section.

3.4.1.5.2 Between phase

Through visually examining the last three data points of baseline and first three of the intervention, there was a delayed effect of the intervention on sleep quality. As shown in table 3.6, the mean and median scores increased from baseline to intervention and from intervention to maintenance, indicating

improvements in sleep quality. The trend continued to stay accelerating-improving in baseline to accelerating-improving during intervention and downward-decelerating in maintenance. This improving, unstable trend during baseline level might have been due to the sudden change from 0 to 80, potentially explained by external factors influencing sleep pre-intervention.

From baseline to intervention stage, the PEM score (93%) indicated the sleep intervention was very effective (≥90) on sleep quality. This demonstrates 93% of the data points in the intervention stage exceeded the median for the baseline phase. However, Tau-U, after correcting for baseline, showed a non-significant small effect size from baseline to intervention (Tau-u=-0.3194, p=0.1753). Similarly, from baseline to maintenance the PEM score (PEM=100%) demonstrated the sleep intervention was very effective (≥90) on sleep quality. However, the Tau-U effect size (-0.2188, p=0.5522), showed a non-significant small effect between these stages. This shows there were observable but non-significant improvements at maintenance.

3.4.1.6 Consistency

The Tau-U weighted average showed a significant small effect size (TAU=0.32 p=0.0406) between baseline and intervention stage. This suggests the sleep intervention had on average a significant small effect on sleep quality across all participants, controlling for any unstable baseline trends. However, only one participant had a significant Tau-U effect size from baseline to intervention, limiting the generalisability of these findings.

All three participants' intervention and maintenance stages were consistent in relation to stable variability. However, Bob12_8's baseline stage was unstable compared to Harrison and Peter's who were stable. For all three participants, upwards trends and increasing level changes were found within the intervention stage, indicative of improvements in sleep quality during the intervention across the three participants. Both Harrison and Peter, had a downwards baseline trend and reducing level change, indicative of sleep quality worsening before the intervention. Contrastingly, Bob12_8 had an upward, unstable baseline trend and increasing level change, likely due to confounding variables. For the maintenance stage, all three participants trends and level changes differed. Harrison had an increasing maintenance trend and level change, demonstrating continued improvement in sleep quality. Peter had a constant maintenance trend and level change, indicative of sleep quality continuing to remain at a similar level. Bob12_8 had a downward maintenance trend and level change, suggestive of reduction in sleep quality, following the intervention.

Table 3.8

Between Phase Analysis PEM Effect Sizes

Phases	**Bas-Int**	**Bas-Main**
Harrison	81% (effective)	80% (effective)
Peter	50% (questionable)	100% (very effective)
Bob12_8	93% (very effective)	100% (very effective)

Table 3.9

Between Phase Analysis Tau-U Effect Size Estimates

	Bas-Int			Bas-Main		
	TAU	*p value*	*CI 90%*	*TAU*	*p value*	*CI 90%*
Harrison	0.6574 Medium	0.0365*	0.140 <> 1	0.75 Medium	0.0662	0.078<>1
Peter	0.0459 Small	0.8528	-0.361<>0.453	0.4286 Small	0.3051	-0.259 < > 1
Bob12_8	0.3194[1] Small	0.1753	-0.068<>0.707	-0.2188[1] Small	0.5522	-0.824<>0.387
Weighted average	0.3168 Small	0.0406*	0.0622<>0.5714	0.3 Small	0.1923	-0.0785<>0.6786

*Significance at p<.05 [1]Corrected at baseline due to significant baseline trend (p<.05 level)

3.4.1.7 Reliable Change Index

To examine the effectiveness of the sleep intervention on sleep quality and mental health, all six participants completed the CSHQ and RCADS-P pre-intervention, post-intervention and at 1 month follow up. The reliable change index (RCI) (Jacobson & Truax, 1991) was used to examine whether the change in sleep quality and mental health from pre-post intervention and follow-up, was statistically significant and reliable not due to measurement error but instead due to the interaction between the independent and dependent variables. Change scores above 1.96 are deemed statistically significant (Jacobson & Truax, 1991).

Zahra's (2010) online calculator was used to calculate the RCI, using the calculations outlined in figure 3.4. Since appropriate re-test reliability scores could not be found for the participants, Cronbach's alpha was used instead. Cronbach's alpha was used for both the CSHQ (α=0.78) (Owens et al., 2000) and RCADS-P (0.93) (Ebesutani et al., 2010) and the standard deviation for CSHQ (sd=13.70) and RCADS-P (sd=13.53).

Figure 3.4

Reliable Change Index Formula

$$RCI = \frac{x_2 - x_1}{S_{diff}}$$

$$S_{diff} = \sqrt{2(S_E)^2}$$

$$S_E = s_1\sqrt{1 - r_{xx}}$$

As shown in table 3.10, from pre-post intervention, the sleep intervention demonstrated statistically reliable change for sleep quality for one participant (participant 2) and statistically reliable change for mental health for four participants (Gabz, participant 2, Peter and Bob12_8). The significant decrease in scores indicate improvements in sleep quality and mental health for these participants.

When comparing pre-intervention to follow-up scores, a statistically reliable change for mental health was found for Peter, Gabz and participant 2. Participant 2 and Peter had a statistically reliable change for sleep quality pre-intervention to follow-up. From intervention to follow-up, Gabz had a statistically reliable change in mental health but no other participants had statistically reliable changes between these stages.

Table 3.10

Reliable change index

Participant	Dependent variable	Pre-intervention	Post-intervention	Follow-up	RCI Pre-Post	RCI Pre-follow-up
Gabz	Sleep	43	43	41	0	-0.220
	Mental health	44	33	20	-2.173*	-4.741*
Participant 2	Sleep	70	47	43	-2.531*	-2.971*
	Mental health	56	20	18	-7.111*	-7.506*
Harry	Sleep	50	50	49	0.000	-0.110
	Mental health	11	11	9	0.000	-0.395
Harrison	Sleep	61	59	56	-0.220	-0.550
	Mental health	62	58	63	-0.790	-8.889
Peter	Sleep	61	45	42	-1.761	-2.091*
	Mental health	46	9	1	-7.309*	-8.889*
Bob12_8	Sleep	53	43	43	-1.100	-1.100
	Mental health	24	13	19	-2.173*	-0.988

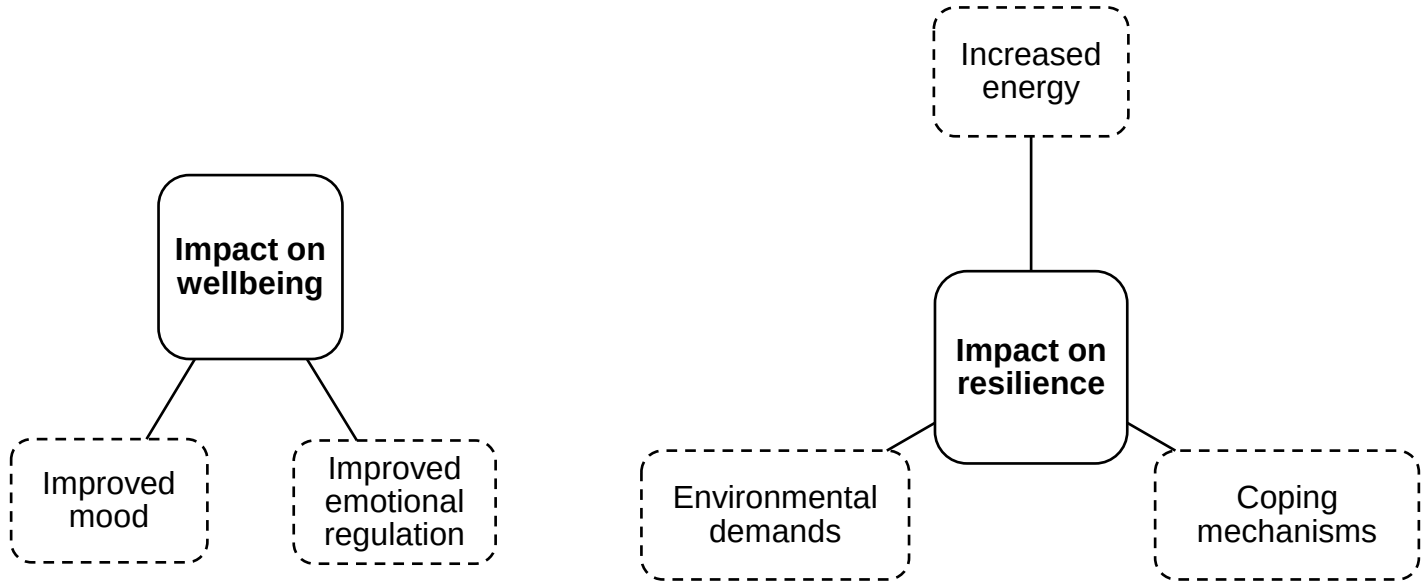
*Significant decrease (improvement) between times ($p<0.05$)

3.4.2 RQ2. What is the relationship between autistic children's sleep and mental health?

Child and parent interview data was analysed together through thematic analysis and coded into themes and subthemes (see Appendix Q). Two themes and five subthemes were developed through thematic analysis. The first theme was 'impact on wellbeing' with two subthemes; improved mood and improved emotional regulation. The second theme was 'impact on resilience' with three subthemes; motivation, environmental demands and coping mechanisms. Figure 3.5 shows a Thematic Map and Appendix N illustrates the themes, subthemes and codes.

Figure 3.5

RQ2 Relationship between sleep and mental health thematic map



Note Key: Theme = ▭ Subtheme = ⬚

3.4.2.1 Theme 1 Impact on Wellbeing

This theme captured two subthemes, Improved mood and improved emotional regulation. At first, the researcher considered using one overall theme of ‘emotional regulation’ for the data in this section. However, when reviewing the themes and reflecting on the researcher’s own assumptions, the researcher acknowledged that the participants’ views within this area were distinct. Some participants were sharing views about managing and regulating emotions whereas others were sharing views about how sleep affected their child’s emotions and mood. Therefore, two distinct subthemes were created.

3.4.2.1.1 Subtheme Improved mood

Both parents and children commented on the impact of sleep on their mental health. For example, when asking Peter how he felt when he has slept well, he said “I started to feel a bit more happier and more calm than before.” This was similar to Gabz who said, “my feelings felt happy or like normal for stuff. Yeh just normal.” Parents also noticed the effect of sleep on mood, with Harry’s mum saying, “I do think having adequate sleep is helpful for mental health and emotional health as well as behaviours.” This demonstrates how sleep can improve children’s wellbeing. This was the consensus among the majority of participants. However, participant 2’s parent did not have this view with her child and said, “I've never had a problem with her waking up in the morning and being moody.” This suggests that the impact of sleep on children’s mood differs with some individuals’ mood being less impacted by their sleep.

3.4.2.1.1 Subtheme Improved emotional regulation

The second subtheme was ‘Improved Emotional Regulation.’ Parents commented on the effect of sleep on their child’s emotional regulation. For example, Peter’s mum said, “I would in like a four-week period expected there to have been a couple of meltdowns, but we've not, it's been really good.” This demonstrates how improved sleep can reduce meltdowns, suggestive of sleep improving emotional regulation. Similarly, Harry’s mum commented:

“So if you have enough energy you'll be, your mood will be better during the day, and then your thinking will be more positive as well. So because if you feel fatigued or tired during the day it, you know it can affect your thoughts and your behaviours.”

This demonstrates how sleep can affect feelings, thoughts and behaviours which can impact on emotional regulation. Gabz’s parent said, “if he’s not got enough hours, you can see he's a bit short, you know, a bit more irritated if he doesn't get the full 9 hours or whatever.” This suggests less sleep can lead to children being more agitated more easily, being less able to regulate emotions well.

3.4.2.2 Theme 2 Impact on resilience

The theme represents participants’ views on the impact of sleep on children’s resilience. It encompasses three subthemes; motivation, environmental demands and coping mechanisms.

3.4.2.2.1 Subtheme Increased energy

This subtheme stemmed from participants sharing views about how sleep affects their alertness, energy levels and focus. For example, Gabz noted, “I felt well, I felt wide awake. Like wide awake, more alert.” Aligning with this, Gabz’s parent said, following sleeping better, Gabz is “much more sort of like alert in the morning and more most probably focused as well.” This demonstrates the impact sleep can have on alertness and being more focused. Participant 2 said, “In the morning, I felt like I was really energetic and I can do lots of stuff and activities.” This demonstrates how sleep can increase energy and ability to engage in activities.

3.4.2.2.2 Subtheme Environmental demands

This subtheme describes how sleep can impact on children’s ability to manage environmental demands. For example, Peter’s parent said, “I think it also helps with the . . . sensory load of being at school and dealing . . . with people because it's tiring in itself.” This demonstrates how sleep can support children with managing the sensory environment and social demands. This is further explained through, Peter’s parent noting:

> “I think from a sensory perspective if you're tired, you're not already starting thinking I've got a headache. Or uhhh it's too loud, it's too bright, and so you're not starting from that disadvantage because you've had a better night's sleep. And yeah, the lights might be too bright . . . but . . . you’re in a better place to deal with them because you're not . . . as tired so . . . it's not further tiring you out.”

This shows how sleep can increase resilience in relation to managing sensory demands better. Peter's parent also said:

"It's putting you at a disadvantage when you're trying to deal with all the interactions in your life because you're already tired you're already grumpy. You read things in different ways. You might react more strongly than you might have done."

Similarly, Gabz's parent said, "if he's not got enough hours, you can see he's a bit short, you know, a bit more irritated if he doesn't get the full 9 hours or whatever." This demonstrates how sleep can impact on children's interactions with others, affecting managing feelings and reactions.

3.4.2.2.3 Subtheme Coping mechanisms

This subtheme describes how sleep affects children's coping strategies, in areas such as managing transitions, managing setbacks and feeling stronger to manage challenges. For example, Peter's parent said:

"it's a bit like if you've got a, I suppose if you've got a big jar full of beads and those beads of resilience. If you're tired to begin with, you've already taken the first layer out, and then if you don't quite get decent sleep the next night, you're running a deficit all the time."

This highlights how sleep can increase resilience to manage challenges. Moreover, Peter's parent noted:

"I think I think it's had a very positive impact. And I think for me, I mean, we could have done this at any time, but in theory we could have done this at any point in the year, but we've been doing to the point in which he's

had some big, big, big transitional things for him, which have been difficult for him in previous years."

This demonstrates how sleep can support children to cope with transitions and changes. Gabz's parent said, "he's more cooperative, I think. When he's had a good night's sleep", demonstrating how sleep can increase cooperativeness.

3.4.3 RQ3. What are parents' and children's views on a personalised sleep hygiene intervention?

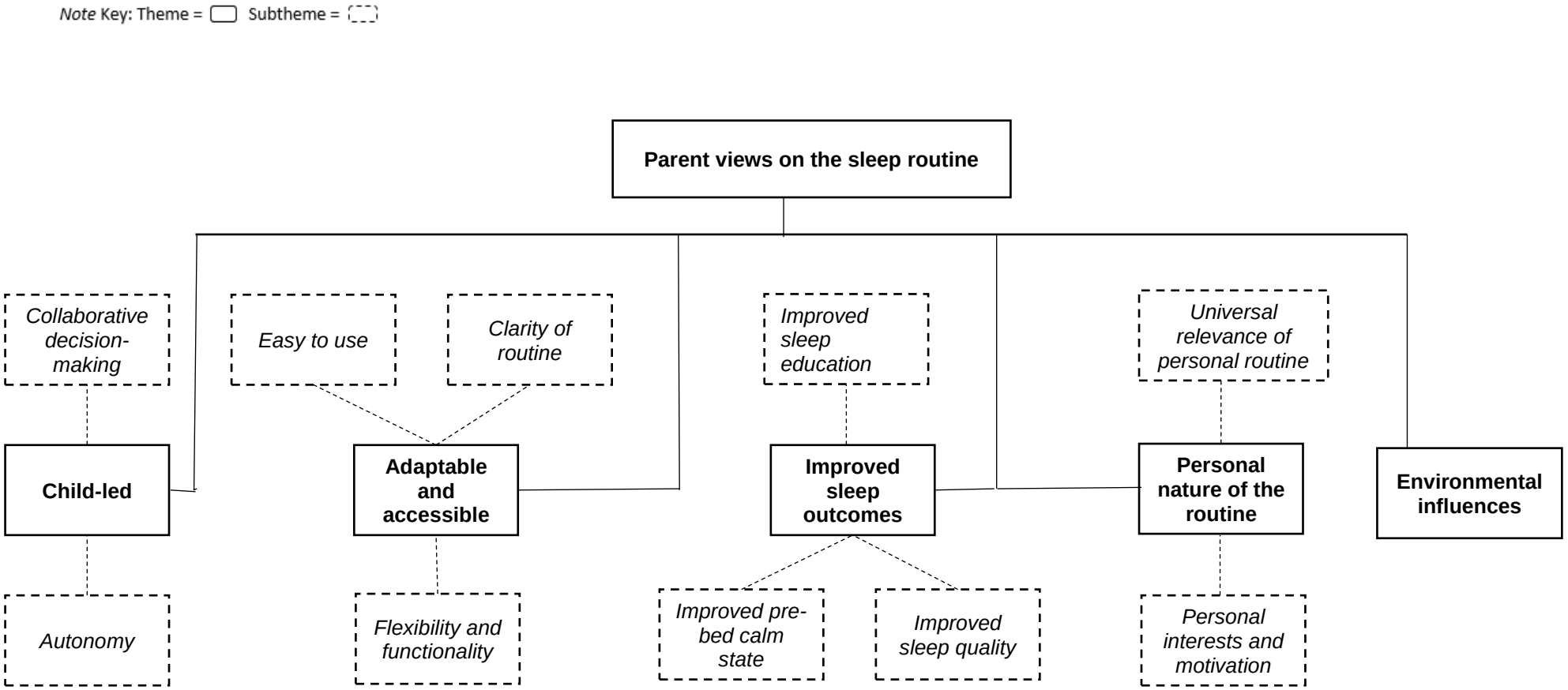
At first, the researcher considered analysing the parents' and children's views together but when becoming familiar with the data, the researcher realised the difference in their perspectives. The researcher also realised she resonated more with the parents' perspectives, perhaps due to being a neurotypical adult and having had past experience of working with parents to support children's sleep. Therefore, to respect the distinct perspectives, children's and parents' views were analysed separately. Interview data was coded and placed into subthemes and themes (see Appendix R and S).

3.4.3.1 Parent views

Five themes were developed from parent views on the sleep routine; child-led, adaptable and accessible, improved sleep outcomes, personal nature of the routine and environmental influences. This is outlined in the thematic map in figure 3.5.

Figure 3.6

Thematic map for parent views on the sleep routine



3.4.3.1.1 Theme 1 Child Led

This theme captured all parent views and was separated into two subthemes; “autonomy” and “collaborative decision-making”.

3.4.3.1.1.1 Subtheme Autonomy

The results indicate that parents saw their children taking ownership of the routine, making key decisions, choosing what they wanted to do and being motivated to follow it. For example, Peter’s parent said:

> “I suppose because it's what Peter came up with. It's what he wanted that it is quite different also to when they are babies and toddlers it's parent led. It's like, right you're having . . . your bottle, you're having your bath, changing your nappy, you're going to bed. This [his sleep intervention] is what he finds relaxing. So that I think has been the key difference in this. It’s not me deciding right let's do this because I've read something in a book or on the Internet. It's what he's said.”

This highlights the change in autonomy with age and the importance of the child sharing their views and making decisions.

Participant 2’s parent said, “She is the one that even have to remind me, ‘mom, this is what we're going to do, mom, this is what we're going to do.” This demonstrates motivation and willingness of the child to engage with the routine. Similarly, Harry’s parent said, “Yeah, I think he wants to do that himself. So it is very important that I think if they have the motivation to want to have a better sleep and nicer sleep then it's easier as well.” This shows

how motivation and autonomy over the routine can impact on the child's willingness to follow the routine.

3.4.3.1.1.2 Collaborative decision making

This subtheme demonstrates the views of parents on the importance of creating and following the routine in a collaborative manner. It captured views on the co-production of the routine, the importance of making decisions together, gaining the child's views and the child feeling empowered to make decisions. For example, Gabz's parent noted:

"It's good because it comes from them. When it was created, it actually came from them. So it's not something you're saying, OK you're going to follow this, this and this. It actually came from them personally. So I think they're more likely to want to follow it because they were a part of creating it."

This demonstrates the importance of the child making decisions, increasing their desire to follow and engage with the routine.

Peter's parent commented on the importance of the routine being child-led, saying, "I think what's been really useful is making it child led, because funnily enough, there's not a huge amount of that on sleep stuff. It's all very it's all very parents need to do this." This highlights the importance of changing the narrative to supporting the child to make decisions and lead on the routine. Reinforcing this view further, Peter's parent noted the importance of compromising and asking the child what they want to do, saying:

"T*he parent as well as the adult you are meant to be overseeing these things, but it implies that it is very much*, right, you need to put limits on things you need to do that, but that's very top down. Actually, you need to kind of meet in the middle and have a, you know, but what do you what do you need? What would you like? What? You know what can I then do as a parent to help you do that? And so, yeah, I'd say that's the big. Yeah. Shifting my focus, I think, but what does my, you know, what does Peter think about this and how you know, finding a compromise on it?"

3.4.3.1.2 Theme 2 Adaptable and accessible

This theme captured views from parents about the adaptability and accessibility of the routine. This was separated into three subthemes; easy to use, clarity of routine and flexibility and functionality.

3.4.3.1.2.1 Subtheme Easy to Use

All parents shared views about the ease of use of the routine, in relation to it being simple to implement and follow, easy to adapt and being able to use accessible, low cost resources. For example, Harry's parent said, "It was quite easy because I think . . . after school he's got quite a busy schedule, so we just move on from one to the other." This demonstrates the simplicity and flow of the routine, considering other activities children engage with after school. Similarly, Participant 2's parent said, "oh to be honest it's very easy. As I said before, it kind of make [participant 2] organize more" and Peter's parent said, "it's just been really easy to follow." This suggests the routine was simple and easy to use and follow and also helped with organisation.

Peter's parent also commented on the use of accessible resources, noting, "because everything else was erm stuff that we already had or just required us to remember to talk about 3 positives in our day and it's become it's been easy to make that a habit." This demonstrates the low cost, accessible nature of the chosen routine, being able to choose readily available resources.

3.4.3.1.2.2 Subtheme Clarity of routine

This subtheme was developed from parents commenting on the clear nature of the routine, including visual reminders, having clear transitions, preparation and reminders for evening activities. For example, Gabz's parent said, "trying to follow the routine was good as a visual prompt. It's in the kitchen on the wall." This suggests the importance of having a visually clear routine to support children with understanding and following the routine. Participant 2's parent similarly commented on the routine acting as a reminder for activities each day, saying, "so it kind of keeps her updating on the routine every day, what we're doing every day, kind of reminder." Aligning with this, Peter's parent said:

"I found that it's also, given us a bit of a countdown to things or making it visible about . . . things that we do before dinner. We have things we do during dinner other than eat . … Going through the three positives and then hot chocolate, the relaxing TV, then bath and bed."

This suggests the routine supported children and families' preparation for the evening activities.

3.4.3.1.2.3 Subtheme Flexibility and Functionality

This subtheme captured parents' views on the flexibility and functionality of the routine and activities, in relation to being able to adapt the routine, needing to prioritise activities, understanding interests change and placing value on the functional purpose of activities (e.g. exercise, calming activity) rather than the activity itself. For example, Peter's parent stated:

"There are ways to think about what if you know if we, kick about ends because you've kicked the ball but what could you do that's similar and it could be like trampet or even swing ball something like . . . that. So there are solutions to all of these things."

This indicates parents' views on understanding the functional purpose of activities and being able to adapt and change activities, based on resources and time available.

Gabz's parent demonstrated her views about the importance of following the steps rather than exact timings by noting:

"Sometimes to keep to the exact times is a bit difficult sometimes. I think the whole thing about it is just to follow the steps. Sometimes they don't have to, to the minute and you know to that hour. But as long as you kind of follow the steps and that consistency of trying to keep it going following the steps would only benefit him."

This highlights the importance of being flexible with the timings. Similarly, Harry's parent said:

"The only problem I would say is just that we're not able to keep the timing to keep things to the exact time, or sometimes maybe we'll have to miss out on one or two things. Just skip to the next one. But we never skipped the music and the reading, so that one we definitely will do every single evening and almost, yeah, even if even if it goes to bed a bit later than normal, he would still do that because that really, really does help. So it's only, yeah the only problem, I'll say just that keeping the timing, you know to the exact as the routine that's something that we haven't been able to do for the last two weeks."

This suggests the importance of prioritising key activities that the child likes and finds helpful for sleeping. It also highlights the difficulties in following the exact same routine and timings every night due to other evening commitments.

3.4.3.1.3 Theme 3 Improved Outcomes

The researcher first considered using the theme 'improved sleep quality.' However, when revisiting the codes, the researcher noticed that this had too narrow of a focus and this did not capture other views about feeling calmer and increasing knowledge about sleep and the benefits of it. Moreover, with the subjectivity of the meaning of 'sleep quality' and the potential influence of the researcher's own beliefs of what they believe 'sleep quality' is on the data, it felt more appropriate to hone this into subthemes more closely related to what the participants' reported. Therefore, a broader theme of 'improved outcomes' with three subthemes (improved pre-bed calm state, improved sleep education and improved sleep quality) was chosen.

3.4.3.1.3.1 Subtheme Improved Pre-bed Calm State

This subtheme was developed from all parents sharing views about the routine activities supporting their children to feel relaxed before bedtime. When the routine was initially created, the science behind sleep was shared, including explaining the importance of reducing cortisol levels (excitement/stress/anxiety) before bedtime. Therefore, when the routine was created, parents and children considered pre-bed activities that would be relaxing. Parents shared their views about the importance of making the bedroom environment calming and engaging in calming activities, as part of the routine, which helped their child to sleep. For example, Harry's parent said:

> "Listening to classical music, which he likes. He enjoys and it helps to calm him down. And you know, just to bring his mind to a more peaceful, you know, just bring it to a peaceful level before bed. And then reading the books that he enjoys reading before bed. So it just feels more just making the bedtime or the bedroom feel more calm, more calm and more, you know like room where you feel that you can have your space and then you can just get ready to go to sleep once you finish your reading and music listening."

This demonstrates the importance of finding calming activities that the child wants to engage with and ensuring the bedroom environment feels calm, as part of the personalised routine, to support the child to destress and subsequently fall asleep easier. Other parents noted how baths and showers helped the child to relax before bed. For example, participant 2's parent said,

“I think the thing that makes her to sleep more better is like when I give her a shower in the night sometime bath. It kind of make her relax.” These highlight parental perceptions of the importance of incorporating relaxing, comforting activities before bed into the routine alongside understanding that different children will find different activities relaxing. This shows the importance of not assuming the same activity (e.g. music) is relaxing for everyone.

3.4.3.1.3.2 Subtheme Improved Sleep Quality

This subtheme was developed from parents’ views about the sleep routine improving their child’s sleep quality, in relation to more consistent night’s sleep, falling asleep more quickly, sleeping longer and highlighting issues with sleep. For example, when asked about the impact of the sleep routine on sleep, Harry’s parent said:

“I think it helps him settle in quicker and fall asleep quicker. Also sleeping through the night, not really having any, you know, not restless before night. I definitely think that helps. Just bringing the whole body and mind into a more peaceful state so it actually helps with the, you know, falling asleep. And this the whole sleep. So it's not like abrupt, like going to bed suddenly.”

This illustrates the importance of the pre-bed routine in supporting the child to feel relaxed and ready to sleep, subsequently falling asleep quicker. Moreover, parents shared views about their child sleeping better during stressful periods while using the routine. For example, Peter’s parent said,

“His sleep has improved. He's getting more sleep. It's more consistent, and even when he's had nights when it's been harder to settle, and

whether that's the weather or it it's been you know, things like it's the last day of, you know, you're nervous about performance, that you're doing, or it's all those, you know, the big, big things you're doing. It might have taken him longer to settle, but he was able to do so, he'd got, it was a lot smoother."

This demonstrates how the sleep routine supported the consistency of quality of sleep, taking into consideration factors that can affect sleep quality, such as hot weather or feeling nervous for upcoming events.

Gabz's parent commented on how the sleep routine and tracker helped to identify things that affected her child's sleep which helped to mitigate these factors. Gabz's parent said:

"It's highlighted where he has his issues, like he's seen it in his own mind. Where you know what bed he's sleeping in. You know which position he's sleeping in? That seems to be more crucial for him, I think."

This demonstrates the importance of considering comfort within the sleep routine to support sleep quality and identify issues that affect sleep quality in order to make changes.

3.4.3.1.3.3 Subtheme Improved sleep education

The third subtheme was 'improved sleep education' which captured parents views about the importance of understanding factors that affect sleep to improve sleep quality. For example, Harry's parent said:

"It's just important to understand how important you know, good sleep is for health, good health, physical health and mental health and also about

how to do it. Creating the thing and the sleep hygiene, I think just information and knowledge are important before we start jumping into doing things. So it's really good that you gave us the, you know, the PowerPoint slide when we were, when we saw in person and you show us all the information. So we learned exactly why, you know, sleep is important. And yeah, and then we just, yeah, created a routine and then we follow through, you know."

This demonstrates the importance of supporting children and parents to understand the benefits of sleep and factors that affect sleep as part of sleep intervention. Similarly, Peter's parent said:

"I think what I did like was starting with why sleep matters and the science of it because it helps because [Peter] is very he's a very science minded child but it helped both of us think well actually, oh yeah and to see why it's important."

This shows how understanding factors that impact sleep and the benefits of sleep can help to promote sleep hygiene. Lastly, participant 2's parent said, *"*she knows what we're gonna do. Since we came to that meeting, she knows every evening." This highlights the importance of children understanding the routine to be able to follow and implement it effectively.

3.4.3.1.4 Theme 4: Personal Nature of Routine

This theme was developed from parents' sharing views about the importance of personalising the routine to their child's interests and the relevance of this to every individual. It was separated into two subthemes; personal interests and motivation and universal relevance of personalisation

3.4.3.1.4.1 Subtheme Personal interests and motivation

This subtheme related to all parents recognising the value of incorporating activities in the routine that their child enjoys and is motivated by. Views were shared about children being more motivated to engage with the routine due to their interests. For example, Gabz's parent said:

"It's good because it comes from them. When it was created, it actually came from them. So it's not something you're saying, OK you're going to follow this, this and this. It actually came from them personally. So I think they're more likely to want to follow it because they were a part of creating it."

Similarly, Harry's parent noted, "I think he wants to do that himself. So it is very important that I think if they have the motivation to want to have a better sleep and nicer sleep then it's easier as well." This illustrates the importance of involving children in creating their sleep routine and finding activities they are interested in to increase engagement.

Parents shared views about children having different interests and the importance of identifying these interests. For example, participant 2's parent said,

"talk to the children and ask them what will make you relax, what will make you relax before going to bed. Some children like reading in the night. Maybe some children, like a bit of game with their parents. Or some children like the parents to tell them story time."

Similarly, Harry's parent said:

“I mean maybe not everyone likes music, so that's I think that's personalised, but I think music is helpful, music's nice and yeah, it's good for mental health as well. If it's a you know if it's calming. Reading as well, but then again, not everyone likes to reading so it depends, I think that's another, just more personalised, it depends on children, I guess.”

Both of these quotes demonstrate the recognition that every child has different interests and different activities they find calming, highlighting the value of the personalised nature of the sleep routine.

3.4.3.1.4.2 Subtheme Universal relevance of personal routine

This subtheme related to parents sharing views about believing the personalised routine could be relevant for all individuals, regardless of age or diagnosis. For example, participant 2’s parent said, “so in term of sleeping I just feel that it's not just a child with learning disability. I just feel that every child deserves to be, for them to know what makes them relax.” This demonstrates the importance of personalising routines for every child, considering their needs and what helps them to relax. Harry’s parent noted how the concept of the personalised routine is important for everyone, including adults, stating:

“I think creating a calming environment before bed is definitely really, really helpful. I think that's for everyone, for adults as well. Yeah. So I think all those three things I was talking about I think they're helpful for [Harry]. I think those could be helpful for other children as well.”

3.4.3.1.5 Theme 5: Environmental Influences

This theme was developed, based on views from parents about environmental influences on sleep which the routine cannot always control for. Parents shared views about the effect of the weather on sleep, illness on sleep, sharing rooms with siblings or sleeping outside of the home environments. For example, Harry's parent said:

"I think the room temperature. That's another thing that I find that actually does affect people's sleep is their room temperature. If it's too hot, it would definitely affect people's falling asleep and staying asleep. So, I think a slightly cooler temperature in the room. It's actually helpful for one to ease into sleep and staying asleep, so not having too hot temperature."

This demonstrates parents' perceptions on considering the importance of room temperature on sleep and how weather might affect children's sleep quality. Peter's parent also commented on the effect of weather or sleeping in a different environment, saying:

"It's something that [Peter] thinks is helpful and we can roll with it if we're camping or even if it's like when it's been horrible, well not saying that it's been horribly 37 degrees or anything like that, but we've had hot, humid nights and you know that's always going to mess things up, but you still have the, the routines not thrown out by it. You can adapt it so."

This suggests parents believe the routine can still be used and adapted, regardless of environmental influences.

Participant 2's parent commented on the impact of participant 2 being ill while following the sleep routine, making it difficult to sleep. Participant 2's parent said, "It's just that at the moment, like I told you, [participant 2] has been having this serious cough that we don't even understand what's going on. This cough only happen when she's going to bed in the night." This demonstrates the impact of other physical factors on sleep.

Lastly, Gabz's parent commented on the problem of different siblings' bedtimes and sharing a room. For example, noting:

"The only problem that we thought we raised was just the issue of, OK, if he needs to go to bed and then his brothers on the game thing that would be the obstacle for everything, but everything else is fine."

This shows parents' views on the importance of considering the whole family routine and how this can impact on the sleep routine.

3.4.3.2 Child views

Four themes were developed from child views on the sleep routine; easy to use, importance of comfort and calmness, improved sleep quality and enjoyment of the personal routine. This is outlined in the thematic map in figure 3.6.

3.4.3.2.1 Theme 1 Easy to use

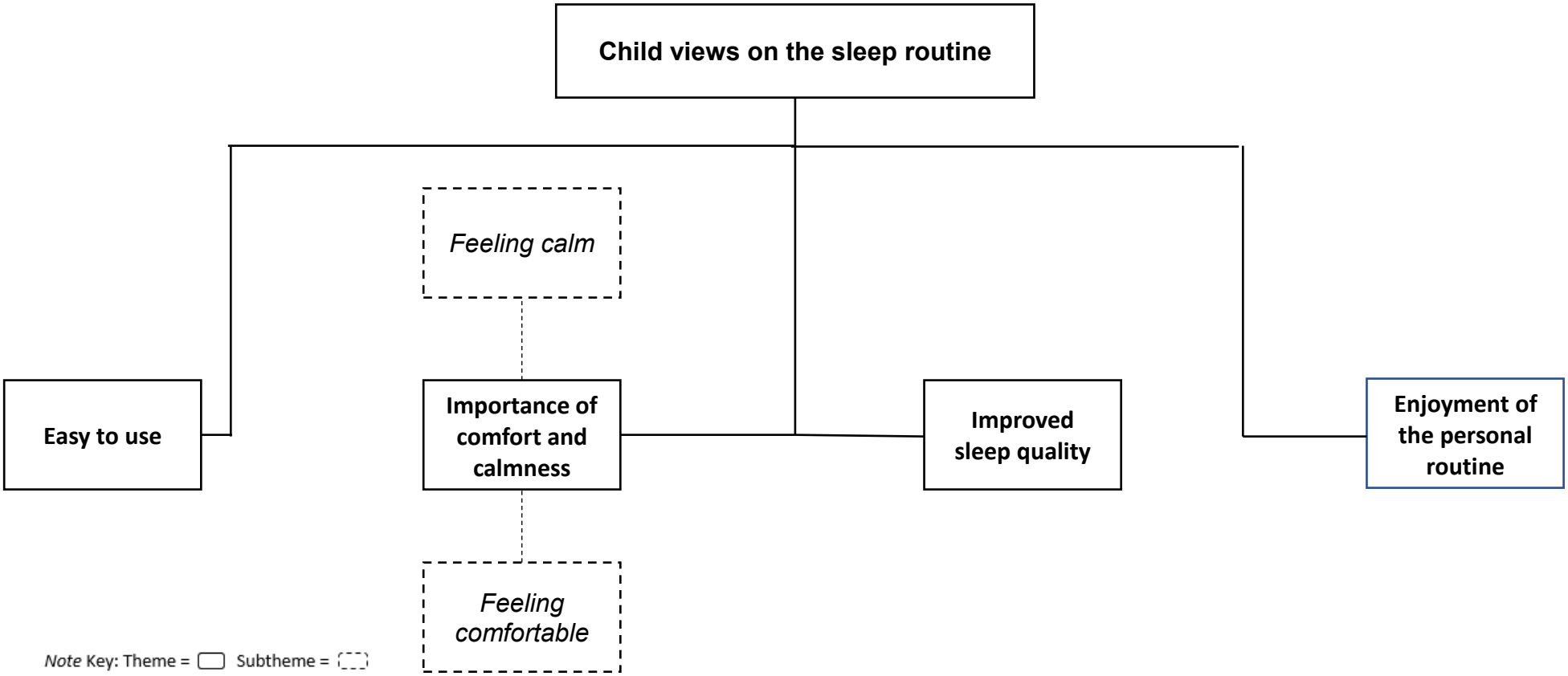
This theme captured children's views about the ease of using and implementing the routine. Children shared their views about understanding the routine, using readily available resources and being able to engage with the activities easily. For example, when asking participant 2 about how she

found using the routine, she said, “Very easy…that I can like do it and feel relaxed and do it properly.” Similarly, Peter said, “It was easy to do some parts like it was easy to have bath because you know just how it was easy to have one.” Both of these quotes illustrate children’s views on the simplicity of the routine and readily available resources used.

Moreover, the children demonstrated their understanding of the routine. For example, Gabz said, “I know at six I have trumpet, then at seven I have dinner. And at 8 I have like a bath. And I think at 9:00 I go to sleep.” This suggests the routine was clear and easy to understand. However, one child highlighted the issue of not being able to engage with all activities when the resources were not available or time was limited. For example, Peter said, “but sometimes it was hard to have a hot chocolate because sometimes you didn't have time or sometimes I forgot.” This demonstrates how time and resources available can affect the ability to implement all routine activities.

Figure 3.7

Child views on the sleep routine



3.4.3.2.2 Theme 2 Importance of Comfort and Calmness

This theme was developed from interview data about the participants sharing their views about feeling calm and comfortable before sleeping. It was separated into two subthemes; feeling calm and feeling comfortable.

3.4.3.2.2.1 Subtheme Feeling Calm

Children shared views about the importance of feeling calm before bed and the activities helping them to feel sleepy. For example, participant 2 commented on how the routine helped her to sleep through feeling more relaxed. When asked about her views on the routine, she said, “Very good…That I could relax…That I can sleep longer. And I can erm I cannot feel like stressed out or anything…I liked everything.” This highlights the importance of reducing stress before bed through calming activities. They spoke about different activities they found relaxing and how this helped them to sleep. For example, Peter said, “Yeah, I felt calm watching on the TV.” This highlights the importance of considering the function of the activity and choosing activities in the routine that support the child to feel calm.

3.4.3.2.2.2 Subtheme Feeling Comfortable

All the children spoke about calming activities which evoked notions of comfort. For example, Peter spoke about how a bath helped him to sleep which was a common theme across all participants. He said, “it (bath) made it, it made me feel more calm and make it easier for me to get to sleep without any with less issues or anything.” Similarly, Gabz said, *“*Oh so so the bath it helps me because like when you like, when you like, dry yourself, you feel fresh and stuff. It feels nice.” Considering comfort when in bed appeared important. For example, Gabz said, “The bunk bed is quite big and then I can

finally find a position I can sleep in. It's just the small bed I can't." This highlights the importance of considering sensory aspects of routine activities which can help to feel relaxed and subsequently help sleep.

3.4.3.2.3 Theme 3 Improved sleep quality

This theme stemmed from children sharing views about how the sleep routine led to improvements in their sleep, such as sleeping longer and settling more quickly. For example, Peter said, "Ohh it's I've started to get better sleep. And so basically my sleep is gone, has started to get better and better", highlighting improvements in his sleep. Children shared views about feeling more relaxed through using the routine, leading to them sleeping more easily. For example, when asked about how the sleep routine made participant 2 feel, she said, "relax. It made me feel sleepy, so I can go to sleep better." Furthermore, Gabz demonstrated how the routine helped, even when waking up in the night, saying, "I mostly sleeped, but I did wake up a bit. But I end up just sleeping." This suggests the routine might have helped improve sleep difficulties in the night, settling more quickly when waking in the night.

3.4.3.2.4 Theme 4: Enjoyment of the personal routine

Children shared views which elicited notions of enjoying the routine, finding activities they found fun, interesting and calming. For example, when asking Peter about one of the activities in his routine he said, "I found it nice because I like being able to go outside for a bit and to have fun." This demonstrates the importance of enjoying the activities. Finding personal interests also appeared key to the children. For example, when asking participant 2 what she would recommend to other children, she said:

“I would tell them to go to bed early, read their book or like, do something that they enjoy and stuff like that and they have to get everything done so in the morning they're ready and they don’t have to be like stressed out.”

This illustrates the importance of finding activities children enjoy and also feeling calm before bed. In addition, children shared views about different activities they enjoyed. For example, Peter placed importance on a hot drink before bed, saying, “Ohh I liked having a hot chocolate before going to bed as well” whereas D said “taking a warm shower. Reading my book.” This demonstrates the importance of personalising the routine to the individual’s interests.

3.5 Discussion

This study sought to examine the effectiveness of a novel personalised, co-produced sleep intervention on autistic children’s sleep quality and mental health. Alongside this, parental and child views on the sleep intervention and the relationship between sleep and mental health were explored. The mixed methods approach enabled an in-depth exploration of these effects. The quantitative method investigated the effects of the personalised sleep intervention on sleep quality and mental health. The qualitative methods explored participants’ views on the sleep intervention and the relationship between sleep and mental health.

3.5.1 RQ1 What is the effectiveness of a personalised, co-produced sleep intervention on autistic children's sleep quality and mental health?

To assess the effectiveness of the intervention on sleep quality, visual analysis, PEM effect sizes and Tau-U statistical analysis were employed for three of the participants (Harrison, Bob12_8 and Peter) who participated in the single case experimental design. Visual analysis showed an increasing level of sleep quality and upwards trend within the intervention stage for all three participants, indicating the sleep intervention led to improvements in sleep quality during the intervention. However, only Harrison had a statistically significant improvement in sleep quality between the baseline and intervention phases, demonstrated through the significant Tau-U medium effect size and supported by the 'effective' PEM effect size. PEM effect sizes showed the intervention to be 'very effective' for Bob12_8 and 'questionable' for Peter. However, they both had non-significant Tau-U small effect sizes. Horner et al. (2005) propose three demonstrations of an effect are necessary to suggest the intervention is the causal reason for the change in dependent variables. Although this is not the case with these results, the weighted average Tau-U effect size across all three participants demonstrated a significant small effect size, suggestive of the sleep intervention being effective on sleep quality on average across the three participants for improving sleep quality. The small sample size might have affected the ability to show 'three demonstrations' of experimental effect, limiting the generalisability of these findings.

Alongside the single case experimental design analysis, Reliable Change Index (RCI) was used for all six participants to assess the change in sleep quality and mental health pre-post intervention and at follow-up. For sleep quality, the RCI demonstrated reliably significant improvements in sleep quality for one of the six participants pre-intervention to post-intervention and for two of the participants pre-intervention to follow-up. Similar to this study, Malow et al. (2016) found mixed findings between participants in the effectiveness of a parent training sleep intervention. Parent-reported sleep improvements were shown in at least one domain (night wakings, cosleeping, bedtime resistance, falling asleep) for six of eight children. The actigraphy measurement showed improvements for sleep onset delay and night wakings but significance was not achieved (Malow et al., 2016). However, this was a manualised intervention approach, differing from the nature of the current study's personalised intervention. In relation to individualised interventions, Papadopoulos et al. (2022) found through a randomised controlled trial, significant improvements in sleep quality, measured by the CSHQ, following an individualised behavioural sleep intervention. Although children and parents did not personally create their own routine, they were given a choice of behavioural sleep strategies, to meet their individual sleep needs (Papadopoulos et al., 2022). Reinforcing these findings, a single case multiple baseline design, found an individualised behavioural approach to treating sleep problems in young children (two with a diagnosis of autism) was effective for all three children (Jin et al., 2013). This study similarly assessed the children's specific sleep difficulties and tailored the intervention to meet specific sleep needs.

In relation to the effects of the sleep intervention on mental health, the RCI demonstrated reliably significant improvements in mental health pre-intervention to post- intervention for four of the six participants. This change remained reliably significant for three of these four participants from pre-intervention to follow up. This indicates long term improvements in mental health following the personalised sleep intervention. However, these improvements cannot be attributed to change in sleep quality as the specific relationship between sleep quality and mental health was not directly measured. The improvements in mental health could have been related to sleep quality or the personal nature of the routine, aligning with the child's interests and increasing their sense of agency with choice of activities. This aligns with Pavlopoulou's (2020) research, finding sense of agency was important when creating sleep routines, ensuring the child had control and choice over activities and subsequently increasing positive feelings. Although limited research has explored the effects of sense of agency for children within sleep interventions, Kumpulainen et al. (2014) argues co-participatory practices can have a positive impact on children's lives and promote a sense of agency, having positive effects on socio-emotional wellbeing. Further research is needed to investigate the effects of personalised sleep interventions on autistic children's mental health.

3.5.2 RQ2. What are parent and children's views on the relationship between autistic children's sleep and mental health?

The relationship between sleep and mental health was explored through interviews with parents and children to gain an in depth understanding of

parent and child views. Child and parent views were analysed together through thematic analysis. The findings illustrated the shared experiences of sleep on mental health. This led to two key themes being developed from the interview data; ‘impact on wellbeing’ and ‘impact on resilience.’

Impact on wellbeing had two subthemes; improved mood and improved emotional regulation. All children and parents shared views which illustrated the positive impact of good sleep on mood. For example, children shared views about feeling happier and calmer. Parents also noted the positive impact sleep can have on mental health. Only one parent reported not noticing an impact of sleep on her child’s mood which highlights the importance of recognising individual differences in relation to the impact of sleep on wellbeing. With regards to ‘improved emotional regulation’ this captured more of the parent’s views compared to child’ views. For example, parents commented on there being fewer meltdowns and more positive thoughts and behaviours, following a good night’s sleep. Although children commented on their feelings, they shared fewer views about how this impacted on their regulation. This might be related to the children’s age and social communication needs, still developing their understanding and articulation of the impact of sleep on their emotional regulation. This theme is mirrored by previous research, with Kirkpatrick et al. (2019) reporting parents’ perceptions about the impact of poor sleep leading to reduction in daytime functioning, reduced mood, poor concentration and a lack of energy. Moreover, previous research has found an association between sleep problems and internalising and externalising behaviour with autistic children (Schreck, 2021).

Impact on resilience encompassed three subthemes; increased energy, coping mechanisms and environmental demands. The theme reflected how tiredness and sleep can affect resilience with managing everyday demands. The subtheme, ‘increased energy’ demonstrated majority views from children and parents about sleep increasing their alertness, energy levels and focus. The subtheme ‘environmental demands’ illustrated the impact of sleep on children managing environmental demands, including sensory aspects (i.e. light, noise) of the environment and social demands. The final subtheme, ‘coping mechanisms’ stemmed from views about managing transitions, setbacks, having more energy and feeling stronger to manage challenges. This theme and subthemes align with previous research, with parents explaining how social interaction difficulties were further exacerbated by lack of sleep, leading to ‘tantrums’ or not wanting to play with others (Kirkpatrick et al., 2019). This might impact on children’s experience managing the school and other environments, including focusing in class, managing the sensory environment (e.g. noisy corridors) and social interactions.

3.5.3 RQ3. What are parents’ and children’s views on a personalised sleep routine?

Child and parent views of the personalised sleep routine were gathered through interviews. These views were analysed separately in the results section and subsequently integrated in the discussion section, to reflect similarities and nuances in parent and child views.

All parents appeared to like the intervention, sharing views that captured the child-led and personal nature of the routine, the adaptability and accessibility of the routine and leading to improved sleep outcomes. Views about the

impact of environmental factors on the routine were expressed. Similarly, children appeared to like the routine, with themes emerging of the ease of use of routine, improved sleep quality, enjoyment of the personal routine and importance of comfort and calmness.

All parents shared the positive impact of the child-led nature of the routine, particularly in relation to children having autonomy with creating and following the routine and making collaborative decisions. The results indicated that this increased children's motivation and willingness to engage with the routine. Moreover, as the children created their own routine, this appeared to increase empowerment and sense of agency. This mirrors Pavlopoulou's (2020) research, highlighting the importance of sense of agency when developing sleep routines. There is increasing evidence on the importance of self-determination on motivation, wellbeing and optimal functioning (Deci & Ryan, 1994; Guay et al., 2010; Kumpulainen et al., 2014). For example, Kumpulainen et al.'s (2014) results demonstrate the positive impact of co-participatory practices on children's lives and the promotion of sense of agency to support their socio-emotional wellbeing. However, further research is needed for the impact of sense of agency in relation to sleep.

Following the personal sleep intervention all four parents and three children who participated in the interviews commented on improved sleep outcomes, which supports the improvements seen in the quantitative data. The interviews led to a deeper understanding of these improvements, including settling more easily, having more consistent night's sleep, sleeping longer and understanding individual sleep difficulties. This is consistent with previous research finding individualised sleep interventions improve sleep

outcomes (Jin et al., 2013; Papadopoulos et al., 2022). A meta-synthesis examined the efficacy of sleep interventions for autistic children and found that melatonin, behavioural interventions and parent education programmed appeared the most effective for reducing a range of sleep problems compared with other interventions (Cuomo et al., 2017) . However, they suggest no single intervention is effective for all components of sleep problems. Although this research does not consider the personal nature of routines, it emphasises the importance of needing different types of interventions for different individuals, dependent on the nature of their sleep difficulties.

All parents and children shared views about the routine supporting the child to feel relaxed before bedtime. This helped with settling better and falling asleep more quickly. This indicates the impact of reducing cortisol levels (e.g. stress, anxiety) on sleep quality. As shown in previous research, high cortisol levels have been found to increase sleep problems in children (El-Sheikh et al., 2008). Therefore, this points to the potential value in engaging in activities which might reduce cortisol levels before bedtime. In addition, parents commented on the positive impact of the sleep psychoeducation in understanding the functions and benefits of sleep. This is consistent with Malow et al.'s (2014) study who found parent sleep education was associated with improved sleep parameters and behavioural measures (Malow et al., 2014).

Alongside feeling calm, the children's data evoked the notion of the importance of comforting activities before bed, such as having a bath or a hot drink. This perhaps relates to the sensory needs of autistic children.

Consistent with this, previous case study research investigated the impact of an ecological, behavioural and sensory intervention on sleep quality, finding measurable improvements in sleep and anxiety were found (Souders et al., 2017). Interview data could have helped to further understand the impact of the sensory elements on the child's sleep.

Another theme developed from all parents' interview data was the benefit of the adaptability and accessibility of the routine. Similarly, a theme emerged from children's data on the ease of use of the routine. Parents and children shared views about finding the routine easy to use, flexible and clear. This appeared important for the child being able to more independently follow the routine, with accessible resources. Parents also found the routine flexible for incorporating into daily life, considering other commitments. The flexibility was supported by parents and children understanding the benefits of the function of the activity rather than the activity itself. For example, choosing an alternative relaxing activity before bed or a different physical activity that fits into the evening routine. However, barriers to following the routine were highlighted by one child and one parent, considering the time available or forgetting to do an activity. As found in previous qualitative research, sticking rigidly to the bedtime routine can interfere with family life (Sinha et al., 2024). The personalised, child-led nature of this study's sleep routine made the routine flexible and adaptable, fitting with different children's needs, family contexts, interests and priorities.

All parents and children appeared to value the personal nature of the sleep routine, aligning with their child's interests and subsequently increasing their child's engagement and motivation to follow the routine. One qualitative study

found bedtime routines were beneficial for improving sleep for some children. However, when children did not want to follow the routine it could delay sleep onset (Sinha et al., 2024). This highlights the importance of ensuring the child is interested and motivated by the routine.

All children's views demonstrated their enjoyment of the routine and all parents expressed views that recognised differences in children's interest. Although all the children valued similar activities, such as having a bath, they also found different activities relaxing for sleeping, such as listening to music, watching TV or reading a book. This accentuates Pavlopoulou's research (2020), recognising personalised sleep habits that support children's sleep and the importance of gaining children's views when creating sleep routines. Moreover, parents recognised the universal relevance of the personal sleep routine, believing the routine could be helpful for children and adults regardless of age or diagnosis. This highlights the concept that like neurotypical children, autistic children are all unique and need personalised routines to fit their needs.

Lastly, interview data captured parent views about the impact of environmental factors on following the bedtime routine. This included consideration of weather, illness, sharing rooms with siblings and sleeping away from home. These factors can all impact on sleep and interfere with following sleep routines. However, parents appeared to recognise the value of the adaptable nature of the personal sleep routine, meaning exact timings or activities could be changed to fit in with other commitments. When creating sleep routines, it is important to ensure the routine is flexible and recognise other daily commitments in children' and parents' lives. The

personalised sleep routine in this study took these factors into account, ensuring it was flexible and accessible.

3.5.4 Strengths and limitations

3.5.4.1 Strengths

A key strength of this study is the mixed method design which enabled a more in-depth understanding of the effectiveness of the personalised sleep routine. Few studies have explored parents' and autistic children's perceptions of sleep interventions. Qualitative data can help to examine the validity of quantitative findings, understand contextual factors during the intervention that might have affected outcomes and help to explain the results (Fetters et al., 2013). Through gaining both children and parent's perceptions of the intervention, it can help to increase understanding to improve sleep interventions for autistic children.

Furthermore, the single case experimental design (SCED) allowed an in-depth examination of the effect of the intervention on individual participants. SCEDs allow high quality research with a small sample in heterogeneous populations. Experimental control was established through the multiple baseline design through having three participants and increasing the baseline length for each participant (Barlow et al., 2009). Through examining the effects of the intervention more intensely and comprehensively, it enables insight into the mediating effects of interventions and increased understanding of the individual participant changes (Krasny-Pacini & Evans, 2018). Alongside the daily sleep data, through using well validated, reliable mental health and sleep questionnaires, this increased the quality of the research. Follow-up measures helped to assess longer term effects of the

sleep intervention on sleep and mental health. The fidelity of the intervention was enhanced by the researcher checking in with the parent participants each week to troubleshoot any difficulties and support implementation. However, as it was a personal sleep routine, it was adaptable and therefore parents and children could implement the intervention how they wanted.

3.5.4.2 Limitations

A limitation of the study can be found in the lack of pilot intervention. This was an inevitable consequence of conducting real world research in a limited time frame with the complex timeline inherent in the multiple baseline design. Moreover, although a strength of this study was its ecological validity arising from the 'real world' setting, this also increased the potential confounding variables. For example, the weather was hot during the time of the intervention which might have impacted on sleep quality and influenced the sleep scores. Nevertheless, this reflects real world situations. Future studies able to utilise larger samples and longer timeframes may be able to examine or control for such confounding variables in way that was not possible in this research.

Another limitation of this research was the small sample size. Although recommended experimental control requirements were met with three participants at three different baseline points, more participants would have increased internal validity. Moreover, although the single case design provided an in-depth understanding of the effects of the intervention for each participant, these findings cannot be generalised to the wider population. In addition, convenience sampling was used in this research instead of random sampling. This was due to the strict inclusion criteria (e.g. autism diagnosis,

sleep problems, age) and time constraints. This can lead to a risk of sampling and selection bias (Robson, 2011).

Social desirability bias might have been present through the questionnaires and interviews. Social desirability bias refers to over reporting ‘desirable’ things in order to be portrayed in a good light (Robson, 2011). Objective sleep measures are considered the ‘gold standard’ sleep measures due to reducing subjectivity and therefore providing a more accurate reflection of sleep quality (Hughes et al., 2018; Lujan et al., 2021). However, due to cost and time restraints, objective measures were not used in this study. Moreover, with different views on what constitutes a ‘sleep problem’, considering different family and cultural expectations (Wiggs, 2007), interviews and self-reported child ratings enabled a richer understanding of sleep difficulties and the impact of the intervention.

A scale of 0-100 was chosen for the sleep self-report daily measure. This size scale was chosen to have enough sensitivity to show the variability of sleep each night over a 4 to 5 week period. However, with the length of the scale, it might have been difficult for the children to conceptualise the difference and meanings of ratings. Nevertheless, this was felt to be mitigated by having the parents support their children to complete the scale thus increasing reliability of the ratings. Parents were able to support their child complete the scale each day. However, with the nature of self-reports, there was a limitation of not knowing when the scale was completed each day. Stone and Shiffman (2002) propose that self-report measures are prone to recall bias, with participants not remembering past events accurately leading to distorted or unreliable data. This can be influenced by emotions,

difficulty remembering information and other factors. Therefore, not knowing when participants completed the sleep self-report might have affected the accuracy and reliability of the sleep rating. Lastly, there might have been risk of confirmation bias with the researcher delivering the intervention and analysing the data. Confirmation bias refers to a desire to confirm beliefs, through searching for evidence that confirms beliefs, rather than looking for evidence that might disconfirm them which can influence human judgement (Hallihan & Shu, 2013). These biases can be reduced and credibility increased through peer checks of data. Due to time constraints, this did not occur but this would be beneficial in future research.

3.5.5 Implications for practice and future research

Through quantitative and interview data, this research suggests personalised sleep interventions can have a positive effect on both sleep quality and mental health. Although previous research has found behavioural interventions, such as parent training, sleep hygiene and environmental changes can significantly reduce sleep problems for autistic children (Carnett et al., 2020; Kirkpatrick et al., 2019), no research to date has examined the effect of a co-produced, personalised sleep interventions on autistic children's sleep quality and mental health. Although this research provides some evidence for the positive effects of personalised sleep interventions, the SCED means the findings cannot be generalised to individuals of other ages or ability. Therefore, there is scope for future research to investigate the effect of personalised sleep interventions on autistic children of different ages and abilities, typically developing children and children with other special educational needs.

With sleep problems encompassing many different domains (e.g. sleep onset, sleep maintenance), it would be beneficial for future research to investigate the effects of a personalised sleep intervention on different sleep domains. This might develop the understanding of how personal sleep interventions can affect changes in sleep. Furthermore, although this research examined the effect of the personal sleep intervention on mental health through questionnaires and interviews, future research could investigate this in more depth. Considering the components of the personal sleep interventions, alongside investigating the relationship between sleep and mental health would develop a more comprehensive understanding of the effects. Moreover, exploring sense of agency and value of coproduction during sleep interventions for autistic children could deepen the understanding of how this impacts on wellbeing.

Educational psychologists (EPs) support children's needs holistically, considering their socio-emotional mental health and cognition and learning, which as research has shown is affected by sleep. With extensive child development knowledge, EPs are arguably well placed to support children's sleep needs (Rydzkowski et al., 2016). Moreover, through working with education, health and social service professionals, EPs can contribute by training teachers, parents and young people in the psychology of sleep, appropriate assessments and interventions (Rydzkowski et al., 2016). Through consultations and assessments, they can gather children and young people's views about sleep and what support they need. EPs could support children, young people and parents during direct work and consultations to create personalised sleep interventions. For example, using psychological

consultation skills, such as Socratic questioning, active listening, collaboration and problem-solving skills, to find out about their individual interests and what they find relaxing to support sleep.

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Chapter 4: Dissemination and Impact

4.1 Introduction

This chapter provides a critical overview of evidence-based practice and practice-based research, alongside the positioning of both chapter two and three in relation to these concepts. The impact of the research is discussed, in relation to the academic, societal, political and economic impact. Lastly, dissemination strategies and pathways to impact are outlined, considering how to share the research with academic and non-academic audiences. This includes considering publishing in relevant journals, sharing research findings at conferences and sharing findings with charities, professionals and other organisations.

4.2 Evidence-Based Practice

Evidence based practice (EBP) stemmed from the medical field when making decisions to improve patient outcomes with the best available and updated empirical evidence (Sackett et al., 1996). There has been a movement towards using EBP in psychology and education with EBP being defined by the American Psychological Association (APA) as “the integration of the best available research with clinical expertise in the context of patient characteristics, culture and preference” (American Psychological Association, 2006, p.273). If there is some evidence that practice has been shown to work under certain conditions in some samples, this is proposed to have strong research support (Shaw & Pecsi, 2021). Clinical judgement is then used to decide whether practices with established support can be applied to an

individual's needs, systemic issues and goals of practice (Kahn & Schlosser, 2014).

Providing high quality care is important for educational psychologists, with educational psychologists having direct access to children and families in schools, being able to focus on prevention at different levels, working with different individuals (i.e. teachers, parents, children) (Kratochwill, 2007). Moreover, children are in school from age 0 to 18 and therefore there are opportunities to support children's mental health and learning across child development (Kratochwill, 2007). The Elementary and Secondary Education Act outlines four tiers for EBP from 'demonstrates a rationale' to 'strong evidence', outlined in table 4.1 (Shaw & Pecsi, 2021).

Table 4.1

Tiers of evidence-based interventions from the Elementary and Secondary Education Act

Tier	Definition
1 Strong evidence	One or more well-designed and well-implemented experimental study or randomised control trials.
2 Moderate evidence	One or more well-designed and well-implemented quasi-experimental studies.
3 Promising evidence	One or more well-designed and well-implemented qualitative or correlational studies.
4 Demonstrates a rationale	No direct support but a strong theory or logic while currently trying to determine effectiveness.

Kratochwill (2012) proposes four guiding principles for evidence-based practice for mental health and educational care, shown in table 4.2. These principles provide a metasystemic orientation, considering contexts and environments influencing child development, providing a framework for public health and quality improvement, outlined in figure 4.1.

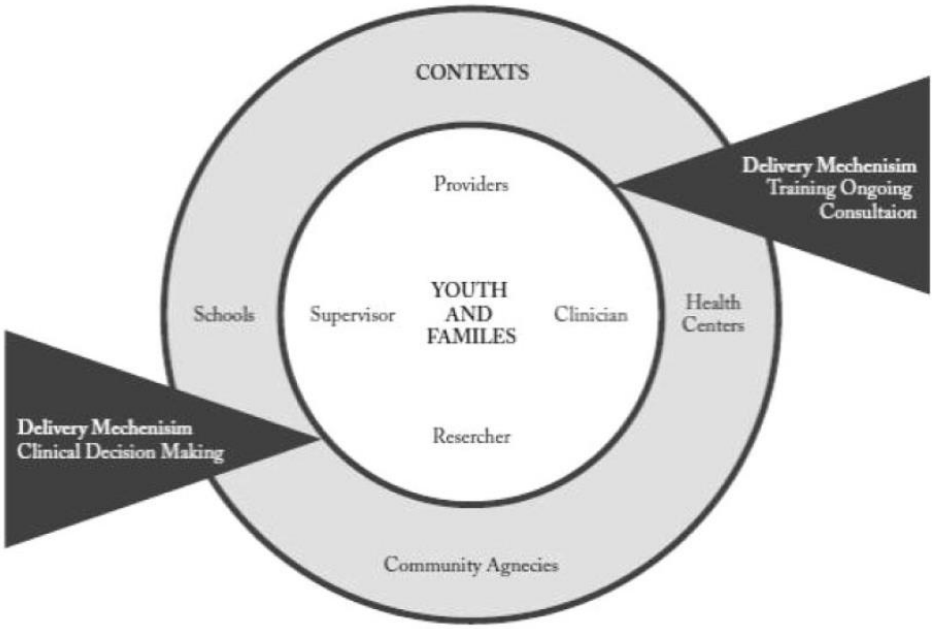
Table 4.2

Guiding Principles for Evidence-Based Practice for Children and Adolescents (from Kratochwill et al., 2012, p.217)

Guiding Principles for Evidence-Based Practice
1. Children and adolescents should receive the best available care based on scientific knowledge and integrated with clinical expertise in the context of patient characteristics, culture, and preferences. Quality care should be provided as consistently as possible with children and their caregivers and families across clinicians and settings.
2. Care systems should demonstrate responsiveness to youth and their families through prevention, early intervention, treatment, and continuity of care.
3. Equal access to effective care should cut across age, gender, sexual orientation, and disability, inclusive of all racial, ethnic, and cultural groups.
4. Effectively implemented EBP requires a contextual base, collaborative foundation, and creative partnership among families, practitioners, and researchers.

Figure 4.1

Metasystemic social-ecological framework guiding evidence based practice from American Psychological Association (2008)



It is argued that interventions that have been shown to be effective through strong research, such as randomised controlled trials, should be applied in practice to improve academic and mental health outcomes for children (Kratochwill et al., 2012). However, there is argued to be a lack of consensus defining and rating research quality and evidence within psychology, education and many other fields, including medicine. This is partly due to different groups adopting their own set of review criteria when reviewing evidence based interventions, making it difficult to draw conclusions about the most effective practice (Kratochwill, 2007).

Moreover, there is a gap between research and practice with findings suggesting research is often not translated into practice and policy in clinical

and health services which results in patients not benefiting from the advances in healthcare systems (Grimshaw et al., 2012). Similarly, the use of EBP is argued to be low in schools which hinders the progress of interventions (Forman et al., 2013). This might be partly due to research not capturing the effects of interventions in all real world settings, making it difficult to ascertain the effectiveness and how to implement in these settings (Weisz et al., 2005). This relates to the 'knowledge transfer', which involves the integration of psychological theory, research and practice. This is proposed to encompass three different terms; diffusion (communication of research to the wider public to raise awareness), dissemination (sharing research findings to change awareness, attitudes and knowledge) and implementation (changing practice based on research findings) (Lomas, 1993).

4.3 Practice Based Research

Practice based research is suggested to be an alternative way to improve knowledge for implementation and adoption of evidence-based interventions, bridging the gap between experimental research and practice (Kratochwill et al., 2012). It is argued randomised clinical trials (RCT) are not always effective in real world practice, with the effects and benefit-to-harm ratio reported to be different in clinical practice. RCTs are proposed to not consider patient-specific factors and skills needed in various communities (Westfall et al., 2007). It is estimated that it takes on average 18 years to turn 14% of original research findings into changes that benefit patients (Balas & Boren, 2000).

Instead, practice based research is based on a bidirectional relationship between research and practice, involving practice that uses assessment, intervention and ongoing monitoring (Kratochwill et al., 2012). This is argued to be a solution to the problems of EBP and being able to identify problems that occur in daily practice, showing whether treatments with proven efficacy are truly effective and sustainable in real world settings (Westfall et al., 2007). Therefore, it is argued studies from practice-based research have strong external validity. However, there might be weaker internal validity due to more potential for confounds explaining why a result occurred (Barkham & Mellor-Clark, 2003). Nevertheless, Practice Based Research reduces the gap between researchers and clinicians, with clinicians participating in the research and therefore being more likely to use the results (Mold & Peterson, 2005). This makes the research more relevant, tailored and actionable to populations and their circumstances of practice (Green, 2008). It is argued to increase evidence-based practice, more practice-based evidence is needed (Green, 2008).

Research is one of the five core functions of the EP role (Farrell et al., 2006). EPs complete postgraduate training, now at the doctorate level, which involves training in research alongside practicing in schools (Farrell et al., 2006). This training provides EPs with skills in understanding, conducting and critiquing research, placing them in a good position for engaging in practice-based research and evidence-based practice. Therefore, EPs can make an important contribution to practice-based research, working at the individual, group and systemic level within schools and other community contexts (Kratochwill et al., 2012).

4.4 Positioning of Current Research

This research used a mixed methods approach involving a single-case experimental design (SCED) and interviews. Kratochwill et al. (2012) argues SCEDs could be considered both practice-based research and evidence-based practice. It is argued that using an AB design with a baseline comparison provides methodological and statistical advantages for the use of single-case design in generating practice-based evidence (Kratochwill et al., 2012). The sleep intervention in this study was implemented within the natural home setting and sleep was measured repetitively through self-reported ratings, considering the individual's views on their own sleep quality. Views on the sleep intervention were gathered from both parents and children through interviews, capturing what they found helpful about the intervention. Therefore, through implementing a personal intervention in a real-world practice setting, considering individual needs and providing flexibility with the implementation, this ensures findings are relevant and generalisable to real world practice settings.

A SCED is also argued to be a scientific, rigorous approach which documents experimental control, like RCTs, and is therefore argued to establish evidence-based practice (Horner et al., 2005). SCEDs are an experimental method which creates empirical evidence to inform treatment adoption, innovation or improvement (Hitchcock et al., 2015; Horner et al., 2005). Design and evidence standards and guidelines for SCEDS were followed from "What Works Clearinghouse single-case design technical documentation" (Hitchcock et al., 2015) and Lane and Gast's (2014) guidelines. It is argued that SCEDs can provide a strong basis for

establishing causal inference, being widely used in clinical and applied psychology and education disciplines. Experimental control was gathered through the staggered introduction of the sleep intervention across different time points with three different participants, with each individual serving as their own control (Horner et al., 2005). Through measuring a participants' performance repeatedly across different time points before, during and after interventions, this can show the process of change (Horner & Odom, 2014). Internal validity and a functional relation (experimental control) is demonstrated in SCEDs through repeated documentation of effects while holding constant confounding variables (Horner & Odom, 2014). It is proposed that experimental control in SCEDs is shown when there is a demonstration of experimental effect at three different time points with a single participant or across different participants (Horner et al., 2005). Therefore, through measuring sleep repetitively at three different time points for each participant and across three participants, this enabled experimental control. Moreover, effect sizes were calculated to objectively measure the effects of the sleep intervention pre-post intervention and at maintenance. Through using reliable change index (RCI) to objectively assess changes in sleep and mental health pre-post intervention and at follow-up, using reliable, well validated questionnaires, this also contributes to consideration of this study showing EBP.

However, there were constraints to the rigorousness of this research, with having only one researcher instead of a team and limited time and funding. The limitations included having recruitment difficulties and having to conduct the research in the summer term to align with the research timeline which led

to potential confounding variables, such as the hot weather affecting sleep. Although the baselines were staggered sequentially, the baselines could have been longer in length to establish a more stable baseline which might have impacted on the results.

4.5 Impact of Research

Research impact can be defined as the demonstratable contribution research makes to the economy and society which includes an academic, economic and societal impact (Research Council UK, 2022). The research impact can be shown through how much its findings are “read, used, applied, built upon and cited by researchers in their own further research and applications” (Harnad et al., 2008, p.36). The academic and wider impact (societal, economic, political) will be considered in the following section.

4.5.1 Academic

As outlined above, this study could be considered to be contributing to both PBR and EBP. Therefore, this research could have an academic impact and influence other researchers, academic authors or organisations. Research needs to be peer reviewed and then published in order for others to use and apply the findings (Harnad et al., 2008). Research with non-significant or negative results from practice-based research or highly controlled research trials should also be published. This is particularly important in educational psychology practice with practice-based evidence showing why an intervention is not effective under certain practice conditions or the negative effects of the intervention (Kratochwill et al., 2012).

This present study has academic implications, particularly in relation to Chapter Two and Three. Firstly, Chapter Two provides a systematic literature review on the relationship between autistic children's sleep and mental health. Although previous research has investigated the relationship between sleep and mental health in typically developing children (Gregory & Sadeh, 2012) and the relationship between sleep and behaviour in autistic children (Cohen et al., 2014), this is one of the first systematic literature reviews to investigate the relationship between sleep and mental health in autistic children from age 0 to 18. This could help to further understand the relationship between sleep and mental health for autistic children across the age span. More research will be needed to understand this relationship further, particularly in relation to developmental changes in the relationship across childhood through methods such as longitudinal research. In addition, further research comparing the relationship between autistic and non-autistic children could be insightful.

Secondly, Chapter Three, provides a unique insight into the effects of a personalised sleep intervention on autistic children's sleep quality and mental health. This was a novel intervention, based on research findings about the importance of co-producing and personalising sleep interventions for autistic children (Pavlopoulou, 2020). Through using a multiple baseline single case design and interviews with parents and children, this helped to gain a deeper understanding of the effects of the intervention on individuals in a real practice setting. The single case design shed light on the effects of the intervention and process of change over time, rather than at solely single time points which might be helpful for future research when considering the

effects of sleep interventions. The interviews captured the views of the intervention from autistic children and their parents, which little research to date has done. These insights can help to inform future research projects on personalised sleep interventions. Further research about the effects of personalised sleep interventions on autistic children's sleep quality and mental health will increase the ability to generalise the results to the target population.

4.5.2 Wider Impact (social, economic and political)

Sleep and mental health problems are becoming increasingly prevalent among children and young people, with sleep problems being one of the most commonly reported complaints for autistic children (Cortese et al., 2020; Ming et al., 2008). However, there are limited interventions to support autistic children's sleep with research suggesting mainstream sleep hygiene recommendations do not always align with factors supporting autistic children's sleep (Pavlopoulou, 2020). Supporting this, the empirical paper findings demonstrate the importance of personalising sleep intervention to individual needs of autistic children. Although results varied by each individual participant, the qualitative and quantitative findings together suggest the personal sleep intervention might be beneficial for improving autistic children's sleep outcomes and mental health. The interviews enabled the researcher to receive feedback on child and parent views of the intervention which could be considered when developing and implementing future sleep interventions. The personal nature of the co-produced intervention led to participants sharing their views on feeling more motivated, empowered and enjoying the routine. The accessibility and adaptability of the

routine was important for participants, being easy to use and follow, considering everyday life commitments. These factors are important to consider when educational psychologists (EP) and other professionals are supporting children's sleep in consultations and interventions.

Systematic review findings suggest mental health difficulties are more prevalent among the autistic population compared to the neurotypical population (Lai et al., 2019). The systematic literature review findings highlight the important relationship between sleep and mental health and the empirical paper demonstrates the importance of personalising sleep interventions for autistic individuals. Considering the prevalence of sleep and mental health difficulties and interactions between the two, these findings could be shared with other professionals in health, education and psychology to inform practice when working with autistic children and their parents. Sleep training could be developed, highlighting the importance of personalising sleep interventions alongside considering the science behind sleep (i.e. lowering cortisol levels before bedtime, circadian rhythm etc.).

On a political level, this research has implications for existing mental health and sleep guidance for autistic children. The findings could be relevant and useful for organisations, such as NICE, who provide guidelines on sleep interventions. The findings illustrate the importance of personalising sleep interventions to autistic children's interests and needs and involving children in the production of the sleep routine. Furthermore, the findings could inform mental health policies and guidelines. For example, the Green Paper for Transforming Children and Young People's Mental Health (Department of Health and Social Care & Department for Education, 2017, p.26) states,

“those with learning disabilities or autism, are at increased risk of mental health problems, consideration of what support to provide them should include consideration of their mental health needs” and also outlines the importance of “ensuring there are appropriate interventions…available to support children and young people in school.” Therefore, considering the impact of sleep on mental health within policies and guidelines will be important. Moreover, the SEND Code of Practice (Department for Education & Department of Health and Social Care, 2015) also highlights the need to gather children’s views and work alongside parents, schools and other professionals. This should include incorporating views on interventions.

On an economic level, the findings from the empirical study, show this is a low cost, accessible intervention which could be valuable to professionals and organisations with constrained resources, funding and long waiting lists. The intervention needs initial involvement from a trained practitioner, supporting children and parents to create the sleep routine, but little involvement is needed once the routine is created. This is due to the accessible, child-led nature of the sleep routine, making it more cost-effective.

At a societal level, these findings could raise awareness about the need to create more personalised sleep interventions, considering the heterogeneity of the autistic population. Involving autistic children in creation of interventions and capturing their voices, could help to create more relevant, appropriate interventions in the future. More participatory and qualitative research in this area would be useful. This research could also help schools and charities, such as National Autistic Society and MIND, recognise the

importance of sleep for mental health and involve autistic children in development of new practices and guidelines. Considering these sleep materials came from NELFT Mental Health Support Team, mental health support teams in schools might be well positioned to support children and young people's sleep.

4.6 Dissemination and Pathways to Impact

4.6.1 Beneficiaries and stakeholders

Dissemination involves communicating research findings and the understanding of the findings to academic and non-academic audiences (Barker et al., 2016). Information needs to be targeted and tailored for the intended audience (Lomas, 1993). Disseminating doctoral research is important for sharing findings with the wider scientific community who might benefit from the research (Pollard, 2004). It is also important for informing practice, including educational psychology practice. Therefore, this section will outline the pathway and plan for dissemination of Chapter Two and Three to academic and non-academic audiences.

4.6.2 Non-academic Audience

Non-academic audiences include children, parents, school staff and charities. Disseminating findings to this audience is important with the systematic literature review increasing knowledge about the relationship between sleep and mental health for autistic children. Furthermore, the empirical paper can increase understanding and knowledge about personal sleep interventions for autistic children.

The first stage of dissemination will involve providing a summary of the empirical paper findings to participants of the empirical paper research. This will be written feedback which will be distributed via email, using accessible lay language. Secondly, information from the systematic literature review and empirical paper will be distributed to organisations and charities which support autistic children, their sleep and mental health. For example, providing a summary of the findings to the National Autistic Society who provide support and guidance for autistic children and their families, in a range of areas, including sleep and mental health (National Autistic Society, 2024). Information will also be distributed to sleep charities and organisations, including The Sleep Charity who advocate to improve sleep support and high quality information (The Sleep Charity, 2024). A summary of findings will be provided to charities and organisations supporting children's mental health, including MIND who support children's mental health through advocating for mental health support and providing mental health information and advice (Mind, 2024). Information will be distributed to other relevant charities, including Mental Health Foundation and Young Minds.

4.6.3 Academic and Professional Audience

4.6.3.1 Journals

Publishing research through academic journals is a key method for dissemination and knowledge transfer. To do this Pollard's (2004) guidelines were followed which includes considering the number of relevant fields for the thesis, then within these fields generating a list of possible relevant journals and next listing journal characteristics, considering the focus,

argument and goals of the research. Other considerations included the intended audience and impact factor. The impact factor is calculated though counting the number of times the journal was cited in the previous 2 years compared to the total number of articles published in the journal in the same time period (Garfield, 2006).

Although both the empirical paper and systematic literature review are within related fields, the purpose of the papers and focus is different. Therefore, these papers will be published separately. Table 4.3 summarises the shortlisted journals for the systematic literature review and empirical paper, including the journal title, description, audience and impact factor. The following pages outline draft titles and abstracts for the potential papers for journal publication.

Abstract: Paper 1 – Empirical Paper

Title: The impact of a personalised, co-produced sleep intervention on autistic children's sleep quality and mental health

Abstract: Sleep problems are prevalent among autistic children yet there is limited research on personalised sleep interventions for autistic children. Finding appropriate sleep interventions for autistic children is crucial due to the important role sleep plays for daytime functioning and mental health. Therefore, this study aimed to investigate the effectiveness of a personalised, co-produced sleep intervention on autistic children's sleep quality and mental health. Alongside examining the effects of the sleep intervention, the study examined parent and child views on the relationship between sleep and mental health and thirdly their views on the sleep intervention. The study used a mixed methods approach, employing a multiple baseline single case experimental design and a qualitative element, interviewing parents and children to find out their views on the sleep intervention. Six autistic children and their parents participated in this study with pre-post and follow-up data collected for all six participants. Single case experimental design data was collected for three of the six participants due to research constraints. A significant weighted average Tau-U effect size across all three participants was found, suggestive of the sleep intervention being effective on average across all three participants. However, visual analysis and Tau-U effect size showed significant improvements for only one of the three participants, from baseline to intervention, limiting the generalisability of these findings. There were mixed results shown through the reliable change index with only one of six participants showing significant improvements in sleep quality pre-intervention to post-intervention and two of six participants showed a reliably significant improvement in sleep quality pre-intervention to follow-up. Reliably significant improvements in mental health were found for four of the six participants pre- to post-intervention with the change remaining significant at one month follow up for three of the participants. The interviews provided a more extensive understanding of parental and child views on the relationship between sleep and mental health and views of the sleep intervention. Themes emerged, such as improvements in sleep quality, the child-led nature and accessibility of the routine, helping to inform future sleep interventions for autistic children. This is the first study to investigate the effects of a personalised, co-produced sleep routine, adding new research to the field. Further research will be needed to extend the knowledge and understanding of the impact of personalised sleep interventions.

Paper 2 – Systematic Literature Review

Title: The relationship between autistic children's sleep and mental health

Abstract: Sleep is a basic human function which is suggested to be important for daily functioning, child development and mental health. This systematic literature review examined the relationship between autistic children's sleep and mental health, from age 0 to 18. A systematic search on three databases (Web of Science, Psycinfo, Medline) identified 14 correlational studies for the final review. The studies quality and relevance were assessed through using Gough' (2007) Weight of Evidence Framework and the methodological quality through the Axis Checklist (Downes et al., 2016). The majority of studies received an overall 'medium' weight of evidence rating, considering the studies' methodological quality and relevance and topic relevance. The majority of studies demonstrated a significant positive relationship between sleep and mental health, with effect sizes ranging from small to large. This suggests poor sleep can negatively impact children's mental health. Although more research is needed in this area, examination of the relationship between specific mental health and sleep variables, developmental differences and comparisons with typically developing peers helped to better understand the relationship. This review highlights the importance of considering the impact sleep has on autistic children's mental health. Implications are discussed, including the need for educational psychologists and other professionals to assess and support children's sleep. Further research into developmental differences, sleep facilitating factors and appropriate sleep interventions for autistic children will be beneficial.

Table 4.3

Potential Journals for the systematic literature review and empirical paper

Journal	Description	Rationale for Choice	Requirements	Impact Factor
Research in Autism Spectrum Disorders	Publishes high quality empirical articles and reviews to extend understanding of autism at a genetic, neurobiological, cognitive and behavioural level.	This journal is suitable for empirical papers and review paper which aims to better understand questions and the difficulties autistic individuals face, alongside their carers, educators and clinicians.	• **Brief reports:** No more than 2500 words that report an original piece of research of limited scope and/or that serve as proof of principle for large scale studies. • **Regular articles**: No more than 6000 words reporting a substantive piece of research which makes a significant contribution and has clear implications for practice. • **Reviews**: No more than 10,000 words which provides a comprehensive overview of a significant area of research, Quantitative and qualitative reviews which provide clear implications for future practice and directions. PRISMA guidelines must be followed for systematic reviews.	2.2
Focus on Autism and other Developmental Disabilities	Publish original research reports, position papers, effective intervention procedures, description of successful programs and media reviews. Addresses issues relevant to individuals with autism or other	Offers practical treatment and education suggestions for parents of autistic children, teachers and trainers. Welcomes single	• **Original research reports:** Investigations related to understanding and meeting the needs of autistic individuals and individuals with other developmental disabilities. Different research methodologies, including single-subject designs and qualitative studies are encouraged.	1.2

Journal	Description	Rationale for Choice	Requirements	Impact Factor
	developmental disabilities and their families. Relevant to a range of disciplines, including psychology, psychiatry, medicine etc.	case design and qualitative research.	• **Reviews:** Accept quantitative or qualitative reviews which provide implications for policy and practice. • Manuscripts should be 15-30 double spaced pages long.	
Sleep Medicine	Publishes reviews, original research articles, full-length articles, brief communications, controversies, case reports and letters to the editor. Focuses on human aspects of sleep within various sleep medicine disciplines, including psychology, psychiatry, paediatrics etc.	Relevant for empirical paper and reviews that better the understanding of sleep and sleep treatments.	• **Original articles:** related to treatment (all types including behavioural), diagnosis, clinical features etc. Need to have a direct impact on or better the understanding of clinical aspects of sleep. Experimental studies are encouraged. • **Review articles:** focus on all aspects of clinical sleep medicine and basic science that extends understanding of clinical sleep medicine. • **Abstract:** word count should not exceed 250 words.	3.8
Journal of child psychology and psychiatry	International journal related to child and adolescent psychology and psychiatry, publishing empirical research, clinical studies and reviews. Publishes research related to	Welcomes contributions that further knowledge of behaviour and mental health of	• **Original articles:** Papers need to contribute to empirical knowledge, develop theoretical understanding or develop clinical research and practice. Maximum word count of 5000 words with recommendations of 500 words for the	6.5

Journal	Description	Rationale for Choice	Requirements	Impact Factor
	psychotherapeutic treatments, behaviour, cognition, neuroscience, neurobiology etc.	children and adolescents.	introduction and 750 for the discussion, using the remaining words for the methods and results. • **Review articles:** Welcome systematic reviews which reviews an important area of interest within a general field and if appropriate should follow PRISMA guidelines.	
Educational psychology in practice	Publishes peer reviewed articles incorporating theory, research and practice relevant to educational psychologists practicing in the UK context.	This journal is relevant to the UK setting and publishes a range of papers relevant to educational psychology practice in the UK. This journal is widely read by educational psychologists.	• The recommended word count is 6000 words.	1.0

4.6.4 Research Conference and Presentations

The empirical paper research will first be presented to trainee educational psychologists (TEP) and academic tutors at the University College London (UCL) Doctorate of Educational and Child Psychology research conference in May 2025. Following this, the researcher will present the findings to the local authority EPs. It is hoped that this will help to increase understanding of the effects of personalising sleep interventions for autistic children and how EPs can use this knowledge in consultations and interventions. To disseminate the empirical paper and systematic literature findings to a wider audience, the researcher hopes to present at the annual British Psychological Society (BPS) Division of Educational and Child Psychology (DECP) conference in January 2026 and in November 2026 at the Association for Educational Psychologists annual conference.

Alongside sharing this research with EPs, the researcher hopes to disseminate the findings with other professionals, including Mental Health Support Teams (MHST), health professionals (e.g. GPs, paediatricians) and family support organisations (e.g. Family Hubs). This could be disseminated through a poster with a summary of the findings and training materials, to support professionals support families to create and implement personalised sleep interventions.

4.6.5 Timeline

To disseminate the proposed research in a timely manner, a Gantt chart has been created to outline tasks and approximate timeframes for completion (see figure 4.2).

Figure 4.2

Gantt Chart Dissemination Timeline

	2025									2026		
	April	May	June	July	Aug	Sept	Oct	Nov	Dec	Jan	Feb	Mar
Prepare and present empirical paper presentation for UCL research conference day												
Prepare and present empirical paper to EPs in the local authority												
Prepare and send research summary to participants												
Contact autism, sleep and mental health charities and organisations to discuss sharing a summary of the empirical paper findings												
Meet with thesis supervisor (Dr Jennifer Wills, co-author) to discuss plans for publication												
Prepare draft manuscript for journal publication with thesis supervisor												
Submit draft manuscript to supervisor for feedback												
Application for conferences												
Submit manuscripts to journals												

4.7 Conclusion

This chapter has discussed the importance of both evidence-based practice and practice-based research. Educational psychologists play an important role in bridging the gap between research and practice, contributing to the academic field and psychological practice. Therefore, the current research has been positioned between both evidence-based practice and practice-based research.

The impact of the research is discussed, considering the academic, societal, economic and political impact. Considering the impact the research could have, this helped to inform the dissemination strategies and timeline. It is hoped disseminating the research will benefit academic and non-academic audiences, increasing awareness about the relationship between sleep and mental health and the effectiveness of personalised sleep interventions.

4.8 References

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Appendix

Appendix A

Search History

Medline

Ovid MEDLINE(R) ALL <1946 to August 05, 2024>

1 (autis* or asc or asd).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word] 99483

2 exp Sleep/ 103432

3 (mental health or well*being or anxiety or depressi* or behaviour or behavior).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word] 2515476

4 (Child* or adolescen*).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word] 4075848

5 1 and 2 and 3 and 4 200

6 limit 5 to english language 192

7 limit 6 to yr="2023 - 2024" 32

Psycinfo

APA PsycInfo <1806 to July Week 5 2024>

1 (autis* or asc or asd).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word] 75710

2 exp Sleep/ 46465

3 (mental health or well*being or anxiety or depressi* or behaviour or behavior).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word] 1873091

4 (Child* or adolescen*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word] 1226797

5 1 and 2 and 3 and 4 256

6 limit 5 to (english language and yr="2023 - 2024") 24

7 limit 6 to peer reviewed journal 23

Appendix B

Excluded Studies

Excluded Studies	Rationale
1. Avci D. (2024). Mental Health Problems Among Adolescents With Mild Intellectual Disability and Relation to Sleep Quality and Perceived Social Support: A Comparative Study. *Journal of psychosocial nursing and mental health services*, *62*(3), 39–50. https://doi.org/10.3928/02793695-20230821-04	Criterion 3: Participants have 'mild intellectual ability' but it does not specify an autism diagnosis.
2. Baglioni, C., Nanovska, S., Regen, W., Spiegelhalder, K., Feige, B., Nissen, C., Reynolds, C. F. I., & Riemann, D. (2016). Sleep and mental disorders: A meta-analysis of polysomnographic research. *Psychological Bulletin*, *142*(9), 969–990. https://doi.org/10.1037/bul0000053	Criterion 5: This is a meta-analysis
3. Bangerter, A., Chatterjee, M., Manyakov, N., Ness, S., Lewin, D., Skalkin, A., Boice, M., Goodwin, M., Dawson, G., Hendren, R., Leventhal, B., Shic, F., Esbensen, A., & Pandina, G. (2020). Relationship Between Sleep and Behavior in Autism Spectrum Disorder: Exploring the Impact of Sleep Variability. *Frontiers in Neuroscience, 14*. https://doi.org/10.3389/fnins.2020.00211	Criterion 2: Includes participants over the age of 18
4. Bernardi K, Prono F, Bruni G, Panerai S, Ferri R & Bruni O (2023). Sleep disturbances in subjects with autism spectrum disorder: a parental perspective. *Sleep Medicine, 110,* 220-224. https://dx.doi.org/10.1016/j.sleep.2023.08.020	Criterion 2 and 5: Included participants over the age of 18 and this study does not use a correlational design
5. Carnett, A., McLay, L., Hansen, S., France, K., & Blampied, N. (2021). Sleep Problems in Children and Adolescents with Autism: Type, Severity and Impact. *Journal of Developmental and Physical Disabilities*, *33*(6), 977–991. https://doi.org/10.1007/s10882-020-09783-5	Criterion 3: Does not state participants have an autism diagnosis
6. Chen, H., Yang, T., Chen, J., Chen, L., Dai, Y., Zhang, J., Li, L., Jia, F., Wu, L., Hao, Y., Ke, X., Yi, M., Hong, Q., Chen, J., Fang, S., Wang, Y., Wang, Q., Jin, C., & Li, T. (2021). Sleep problems in children with autism spectrum disorder: A multicenter survey. *BMC Psychiatry*, *21*(1). https://doi.org/10.1186/s12888-021-03405-w	Criterion 4: Not measuring mental health (no mental health outcome measure)

Excluded Studies	Rationale
7. Delahaye, J., Kovacs, E., Sikora, D., Hall, T. A., Orlich, F., Clemons, T. E., van der Weerd, E., Glick, L., & Kuhlthau, K. (2014). The relationship between Health-Related Quality of Life and sleep problems in children with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders*, *8*(3), 292–303. https://doi.org/10.1016/j.rasd.2013.12.015	Criterion 4: No specific mental health measure
8. Estes A, Munson J, St John T, Finlayson R, Pandey J, Gottlieb B, Schultz RT (2023). Sleep problems in autism: sex differences in the school-age population. *Autism research, 16(1),* 164-173. https://dx.doi.org/10.1002/aur.2848	Criterion 4: Does not measure the relationship between sleep and mental health specifically for autistic participants. Measures the relationship in the whole sample of typically developing participants and autistic participants.
9. Favole I, Davico C, Marcotulli D, Sodero R, Svevi B, Amianto F, Vitiello B (2023). Sleep disturbances and emotional dysregulation in young children with autism spectrum, intellectual disability, or global developmental delay. *Sleep Medicine, 105*, 45-52. https://dx.doi.org/10.1016/j.sleep.2023.02.026	Criterion 2: Includes participants in the ASD group who met the criteria on the ADOS of being 'at risk of ASD' but without a diagnosis.
10. Fletcher, F. E., Foster-Owens, M. D., Conduit, R., Rinehart, N. J., Riby, D. M., & Cornish, K. M. (2017). The developmental trajectory of parent-report and objective sleep profiles in autism spectrum disorder: Associations with anxiety and bedtime routines. *Autism*, *21*(4), 493–503. https://doi.org/10.1177/1362361316653365	Criterion 4: Does not measure the relationship between sleep and mental health specifically for autistic participants. Measures the relationship in the whole sample of typically developing participants and

Excluded Studies	Rationale
	autistic participants.
11. Foster, Miranda, Federico, Alexis, Klaiman, Cheryl & Bradshaw, Jessica. (2023). Early sleep differences in young infants with autism spectrum disorder. *Journal of Developmental and Behavioral Pediatrics, 44(8),* 519-526. https://doi.org/10.1097/DBP.0000000000001207	Criterion 4: Does not measure the relationship between sleep and mental health.
12. Galli, J., Loi, E., Visconti, L., Mattei, P., Eusebi, A., Calza, S., Fazzi, E., & ASD Collaborative Grp. (2022). Sleep Disturbances in Children Affected by Autism Spectrum Disorder. *Frontiers in Psychiatry*, *13*. https://doi.org/10.3389/fpsyt.2022.736696	Criterion 2: Includes a sample of participants who are treated with melatonin medication. This sample is included in the correlational analysis and therefore may act as a confounding variable.
13. Gernert CC, Falter-Wagner CM, Noreika V, Jachs B, Jassim N, Gibbs K, Bekinschtein TA (2024). Stress in autism (stream): a study protocol on the role of circadian activity, sleep quality and sensory reactivity.. *PLoS ONE, 19*(5). https://dx.doi.org/10.1371/journal.pone.0303209	Criterion 2: Includes participants over the age of 18
14. Gustemps, L., Marin, J., Ramos, I., Jimenez, P., Santo-Tomas, O., Luque, M., Navarro, P., Cruella, A., Villoria, E., Bedia, R., & Quiroga, J. (2021). Sleep disturbances in autism spectrum disorder without intellectual impairment: Relationship with executive function and psychiatric symptoms. *Sleep Medicine, 83*, 106–114. https://doi.org/10.1016/j.sleep.2021.04.022	Criterion 2: Includes participants over the age of 18
15. Hodge, D., Carollo, T. M., Lewin, M., Hoffman, C. D., & Sweeney, D. P. (2014). Sleep patterns in children with and without autism spectrum disorders: Developmental comparisons. *Research in Developmental Disabilities*, *35*(7), 1631–1638. https://doi.org/10.1016/j.ridd.2014.03.037	Criterion 4: Not measuring the relationship between sleep and mental health (no mental health measure)
16. Hoffman, C. D., Sweeney, D. P., Gilliam, J. E., Apodaca, D. D., Lopez-Wagner, M. C., & Castillo, M. M. (2005). Sleep Problems and Symptomology in Children With Autism. *Focus*	Criterion 4: Not assessing the relationship between sleep and

Excluded Studies	Rationale
on Autism and Other Developmental Disabilities, *20*(4), 194–200. https://doi.org/10.1177/1088357605020004010 1	mental health (no mental health outcome measure)
17. Hoşoğlu, E., Akça, Ö. F., Bilgiç, A., & Tuzcu, M. S. (2024). Evaluation of sleep problems and related factors in children newly diagnosed with autism spectrum disorder. *International Journal of Developmental Disabilities*, 1–15. https://doi.org/10.1080/20473869.2024.233183 9	Criterion 4: No specific mental health measure
18. Iwamoto, B. K., Neece, C. L., Nair, A., Rockwood, N. J., Fenning, R. M., Krantz, M. L., & Van Dyk, T. R. (2023). Exploring bidirectional relationships: Child sleep duration, child behavior problems, and parenting stress in families of children with autism spectrum disorder. *Research in Autism Spectrum Disorders*, *106.* https://doi.org/10.1016/j.rasd.2023.102197	Criterion 4: No internalising mental health measure.
19. Joels H, Benny A, Sharpe A, Postigo B, Joseph B, Piantino C, Hill CM (2023). Sleep related rhythmic movement disorder: phenotypic characteristics and treatment response in a paediatric cohort. *Sleep Medicine, 112,* 21-29. https://dx.doi.org/10.1016/j.sleep.2023.09.020	Criterion 3: Includes participants with other neurodevelopment al conditions
20. Johnson, K.P., & Zarrinnegar, P. (2021). Autism Spectrum Disorder and Sleep. *Child and Adolescent Psychiatric Clinics, 30(1),* 195-208. https://doi.org/10.1016/j.chc.2020.08.012	Criterion 4: Not assessing the relationship between sleep and mental health
21. Kelmanson, I. A. (2020). Sleep disturbances and their associations with emotional/behavioural problems in 5-year-old boys with autism spectrum disorders. *Early Child Development and Care*, *190*(2), 236–251. https://doi.org/10.1080/03004430.2018.146462 2	Criterion 5: This study does not employ a correlational design
22. Kotagal, S., & Broomall, E. (2012). Sleep in Children With Autism Spectrum Disorder. *PEDIATRIC NEUROLOGY*, *47*(4), 242–251. https://doi.org/10.1016/j.pediatrneurol.2012.05. 007	Criterion 5: This is a literature review
23. Lawson, L., Richdale, A., Haschek, A., Flower, R., Vartuli, J., Arnold, S., & Trollor, J. (2020). Cross-sectional and longitudinal predictors of quality of life in autistic individuals from	Criterion 2: Includes participants over the age of 18

Excluded Studies		Rationale
	adolescence to adulthood: The role of mental health and sleep quality. *Autism*, *24*(4), 954–967. https://doi.org/10.1177/1362361320908107	
24.	Lee, Jiwon, Schwichtenberg, A. J, Bliwise, Donald, Ali, Syeda Zahra, Hayat, Matthew J, Clark, Patricia C & Spratling, Regena. (2024). Simultaneous recording of objective sleep in mothers and school-aged children with developmental disabilities: A pilot study of actigraphy and videosomnography. *Journal of Developmental and Physical Disabilities*, *36(1),* 63-85. https://doi.org/10.1007/s10882-023-09896-7	Criterion 2 and 4: Includes participants without a diagnosis of autism and not assessing relationship between child's sleep and mental health.
25.	Li, S.Y., Jin, Y., Jing, J., Huang, L.-J., & Zhou, J.-X. (2012). Sleep behaviors in children with autism spectrum disorders. *Chinese Mental Health Journal*, *26*(6), 471–475.	Criterion 6: Not published in English
26.	Limoges, E., Mottron, L., Bolduc, C., Berthiaume, C., & Godbout, R. (2005). Atypical sleep architecture and the autism phenotype. *Brain: A Journal of Neurology*, *128*(5), 1049–1061. https://doi.org/10.1093/brain/awh425	Criterion 2: Includes participants over the age of 18 and not participants under the age of 18
27.	MacDuffie, K., Munson, J., Greenson, J., Ward, T., Rogers, S., Dawson, G., & Estes, A. (2020). Sleep Problems and Trajectories of Restricted and Repetitive Behaviors in Children with Neurodevelopmental Disabilities. *Journal of Autism and Developmental Disorders*, *50*(11), 3844–3856. https://doi.org/10.1007/s10803-020-04438-y	Criterion 4: Does not assess the relationship between sleep and mental health
28.	Mayes, S. D., Fernandez-Mendoza, J., Waschbusch, D. A., & Calhoun, S. L. (2024). Concurrent and Longitudinal Predictors and Stability of Parent-Reported Sleep Problems in a Population-Based Sample at Mean Ages 8 and 15. *Journal of Psychopathology and Behavioral Assessment*, *46*(1), 103–115. https://doi.org/10.1007/s10862-023-10111-2	Criterion 2: Does not specify participants have an autism diagnosis.
29.	Mazzone, L., Postorino, V., Siracusano, M., Riccioni, A., & Curatolo, P. (2018). The Relationship between Sleep Problems, Neurobiological Alterations, Core Symptoms of Autism Spectrum Disorder, and Psychiatric Comorbidities. *Journal of Clinical Medicine*, *7*(5). https://doi.org/10.3390/jcm7050102	Criterion 5: This is a review

Excluded Studies	Rationale
30. Nadeau, J., Arnold, E., Keene, A., Collier, A., Lewin, A., Murphy, T., & Storch, E. (2015). Frequency and Clinical Correlates of Sleep-Related Problems Among Anxious Youth with Autism Spectrum Disorders. *Child Psychiatry and Human Development*, *46*(4), 558–566. https://doi.org/10.1007/s10578-014-0496-9	Criterion 2: A subset of participants were having CBT as part of the study
31. Richdale, A. (2001). Sleep in children with autism and Aspergers syndrome. In G. Stores & L. Wiggs (Eds.), *Sleep disturbance in children and adolescents with disorders of development: Its significance and management* (pp. 181–191). Cambridge University Press.	Criterion 5: This is a book chapter.
32. Richdale, A., Chetcuti, L., Hayward, S., Abdullahi, I., Morris, E., & Lawson, L. (2023). The impact of sleep quality, fatigue and social well-being on depressive symptomatology in autistic older adolescents and young adults. *Autism Research*, *16*(4), 817–830. https://doi.org/10.1002/aur.2899	Criterion 2: This includes participants over the age of 18
33. Richdale, Amanda L., Lawson, Lauren P., Chalmers, Alexa, Uljarević, Mirko, Morris, E ric M. J., Arnold, Samuel R. C., Trollor, Julian N. (2023) Pathways to Anxiety and Depression in Autistic Adolescents and Adults. *Depression and Anxiety.* https://doi.org/10.1155/2023/5575932	Criterion 2: Includes participants over the age of 18 in the path analysis.
34. Rzepecka, H., McKenzie, K., McClure, I., & Murphy, S. (2011). Sleep, anxiety and challenging behaviour in children with intellectual disability and/or autism spectrum disorder. *Research in Developmental Disabilities*, *32*(6), 2758–2766. https://doi.org/10.1016/j.ridd.2011.05.034	Criterion 3: Includes participants with other disabilities and comorbidities.
35. Schroder, C.M., Zanfonato, T., Royant-Parola, S., & Mazza, S. (2024) Sommeil et santé mentale chez l'enfant et l'adolescent. *Bulletin de l'Académie Nationale de Médecine*, 208(7), 928-934. https://doi.org/10.1016/j.banm.2024.05.003.	Criterion 6: Not available to read in English.
36. Shui AM, Lampinen LA, Richdale A & Katz T (2023). Predicting future sleep problems in young autistic children. Autism, 27(7), 2063-2085. https://dx.doi.org/10.1177/13623613231152963	Criterion 2: Includes participants receiving an intervention which might act as a

Excluded Studies	Rationale
	confounding variables
37. Sikora, D. M., Johnson, K., Clemons, T., & Katz, T. (2012). The relationship between sleep problems and daytime behavior in children of different ages with autism spectrum disorders. *Pediatrics*, *130*(2), 83–90. https://doi.org/10.1542/peds.2012-0900F	Criterion 5: This study does not employ a correlational design
38. Sivertsen, B., Posserud, M., Gillberg, C., Lundervold, A., & Hysing, M. (2012). Sleep problems in children with autism spectrum problems: A longitudinal population-based study. *Autism*, *16*(2), 139–150. https://doi.org/10.1177/1362361311404255	Criterion 3: Participants do not have an autism diagnosis
39. Taylor, B. J., Pedersen, K. A., Mazefsky, C. A., Lamy, M. A., Reynolds, C. F., Strathmann, W. R., & Siegel, M. (2023). From Alert Child to Sleepy Adolescent: Age Trends in Chronotype, Social Jetlag, and Sleep Problems in Youth with Autism. *Journal of Autism and Developmental Disorders, 54,* 4529-4539. https://doi.org/10.1007/s10803-023-06187-0	Criterion 2 and 4: This includes participants over the age of 18 and does not include a mental health measure.
40. Uren, J., Richdale, A., Cotton, S., & Whitehouse, A. (2019). Sleep problems and anxiety from 2 to 8years and the influence of autistic traits: A longitudinal study. *European Child and Adolescent Psychiatry*, *28*(8), 1117–1127. https://doi.org/10.1007/s00787-019-01275-y	Criterion 3: Participants do not have autism diagnosis
41. William, S., Leader, G., Mannion, A., & Chen, J. (2015). An investigation of anxiety in children and adolescents with autism spectrum disorder. *Research in Autism Spectrum Disorders, 10*, 30–40. https://doi.org/10.1016/j.rasd.2014.10.017	Criterion 3 and 4: Participants also have gastrointestinal symptoms which is being assessed.
42. Wolff, B., Franco, V. R., Roberts, R., Skoss, R., Magiati, I., & Glasson, E. J. (2024). Stability and change in self-reported risk and resilience factors associated with mental health of siblings of individuals with and without neurodevelopmental conditions over 15 months. *Advances in Mental Health, 22(3),* 653-681. https://doi.org/10.1080/18387357.2024.2305726	Criterion 3: Includes participants with other neurodevelopmental conditions

Appendix C

Weight of Evidence

Weight of Evidence A

Study	Checklist Score	WoE A	Descriptor
Bianca et al. (2024)	15/20	2.25	Medium
Goldman et al. (2011).	12/20	1.8	Medium
Kang et al. (2020)	14/20	2.1	Medium
Martinez-Cayuelas et al. (2023)	14/20	2.1	Medium
May et al. (2015)	12/20	1.8	Medium
Mazurek et al. (2019)	16/20	2.4	High
Mazurek & Petroski (2015)	13/20	1.95	Medium
Park et al. (2012)	13/20	1.95	Medium
Phung, Abdullah & Goldberg (2019)	14/20	2.1	Medium
Richdale et al. (2014)	16/20	2.4	
Richdale & Baglin (2015)	15/20	2.25	Medium

Study	Checklist Score	WoE A	Descriptor
Schreck, K. (2021)	13/20	1.95	Medium
Sommers et al. (2024)	13/20	1.95	Medium
Zaidman-Zait et al. (2020)	11/20	1.65	Low

Note <1.7=low, 1.7-2.3=medium, 2.4-3 =high

Weight of Evidence B

Methodological Relevance – appropriateness of the research design for addressing the review question – typology of evidence

Typology of Correlational Analysis

Weighting	Design	Rationale
1	Bivariate Correlation or partial correlation	Bivariate correlation is a simple form of correlation which assess the relationship between two variables. However, it does not take into account other variables which might affect the relationship. Partial correlation assesses the relationship between two variables while holding a third variable constant.
2	Study meets one of the following criteria: -Structural equation modelling (SEM), multiple regression or path analysis -Longitudinal study design	Longitudinal studies are proposed to be useful for establishing evidence of causality through taking measurements at two or more time points (Johnson, 2001).
3	Study meets both of the following criteria: -Structural equation modelling (SEM), multiple regression or path analysis	These techniques can take into account more independent variables. SEM is a more sophisticated form of correlational analysis which has the closest approximation to a causal relationship between the predictor and outcome variable (Thompson et al., 2005). SEM

Weighting	Design	Rationale
	-Longitudinal study design	can indicate the direction of causality between two variables. Longitudinal studies are proposed to be useful for establishing evidence of causality through taking measurements at two or more time points (Johnson, 2001).

WoE B Ratings

Study	WoE B rating	Descriptor
Bianca et al. (2024)	1 • Spearman's correlation	Low
Goldman et al. (2011).	2 • Multivariate logistic regression models to assess association of behavioural problem with CSHQ scales	Medium
Kang et al. (2020)	2 • Pearson's or Spearman's correlation for relationship between CSHQ and SDQ subscales • Multiple linear regression with CSHQ subscales as independent variables (against SDQ scores) • Adjusted linear regression for SDQ total scores by each domain of the CSHQ	Medium
Martinez-Cayuelas et al. (2023)	1 • Correlations but not clear whether parametric or non parametric tests were chosen	Low

Study	WoE B rating	Descriptor
May et al. (2015)	3 • Hierarchical regression • Longitudinal	High
Mazurek et al. (2019)	3 • Simple correlation • Path analyses • Longitudinal	High
Mazurek & Petroski (2015)	2 • Pearson's correlation – bivariate analysis • Path modelling	Medium
Park et al. (2012)	2 • Multivariate regression analysis	Medium
Phung, Abdullah & Goldberg (2019)	2 • ANCOVA • Pearson's correlation analysis • Ordinary least square regression models	Medium
Richdale et al. (2014)	2 • Pearson's correlation • Standard multiple regression	Medium
Richdale & Baglin (2015)	1 • Non parametric tests – Spearman's correlations and Chi-square analyses	Low
Schreck, K. (2021)	2 • Pearson correlations • Stepwise multiple linear regression analyses	Medium
Sommers et al. (2024)	1 • Partial correlation	Low
Zaidman-Zait et al. (2020)	2 • Spearman's correlation	Medium

Study	WoE B rating	Descriptor
	• Hierarchical multiple regression	

Weight of Evidence C

Appropriateness of focus of study to the review question (topic relevance)

Criteria	WoE Rating	Descriptor	Rationale
A. Participant Diagnosis	3	Children have a diagnosis of autism from a medical professional, confirmed by a study based screening	This review is evaluating the relationship between sleep and mental health in autistic children
	2	Children have a diagnosis of autism from a medical professional but no study-based screening	
	1	Diagnosis details unspecified	
B. Participant Age Range	3	Participants cover at least ½ of the target age range (a range of 9 years or more)	This study is examining the relationship between sleep and mental health from age 0-18 and therefore the larger the age range, the more generalisable the findings
	2	Participants cover between ¼ to ½ of the target age range (a range of 4.5-9 years)	
	1	Participants cover less than a ¼ of the	

Criteria	WoE Rating	Descriptor	Rationale
		target age range (a range of 4.5 years or less)	
C. Sleep Outcome Measures	3	Study has two or more sources of information for sleep measures or use a gold standard sleep measure (e.g. ACM). Additionally, all subscales of the sleep measure are included in the correlational analysis.	This review is examining the relationship between sleep and mental health. Therefore, through using more than one source of information, this increases reliability and validity. Through including all subscales in the correlational analysis, this gives a more in depth understanding of the relationship between particular sleep factors and mental health.
	2	Study has one source of information for sleep measure. Additionally, all subscales of the sleep measure are included in the correlational analysis.	
	1	Study has one source of information for sleep measure. Not all subscales are included in the correlational analysis.	
D. Mental Health Outcome Measures	3	Study has two or more sources of information for mental health measures. Additionally, all	This review is examining the relationship between sleep and mental health. Therefore, through using more

Criteria	WoE Rating	Descriptor	Rationale
		subscales of the mental health measure are included in the correlational analysis.	sources of information, this increases reliability and validity. Through including all subscales in the correlational analysis, this gives a more in depth understanding of the relationship between sleep and particular mental health factors.
	2	Study has one source of information for the mental health measure. Additionally, all subscales are included in the correlational analysis.	
	1	Study has one source of information for mental health measures. Not all subscales are included in the correlational analysis.	

WoE C Ratings

Study	Criteria A	Criteria B	Criteria C	Criteria D	Overall WoE C	Descriptor
Bianca et al. (2024)	3	2	2	1	2	Medium
Goldman et al. (2011).	2	3	2	2	2.25	Medium
Kang et al. (2020)	2	1	2	2	1.75	Medium
Martinez-Cayuelas et al. (2023)	2	3	3	2	2.5	High
May et al. (2015)	3	2	2	1	2	Medium
Mazurek et al. (2019)	2	2	1	2	1.75	Medium
Mazurek & Petroski (2015)	2	3	2	2	2.25	Medium
Park et al. (2012)	3	3	1	2	2.25	Medium
Phung, Abdullah & Goldberg (2019)	3	2	3	3	2.75	High
Richdale et al. (2014)	3	1	3	2	2.25	Medium
Richdale & Baglin (2015)	3	1	3	3	2.5	High
Schreck, K. (2021)	1	3	2	1	1.75	Medium

Study	Criteria A	Criteria B	Criteria C	Criteria D	Overall WoE C	Descriptor
Sommers et al. (2024)	3	2	2	2	2.25	Medium
Zaidman-Zait et al. (2020)	3	1	2	2	2	Medium

Note 1-1.6=low, 1.7-2.3=medium, 2.4-3 =high

Appendix D Summary and Example AXIS Coding Protocols

Example AXIS Coding Protocol

Bianca, B., Silvia, G., Elisa, F., Deny, M., Giovanni, V., Lino, N., & Stefano, V. (2024). Insomnia in Children with Autism Spectrum Disorder: A Cross-Sectional Study on Clinical Correlates and Parental Stress. *Journal of Autism and Developmental Disorders*, *54*(1), 46–55. https://doi.org/10.1007/s10803-022-05793-8

	Question	Yes	No	Don't know	Comment
	Introduction				
1	Were the aims/objectives of the study clear?	X			"The purpose of the current study was to assess the prevalence of a co-occurring diagnosis of insomnia using the International Classification of Sleep Disorders—Third Edition (ICSD-3) criteria (American Academy of Sleep Medicine, 2005) in a cohort of 270 children with ASD." "In addition, we were aimed at investigating the relationship between insomnia symptoms and the severity of core symptoms of ASD, age, cognitive development, adaptive behavior, parental stress, co-occurring behavioral and emotional problems." Hypotheses included.
	Methods				
2	Was the study design appropriate for the stated aim(s)?	X			Cross-sectional, cohort survey – appropriate for

					measuring relationship
3	Was the sample size justified?		X		No sample size analysis/comment on size
4	Was the target/reference population clearly defined? (Is it clear who the research was about?)	X			270 autistic children aged 1.8-9.6 years, 81% males, 19% females
5	Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation?		X		Participants from neuropsychiatry unity of one hospital. But did include all participants with autism diagnosis.
6	Was the selection process likely to select subjects/participants that were representative of the target/reference population under investigation?		X		No random sampling.
7	Were measures undertaken to address and categorise non-responders?			X	Not specified
8	Were the risk factor and outcome variables measured appropriate to the aims of the study?	X			-CBCL for behavioural/emotional symptoms – gives test retest reliability scores -Paediatric Sleep Clinical Impression Scale for sleep problems – convergent validity between CSHQ and S-CGI provided
9	Were the risk factor and outcome variables measured correctly using instruments/measurements that had been trialled, piloted or published previously?	X			
10	Is it clear what was used to determined statistical significance and/or precision estimates? (e.g. p-values, confidence intervals)	X			P values provided

11	Were the methods (including statistical methods) sufficiently described to enable them to be repeated?	X			Spearman's rank correlation, Bonferroni correction, Mann Whitney U test etc.
	Results				
12	Were the basic data adequately described?	X			Information about S-CGI scores and subscales for participants younger and older than age 6 given
13	Does the response rate raise concerns about non-response bias? (reverse scored)		X		270 children – matches number in table.
14	If appropriate, was information about non-responders described?		X		Not specified
15	Were the results internally consistent?	X			Tables include the same amount of participants as outlined in the text
16	Were the results presented for all the analyses described in the methods?	X			
	Discussion				
17	Were the authors' discussions and conclusions justified by the results?	X			Relates aim to findings Relates to other studies
18	Were the limitations of the study discussed?	X			
	Other				
19	Were there any funding sources or conflicts of interest that may affect the authors' interpretation of the results?		X		Declare no conflict of interest
20	Was ethical approval or consent of participants attained?	X			Informed consent gained

Introduction: 1/1 Methods: 6/10 Results: 4/5 Discussion: 2/2 Other: 2/2

Overall = 15/20

(WoE 15/20 x 3 = 2.25)

Summary Coding Scores

Study	Introduction	Methods	Results	Discussion	Other	Overall
Bianca et al. (2024)	1/1	6/10	4/5	2/2	2/2	15/20
Goldman et al. (2011)	1/1	6/10	4/5	0/2	1/2	12/20
Kang et al. (2020)	1/1	6/10	3/5	2/2	2/2	14/20
Martinez-Cayuelas et al. (2023)	1/1	6/10	3/5	2/2	2/2	14/20
May et al. (2015)	1/1	6/10	2/5	2/2	1/2	12/20
Mazurek et al. (2019)	1/1	6/10	5/5	2/2	2/2	16/20
Mazurek & Petroski (2015)	1/1	6/10	3/5	2/2	1/2	13/20
Park et al. (2012)	1/1	6/10	3/5	2/2	1/2	13/20
Phung et al. (2019)	1/1	6/10	3/5	2/2	2/2	14/20

Richdale et al. (2014)	1/1	8/10	4/5	2/2	1/2	16/20
Richdale & Baglin (2015)	1/1	7/10	3/5	2/2	2/2	15/20
Schreck (2021)	1/1	6/10	3/5	2/2	1/2	13/20
Sommers et al. (2024)	1/1	5/10	3/5	2/2	2/2	13/20
Zaidman-Zait et al. (2020)	1/1	5/10	1/5	2/2	2/2	11/20

Appendix E

Sleep Diary

My Sleep Tracker

When we make a sleep routine it is important to see what is working.

Try your routine for 4 weeks and track your sleep to see if it works.

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
What time did you go to bed?							
What time did you wake up?							
Rate how well you slept on a scale of 1 to 100. 1 100 1 = I had the worst night sleep 100 = I had the best night sleep							
Notes: Did you stick to your plan? What went well? What didn't go well? Anything else to note?							

Appendix F

Revised Child Anxiety Depression Scale (Parent Version) (Chorpita et al.,2005)

Child/Young Person's Name:

Relationship to Child/Young person:

Date:

Please put a circle around the word that shows how often each of these things happen to your child. There are no right or wrong answers.

1	My child worries about things	Never	Sometimes	Often	Always
2	My child feels sad or empty	Never	Sometimes	Often	Always
3	When my child has a problem he/she gets a funny feeling in his/her stomach	Never	Sometimes	Often	Always
4	My child worries when he/she thinks he/she has done poorly at something	Never	Sometimes	Often	Always
5	My child feels afraid of being alone at home	Never	Sometimes	Often	Always
6	Nothing is much fun for my child anymore	Never	Sometimes	Often	Always
7	My child feels scared when taking a test	Never	Sometimes	Often	Always
8	My child worried when he/she thinks someone is angry with him/her	Never	Sometimes	Often	Always

9	My child worries about being away from me	Never	Sometimes	Often	Always
10	My child is bothered by bad or silly thoughts or pictures in his/her mind	Never	Sometimes	Often	Always
11	My child has trouble sleeping	Never	Sometimes	Often	Always
12	My child worries about doing badly at school work	Never	Sometimes	Often	Always
13	My child worries that something awful will happen to someone in the family	Never	Sometimes	Often	Always
14	My child suddenly feels as if he/she can't breathe when there is no reason for this	Never	Sometimes	Often	Always
15	My child has problems with his/her appetite	Never	Sometimes	Often	Always
16	My child has to keep checking that he/she has done things right (like the switch is off, or the door is locked)	Never	Sometimes	Often	Always
17	My child feels scared to sleep on his/her own	Never	Sometimes	Often	Always
18	My child has trouble going to school in the mornings because of feeling nervous or afraid	Never	Sometimes	Often	Always

19	My child has no energy for things	Never	Sometimes	Often	Always
20	My child worries about looking foolish	Never	Sometimes	Often	Always
21	My child is tired a lot	Never	Sometimes	Often	Always
22	My child worries that bad things will happen to him/her	Never	Sometimes	Often	Always
23	My child can't seem to get bad or silly thoughts out of his/her head	Never	Sometimes	Often	Always
24	When my child has a problem his/her heart beats really fast	Never	Sometimes	Often	Always
25	My child cannot think clearly	Never	Sometimes	Often	Always
26	My child suddenly starts to tremble or shake when there is no reason for this	Never	Sometimes	Often	Always
27	My child worries that something bad will happen to him/her	Never	Sometimes	Often	Always
28	When my child has a problem, he/she feels shaky	Never	Sometimes	Often	Always
29	My child feels worthless	Never	Sometimes	Often	Always
30	My child worries about making mistakes	Never	Sometimes	Often	Always
31	My child has to think of special thoughts (like	Never	Sometimes	Often	Always

	numbers or words) to stop bad things from happening				
32	My child worries what other people think of him/her	Never	Sometimes	Often	Always
33	My child is afraid of being in crowded places (like shopping centres, the movies, buses, busy playgrounds)	Never	Sometimes	Often	Always
34	All of a sudden my child will feel really scared for no reason at all	Never	Sometimes	Often	Always
35	My child worries about what is going to happen	Never	Sometimes	Often	Always
36	My child suddenly becomes dizzy or faint when there is no reason for this	Never	Sometimes	Often	Always
37	My child thinks about death	Never	Sometimes	Often	Always
38	My child feels afraid if he/she has to talk in front of the class	Never	Sometimes	Often	Always
39	My child's heart suddenly starts to beat too quickly for no reason	Never	Sometimes	Often	Always
40	My child feels like he/she doesn't want to move	Never	Sometimes	Often	Always
41	My child worries that he/she will suddenly get a scared feeling	Never	Sometimes	Often	Always

	when there is nothing to be afraid of				
42	My child has to do some things over and over again (like washing hands, cleaning or putting things in a certain order)	Never	Sometimes	Often	Always
43	My child feels afraid that he/she will make a fool of him/herself in front of people	Never	Sometimes	Often	Always
44	My child has to do some things in just the right way to stop bad things from happening	Never	Sometimes	Often	Always
45	My child worries when in bed at night	Never	Sometimes	Often	Always
46	My child would feel scared if he/she had to stay away from home overnight	Never	Sometimes	Often	Always
47	My child feels restless	Never	Sometimes	Often	Always

Appendix G

The Child Sleep Habits Questionnaire (Owens et al., 2000)

The following statements are about your child's sleep habits and potential sleep difficulties. Think about the past week when answering the questions or if last week was unusual for a certain reason, choose the most recent typical week. Put a 'X' in the relevant box. Check 'usually' if the behaviour occurs 5 to 7 times a week, 'sometimes' for two to four times a week and 'rarely' for zero to one time a week.

	3 Usually (5-7 times a week)	**2 Sometimes (two to four times a week)**	**1 Rarely (zero to one time a week)**
Bedtime Resistance			
Goes to bed at same time			
Falls asleep in own bed			
Falls asleep in other's bed			
Needs parents in room to sleep			
Struggles at bedtime			
Afraid of sleeping alone			
Sleep Onset Delay			
Falls asleep in 20 minutes			
Sleep Duration			
Sleeps too little			
Sleeps the right amount			
Sleeps the same amount each day			
Sleep Anxiety			

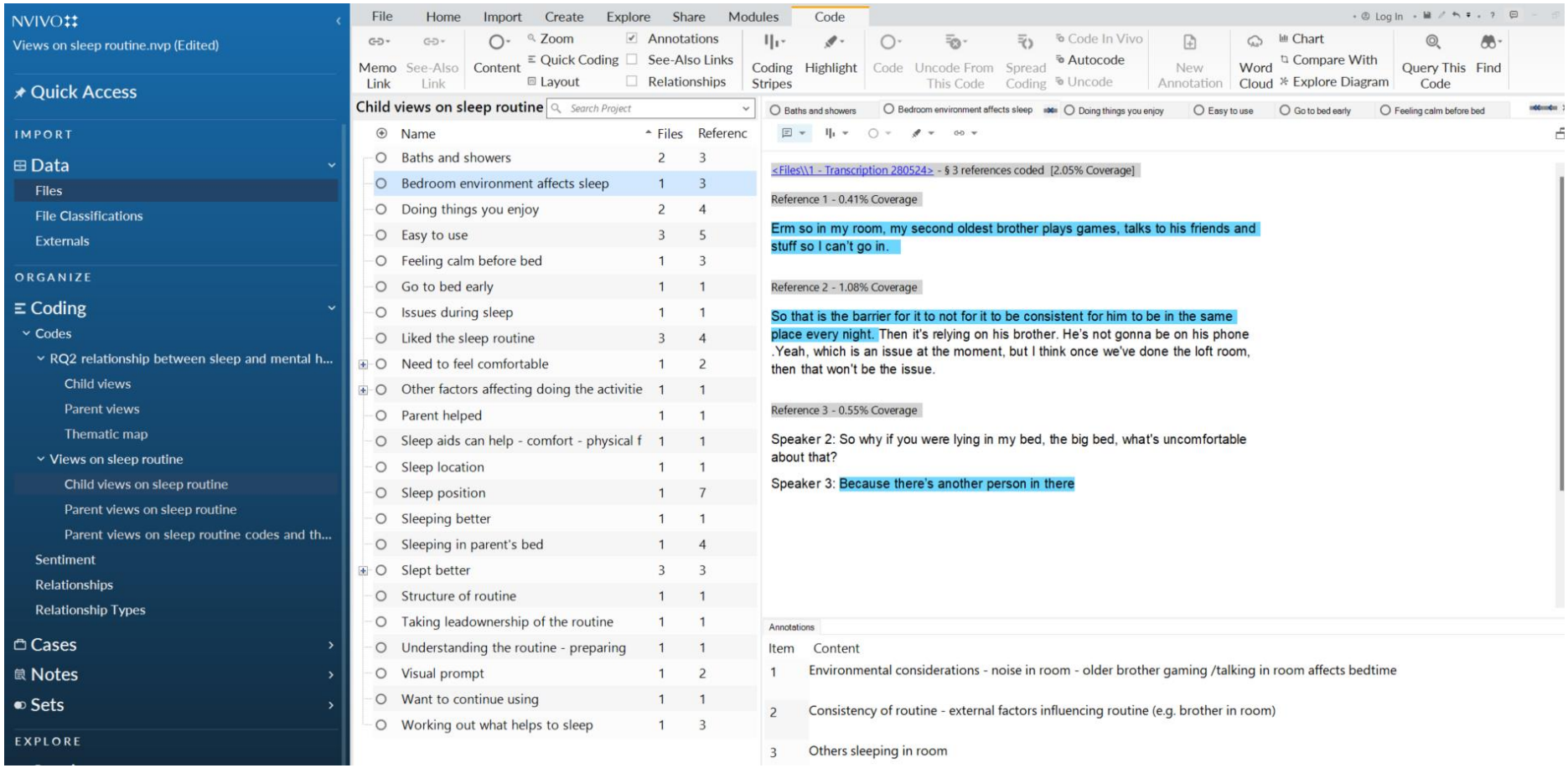
Needs parent in room to sleep			
Afraid of sleeping in the dark			
Afraid of sleeping alone			
Trouble sleeping away			
Night Wakings			
Moves to other's bed in night			
Awakes once during night			
Awakes more than once			
Parasomnias			
Wets the bed at night			
Talks during sleep			
Restless and moves a lot			
Sleepwalks			
Grinds teeth during sleep			
Awakens screaming, sweating			
Alarmed by scary dream			
Sleep Disordered Breathing			
Snores loudly			
Stops breathing			
Snorts and gasps			
Daytime Sleepiness			

Wakes by himself			
Wakes up in negative mood			
Others wake child			
Hard time getting out of bed			
Takes long time to be alert			
Seems tired			
Watching TV			
Riding in car			

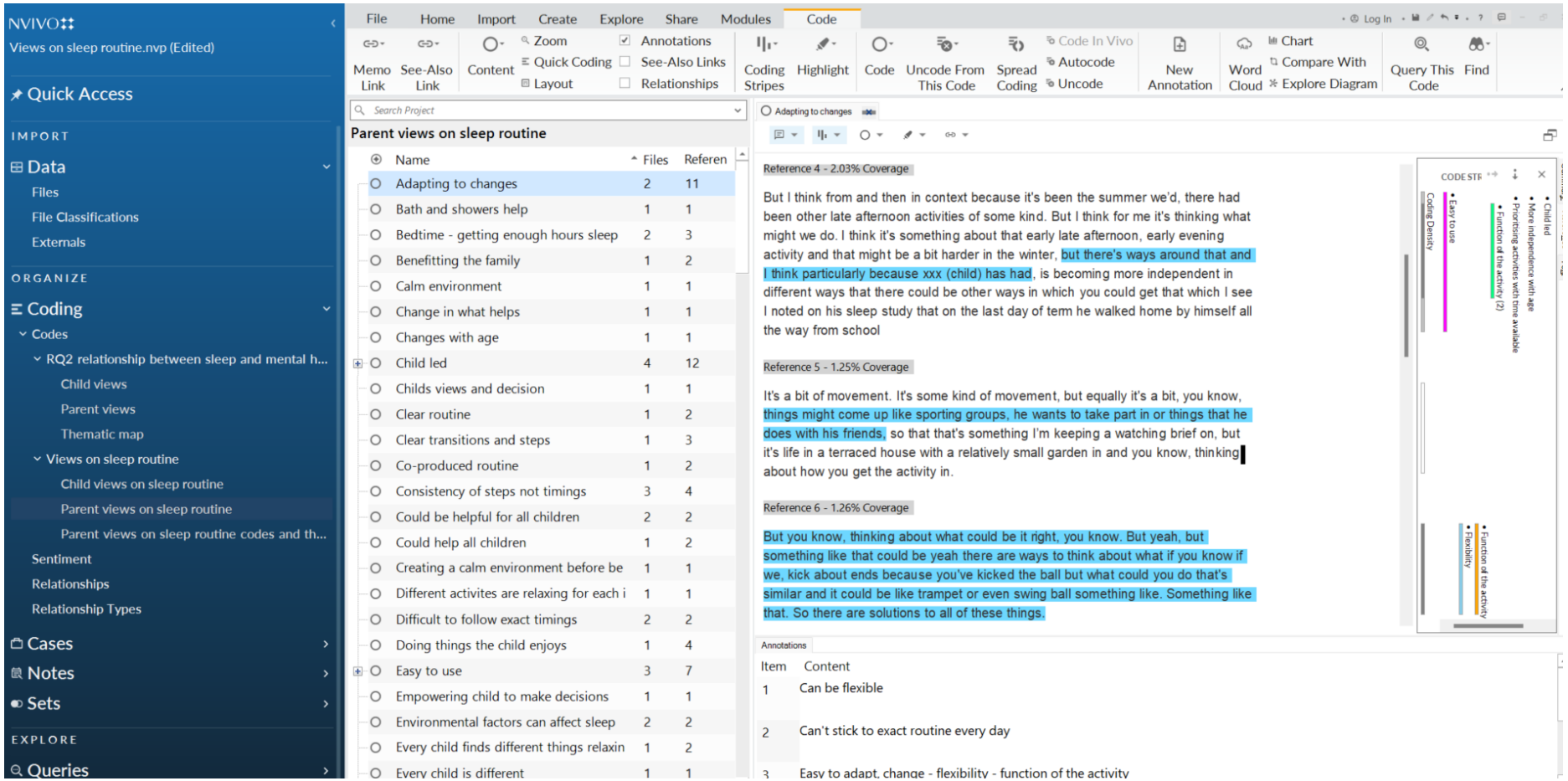
Appendix H

Thematic Analysis Audit Trail

Child views on sleep routine examples with annotations



Parent views on sleep routine example with annotations



Parent views on sleep routine with codes

Codes	Quotes
Personally created by child More child autonomy with the routine	Gabz's mum: "It's good because it comes from them. When it was created, it actually came from them. So it's not something you're you're saying, OK you're going to follow this, this and this. It actually came from them personally. So I think they're more likely to want to follow it because they were a part of creating it
Child taking ownership of routine Motivated to engage with routine	Participant 2's mum: "She is the one that even have to remind me, 'Mom, this is what we're gonna do, Mom, this is what we're gonna do. So she has to like, tell me everything I said. She's quite good" Asking about barriers, D's mum, ""No, there's nothing she does it, even when I'm at work she actually text me." D's mum: "So it's kind, it's very good. I'm not gonna lie. It's very good. Like kind of remind, like when I'm at work, when I call her in the morning, she said, 'Mom, I've done this. I've recorded in my book. I've done this. I've done this. Trust me. I'm organized'."
Increasing autonomy with age Child making decisions/child led	Peter's mum: "Well but also I suppose because it's what Peter came up with. It's what he wanted that it is quite different also to when they are babies and toddlers it's parent led. It's like, right you're having you're having your bottle, you're having your bath, changing your nappy, you're going to bed. This is what he finds relaxing. So that I think has been the key difference in this. It's not me deciding right let's do this because I've read something in a book or on the Internet. It's what he's said." Peter's mum: "So I think you do get those you know, you know it does get a lot more messy at this age for lots of different reasons, but this is, you know, it's not suddenly it's not me suddenly imposing something." Peter's mum: "Like I need my hot chocolate now run, you know. Yeah. And you know, just knowing or and having some control over what should happen. Like I want to watch. So it's time for my relaxing TV now. So those kind of those kind of things." Peter's mum: "I think what's been really useful is making it child led, because funnily enough, that's there's not a huge amount of that on sleep stuff. It's all very it's all very parents need to do this...."
Co-produced routine	Peter's mum: "I think it's going to be Co-produced that it's parent and parent and child working together on it" "All those kinds of things. So yeah, it allows you to yeah, agree some parameters and what that looks like rather than you will do this."
Importance of meeting in the middle Gaining child's views are important Empowering child to make decisions	Peter's mum: "the parent as well as the adult you are meant to be overseeing these things, but it implies that it is very much. Right, you need to put limits on things you need to do that, but that's very top down. Actually you need to kind of meet in the middle and have a, you know, but what do you what do you need? What would you like? What? You know what can I then do as a parent to help you do that? And so, yeah, I'd say that's the big. Yeah. Shifting my focus, I think, but what does my, you know, what does xxx think about this and how you know, finding a compromise on it? "

Child needs to be invested in the routine	Harry's mum: "Yeah, I think he wants to do that himself. So it is very important that I think if they have the motivation to want to have a better sleep and nicer sleep then it's easier as well."
Stability of routine	Peter's mum: "It's something that Peter thinks is helpful and we can roll with it if we're camping or even if it's like when it's been horrible, well not saying that it's been horribly 37 degrees or anything like that, but we've had hot, humid nights and you know that's always going to mess things up, but you still have the, the routines not thrown out by it. You can adapt it so."
Easy to make changes to the routine	Peter's mum: "I think we've, we've, we've had to make a few, make a few tweaks along the way" Peter's mum: "The key noticeable thing is that yes, you are going to get these bumps in the road because life happens, but they were not as, they didn't derail things we didn't, you know, we didn't end up with erm like what might have happened I think in in the past, is kind of getting into a bit of a spiral about worries and that coming out at bedtime, but this is I suppose it's the calming, is kind of allowing. Well, I suppose allowing kind of xxx (child) that relaxation time so that he can sleep."
Need to be flexible Thinking of the functional purpose of the activities	Peter's mum: "But I think from and then in context because it's been the summer we'd, there had been other late afternoon activities of some kind. But I think for me it's thinking what might we do. I think it's something about that early late afternoon, early evening activity and that might be a bit harder in the winter, but there's ways around that and I think particularly because xxx (child) has had, is becoming more independent in different ways that there could be other ways in which you could get that which I see I noted on his sleep study that on the last

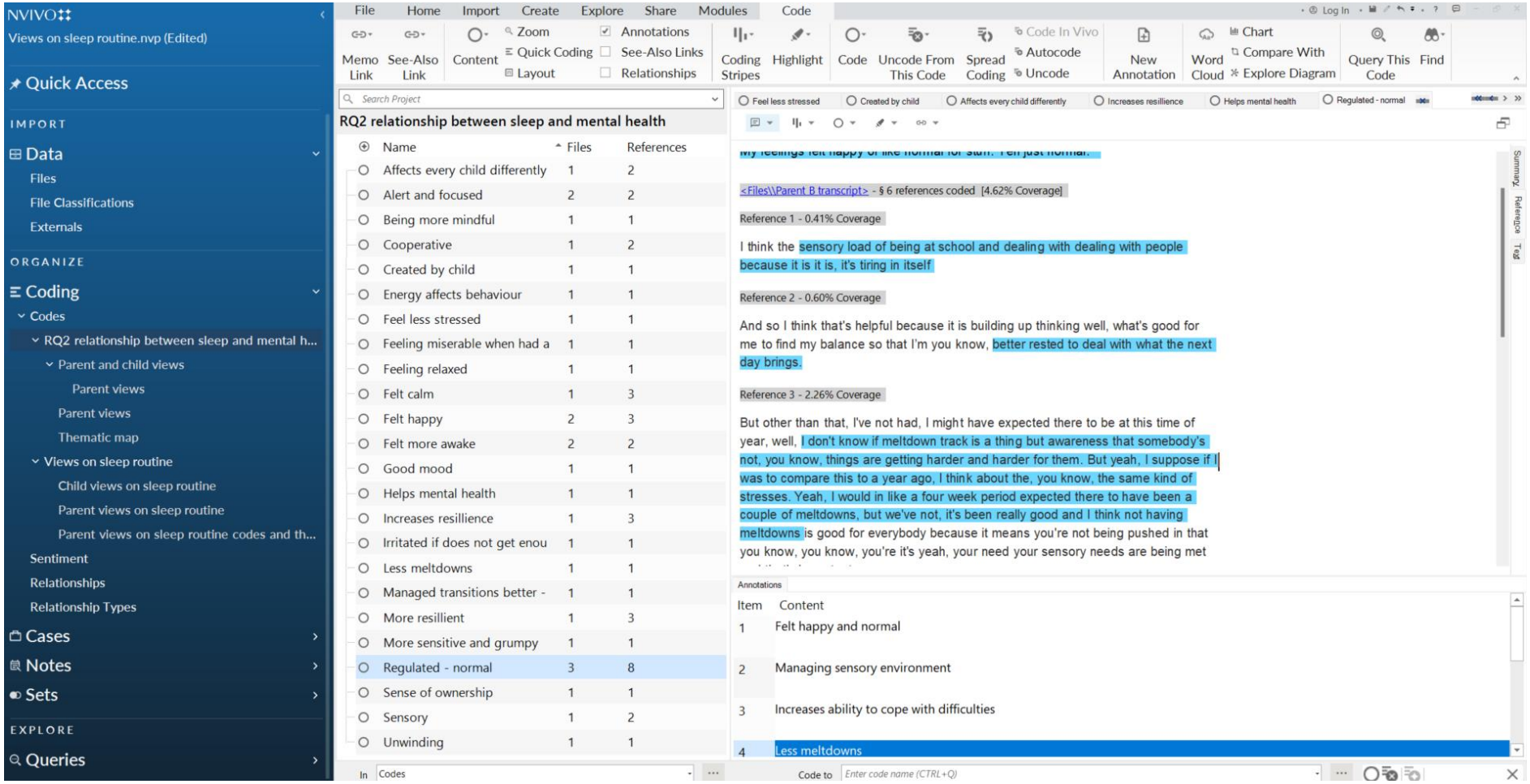
Child views on sleep routine with codes and annotations

Thesis

Codes\\Views on sleep routine\\Child views on sleep routine

Name	Description
Baths and showers	Child B: "I found a having like think for example having baths before bed quite helpful. Speaker 2: Great so baths before bed and and what helped about the bath? Speaker 1: Uh, it maybe feel quite relaxed." Child 2 "Well, taking a warm shower." – sensory? Comforting?
Bedroom environment affects sleep	Particiapant 1: Erm so in my room, my second oldest brother plays games, talks to his friends and stuff so I can't go in.[1] Speaker 2: So why if you were lying in my bed, the big bed, what's uncomfortable about that? Speaker 3: Because there's another person in there[3] - having own room?
Doing things you enjoy	Participant 2: "I would tell them to go to bed early, read their book or like, do something that they enjoy and stuff like that and they have to get everything done so in the morning they're ready and they don't have to be like stressed out." – finding enjoyable activities – different for everyone Participant B: Speaker 1: Ohh I liked having a hot chocolate before going to bed as well.

Parent and child views on relationship between sleep and mental health with annotations



Parent and child views on the relationship between sleep and mental health with codes

Thesis

Codes\\RQ2 relationship between sleep and mental health\\

Codes	Description
Every child is different	Participant 2's mum: As I said, I've never had a problem with her waking up in the morning and being moody Participant 2's mum: "You know, some children going to school in the morning. They will say, 'I don't want to go to school'. My child is not like xx. She knows she has never."
Increased alertness	Gabz's mum: "much more sort of like alert in the morning and more most probably focused as well." Harry's mum: "Yeah, he's, he wakes up refreshed and yeah, happy and in a good mood. I think it's just not feeling tired during the day. "
Increased engagement	Gabz's mum: "Like he'll get up and say ohh he's gonna read his book for 10-15 minutes. Do this and you know. Much more, you know, cooperative in that sense. Whereas if he had, said, a less good quality of sleep and you said do you wanna read your book for 15 minutes. 'Oh, no, no, no, no.' You know less likely to want to that in the morning" Gabz's mum: "He's more cooperative, I think. When had a good night's sleep."
Increased energy levels Improved mindset	Harry's mum: "Yeah, he's, he wakes up refreshed and yeah, happy and in a good mood. I think it's just not feeling tired during the day. So it's actually, yeah, it keeps him more uplifted and upbeat. I think not being tired is really important. I guess it's energy is important for mood. So if you have enough energy you'll be, your mood will be better during the day, and then your thinking will be more positive as well. So because if you feel fatigued or tired during the day it, you know it can affect your thoughts and your behaviors and everything."
Improved wellbeing	Harry's mum: "So I do think having adequate sleep is helpful for mental health and emotional health as well as behaviors."

Codes	Description
Improved parental wellbeing	Peter's mum: "would in like a four week period expected there to have been a couple of meltdowns, but we've not, it's been really good and I think not having meltdowns is good for everybody"
Heightened irritability Social fatigue Affects social interactions	Peter's mum: "it's putting you at a disadvantage when you're trying to deal with all the interactions in your life because you're already tired you're already grumpy. You read things in different ways. You might react more strongly than you might have done" Gabz's mum: "if he's not got enough hours, you can see he's a bit short, you know, a bit more irritated if he doesn't get the full 9 hours or whatever." Peter's mum: "You might react more strongly than you might have done, and so it very much very much helps and I think it also I think it also helps with the I think the sensory load of being at school and dealing with dealing with people because it is it is, it's tiring in itself"

Appendix I

Interview Schedule

Introduction

You may remember when you agreed to take part in this study that we wanted to hear about your and your child's views on the personalised sleep routine? If you are still happy to take part, I have a few questions to ask which should take between 15 to 20 minutes. As outlined previously, I will record this conversation, transcribe it and then delete it following the conversation being transcribed. If this is ok with you, when you are ready, I will turn the tape recorder on and we can start?

For parents/carers:

1. What are your views on the personalised sleep routine?

Prompts: What was helpful? How easy was it to use? Impact on sleep?

2. Were there any problems you faced during the 4-weeks with the sleep routine?

Prompts: Implementation? Barriers?

3. What things helped your child sleep better?

Prompts: Senses? Pre bed routine? Relaxing activities?

4. How did sleep quality affect your child's mental health?

Prompts: Impact of sleeping well on mood? Impact of poor sleep on mood the next day?

5. Is there anything else that you think would be helpful for me to know?

Introduction

You may remember when you agreed to take part in this study that we wanted to hear about your views on the personalised sleep routine? If you are still happy to take part, I have a few questions to ask which should take between 15 to 20 minutes. As we talked about before, I will record this conversation, transcribe it and then delete it following the conversation being transcribed. If this is ok with you, when you are ready, I will turn the tape recorder on and we can start?

For children:

1. How did you find the personalised sleep routine?

Prompts: What was helpful? How easy was it to use? Impact?

2. Was there anything you did not like about the intervention?
Prompts: Implementation? Barriers?

3. What things helped you sleep better?
Prompts: Senses? Pre bed routine? Relaxing activites?

4. How did you feel when you slept well?
Prompts: Impact of sleeping well on mood? Impact of poor sleep on mood the next day?

5. Is there anything else that you think would be helpful for me to know?

Appendix J

Ethical Approval

RESEARCH AND INNOVATION SERVICES

UCL

17th November 2023

Dr Jennifer Wills
Research Department of Clinical, Educational and Health Psychology
UCL

Cc: Emily Thompson

Dear Dr Wills

Notification of Ethical Approval
Project ID/Title: 25973/001: Investigating the Effects of a Personalised Parent-Led Sleep Hygiene Intervention on Autistic Children's Sleep Quality and Mental Health

Further to your satisfactory responses to reviewer comments, I am very pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the UCL REC until **1st September 2025.**

Ethical approval is granted on condition that you provide written evidence in due course of the schools' agreement to collaborate with you and assist with recruitment for our records.

Ethical approval is also subject to the following conditions:

Notification of Amendments to the Research
Please seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed

separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form'
https://www.ucl.ac.uk/research-ethics/responsibilities-after-approval

Adverse Event Reporting – Serious and Non-Serious
It is your responsibility to report to the REC any unanticipated problems or adverse events involving risks to participants or others. The REC should be notified of all serious adverse events via the Research Ethics Service (ethics@ucl.ac.uk) immediately after the incident occurs. Where the adverse incident is unexpected and serious, the Chair will decide whether the study should be terminated pending the opinion of an independent expert.

For non-serious adverse events, the Chair should again be notified via the Research Ethics Service within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair will confirm that the incident is non-serious and report to the REC at the next meeting. The final view of the REC will be communicated to you.

Research Ethics Service
Research and Innovation Services
University College London
ethics@ucl.ac.uk
www.ucl.ac.uk/research-ethics/

Final Report
At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes issues relating to the ethical implications of the research i.e., any issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research;
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely

Professor Sarah Edwards
Chair, UCL Research Ethics Committee

Appendix K

Ethic Amendment Approvals

Dear Emily

Further to your satisfactory responses to reviewer comments, I am pleased to confirm that your attached request to amend your study has been approved by the UCL Research Ethics Committee.

Please take this email as confirmation of approval.

IMPORTANT: For projects collecting personal data only

If necessary, please inform the UCL Data Protection team – data-protection@ucl.ac.uk - of your proposed amendments, including requests to extend ethics approval for an additional period. Please ensure that you quote your Data Protection registration number when you correspond with the team.

With best wishes for your ongoing research, Helen

Helen Dougal
Research Ethics Facilitator
Research Ethics Service
Compliance and Assurance | Research and Innovation Services
University College London | Gower Street, London, WC1E 6BT
Research Ethics Service | Research and Innovation Services
ethics@ucl.ac.uk

Dear Emily

Many thanks for submitting an amendment request form.

I can confirm that the UCL REC has now approved your attached request. Please take this email as confirmation of approval.

Please ensure that you follow the same recruitment methods that have already been granted ethical approval when recruiting new participants.

IMPORTANT: For projects collecting personal data only
If necessary, please inform the UCL Data Protection team, data-protection@ucl.ac.uk, of your proposed amendments, including requests to extend ethics approval for an additional period. Please quote your Data Protection registration number when you correspond with the team.

Very best wishes

Christopher Griffin (he/him) | Research Ethics Facilitator, Research Ethics Service
Compliance and Assurance | Research and Innovation Services | UCL – London's Global University
ethics@ucl.ac.uk
I work part-time Wednesday–Friday

Research Ethics Service | Research and Innovation Services ethics@ucl.ac.uk

Give us your feedback
As we work to improve our service, please help us by completing this short service feedback form (feedback can be anonymous).

Book a drop-in session
We hold weekly drop-in sessions on Thursdays from 2-3pm during term time. Click here for information and to book.

Appendix L

Parent Information and Consent Sheet

Information Sheet

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

Title of Study: Investigating the Effects of a Personalised Parent-Led Sleep Hygiene Intervention on Autistic Children's Sleep Quality and Mental Health

Department: Division of Psychology and Language Sciences

Name and Contact Details of the Researcher(s): Emily Thompson (xxx)

Name and Contact Details of the Principal Researcher: Dr Jennifer Wills

Name and Contact Details of the UCL Data Protection Officer: Alexandra Potts, data-protection@ucl.ac.uk

This study has been approved by the UCL Research Ethics Committee: Project ID number: 25973/001

1. Invitation

My name is Emily Thompson. I am a second year Trainee Educational Psychologist studying at University College London and on placement in xxx Educational Psychology Service. You are being invited to take part in this research project. This research project is for my UCL doctoral programme and is separate from my role as a Trainee Educational Psychologist in Lewisham. Before you decide, it is important for you to understand why the research is being done and what participation will involve for yourself and your child. Please read this information carefully before you make up your mind about taking part and letting your child take part and contact us if you have any questions or concerns. If you are happy that you understand what taking part will involve for yourself and your child and you are happy for both to participate, then we will ask you to sign the consent form and will give you a copy of this information sheet to keep.

2. What is the project about?

Sleep is crucial for children's mental health and daytime functioning. Sleep problems are particularly prevalent among autistic children. However, there are limited interventions supporting autistic children and adolescents' sleep. Few studies have captured autistic children's and their parent's views on sleep facilitating factors. Therefore, this study aims to investigate the effects of a personalised parent-led sleep hygiene intervention on autistic children's sleep quality and mental health.

3. Why have my child and I been chosen?

This study is inviting autistic children in Year 4, 5 and 6 who are experiencing sleep difficulties and their parents to participate. Your participation is important because the programme is a parent-led sleep intervention, where you will support your child to carry out a personalized sleep routine. This study requires six to eight child and parent participants to take part.

4. Do my child and I have to take part?

It is up to you to decide whether or not you and your child 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. Your child will also be given an information sheet and consent form to sign. You and your child can withdraw your data at any time, up until 2 weeks after the intervention has finished, without giving a reason and without negative consequences for doing so.

If you and your child decide to take part in the follow up interview but then change your mind and want to withdraw your data, that is fine. You will be asked what you wish to happen to your and your child's data up until that point..

5. What will taking part involve?

As part of this project, you will first be sent two online questionnaires to assess your child's sleep quality and mental health. Following this, you and your child will be asked to attend a one hour training session at school, where I will provide information about sleep and autism, and guidance on how to use the personalised materials. At the end of the session, the sleep intervention materials can be completed together with my support. These materials include considering what helps your child relax, senses they like and dislike and completing a personalised sleep routine based on this information. Your child, with your support, should follow this sleep routine for 4 weeks and fill in a sleep tracker each morning. I will be available via email if you have any questions and will check in with you on the phone 1 week into the intervention. If you have any problems or questions throughout the 4 weeks, please contact me via email or phone. Following these 4-weeks, your child can continue to follow the personalised sleep routine if they want

to. You will be asked to fill in the two online questionnaires again after 4-weeks and at follow up 3-months later.

To gain a greater understanding of your experience using the materials, there will be a second phase where you can choose whether you and your child want to participate in a brief semi-structured phone interview. If you would like to participate, you can tick the relevant box for this on the consent form. The interview will be 15 minutes and will be recorded with your consent. It will involve asking you and your child questions about how your child found the personalised sleep routine, any problems they or you encountered and things your child found helped them sleep well.

6. Will I be recorded and how will the recorded media be used?

If you and your child choose to take part in the interview, I will need to record your and your child's interview (audio recording) and I will ask for your permission to do this. I (the researcher) will transcribe your interview recording. The interview will be transcribed and analysed alongside other parent/child interviews. The recording will be deleted after it has been transcribed and checked. It will not be shared with anyone outside of the project team. Names will be changed to fake names and no identifiable data will be included in the write up. The data will be used for analysis and for illustration in conference presentations and lectures. No other use will be made of it without your written permission.

7. What are the possible disadvantages and risks of taking part?

To minimise disruption to your child's school day, the training session will occur at the end of the day, after pick up. I do not foresee any significant risks from taking part. However, if the sleep routine causes you and your child any distress, you will have the option to contact me or seek support through organisations provided who support with sleep or mental health difficulties.

8. What are the possible benefits of taking part?

Your and your child's contribution to this study will help Educational Psychologists and other professionals understand sleep facilitating factors for autistic children which could help improve support and interventions. The personalised sleep routine might help improve your child's sleep and mental health, however this cannot be guaranteed and this is what the research is aiming to investigate. It will also help to capture and promote the views of autistic children and their parents.

9. What if I am unhappy about something that happens?

If you are unhappy about something that happens, then please contact me in the first instance. You can also contact Jennifer Wills (xxx) if you have a more significant complaint or feel your complaint has not been handled. If you still feel your complaint has not been handled to your satisfaction, you can contact the Chair of the UCL Research Ethics Committee (ethics@ucl.ac.uk).

10. Will taking part in this project be kept confidential?

I will be storing or processing your and your child's data against a pseudonym (fake name) so no one will know who will be taking part. You will be asked for your phone number to contact you during the intervention, your child's age, gender and confirmation of their autism diagnosis. Your and your child's views from the interviews will be collected but your identity will be kept confidential throughout, using fake names and removing identifying details. All of this data will be stored securely on a UCL system and no one outside of the project will have access to this data. Confidential information will be deleted following the analysis.

11. Limits to confidentiality

Please note that confidentiality will be maintained as much as possible, unless during the conversations with you and your child, I hear something that makes me worried that someone might be in danger of harm. I may have to inform relevant agencies of this in order to support you and your child. I will, where possible, speak to you first before doing this.

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

The results of this research will be presented within a doctoral thesis in June 2025 and might be published. You or your child will not be identifiable in any reports or publication. If you want a copy of the results, please email me and I will provide you with a copy.

13. Local Data Protection Privacy Notice

In addition to the information above, we also need to let you know some specific information relating to our processing of your data for this project. Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

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: UCL General Research Participant Privacy Notice | Legal Services - UCL – University College London

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 categories of personal data used will be as follows:

-Child's name

-Child's gender

-Confirmation of child's autism diagnosis from parent

-Child's age

-Parent's phone number

The lawful basis that would be used to process your personal data is: 'Public task' for personal data.

The lawful basis used to process special category personal data will be for scientific and historical research or statistical purposes.

Your child's personal data will be assigned a pseudonym (fake name) and the data will be held only as long as it is needed for the project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

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. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

Further information

If you have any questions about this project please contact me via email (xxx). This information sheet is for you to keep.

If you are happy to participate, please now read and complete the signed consent form. We will ask for a copy and will also ensure you have a copy to keep.

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

CONSENT FORM

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

Title of Study: Investigating the Effects of a Personalised Parent-Led Sleep Hygiene Intervention on Autistic Children's Sleep Quality and Mental Health

Department: Division of Psychology and Language Sciences

Name and Contact Details of the Researcher(s): Emily Thompson (xxx)

Name and Contact Details of the Principal Researcher: Dr Jennifer Wills (xxx)

Name and Contact Details of the UCL Data Protection Officer: Alexandra Potts, data-protection@ucl.ac.uk

This study has been approved by the UCL Research Ethics Committee: Project ID number: 25973/001

Please circle your answer to the following questions below:

	Yes	**No**
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.		

I am willing for myself and my child to take part in the intervention.	**Yes**	**No**
I am willing to take part in the brief individual interview to share my views on the personalised sleep hygiene intervention. I confirm that I am happy for my interview to be audio recorded and transcribed. I understand that once the data has been transcribed, the audio recording will be deleted	**Yes**	**No**
I am willing for my child to take part in the brief individual interview to share their views on the personalised sleep hygiene intervention. I confirm that I am happy for my child's interview to be audio recorded and transcribed. I understand that once the data has been transcribed, the audio recording will be deleted.	**Yes**	**No**
I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified. However, if during conversations the project team hear anything which makes them worried that someone might be in danger of harm, I understand that they may need to inform relevant agencies of this.	**Yes**	**No**
I understand that my participation is voluntary and that I am free to withdraw my data without giving a reason, as long as this is before 2 weeks after the intervention has finished.	**Yes**	**No**
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.	**Yes**	**No**
I consent to the processing of my personal information (my name and phone number) and my child's personal information (their name, age gender and autism diagnosis) for the purposes explained to me. I understand that such information will be	**Yes**	**No**

handled in accordance with all applicable data protection legislation.		
I understand that the data will not be made available to any commercial organisations, but is solely the responsibility of the researchers undertaking this project.	**Yes**	**No**
I understand that the information I have submitted will be published within a report, and that I will not be identifiable in any report.	**Yes**	**No**
I confirm that I understand why myself and my child have been invited to participate, as detailed in the Information Sheet.	**Yes**	**No**
I am aware of who I should contact if I have any concerns or wish to lodge a complaint	**Yes**	**No**
I voluntarily agree to take part in this study.	**Yes**	**No**

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Name of researcher	Date	Signature

Appendix M

Child Information Sheet and Consent Form

Things you Need to Know

Title of Project: Investigating the Effects of a Personalised Parent-Led Sleep Hygiene Intervention on Autistic Children's Sleep Quality and Mental Health

Who am I?

My name is Emily Thompson and I am a Trainee Educational Psychologist. I help children and young people with their learning and wellbeing.

What is this investigation?

Lots of children are not getting enough sleep for lots of different reasons. Research shows that sleep can affect how you feel. I want to learn more about how to help autistic children sleep better and if this helps to make you feel better.

Who is being asked to take part in this investigation?

This study will include six to ten autistic children in year 5 and 6 from different schools and their parents. Your parent will take part in this investigation with you.

What will I be asked to do?

You will be asked to come to a talk with your parent and a few other children and their parents to learn about how to improve your sleep routine. You will fill in some information about what you like, what helps you relax and you will create a personal sleep routine that works for you, together with your parent. You will be asked to follow this sleep routine for 4-weeks and keep a sleep diary, filling it in each day, to say how well you slept each night.

You will also have the option to share your views on how you found the personalised sleep routine, things that helped you to sleep and any problems you faced with the routine. The questions you will be asked are not a test and you do not have to answer them.

Are there any benefits of taking part?

It might show you what helps you sleep. Through sleeping better, you might feel better.

This investigation will help others to understand how to support children like you to sleep better and feel better. This could help other children in the future.

Are there any risks of taking part?

I do not think anything bad will happen if you take part but if you feel upset at any point and do not want to continue, it is okay for you to stop.

What will the information be used for?

The information collected will be confidential. Confidential means it is kept between you, your parent, and me. I will make sure your information is kept private by using numbers or letters and not names. However, if there is any information that makes us worried about your safety, we might need to tell another adult.

Do I have to take part?

It is your decision whether you take part or not. If you do take part, you and your parent will be asked to sign a consent form. If you change your mind about taking part and want to stop, that is fine.

Do you want to know anything else?

If you have any questions, please ask your parent or myself. You can contact the research team on the following emails:

Researcher: xxx

Supervisor: xxx

Consent Form

Please circle your answers to questions below:

Have you read the information sheet for children?	Yes	No
Do you understand what the project is about?	Yes	No
Have you had the opportunity to ask any questions and had them answered?	Yes	No
I understand that I am able to stop taking part without giving a reason and that is OK	Yes	No
I understand that any information I give will only be used for this project and not anything else	Yes	No
I understand that all information I give will be kept confidential	Yes	No
Are you happy to take part in the intervention?	Yes	No
Are you happy to take part in the interview?	Yes	No

_____ _____ _____

Name of child Date Signature

_____ _____ _____

Name of researcher Date Signature

Appendix N

Parent-Child Sleep Training

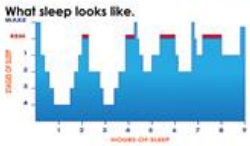
How much sleep?

Age	Hours
Infants 4-12 months	12-16 (including naps)
Children 1-2 years	11-14 hours (including naps)
Children 3-5 years	10-13 hours
Children 6-12 years	9-12 hours
Children 13-18 years	8-10 hours
Adult 18+	7 hours or more

What is sleep?

- An important state of rest
- A time of various physical and mental processes, needed for health and wellbeing

Hypnograph



Benefits of Sleep

- Wellbeing
- Learning e.g. attention, memory
- Appetite
- Physical health benefits e.g. growth, muscles

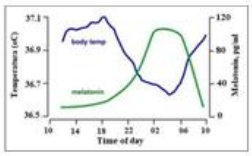
What do we need to sleep?

- Sleep pressure
- Body clock
- Environmental Factors

Sleep Problems

- Not wanting to go to bed
- Difficulty falling asleep
- Difficulties with waking up
- Waking up in the night
- Nightmares
- Sleep anxiety
- Daytime sleepiness

Circadian Rhythm



Personal Sleep Routine

- Sleep should be treated individually, considering environmental and personal factors that affect each individual

Sleep Hygiene

Before bed:

- Personal sleep routine
- Relaxing before bed e.g. listen to music, self-care exercise, familiar videos
- Spending time with family e.g. rule based game, familiar bedtime conversations

P

Sleep Hygiene

During the day:

- Physical activity
- Things that make you feel good e.g. attend a club, talk through school work, talk about good things that have happened

Sleep Hygiene

- Get out into natural light for at least 30 minutes as early as possible
- Consistent routine
- Avoid too many caffeine-based drinks
- Find ways of managing stress and anxiety
- Finish homework at least one hour before bed
- Having a good meal not too close to bed
- Have a bath

Creating a Personalised Sleep Routine

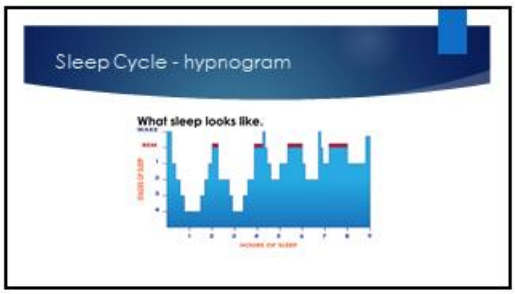
Sleep Hygiene

- Do any stimulating activities earlier in the evening e.g. playing computer games, exercise
- Read or listen to relaxing music e.g. audiobooks
- Relaxation exercises
- Make the bedroom comfortable e.g. block out light, reduce noise, reduce smells coming into the room, remove distractions

Creating a Personalised Sleep Routine

Appendix O

Parent Sleep Training



Benefits of Sleep

- Regulation of mood
- Cognitive functions e.g. memory, attention, impulse control
- Parental wellbeing
- Parent-child relationship
- Appetite

Sleep Problems

- Difficulty falling asleep
- Difficulties waking up
- Night awakenings
- Night Terrors
- Nightmares
- Bedtime resistance
- Sleep anxiety
- Daytime sleepiness

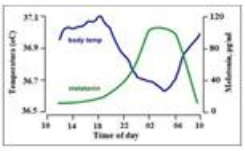
Sleep and Autism

- 50-80% of autistic children experience sleep problems
- Particular difficulties with sleep onset and maintenance
- Neurobiological, medical, behavioural and environmental influences
- Individual differences

What do we need to sleep?

- Sleep pressure
- Circadian rhythm/body clock
- Environmental Factors

Circadian Rhythm



Teenage Sleep

- Adolescents typically need 8 to 10 hours of sleep per night
- Changes in their circadian rhythm
- Stress and schoolwork
- Sleep hygiene
- Social reasons e.g. independence, friends
- Technology (what doing on the device)

Personal Sleep Routine

- Research suggests that sleep should be treated individually, considering environmental and personal factors that affect each autistic individual

Personal Sleep Routine

Appendix P

Intervention Materials

The intervention was created individually with each participant, using the sleep materials below, supported by the researcher's psychological consultation skills. The researcher asked the participant questions, including questions outlined in the materials and other Socratic questions, open ended and closed questions to help the development of the routine, such as 'what helps you to relax', 'what do you enjoy doing with your family?' and 'when would be the best time to fit this activity into your evening?'

NELFT NHS
NHS Foundation Trust

A GOOD NIGHT'S SLEEP

What helps you to feel relaxed and ready to sleep?

What do you do to relax before bed?	How do you like to spend time with others in the evening?
1.	1.
2.	2.
3.	3.

NELFT NHS
NHS Foundation Trust

My Personalised Sleep Routine

Time (__:__)	What I will do (You can draw, write or stick)

NELFT NHS
NHS Foundation Trust

A GOOD NIGHT'S SLEEP

When we have trouble sleeping it can be useful to think about what helps us feel relaxed and ready to fall asleep.

How we spend time during the day can affect how well we sleep at night.

Stick or draw pictures of things you like in this box

What are your interests?

Spending time doing things that interest you can help you get a good night's sleep.

1.

2.

3.

How do you stay active?

Physical activity in the day can help us sleep at night. We all like to stay active in different ways.

1.

2.

3.

Things that make you feel good

Doing things we enjoy can help us to sleep.

1.

2.

3.

A chance to choose

There are lots of things we have to do, so it is important to plan how we do them. It helps to save some time for the things we want to do too!

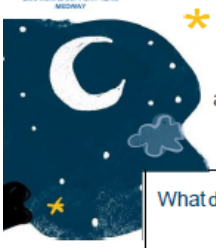
Who can help you plan and solve problems?

When can you have some free time?

Who can you discuss your day with?

NELFT NHS
NHS Foundation Trust

Being kind to your senses



Our senses are important. They tell us about the world around us. Being kind to our senses can help us feel happy and calm so we can get a good night's sleep.

What do you like looking at? What don't you like looking at?	What smells do you like? What smells don't you like?

What do you like to touch/feel? What don't you like to touch/feel?	What tastes do you like? What tastes don't you like?

What do you like to listen to? What don't you like to listen to?	There are three extra senses that people often forget – movement, balance and internal. We sense how we are moving and balancing. We also sense where our body is and what it is doing without looking. The activities below use our extra senses.

Circle any that you enjoy. Cross out any that you don't Like.

a big squeeze/hug sit under a heavy blanket massage yoga
move something heavy (e.g. weights) scooter/skate
hang upside-down swinging jump pull a stretchy band
balance holding something cold/hot rocking in a chair
bounce (e.g. on a yoga ball) having something to eat/drink

Are there any other sensory activities you enjoy?

Appendix Q

Relationship between sleep and mental health final themes, subthemes, codes and illustrative quotes

Theme	Subtheme	Code	Illustrative quotes
Impact on wellbeing	Improved emotional regulation	• Feeling calm • Less meltdowns • Less irritated • Tiredness affects thoughts, feelings and behaviours	**Gabz's mum:** *"if he's not got enough hours, you can see he's a bit short, you know, a bit more irritated if he doesn't get the full 9 hours or whatever."* **Peter's mum:** *"I would in like a four-week period expected there to have been a couple of meltdowns, but we've not, it's been really good and I think not having meltdowns is good for everybody"* **Harry's mum:** *"he wakes up refreshed and yeah, happy and in a good mood. I think it's just not feeling tired during the day. So it's actually, yeah, it keeps him more uplifted and upbeat. I think not being tired is really important. I guess it's energy is important for mood. So if you have enough energy you'll be, your mood will be better during the day, and then your thinking will be more positive as well. So because if you feel fatigued or tired during the day it, you know it can affect your thoughts and your behaviours and everything."*
	Improved mood	• In a good mood • Feeling calm • Feeling happy	**Harry's mum:** *"So I do think having adequate sleep is helpful for mental health and emotional health as well as behaviors."* **Peter:** *"Yeah, I started to feel a bit more happier and more calm than before."* **Gabz:** *"My feelings felt happy or like normal for stuff. Yeh just normal."*

Theme	Subtheme	Code	Illustrative quotes
			Participant 2's mum: *"I've never had a problem with her waking up in the morning and being moody"*
Impact on resilience	Coping mechanisms	• Manage transitions better • Manage setbacks better • Feel stronger to manage challenges	**Peter's mum:** *"It's a bit like if you've got a, I suppose if you've got a big jar full of beads and those beads of resilience. If you're tired to begin with, you've already taken the first layer out, and then if you don't quite get decent sleep the next night, you're running a deficit all the time."* **Peter's mum:** *"I think I think it's had a very positive impact. And I think for me, I mean, we could have done this at any time, but in theory we could have done this at any point point in the year, but we've been doing to the point in which he's had some big, big, big transitional things for him, which have been difficult for him in previous years."* **Peter's mum:** *"I think from a sensory perspective if you're tired, you're not already starting thinking I've got a headache. Or uhhh it's too loud, it's too bright, and so you're not starting from that disadvantage because you've had a better night's sleep. And yeah, the lights might be too bright, and but they won't, you're in a better place to deal with them because you're not you know, you're not, you're not as tired so it doesn't. It's not further tiring you out."* **Gabz's mum:** *"He's more cooperative, I think. When he's had a good night's sleep."*

Theme	Subtheme	Code	Illustrative quotes
	Increased energy	• Sleep increases focus • More energy to do things • Sleep increases alertness	**Gabz:** *"I felt well, I felt wide awake. Like wide awake, more alert*." **Gabz's mum:** *"much more sort of like alert in the morning and more most probably focused as well."* **Participant 2:** *In the morning, I felt like I was really energetic and I can do lots of stuff and activities.*
	Environmental demands	• Manage the sensory environment better • Manage social interactions better	**Peter's mum:** *"I think it also helps with the I think the sensory load of being at school and dealing with dealing with people because it is it is, it's tiring in itself"* **Peter's mum:** *"I think from a sensory perspective if you're tired, you're not already starting thinking I've got a headache. Or uhhh it's too loud, it's too bright, and so you're not starting from that disadvantage because you've had a better night's sleep. And yeah, the lights might be too bright, and but they won't, you're in a better place to deal with them because you're not you know, you're not, you're not as tired so it doesn't. It's not further tiring you out."* **Peter's mum**: "*it's putting you at a disadvantage when you're trying to deal with all the interactions in your life because you're already tired you're already grumpy. You read things in different ways. You might react more strongly than you might have done"*

Theme	Subtheme	Code	Illustrative quotes
			Gabz's mum: *"if he's not got enough hours, you can see he's a bit short, you know, a bit more irritated if he doesn't get the full 9 hours or whatever."*

Appendix R

Children's views on the sleep routine final themes, subthemes, codes and illustrative quote

Themes	Subthemes	Codes	Illustrative quotes
Easy to use		• Able to do it • Understand the routine • Accessible resources • Depends on time and resources available	**Participant 2:** *"Very easy…that I can like do it and feel relaxed and do it properly"* **Peter:** *"Well found it fairly easy…. it was easy to do some parts like. It was easy to have bath. because you know just how it was easy to have one."* **Gabz:** *"So I know at six I have trumpet, then at seven I have dinner. And at 8 I have like a bath. And I think at 9:00 I go to sleep."* **Peter:** *"But sometimes it was hard to have a hot chocolate because sometimes you didn't have time or sometimes I forgot."*
Improved sleep quality		• Slept longer • Sleep improved • Increased knowledge	**Peter:** *"Ohh it's I've started to get better sleep. And so basically my sleep is gone, has started to get better and better."*

Themes	Subthemes	Codes	Illustrative quotes
		• Helped to feel sleepy before bed • Slept well • Felt relaxed before bed	**Participant 2:** *"I could tell other children what to do to get yours to sleep more and to sleep better"* **Gabz:** *"And then and then for my sleep routine, I got it like most of them were. Like I mostly sleep, I mostly sleeped, but I did wake up a bit. But I end up just sleeping. And then and then and then there were three fives and there were some threes or there were 4 fours."* **Participant 2:** *"Relax. It made me feel sleepy, so I can go to sleep better"*
Importance of comfort and calmness	Feeling relaxed	• Feeling calm before bed • Feeling relaxed • Feeling sleepy	**Peter:** *"I found a having like think for example having baths before bed quite helpful…it made me feel quite relaxed"* **Peter:** *"Yeah, I felt. Calm watching on the TV"* **Peter:** *"I liked being able to have it, but because it. It's was. I liked having it and it was a nice to, er, calm down and have a bit of a drink before getting ready to go to bed."* **Peter:** *""Ohh it's made me feel more calm before going to bed and that's definitely helped."*

Themes	Subthemes	Codes	Illustrative quotes
			Participant 2: *"Very good…That I could relax…That I can sleep longer. And I can erm I can not feel like stressed out or anything…I liked everything"*
	Feeling comfortable	• Importance of comforting activities • Feeling fresh • Baths and showers help to feel relaxed • Sleep position affects sleep • Sleep location affects sleep	**Peter:** *"it made me feel more calm and make it easier for me to get to sleep without any with less issues or anything."* **Gabz:** *"Oh so so the bath it helps me because like when you like, when you like, dry yourself, you feel fresh and stuff. It feels nice."* **Gabz:** *"I slept in mum's bed so for mum's bed, sometimes I can't sleep in it but sometimes I can sleep in it, it's a mix."* **Gabz:** *"The bunk bed is quite big and then I can finally find a position I can sleep in. It's just the small bed I can't"* **Gabz:** *"Because there's another person in there"*

Themes	Subthemes	Codes	Illustrative quotes
Enjoyment of the personal routine		• Having fun is important • Need to like the activities • Reduces stress • Enjoyed reading • Enjoyed having a hot drink • Important to find activities you enjoy	**Peter:** *"I found it nice because I like being able to go outside for a bit and to have fun."* **Gabz:** *"I did like the sleep routine"* **Participant 2:** *"Very good…That I could relax…That I can sleep longer. And I can erm I can not feel like stressed out or anything…I liked everything"* **Participant 2:** *"I would tell them to go to bed early, read their book or like, do something that they enjoy and stuff like that and they have to get everything done so in the morning they're ready and they don't have to be like stressed out."* **Participant 2:** *"when mummy massage my body, taking a warm shower. Reading my book."* **Peter:** *"Ohh I liked having a hot chocolate before going to bed as well."* **Participant 2:** *"I would tell them to go to bed early, read their book or like, do something that they enjoy and stuff like that and they have to get everything done so in the morning they're ready and they don't have to be like stressed out."*

Appendix S

Parent views on sleep routine final themes, subthemes, codes and illustrative quotes

Theme	Sub Theme	Code	Illustrative quotes
Child-led	*Autonomy*	• Personally created by child • More child autonomy with the routine • Child taking ownership of routine • Motivated to engage with routine • Increasing autonomy and independence with age • Child making key decisions • Taking ownership of routine • Child needs to start learning how to follow a sleep routine • Child needs to start choosing what they want to do	**Peter's mum**: *"Well but also I suppose because it's what Peter came up with. It's what he wanted that it is quite different also to when they are babies and toddlers it's parent led. It's like, right you're having you're having your bottle, you're having your bath, changing your nappy, you're going to bed. This is what he finds relaxing. So that I think has been the key difference in this. It's not me deciding right let's do this because I've read something in a book or on the Internet. It's what he's said."* **Peter's mum:** *"Like I need my hot chocolate now run, you know. Yeah. And you know, just knowing or and having some control over what should happen. Like I want to watch. So it's time for my relaxing TV now. So those kind of those kind of things."* **Participant 2's mum:** *"She is the one that even have to remind me, 'Mom, this is what we're gonna do, Mom, this is what? We're gonna do. Mom.' So she has to like, tell me everything I said. She's quite good. Yeah, yeah."* ***Harry's mum:*** *"Yeah, I think he wants to do that himself. So it is very important that I think if they have the motivation to want to have a better sleep and nicer sleep then it's easier as well."*

	Collaborative decision making	• Co-produced routine • Importance of meeting in the middle • Gaining child's views are important • Empowering child to make decisions • Child needs to be invested in the routine • Compromising on decisions	**Gabz's mum:** *"It's good because it comes from them. When it was created, it actually came from them. So it's not something you're you're saying, OK you're going to follow this, this and this. It actually came from them personally. So I think they're more likely to want to follow it because they were a part of creating it."* **Peter's mum:** *"I think what's been really useful is making it child led, because funnily enough, that's there's not a huge amount of that on sleep stuff. It's all very it's all very parents need to do this."* **Peter's mum:** *"the parent as well as the adult you are meant to be overseeing these things, but it implies that it is very much. Right, you need to put limits on things you need to do that, but that's very top down. Actually you need to kind of meet in the middle and have a, you know, but what do you what do you need? What would you like? What? You know what can I then do as a parent to help you do that? And so, yeah, I'd say that's the big. Yeah. Shifting my focus, I think, but what does my, you know, what does Peter think about this and how you know, finding a compromise on it? "*
Adaptable and accessible	*Flexibility and functionality*	• Routine is adaptable to environmental factors • Easy to make changes to the routine • Need to be flexible with timings • Interests change	**Harry's mum:** "*The only problem I would say is just that we're not able to keep the timing to keep things to the exact time, or sometimes maybe we'll have to miss out on one or two things. Just skip to the next one. But we never skipped the music and the reading, so that one we definitely will do every single evening and almost, yeah, even if even if it goes to bed a bit later than normal, he would still do that because that really,*

	• Difficult to follow exact timings • Prioritising activities • Change in what they need when they get older • Functional purpose of the activity • Choosing feasible and simple activities	*really does help. So it's only, yeah the only problem, I'll say just that keeping the timing, you know to the exact as the routine that's something that we haven't been able to do for the last two weeks."* **Gabz's mum:** *"Sometimes to keep to the exact times is a bit difficult sometimes. I think the whole thing about it is just to follow the steps. Sometimes they don't have to, tothe minute and you know to that hour. But as long as you kind of follow the steps and that consistency of trying to keep it going following the steps would only benefit him."* **Peter's mum**: *"It's something that Peter thinks is helpful and we can roll with it if we're camping or even if it's like when it's been horrible, well not saying that it's been horribly 37 degrees or anything like that, but we've had hot, humid nights and you know that's always going to mess things up, but you still have the, the routines not thrown out by it. You can adapt it so."* **Peter's mum:** *"But you know, thinking about what could be it right, you know. But yeah, but something like that could be yeah there are ways to think about what if you know if we, kick about ends because you've kicked the ball but what could you do that's similar and it could be like trampet or even swing ball something like. Something like that. So there are solutions to all of these things."* **Peter's mum:** *"So what does what does getting home need to look like in terms of going to bed so that you're ready for school in the morning and not tired by what you've done? So yeah, it's that. Yeah, remembering that it's not it, you can't just go, right.*

		It's 830 you're going to bed. It's it's got to have. You've got to think about how you get, get from earlier in the day to that point, which is." **Peter's mum:** *"it's thinking what might we do. I think it's something about that early late afternoon, early evening activity and that might be a bit harder in the winter, but there's ways around that and I think particularly because xxx (child) has had, is becoming more independent in different ways that there could be other ways in which you could get that"*
Easy to use	• Easy to use and follow • Simple to implement • Easy to adapt along the way • Low cost routine • Accessible resources	**Participant 2's mum:** *"Oh to be honest it's very easy. As I said before, it kind of make xxx organize more. There's no problem"* **Peter's mum:** *"It was very easy. The only the only complexity in it was that on the day we started it, I didn't have his favoured hot chocolate in, so I had to go to Morrisons to buy, to buy some so that we're ready for on the day that we we worked out the routine so, but that's that's the greatest difficulty in it because everything else was erm stuff that we already had or just required us to remember to talk about 3 positives in our day and it's become it's been easy to make that a habit. I think it's benefited us all, but yeah, there's, there's nothing complicated about it. "* **Peter's mum:** *"But I think from and then in context because it's been the summer we'd, there had been other late afternoon activities of some kind. But I think for me it's thinking what might we do. I think it's something about that early late afternoon,*

		early evening activity and that might be a bit harder in the winter, but there's ways around that and I think particularly because xxx (child) has had, is becoming more independent in different ways that there could be other ways in which you could get that which I see I noted on his sleep study that on the last day of term he walked home by himself all the way from school" **Peter's mum:** *"it's just been really easy to follow"* **Peter's mum:** *"because everything else was erm stuff that we already had or just required us to remember to talk about 3 positives in our day and it's become it's been easy to make that a habit."* **Harry's mum:** *"It was quite easy because I think because after school he's got quite a busy schedule, so we just move on from one to the other."*
Clarity of routine	• Clarity of routine • Visual reminders • Clear transition to bed • Importance of structure • Clear transitions and preparation • Adhering to the routine	**Participant 2's mum:** *"So it kind of keep her updating on the routine everyday, what we're doing every day. Kind of reminder."* **Peter's mum:** *"And I found that it's also, given us a bit of a countdown to things or making it visible about visible that there are things that we do before dinner. We have things we do during dinner other than eat. Go for us. Going through the three positives and then hot chocolate, the relaxing TV, the the bath and bed."*

			Gabz's mum: *"Trying to follow the routine was good as a visual prompt"*
Improved sleep outcomes	*Improved pre-bed calm state*	• Creating a calm bedroom environment • Reducing excitement • Feeling calm before bed helps sleep • Need to unwind before bed • Consideration of timing of relaxing activities • Comforting activities help to relax • Switching off before bedtime • Baths and showers help relax • Choosing calming activities	**Harry's mum:** *"Listening to classical music, which he likes. He enjoys and it helps to calm him down. And you know, just to bring his mind to a more peaceful, you know, just bring it to a peaceful level before bed. And then reading the books that he enjoys reading before bed. So it just feels more just making the bedtime or the bedroom feel more calm, more calm and more, you know like room where you feel that you can have your space and then you can just get ready to go to sleep once you finish your reading and music listening"* **Harry's mum:** *"So it just feels more just making the bedtime or the bedroom feel more calm, more calm and more, you know like room where you feel that you can have your space and then you can just get ready to go to sleep once you finish your reading and music listening"* **Participant 2's mum:** "*I think the thing that makes her to sleep more better is like when I give her a shower in the night sometime bath. It kind of make her relax and the body massage it makes her relax more."*

	Improved sleep quality	• More consistent night sleep • Sleeping better during stressful periods • Falling asleep more quickly • Settling to sleep quicker • Sleeping longer • Better night's sleep • Importance of getting enough hours • Highlighted issues with sleep	**Gabz's mum:** *"I think it was positive. Most of the last four, four to five weeks he's had quite good sleep, even during Sats week he was fine. You know, his sleep wasn't really affected. He actually was fine. He seemed he was tired by the end of the week. But he was fine. Like, he sleep wasn't affected during days that he had exams on."* **Gabz's mum:** *"It's highlighted where he has his issues, like he's seen it in his own mind. Where you know what bed he's sleeping in. You know which position he's sleeping in? That seems to be more crucial for him, I think"* **Participant 2's mum:** "*It's getting better with her, to be honest."* **Harry's mum:** *"I think it helps him settle in quicker and fall asleep quicker."* **Peter's mum:** *"It has, his sleep has improved. I, he's getting more sleep. It's more consistent, and even when he's had nights when it's been harder to settle, and whether that's the weather or it it's been you know, things like it's the last day of, you know, you're nervous about performance, that you're doing, or it's all those, you know, the big, big things you're doing. It's, it might have taken him longer to settle, but he was able to do so, he'd got, it was a lot smoother."* **Peter's mum:** *"but he's I'd say, yeah, his sleep has been better and there's been more of it."* **Harry's mum:** *"helps with quality sleep, staying asleep and more peaceful and calming sleep.*

		Gabz's mum: *"it's highlighted where he has his issues, like he's seen it in his own mind. Where you know what bed he's sleeping in. You know which position he's sleeping in? That seems to be more crucial for him, I think."* **Gabz's mum:** *"That's been an eye opener for me actually as well because I never used to understand why he couldn't really sleep but."*
Improved sleep education	• Importance of the child understanding the routine • Understanding the benefits of sleep • Sleep hygiene is important	**Participant 2's mum:** *"She knows what we're gonna do. Since we came to that meeting, she knows every evening."* **Peter's mum:** *"I think what I did like was starting with why sleep matters and the science of it because it helps because xxx is very he's a very science minded child but it helped both of us think well actually, Oh yeah and to see why it's important"* **Harry's mum:** *"it's just important to understand how important you know, good sleep is for health, good health, physical health and mental health and also about how to do it. Creating the thing and the sleep hygiene, I think just information and knowledge are important before we start jumping into doing things. So it's really good that you gave us the, you know, the PowerPoint slide when we were, when we saw in person and you show us all the information. So we learned exactly why, you know, sleep is important. And yeah, and then we just, yeah, created a routine and then we follow through, you know."*

Personal nature of the routine	*Personal interests and motivation*	Finding activities the child enjoys Enjoys the routine activities Increased engagement with activities Understand the benefits Enjoys the relaxing activities Found it helpful Like having a routine Every child is different Finding what works for each child Benefits from a personal routine Each child has different likes and dislikes More likely to want to follow as child creates the routine Motivated to follow	**Harry's mum:** *"You know, listen to calming music and reading books that's nice and fun, you enjoy doing before bed. Definitely. Those two things for him are the most beneficial and helpful."* **Harry's mum:** *"I think listening to classical music that he really, really enjoys and he loves it and reading."* **Participant 2's:** *"this type of sleep routine so that they are able to talk to the children and ask them what will make you relax, what will make you relax before going to bed. Some children like reading in the night. Maybe some children, like a bit of game with their parents. Or some children like the parents to tell them story time."* **Harry's mum:** *"I think it's it's really, really helpful and it's really useful to have a personalized routine to be in place for the individual who you know who can benefit from, you know what, what can help them individually"* **Harry's mum:** *"If it helps them feel calm it depends, I mean maybe not everyone likes music, so that's I think that's personalized, but I think music is helpful, music's nice and yeah, it's good for mental health as well."* **Harry's mum:** *"Reading as well, but then again, not everyone likes to read so it depends, I think that's another, just more personalized, it depends on children, I guess."* **Gabz's mum:** *"It's good because it comes from them. When it was created, it actually came from them. So it's not something you're you're saying, OK you're going to follow this, this and*

		this. It actually came from them personally. So I think they're more likely to want to follow it because they were a part of creating it." **Harry's mum:** *"Yeah, I think he wants to do that himself. So it is very important that I think if they have the motivation to want to have a better sleep and nicer sleep then it's easier as well."* ***Peter's mum:*** *"Well but also I suppose because it's what Peter came up with. It's what he wanted that it is quite different also to when they are babies and toddlers it's parent led. It's like, right you're having you're having your bottle, you're having your bath, changing your nappy, you're going to bed. This is what he finds relaxing. So that I think has been the key difference in this. It's not me deciding right let's do this because I've read something in a book or on the Internet. It's what he's said."*
Universal relevance of personal routine	Could be useful for all children Relevant to all children and adults	**Participant 2's mum:** "*So in term of sleeping I just feel that it's not just a child with learning disability. I just feel that every child deserves to be, for them to know what makes them relax"* **Harry's mum:** *"I think creating a calming environment before bed is definitely really, really helpful. I think that's for everyone, for adults as well. Yeah. So I think all those three things I was*

		talking about I think they're helpful for xx. I think those could be helpful for other children as well"
Environmental influences	• Sleeping outside of home affects sleep • Room temperature can affect sleep • Illness can affect sleep • Sharing room with siblings affects sleep • Family routine affect sleep	**Participant 2's mum:** *"It's just that at the moment, like I told you, xxx has been having this serious cough that we don't even understand what's going on. This cough only happen when she's going to bed in the night"* **Harry's mum:** *"Also, I think the room temperature. That's another thing that I find that actually does affect people's sleep is their room temperature. If it's too hot, it would definitely affect people's falling asleep and staying asleep. So I think a slightly cooler temperature in the room. It's actually helpful for one to ease into sleep and staying asleep, so not having too hot temperature."* **Peter's mum:** *"It's something that Peter thinks is helpful and we can roll with it if we're camping or even if it's like when it's been horrible, well not saying that it's been horribly 37 degrees or anything like that, but we've had hot, humid nights and you know that's always going to mess things up, but you still have the, the routines not thrown out by it. You can adapt it so."* **Gabz's mum:** *"Yeah, you get that a lot with siblings sometimes it's not an issue, but I think the older they get, it becomes more of an issue. When they're younger it's easier because they all tend to just go to bed at the same time, isn't it? Then you have to get older then it's. Like. One sleeping one's not sleeping."*

	Gabz's mum: *"The only problem that we thought we raised was just the issue of, OK, if he needs to go to bed and then his brothers on the game thing that would be the obstacle for everything, but everything else is fine."*

Appendix T Reflexive Diary and Research Diary

Topic	Reflections
Sleep diary	Choosing sleep tracker – following for 4 weeks. Needs to be manageable/short measures to ensure recording each day. Subjective? – thought about sleep watch but did not have funding for this for the size of the project. Had to be completed on a daily basis.
Self-reports and parent questionnaires	Parental questionnaires were chosen for measuring sleep pre-post intervention due to the wording of the questionnaires, children's age and social communication needs – thinking parent ratings might be more accurate. However, a simpler child self-rating for sleep each day was chosen to gather children's views of their sleep – considering their perspective and view which not enough studies have done. Children also included in the interviews.
RQ2 – interviews or quantitative analysis?	Too small sample size for correlation analysis. Gained a deeper understanding of the relationship through interviews – few studies to date have done this.
Not all participants able to be included for SCED	Spoke to Jen and Ravi about baseline lengths. Misunderstanding about needing multiple points for collecting data during 'baseline period.' Want to include the participants data still as they chose to participate and can still use pre-post and follow up data. However, need to re recruit participants to use SCED design.
SCED baseline trends	Bob's baseline trend not stable – makes it difficult to establish whether the introduction of the

Topic	Reflections
	intervention led to a change in sleep quality or other factors. Not enough time to lengthen. However, effect sizes help overcome this limitation.
Visual analysis	Visual analysis shows direction of change, shifts, more in depth analysis (e.g. day by day) which statistical analysis is unable to.
Short measure – sleep diary (multiple times)	Need to take measures multiple times at baseline to be able to establish a pattern before starting the intervention. This made me realise I needed a quick measure that could be easily recorded every day (sleep diary/tracker).
Multiple baseline	Questioned whether I needed to start baseline measures at the same time with every participant. Through doing this and staggering the intervention start, this served as a control/showed the difference between no sleep routine and sleep routine. The point of the staggered baselines is to ensure 1) that the change during the intervention isn't just due to some testing effect that occurs after X number of responses - this is why you have different numbers of baseline datapoints 2) that an external event/stimulus isn't driving the change (e.g. everyone doesn't start the intervention on the first day of term). Staggering the baselines and data collection period serves these purposes and the practical limitations of capacity for an experimenter mean that most SCEDs will have different people's data collected at different times.
Why AB design and not ABA?	Difficult to remove the sleep routine effects/felt unethical so only included two phases
Data analysis	– SCED (visual analysis and Tau-U) -RCI – can measure the change pre-post intervention

Topic	Reflections
Sleep tracker	-Too small sample size for correlation Time falling asleep/going to bed could have been made clearer Participants found the diary helpful for becoming aware of factors affecting sleep -Social desirability bias? Lots of variable factors on scores (e.g. heat, exams, school plays etc.)
Participant criteria	Sleep: The sleep routine was personal to the needs of the child. Advertised to parents who felt their child had difficulties with sleep. Checked in with parents about their child's sleep difficulty when checking informed consent. Cognitive ability: Did this through conversation with SENCo, explaining the sleep materials and what the child would need to do with my and their parents support. I thought a cognitive assessment was not needed/was not appropriate (cultural biases). Time constraints.
Baseline length	-Waited for consent from three parents, then gave date options to the three parents. Organised baseline lengths, based on when parent could come into the workshop and before the summer holidays started. - It could have been beneficial having a longer baseline length to understand the sleep pattern pre-intervention better. However, for practical and logistical reasons (summer holidays close by) – 8 days was the max.
Themes/subthemes	Don't need to have subthemes for every theme or same number. Meant to use subthemes sparingly so the data/analysis does not become too thin.
Peer checks/inter coder reliability	Time constraints – checking themes with supervisor but don't have time for peer checks

Coding reflections/analysis

* I have a lot of information from parents + children which is great but also feels overwhelming. What if I do it wrong? Where to start?
* I have 2 different RQs + parent + child views - how best to structure/analyse?
  - Seperate RQs
  - Seperate parent + child views on sleep routine as they might value different things. Important to gain child's voice.
  - MH RQ2 - less Qs on this so could combine (smaller question)
* Annotate on NVivo / Word / paper - NVivo getting confusing!!
* Lots of codes - need to group into subthemes / themes
* Some quotes have more than 1 meaning / code - need to move onto themes

To do

- Table on word - start putting quotes + codes in
- Have a look for themes / subthemes between codes
- Don't make too many - will make the meaning less rich

Themes/subthemes

* Finding it hard to narrow down! Lots of meaning
* What constitutes 'sleep quality'? - falling asleep, length of sleep, feeling sleepy? Sleep outcomes or sleep quality? Maybe individual to the person, what they find helps them sleep
* How to group 'having fun', 'enjoying activities', 'enjoying reading' - Engaging different activities? Routine provides enjoyment? Fun? Reduced stress?
  ↳ all about liking/enjoying routine