

**BELIEFS ABOUT SLEEP IN PARENTS WHO HAVE AND HAVE NOT MANAGED  
A SLEEP PROBLEM IN THEIR CHILD WITH AUTISM:  
EFFECTS ON HELP-SEEKING BEHAVIOUR  
AND TREATMENT CHOICE**

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### **Abstract**

The aim of this study was to investigate the beliefs of parents of children with Autism Spectrum Disorder (ASD) who had varying experiences with sleep problems and the factors affecting parental help-seeking behaviour and treatment selection. The study included 61 primary caregivers of children with ASD from around New Zealand (NZ). A descriptive analysis revealed that help-seeking and treatment selection was similar between groups and parental beliefs were correlated to treatment choice. Further, parental attributions about the stability of sleep problems in children with ASD tended to vary between our parent groups but attributions that were internal to the child and outside of the child's control showed no significant differences. Lastly, evidence was unable to support the belief that parenting a child with a sleep problem was a moderator for parent's attributions about sleep problems in children.

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## **Sleep problems in children with ASD**

ASD is a neurodevelopmental disorder that is characterised by deficits in social communication, and repetitive and stereotyped interests and behaviours (American Psychiatric Association, 2013; Ousley & Cermak, 2014). For children with ASD, sleep problems often co-occur with a child's ASD diagnosis. This behaviour can be perceived as being a feature of the child's ASD diagnosis. It is important that sleep problems are perceived as a separate condition to ASD because while sleep related problems can be treated, the core sensory and communication problems in ASD will likely remain. Research indicates that children with ASD tend to have a greater risk of developing sleep problems than typically developing (TD) children. Some estimates suggest that the number of children with ASD who experience sleep problems ranges between 44% and 83% (Krakowiak et al., 2008). This is compared to 26% to 32% of TD children (Couturier et al., 2005). Sleep problems are important to treat because clinically significant sleep problems may have a negative impact on the well-being of the child and the family (Gail et al., 2004). Furthermore, research has shown that a reduction in sleep quality and quantity in children with ASD may lead to lower performance on nonverbal tasks (Gruber et al., 2010), academic performance difficulties (Paavonen et al., 2013) and problem behaviours when compared to children with ASD without sleep problems (Goldman et al., 2011).

Child sleep problems may have a negative impact on the parents too. For example, greater sleep problems in children with developmental disabilities have been associated with maternal anxiety and depression (Chu & Richdale, 2009), and parental sleep problems (Boergers et al., 2007; Robinson & Richdale, 2004). Furthermore, research investigating the relationship between children's sleep and maternal mental health among families with children with ASD



found that sleep problems contributed to depression, anxiety, and maternal stress above symptom severity of ASD (Hodge et al., 2013; Levin & Scher, 2016).

### **Sleep problems**

Sleep disorders are generally categorised as parasomnias and dyssomnias. These categorisations are defined by which stage of sleep they occur in and affect. Sleep problems may also be classified in a third category which includes sleep problems related to mental or medical disorders (Krakowiak et al., 2008). Parasomnias include problems affecting arousal, partial arousal, and transitions between sleep stages (sleep walking, nightmares, sleep paralysis). Dyssomnias involve problems with the initiation and maintenance of sleep (insomnia), such as delayed sleep onset, bedtime resistance, and night awakenings, as well as problems with excessive sleep, known as hypersomnia (Mindell, 1993). Both dyssomnias and parasomnias can develop in children with ASD. However, problems involving sleep onset and maintenance are most commonly reported by parents of children with ASD (Cortesi et al., 2010).

Some insomnias, such as sleep onset associations, are behaviourally based while other dyssomnias can be related to medical factors, such as sleep apnoea (Murata et al., 2017). It is important to understand that there are a number of different causes for sleep problems in children, including those with ASD, because if we are to treat sleep problems, we must select the most appropriate treatment. While children with ASD are more vulnerable to sleep problems than other children, the reasons for this are largely unknown. Some theories suggest that it may be the result of neurodevelopmental factors such as the irregular secretion of melatonin; environmental factors that stimulate pre-sleep arousal; and/or behavioural problems including

oppositional behaviours interfering with sleep onset (Cohen et al., 2014; Kohlhuber & Bolte, 2011; Simakajornboon et al., 2009).

Additionally, children with ASD have been found to experience a higher rate of externalising and internalising problems compared to children that are TD (Magnuson & Constantino, 2011). Both externalising and internalising behaviours such as anxiety may also contribute to sleep difficulties in children with ASD (Meltzer & Mindell, 2008; Hollway & Aman, 2011). In addition, research commonly identifies familial factors such as parental stress, feelings of incompetence, and mental health, as contributors to sleep difficulties in children (Bell & Belsky, 2008; Meltzer & Mindell, 2007; Richdale & Schreck, 2009).

### **Treatments for sleep problems**

Many options exist for the treatment of sleep problems in children, including children with ASD. The most empirically supported treatment options for sleep problems in children, including children with ASD, are pharmacological and/or behavioural (Vriend et al., 2011). However, while pharmacological treatments are supported for the treatment of insomnia in children and adolescents with ASD, research indicates that behavioural treatments should be considered prior to pharmacological treatments (Malow et al., 2012; Mannion & Leader, 2013; Weiskop et al., 2001). Despite this, it is believed that families of children with ASD may choose treatments which are non-pharmacological and non-behavioural; such as homeopathic remedies, weighted blankets, white noise, and exercise (Dardennes et al., 2011; Matson & Williams, 2015; Miller et al., 2012). However, there is limited research that supports the use of these treatments for sleep problems in children with ASD (McLay & France, 2016).

Why parents may select non-scientifically supported treatments remains somewhat unclear. Some research indicates that parents may not seek treatment because they are misinformed due to external factors such as beliefs about their child's sleep problem; they are not aware of treatments or where to seek help; or they experience barriers to accessing treatment (Carlson et al., 2013; Miller et al., 2012; Robinson & Richdale 2004; Matson & Williams, 2015). However, it is important parents are offered the most appropriate treatments because some treatments, unsupported by empirical research, are more likely to result in failure; can be unsafe for the child; and waste time and energy of families seeking treatment (Miller et al, 2012).

### *Pharmacological treatments*

Melatonin is the predominant medication used for the pharmacological treatment of sleep problems in children with ASD and/or other neurodevelopmental disorders (Miano & Ferri, 2010; Malow, 2004). The most supported method for the use of medication in children with ASD is controlled-release melatonin which helps regulate circadian rhythms and targeting sleep-onset. Evidence from pharmacological research treatments has highlighted improvements in sleep latency and sleep duration with the use of melatonin (Malow, 2012). When melatonin has been ineffective, other pharmacological options have been used as alternatives. However, melatonin is generally seen as the safer and more successful treatment option compared to other pharmacological treatments (Malow, 2012; Whitehouse, 2013).

### *Behavioural treatments*

Behavioural interventions have been shown to be effective in the treatment of behavioural sleep problems in children with ASD and can have a positive effect on parental feelings of competence (Vriend et al., 2011). There is a large body of research to support the use of a number of behavioural treatments, such as bedtime fading, stimulus fading, standard extinction, and modified extinction (Turner & Johnson, 2012). Behavioural approaches are often viewed as more desirable than pharmacological treatments due to a reduced risk of side effects, more durable treatment effects, and the benefit of improving parental competence and confidence (Christodulu & Durand, 2004; Vriend et al., 2011; Weiskop et al., 2001). For example, standard extinction has been found to be effective in reducing co-sleeping and improving night-time awakenings for up to 12 months in children with ASD (Weiskop et al., 2005). Likewise, bedtime fading has also been shown to be effective in improving sleep latency and reducing the frequency of night-wakings in children that are TD (Ashbaugh & Peck, 1998; Piazza & Fisher, 1991). However, while there is evidence that behavioural interventions can be highly effective in the treatment of sleep problems in children that are TD, relatively fewer studies have researched the effectiveness of these treatments for sleep problems in children with ASD. As such, researchers have suggested that some behavioural treatments for children with ASD, including bedtime fading and graduated extinction, still require further research to establish the efficacy of these treatments (Vriend et al., 2011).

Behaviorally-based treatments are based on the behavioural model of insomnia and the principles of learning theory (Weiskop et al., 2001). For sleep problems, behavioural treatments may use functional behavioural assessment to identify factors that may precipitate or maintain

the sleep problem (Blampied, 2013). Commonly, sleep is thought of as a behaviour, but this is a misunderstanding as sleep itself does not consistently respond to an event or an unconditioned stimulus (Blampied & France, 1993). Rather, behavioural theory depicts the act of falling asleep as a conditioned response to the stimuli present in the sleep environment at the time of sleep onset. As a result, behavioural interventions will not target the child's sleep directly, but the stimuli in the child's sleep environment will be targeted. This may be involved in the onset and maintenance of sleep (Blampied & France, 1993).

Parents can be a major part of their child's sleep environment, as often it is the parents' role to manage their child's sleep related behaviour. For example, maintaining consistent bedtime routines, removing sources of distraction, and reinforcing bed preparation. (Owens & Mindell, 2005; Blampied, 2013). Interventions for sleep problems are predominantly implemented within the home setting by parents as the primary medium for changing the behaviour. Furthermore, parenting behaviours may also act as a stimulus within the child's sleep environment and interact with their child's sleep process. For example, behaviours such as, singing, breast feeding, and co-sleeping have been commonly documented as parental behaviours around bedtime in infants (Teng et al., 2012). In some cases, these parental behaviours may act as more dominant sleep cues when compared to the natural stimuli within the child's sleep environment (Blampied & France, 1993). Consequently, this may cause the child's sleep to become more dependent on parenting behaviour, resulting in problems with sleep onset. This scenario depicts the idea that in some cases, childhood sleep problems may be maintained and developed by the interaction between the child at bedtime and the parents' behaviour (Weiskop et al., 2001).

As a result of these associations, behavioural interventions will often target parents' behaviour towards their child at bedtime as a method of achieving an improvement in the child's sleep behaviour (Weiskop et al., 2001). Parents are also commonly involved in the treatment of sleep problems in children with ASD (Wiggs & Stores, 2004; McLay et al., 2018; Vriend et al., 2011; Weiskop et al., 2005). Parental participation has been shown to be effective in treatments for settling and night-waking problems in children (Carr, 2009) while parental education has also been found to be associated with an improvement in sleep onset delay in children with ASD (Malow et al., 2013). It is important to acknowledge that parental education alone is not likely to be enough to improve sleep patterns in children with insomnia, as research indicates parents may require further instruction about the implementation of behavioural strategies and interventions (Adkins et al., 2012). Numerous studies have reported findings on the benefits of parental involvement and education during behavioural sleep treatment (Malow et al., 2013, Mannion & Leader, 2013; Weiskop et al., 2005).

Behavioural interventions may also include a cognitive aspect when working in a family context (Owens et al., 1999). This is because targeting parental thoughts and beliefs about their child's sleep problem may influence their behaviours (Keenan et al., 2007; Bessey et al., 2013). For example, a parent who only perceives sleep problems as biological or inherent to the child may overlook their own ability to influence their child's behaviour. In recent years, research has begun to incorporate attribution theory to help understand how parental beliefs and attitudes about sleep problems in children with ASD may affect parental help-seeking and treatment decisions.

## **Attribution Theory**

Attribution theory, as proposed by Weiner's (1980) attribution-emotion-action model of behaviour, suggests that when an individual ascribes causes to an event there are both psychological and behavioural effects. An attribution refers to the process of an individual ascribing a cause to a behaviour or event. Depending on how the individual making the attribution perceives the cause of the behaviour or event, they may have a different emotional or behavioural effect. For example, parents who believe ASD is caused genetically will likely seek help from medical professionals and pharmacological treatment (Dardennes et al., 2011). Further, parents who attribute sleep problems to more chronic (stable) factors are more likely to accept a behavioural treatment for their child's sleep problem compared to the use of melatonin. Attributions as referred to in attribution theory are classified in three causal dimensions: locus, stability, and controllability (Frey, 2018). Locus refers to whether the individual perceives the cause as internal or external to the subject (Weiner, 1980). Stability refers to whether the individual perceives the problem to be temporary or permanent – how an individual perceives stability can influence how likely they are to act in relation to their future expectations (Frey, 2018). Finally, controllability refers to whether the individual perceives the behaviour as within the control of the child (Weiner, 1980).

In research, attributions are often further categorised to distinguish between who the subject of the attribution refers to (i.e., the parent or child). Parent-referent attributions are beliefs about the parent's causal role in the behaviour while child-referent attributions are beliefs about the causes related to the child. Both parental attributions and parents' beliefs about child-referent causes may affect parents' help-seeking behaviour (Morrissey-Kane & Prinz, 1999). For example, a parent who attributes the cause of their child's sleep problems to biological factors

would be viewing the problem as having an internal locus because they perceive the cause to be something that is internal to the child. This perception of a biological cause may mean that this parent is more likely to seek medical treatment (Dardennes et al., 2011; Phelan et al., 2006). Likewise, a parent who attributes the cause to environmental factors would be viewing the problem as having an external locus because they perceive the cause to be something that is external to the child. This perception may mean that this parent is more likely to seek behavioural treatment because they perceive their own behaviour to be a part of the child's environment.

Parental attributions do not need to be factual and may become misinformed due to reasons such as: having limited access to empirically supported information, inadequate training in local professionals, and information spread between parent to parent (Johnston & Ohan, 2005; Miller et al., 2012; Mindell, et al., 1994; Carlon et al., 2013). A potential risk for parents who have misinformed beliefs is they are less likely to access the most effective treatment for their child's problem behaviour. This is because a parent's beliefs about a disorder or treatment of the disorder can affect how likely the parent is to seek help and who they seek treatment from (Carlon et al., 2013; Dardennes et al., 2011). For example, beliefs such as 'children grow out of sleep problems' and 'sleep problems are untreatable' may result in parents failing to seek treatment, compared to a parent who believes sleep problems are treatable. Because parents may lack the knowledge of – or access to – best practice, they can be led to not-empirically-supported treatments or to health professionals without adequate training to provide treatment advice (Miller et al., 2012).



## Literature review

### Aims of this review

So far, this review has introduced research on sleep problems in children with ASD and the treatments commonly used. This was done with an emphasis on the evidence-base that underpins behavioural treatments and highlights the importance of parent's roles in the treatment and maintenance of sleep problems. The principles of attribution theory and its role in parental help-seeking behaviour were also introduced. Attribution theory is one method of exploring parental beliefs about their role in their child's sleep problem. Studies researching parental attributions about problem behaviours have been successful in finding interactions between parental help-seeking and treatment selection in families with children with ASD (Al Anbar et al., 2010; Johnston et al., 2010; Dardennes et al., 2011). However, it is not as well known how these factors may interact in families with children with ASD and sleep problems.

Therefore, the next aim of this literature review is to review the contemporary research available on parental attributions about sleep problems in children with ASD and a co-occurring sleep problem. To do this, studies investigating parental attributions about their child's ASD and/or sleep problem and the factors affecting help-seeking and treatment selection have been gathered. This was to address two main key research questions:

1. What attributions do parents of children with ASD and a sleep problem have about their child's problem behaviour?
2. What relationship is there between parental attributions about sleep problems in ASD and the factors affecting help-seeking behaviour and treatment selection?

## Methods of the review

Articles used in this review were gathered through the Ebscohost suite of databases (e.g., academic search and primary search), Google Scholar, and The University of Canterbury Library's database. The databases yielding the most relevant results were The University of Canterbury Library's database and Google Scholar. Search terms included "parental attributions", "help-seeking behaviour", "treatment choice", "treatment acceptability", "problem behaviours", "parent engagement", "children with ASD", "parenting program", and "sleep problems". Selection criteria for the articles included (1) published in 1990 or after, (2) published in English, (3) participants were parents or primary caregivers, (4) children of parent/caregiver were aged 18 years of age or younger, (5) studies focused on parent's attributions regarding a sleep problem and/or ASD or developmental disability and/or ADHD. The chosen studies (see Table 1) were based on their eligibility according to our selection criteria and were selected from a larger pool of eligible studies that were later narrowed down to six. Of the pooled eligible studies, the chosen studies were narrowed down according to the relevance of the study, our accessibility to the study, repeated findings between studies, and the studies ability to address the two research questions of the current review (see Table 1).

*Table 1. Description of the studies included in the literature review*

<i>Author</i>	<i>Participants</i>	<i>Design and procedure</i>	<i>Objective</i>	<i>Significant findings</i>
Al Anbar et al., (2010)	Parents of children with ASD (n=89).	Cross-sectional design via a questionnaire	To explore the relationship between causal beliefs about autism (CBA) and treatment choices.	Parental attributions about severity, beliefs about the cause, and the duration were associated to treatment choices. Beliefs about the causes of ASD were the strongest predictors of treatment choice.
Bessey et al., (2013)	Parents of children who were TD, had ADHD, or ASD and had a sleep problem (n=355).	Between-subjects design of the SABS via a questionnaire	Investigate differences in parental attributions among parents of children with ADHD, ASD, or TD using the SABS	Parents attributed sleep problems to factors that were internal to the child and stable compared to families with children that were TD.
Dardennes et al., (2011)	Parents of children with ASD (n=78).	Cross-sectional design via a questionnaire	Investigate different parental beliefs about ASD and the associations to parental information and treatment seeking.	Parental attributions about the causes of ASD were shown to be associated with five treatment choices including supported and unsupported treatments for ASD.
Keenan et al., (2007)	Parents of children with a sleep problem (n=58).	Within-subject correlation design	Asses parents' attributions about sleep problems and the acceptability of two treatments	Parental attributions about the duration of sleep problems and number of beliefs were associated to behavioural treatment acceptability. Severity of sleep problem was associated to pharmacological treatment

*Table 1. Description of the studies included in the literature review continued*

<i>Author</i>	<i>Participants</i>	<i>Design and procedure</i>	<i>Objective</i>	<i>Significant findings</i>
Miller et al., (2012)	Parents of children with ASD (n=400).	Cross-sectional design via a questionnaire	Investigate factors related to parents' choices of treatments and sources parents seek	Professionals may not be consistently recommending scientifically supported treatments to parents of children with ASD. Parents may also access a variety of sources of information for their child's ASD. Professionals recommendations, ASD books, and word of mouth were strong influences.
Robinson & Richdale (2004)	Parents of children with a developmental disability and a sleep problem (n=149).	Cross-sectional design via a questionnaire	Investigate sleep problems in children with an intellectual disability and the parents' perceptions of sleep problems and treatments	Parents gave explanations that they did not seek treatment for their child's sleep problem due to their beliefs that sleep problems were internal to the child and stable.

*Key words: Autism spectrum disorder (ASD), Sleep Attitude beliefs scale (SABS), Attention deficit hyperactivity disorder (ADHD, typically developing (TD), Causal beliefs about Autism (CBA)*

### **What attributions do parents of children with ASD and a sleep problem have about their child's problem behaviour?**

Two articles (Bessey et al., 2013; Robinson & Richdale, 2004) were found to have addressed the question, 'what attributions do parents make about their child with ASD and a sleep problem?'. The study by Robinson & Richdale, (2004) investigated sleep problems in children with an intellectual disability and the parents' perceptions of their child's sleep problem and treatment. The study was conducted in a survey which was distributed to parents of children from six schools in north west Melbourne. The children of this study were included if they had either experienced a past sleep problem or were currently experiencing a sleep problem. Amongst the 149 participants, it was found that around half of the parents either believed treatment for their child's sleep problem was not possible or that they did not need to seek treatment. The most common explanation for parents who believed treatment for their child's sleep problem was not possible (n=38) was that the sleep problem was due to a medical condition/disability (18%), treatment was not necessary (13%), or they were not aware of any possible treatments (13%). The most common explanations parents gave for not seeking treatment (n=42) was because their child got enough sleep (29%), they could fix it themselves (19%), or they were unsure how to get help (10%).

The second study by Bessey et al., (2013), found complementary findings. Bessey et al., (2013) assessed parents' beliefs using the Sleep Attitudes and Beliefs Scale (SABS). The SABS was administered to parents of children that were TD (n=179), children with ADHD (n=84), and children with ASD (n=92). The results from this study found significant differences in parents' beliefs about sleep problems when comparing them to parents of children that were TD and parents of children with ASD. Specifically, parents of children with ASD were more likely to

attribute sleep problems as being internal to the child and stable when compared to parents of children who were TD. The results from this study indicate that parents of children with ASD may have unique beliefs about sleep problems when compared to children who are TD. The treatment choices and help-seeking behaviour of parents of children with ASD and a sleep problem may be different due to their tendency to view sleep problems as internal and stable. Specifically, as shown by the Robinson & Richdale (2004) study, it may be found that the parents with more internal and stable attributions may not seek treatment. Similar findings can be drawn when research has investigated the beliefs of families with children who are TD, compared to families of children with ADHD, CD, and ODD (Johnston & Ohan, 2005).

When comparing the beliefs of parents of children with ADHD to parents of children with ASD, differences were only shown between the parents' beliefs about the nature of the disorder (Bessey et al., 2013). This meant parents of children with ASD tended to attribute sleep problems to beliefs that were more intrinsic to the child than parents of children with ADHD. However, no differences were shown in parents' beliefs about stability of the sleep problem. This may suggest that a parents' beliefs about the general behaviour related ASD or ADHD may be generalised to their child's sleep related behaviour. Previous research suggests that parents of children with ASD tend to attribute their child's problem behaviour to their child's disorder while parents of children with ADHD tend to attribute their child's problem behaviour to their perception of their own parenting and the child's intent (Whittingham et al., 2009; Donenberg & Baker, 1993). Together, with the findings from the Bessey et al., (2013) study, evidence further suggests that parents of children with ASD and a sleep problem may exhibit their own beliefs, thoughts, and feelings about sleep problems compared to other parents of children with a sleep problem. Therefore, it may be necessary to understand the underlying beliefs and attributions

parents of children with ASD have about sleep problems and how this may affect their treatment choices and help-seeking behaviour. This is important for clinicians to understand when undertaking assessments and developing case formulations.

Regarding our first research question, the studies by Robinson & Richdale (2004) and Bessey et al., (2013) both found evidence that parents of children with a sleep problem tended to attribute sleep problems to factors that are internal to the child and stable. Research has previously found that parents of children with an intellectual disability often fail to seek treatment for their child's sleep problem (Wiggs & Stores, 1996). This finding was supported in the study by Robinson & Richdale (2004), where some parents of children with an ID who attributed their child's sleep problem to factors that were internal and stable were found to have not sought treatment for their child's sleep problem. Further, the study by Bessey et al., (2013) indicated parents' attributions were statistically different when compared to parents of children with a sleep problem that were TD and children that had ADHD. Collectively, these findings indicate some parents of children with ID may not be seeking treatment for their child's sleep problem due to misattributing them as a part of their child's ASD and untreatable. Additionally, parents of children with ASD and a sleep problem were shown to make similar attributions about sleep problems in their own child. Further, these parents may be more likely to not seek treatment for their child's sleep problem compared to parents with children that are TD or have ADHD.

While study findings between the studies by Bessey et al., (2013) and Robinson & Richdale (2004) were consistent, some limitations did exist. Regarding the study by Robinson & Richdale (2004), parents indicated that they did not seek treatment for their child's sleep problem for reasons alternative to internal and stable factors. For example, parents responded that they

believed it was ‘not necessary’ or they were ‘not aware of any treatments’. This may indicate parents’ beliefs about sleep problems may not be the only predictor of parents’ help-seeking. Instead, it seems factors such as the information parents have on treatments for their child’s sleep, can be as important as their beliefs when predicting treatment seeking behaviour. Research is needed to determine the strength of the relationships between parental beliefs about sleep problems and their help-seeking behaviour. It may be found that a parent’s lack of knowledge about their child’s sleep problem is a better indicator of their help-seeking compared to their beliefs about the disorder. The finding that parents may view the child’s sleep problem as part of a medical condition or the disability also seems to be consistent amongst other research (Stores, 2001; Bramble, 1996). Although, the findings from Robinson & Richdale (2004), were not tested for a correlation and thus we can only make inferences from this data.

Neither Robinson & Richdale (2004) or Bessey et al., (2013) investigated whether parents’ beliefs were influenced by the age of the child. In the study by Robinson & Richdale (2004), some explanations for not treating their child’s sleep problem were more common for certain age groups. Parents may also attribute sleep problems as being more stable in children who have experienced a sleep problem for a longer duration. Future research could use longitudinal studies in order to track how parents’ beliefs might develop over time and the influence this may have on the parents’ help-seeking. Further, the perceived severity of sleep problems can differ between individuals however, only Bessey et al., (2013) had reviewed the parents’ perceptions of the severity of the condition. The influence of a parent’s perception on the severity of their child’s condition has previously been shown to impact treatment selection (Keenan et al., 2007). This might indicate that the present studies may not be representative of all



the factors influencing help-seeking or why parents of children with ASD might attribute sleep problems differently when compared to families of children that are TD.

**What relationship is there between parental attributions about sleep problems in ASD and the factors affecting help-seeking behaviour and treatment selection?**

Four studies (Al Anbar et al., 2010; Dardennes et al., 2011; Keenan et al., 2007; Miller et al., 2012) were found to have addressed the relationship between parental attributions about sleep problems in ASD and the factors affecting help-seeking behaviour and treatment selection. The study by Miller et al., (2012), investigated different sources of information related to ASD available to parents and whether those sources of information influenced parental help-seeking. The study was conducted through a survey of 400 families seeking information about the treatment's parents used, who recommended the treatment, and variables influencing their decisions. The study evaluated the level of research support for treatments based on available research from Jacobson et al., (2005), Richdale & Schreck (2008), and Romanczyk et al., (2008). The study found that almost half of parents (45%) were using applied behaviour analysis, which the study claimed was a supported treatment for ASD in children. However, it was also found that a larger number of parents (68%) were selecting speech therapy, which was recognised as having mixed scientific support. Furthermore, about a third of participants (31%) selected vitamin therapy, which was recognised as being unsupported in the treatment of ASD for children.

Complementing their findings for parents' treatment choices, it was found parents reported a variety of influences from a number of sources when choosing a treatment for their child's ASD. Professionals were reported as one of the most common influences on parents'

treatment decisions (85%), but parents were equally influenced by books on ASD (85%). Other common sources of information included other parents (75%), their child's school (67%), and ASD media (53%). Lastly, the study found that psychologists (39%) and behaviour analysts (30%) were the most likely to recommend supported treatments. In comparison, medical doctors (35%) and occupational therapists (21%) were the most likely to recommend treatments that had mixed support.

The study by Al Anbar et al., (2010), investigated parents' perceptions about their child's ASD diagnosis and the influence on their treatment choices. This study included a questionnaire which was sent out to families with children that have ASD. The questionnaire measured the parents' perception of illness through a modified version of the Revised Illness-Perception Questionnaire (IPQ-R). This questionnaire asked parents from 89 families about a range of beliefs about their child's ASD. Questions related to parents' beliefs about the causes of their child's ASD, beliefs about the seriousness of the disorder, the duration the disorder (stability), and the consequences of the disorder. The study found that parents reported having multiple beliefs about their child's ASD but parents' beliefs about the causes of ASD were shown to be the most significantly associated with treatment use. For example, parents who attributed causes as external to the child and that ASD was hereditary were associated with metabolic treatments. Genetic causal beliefs were the predominately held belief by parents (48%) and were associated with biological forms of treatment. It was also found that there was a significant negative association between a parents' sense of personal control (controllability) and their use of medication. In summary, the study showed different parental beliefs were associated with

treatment use and that causal beliefs are strong predictors of treatment use compared to beliefs about the severity and duration.

A continuation of the research undertaken by the previous authors was conducted by Dardennes et al., (2011) and focused on parents' causal beliefs alone. This study used a different instrument for measuring parents' causal beliefs, Lay-beliefs about Autism Questionnaire (LBA-Q). The results from this study supported the previously reported association between parents' beliefs about the causes of ASD and their treatment selection. The beliefs about causes included genetic causes, pregnancy hazards, food allergies, and brain abnormalities. Amongst these beliefs, five associations were identified with parent's treatment selection. These were: illness during pregnancy and the use of medication; traumatic early life experiences and behaviour therapy; genetic factors and the TEACCH program; and chemical imbalances and vitamin supplements. Interestingly, the study reported fathers of children with ASD were more likely to use the TEACCH educational program than mothers. This could suggest that interparental differences may exist between parents' lay beliefs about illness.

The last study to address this question was by Keenan et al., (2007), who investigated the relationship between parents' perceptions of treatments for sleep problems in children with ASD and their beliefs about the severity and duration of the sleep problem. Parents from 58 families were asked to complete questionnaires relating to their beliefs about their child's sleep problem and the acceptability of behavioural and melatonin treatments. The study found participants rated the acceptability of both treatments equally. Results from this study found that parents who held a greater belief that their child's sleep problem was chronic were more likely to accept behavioural treatment. Alternatively, parents with a greater perception of the severity of the sleep problem were more likely to accept melatonin as a treatment. The study did not indicate which

treatments were chosen by parents who held beliefs that their child's sleep problems were chronic and who also had a greater perception of the severity. However, research did show that parents tended to choose behavioural interventions (53%) compared to melatonin treatments (34%) but this was not a significant difference.

In summary, the studies by Keenan et al., (2007), Al Anbar et al., (2010), Dardennes et al., (2011), and Miller et al., (2012) collectively present significant evidence for a relationship between parental attributions and parents' help-seeking behaviour and treatment choices. The finding of a relationship between parental beliefs and treatment selection may explain why parents of children with ASD select treatments that are scientifically unsupported despite supported treatment existing for child insomnia. Regarding parental help-seeking, the study by Miller et al., (2012) highlights three key observations for understanding the factors which may influence help-seeking in families with children with ASD.

1. While seeking information and advice for their child's ASD, parents tend to be highly influenced by a number of sources.
2. Professional recommendations about treatments for ASD may be as influential as 'word of mouth' recommendations.
3. It is not guaranteed that parents who seek advice/information from professionals will be recommended best practice treatments.

Overall, it seems current research on parents help-seeking is mostly exploratory in design. Studies are still looking to understand what possible factors may influence parental help-seeking. However, research has yet to determine the strength of the relationships between the factors relating to parental help-seeking and sources of information parents may seek.

Regarding parental treatment selection, the studies by Al Anbar et al., (2010), Keenan et al., and Dardennes et al., (2011) indicated that there may be multiple associations between parents' beliefs about the causes of ASD and sleep problems, and parental treatment use. Furthermore, evidence suggested that beliefs about the causes of ASD tend to be stronger predictors of treatment use than beliefs about the duration of the problem behaviour, parents' sense of control, and perceived severity of the problem behaviour. It is important to understand which factors are most likely to influence a parent's treatment decision if we are to provide parents with the most appropriate treatments. A better understanding of the relationships between parental beliefs and their treatment decisions may benefit clinicians in designing support and interventions for families of children with ASD which can direct them towards more appropriate treatment choices (Dardennes et al., 2011). Furthermore, it is critical to have a strong knowledge about which factors may influence a parent's decision making as promoting beliefs in parents that are unresearched may direct them towards treatments that are unsupported or limited in evidence.

There are a number of limitations that should be considered when interpreting the literature such as the influence of age, gender, and the severity of ASD related behaviour on parents' treatment selection. Dardennes et al., (2011), found that age was not associated with parents' treatment choices in parents of young children (<10yo) and parents of older children (>10yo) with ASD. This suggests that age may not be an influence on parents' treatment choices. However, longitudinal data should be included in future research as it might demonstrate whether parents' beliefs are stable over time or if they change as their children grow. The studies by Al Anbar et al., (2010) and Dardennes et al., (2011) did not validate the clinical diagnosis of

ASD prior to the study. This may mean that these findings are not representative of parents of children with ASD and future research should attempt to replicate the results with a more representative sample.

Additionally, the finding that fathers were more likely to use the TEAACH program than mothers may indicate that gender differences exist between the treatment decisions of parents of children with ASD (Al Anbar et al., 2010). However, this was the only variable to show significant gender differences, and previous studies have not revealed associations between gender and treatment choice in parents of children with ASD (Furnham & Buck, 2003). Finally, the study by Al Anbar et al., (2010) found that parents' beliefs about the symptom severity of their child's ASD were not as predictive of treatment use when compared to parents' beliefs about the cause of ASD. In contrast, the study by Keenan et al., (2007) did not research parental beliefs about the cause of sleep problems in children with ASD. Therefore, we are unable to infer from this study whether parents' beliefs about the causes of sleep problems would have been more closely associated with parents' treatment use compared to parental beliefs about the severity or duration of the sleep problem.

### **Discussion of the existing literature**

This literature review discussed studies that had answered one of two key questions:

1. What attributions do parents of children with ASD and a sleep problem have about their child's problem behaviour?
2. What relationship is there between parental attributions about sleep problems in ASD and the factors affecting help-seeking behaviour and treatment selection?

Based on the findings of this review, there is not enough available research to fully understand the underlying relationships between parental beliefs about sleep problems in children with ASD

and the influence on parents' help-seeking behaviour and treatment selection. However, research that does exist tends to support the association between parental beliefs and treatment selection. Specifically, associations between parents' beliefs about the causes of ASD in children without sleep problems and beliefs about the severity and duration of sleep problems in children with ASD have all been significantly associated with parents' treatment selection (Al Anbar et al., 2010; Dardennes et al., 2011; Keenan et al., 2007). Most importantly, there is evidence to suggest that parental beliefs about the causes of ASD and the severity of sleep problems in ASD could lead parents to using behavioural treatments (Keenan et al., 2007). This is important as behavioural interventions tend to be considered best practice for the treatment of sleep problems in children, including those with ASD.

Research has shown that people's beliefs about illnesses are not stable and can be targeted during treatment. For example, findings on myocardial infarctions have shown that modifying illness beliefs can increase treatment adherence in patients (Petrie et al., 2002). Additionally, increasing emphasis on the genetic causes of mental illnesses has also been found to direct people's help-seeking behaviour towards biological forms of intervention (Phelan et al., 2006). Therefore, it might also be assumed that similar results could be found when targeting parental beliefs about sleep problems in children with ASD. This has already been shown in families with children with ADHD, CD, and disruptive problem behaviours through behavioural parenting programs designed to promote positive changes to the parents' attributions about their child's diagnosis (Johnston et al., 2010; Nordstrom et al., 2008; Moreland et al., 2016; Peters et al., 2005). Specifically, these programs found that increasing parents' perceptions of an internal locus of control, as it relates to the parent, was associated with a decrease in children's disruptive behaviour (Moreland et al., 2016). Together, the study by Bessey et al., (2013) and the study by

Robinson & Richdale (2004), showed that parents of children with ASD or an ID who also had a sleep problem tended to attribute sleep problems to factors intrinsic to the child. Therefore, we might predict that behavioural parenting programs helping parents to attribute sleep problems to factors that are external to the child may also improve parental and child treatment outcomes.

However, it also is likely that there are many underlying factors influencing parents' help-seeking behaviour and treatment selection. For example, Miller et al., (2012) showed that the recommendations of professionals may be as much of an influence on parental treatment decision making in families of children with ASD, as recommendations by word of mouth. Furthermore, Robinson & Richdale (2004) found that parents gave explanations for not seeking treatment for their child's sleep problem that were beyond their beliefs about the behaviour itself. This may indicate that factors such as the information parents have about their child's problem behaviour or treatments may act as a barrier to accessing treatments (Matson & Williams, 2015). It is not enough to make more research available for parents however, as even beliefs about treatments that have no scientific support may be held by some parents (Matson & Williams, 2015). For example, while there is no scientific support that vaccines may cause ASD, this has been a common belief over time. Thus, improving the communication of information between clinician and client as well as the accessibility of information for parents should be considered a high priority in addressing parental beliefs about their child's sleep problem. Doing so is important not only for appropriate case formulation and provision of support but also for communicating intervention plans with parents (Dardennes et al., 2011; Sanders & Burke, 2013).



### *Future research*

Research is yet to understand why there are differences between the beliefs of parents of children with ASD who have a sleep problem, and the beliefs of parents of TD children and the factors that may account for these differences. In general, this is an area of research that has received little scientific attention to date. However, there have been promising findings from research on families of children with ADHD which suggests that the relationship between parental attribution, child behaviour, and parenting behaviour might be moderated by the parent's history with interacting with their child who has ADHD (Johnston & Ohan, 2005).

To clarify, this would indicate that a parent's thoughts, feelings, beliefs, and attitudes towards their child's ADHD are shaped by parents' continued interaction with their child's behaviour. Meaning that we might expect parents of children with ASD and a sleep problem to make attributions that reflect their history of interaction with their child's behaviour, health care professionals, treatments, or the lack of these factors. For example, research indicates that parents of children with ASD who currently have a sleep problem will likely attribute their child's sleep problem as untreatable or a part of their ASD (Bessey et al., 2013; Robinson & Richdale, 2004). In contrast, we might expect parents of children with ASD who have never experienced a sleep problem to attribute their child's sleep problems to factors that are external to the child rather than internal. This is because the parents of children with ASD who have never displayed a sleep problem may not view sleep problems as a characteristic of their child's diagnosis. Rather, parents may attribute the causes of sleep problems in children with ASD to something external to the child, such as the environment.

Establishing the differences found between the attributions of parents with different experiences of sleep problems may be beneficial for researchers as it may improve our understanding the help-seeking and treatment selection of parents of children with ASD. Specifically, why some parents of children with ASD and a sleep problem are likely to not seek treatment or use treatments that are scientifically unsupported. For example, parents of children with ASD and a co-occurring sleep problem who perceive sleep problems as internal to the child may be more likely to believe in biological causes and therefore more likely to seek pharmacological treatment. Likewise, parents of children with ASD who are without a sleep problem may believe in an external cause, such as learned behaviour, and are therefore more likely to seek a behavioural treatment. Consequently, future research should begin to investigate how the different experiences of parents of children with ASD and sleep problems may affect their help-seeking behaviour and treatment decisions. This research may be beneficial in understanding what factors may contribute to a parent's decision to not seek treatment for their child's sleep problem and further, how we may be able to inform parents about treatments that are most appropriate for their child's sleep problem.

### *Limitations*

Limitations to the studies used within this review have been mentioned previously when presenting the research. Another common limitation not previously noted was that the studies by Al Anbar et al., (2010), Dardennes et al., (2011), Bessey et al., (2013) did not confirm the diagnosis of ASD in their populations, nor had they differentiated between children with and without a sleep problem. As a result, findings from these studies may be less representative of parental help-seeking behaviour within the population than suggested. Future research should

focus on establishing validity of their findings by replicating previous research with different demographics or larger sample sizes.

### **Current research**

Previous research investigating the factors relating to parental help-seeking behaviour, treatment selection, and beliefs about sleep problems in ASD has led researchers to believe that parental attributions may help explain why some parents may not be seeking treatment for their child's sleep problem and also why parents may not select treatments for their child that are scientifically supported when such treatments exist (Keenan et al., 2007; Robinson & Richdale, 2004; Al Anbar et al., 2010; Dardennes, et al., 2011; Miller et al., 2013). Researchers often suggest that behavioural treatments should be the first-choice treatment for insomnia in children and adolescents with ASD (Malow et al., 2012; Mannion & Leader, 2013; Weiskop et al., 2001). However, research suggests that parents of children with ASD may not always select treatments for their child that are empirically supported (Dardennes et al., 2011; Matson & Williams, 2015; Miller et al., 2012). It is imperative that families are receiving the most appropriate treatment for their child's sleep problem because the use of some scientifically unsupported treatments can be more likely to result in failure, can be more unsafe for the child, and waste the time and energy of families seeking treatment (Miller et al., 2012). Additionally, a better understanding of the relationships between a parent's beliefs about their child's sleep problem and their help-seeking behaviour may be beneficial for clinicians who can help design better interventions for families of children with ASD which can address parental beliefs about their child's sleep problems and direct families towards more appropriate treatment choices (Dardennes et al., 2011).

The current research combines the ideas from the previous research on parents' help-seeking behaviour in parents with different experiences with sleep and developmental problems in children (Bessey et al., 2012; Johnston & Ohan, 2005), and the ideas of attribution theory (Werner, 1980), to investigate whether there are any relationships between parents with different experiences with sleep problems in children with ASD and their attributions about sleep behaviour in children with ASD. Further, it asks whether the differences between the attributions of parents of children with ASD who have a current sleep problem (CSP), parents of children with ASD and a past experience with sleep problems (PSP), and parents of children with ASD who have never experienced a sleep problem (NSP), will predict the parent's help-seeking behaviour and treatment decisions. Therefore, the current study is an exploratory study with three key research questions:

1. To investigate whether there is a difference in parental attributions and beliefs about sleep problems between parents of children with ASD who either currently have, previously have had, or have never had a sleep problem.
2. To investigate whether there is a relationship between parental attributions about sleep problems in children with ASD, and their help-seeking behaviour, and treatment choice.
3. To investigate whether there is a relationship between the different experiences of treatment or lack of treatment for their child's sleep problem and the parent's attributions about sleep behaviour in children with ASD

### *Hypotheses*

We have proposed four hypotheses which relate directly to the research questions for the current study. These hypotheses will reflect the expected outcomes of parents' attributions,

causal beliefs, treatment selection, and help-seeking behaviour in our three participant groups. The expected outcomes were determined due to the existing findings from previous research on parental attributions about sleep problems in children with ASD (Bessey et al., 2012; Keenan et al., 2007; Robinson & Richdale, 2004) and parental attributions about ASD in children (Al Anbar et al., 2010; Dardennes et al., 2011; Miller et al., 2013), and how these factors affected their help-seeking behaviour and treatment selection.

**We will find statistically significant differences between the attributions made by parents of children with ASD across the three groups (CSP, PSP, and NSP).**

Based on the findings of previous research that has investigated parents' attributions about their child's ASD and sleep problems we expect to find that there will be differences between the attributions made by parents among the CSP, PSP, and NSP groups (Hartley et al., 2013; Robinson & Richdale, 2004; Bessey et al., 2013). From this research, we expect to find that parents from the CSP group will attribute sleep problems in children with ASD to factors that are internal to the child and stable more often than parents from the PSP and NSP groups. We expect to find that parents from the PSP group will attribute sleep problems as less stable compared to parents from the CSP group. This because parents from the PSP group are most likely to have successfully treated their child's sleep problem and thus will not view it as chronic or untreatable. Likewise, we expect parents from the NSP group to attribute sleep problems in children with ASD as external to the child and unstable. This is because the parents from the NSP group will not view sleep problems as a characteristic of their child's diagnosis and instead attribute sleep problems to factors such as learned behaviour and their environment.

**Parents from the PSP group will believe in parent-referent causes of sleep problems more often than parents from the CSP and NSP groups.**

We expect to find differences between parents' beliefs about the cause of sleep problems across each of the three groups. Parents of children with challenging behaviours tend to attribute their child's negative behaviour to factors that are within the child as opposed to parental factors (Morrissey-Kane & Prinz, 1999). This same pattern has been found among parents of children with sleep problems (Robinson & Richdale, 2004; Bessey et al., 2013). Therefore, we expect to find that parents from the CSP group will have beliefs about the cause of sleep problems that are child-referent (i.e., beliefs about causes related to the child). As such, they are more likely to attribute sleep problems to medical or sensory problems and are also likely to minimize the role of themselves as the parent in contributing toward the sleep problem. In contrast, parents from the PSP and NSP group will be more likely to make parent-referent attributions (i.e., beliefs about parents' causal roles in the behavior). Therefore, they will be more likely to believe that the sleep problem is a result of learned or acquired factors or the sleep environment.

**Parents from the CSP group will select behavioural treatments more often than parents of children from the PSP group.**

Previously, research has established associations between parents' beliefs about the cause of ASD and a parent's treatment selection (Al Anbar et al., 2010; Dardennes et al., 2011). Therefore, we may also expect to find this in parents of children with ASD and a co-occurring sleep problem. The available research on parental beliefs of parents of children with ASD and a sleep problem indicate that parental beliefs about the severity and duration of sleep problems

may be associated with a parent's choice between behavioural and pharmacological treatments (Keenan et al., 2007). Specifically, parents who tended to view sleep problems as more chronic were more likely to accept behavioural treatments whereas parents who tend to view sleep problems as more severe were more likely to accept melatonin. Therefore, we hypothesize that the CSP group will select treatments that are behaviorally based more often than parents from the PSP group as they are more likely to attribute sleep problems to factors that are chronic/stable.

### **Parenting a child with a sleep problem will act as moderator between parents' attributions about sleep problems in children with ASD**

It is predicted that parents from the CSP and PSP group will make similar attributions about sleep problems in their own child and in the children described in the four vignettes we have created which depict children with differing sleep problems and levels of autism functioning. Research suggests parents' beliefs and attributions about problem behaviours in children are partially formed by their history of experience with the behaviour (Johnston & Ohan, 2005). This has been shown in mothers of children with ADHD who, compared to parents of children without ADHD, tended to extend their attributions about their own child's inattentive/impulsive behaviour to the oppositional and defiant behaviour in children from the vignettes. Thus, if parents' attributions about their child's sleep problem are partially formed by their experiences with the behaviour, we might expect parents of children with ASD and a co-occurring sleep problem to extend their beliefs about sleep problems in their own child to the attributions about children in the vignettes.

## **Methods**

### *Ethics and consent*

Ethical approval for this study was provided by the University of Canterbury Human Ethics Committee (HEC 2017/32/LR-PS). This was obtained during the registration of the thesis proposal and prior to the distribution of the survey. All parents were required to give consent for the use of their data. This process is described in detail later in this chapter.

### *Recruitment and screening*

The survey was distributed throughout New Zealand to parents of children with ASD. Participants were recruited using snowball sampling in which an initial email was sent to a variety of national service providers (e.g., Autism New Zealand and Parent-to-Parent), with a request to disseminate information about the survey via their distribution lists. This email included a flyer that provided information about the survey as well as a survey link. All groups of participants were recruited through the same system and there was no restriction on the number of participants.

### *Participants*

Participants were parents or primary caregivers with children aged 0-18+ who had a diagnosis of ASD and did or did not have a co-occurring sleep problem. The participants were recruited from throughout New Zealand (NZ). Parents were excluded from the survey if, (1) the child had a sleep problem but did not have a confirmed diagnosis of ASD, (2) the participant was not a primary caregiver. Confirmation of a clinical diagnosis of ASD was confirmed by the parents within the questionnaire. Out of the initial 63 respondents, 61 had completed the survey,



had a child diagnosed with ASD, and were included in the study. Table 2 provides a summary of the demographic characteristics obtained from the participants of our study. Participants were mostly parents of children with a CSP (n=44, 72%), followed by parents of children with PSP (n=11, 18%), and parents of children with NSP (n=6, 10%) (see Table 2). As shown by Table 2, parents were commonly aged between 25-34 (20%), 35-44 (37%), 45-65 (42%), and their children were commonly aged between 5-7 (26%), 8-10 (20%), 11-14 (18%). Because the small sample of parents of children with NSP, data for this group has not been reported in the body of this thesis. Instead, this data is presented in Appendices 1-4.

Table 2 provides a summary of the demographic characteristics obtained from the participants of our study. The majority of participants (N = 61) were mothers (n=57, 93%), of NZ European descent (n=45, 74%) and had an annual household income of  $\geq$ \$70,001-\$100,000. Income for parents of children with a CSP demonstrated a wide range of annual income. However, parents with a PSP, or no experience with a SP, were found to be less varied. Furthermore, having some level of university qualification was found to be represented by the slight majority in parents with a PSP (63%) or no NSP (67%). However, the majority parents of children with a CSP were found to be represented by parents who had achieved a university level qualification (82%) compared to those who had achieved a High school level qualification. Overall, the majority of respondents were NZ European mothers with a University level qualification and with a steady income.

Table 2. Demographic Characteristics of the Sample

Demographic data	N	%
Parent age		
25-34	12	20%
35-44	22	37%
45-65	26	42%
Child age		
3-4	5	8%
5-7	16	26%
8-10	12	20%
11-14	11	18%
15-18	10	16%
18+	6	10%
Relationship to child		
Mother	57	93%
Father	3	4%
Other	1	
Status of child's sleep problem		
Has a sleep problem	44	72%
Past sleep problem	11	18%
Never had a sleep problem	6	10%
Ethnicity		
NZ European/Pakeha	45	74%
Maori	4	6%
Pasifika	1	
Asian	1	
Other	9	15%
Marital status		
Single	5	8%
Married	50	82%
Divorced or separated	6	10%
Total members of household		
2	3	5%
3	13	21%
4	29	48%
5	9	15%
6+	7	11%
Employment status		
Employed	28	46%
Self-employed	6	10%
Not currently working	7	12%
Homemaker	17	28%
Student	1	
Unable to work	2	3%
Level of Qualification		
Did not complete High school	6	10%
High school	8	13%
College/ University undergraduate	31	51%
College/University postgraduate	16	26%

### *Survey Instrument*

A cross-sectional research design was used for this study. The survey was managed using Qualtrics ([www.qualtrics.com](http://www.qualtrics.com)). The first page of the survey included information about the study, a mandatory consent form, and information about how participant data will be used. Then participants were asked to respond to a selection of demographic questions, whether their child has a confirmed diagnosis of ASD, who provided the diagnosis, and whether their child has a sleep problem. At this point, the survey stemmed into three versions based on the participants' responses to whether their child had a sleep problem.

The three versions comprised the survey originally developed by researchers from the University of Canterbury (Appendix G); and two adapted versions of that survey. The original survey applied to parents from the CSP group (see Appendix G). Both adapted versions were altered so that they applied to the two additional new groups of parents. These were those whose child with ASD had a sleep problem which is no longer present (Appendix H) and those whose child with ASD had never had a sleep problem (Appendix I). All surveys included the exact same consent form (see Appendix E), questions for demographic information, and response format. However, the two adapted surveys had additional questions pertaining to whether their child has had a sleep problem or not. For example, the survey for parents from the PSP group included questions regarding the age at which the sleep problem was present and the age that it ceased. For the NSP group, the survey included questions designed to determine whether the parents felt concerned about the possible development of sleep problems, whether preventative measures had been taken; and what treatment measures they would access if a sleep problem were to emerge. Some questions in the two adapted surveys were altered according to the group

that the parent selected to ensure that they were appropriate for that group. Additional questions were minimized to ensure all groups included received as similar a measure as possible.

Information on parental attributions about sleep problems in children with ASD were collected using three five-point Likert scales. One Likert scale asked participants about the extent of their concern regarding sleep problems (1=not at all; 5=primary and most significant concern). Another Likert scale asked participants to rate the extent to which they agreed with the following statements about sleep problems in their child (1=Strongly disagree; 5=Strongly agree): The sleep problem: *it is a feature of my child's diagnosis* (locus); *it is a part of who they are* (i.e., it's just the way they are (locus); *is intentional* (controllability); *is unlikely to change* (stability); *my child should be responsible for managing their own sleep and sleep-related behavior* (controllability); *my child's sleep problems are outside of their control* (controllability). The final Likert scale asked participants to indicate whether they believed sleep problems would resolve without treatment.

There were 19 questions which were designed to assess parents' beliefs about the causes of sleep problems in children with ASD. These 19 items about causes were categorised into four high-level causes which were medical (i.e., related to the medical conditions previously noted), sensory (e.g., sensitivity to noise levels), related to poor sleep hygiene (e.g., inconsistent bedtime), or whether the parents considered them to be learned or acquired sleep problems that interfere with falling asleep or staying asleep (e.g., child is seeking parental attention). Participants who selected one of these high-level causes were led to questions about the specific aspects of each high-level cause; e.g., if poor sleep hygiene was selected, participants were asked whether they believed it to be bedroom conditions, inconsistent bedtime, inconsistent bedtime routine, use of digital device, or other, etc.

Help-seeking behaviour was determined by participants' responses to questions about the sources of information and help that they had sought, and the treatments previously tried or considered. Data on treatment use was gathered by participants indicating if they had ever used an intervention to treat the sleep problem; whether their child was on sleep medication and what this was; and any treatments that they had previously tried or were currently trying for the sleep problem. For participants from the NSP group, data on treatment use of medication also included a five-point Likert scale on which participants rated how likely they were to consider medication as treatment (1=never; 5=first choice). Treatment options were selected from a list of 14 treatments and one option for a written ("other") response was provided. Participants were asked to rate their perceived effectiveness of these treatments via a five-point Likert scale (1 = ineffective; 5 = resolved the sleep problem). Options included unconventional treatments (e.g., homeopathy), behavioral strategies (e.g., systematic ignoring) and pharmacological approaches (e.g., prescribed medication). Treatments were classified as being empirically-supported or non-supported based on relevant research (McLay & France, 2016; Turner & Johnson, 2013). Sources of information and help was determined by participants' selection from a list of 13 possible sources, including sources of professional help as well as self-directed learning options (e.g., books and websites).

An additional four questions were created specifically for participants with children with ASD that have never experienced a sleep problem. Each of these questions required participants to rate their responses using a five-point Likert scale (1=not important; 5=important) relating to their child's sleep: How important is maintaining consistent sleep routines/ bedtimes to you?; How important are you in maintaining your child's sleep routine?; How important is your child in maintaining their own sleep routine?; How would you rate your ability to regulate your child's

sleep? These questions were used to obtain information about parent's beliefs about their child's sleep and the parental role in their child's sleep.

Finally, identical vignettes were constructed for all versions of the survey (see Appendix J). The vignettes described scenarios about different fictional children with varying levels of ASD functioning who were displaying sleep related problem behaviours. All surveys asked the participants to answer the vignettes in a similar format to the previous five-point Likert scales. By creating vignettes about fictional children, we were able to show whether certain experiences with sleep problems in ASD influenced parent's attributions. There was also a second purpose for the vignettes which was to understand how parents might respond to scenarios which reflected a slight emphasis on different causes of a sleep problems in children. Specifically, the vignettes were created to subtly represent four different contributing factors: sleep resisting behaviour (Antonio), circadian rhythm disturbances (Madi), sleep competing stereotypy (Tane), and sleep interfering anxiety (Awhina). This was to determine whether parents' beliefs about sleep problems in children changed depending on how the context of the behaviour was presented to the parent (see Appendix G). The vignettes also represented varying levels of ASD functioning in the vignettes about fictional children. For the vignettes about Antonio (no verbal skills) and Madi (strong verbal skills), their verbal capabilities were explicitly written into the statements of the respective vignettes. However, the vignette for Awhina subtly depicted her ability to communicate with her mother while the vignette for Tane did not disclose whether he is able to communicate his feelings. This was to determine whether parents made different attributions about the intent of the child's behaviour depending on whether the child was unable to verbally communicate.

### *Data Analysis*

For the purposes of this study, the Statistical Package for Social Sciences (SPSS) version 25 and Jamovi version 1.2.12 were used to analyse the data. Information about treatment selection was obtained by examining parents' responses to whether they had ever used an intervention to treat their child's sleep problem; whether their child was on medication to treat the sleep problem, and any treatments that they had tried or were currently trying to treat their child's sleep problem. Information on parents' help-seeking behaviour was obtained by parents' responses to questions about what sources of information they sought and the perceived efficacy of treatments. The obtained participants' responses to questions about their previous treatment used, professional help received, and their perception of the efficacy of treatments were then analysed using basic descriptive statistics (i.e., median, standard deviation, frequency).

Relationships between parents' causal beliefs and treatment selection in the groups containing the parents with experience of sleep problems in their children (the CSP and PSP group) were investigated by pooling parents' responses about causal beliefs and treatment selection. Chi-square correlations were used to assess the nature of the relationship and significant relationships were indicated by a p-value that is less than 0.05 ( $p < 0.05$ ). Due to our sample size, the number of cases for the Chi-square were violated and so the Likelihood ratio was used instead.

Pearson's  $r$  correlations were used to determine relationships between parental beliefs about sleep problems and parents' experience with sleep problems for the CSP and PSP groups. Significant relationships were indicated by a p-value that is less than 0.05 ( $p < 0.05$ ). Correlations between parental attributions about sleep problems were first made with the data

from the CSP and PSP group pooled together. After, correlations between the attributions from each group were compared to the pooled correlation sample. Parents from the NSP group were not included in the analysis due to the small N for this sample.

Whether parents' history of experience influenced their attributions towards sleep problems was determined by parents from the CSP and PSP groups answering similarly to the vignettes as they did for the related questions about their own child. This relationship was also tested using Person's  $r$  correlations with significant relationships indicated by a  $p$ -value that is less than 0.05 ( $p < 0.05$ ). The attributions made by parents from the CSP and PSP group about the vignettes were correlated separately and afterwards were compared to the correlations made by parents which were not from the pooled sample. Inferences were then made about the nature and direction of parents' attributions between the attributions for the vignettes compared to the attributions about their own child.

## Results

### *Parental attributions about sleep problems in children with ASD*

There were seven questionnaire items which related to parental attributions about sleep problems in children with ASD. These items were designed to represent beliefs about the locus, stability and controllability of the sleep problem, and were presented as: (a) *it is a feature of my child's ASD diagnosis (locus)*, (b) *it is a part of who they are (locus)*, (c) *it is intentional (controllability)*, (d) *it is unlikely to change (stability)*, (e) *my child should be responsible for managing their own sleep and sleep-related behaviour (controllability)*, (f) *my child's sleep problems are outside of their control (controllability)*, and (g) *my child's sleep problem will resolve without treatment (stability)*. Table 2 shows the percentage of parents from the CSP and



PSP group who made each attributional response. As shown in Figure 1, parents tended to attribute sleep problems to factors intrinsic to the child and as being outside of the child's control. Of the three dimensions of causality, parental attributions about the stability showed the most variation between CSP and PSP groups. Parents from the CSP group tended to attribute sleep problems to stable factors (see Figure 1) and in contrast, parents of the PSP group tended to view sleep problems as unstable but only if the sleep problem was treated (see Figure 2). A detailed explanation of the descriptive results for the CSP and PSP groups is presented below.

*Table 3. Total number/percent of parents who responded to each attributional response for groups CSP and PSP*

Attributional response	CSP		PSP	
	n	%	n	%
ASD feature	42	94%	11	100%
Intrinsic	41	93%	10	91%
Intentional	42	94%	11	100%
Unlikely to change	38	86%	10	91%
Child responsible	41	93%	11	100%
Outside of control	40	91%	10	91%
Do not need treatment	41	93%	11	100%

*Parental attributions about sleep problems – group CSP*

As shown in Figure 1, parents in the CSP group tended to attribute sleep problems to factors intrinsic to the child. Specifically, the majority (79%) tended to agree and strongly agree

that their child's sleep problem was a part of their ASD diagnosis, that it was part of who they were (57 %) and that it was outside their child's control (59.5%). Parents also tended to not view sleep problems as being controllable with the majority of parents disagreeing and strongly disagreeing that their child's behaviour was intentional (89%) and that their child should be responsible for their own sleep-related behaviour (62%). Parents' attributions about the stability of their child's sleep problem tended to show the most variance in the CSP group. Results showed that 50% of parents "somewhat" agreed that sleep problems were stable while the remaining 50% of parents' responses were divided between those that attributed sleep problems as unstable (disagree, 22.5%) and those that attributed them as stable (agree, 20%). Despite this, the majority of parents tended to disagree that their child's sleep problem would resolve without treatment (78%).

*Parental attributions about sleep problems – group PSP*

As shown by Figure 2, the parents in the PSP group also tended to attribute sleep problems to factors that were intrinsic to the child. Only two parents disagreed or strongly disagreed that it was a feature of their child's ASD diagnosis (18%) and that it was a part of who they are (18%). Furthermore, all parents agreed to some extent that their child's sleep problem was outside of their control. Parents rarely attributed sleep problems as controllable with only one parent somewhat agreeing that the behaviour was intentional (9%) and the majority disagreeing to strongly disagreeing that their child should be responsible for their own sleep-related behaviour (91%). The majority of parents disagreed or strongly disagreed that the sleep problem was unlikely to change (73%) and that it would resolve without treatment (82%).

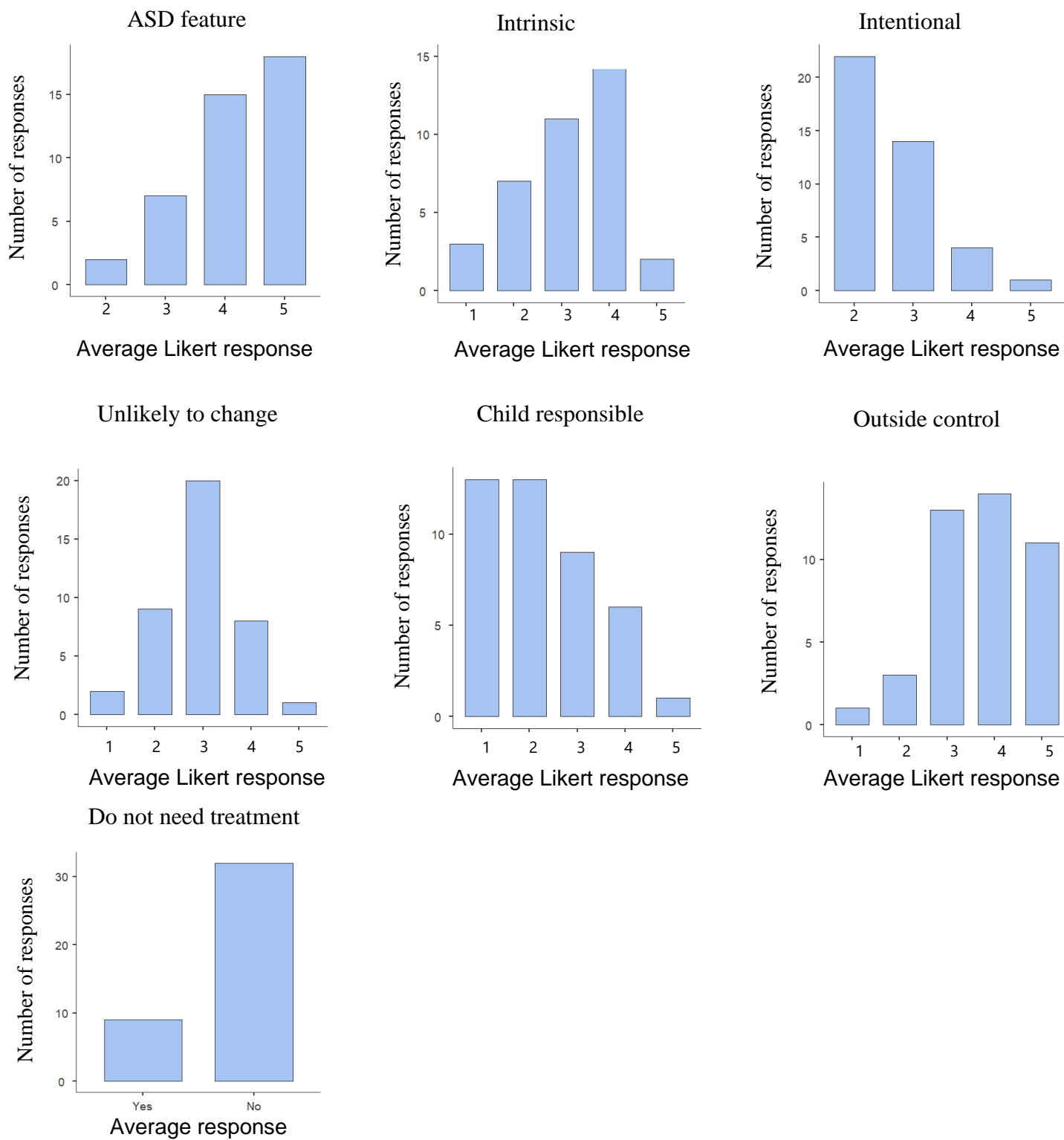


Figure 1. Likert scale responses about sleep problems from parents in the CSP  
\*Note cases with no data are excluded from Figures.

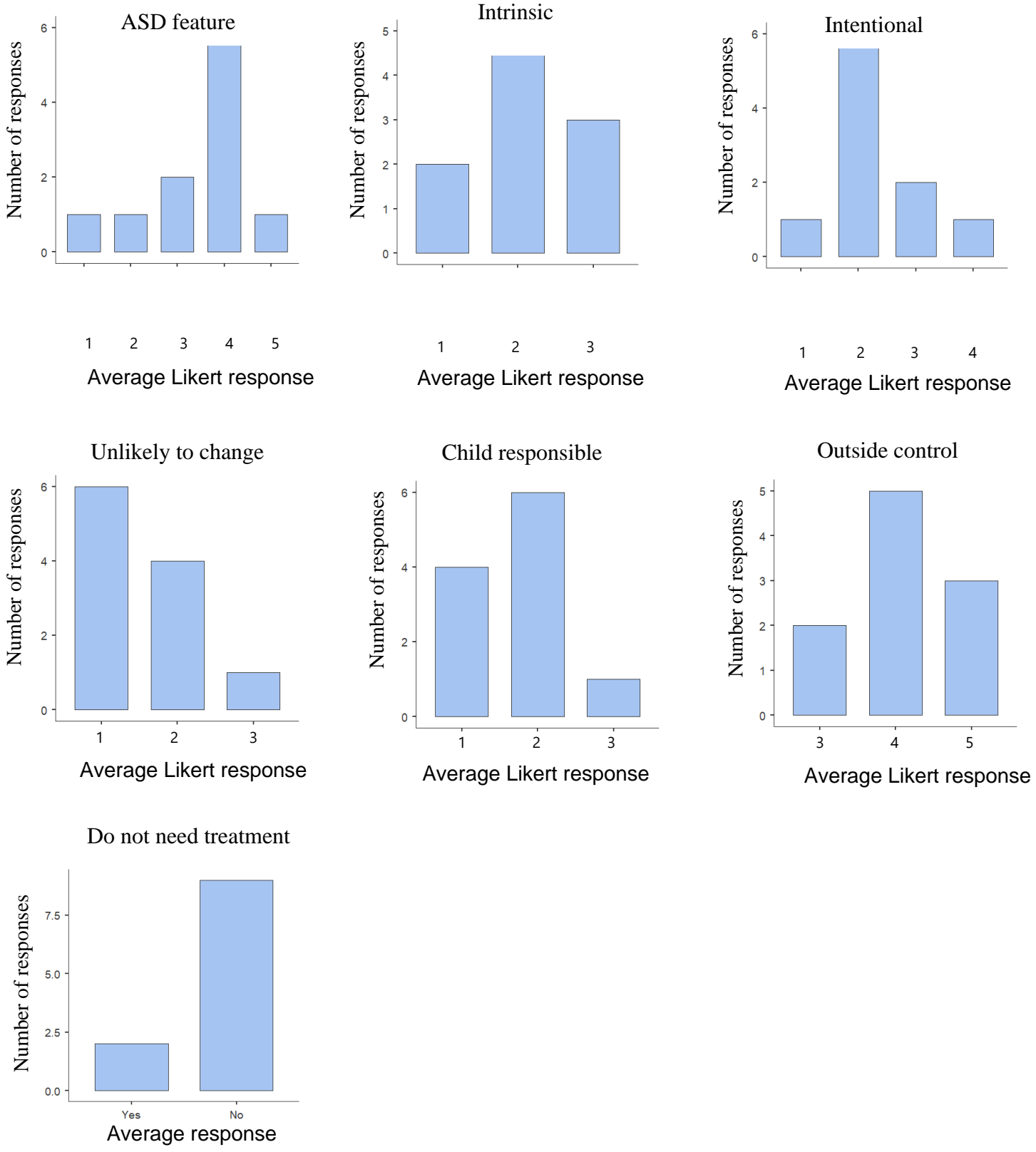


Figure 2. Likert scale responses about sleep problems from parents in the PSP

*Relationship between parental attributions and parenting experience*

Pearson's product-moment correlations were used to determine the strength and direction of relationships between parental attributions about sleep problems amongst the CSP and PSP groups. Relationships between parental attributions were first explored with the data pooled from the CSP and PSP groups (see Table 4). [Parents from the NSP group were excluded from this analysis due to their small sample size]. Two correlations were negative, and were small to moderate in size: The first refers to the correlation between the attributions '*it is a feature of my child's ASD*' and '*it is intentional*'  $r = -.285$  ( $p < 0.05$ ); and the second is between '*it is intentional*' and '*it is unlikely to change*'  $r = -.45$  ( $p < 0.05$ ). Positive correlations of small to moderate size were between the attribution '*it is a feature of my child's ASD*' and '*it is unlikely to change*'  $r = .57$  ( $p < 0.05$ ) and between '*it is a feature of my child's ASD*' and '*my child's sleep problem are outside of their control*'  $r = .27$  ( $p < 0.05$ ).

Table 4. Correlations between parental attributions about sleep problems in children with ASD

		A	B	C	D	E	F	G
Attribution A ASD feature	Pearson's r	—						
Attribution B Intrinsic	Pearson's r	0.080	—					
Attribution C Intentional	Pearson's r	<b>-0.285 *</b>	0.152	—				
Attribution D Unlikely to change	Pearson's r	<b>0.572 *</b>	0.128	0.091	—			
Attribution E Child responsible	Pearson's r	0.122	0.052	0.085	0.054	—		
Attribution F Outside control	Pearson's r	<b>0.274 *</b>	-0.070	<b>-0.452 *</b>	0.080	-0.208	—	
Attribution G Needs treatment	Pearson's r	<b>0.345*</b>	-0.068	-0.242	<b>0.361*</b>	-0.070	<b>0.341*</b>	—

Note \*  $P < .05$

After calculating correlations between parental attributions about sleep problems in children with ASD the correlations between parental attributions were explored separately for the CSP and PSP groups (see Tables 5 and 6). For the CSP group, almost the same pattern of correlations is seen in Table 5 as for Table 4 (the whole sample). The exception to this is that the correlation between the attribution ‘*It is a feature of ASD*’ and ‘*It is intentional*’ is non-significant as is the correlation between ‘*It is outside of my child’s control*’ and ‘*It will resolve without treatment*’. The remaining substantive correlations made by parents from the CSP group (Table 5) are smaller than in the pooled sample (Table 4) almost certainly reflecting the reduction in sample size relative to Table 4. For the PSP group, the only remaining substantive correlation is between ‘*It is a feature of ASD*’ and ‘*Unlikely to change*’  $r = .67$  ( $p < .05$ ; see Table 6).

Table 5. Correlations between parental attributions made by group CSP

		A	B	C	D	E	F	G
Attribution A ASD feature	Pearson's r	—						
Attribution B Intrinsic	Pearson's r	0.022	—					
Attribution C Intentional	Pearson's r	-0.301	0.109	—				
Attribution D Unlikely to change	Pearson's r	<b>0.491 *</b>	0.101	0.069	—			
Attribution F Child responsible	Pearson's r	0.127	0.098	0.135	-0.027	—		
Attribution G Outside control	Pearson's r	<b>0.405 *</b>	-0.025	<b>-0.441 *</b>	0.108	-0.131	—	
Attribution H Need treatment	Pearson's r	<b>0.370 *</b>	-0.121	-0.229	<b>0.376 *</b>	-0.031	0.243	—

Note. \*  $p < .05$

Table 6. Correlations between parental attributions made by group PSP

		A	B	C	D	E	F	G
Attribution A ASD feature	Pearson's r	—						
Attribution B Intrinsic	Pearson's r	0.205	—					
Attribution C Intentional	Pearson's r	-0.094	0.532	—				
Attribution D Unlikely to change	Pearson's r	<b>0.667 *</b>	0.311	0.286	—			
Attribution E Child responsible	Pearson's r	-0.087	0.067	0.143	0.180	—		
Attribution F Outside control	Pearson's r	-0.051	-0.429	-0.319	-0.055	-0.379	—	
Attribution G Need treatment	Pearson's r	0.418	-0.286	-0.327	0.192	0.174	0.071	—

Note. \*  $p < .05$

## Parents' beliefs about causes of sleep problems

### *Beliefs about cause of sleep problems - CSP group*

As shown in Table 7, the majority of parents from the CSP group believed sleep problems were caused by sensory problems (68%). This was followed closely by medical factors (48%) however, learned or acquired sleep problems (29.5%) and sleep hygiene (7%) were believed by few parents from the CSP group. The 68% of respondents who believed sensory problems were a cause tended to also believe in a variety of sensory-related sleep problems e.g., 'identified noise levels' (27%), 'bedroom temperature' (24%), 'bedroom light' (21%), and 'issues with bedding' (21%). In comparison, the 29.5% respondents for learned or acquired sleep problems tended to commonly believe in two causes of sleep problems related to learned or acquired sleep problems, which were the 'child does not want to be left alone' (45.5%) and that

they were *'avoiding bedtime'* (36%). Parents from the CSP group also reported a number of *'other'* causal beliefs (54.5%), including anxiety, bed-sharing, environmental over-stimulation, and obsessive routines. Few participants endorsed sleep hygiene as a cause of sleep problems (7%) and 33% of these parents indicated that these were caused by *'bedroom conditions'*.

#### *Beliefs about cause of sleep problems - PSP group*

As shown by Table 7, parents from the PSP group most commonly believed sleep problems were caused by medical factors (64%). This was followed closely by sensory problems (54.5%) and learned or acquired sleep problems (54.5%). However, sleep hygiene was not commonly believed to be a cause of sleep problems for those in the PSP group (18%). Parents who endorsed learned or acquired sleep problems believed that *'access to preferred activities, items, or toys'* (83%) the *'child did not want to be alone'* (33%), and the child *'seeking parent's attention'* (33%) were causes of sleep problems. Few participants endorsed sleep hygiene as a cause of sleep problems (18%) and 50% of the parents who endorsed sleep hygiene indicated that it was caused by *'bedroom conditions'*. Of the 54.5% parents from the PSP group who responded to sensory problems, 50% of these parents identified *'noise levels'*, *'bedroom light'*, and *'issues with bedding'* as causes related to sensory problems.



*Table 7. Parents' beliefs about the causes of sleep problems in children with ASD*

Beliefs about the cause	Percentage of responses	
	N	%
<b>CSP</b>		
Sleep hygiene	3	7%
Learned or acquired behaviour	13	29.5%
Sensory problem	30	68%
Medical factors	21	48%
Other	13	29.5%
<b>PSP</b>		
Sleep hygiene	2	18%
Learned or acquired behaviour	6	54.5%
Sensory problems	6	54.5%
Medical factors	7	64%
Other	1	
<b>NSP</b>		
Sleep hygiene	5	83%
Learned or acquired behaviour	5	83%
Sensory problems	6	100%
Medical factors	3	50%
Other	1	17%

### Parents' help-seeking behaviour

As shown in Table 8, parents from the CSP group ( $M=1.9$ , Range 0-10) had sought help for their child's sleep problem from a wider range of sources when compared to parents from the PSP group ( $M=1.6$ , Range 0-6). On average, parents from the CSP group were also slightly more likely to seek advice/help for their child's sleep problem compared to parents from the PSP

group. ‘*Pediatricians and/or other medical doctor*’ tended to be the most likely source of information that had been sought by parents from the CSP (52%) and PSP (64%) groups compared to other sources of advice/help and were selected by the majority of parents (see Table 8). ‘*Web-based sources*’ (25%), ‘*Other parents*’ (25%), and ‘*Psychologists*’ (20.5%) were similarly chosen by parents from the CSP and PSP group and were amongst the most likely sources of advice/help that parents had/were likely to seek (see Table 8). As shown in Table 8, there were no parents from the CSP or PSP group that had sought advice/help from ‘*Physiotherapists*’ and ‘*Speech language therapists*’. Further, only one parent from the CSP group had sought advice from a ‘*BCBA*’ and few parents were likely to seek information from ‘*No-one*’ (20.5%).

*Table 8. Sources of advice/help parents have sought for their child’s sleep problem*

Sources of advice/help	CSP		PSP		NSP	
	n	%	n	%	n	%
Psychologist	9	20.5%	2	18%	1	17%
Behaviour analyst	1		-		1	17%
Occupational therapist	3	7%	1	9%	2	33%
Physiotherapist	-		-		-	
Speech therapist/Pathologist	-		-		-	
Teacher	2	4.5%	-		-	
Researcher	1		-		-	
Pediatrician/other medical doctor	23	52%	7	64%	5	83%
Web-based sources	11	25%	3	27%	3	50%
Books	12	27%	1	9%	1	17%
Parents	11	25%	3	27%	-	
No-one	9	20.5%	1	9%	-	

## Parental treatment choices and perceived efficacy

### *Treatment selection*

The majority of parents in the PSP (82%) and CSP group (72%) had received some type of treatment for their child's sleep problem. Parents in the CSP group tended to indicate that the perceived level of support received during treatment was 'occasional/moderate' (37%), 'little' (30%), or 'none' (17%). Comparatively, parents from the PSP group perceived the support received as either 'little' (40%), 'none' (40%), or as 'occasional/moderate' (20%). Parents from the CSP group had, on average, tried seven treatments for their child's sleep problem (M=7.1, Range 0-12). In comparison, parents from the PSP group had tried fewer treatments for their child's sleep problem but had accessed the same range of treatments for their child's sleep problem (M=5.8, Range 0-12). These findings indicate that parents from both the CSP and PSP groups accessed treatments with varying degrees of scientific support.

As shown by Table 9, parents from the PSP (64%) and CSP (67%) groups most commonly used 'medication' as a treatment for their child's sleep problem(s). However, both groups also tended to select treatments that were unsupported or had limited support slightly more frequently than behavioural treatments. For example, four treatments with limited or mixed evidence were found to have been used by the majority of parents from the CSP group (see Table 9). The most common treatment selected by parents in the PSP group, that has no evidence of efficacy, was 'weighted blankets' (64%). While 'modified systematic ignoring' (45%) tended to be amongst the most likely treatments to be used by parents from the PSP group, other behavioural treatments such as 'scheduled awakenings' (18%) and 'bedtime fading' (18%) were amongst the least likely to have been used by the same parents.

In comparison, ‘*systematic ignoring*’ (48%), ‘*bedtime fading*’ (45%), and ‘*modified systematic ignoring*’ (45%) were selected by slightly under half of parents from the CSP group indicating that parents from the CSP group were more likely to select a behavioural treatment compared to parents from the PSP group (see Table 9). However, parents from the CSP group were also more likely to select a variety of treatments with no evidence of efficacy compared to parents from the PSP group including ‘*homeopathic remedies*’ (54.5%), ‘*co-sleeping*’ (54.5%), and ‘*exercise*’ (48%).

#### *Perceived effectiveness of treatments*

Parents from the CSP (87%) and PSP (100%) group perceived ‘*prescribed medication*’ as the most effective treatment for sleep problems in children with ASD (see Table 9). Parents from the CSP group overall did not tend to perceive behavioural treatments as being effective, with ‘*systematic ignoring*’ (14%) and ‘*bedtime fading*’ (15%) being perceived as effective by a minority of parents (see Table 9). In contrast, treatments with mixed evidence or those which were unsupported by research were perceived as more effective than treatments with scientific support, by parents from the CSP group. Interestingly, while parents from the CSP group perceive unsupported and mixed evidence treatments as being more effective than behavioural treatments, only ‘*white noise*’ was found to be perceived as effective by the majority of parents (50%). As shown in Table 9, parents in the PSP group did not tend to view many treatments as being effective. This may be due, in part, to the low number of responses made by parents from the PSP group. However, with consideration to the lower number of responses made by parents from the PSP group, ‘*weighted blankets*’ was also perceived by the majority of parents as being effective (71%) (Table 9).

*Table 9. Parents treatment use, the level of scientific support for treatments used by parents, and the perceived effectiveness of treatments used by parents*

<i>Treatment</i>	<i>Parents treatment use by group</i>						<i>Level of support</i>	<i>Treatments rated as likely to be effective by users</i>					
	CSP (n=44)		PSP (n=11)		NSP (n=6)			CSP		PSP		NSP	
	n	%	n	%	n	%		n	%	n	%	n	%
Prescription medication	30	68%	7	64%	1	17%	Supported	26	87%	7	100%	-	
Exercise	21	48%	2	18%	-		Unsupported	9	43%	1	50%	-	
Co-sleeping	24	54.5%	4	36%	1	17%	Unsupported	9	37.5%	2	50%	-	
Homeopathic	24	54.5%	4	36%	1	17%	Unsupported	10	42%	1	25%	1	100%
Systematic ignoring	21	48%	4	36%	2	33%	Supported	3	14%	1	25%	2	100%
Bedtime fading	20	45%	2	18%	-		Supported	3	15%	1	50%	-	
Modified systematic ignoring	20	45%	5	45%	2	33%	Supported	6	30%	2	40%	2	100%
Social stories	18	41%	2	18%	1	17%	Some support	-		-		1	100%
White noise	24	54.5%	5	45%	2	33%	Some support	12	50%	2	40	1	50%
Weighted blanket	25	57%	7	64%	1	17%	Unsupported	10	40%	5	71%	1	100%
Scheduled awakenings	11	25%	2	18%	-		Supported	-		-		-	
Video modelling	9	20%	2	18%	-		Unsupported	-		-		-	

\*Classifications based on evidence from systematic reviews and meta-analyses (e.g., Carnett et al., 2019; Hollway & Aman, 2011; McLay et al., 2016; Turner & Johnson, 2013).

*Relationship between treatment choice and beliefs about the causes of sleep problems*

Significant relationships between the variables of parental beliefs about sleep problems and parental treatment choice were determined by the Likelihood ratio (see Table 10). [This was due to the number of responses for parents' treatment choices which led to a violation of the assumptions of a Chi-square analysis]. Parental beliefs about cause and parental treatment selection were pooled together from the CSP and PSP groups (see Table 10). [Group NSP was excluded from analysis due to the small sample]. Table 10 found two positive correlations, weak in size, between parent's treatment choices and their belief that sleep problems were caused by 'medical factors'. The first relationship was between 'medical factors' and 'bedtime fading'  $r=0.025$  ( $p < .05$ ) and the other was between 'medical factors' and 'systematic ignoring'  $r=0.020$  ( $p < .05$ ). Two more weak positive correlations were found between two different beliefs about the cause of sleep problems and the same treatment, 'systematic ignoring'. These were the between 'sleep hygiene' and 'systematic ignoring'  $r=0.035$  ( $p < .05$ ) and between 'sensory problems' and 'systematic ignoring'  $r=0.033$  ( $p < .05$ ) (see Table 10).

Table 10. Significant correlations found between parents' causal beliefs and treatment selection for groups CSP and PSP from Likert ratio

	Treatment	Value	Df	Asymptotic significance
<b>Causal Belief</b>				
Hygiene	Systematic ignoring	5.00	2	<b>0.035*</b>
Medical	Systematic ignoring	14.1	4	<b>0.20*</b>
Medical	Bedtime fading	7.87	2	<b>0.25*</b>
Sensory	Systematic ignoring	11.2	3	<b>0.33*</b>

Note.  $P < .05$  \*

### Parents' history of experience with sleep problems

There were five questionnaire items which related to parental attributions about sleep problems in children with ASD. These questions related to four vignettes which each described a different child with varying presentations of sleep problems and ASD related behaviour (see Appendix J). The questionnaire items were designed to represent beliefs about the locus, stability and controllability of the sleep problem, and were presented as: (a) *it is likely to resolve without treatment (stability)*, (b) *it is a part of their natural sleep cycle (locus)*, (c) *the behaviour is a part of their ASD (locus)*, (d) *the behaviour is learnt and can be changed (controllability)*, (e) *if the parents change their response the behaviour will change (locus)*. Pearson's correlations were used to determine the strength and direction of relationships between parental attributions about sleep problems amongst the CSP and PSP groups (see Tables 12-19). A detailed explanation of the descriptive results for the CSP and PSP groups are presented below.

*Vignette attributions – CSP group*

For parents from the CSP group, results showed that there were seven statistically significant relationships between parental attributions from the vignettes (see Table 11-14). One correlation was a weak negative relationship between '*It is likely to resolve without treatment*' and '*it is a part of their ASD*' in the vignette for Antonio (sleep resisting behaviour)  $r = -.40$  ( $p < 0.05$ ). Positive correlations of weak to strong size were between attribution '*It will resolve without treatment*' and '*It is a part of their sleep cycle*' =  $r = .406$  ( $p < 0.05$ ) and between '*The behaviour is learnt and can change*' and '*If the parents change their response the behaviour will change*'  $r = .868$  ( $p < 0.05$ ) in the vignette for Antonio (sleep resisting behaviour). Further, two positive correlations, weak to strong size, were found in the vignette for Madi (circadian rhythm disturbance) between attribution '*It is likely to resolve without treatment*' and '*If the parents change their response the behaviour will change*' =  $r = .371$  ( $p < 0.05$ ) and between '*The behaviour is learnt and can change*' and '*If the parents change their response the behaviour will change*'  $r = .868$  ( $p < 0.05$ ). Lastly, two strong positive correlations were found between attributions '*The behaviour is learnt and can change*' and '*If the parents change their response the behaviour will change*' in the vignette for Tane (sleep competing stereotypy)  $r = .747$  ( $p < 0.05$ ) and the vignette for Awhina (sleep interfering anxiety)  $r = .907$  ( $p < 0.05$ ).



*Table 11. Correlation matrix Antonio for group CSP (sleep resisting behaviour)*

		<b>Antonio A</b>	<b>Antonio B</b>	<b>Antonio C</b>	<b>Antonio D</b>	<b>Antonio E</b>
Antonio A	Pearson's r	—				
No treat						
Antonio B	Pearson's r	<b>0.406 *</b>	—			
Sleep cycle						
Antonio C	Pearson's r	<b>-0.400 *</b>	-0.146	—		
Part of ASD						
Antonio D	Pearson's r	0.081	-0.209	0.016	—	
Can change						
Antonio E	Pearson's r	0.069	-0.207	-0.103	<b>0.868 *</b>	—
Parents change						

Note. \* p < .05

*Table 12. Correlation matrix Madi for group CSP (circadian rhythm disturbance)*

		<b>Madi A</b>	<b>Madi B</b>	<b>Madi C</b>	<b>Madi D</b>	<b>Madi E</b>
Madi A	Pearson's r	—				
No treat						
Madi B	Pearson's r	0.229	—			
Sleep cycle						
Madi C	Pearson's r	-0.068	0.023	—		
Part of ASD						
Madi D	Pearson's r	0.308	-0.272	-0.245	—	
Can change						
Madi E	Pearson's r	<b>0.371 *</b>	-0.154	-0.162	<b>0.883 *</b>	—
Parents change						

Note. \* p < .05

*Table 13. Correlation matrix Tane for group CSP (sleep competing stereotypy)*

		<b>Tane A</b>	<b>Tane B</b>	<b>Tane C</b>	<b>Tane D</b>	<b>Tane E</b>
Tane A	Pearson's r	—				
No treat						
Tane B	Pearson's r	0.304	—			
Sleep cycle						
Tane C	Pearson's r	-0.017	-0.100	—		
Part of ASD						
Tane D	Pearson's r	-0.103	-0.118	-0.053	—	
Can change						
Tane E	Pearson's r	-0.093	-0.101	0.110	<b>0.747 *</b>	—
Parents change						

Note. \* p < .05

*Table 14. Correlation matrix Awhina for group CSP (sleep interfering anxiety)*

		<b>Awhina A</b>	<b>Awhina B</b>	<b>Awhina C</b>	<b>Awhina D</b>	<b>Awhina E</b>
Awhina A	Pearson's r	—				
No treat						
Awhina B	Pearson's r	0.210	—			
Sleep cycle						
Awhina C	Pearson's r	-0.220	-0.311	—		
Part of ASD						
Awhina D	Pearson's r	-0.042	0.227	0.048	—	
Can change						
Awhina E	Pearson's r	-0.020	0.283	0.020	<b>0.907 *</b>	—
Parents change						

Note. \* p < .05

*Vignette attributions - PSP group*

For parents from the CSP group, results showed that there were six statistically significant relationships between parental attributions within the four vignettes (see Table 15-18). One correlation was a strong negative relationship between ‘*If the parents change their behaviour*’ and ‘*it is a part of their ASD*’ in the vignette for Tane (sleep competing stereotype)  $r = -.817$  ( $p < 0.05$ ). Two strong positive correlations were found between attributions ‘*The behaviour is learnt and can change*’ and ‘*If the parents change their behaviour*’ for the vignette for Antonio (sleep resisting behaviour)  $r = .801$  ( $p < 0.05$ ) and the vignette for Madi (circadian rhythm disturbance)  $r = .885$  ( $p < 0.05$ ). The remaining correlations were strong positive relationships in the vignette for Awhina (sleep interfering anxiety) between attribution ‘*The behaviour is learnt and can change*’ and ‘*If the parents change their behaviour*’ =  $r = .889$  ( $p < 0.05$ ) and between ‘*it is likely to resolve without treatment*’ and ‘*If the parents change their behaviour*’ =  $r = .747$  ( $p < 0.05$ ) and between ‘*it is likely to resolve without treatment*’ and ‘*The behaviour is learnt and can change*’  $r = .802$  ( $p < 0.05$ ).

*Table 15. Correlation matrix Antonio for group PSP (sleep resisting behaviour)*

		<b>Antonio A</b>	<b>Antonio B</b>	<b>Antonio C</b>	<b>Antonio D</b>	<b>Antonio E</b>
Antonio A	Pearson's r	—				
No treat						
Antonio B	Pearson's r	0.000	—			
Sleep cycle						
Antonio C	Pearson's r	0.000	-0.540	—		
Part of ASD						
Antonio D	Pearson's r	0.113	0.734	-0.510	—	
Can change						
Antonio E	Pearson's r	0.539	0.382	-0.539	<b>0.801 *</b>	—
Sleep cycle						

Note. \*  $p < .05$

*Table 16. Correlation matrix Madi for group PSP (circadian rhythm disturbance)*

		<b>Madi A</b>	<b>Madi B</b>	<b>Madi C</b>	<b>Madi D</b>	<b>Madi E</b>
Madi A	Pearson's r	—				
No treat						
Madi B	Pearson's r	0.258	—			
Sleep cycle						
Madi C	Pearson's r	-0.370	-0.458	—		
Part of ASD						
Madi D	Pearson's r	0.372	0.600	-0.240	—	
Can change						
Madi E	Pearson's r	0.415	0.520	-0.374	<b>0.885 *</b>	—
Parents change						

Note. \*  $p < .05$

*Table 17. Correlation matrix Tane for group PSP (sleep competing stereotypy)*

		<b>Tane A</b>	<b>Tane B</b>	<b>Tane C</b>	<b>Tane D</b>	<b>Tane E</b>
Tane A	Pearson's r	—				
No treat						
Tane B	Pearson's r	0.418	—			
Sleep cycle						
Tane C	Pearson's r	-0.292	0.132	—		
Part of ASD						
Tane D	Pearson's r	0.000	0.000	-0.519	—	
Can change						
Tane E	Pearson's r	0.320	0.000	<b>-0.817 *</b>	0.750	—
Parents change						

Note. \* p < .05

*Table 18. Correlation matrix Awhina for group PSP (sleep interfering anxiety)*

		<b>Awhina A</b>	<b>Awhina B</b>	<b>Awhina C</b>	<b>Awhina D</b>	<b>Awhina E</b>
Awhina A	Pearson's r	—				
No treat						
Awhina B	Pearson's r	0.552	—			
Sleep cycle						
Awhina C	Pearson's r	-0.424	-0.234	—		
Part of ASD						
Awhina D	Pearson's r	<b>0.802 *</b>	0.147	-0.340	—	
Can change						
Awhina E	Pearson's r	<b>0.747 *</b>	0.112	-0.086	<b>0.889 *</b>	—
Parents change						

Note. \* p < .05

## Discussion

The purpose of the current study was to investigate the differences between parental beliefs about sleep problems in children with ASD made by parents who had varying experiences with sleep problems in children with ASD. Additionally, we were interested in the relationship between parental beliefs about sleep problems and the factors affecting the parents' help-seeking behaviour and treatment selection. Overall, our results showed that parents from the CSP and PSP groups tended to view sleep problems as internal to the child and outside of the child's control. However, evidence found that parents with children with a PSP may attribute sleep problems to factors that are less stable compared to parents of children with a CSP. Parents from the PSP group were more likely to believe in a cause of sleep problems where the parent has a role in the cause of their child's sleep problem compared to parents from the CSP group. However, it was also found that parents from the PSP group tended to have beliefs about the cause of sleep problems that were child-referent more often than beliefs which were parent-referent suggesting that parents of children with ASD and a CSP or PSP may minimize their role in their child's behaviour.

Interestingly, a meaningful difference between the treatment selection of parents from the CSP and PSP groups was not established within our data but parents from both groups were slightly more likely to use treatments that are unsupported or have limited evidence compared to those with scientific support (e.g., behavioural treatments). This was despite the identification of a relationship between parents' causal beliefs about sleep problems and their likelihood to select two behavioural treatments: systematic ignoring, and bedtime fading. This may suggest that

parents' choice of an unsupported treatment for their child's sleep problem is associated with factors other than causal beliefs. Finally, evidence showed that the attributions made by parents from the CSP and PSP groups about their own child are different to the attributions the same parents made for the vignettes. This may indicate that parents' attributions about sleep problems in children with ASD are not moderated by their experiences with the problem behaviour and therefore are unlikely to extend their beliefs about sleep problems to other families with children with a CSP. These findings are discussed in depth below with respect to our hypotheses.

#### *Parental attributions about sleep problems in parents of children with ASD*

We hypothesised there would be statistically significant differences in the attributions made by the parents of children with different experiences with sleep problems (CSP and PSP). Because of the sample size for parents from the NSP group, we removed this group from the correlational analysis of parental attributions about sleep problems to preserve statistical meaning. Our data supported our hypothesis by finding a statistically significant difference between parents' attributions about the stability of their child's sleep problem in the CSP and PSP groups. Specifically, our data found that parents from the PSP group tended to attribute sleep problems in children with ASD as being unstable but still requiring treatment in order to resolve. In comparison, parents from the CSP group were more likely to attribute sleep problems to stable factors than parents of children with a PSP but they also believed that their child's sleep problems would require treatment to resolve.

Our finding that parents from the CSP group tended to make attributions that were both internal and stable aligned with the previously established research on parental attributions about sleep problems (Bessey et al., 2013; Robinson & Richdale, 2004). Until now, research has not yet investigated what attributions parents of children with a PSP might make about their child's sleep problem. However, the finding that parents from the PSP group tended to attribute sleep problems to less stable factors compared to parents from group CSP might be the result of parents from the PSP group being more likely to have experienced receiving treatment for their child's sleep problem. As a result, parents from the PSP group may be less likely to view sleep problems as chronic/untreatable compared to the parents from the CSP group who may view sleep problems as stable and treatment resistant, as they have not yet been resolved.

Our data did not find a statistically significant difference between parents' attributions about the locus or controllability of their child's sleep problem, between the CSP and PSP groups. Previously, research found that parents may misattribute their child's sleep problem to their medical condition and factors that are inherent to their child (Robinson & Richdale, 2004). However, parental beliefs that sleep problems are caused by factors inherent to their child are not entirely true as although sleep problems often co-occur with a child's ASD diagnosis they are separate conditions. This is shown through the treatment of problematic sleep problems in children with ASD where the sleep related problem can be treated but the core sensory and communication problems related to ASD will likely remain. Therefore, it was hypothesised that parents from the PSP group would attribute sleep problems to factors that were external to their child because of their experiences with treating their child's sleep problem. However, this was not found in the current study which could indicate that receiving treatment for their child's sleep



problem may not have led to a meaningful change in parents' attributions about their child's sleep problem. This could explain why parents from the PSP group may tend to attribute sleep problems as unstable while misattributing sleep problems to factors inherent to the child.

There may be multiple other reasons why parents remain misinformed about their child's sleep problem despite receiving treatment. For example, parents' thoughts and feelings about their child's sleep problem may not be addressed during treatment and parents may not be receiving adequate information about their child's sleep problem during treatment. Furthermore, parents from our sample tended to have used medication compared to behavioural treatments therefore, parents may not be given an opportunity to understand their own ability to change the behavior. It is also important to note that due to the number of parents in the PSP group our sample may not have been an accurate representation of the attributions parents who have received treatment tend to make for their child's sleep problem. Additional research is warranted to understand what factors might be influencing parents' attributions during treatment and whether parents are receiving adequate information.

#### *Differences between parental beliefs about sleep problems in children with ASD*

Our second hypothesis that parents from the PSP group would endorse beliefs about the parent's causal role in the behaviour (parent-referent attributions) more often than parents from the CSP group was supported by our descriptive analysis. This was shown by the majority of parents from the PSP group who believed in one of the parent-referent beliefs (i.e., learned or acquired) compared to parents from the CSP group who tended to have beliefs that were child-

referent (i.e., medical factors and sensory problems). Furthermore, only a few parents from the CSP group tended to believe in causes where the parent may have a potential role in the sleep problem (i.e., learned or acquired sleep problems and sleep hygiene) which may indicate that parents from the PSP group are more likely to perceive themselves as having a causal role in their child's behaviour compared to parents from the CSP group.

However, parents from the PSP group rarely believed that sleep hygiene was a cause of sleep problems in children with ASD despite being a parent-referent belief. Furthermore, parents from the PSP group most commonly believed that sleep problems were caused by medical factors and were as likely to believe sensory problems were a cause compared to learned or acquired behaviour. Therefore, while parents from the PSP group did tend to endorse parent-referent beliefs more often than parents from the CSP group, both the CSP and PSP groups tend to believe in causes about sleep problems that are related to the child.

Previously, research has shown that parents of children with challenging behaviours tend to attribute their child's negative behaviour to factors that are within the child as opposed to parental factors (Morrissey-Kane & Prinz, 1999). This finding seems to have been replicated in our study. Specifically, parents from the CSP and PSP groups tended to attribute sleep problems to factors that are internal to the child, thus minimizing the role of the parent in the sleep problem. Our findings also suggest that for some parents with children with ASD and a CSP these child-referent beliefs may continue to be held after the sleep problem has been resolved. It is possible that parents continue to minimize their role in their child's sleep problems as parents' beliefs are not appropriately addressed during treatment or because parents are not accessing

treatments which promote their ability to change the behaviour. While we were unable to establish this in our current study it is important for both the parent and child that clinicians are addressing parents' beliefs about their child's sleep problem. This is because parents can have an important role in the maintenance (Owens & Mindell, 2005; Blampied, 2013) and treatment of their child's sleep problem (Wiggs & Stores, 2004; McLay et al., 2018; Vriend et al., 2011; Weiskop et al., 2005). Further, previous research has shown that promoting the parents' perception of their own ability to change their child's problem behaviour can lead to better mental health outcomes for the parent (Moreland et al., 2016; Peters et al., 2005; Johnston et al., 2010). Therefore, future research should continue to further our understanding of the relationships between parental beliefs about sleep problems in children with ASD and help-seeking behaviour as a means to improving treatment and health outcomes for these families.

#### *Parental help-seeking and treatment selection*

Our results found that parents in the CSP and PSP groups most commonly sought advice/help from the services of medical professionals and pediatricians compared to other sources of advice and help. Furthermore, a descriptive analysis indicated there were no meaningful differences between the two groups' help-seeking behaviour. Interestingly, while the PSP (up to 6) and CSP (up to 10) groups had sought a range of sources of advice/help, there was no secondary source of advice/help that either group of parents had commonly sought. Rather, parents were relatively less likely to seek advice/help from a range of different sources compared to their likelihood of seeking assistance from a pediatrician/medical professional. Most notably, parents from the CSP and PSP group indicated that they did not/would not or rarely had sought

advice/help from psychologists and BCBA. This finding may be troubling for clinicians wanting to direct parents to psychologists and BCBA, which have been previously found to be the most likely professionals to offer supported treatments for children with ASD and are shown to be most likely to offer a behavioural treatment (Miller et al., 2012).

The study by Robinson & Richdale (2004), found that parents of children with a sleep problem may not seek treatment for their child's sleep problem because the parent may perceive the sleep problem as being part of their medical condition (internal) or untreatable (stable). In comparison, while parents from the CSP group tended to attribute sleep problems to internal and more stable and treatment resistant factors, the same parents were found to perceive sleep problems as important to treat and tended to have sought advice/help from around two sources of information and an average of seven treatments. The contradiction between the parents' attributions about the stability of the sleep problem and help-seeking behaviour in the CSP group may suggest that while parents perceive sleep problems as severe and chronic, they may remain optimistic or hopeful that the behaviour can be treated. This optimism may be a reason why parents from the CSP group tended to have commonly sought multiple treatments and advice/help for their child's sleep problem.

#### *Parental treatment selection*

Our third hypothesis that parents from the PSP group would be most likely to select supported treatments for their child's sleep problem was not supported by our analysis. Due to the few parents of children with NSP or PSP who responded to parental treatment selection, we

were unable to draw any meaningful comparisons between our study population. However, a descriptive analysis did find that parents from the CSP and PSP groups tended to select treatments with a mixed range of scientific support. Specifically, parents from the CSP and PSP group were shown to be most likely to use medication for their child's treatment over and above any other treatment. Furthermore, both groups found the use of medication to be the most effective of the treatments for sleep problems. In comparison, both groups were rarely found to use behavioural treatments for their child's sleep problem and additionally, behavioural treatments were not seen as effective by either group of parents. Of greater concern, treatments that had limited or no scientific support tended to be viewed as more effective and had been used more often than treatments that had an evidence-base, among parents from the CSP and PSP groups.

It remains unknown as to why parents perceive unsupported treatments or those with limited support as more effective than behavioural treatments with scientific support. One reason may be due to a cognitive and behavioural response to the contradiction between parental attributions about their child's problem behaviour and the assumptions of a behavioural treatment (Peter et al., 2005). More precisely, some research has indicated that parents may have a negative emotional reaction to treatments that focus on the parents' role and behaviour during treatment for problem behaviours. This is due to the parents' tendency to perceive problem behaviours in children as internal to the child and external to the parent (Morrissey-Kane & Prinz, 1999). Thus, when treatments target the parents' role during treatment, this may cause a parent to have negative emotional and behavioural reaction that results in parent's decision to stop the treatment or seek alternatives.

Alternatively, parents may perceive unsupported treatments as being more effective due to characteristics of the unsupported treatments themselves. Research by Matson & Williams (2015), have found that parents of children with ASD tend to select treatments due to several declared factors (money, time, effort, barriers to treatment, ease of implementation), in addition to implicit factors such as parents' beliefs and attributions (Al Anbar et al., 2010; Dardennes et al., 2011; Keenan et al., 2007). Therefore, it may be found that a parent's perception of the treatment such as the ease of implementation of an unsupported treatment compared to a more labor intensive behavioural treatment, may further account for their perception of the effectiveness or usability of the treatment. However, this is currently unclear and further investigation is required to better understand which factors improve parental perceptions of effectiveness outside of a reduction in the problem behaviour.

It is promising to find that parents from the CSP and PSP group most commonly selected a treatment that has empirical support; namely, medication. However, while pharmacological treatments may be considered a preferred treatment compared to treatments with limited or no support, they are not recommended as the first-choice treatment for sleep problems in children (Christodulu & Durand, 2004; Vriend et al., 2011; Weiskop et al., 2001). Rather, to reduce the chance of risk to the child and family, and in line with international recommendations (American Academy of Sleep Medicine, 2020) behaviorally supported treatments should be considered as the first-choice treatment. Thus, the current study highlights that there is more needed research on the treatment selection of parents of children with ASD and a CSP if we are to help these parents get to a stage where they are accessing the most appropriate treatments.

*Relationship between parental treatment selection and causal beliefs*

All four of the statistically significant relationships between parental treatment choices and parents' causal beliefs were found to be associated with treatments that were behaviorally based. Interestingly, beliefs that sleep problems were caused by medical factors were found to be associated with a parent's likelihood of selecting two different behavioural treatments (bedtime fading and systematic ignoring). However, beliefs related to medical factors were not shown to be associated with a parent's use of prescribed medication. Seemingly, despite parents believing in a biological cause for sleep problems, this was more strongly associated with the selection of a behavioural treatment compared to a pharmacological one. A finding that was similarly shown in the study by Dardennes et al., (2011), where genetic factors for the cause of ASD were shown to be associated to the use of a behavioural parent training program TEAACH.

In contrast, behavioural treatments were not found to be associated with parents endorsing learned or acquired sleep problems, despite this belief being behaviorally based. Although it is beneficial parents are aware of their role in their child's environment for the treatment of their child's sleep problem (Owens & Mindell, 2005; Blampied, 2013; Teng et al., 2012), it seems this belief is not associated with the parent's likelihood of selecting a behavioural treatment. Alternatively, parents' beliefs that are biological and environmental seem to be more closely associated with a parent's use of a behavioural treatment. Although few parents endorsed factors related to sleep hygiene, it may be promising to find that promoting supported information to parents, such as that sleep problems can be caused by external factors such as sleep hygiene, may influence a parents' decision towards a supported treatment.

Somewhat troubling is that our data did not show any associations between parental causal beliefs about sleep problems and the use of an unsupported treatment or a treatment with limited empirical support. However, both the CSP and PSP groups commonly reported that they had used a range of treatments that had limited empirical support or were not supported. This may reflect that parents rated treatments as supported based on obtainable evidence, such as the recommendations of other parents or from websites, as it is unlikely they had access to the empirical evidence used in the current study. As previously mentioned, declared factors may be one example of those that may influence parents' treatment decisions (Matson & Williams, 2015) but beliefs about the severity and duration of sleep problems have also been shown to be associated with parental treatment choices in parents of children with ASD and a CSP (Keenan et al., 2007). It is possible that an association was not observed in this study between beliefs about the cause of sleep problems and selection of unsupported treatments for sleep problems because there is a better predictor of treatment choice compared to parental causal beliefs about sleep problems in children with ASD.

*Relationship between parental experience with sleep problems and a parent's attributions*

Our final hypothesis that parents' attributions about sleep problems in children with ASD will be moderated by the parents' experience with sleep problems was not supported by our data. Our research showed that parents' attributions about the locus and controllability do not tend to be replicated when parents are asked to make attributions about sleep problems in their own child compared to vignette scenarios. However, parental attributions about the stability of sleep



problems in their own children were shown to be extended to sleep problems in other children in both the CSP and PSP groups. Specifically, parents from the CSP group may view sleep problems as a learnt behaviour in children who were not their own as they might believe that parents of other children are more capable of changing their child's problem behaviour than they are themselves. This may explain the disparity between parents from the CSP group minimizing their own role in the cause of their child's behaviour whilst viewing other parents as able to change their child's sleep behaviour. Interestingly, the attributions made by parents from the PSP group about sleep problems in other children were more representative of our prediction of a parent who was informed about sleep problems in children. What is meant by this is that parents from the PSP group tended to view parents of other children with sleep problems as being a part of the child's environment and further, that sleep problems were a learned behaviour that was able to be changed.

Parents' attributions about the stability of the sleep problem may have been extended to other children because of parents' experiences with resolving or not being able to resolve their child's sleep problem is less likely to be attributed to the parent's perception of their own ability compared to their perceptions about the locus or controllability. This tendency may be related to a parent's perception of competence in dealing with their child's behaviour compared to other parents. However, we were unable to obtain results from the NSP group to compare whether parents from the CSP and PSP groups tended to perceive themselves as having a greater perception of their ability to manage their child's problematic sleep behaviour. Therefore, it remains somewhat unclear why parents' attributions about the stability of sleep problems may be more likely to be extended to other children compared to the other dimensions.

Furthermore, our research showed that parents' attributions about sleep problems in children who are not their own may have been associated with the presentation of the sleep behaviour. In the case of the CSP group, it seems that parents from the CSP group may be more likely to extend their attributions about the locus of sleep problems to the child when the child is depicted as displaying oppositional sleep behaviour and being unable to verbally communicate their needs (Antonio). In contrast, parents from the CSP group were not shown to extend their attributions about the locus of sleep problems when the sleep problem was being depicted as a part of the child's anxiety, circadian rhythm disturbance, stereotypy, or when the child was able to communicate verbally. Therefore, evidence might suggest that parents from the CSP group may be more likely to extend their attributions when the intent of the child's behaviour is not presented or is ambiguous to the parent. This could reflect a parents' tendency to make automatic appraisals of a child's sleep behaviour due to their experience of raising a child with ASD and a sleep problem.

For the PSP group, it seems that parents from the PSP group may be more likely to extend their attributions about the locus of sleep problems when the sleep problem is depicted as being a part of the child's sleep interfering anxiety (Awhina). However, no evidence was found to suggest that the presentation of children with varying levels of ASD functioning may have had an effect on the attributions made by parents from the PSP group. This could suggest that parents from the PSP group tended to not make automatic interpretations that a child's sleep problem was internal to the child. This may be the result of parents from the PSP group being more informed about sleep problems in children and thus making a more objective and informed

appraisal. Overall, this evidence suggests that parents of children with ASD and a sleep problem may make different attributional responses based on the presentation of the child's sleep behaviour. Thus, future research should carefully consider their methods for acquiring data on parents' thoughts, and feelings about their child's sleep problem.

Previously, the study by Johnston & Ohan (2005) established that the causal attributions parents make for their child's problem behaviour may reflect the accumulation of the child's behaviour, characteristics of the parent, and the parent's history with the child. The study later found that parents of children with ADHD would tend to generalise their internalising beliefs about their child's negative problem behaviour to vignettes of children with ODD suggesting that raising a child with ADHD acted as a moderator for parental attributions and child behaviour (Johnston & Ohan, 2005). Our findings contradict the study by Johnston & Ohan (2005) as we were unable to find strong evidence to support that the parents' experience of raising a child with ASD and a sleep problem moderated the parents' beliefs about sleep problems in children.

It is plausible that the process that drives the beliefs of parents of children with ASD and a sleep problem differs when compared to parents of children with ADHD. For example, parent's beliefs may be moderated by a parent-driven effect where parents of children with ASD and a sleep problem may be more child-referent and also perceive themselves as less able to manage their child's sleep problem compared to other parents. Alternatively, there could also be a child-driven effect where the repeated exposure of the characteristics of their child's problematic sleep behaviour may result in the parents of these children making less objective and more automatic attributions about the intent of their child's behaviour (Johnston & Ohan, 2005). Additional

research is required to better understand what processes may underly the interplay between parental attributions and child behaviour as it currently remains unknown to researchers.

### *Limitations*

There are a number of limitations to consider in the current study. First, due to the number of parents included in this study there is a chance that the data may not accurately represent the true help-seeking behaviour, treatment selection, and attributions of parents with children with a CSP or PSP. Additionally, our descriptive analysis of parents' demographic variables show participants were predominately mothers of children with ASD. This was two implications. The first is that the attributions of fathers are not represented in our study, and the second is that the help-seeking behaviour and treatment decisions in families where both parents may influence the decision were not evident.

Regarding parents' beliefs about the causes of sleep problems, parents from all groups were found to have used the written text field for their own beliefs that were not listed by the survey. However, parents were shown to frequently list beliefs which they had that were not previously endorsed despite being offered on the survey. For example, parents from the CSP group were unlikely to endorse the belief '*sleep hygiene*' despite using the written text field to present factors such as bedroom conditions as a cause of their child's sleep problem. It may be possible that the question was misleading and/or difficult to understand for some parents. Some questions were also adapted so that the terminology was specific for whether the parent was from the CSP, PSP, or NSP group. Thus, parents' responses may have differed due to their interpretation of their own groups' question. Although, the edits that were made to the survey

questions were carefully considered before and after making any edits to ensure that the number of edits was kept to the minimum.

The lack of statistical meaning due to the small sample size for parents of children with a PSP meant we were unable to investigate differences between parents' treatment choices and their perceived effectiveness. This information may have been useful for comparing the perceptions of the effectiveness of treatments in parents who have experienced sleep problems in children with ASD (i.e., CSP and PSP groups) to a control group of parents who have not experienced treatments for sleep problems in children with ASD (i.e., NSP group). Further, differences between the perceived effectiveness of treatments between the two groups who have experienced treatments for sleep problems in children with ASD may have helped us understand whether a parents' attributions about their child's sleep problem were associated with their treatment experiences.

### *Future research*

The findings from this study present multiple areas of interest for future research. Future research may wish to explore how parental attributions about their child's sleep problem, beliefs, and help-seeking behaviour evolve over time. This could be achieved through longitudinal research and help establish the development of parental beliefs about sleep problems at different stages of treatment or across age groups. Parents from the CSP and PSP group tended to report multiple treatments that were unsupported by scientific research as an effective treatment for their child's sleep problem. It may be useful to understand what implicit and declared reasons

parents make for rating treatments as effective including what barriers might exist for parents perceiving supported treatments as being effective.

Research should investigate the recommendations and the quality of information parents receive from different professionals that they are likely to access for their child's sleep problem. A comparison of the quality of these sources may better enable targeted approaches for improving the transmission of information to parents. Furthermore, research should investigate whether beliefs about sleep problems other than causal beliefs have an association with treatment choice and whether they are stronger predictors of treatment choice in parents of children with ASD and a sleep problem. For example, beliefs about the duration and perceived severity of sleep problems in children have previously been associated with parental treatment selection in parents of children with ASD and CSP.

## **Conclusion**

The current study found some evidence to suggest that there were differences between the attributions made by parents with different experiences with sleep problems in children with ASD. However, it remains unclear whether the differences found between the attributions of these parents shared a relationship with their help-seeking and treatment selection. Furthermore, it was found that parents did not tend to extend their attributions about their own child's problematic sleep behaviour to sleep problems in other children. Understanding why parents of children with ASD and a sleep problem may not extend their attributions about their own child's sleep problem may be beneficial in establishing underlying processes driving parental attributions about sleep problems in children with ASD. Investigating what factors may lead a

parent of a child with ASD to attribute their child's sleep problem as being internal compared to sleep problems in other children could help us in addressing misattributions some parents may have about their child's problematic sleep behaviour. This may be achieved in a clinical setting where the clinician is able to talk with the parent about their thoughts, feelings, and beliefs about their own child's sleep problem. Additionally, we may also be able to develop methods which can target parents' attributions at pretreatment such as improving the quality of information and parent's access to trusted sources of advice/help.

Further, by addressing parent's misattributions that sleep problems in children with ASD are internal and stable, we may be able to direct parents' help-seeking to treatments that are the most appropriate for their child's sleep problem. This would be beneficial for increasing the number of parents who have been shown to access unsupported treatments for their child's sleep problem compared to the supported behavioural treatments that are available for parents. This may also be achieved through promoting supported beliefs about the causes of sleep problems in children with ASD amongst parents. However, more research is needed in order to fully understand the strength and direction of these relationships amongst parents with different experiences with sleep problems in children with ASD.

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## Appendices

### Appendix A: Descriptive data for the attributions of parents of group NSP

Similar to the parents from the CSP and PSP groups, parents from the NSP group tended to attribute sleep problems to factors that were intrinsic to the child and uncontrollable. This was shown by all parents from the NSP group agreeing to some extent that sleep problems were '*a part of a child's ASD diagnosis*' and the majority agreeing to some extent that sleep problems were '*a part of who the child is*' (67%). Additionally, the majority of parents from the NSP group tended to disagree to some extent that the child's behaviour was '*intentional*' (83%), disagree that '*the child should be responsible for their own behaviour*' (67%), and agree that sleep problems were '*outside of a child's control*' (83%). Attributions about the stability of sleep problems showed the most variation compared to the CSP and PSP groups. It was shown that all parents from the NSP group believed sleep problems would resolve without treatment and the majority of parents tended to attributed sleep problems as unstable (83%). This suggested that parents from the NSP group tended to attribute sleep problems to unstable factors and did not believe treatment was necessary to resolve the problem behaviour.

**Appendix B: Correlational data for the attributions of parents from group NSP**

For parents from the NSP group, a Pearson's product moment correlation found one statistically significant relationship between a parent's attributions about sleep problems. This relationship was a positive correlation, moderate strength, shown between the attribution '*it is a feature of my child's ASD diagnosis*' and '*it is unlikely to change*'  $r = .667$  ( $p < 0.05$ ).

### Appendix C: Help-seeking behaviour and treatment selection – NSP group

Parents from group NSP were asked what treatments they might consider using for a child's sleep problem. On average, parents of children with ASD and without a sleep problem tended to show that a parent would be likely to consider about two treatments ( $M=2.2$ , Range 0-12). As shown by Table 8, parents from group NSP were most likely to seek help/advice from a '*Pediatrician/other medical doctor*' (83%) but half of parents were also likely to seek advice from '*web-based sources*' (50%). Parents from the NSP group were not likely to seek advice/help from any other source. As shown by Table 9, no treatment was found to be selected by a majority of parents from the NSP group. Treatments which were amongst the most likely to be used by parents from the NSP group were '*white noise*', '*systematic ignoring*', and '*modified systematic ignoring*' which were all selected by 33% of parents.

### **Appendix D: Ethics application and approval**

Ethics for this study was approved from the University of Canterbury Human Ethics Committee (HEC 2017/32/LR-PS). This was obtained during the registration of the thesis proposal and prior to the distribution of the survey. All parents were required to give consent for the use of their data.



## **Appendix E: Copy of the consent form show to parents**

### **University of Canterbury Sleep and Autism Survey**

The purpose of this research project is to help researchers understand parents' perceptions of the nature and cause of sleep problems in their children with autism spectrum disorder (ASD) and their experiences with interventions. This is a research project led by Associate Professor Laurie McLay, Associate Professor Karyn France, Thesis Student Liam Hutchinson, and Lecturer Sarah Whitcombe-Dobbs at the University of Canterbury. You are invited to participate in this research project because you are a parent/caregiver of a child with ASD, with or without sleep problems.

Your participation in this research is voluntary. You may choose not to participate. If you decide not to participate in this study, you will not be penalised. The procedure involves filling an online survey that will take approximately 15 minutes. Your responses will be confidential, and we do not collect identifying information such as your name, email address or IP address. The survey questions will be about your child sleep problems.

We will ensure that any information that you provide will be kept confidential. All data is stored in a password protected electronic format. To help protect your confidentiality, the surveys will not contain information that will personally identify you. The results of this study will be used for scholarly purposes only.

**Appendix F: Email to organizations and service providers for people with ASD and their families**

Dear XXX,

I am a Senior Lecturer at the University of Canterbury. Associate Professor Karyn France and I are currently conducting research that investigates the sleep disturbance in children with autism. As a part of this larger study, we are interested in gathering information pertaining to parents' understandings about sleep problems in children with autism, whether they have sleep problems or not. We have developed a short (10-15 minute) online survey and would be grateful if you could send this survey link and attached flyer, via email, to parents of children with autism, within your networks, regardless of whether there is a known sleep problem. The survey results will be completely anonymous, and the survey is able to be accessed via the following link.

If you have any questions, please don't hesitate to get in touch with me.

Kind regards,

**Appendix G: Sleep survey group CSP****What is your age?**

- 18-24 years old
- 25-34 years old
- 35-44 years old
- 45-54 years old
- 55-64 years old
- 65+ years old

**What is your child's age?**

- 0-2 years old
- 3-4 years old
- 5-7 years old
- 8-10 years old
- 11-14 years old
- 15-18 years old
- 18 + years old

**What is your relationship to your child?**

- Mother
- Father
- Primary female caregiver
- Primary male caregiver
- Other (please specify):

**What is your ethnicity**

- NZ/European
- Māori
- Pacific Islander
- Asian
- Other (please specify)

**What is your marital status?**

- Single, never married
- Married or domestic partnership
- Same sex partnership
- Widowed
- Divorced
- Separated

**How many people live in your household (including yourself and your child)?**

- 2
- 3
- 4
- 5
- 6
- 7+

**What is your employment status?**

- Employed for wages
- Self-employed
- Out of work but looking for employment
- Out of work and not looking for employment
- A homemaker
- Student
- Retired
- Unable to work

**What is the highest degree or school level that you have completed?**

- Did not complete High school/Secondary school
- High school
- College or University undergraduate qualification
- College or University post-graduate qualification

**What is your total household income each year?**

- Loss
- Zero income
- \$1 - \$5,000
- \$10,001 - \$15,000
- \$15,001 - \$20,000
- \$20,001 - \$25,000
- \$25,001 - \$30,000
- \$30,001 - \$35,000
- \$35,001 - \$40,000
- \$40,001 - \$50,000
- \$50,001 - \$70,000
- \$70,001 - \$100,000
- \$100,001 or more

**Does your child have a confirmed diagnosis of ASD?**

Y/N

**Who provided this diagnosis?**

- Child psychiatrist
- Psychologist
- Paediatrician
- Other medical doctor

**Has your child previously had a sleep problem that you are aware of which is no longer present? (e.g., frequent night-time awakenings, sleep walking, falling to sleep at unusual times of the day or night)**

- . Yes
- . No
- . My child currently has a sleep disorder

Set up survey so that, if yes, they continue with survey x, if no, they go to survey y, and if they currently have a sleep disorder set up survey so that they don't go any further. Feedback = Thank you for the time you have taken to complete this survey.

**Was your child affected by an insomnia? (e.g., difficulty falling asleep, frequent night wakings) Please select those that apply.**

Y/N

**What was the nature of your child's insomnia? (select all that apply from the list below)**

*Delayed sleep onset latency (e.g., your child takes over 15 minutes to get to sleep after going to bed).*

If you selected delayed sleep onset latency, on average, how long did it take for your child to fall asleep (i.e., the time that elapses between your child being bid goodnight, and sleep onset).

*Parent initiated co-sleeping (e.g., a parent lying with the child in the child's bed until sleep onset).*

If you selected unwanted parent-initiated co-sleeping, when did this occur?

- During initial sleep onset
- During night-time awakenings
- During early morning awakenings
- All of the above

*Child initiated co-sleeping (e.g., child sleeping in the parent/caregiver or other household member's bed)*

If you selected unwanted child-initiated co-sleeping, when did this occur?

- During initial sleep onset
- During night-time awakenings
- During early morning awakenings
- All of the above

*Sleep interfering behaviour (e.g., difficulty staying in bed or remaining in bed after being asked to do so, engaging in activities that interfere with their ability to fall sleep at any stage during the night). If so, please select the type of sleep interfering behaviour:*

- Non-compliance with the pre-bedtime routine (e.g., difficulty or refusal to follow bedtime instructions)
- Bedtime resistance (e.g, resistance or refusing to go to bed).
- Leaving bed
- Calling out
- Crying/upset
- Playing with toys/items/activities in bed or bedroom
- Vocal stereotypy (humming, repetitive speech)
- Motor stereotypy (e.g., rocking, bouncing on the bed repetitively)
- Other – please describe

*Frequent night-time awakenings (e.g., waking throughout the night). If frequent night-time awakenings, on average, how often did your child wake per night?*

*Prolonged night-time awakenings (e.g., waking for periods in excess of 15 minutes during the night). If you selected prolonged night-time awakenings, on average, how long did it take for your child to resume sleep after waking?*

*Early morning wakings (e.g., your child wakes before your desired wake time). If you selected early morning awakenings, what time on average did your child wake to begin the day?*

Other (please specify):

**Was your child affected by parasomnias that you are aware of? (e.g., sleep walking, night terrors)**

**Y/N**

**If yes, please select those that apply.**

- Night terrors
- Nightmares that are frequent, recurring, and vivid
- Sleep walking
- Nocturnal sleep-related eating (e.g., sleep walking accompanied with eating or seeking food)
- Teeth grinding
- Other – please describe

**Was your child affected by circadian rhythm disturbances that you are aware of (e.g., delayed sleep phase syndrome, biphasic sleep disorder)?**

**Y/N**

**If yes, please select those that apply.**

- Circadian Rhythm Disruption (i.e., problematic sleep timing)
- Delayed sleep phase syndrome (e.g., doesn't fall asleep until midnight or later, and wakes correspondingly later in the morning)
- Advanced sleep phase syndrome (e.g., falls asleep more than 2 hours before ideal bedtime, and wakes correspondingly earlier in the morning)
- Biphasic sleep disorder (e.g., falls asleep for two periods over 24 hours. Outside of developmentally appropriate patterns such as naps)

- Polyphasic sleep disorder (e.g., falls asleep for more than two periods over 24 hours. Outside of developmentally appropriate patterns such as naps).

**Was your child on any medication to specifically treat sleep problem/s at the time?**

Y/N

**If yes, please specify.**

**Is your child still on any medication to specifically treat sleep problem/s?**

Y/N

**If yes, please specify.**

**Was your child on any other medication during the treatment of the sleep problem/s?**

Y/N

**If yes, please specify.**

**Is your child on any other medication currently?**

Y/N

**If yes, please specify.**

**Did you use an intervention that was focused on treating your child's sleep problem? This includes interventions that you have selected yourself.**

Yes

No, I have not, the sleep problem diminished over time

**At what age did the sleep problem occur?**

- 0-2 years old
- 3-4 years old
- 5-7 years old
- 8-10 years old
- 11-14 years old
- 15-18 years old
- 18 + years old

**At what age did the sleep problem no longer occur?**

- 0-2 years old
- 3-4 years old
- 5-7 years old
- 8-10 years old
- 11-14 years old

- 15-18 years old
- 18 + years old

**Were you aware of any underlying medical or physical factors that may have contributed toward your child's sleep problem?**

- Abnormal production or synthesis of melatonin
- Asthma
- Bedwetting
- Obstructive sleep apnea
- Restless leg syndrome
- Seizure disorder
- Other comorbid medical condition or diagnosis (please specify):

**Please select the extent to which sleep problems are of a concern to you:**

1-5 (1 = not at all/3=somewhat/5= our primary and most significant concern)

**How do you make sense of sleep problems in children with Autism? Please indicate the extent to which you agree with the following comments: Likert scale – 1-6 (1 Disagree strongly – 6 Agree strongly)**

- They are a feature of a child's Autism Spectrum Disorder diagnosis
- It is a part of who they are (i.e., it's just the way they are)
- It is intentional behaviour
- They are unlikely to change
- The child is responsible for managing their own sleep and sleep-related behaviour
- The child's sleep problems are outside of their control

**What do you consider to be a cause of sleep problem/s?**

*Medical condition/s you have described above*

*Sleep hygiene:*

- Bedroom conditions (e.g., too light, too hot, too noisy).
- Inconsistent bedtime
- Inconsistent bedtime routine
- Use of digital devices (e.g., iPad, cell phone, t.v.)

*Learned or acquired sleep problems that interfere with falling asleep or staying asleep:*

- Child is seeking parental attention
- Bedtime avoidance
- Access to preferred activities, items or toys
- Dependence on sleep item (e.g., pacifier, cuddly)
- Child does not want to be left alone (?)
- Other

*Sensory problems: If so, select those that apply (sub-heading)*

- Sensitivity to the bedroom temperature
- Sensitivity to light in the bedroom



- Sensitivity to noise levels
- Sensitivity to bedding
- Other (please specify)

**In which, if any, aspects of a child's life would do you believe a sleep problem would affect?**

- Communication
- Daytime behaviour at home
- Daytime behaviour at school
- Emotional regulation
- Learning
- Relationships (including friendships)
- Stereotypic behaviour
- None
- Other (please specify)

**In which, if any, aspects of a family's life do you believe a child's sleep problem would affect?**

- Employment
- Sibling relationships
- Siblings sleep
- Spousal relationship
- Your personal sleep
- Spousal sleep
- Your mental health and wellbeing
- Your daytime functioning
- None
- Other (please specify)

**Do you believe that a child's sleep problem can be resolved without treatment?**

Y/N

**How important is maintaining consistent sleep routines or bedtimes to you?**

Scale of 1-5 (Not a priority – somewhat of a priority – number one priority)

**How important are you in maintaining your child's sleep routine?**

Scale of 1-5 (Not important – somewhat important – very important)

**How important is your child in maintaining their sleep?**

Scale of 1-5 (Not capable – somewhat capable – capable)

**How would you rate your ability to regulate your child's sleep?**

Scale of 1-5 (Never – sometimes – always)

**Have you ever used an intervention that is focused on improving your child's sleep? This includes interventions that you have selected yourself.**

Y/N

**If yes, how would you rate the level of support with your child's sleep problem that you have received?**

Scale of 1-5 (1 = no support – 3 – occasional, moderate levels of support – 5 – extensive regular support)

**Who has helped, or is helping you with it?**

Tick all of those that apply:

- A psychologist
- A board certified behaviour analyst
- Occupational therapist
- Physiotherapist
- Speech language therapist/pathologist
- Teacher
- Researcher
- Pediatrician or other medical professional
- Web-based sources
- Books
- Parents
- No-one
- Other (please specify)

**What strategies have you tried or are trying to improve your child's sleep? Please rate their effectiveness**

- Homeopathic or alternative medicines (e.g., lavender oil, sleep drops)
- Prescribed medications (Including melatonin)
- Bedtime fading (e.g. extending bed-time so your child goes to sleep quickly then gradually bringing it earlier)
- Systematic ignoring
- Modified systematic ignoring (e.g., camping out, checking on your child at fixed times)
- scheduled awakenings (e.g., waking your child at a set time or times during the night)
- White noise
- Massage therapy
- Co-sleeping (e.g., sleeping in your child's bed or your child sleeping in your bed)
- Weighted blankets
- Social story or sleep story
- Video modelling
- Exercise

- Rewards for sleeping well or following bedtime instructions
- Other (please specify):

**Thank you for taking the time to complete this survey.**

**Appendix H: Sleep survey group PSP****What is your age?**

- 18-24 years old
- 25-34 years old
- 35-44 years old
- 45-54 years old
- 55-64 years old
- 65+ years old

**What is your child's age?**

- 0-2 years old
- 3-4 years old
- 5-7 years old
- 8-10 years old
- 11-14 years old
- 15-18 years old
- 18 + years old

**What is your relationship to your child?**

- Mother
- Father
- Primary female caregiver
- Primary male caregiver
- Other (please specify):

**What is your ethnicity**

- NZ/European
- Māori
- Pacific Islander
- Asian
- Other (please specify)

**What is your marital status?**

- Single, never married
- Married or domestic partnership
- Same sex partnership
- Widowed
- Divorced
- Separated

**How many people live in your household (including yourself and your child)?**

- 2
- 3
- 4
- 5
- 6
- 7+

**What is your employment status?**

- Employed for wages
- Self-employed
- Out of work but looking for employment
- Out of work and not looking for employment
- A homemaker
- Student
- Retired
- Unable to work

**What is the highest degree or school level that you have completed?**

- Did not complete High school/Secondary school
- High school
- College or University undergraduate qualification
- College or University post-graduate qualification

**What is your total household income each year?**

- Loss
- Zero income
- \$1 - \$5,000
- \$10,001 - \$15,000
- \$15,001 - \$20,000
- \$20,001 - \$25,000
- \$25,001 - \$30,000
- \$30,001 - \$35,000
- \$35,001 - \$40,000
- \$40,001 - \$50,000
- \$50,001 - \$70,000
- \$70,001 - \$100,000
- \$100,001 or more

**Does your child have a confirmed diagnosis of ASD?**

Y/N

**Who provided this diagnosis?**

- Child psychiatrist
- Psychologist
- Paediatrician
- Other medical doctor

**Has your child previously had a sleep problem that you are aware of which is no longer present? (e.g., frequent night-time awakenings, sleep walking, falling to sleep at unusual times of the day or night)**

- . Yes
- . No
- . My child currently has a sleep disorder

Set up survey so that, if yes, they continue with survey x, if no, they go to survey y, and if they currently have a sleep disorder set up survey so that they don't go any further. Feedback = Thank you for the time you have taken to complete this survey.

**Was your child affected by an insomnia? (e.g., difficulty falling asleep, frequent night wakings) Please select those that apply.**

Y/N

**What was the nature of your child's insomnia? (select all that apply from the list below)**

*Delayed sleep onset latency (e.g., your child takes over 15 minutes to get to sleep after going to bed).*

If you selected delayed sleep onset latency, on average, how long did it take for your child to fall asleep (i.e., the time that elapses between your child being bid goodnight, and sleep onset).

*Parent initiated co-sleeping (e.g., a parent lying with the child in the child's bed until sleep onset).*

If you selected unwanted parent-initiated co-sleeping, when did this occur?

- During initial sleep onset
- During night-time awakenings
- During early morning awakenings
- All of the above

*Child initiated co-sleeping (e.g., child sleeping in the parent/caregiver or other household member's bed)*

If you selected unwanted child-initiated co-sleeping, when did this occur?

- During initial sleep onset
- During night-time awakenings
- During early morning awakenings
- All of the above

*Sleep interfering behaviour (e.g., difficulty staying in bed or remaining in bed after being asked to do so, engaging in activities that interfere with their ability to fall sleep at any stage during the night). If so, please select the type of sleep interfering behaviour:*

- Non-compliance with the pre-bedtime routine (e.g., difficulty or refusal to follow bedtime instructions)
- Bedtime resistance (e.g., resistance or refusing to go to bed).
- Leaving bed
- Calling out
- Crying/upset
- Playing with toys/items/activities in bed or bedroom
- Vocal stereotypy (humming, repetitive speech)
- Motor stereotypy (e.g., rocking, bouncing on the bed repetitively)
- Other – please describe

*Frequent night-time awakenings (e.g., waking throughout the night). If frequent night-time awakenings, on average, how often did your child wake per night?*

*Prolonged night-time awakenings (e.g., waking for periods in excess of 15 minutes during the night). If you selected prolonged night-time awakenings, on average, how long did it take for your child to resume sleep after waking?*

*Early morning wakings (e.g., your child wakes before your desired wake time). If you selected early morning awakenings, what time on average did your child wake to begin the day?*

Other (please specify):

**Was your child affected by parasomnias that you are aware of? (e.g., sleep walking, night terrors)**

**Y/N**

**If yes, please select those that apply.**

- Night terrors
- Nightmares that are frequent, recurring, and vivid
- Sleep walking
- Nocturnal sleep-related eating (e.g., sleep walking accompanied with eating or seeking food)
- Teeth grinding
- Other – please describe

**Was your child affected by circadian rhythm disturbances that you are aware of (e.g., delayed sleep phase syndrome, biphasic sleep disorder)?**

**Y/N**

**If yes, please select those that apply.**

- Circadian Rhythm Disruption (i.e., problematic sleep timing)
- Delayed sleep phase syndrome (e.g., doesn't fall asleep until midnight or later, and wakes correspondingly later in the morning)
- Advanced sleep phase syndrome (e.g., falls asleep more than 2 hours before ideal bedtime, and wakes correspondingly earlier in the morning)
- Biphasic sleep disorder (e.g., falls asleep for two periods over 24 hours. Outside of developmentally appropriate patterns such as naps)

- Polyphasic sleep disorder (e.g., falls asleep for more than two periods over 24 hours. Outside of developmentally appropriate patterns such as naps).

**Was your child on any medication to specifically treat sleep problem/s at the time?**

Y/N

**If yes, please specify.**

**Is your child still on any medication to specifically treat sleep problem/s?**

Y/N

**If yes, please specify.**

**Was your child on any other medication during the treatment of the sleep problem/s?**

Y/N

**If yes, please specify.**

**Is your child on any other medication currently?**

Y/N

**If yes, please specify.**

**Did you use an intervention that was focused on treating your child's sleep problem? This includes interventions that you have selected yourself.**

Yes

No, I have not, the sleep problem diminished over time

**At what age did the sleep problem occur?**

- 0-2 years old
- 3-4 years old
- 5-7 years old
- 8-10 years old
- 11-14 years old
- 15-18 years old
- 18 + years old

**At what age did the sleep problem no longer occur?**

- 0-2 years old
- 3-4 years old
- 5-7 years old
- 8-10 years old
- 11-14 years old



- 15-18 years old
- 18 + years old

**Were you aware of any underlying medical or physical factors that may have contributed toward your child's sleep problem?**

- Abnormal production or synthesis of melatonin
- Asthma
- Bedwetting
- Obstructive sleep apnea
- Restless leg syndrome
- Seizure disorder
- Other comorbid medical condition or diagnosis (please specify):

**Please select the extent to which sleep problems are of a concern to you:**

1-5 (1 = not at all/3=somewhat/5= our primary and most significant concern)

**How do you make sense of sleep problems in children with Autism? Please indicate the extent to which you agree with the following comments: Likert scale – 1-6 (1 Disagree strongly – 6 Agree strongly)**

- They are a feature of a child's Autism Spectrum Disorder diagnosis
- It is a part of who they are (i.e., it's just the way they are)
- It is intentional behaviour
- They are unlikely to change
- The child is responsible for managing their own sleep and sleep-related behaviour
- The child's sleep problems are outside of their control

**What do you consider to be a cause of sleep problem/s?**

*Medical condition/s you have described above*

*Sleep hygiene:*

- Bedroom conditions (e.g., too light, too hot, too noisy).
- Inconsistent bedtime
- Inconsistent bedtime routine
- Use of digital devices (e.g., iPad, cell phone, t.v.)

*Learned or acquired sleep problems that interfere with falling asleep or staying asleep:*

- Child is seeking parental attention
- Bedtime avoidance
- Access to preferred activities, items or toys
- Dependence on sleep item (e.g., pacifier, cuddly)
- Child does not want to be left alone (?)
- Other

*Sensory problems: If so, select those that apply (sub-heading)*

- Sensitivity to the bedroom temperature
- Sensitivity to light in the bedroom

- Sensitivity to noise levels
- Sensitivity to bedding
- Other (please specify)

**In which, if any, aspects of a child's life would do you believe a sleep problem would affect?**

- Communication
- Daytime behaviour at home
- Daytime behaviour at school
- Emotional regulation
- Learning
- Relationships (including friendships)
- Stereotypic behaviour
- None
- Other (please specify)

**In which, if any, aspects of a family's life do you believe a child's sleep problem would affect?**

- Employment
- Sibling relationships
- Siblings sleep
- Spousal relationship
- Your personal sleep
- Spousal sleep
- Your mental health and wellbeing
- Your daytime functioning
- None
- Other (please specify)

**Do you believe that a child's sleep problem can be resolved without treatment?**

Y/N

**How important is maintaining consistent sleep routines or bedtimes to you?**

Scale of 1-5 (Not a priority – somewhat of a priority – number one priority)

**How important are you in maintaining your child's sleep routine?**

Scale of 1-5 (Not important – somewhat important – very important)

**How important is your child in maintaining their sleep?**

Scale of 1-5 (Not capable – somewhat capable – capable)

**How would you rate your ability to regulate your child's sleep?**

Scale of 1-5 (Never – sometimes – always)

**Have you ever used an intervention that is focused on improving your child's sleep? This includes interventions that you have selected yourself.**

Y/N

**If yes, how would you rate the level of support with your child's sleep problem that you have received?**

Scale of 1-5 (1 = no support – 3 – occasional, moderate levels of support – 5 – extensive regular support)

**Who has helped, or is helping you with it?**

Tick all of those that apply:

- A psychologist
- A board certified behaviour analyst
- Occupational therapist
- Physiotherapist
- Speech language therapist/pathologist
- Teacher
- Researcher
- Pediatrician or other medical professional
- Web-based sources
- Books
- Parents
- No-one
- Other (please specify)

**What strategies have you tried or are trying to improve your child's sleep? Please rate their effectiveness**

- Homeopathic or alternative medicines (e.g., lavender oil, sleep drops)
- Prescribed medications (Including melatonin)
- Bedtime fading (e.g. extending bed-time so your child goes to sleep quickly then gradually bringing it earlier)
- Systematic ignoring
- Modified systematic ignoring (e.g., camping out, checking on your child at fixed times)
- scheduled awakenings (e.g., waking your child at a set time or times during the night)
- White noise
- Massage therapy
- Co-sleeping (e.g., sleeping in your child's bed or your child sleeping in your bed)
- Weighted blankets
- Social story or sleep story
- Video modelling
- Exercise

- Rewards for sleeping well or following bedtime instructions
- Other (please specify):

**Thank you for taking the time to complete this survey.**

**Appendix I: Sleep survey group NSP****What is your age?**

- 18-24 years old
- 25-34 years old
- 35-44 years old
- 45-54 years old
- 55-64 years old
- 65+ years old

**What is your child's age?**

- 0-2 years old
- 3-4 years old
- 5-7 years old
- 8-10 years old
- 11-14 years old
- 15-18 years old
- 18 + years old

**What is your relationship to your child?**

- Mother
- Father
- Primary female caregiver
- Primary male caregiver
- Other (please specify):

**What is your ethnicity?**

- NZ/European
- Māori
- Pacific Islander
- Asian
- Other (please specify)

**What is your marital status?**

- Single, never married
- Married or domestic partnership
- Same sex partnership
- Widowed
- Divorced
- Separated

**How many people live in your household (including yourself and your child)?**

- 2
- 3
- 4
- 5
- 6
- 7+

**What is your employment status?**

- Employed for wages
- Self-employed
- Out of work but looking for employment
- Out of work and not looking for employment
- A homemaker
- Student
- Retired
- Unable to work

**What is the highest degree or school level that you have completed?**

- Did not complete High school/Secondary school
- High school
- College or University undergraduate qualification
- College or University post-graduate qualification

**What is your total household income each year?**

- Loss
- Zero income
- \$1 - \$5,000
- \$10,001 - \$15,000
- \$15,001 - \$20,000
- \$20,001 - \$25,000
- \$25,001 - \$30,000
- \$30,001 - \$35,000
- \$35,001 - \$40,000
- \$40,001 - \$50,000
- \$50,001 - \$70,000
- \$70,001 - \$100,000
- \$100,001 or more

**Does your child have a confirmed diagnosis of ASD?**

Y/N

**Who provided this diagnosis?**

- Child psychiatrist
- Psychologist
- Paediatrician
- Other medical doctor

**Has your child previously had a sleep problem that you are aware of which is no longer present? (e.g., frequent night-time awakenings, sleep walking, falling to sleep at unusual times of the day or night)**

- . Yes
- . No
- . My child currently has a sleep disorder

Set up survey so that, if yes, they continue with survey x, if no, they go to survey y, and if they currently have a sleep disorder, set up survey so that they don't go any further. Feedback = Thank you for the time you have taken to complete this survey.

**Are you aware of any underlying medical or physical factors that may contribute towards a sleep problem?**

- Abnormal production or synthesis of melatonin
- Asthma
- Bedwetting
- Obstructive sleep apnea
- Restless leg syndrome
- Seizure disorder
- Other comorbid medical condition or diagnosis (please specify):

**Is your child on any medication to specifically help them sleep?**

Y/N

**If yes, please specify.**

**Is your child on any other medication?**

Y/N

**If yes, please specify.**

**Have you in the past, or currently, taken preventative measures against sleeping problems?**

Y/N

**If yes, please specify.**

**Which of these options do you believe would best treat a sleep problem?**

- Homeopathic or alternative medicines (e.g., lavender oil, sleep drops)
- Prescribed medications (Including melatonin)
- Bedtime fading (e.g. extending bed-time so your child goes to sleep quickly then gradually bringing it earlier)
- Systematic ignoring
- Modified systematic ignoring (e.g., camping out, checking on your child at fixed times)
- scheduled awakenings (e.g., waking your child at a set time or times during the night)
- White noise
- Massage therapy
- Co-sleeping (e.g., sleeping in your child's bed or your child sleeping in your bed)
- Weighted blankets
- Social story or sleep story
- Video modelling
- Exercise
- Rewards for sleeping well or following bedtime instructions
- Other (please specify):

**How much of a concern is your child developing a sleeping disorder/s for you?**

Scale of 1-5 (Not a priority – somewhat of a priority – number one priority)

**Has your child developing a sleeping disorder/s ever been a concern for you?**

Scale of 1-5 (Never – sometimes – always)

**How do you make sense of sleep problems in children with Autism? Please indicate the extent to which you agree with the following comments: Likert scale – 1-6 (1 Disagree strongly – 6 Agree strongly)**

- They are a feature of a child's Autism Spectrum Disorder diagnosis
- It is a part of who they are (i.e., it's just the way they are)
- It is intentional behaviour
- They are unlikely to change
- The child is responsible for managing their own sleep and sleep-related behaviour
- The child's sleep problems are outside of their control

**What do you consider to be a cause of sleep problem/s in children with autism?**

*Medical condition/s you have described above*

*Sleep hygiene:*

- Bedroom conditions (e.g., too light, too hot, too noisy).
- Inconsistent bedtime
- Inconsistent bedtime routine
- Use of digital devices (e.g., iPad, cell phone, t.v.)

*Learned or acquired sleep problems that interfere with falling asleep or staying asleep:*



- Child is seeking parental attention
- Bedtime avoidance
- Access to preferred activities, items or toys
- Dependence on sleep item (e.g., pacifier, cuddly)
- Child does not want to be left alone (?)
- Other

*Sensory problems: If so, select those that apply (sub-heading)*

- Sensitivity to the bedroom temperature
- Sensitivity to light in the bedroom
- Sensitivity to noise levels
- Sensitivity to bedding
- Other (please specify)

**In which, if any, aspects of a child's life do you believe their sleep problem would affect?**

- Communication
- Daytime behaviour at home
- Daytime behaviour at school
- Emotional regulation
- Learning
- Relationships (including friendships)
- Stereotypic behaviour
- None
- Other (please specify)

**In which, if any, aspects of a family's life do you believe the sleep problem would affect?**

- Employment
- Sibling relationships
- Siblings sleep
- Spousal relationship
- Your personal sleep
- Spousal sleep
- Your mental health and wellbeing
- Your daytime functioning
- None
- Other (please specify)

**Do you believe that a child's sleep problem can be resolved without treatment?**

Y/N

**How important is maintaining consistent sleep routines or bedtimes to you?**

Scale of 1-5 (Not a priority – somewhat of a priority – number one priority)

**How important are you in maintaining your child's sleep routine?**

Scale of 1-5 (Not important – somewhat important – very important)

**How important is your child in maintaining their sleep?**

Scale of 1-5 (Not capable – somewhat capable – capable)

**How would you rate your ability to regulate your child's sleep?**

Scale of 1-5 (Never – sometimes – always)

**Have you ever used an intervention that is focused on improving your child's sleep? This includes interventions that you have selected yourself.**

Y/N

**If yes, how would you rate the level of support with your child's sleep problem that you have received?**

Scale of 1-5 (1 = no support – 3 – occasional, moderate levels of support – 5 – extensive regular support)

**Who has helped, or is helping you with it?**

Tick all of those that apply:

- A psychologist
- A board certified behaviour analyst
- Occupational therapist
- Physiotherapist
- Speech language therapist/pathologist
- Teacher
- Researcher
- Pediatrician or other medical professional
- Web-based sources
- Books
- Parents
- No-one
- Other (please specify)

**What strategies have you tried or are trying to improve your child's sleep? Please rate their effectiveness (insert rating scale under each category).**

- Homeopathic or alternative medicines (e.g., lavender oil, sleep drops)
- Prescribed medications (Including melatonin)
- Bedtime fading (e.g. extending bed-time so your child goes to sleep quickly then gradually bringing it earlier)
- Systematic ignoring
- Modified systematic ignoring (e.g., camping out, checking on your child at fixed times)
- scheduled awakenings (e.g., waking your child at a set time or times during the night)

- White noise
- Massage therapy
- Co-sleeping (e.g., sleeping in your child's bed or your child sleeping in your bed)
- Weighted blankets
- Social story or sleep story
- Video modelling
- Exercise
- Rewards for sleeping well or following bedtime instructions
- Other (please specify):

**Thank you for taking the time to complete this survey.**

### Appendix J: Vignettes created for the survey

Q1)

Antonio has ASD and is unable to communicate how he feels verbally, Antonio's parents say that he often resists and avoids their attempts to put him to bed at night by crying, having tantrums, and sometimes throwing items around the room when he is left alone. Antonio's parents will let him fall asleep in their bed before transferring him to his own bed later in the night.

A) To what extent do you believe the following statements apply to Antonio's behaviour?

**Rate your responses to the following statements about this behaviour**

1. Is likely to resolve **without** treatment
2. Is part of the child's natural sleep cycle.
3. This behavior is part of the child's ASD
4. This behavior is learnt and can be change
5. If the parents change their responses the behavior will change

*\*Note this vignette depicted low functioning ASD and sleep resisting behaviour*

Q 2)

Madi is a child with ASD who can verbally communicate her needs. It close to midnight before she falls asleep. She frequently wakes during the night for extended periods of time. During the day, Madi's parent's will often let her take naps because Madi says she is too tired. However, later in the night, her parent's struggle to get her to settle into bed on time because she says that she is no longer tired.

A) To what extent do you believe the following statements apply to Madi's behaviour?

**Rate your responses to the following statements about this behaviour**

1. Is likely to resolve **without** treatment
2. is part of the child's natural sleep cycle.
3. This behavior is part of the child's ASD
4. This behavior is learnt and can be changed
5. If the parents change their responses the behavior will change

*\*Note this vignette depicted high functioning ASD and circadian rhythm disturbance*

Q 3)

Tane has ASD and engages in repetitive/stereotypic behaviour in the form of rocking and humming. He is put to bed by his parent's at 7:30 p.m. but he is often found hours later still engaging in this behaviour. Hugo's parents restore his sleep position, then sing lullabies and tell stories in order to help Hugo go back to sleep, however when he wakes in the morning, he still appears to be tired.

A) To what extent do you believe the following statements apply to Hugo's behaviour?

**Rate your responses to the following statements about this behaviour**

1. Is likely to resolve **without** treatment
2. Is part of the child's natural sleep cycle.
3. This behavior is part of the child's ASD
4. This behavior is learnt and can be changed
5. If the parents change their responses the behavior will change

*\*Note this vignette depicted mild ASD functioning and sleep competing stereotypy*

Q 4)

Awhina has ASD. She is doing very well at school but sometimes runs home during the day to tell her mother her worries. At night she calls for her mother repeatedly but will not get out of bed because she is afraid of the dark. Awhina's mother goes to her repeatedly over the evening to reassure her. She herself is exhausted so sleeps in her child's bed so they can both "at least get some sleep"

A) To what extent do you believe the following statements apply to Awhina's behaviour?

**Rate your responses to the following statements about this behaviour**

1. Is likely to resolve **without** treatment
2. Is part of the child's natural sleep cycle.
3. This behavior is part of the child's ASD
4. This behavior is learnt and can be changed
5. If the parents change their responses the behavior will change

*\*Note this vignette depicted mild ASD functioning sleep interfering anxiety*