

Sleep Intervention

Helping children with autism
to sleep better: A Forward
Steps intervention

Believe in
children



Barnardo's
Northern Ireland

No.21

Policy and Practice Briefing
March 2017

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Introduction

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental disorder affecting about 1 per cent of the UK population¹. ASD is a spectrum condition, meaning people with autism will have similar issues but overall their condition will impact upon them in different ways. Across the UK the number of ASD diagnoses continues to rise and Northern Ireland is no different.

Prevalence of autism in Northern Ireland²

2.3%

of school age children were identified with autism. Boys were 4 times more likely to have autism than girls.



1.5x



Children in urban areas were 1.5 times more likely to have autism than those in rural areas.

13%

of children identified with autism were living in the most deprived decile of Northern Ireland.



(Source: DoH, 2016)

Although the Department of Health (DoH) statistics indicate ASD is more prevalent in boys, emerging research suggests ASD in girls is often missed because they are 'excellent at masking their symptoms [and] often behave differently in different settings'³.

DSM-5⁴ criteria for ASD include communication deficits, likelihood of misreading nonverbal interactions, finding it difficult to build friendships appropriate to developmental age, may be overly dependent on routines, likely to be highly sensitive to changes in their environment, or to be intensely focused on inappropriate items.

Aside from the serious developmental effects of ASD for individuals, there are substantial direct and indirect costs. In the UK it is estimated that over a lifespan it costs £0.92m to support an individual with ASD, rising to £1.5m when an intellectual disability is present⁵.

Sleep disturbance is a common problem for children with ASD, impacting upon the quality of their life and that of their families. Approximately 50 to 80 per cent of children with ASD will display sleep problems compared to 9 to 50 per cent of children with typical development⁶. Sleep disturbance in children with ASD remains poorly understood but is thought to be a mix of biological, psychological, social/environmental and family factors⁷.

Defining a sleep disturbance⁸

A sleep disturbance is considered to be present when one or more of the following occur five or more nights per week.

- Bedtime resistance problems
- Delayed sleep onset
- Sleep association problems
- Nighttime awakenings
- Morning awakening.

Due to service providers prioritising daytime behaviour, sleep problems are often overlooked. Types of sleep problems include insomnia, night terrors, sleep walking, repetitive motor behaviour and restless legs syndrome.

This Study

Since 1999, Barnardo's NI Forward Steps service has expertly assisted paediatric services to assess, diagnose and offer interventions to children with autism and related communication difficulties. In recent years, the team of autism specialist interventionists grew increasingly aware of an apparent trend in their case-load, of children presenting with poor sleeping habits.

In response, Barnardo's NI decided to fund a pilot sleep intervention programme that aimed to work alongside parents to promote normal sleeping patterns and to reverse the onset of any established poor sleeping routines and behaviour. The objectives were twofold:

- To provide practical support to families of children with ASD to reduce the child's sleep difficulties and improve the quality of life for the whole family
- To explore, if by supporting children with autism and their families to adopt better sleeping routines, it could be possible to achieve better whole-family outcomes and likely knock-on benefits for society.

This briefing presents an overview of the intervention, its emerging key findings, the related policy context and recommendations for policymakers.

¹ Baron-Cohen, S; Scott, FJ; Allison, C et al. (2009). Prevalence of autism-spectrum conditions: UK school-based population study. *The British Journal of Psychiatry*, 194(6), 500-509.
² DoH, (2016). *The Prevalence of Autism (including Asperger Syndrome) in School Age Children in Northern Ireland 2016*.
³ Middletown Centre for Autism. (2016). *Autism and Girls*, 2(20), 14-15 see p6.

⁴ American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.).
⁵ Buescher, AV; Cidav, Z; Knapp, M; Mandell, DS (2014). *Costs of autism spectrum disorders in the United Kingdom and the United States*. *JAMA pediatrics*, 168(8), 721-728.

⁶ Reynolds, AM; Malow, BA (2011) Sleep and autism spectrum disorders. *Pediatric Clinics of North America*, 58(3), 685-698.
⁷ Cortesi, F; Giannotti, F; Ivanenko, A; Johnson, K (2010). Sleep in children with autistic spectrum disorder. *Sleep medicine*, 11(7), 659-664.
⁸ Johnson, CR; Turner, KS; Folds, E et al. (2013). Behavioral parent training to address sleep disturbances in young children with autism spectrum disorder: a pilot trial. *Sleep medicine*, 14(10), 995-1004.

About Forward Steps

Forward Steps is located in Belfast and is partly funded by the Belfast Health and Social Care (HSC) Trust and the South Eastern HSC Trust. All Forward Steps Services are free for families and children who are referred from either HSC Trust. Its three main strands are:

- **Family Support** offers home visits, autism training and practical information including modelling strategies to enable parents to nurture their child's development and support their autism.
- **Early Intervention Service** is designed for children waiting to be assessed for autism or communication related difficulties. The service provides practical information and advice in the Forward Steps setting and at home.
- **Early Intervention Programme (EIP)⁹** is for pre-school children diagnosed with ASD. Once the child's level of development and degree of autism is established, a visually structured programme is put in place to support the child's communication, learning and autism needs.

Connecting Autism and Sleep Deprivation: the intervention

As noted above, through their practice the Forward Steps team became aware of a possible connection between children with autism and sleep deprivation. An increasing number of families attending the EIP service were reporting that their child recently diagnosed with ASD had sleep problems.

Sleep deprivation for many of these children appeared to be linked to their autism and their ability to learn and function in everyday situations. It was also evident that the children's families were suffering from sleep deprivation and this was impacting on their wellbeing as well as their ability to teach and support their child with autism. The team began reviewing the literature on sleep difficulties linked to autism. While they found significant research regarding the impact of sleep deprivation on children, only a small number of studies had been carried out on the connection between autism and sleep deprivation in children with autism.

The team's experience, coupled with a need to develop more knowledge about the link between sleep and autism for children and families attending Forward Steps, informed the Barnardo's NI decision to fund the team to travel to Glasgow to train as sleep counsellors with Sleep Scotland, with a view to developing a pilot sleep intervention to be trialled in Belfast.

Sleep Scotland

is a charity founded in 1998 by Jane Ansell to promote healthy sleep in children and young people through sleep awareness, sleep counselling and education. For the last fifteen years the charity has worked throughout Scotland developing sleep services and providing intensive sleep programmes for children with additional support needs, by training sleep counsellors to work directly with families in need of sleep support.

By combining the Sleep Scotland training, with the autism knowledge and skills developed within Forward Steps over the previous fifteen years, the team developed multi-component tailored sleep plans to meet the specific needs of a child.

Forward Steps sleep intervention training methods

- **Sleep hygiene** seeks to create a bedtime routine to achieve a consistent sleep schedule. Steps are taken to ensure there is consistency for example the child's room is dark and quiet, stimulating activities are avoided etc.
- **Graduated extinction** involves parents ignoring disruptive bedtime behaviours for a predetermined period (e.g. crying out).
- **Faded bedtime** sets bedtime earlier and earlier each night until the desired bedtime is achieved.
- **Stimulus fading** specifically targets co-sleeping and entails gradually eliminating the presence of a parent from the child's room.

All of Forward Steps sleep training methods are widely recognised by sleep and parenting specialists. Sleep hygiene was the main training method used by the team and then depending upon the child's nighttime behaviour, aspects and combinations of the other methods were introduced.

Throughout the pilot the team was mindful that parents first needed to recognise and be prepared to address poor sleeping habits, bedtime routines, and nighttime interactions to enable the interventions to succeed. For children with ASD, sleep hygiene practices may not be straightforward. Being able to adapt routines to fit with the unique needs of the child and family was critical. Although children with ASD typically respond well to routines, they may become overly fixated on the details of routines. Introducing small variations into elements of the bedtime routine (e.g. have the child wear different pyjamas) can prevent the routine from becoming an unbreakable ritual¹⁰.

⁹ Braiden, HJ; McDaniel, B; McCrudden, E; Janes, M; Crozier, B (2012). A practice-based evaluation of Barnardo's Forward Steps Early Intervention Programme for children diagnosed with autism. *Child Care in Practice*, 18(3), 227-242.

¹⁰ Kodak, T; Piazza, CC (2008). Assessment and behavioral treatment of feeding and sleeping disorders in children with autism spectrum disorders. *Child and adolescent psychiatric clinics of North America*, 17(4), 887-905.

The team was acutely aware that every situation is different and there may be other issues impacting upon the stress levels within a family that may need to be addressed before sleep training can start. Before deciding upon a sleep training technique, the team needed to understand the parent child relationship, the needs of the child and what parents would be comfortable with doing. Carrying out an effective sleep assessment became a critical component of the intervention as did educating parents about the importance of setting limits around their child's sleep and sleep habits.

Methodology

Between March 2015 and September 2016 the Forward Steps team identified 11 children presenting with poor sleeping habits who fitted the inclusion criteria set out by Johnson et al.¹¹ All of the participant families were either part of the EIP from Belfast HSC Trust area or receiving the Family Support Service in the South Eastern HSC Trust area. Of the 11 children, three dropped out for family reasons or because an alternative solution was deemed viable.

Once a child was identified as a likely beneficiary of the pilot, a home visit was organised with the parents to discuss how to progress the programme. During this visit an extensive questionnaire¹² was completed with the parents to build a picture of the child's environment, relationships, routines, likes and dislikes, physical needs, presenting difficulties and any challenging behaviour. Autism specific areas were discussed with parents in great detail to gain as much insight into the child's functioning as possible. This included sensory seeking or avoidance behaviour, forms of expressive and receptive communication, tolerance level

to change of routines, knowledge of using visual supports as communication tools, type of previous professional support and responses to any past sleep interventions.

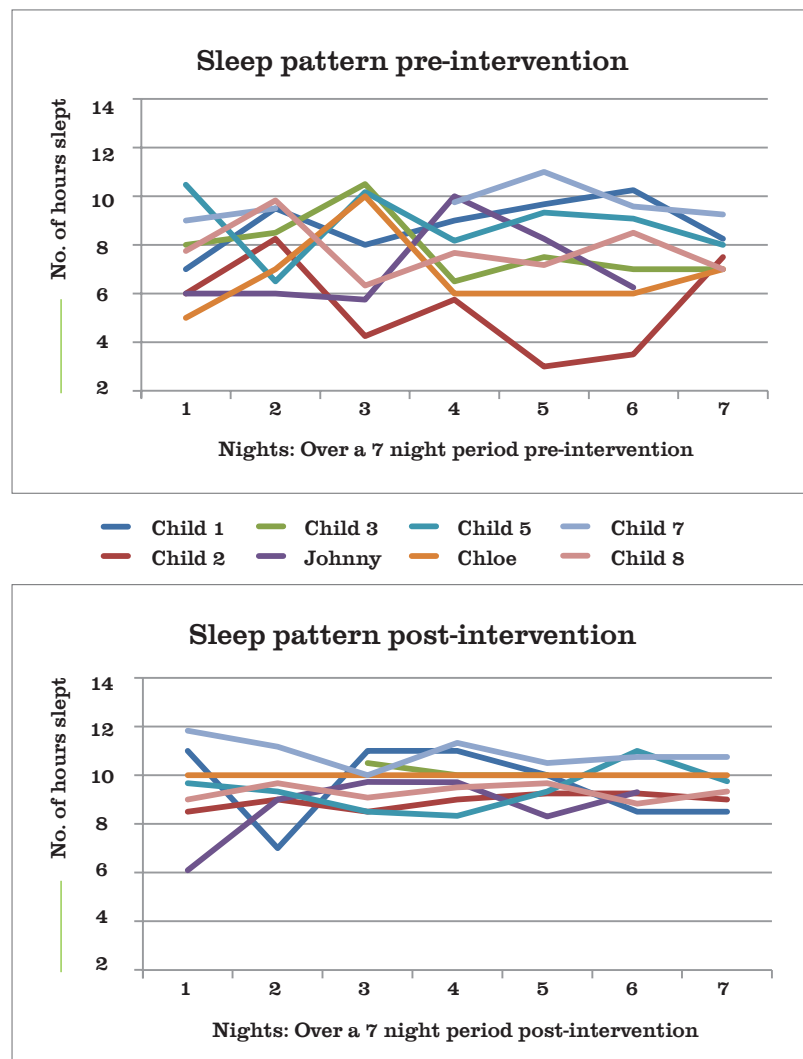
In keeping with the pilot ethos of the study, other measures including the Strengths and Difficulties Questionnaire and the Children's Sleep Habits Questionnaire were trialled with some parents.

Parents were also asked to keep a sleep diary to help gauge total sleep time, sleep latency (length of time taken from lying down for the night until sleep onset), night waking and other behaviours. Together the initial sleep diary and the in-depth interview informed the decision on the intervention method to introduce for the child. As the case studies below show, other issues often had to be addressed prior to beginning the sleep intervention.

Findings

Figure 1 provides a snapshot of the eight children's total hours slept before and after the intervention. Prior to starting the intervention total hours of sleep roughly varied from between 6 and 10 hours of broken sleep. After the intervention, hours of sleep increased to between about 8 and 11 hours of continuous sleep. Although the snapshot is crude, even from a visual perspective it is clear greater consistency in the total hours of sleep was achieved.

Figure 1: Total hours of sleep pre and post intervention



¹¹ See footnote 8.

¹² Adapted from Sleep Scotland Questionnaire and the Children's Sleep Habits Questionnaire (CSHQ).

Table 1 below provides an overview of the intervention including duration and the significant gains achieved for each child, which included:

- Reduced challenging behavior.
- Reduced learned behaviour such as rocking and vocal stimming.
- Restructured preparation for bed and introduction of a more appropriate bedtime routine.
- Reduced sleep latency. Falling asleep at a more appropriate time.
- Co-sleeping ended. Sleeping alone in own bed and own bedroom.
- Comforts like bottles removed.
- Removal of medication.



Table 1: Sample characteristics and overview of intervention

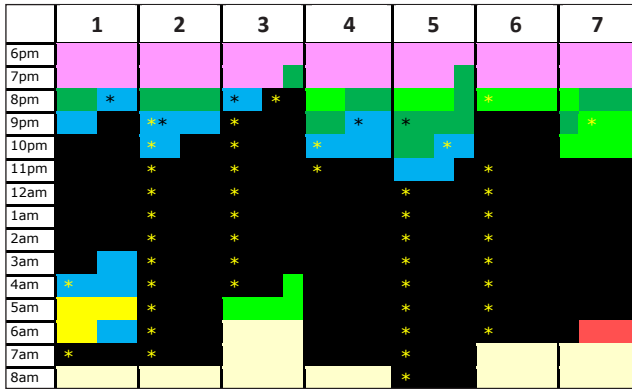
Child	Age	Sex	Diagnosis	Length of intervention	Most significant changes
Child 1	5	M	Autism and learning disability	8 weeks	Removal of co-sleeping, reduced bottle and reduced settling time
Child 2	5	F	Autism and learning disability	6 weeks	Removal of iPad/TV
Child 3	7	M	Autism	3 weeks	Reduced time in bed awake and preparation for bed
Child 4 Johnny	4	M	Autism and learning disability	3 weeks	Reduced time on iPad/TV and increase in play time
Child 5	5	M	Autism	2 weeks	Removal of medication and co-sleeping
Child 6 Chloe	4	F	Autism and learning disability	9 weeks	Challenging behaviour ceased, set times for iPad/TV, structure
Child 7	8	M	Autism	8 weeks	Almost no rocking or vocal stimming
Child 8	4	M	Autism and Global Developmental Delay	3 weeks	Challenging behaviour ceased, time awake in bed significantly reduced, structured time to play

Sleep Diaries

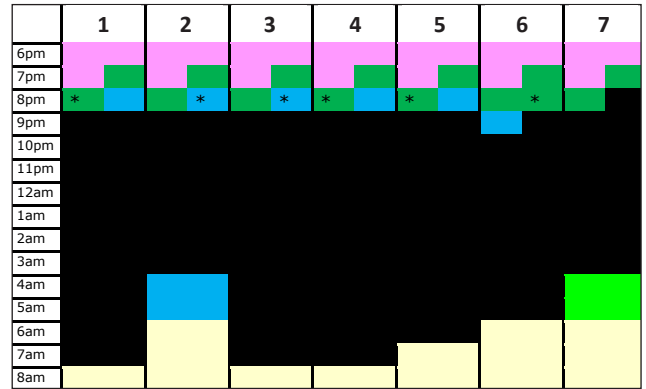
Pre-intervention
and post-intervention

The sleep diaries below delves deeper to show how the quality of each child's sleep was superior and less piecemeal at the end of the intervention compared to their baseline diary.

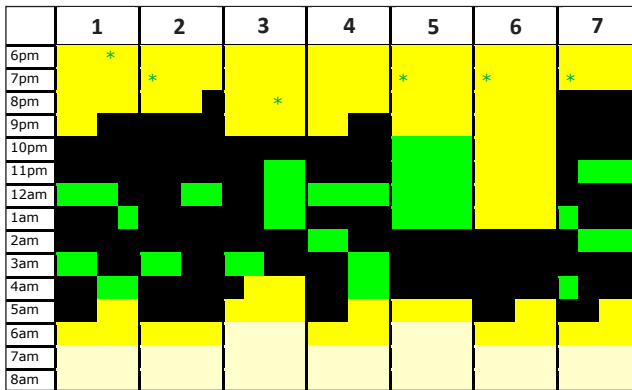
CHILD 1 PRE-INTERVENTION



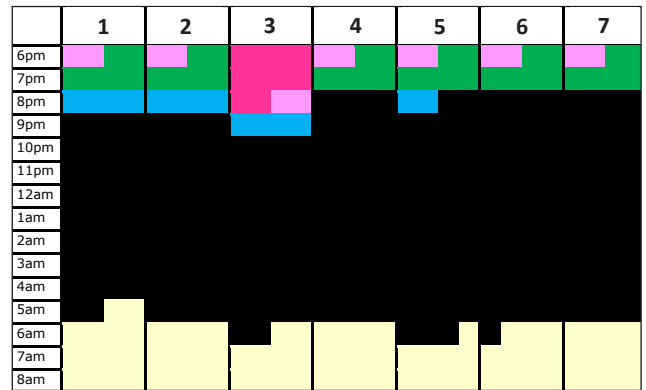
POST-INTERVENTION



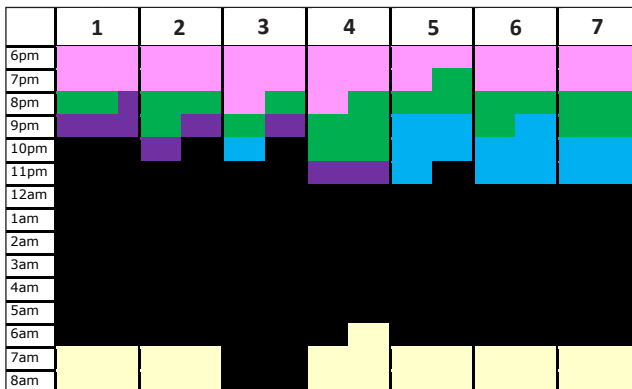
CHILD 2 PRE-INTERVENTION



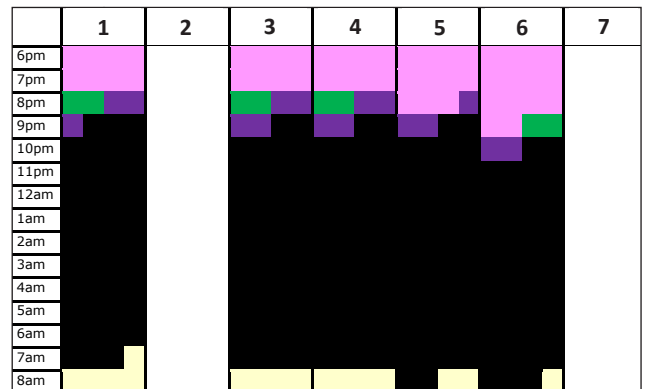
POST-INTERVENTION



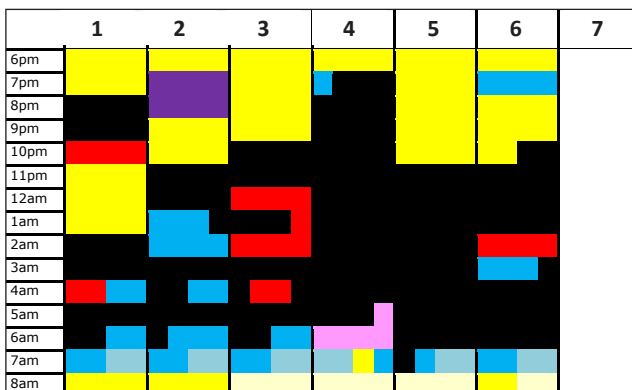
CHILD 3 PRE-INTERVENTION



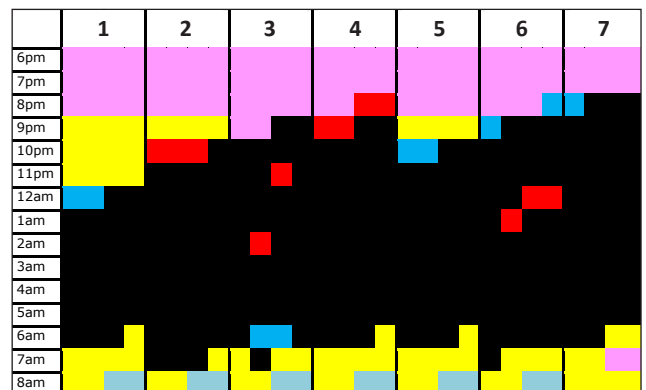
POST-INTERVENTION



CHILD 4 (Johnny) PRE-INTERVENTION



POST-INTERVENTION



Case Study 1

Johnny

Johnny is a four year old boy who is diagnosed with autism and has a mild to moderate learning disability. Following referral onto the EIP, the team became aware of Johnny's poor sleeping habits. His parents agreed he could benefit from being part of the pilot sleep programme.

Over the course of two home visits the practicalities of a sleep intervention were explored with Johnny's parents. A weekly sleep diary was kept to allow the team to understand Johnny's current bedtime routine, his sleep patterns and behaviours.

Johnny's bedtime/sleep routine relied heavily on mum and/or his older brother. Each night the family would watch TV/movies. During this time Johnny would fall asleep in the living room and then be carried to bed. If Johnny woke, he insisted on lying in bed facing Mum, talking with her or he demanded his iPad. While asleep, Johnny would roll onto his mum or across the bed and onto his brother.

A proposed sleep plan was developed, centring on a new routine to remove mum and older brother from Johnny's bed and to encourage him to fall asleep by himself. It was agreed Johnny's older brother would stay with a relative for the initial period of the sleep intervention. For the first few nights a member of the team stayed with the family until midnight to support mum through the bedtime routine.

Johnny's new bedtime routine and sleep plan was explained to Johnny using a social story, containing visual strategies. Each night when the 'playing for five' symbol was shown and counted down, play was over and the bedtime routine got underway i.e. go to the toilet,

brush teeth. Johnny then chose one of three items to take to bed. Once Johnny was in bed mum left the room and sat on a chair in the doorway facing away.

On the first night Johnny lay quietly for 10 minutes before rolling out of bed, asking for the iPad and trying to go to the bathroom. A 'no' symbol was placed on the iPad and mum tapped the bed for Johnny to climb back in. Johnny said 'I need my iPad' but mum did not use any language. Johnny lay on his bed until 9.50pm and fell asleep by himself. He woke briefly at 12.20am and again at 3.20am. Each time Johnny woke, mum returned him to bed and then returned to sitting silently on the chair. It was agreed that bed rails would be installed on the second night because Johnny was inclined to sleep to the edge of his bed.

On the second night Johnny resisted a little but made his choice from the choice box. Once in bed mum sat on the chair. Johnny cried and said 'I don't wanna sleep by my own self'. At one point Johnny tried to leave his bed. Mum said 'time for bed' but did not leave her chair. Johnny lay down but continued like this for 20 minutes before falling asleep at 9.20pm. At this point Johnny's parents decided they were happy to

do the bedtime routine and sleep intervention on their own. Before leaving, the team discussed with Johnny's parents about the next steps, including plans for reintroducing Johnny's brother and equipping dad to carry out the bedtime routine. They highlighted that Johnny's behaviours might progress throughout the night, as and when he wakes with a possibility they may last longer and could increase in intensity.

On the fifth night Johnny's older brother was re-introduced to the family. He became involved in the new bedtime routine. He explained to Johnny why they were not going to bed at the same time. Early in the second week dad took the lead in the bedtime routine. On this occasion Johnny woke once at 5am crying but went back to sleep himself.

During the intervention mum reported Johnny was sleeping for longer. She felt the bed rails had made a big difference - he now cuddled right up to them at night. For her, two full night's sleep was very welcome. She noted seeing a difference since she changed her behaviour with Johnny and since reducing Johnny's time on the iPad before bed (now removed at around 5pm). Before the intervention, he had used the iPad to fall asleep and





Case Study 2

Chloe

Chloe is a four year old girl diagnosed with autism and severe learning disability who was referred by Belfast Trust to Forward Steps Early Intervention Programme. Chloe was displaying difficulty in distinguishing between daytime and nighttime and this was one of the main reasons mum expressed an interest in taking part in the sleep pilot.

During an initial home visit, the team discussed the practicalities of a sleep programme with Chloe's parents. They agreed to keep a sleep diary and to undertake a pre-intervention session at Forward Steps. Chloe was displaying self-harming and significant sensory seeking behaviours. The EIP developed at Forward Steps for Chloe during the day, was adapted for her night time routine. Chloe's parents were also advised to prevent her from accessing her bedroom during the day and to use visual strategies to discourage her from napping.

During the pre-intervention sessions at Forward Steps, the team demonstrated how to implement the sleep programme so as to help Chloe's parents to replicate the strategies at home. During this period, Chloe's parents began a sleep diary of her behaviours and sleep patterns during the night. Her sleep diary was instrumental in enabling the team to understand Chloe's current bedtime routine, her sleep patterns and behaviours.

Using the team's observations of Chloe at Forward Steps, her parents input and the sleep diary, an intervention programme was developed, which included a sensory diet programme. With her sleep pattern established the team was able to design a tailored intervention that contained three core elements:

1. The creation of an appropriate sleep environment to meet Chloe's needs within autism.
2. An individualised bedtime routine.
3. A behaviour management plan to be followed if Chloe woke during the night.

then when required throughout the night.

In retrospect, the sleep intervention was difficult for mum. The hardest and most emotionally challenging part was not speaking or engaging with Johnny once he was in bed. However, family life had changed for the better, mum was feeling more confident and her mental health and happiness had improved. She now wanted to take time for herself and she was thinking about returning to work on a part time basis.

Post intervention, both parents now understood Johnny's behaviour in relation to sleep, self-soothing and managing his own emotions. Mum explained she does not feel guilty about him crying or getting upset because she sees this as behaviour that can be worked through. She is also more consistent in saying 'no' and working through challenging behaviour outside of the family home.

Throughout the sleep intervention, Chloe's parents continued to keep a weekly sleep diary as well as completing a daily motivation scale. The Forward Steps team maintained daily phone contact with Chloe's mum to monitor how the programme was progressing and to provide support if needed.

An emergency short break was provided for Chloe at an early stage of the programme. This allowed Chloe's mum to rest and to give Chloe ongoing intervention during the day. The need for ongoing support was agreed by her parents and therefore contact was made with Chloe's social worker. A Carer's Assessment was completed which eventually resulted in a referral to the Forward Steps sister project Home Links for the provision of a regular short break session each week.

Chloe's response to the intervention was regularly monitored until her parents reported a favourable change in Chloe's self-harming and sensory seeking behaviours.

During a home visit, post intervention Chloe's parents reported that her '*sleep was cracked*', she was now going to bed and sleeping all night and they looked forward to bedtime. Despite subsequent unforeseen issues and family stress, Chloe's parents felt they were better able to manage situations because of Chloe's improved sleep pattern.



Reflections from the pilot

The ability of sleep interventions to achieve improved outcomes for children with autism is not new.¹³ However, the organic nature of this pilot coupled with the specialist autism expertise of the team is an example of how innovative practice delivered in an applied clinical setting focused solely on improving outcomes can make a cost-effective difference to children and families lives. Subject to further replication, the findings are promising and point to an effective suite of interventions¹⁴.

Guided by the study's aims and objectives, the specialist team worked closely with these children and their parents - who were often in the depths of despair - to undertake a journey of learning and at times affirmation that whatever difficulties a typically developing child faces, a child with ASD will experience a heightened version.

Notably, it was evident that families referred on to the

pilot sleep programme from Forward Steps EIP were more knowledgeable about ASD¹⁵. They understood their child's autism and were in a better position to embed the sleep interventions compared to those in receipt of Family Support on its own.

For the team this pilot has shown that when a suitable support system is in place in the home, a critical foundation is laid for enabling children with autism and their families to be more themselves and function without the effects of sleep loss. In particular, the case studies highlight the considerable skill and expertise needed to successfully install and embed a sleep intervention, which felt like a last resort for many of the families. The diaries too highlight the significant changes achieved in behaviour, the helpful substitution of technology by play and structured play and the reduction of stressful behaviours, all of which has

enabled the team to learn and to build their expertise.

The commencement of the Autism Act and the implementation of the Autism Strategy and Action Plans are positive developments, however going forward it is difficult to shy away from the statistics that tell us diagnoses for ASD are on the increase among boys and children living in urban and disadvantaged areas, as well as research indicating the rate of prevalence in girls is more pronounced than what the statistics suggest.

In conclusion, this study has highlighted the unique needs of children with ASD and how a targeted intervention can significantly help these children. To enable this to happen in a more systemic way, families need to be supported to lay solid foundations which can be built upon, by creating autism friendly systems in homes, schools and society.

¹³ Vriend, JL; Corkum, PV; Moon, EC & Smith, IM (2011). Behavioral interventions for sleep problems in children with autism spectrum disorders: current findings and future directions. *Journal of pediatric psychology*, 36(9), 1017-1029.

¹⁴ Chambless, DL; Hollon, SD (1998). Defining empirically supported therapies. *Journal of consulting and clinical psychology*, 66(1), 7.

¹⁵ See footnote 9.

Policy Context



Department of Health (DoH)

A significant policy development for ASD in Northern Ireland was the enactment of the Autism Act (NI) (2011). The act amends Schedule 1 of the Disability Discrimination Act 1995 (DDA 1995), to require consideration of autism when deciding whether or not a physical or mental impairment affects the ability of a person to carry out normal day to day activities. As a result *'taking part in normal social interaction; or forming social relationships'* impacts upon whether a person falls within the definition of a disabled person under DDA 1995.

The Autism Act also requires the DoH to lead on the development, implementation monitoring and reporting of a cross-departmental strategy. The Autism Strategy (2013 – 2020) and Action Plan (2013 – 2016) were approved and launched by the Executive in January 2014.

A further requirement of the Autism Act is for DoH to publish autism statistics on an annual basis.

Department of Education (DE)

Since the launch of the NI Executive Autism Strategy, DE has worked closely with the Education Authority (EA) and the Middletown Centre for Autism to develop support and provision for children and young people with autism. This includes delivering training programmes for teachers, educational professionals, youth workers and parents and providing ongoing support for pupils with autism.

EA has an Autism Advisory and Intervention Service which is working to regionalise autism training, support and provision in order to enhance equity and access for children, their families and schools.

The Autism Advisory and Intervention Service advises schools on reasonable and supportive adjustments that may be made to a child's learning and social environment as well as providing direct support to children to help them develop skills that will enable them to better manage the school's social and learning environment.

EA has undertaken a review of learning support centre provision in mainstream schools, and it proposes to enhance autism specific class provision throughout the region.

There are formal arrangements for collaborative working between the autism services in education and health in relation to autism diagnosis, training and intervention.

Recommendations for Policy and Practice



Sleep is critical for children with ASD but as this study has highlighted, its importance is often overlooked. Early intervention for children with autism is crucial in their development and for achieving better whole-family outcomes, as well as likely knock-on benefits for society. This examination of a Forward Steps autism intervention raises the potential for significant improvement in child and family emotional wellbeing and functioning by addressing children's sleep problems directly in the home using a short-term, intensive and supportive approach.

The findings of this study, taken together with Forward Steps knowledge and extensive experience of working directly with children and families leads Barnardo's NI to offer the following recommendations:

- Resources should be made available by the DoH for further longitudinal research to investigate the longer term effects on child outcomes of sleep intervention programmes to achieve improvements in daytime functioning for children and families.
- During the diagnostic process, it is important that those carrying out clinical assessments establish each child's sleeping habits and the impact of this on the family and child's functioning.
- The Public Health Agency and EA should undertake awareness raising in primary health care and schools on the impact of autism combined with sleep loss on children and families' physical, cognitive and emotional wellbeing.
- Forward Steps services are free to families but are difficult to access unless the child is referred by either the Belfast or South Eastern HSC Trust. Grants bodies that provide support to families and the HSC Trusts should make single payment grants available for parents to directly access sleep and other autism interventions that are evidence based.
- This sleep intervention was easier to embed for those families that had benefited previously from Forward Steps Early Intervention Programme (EIP). Anecdotal evidence suggests a similar trend when families are later referred for speech and language and occupational therapy support. Health and Social Care commissioners within DoH, Health and Social Care Board and HSC Trusts should strongly consider investing in services such as Forward Steps EIP that are evidence based and deliver positive and lasting outcomes for families and children.



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