



Sleep Tight Trafford: Developments and Outcomes

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Sleep Tight Trafford



Commissioned service

Jointly funded by

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- An initial 12 month pilot ran from June 2016
- Delivered by The Together Trust
- Tiered service to residents of Trafford



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Trafford: Setting the scene

- Metropolitan borough of Greater Manchester
- Estimated population of 235,493 in 2017
- Covers 41 square miles (106 km²)
- Includes the areas of Old Trafford, Stretford, Urmston, Altrincham, Partington and Sale.
- Home to Manchester United and Lancashire Cricket club



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Making the case:

- In 2016 in Trafford there was no children's sleep service.
- Children with severe LD could access support from the LD Nursing Team including sleep difficulties.
- Therefore overwhelming majority of children whether they had ASD/ADHD or not had no specific support.
- Skills and knowledge of amongst frontline staff was highly variable



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How big was the problem?

- Similar to many paediatric community services we did not have adequate IT systems to determine what was the actual level of need
- What we did know was that more than 50% of the paediatric clinic cases were ASD/ADHD and more than 2/3 had significant sleep issues and on melatonin.
- We were also increasingly getting referrals regarding behaviour where actually the main issue was sleep masquerading as behavioural problems during the day.
- Many children were prescribed melatonin in the absence of any other available service
- In 2015, Paediatric Medical prescribing budget 30% melatonin. This had doubled from 2012.



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Sleep and autism- what the research tells us:



- Sleep is a critical component of healthy development in children; vital for cognitive, physical and emotional development (Abel et al, 2018)
- Sleep problems are not uncommon in childhood
- Incidence is significantly higher in autistic children than in typically developing children or in children with other forms of disability (40 – 86%)
 - Across age and spectrum
 - Sleep problems are persistent in autistic children
 - Problems may differ across the spectrum



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- One of the primary concerns parents have and one of the major reasons parents seek help.
- Sleep problems worsen ASD symptomatology across most core domains as well as exacerbate pre-existing behavioural problems (Cohen et al. 2018)
- Sleep problems are a cause of stress in families

“Treating disordered sleep in ASD has great potential to improve daytime behaviour and family functioning in this vulnerable population” (Cohen et al. 2018)



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“Interventions aimed at improving overall patterns of sleep may have important cascading effects on challenging behaviors and developmental outcomes for children with ASD and their families”.

(Abel, et al. 2018)



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Research frequently states

- Lack awareness in professionals
- Need for training in professionals
- Need to screen for sleep problems
- Lack of support for parents
- Need for further research

“It is vital for PCPs to be knowledgeable about this topic and to promptly assess for and manage sleep disorders among children with ASDs”
(Herrmann, 2015)



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Sleep Tight Trafford



- **Tier 1 Universal service**

Increase awareness of the importance of sleep

- www.togethertrust.org.uk/sleep-tight-trafford
- Open community events (2016)
- Posters and information packs (2016)
- Red book insert (2017)
- School leaflet (2018)



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- **Tier 2**
 - Training for front line healthcare staff
 - Supervision and co-working for staff (2017)
 - Workshops (2016)
 - 1 to 1 Sleep Clinics for parents (2017)



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Training for front line staff

- Open to staff from paediatric and HYM services
- 20 places first 2 years, 10 places this year
- 6 training sessions

Covers 4 key sections:

- Sleep basics
- Sleep hygiene
- Core strategies
- Autism
 - And Sleep
 - key strategies
- Feedback on each module and at end of course

 Regular supervision sessions and co-working (from 2017)



Outcome from staff training

- 100% of staff agreed that the training provided key strategies to improve children's sleep
- 100% of staff now use the skills and knowledge gained when working with families



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Tier 2: Parent workshops and 1 to 1 Sleep Clinics



- 2016 sleep workshops
- 2017 1 to 1 Sleep Clinics
 - in four community locations across Trafford
 - Special school
 - Open referral to the service
 - Parents receive individualised help, specific to their child.
 - Parental rating scale pre and post intervention (2018)
 - Dates released quarterly and book up quickly



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Tier 2: 1 to 1 Sleep Clinics

- **High demand** for appointments
 - Across range of age and need
 - Extended appointments for children with additional needs
 - Access to personalised resources
- Option to transfer to Tier 3 (2018)
- **Successful outcome for children and parents**
- **Improved quality of life for parent and child**



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Case study

Great Grandma attended 1 to 1 clinic

- Caring for two children
 - Mark 3 ½ years on the diagnostic pathway
 - Molly 2 ½ years is being monitored
 - receiving support from HV
- Sleep problems
 - Both children difficulty settling to sleep
 - Night waking
 - Early morning waking (3 am)
- Great grandparents exhausted and struggling to cope
 - Health concerns



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1 to 1 clinic service

Great grandma received individual advice for both children including

- New bedtime routines
- Strategies to support new routine
- Personalised resources



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Outcome

Tel call to Great Grandma

- Mark's sleep improved from the first night
- Molly initially still woke at 3 am but returned to sleep
- Grandma said "It's been amazing from day one"
- Within 8 weeks both children
 - settling to sleep within 15 minutes
 - sleeping all night
- Family and support team learnt how to use strategies to support the children
- 6 month follow up both children still sleeping well





Tier 3: Highly specialist

- 40 referrals per year
- Paediatrician/ HYM gate keeper
- Referral criteria
 - Diagnosis of autism and /or ADHD and/or complex behavioural/emotional problems
 - on melatonin
 - With no significant learning difficulties
- Objectives
 - Provide access to a specialist service
 - Improve sleep of children
 - Reduce demand on paediatric consultant clinics.
 - Reduce prescription of melatonin



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Service delivery

- Specific referral process
- Home visits
- Base line established
 - Sleep diaries
 - detailed parental interview
 - Children's sleep Habits Questionnaire
 - Parent's sleep quality
 - Pittsburgh Sleep Quality Index
 - Flinders Fatigue Scale
 - Goal setting



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- Detailed individual sleep programme
 - With personalised resources tailored to their needs such as visual schedules, Social Story
- Support for parents during implementation
- Post-intervention follow up
 - Repeat questionnaires and reassess goals
 - General feedback form
- Letter to paediatrician



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Outcomes

- a **36 % reduction** in melatonin budget from first year of service alone
- **“the Sleep Tight service has been really helpful and we are delighted our child is no longer on medication”**
- **96 % of parents** said the Sleep Tight Trafford programme has been successful
- **100 % of parents** felt their **child’s behaviour had improved** at bedtime and
- **100% of parents felt better themselves** after their child had completed the Sleep Tight Trafford programme.



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Case study

Alice aged 5 ½ Years

- ADHD, epilepsy and behavioural problems
- Sleep problems:
 - Late settling to sleep
 - settles in parent's bed
 - multiple night awakenings
 - and early morning waking
 - Sleeping 3 to 4 hours sleep a night
- Mum and Alice exhausted
- Mum mental health concerns and struggling to cope
- Grandmother offering support
- Older sibling sleep affected and relationships affected.
- Parental rating of child's sleep: 1



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- Detailed individual sleep programme provided and supported with personalised resources including
 - Social story
 - visual routine
 - daily planner
 - bed time passes



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Outcomes



Sleep:

- Following her visual routine
- Alice is settling to sleep in her own bed
- Sleeps all night in her own bed
- Sleeps all night
- Set morning routine
- 11 hours sleep per night
- Parental rating of child's sleep: 5

Behaviour improved



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- Relationship with sibling has improved.
- Mum is able to cope and has re-established quality time with both children.
- Mum has more energy and is now considering completing a course to work with families and promote sleep and positive changes for other families.
- Grandma has returned to her own home

Mum said “ Thank you so much for getting my life back. I was hesitant but I can’t believe it worked. I struggled at first but it was so easy when I got started. It’s not going to change”



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Make sleep a priority...

- Always ask parents about their child's sleep
- Don't assume that the sleep problems are inevitable or tell parents that they are!
- Offer a practical means of help
- Refer to NICE guidelines
- Establish a Sleep pathway ..
- Train staff



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Thank you for listening

- www.togethertrust.org.uk/sleep-tight-trafford
- Email: chris.hoyle@togethertrust.org.uk



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References



Abel, E. A.; Schwichtenberg A. J.; Brodhead, M. T.; Christ, S. L. Sleep and Challenging Behaviors in the Context of Intensive Behavioral Intervention for Children with Autism. *Journal of Autism and Developmental Disorders* 2018, 48, Issue 11, pp 3871–3884

Cohen, S.; Fulcher, B. D.; Rajaratnam, S. M. W.; Conduit, R.; Sullivan, J. P.; St Hilaire, M. A.; Phillips, A. J. K.; Loddenkemper, T.; Kothare, S. V.; McConnell, K.; Braga-Kenyon, P.; Ahearn, W.; Shlesinger, A.; Potter, J.; Bird, F.; Cornaish, K. M. and Lockley, S. W. Sleep Patterns Predictive of Daytime Challenging Behavior in Individuals with Low Functioning Autism. *Autism Research*. 2018, Vol 11, 2, pp 391-403

Herrmann, S. Counting sheep: Sleep disorders in children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*. 2016, 30; Issue 2; pp. 143-154.

Malow, B. A.; Byars, K.; Johnson, K.; Weiss, S.; Bernal, P.; Suzanne E. Goldman, S. E.; Panzer, R.; Coury, D. L. and Dan G. Glaze, Practice Pathway for the Identification, Evaluation, and Management of Insomnia in Children and Adolescents with Autism Spectrum Disorders. *Pediatrics*, 2012; pp. 130:S106



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