

Are we missing something?

A challenging presentation of blindness in a child diagnosed with Autism Spectrum Disorder – A case report

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Problems

- Autism spectrum disorder (nonverbal)
- Blindness? cause- possible Vitamin A deficiency
- New onset Focal epilepsy
- Very restricted diet
- Vitamin A and D deficiency
- Past history of atypical febrile convulsions
- Eczema
- Difficulties with sleep – On melatonin
- Incontinence – for both poo and wee
- Obesity

Case summary

A boy born in 2014, diagnosed with Autism spectrum disorder, presented with loss of appetite and weight loss. He had atypical febrile convulsions at age of 3. At the age of 9 years he started new onset focal epilepsy which was difficult to control

He has a very restricted diet and eats only chips and drinks fizzy drinks. He is obese. Parents noted loss of weight in June 2022. One month later, he presented to ophthalmology with redness and itching of both eyes where he was detected to have impaired vision. No concerns about vision/ night blindness from parents.

He was born at term through SVD with a birth weight of 3.2kg. Uneventful birth and antenatal history as recorded.

Examination

Weight > 99.6th

Extremely difficult examination due to lack of cooperation. No signs of nutritional deficiency noted. Redness of eyes only noted during first presentation to ophthalmologist. No eye signs.

References

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- https://eyewiki.org/Nutritional_Optic_Neuropathy

Investigations

EEG – excess rhythms of theta and delta components for the age with no obvious epileptiform activity

Electrodiagnostic studies - Severe bilateral macular and generalized visual pathway dysfunction

MRI head 2023 – Chiari 1 malformation no other abnormalities

Coeliac screen/ FBC/ Liver function/ electrolytes/Thyroid function – normal

Deficient levels of Vitamin B and zinc

	Initial	After correction
Vitamin A (umol/L)	0.3	1.54
Vitamin D (nmol/L)	32	60

Discussion

This child developed blindness within a very short time and the only possible causative factor found was low levels of vitamin A and B12. He did not have classical sequelae of vitamin A deficient eye disease. This arises the question whether nutritional bloods should be routinely and regularly done in a child with ASD who are nonverbal.

It is not a common presentation to have vitamin A deficiency eye disease without the clinical sequelae or acute illness to deplete Vitamin A in the body suddenly. This gives the dilemma of what other possibilities of blindness should be considered? Is nutritional optic neuropathy a possibility?

His records indicate that he was having profoundly reduced eye contact throughout which was attributed to ASD. Will these children benefit from routine eye checks which are overlooked as they are not cooperating for examination?

NICE guidelines in 2021 after an exceptional survey recommended that blood tests may be required to check for nutritional deficiencies in management of children with ASD. Should this be changed to a lower threshold or for routine bloods irrespective of clinical signs?

Acknowledgement

All clinicians of East Kent Hospital University NHS Trust contributing to the management of this child.

Audit of Sleep Related Disordered Breathing (SRDB) in Children with Downs Syndrome attending the Developmental Paediatric Service , Surrey and Borders Partnership NHS Trust.

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INTRODUCTION

Sleep related disordered breathing (SRDB) refers to a group of disorders that affect breathing during sleep. These include: central sleep apnea, obstructive sleep apnea, upper airway obstruction syndrome and sleep related hypoventilation & hypoxaemic syndrome. Children with Down Syndrome (DS) are at increased risk of sleep related upper airway obstruction and nocturnal hypoxaemia. The prevalence of SRDB in DS is 30-77%. This higher prevalence is due to the phenotypic features: small oropharynx, narrow upper airways, midfacial hypoplasia, generalised hypotonia, adenotonsillar hypertrophy and obesity. Polysomnography is the gold standard for diagnosing SRDB. Cardiorespiratory sleep study is first line diagnostic test however pulse oximetry can be considered if this is unavailable.

AIMS

1. To audit the practise of the service against the national standard (All children with DS be offered screening with overnight pulse oximetry once in infancy and thereafter yearly till 5years of age with a low threshold for screening throughout their lifespan; And also, negative test results in the presence of symptoms should be followed up with polysomnography).
2. To find out the prevalence of SRDB in children with DS attending the Developmental Paediatric service of Surreys and Borders Partnership NHS Trust (SABP).
3. As a quality improvement project, we aim to develop a SRDB screening proforma for use in the clinic.

METHODOLOGY

This was a retrospective study. An Email was sent to all Doctors working in Developmental paediatric service of SABP requesting for DS children attending their clinics. The identified DS children were enrolled into the audit - 22 of them were included. There was retrospective review of clinic notes from 2011. We collated information on sleep history, respiratory symptoms and signs, reflux symptoms, complications such as pulmonary hypertension or heart failure, previous investigations including pulse oximetry, cardiorespiratory sleep studies and any other specialist involvement. Data was entered into excel sheet and analysed. Results computed into Bar charts and Pie Charts.

RESULTS

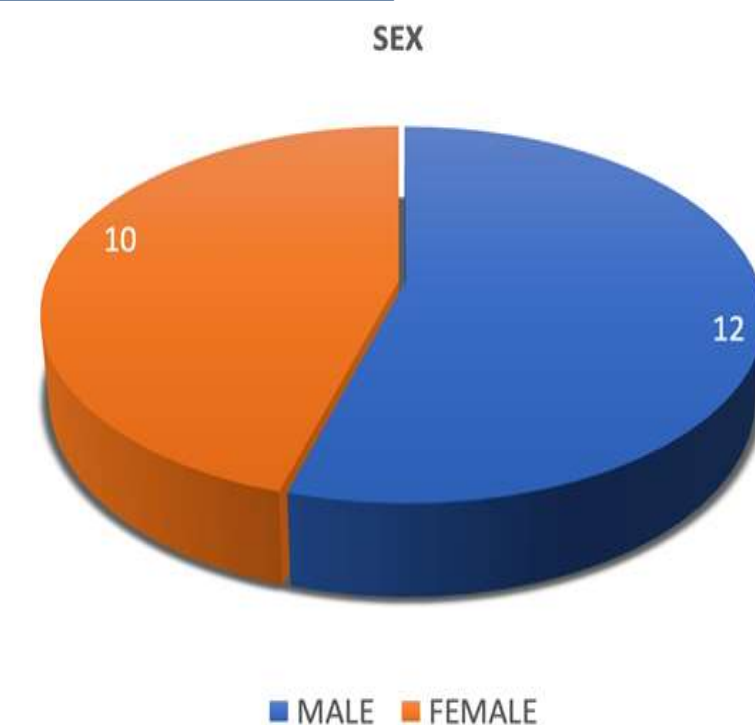


Fig 1: Sex Distribution

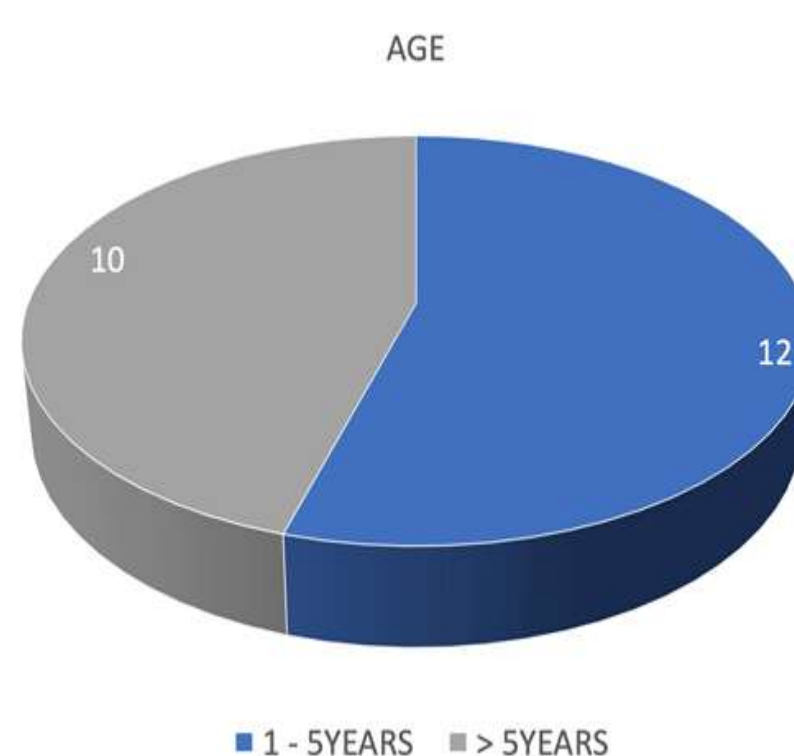


Fig 2: Age distribution

RESULTS

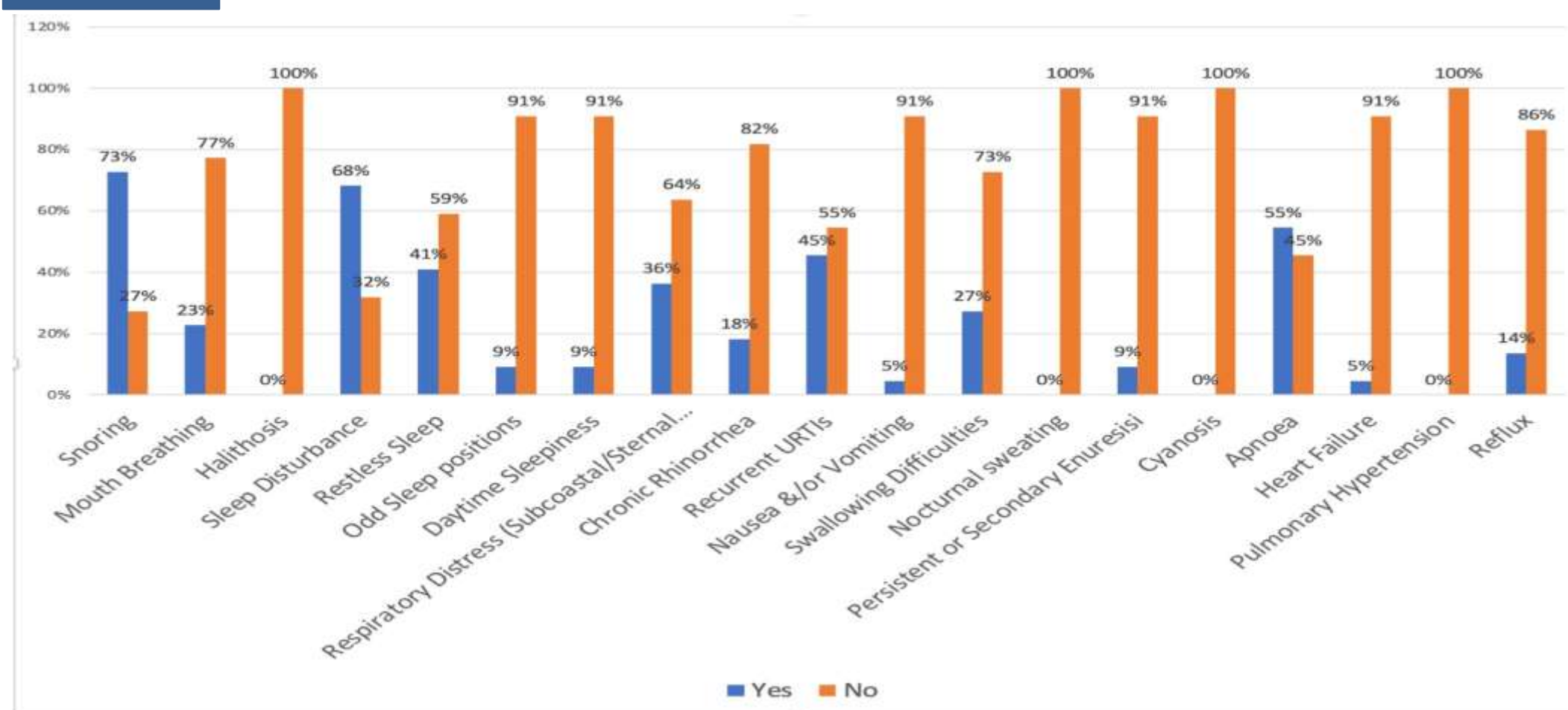


Fig 3: Symptoms and signs recorded for our DS patients

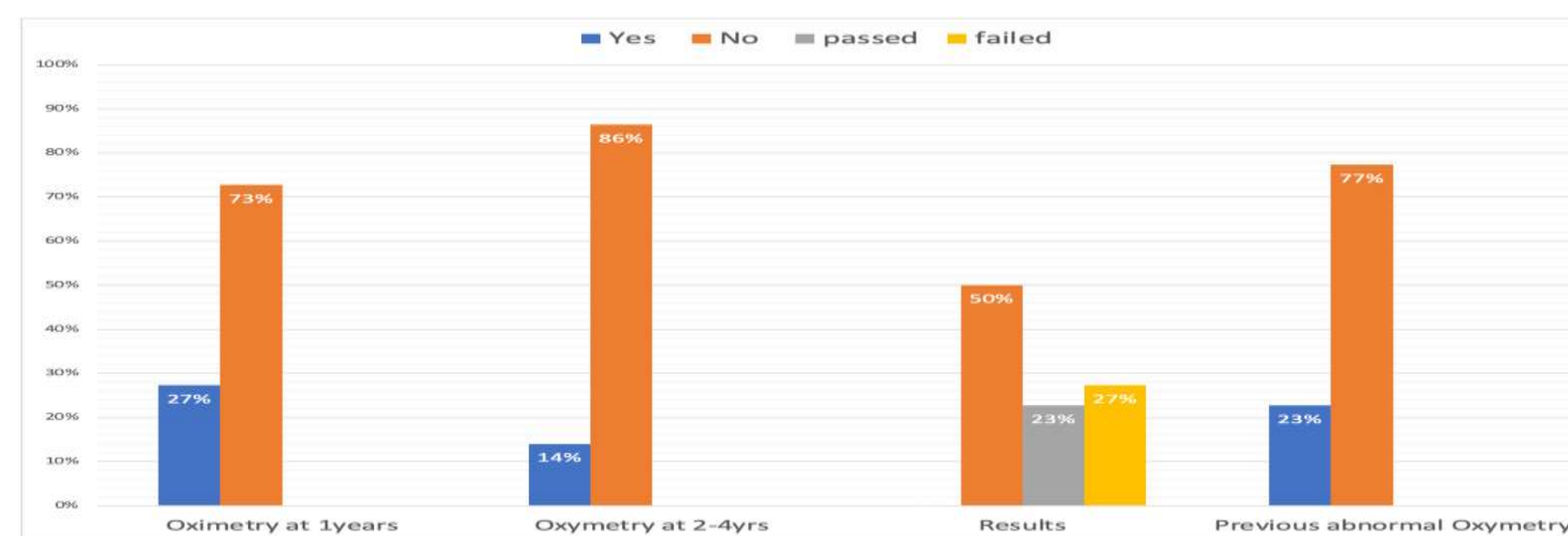


Fig 4: Recorded Oximetry testing in our DS Patients

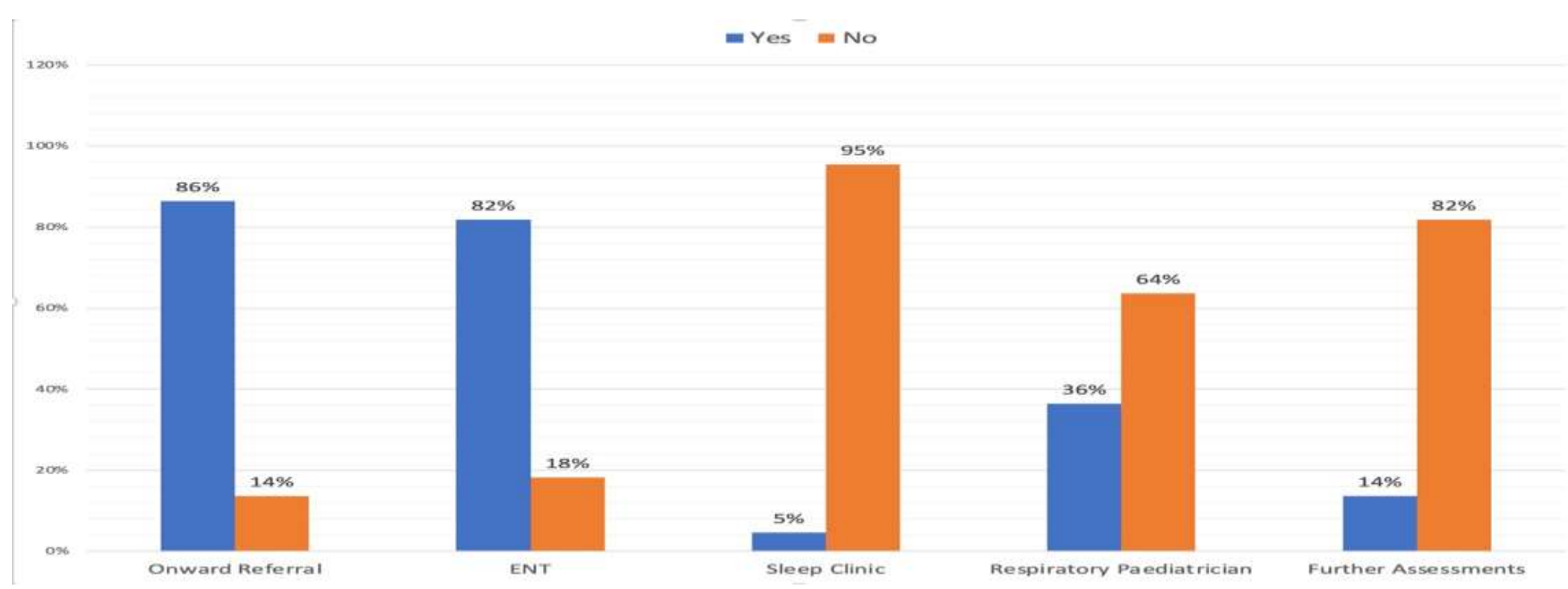


Fig 5: Referral and other specialist involvement

RESULTS

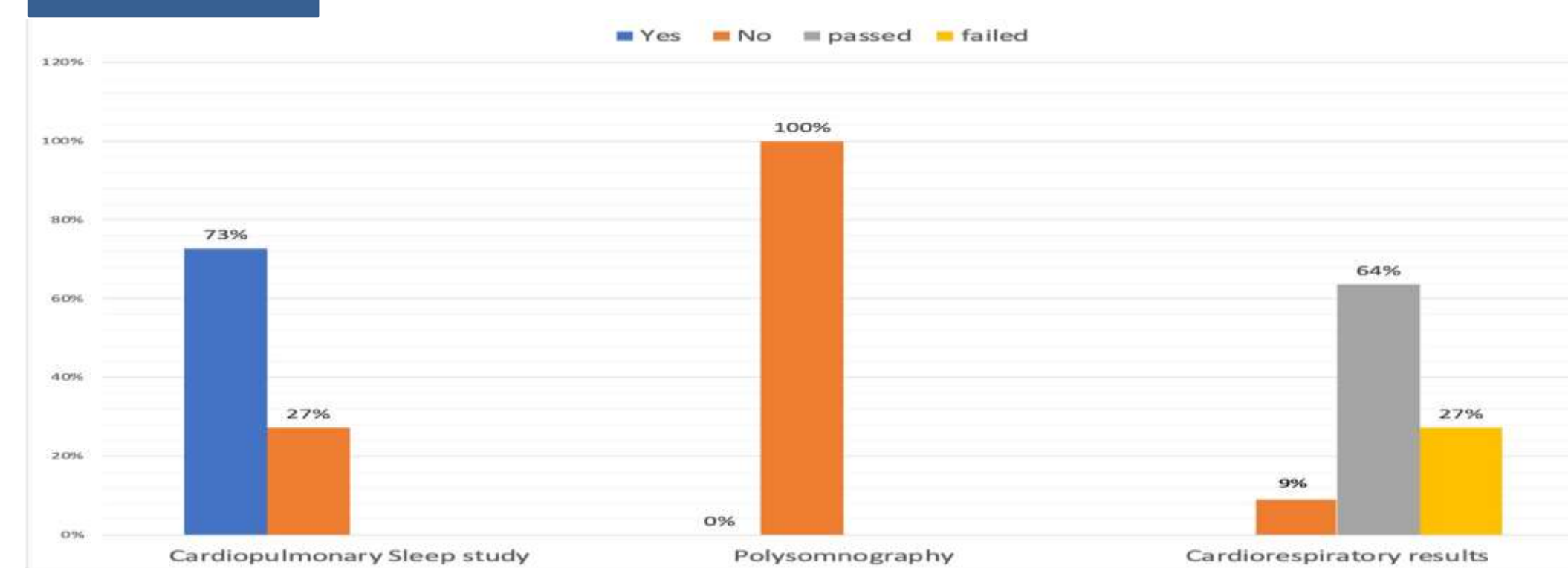


Fig 6: Investigations recorded

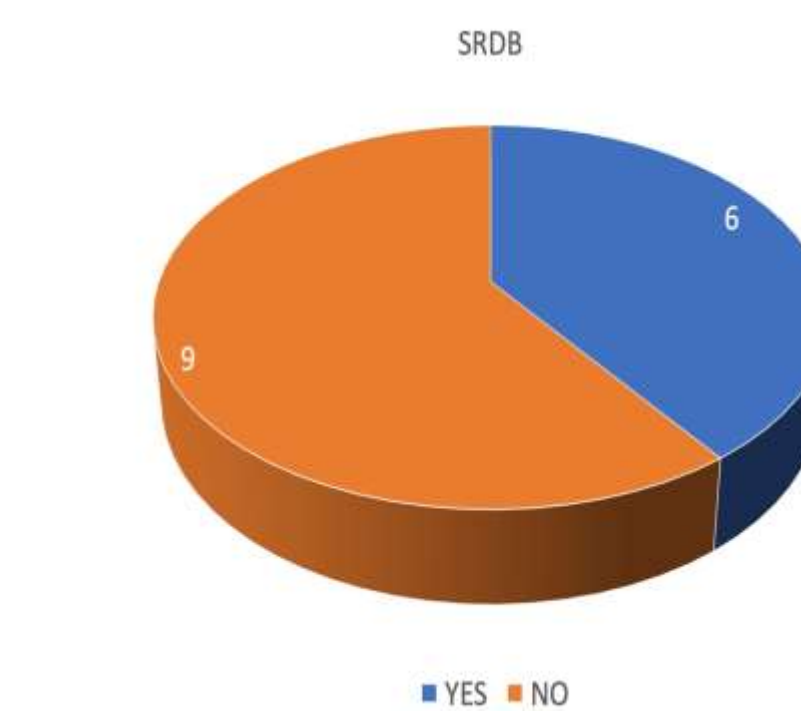


Fig 7: SRDB in our DS Patients

Conclusions

Our study showed that SRDB is quite common in children with DS attending our Trust. As per the national guideline, our screening rate for SRDB in children with DS is low. There is need to review the process and follow the national guideline. Also, during the review of notes, we found that there were limited/or no documentation of symptoms/signs as well as screening results of pulse oximetry during consultation. We recommend detailed exploration and documentation of these during clinic attendances. To help with this, we developed a sleep evaluation questionnaire for SRDB in children with DS. SRDB Proforma https://docs.google.com/document/d/11Xbo4N-qHXkD4A1k_1lr4WT_Fdyj_3FkbMQUuiKg/edit?usp=sharing In addition, we recommended the development of a DS database for patients attending the service as this will help in identifying this cohort and help in future research.

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SRDB PROFORMA

Sleep Evaluation Questionnaire for Sleep related disordered breathing (SRDB) in children with Downs Syndrome

Demographic details
 Child's name: _____ Age (Years and months): _____ DOB: _____
 Gender: Male Female
 School: _____ Mainstream/ specialist/Home schooling
 Date of completing questionnaire: _____

Introduction:
 Sleep related disordered breathing (SRDB) is quite common in children with downs syndrome as they develop obstruction of the upper airways during sleep and this tends to affect the breathing and may lead to other symptoms.
 Below are a series of questions aimed at picking any symptoms/signs of SRDB. Please only select one option for each of the questions and please answer all the questions. In answering the questions, try to think of a typical week when your child has been well.
 Please Tick the response you feel is most appropriate for your child from the options; Never, Rarely, Occasionally, Almost Always, Always or Unsure and in questions requiring writing, please do make a comment.
 Thank you.

Question	never (never in the past 6 months)	Rarely (less than one day/night a week)	Occasionally (1-3 days/nights a week)	almost always (4-6 days/nights a week)	always (every day/night)	Unsure
Snoring How often does your child snore when they do NOT have a cold? How often can you hear your child snoring from outside of the bedroom?						
Breathing Difficulty How often does your child struggle to breathe while asleep? How often does your child's breathing go quiet and then burst again? (Apnoea) When your child is asleep, how often do you notice your child to make them breathe again? (apnoea) Does your child develop any respiratory distress (increased work of breathing, chest sucking in, using abdominal muscles to breathe)						
Mouth Breathing How often does your child tend to breathe through their mouth during the day? Does your child have a foul smell from the mouth (Halitosis)?						
Restless sleep and frequent awakening How often does your child have restless sleep? (Night terrors, nightmares, Head banging) How often does your child sweat while asleep?						
Sleeping position How often does your child wake up during night? (More than other children of a similar age) Does your child have disturbances in his sleep (sleep talking, sleep walking, teeth grinding) How often does your child have difficulty waking up in the morning, even after getting plenty of sleep? How often is your child grumpy first thing in the morning?						
Daytime behaviour How often does your child sleep in unusual positions (tilling the head backwards, sleeping while sitting upright, kneeling with their bottom in the air)						
Other Symptoms related to sleep disordered breathing Does your child frequently get upper respiratory tract infection (cold, Stuffy)? Does your child have nasal discharge that has been ongoing for a long time? Does your child have any difficulties in swallowing, choking or gagging? Does your child have Reflux, nausea or vomiting? Does your child have any headaches? Does your child have enuresis (Bed wetting) that has always been there or new onset (Persistent or secondary enuresis)?						
Investigations Oximetry Sleep study Others (Name)	Last time it was done	Results (if known)	Next scheduled test	Plan	Any failed test previously	Unsure
Specialist involvement ENT Respiratory physician Sleep clinic Other specialist (Name)	None	Yes	Reason for the referral	Not seen in the past 6 months)	Outcome	Unsure

Clinical audit of patients diagnosed with Developmental Coordination Disorder (DCD) in the community and their Body Mass Index (BMI)

By Dr Sze Chun Wilson Lau¹

¹ Paediatric registrar, James Paget University Hospital NHS Foundation Trust

Background

Developmental Coordination Disorder (DCD) is classified under the neurodevelopmental disorders (NDD) and is characterized by impaired motor abilities and coordination that significantly impact daily living. In England 2024, 21.3% of the children aged 4-5 and 36.6% of those between 10-11 were overweight. Patients with DCD are at increased risk of becoming overweight or obese due to their impaired coordination and therefore less participation in physical activities. Fine motor skills such as using cutlery are also impaired, possibly making high caloric finger food the preferred choice for meals.

Aims

This audit aimed to primarily evaluate the BMI centiles amongst paediatric patients newly diagnosed with DCD in the community. It also assessed the prevalence of overweight and obesity within this group.

Method

A retrospective audit was carried out in the DCD clinics in a community setting in the East of England from 1st January to 31st December. All patients who were given a diagnosis of DCD during this period and had with their height and weight recorded were included. 58 out of 66 patients were included in the study. Their age, sex, weight, height, BMI and their percentiles were collected and analyzed.

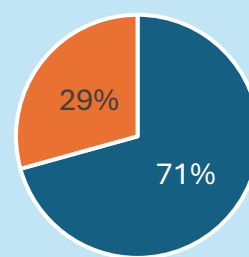
Conclusion and recommendations

- 48.3% of patients with DCD were either overweight or obese
- Lack of physical activities and choice of diet may contribute to obesity in this group
- Early intervention by occupation therapist, physiotherapist, dietician and weight management in the community should be considered at the point of diagnosis

Results

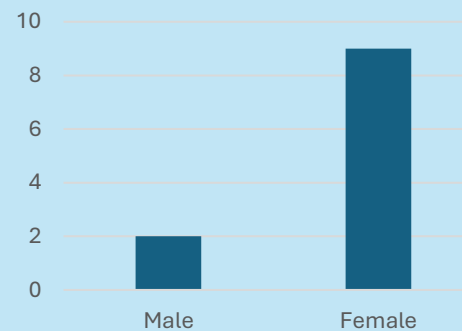
This audit revealed that male were more prevalent than female diagnosed with DCD (70.7% vs 29.3%). The median age was 10 (range from 6-17). The average BMI centile was 72.2. 12% were overweight (BMI 91st-98th) while 17% were obese (BMI 98th-99.6th) and 19% were severely obese (BMI >99.6th). 48.3% of this cohort fell into the category of either overweight or obese. Among the severely obese group, 9 out of 11 were female. The youngest severely obese patients were 7 year old.

DCD diagnosis

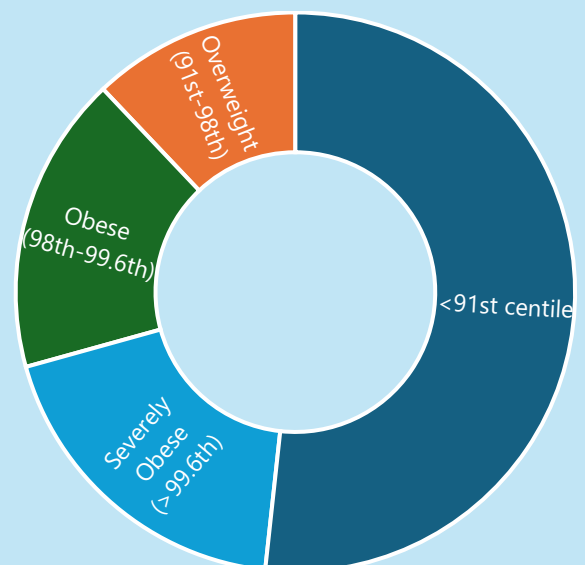


Male Female

Severe obesity



BMI categories



A service improvement project, exploring management and prevalence of sensory eating difficulties, including ARFID, in children within the autism assessment pathway in a local child development centre – is there need for a local support service?

Carina Cox – Brighton and Sussex Medical School supervised by Dr Ian Male – Sussex Community NHS Foundation Trust

Introduction to ARFID

ARFID stands for avoidant restrictive food intake disorder. It has been a recognised eating disorder (ED) since being added to the DSM-5 in 2013

DIAGNOSTIC CRITERIA

An eating or feeding disturbance manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with one (or more) of the following:

- Significant weight loss/faltering growth
- Significant nutritional deficiency
- Dependence on enteral feeding or oral nutritional supplements.
- Marked interference with psychosocial functioning.
- It cannot be explained by lack of available food, occur alongside another ED or medical condition which explains the symptoms.

ARFID does not always, or only, lead to weight loss, but can be associated with normal weight or even overweight or obesity in individuals who are overly reliant on carbohydrates or energy-dense processed foods.

BACKGROUND

Current ARFID related literature often states Autism as a heightened risk factor for developing ARFID and has a wide range in estimated prevalence which is generally higher within Autism cohorts. ARFID more commonly affects younger children and can result in serious mental and physical health conditions. Prevalence in general population = 3% in 2019. In the US – SPARK research studies 100,000 people with autism. Kumar *et al* 2023 estimate the Prevalence of ARFID in this Large Autism Cohort at 21%. Keski-Rahkonen *et al* 2023 - of children diagnosed with ARFID, 8.2-54.8% are autistic.

Treatment Pathways

Fray was born in 2007, ARFID was not yet formed in DSM-5. It was assumed he was anorexic. Weighed weekly in school by school nursing team. Seen by SALT but not a swallowing issue. Offered parenting classes on nutrition. Diagnosed ASC and DCD. DCD sessions – encouraged to use caring cutlery.

CURRENT

- Tertiary multidisciplinary feeding service at the Evelina London Children's Hospital.
- Picked up in local paediatric services
- Must be referred by paediatrician
- Must have evidence of local input prior to referral and pt must remain under their service.

Referrals with insufficient information are rejected. Requires evidence that the nature of the feeding difficulties and their impact on the child are significant. Growth failure, clinically significant nutritional deficiency via bloodwork or increasing aversion to food.

PROPOSED
A local/Sussex wide MDT service to be commissioned for children with sensory eating issues. Replicate Evelina Team = SALT, Neuro-disability consultant, clinical psychologist, OT, dietician. Potentially add in play therapist/nursery nurse.

There are currently 477 children on the waitlist for diagnosis within the local area and 271 children are diagnosed annually within the child development centre. This added with Evelina's waitlist equates to a **2-3 year wait per child.**

The impact can also be seen on staff members. Multiple clinicians staying involved in one child's care equates to further lengthening of the waiting list to be seen at the local child development centre.

Results of the study

A total cohort of 52 children were included in the study, ranging in age from eight months to 18 years. The **mean age was 6.38 years.** 50 of these patients were referred for, or already had a diagnosis ASC. Other existing conditions did not better explain any sensory eating difficulties.

The children attended a variety of appointment types, some in person and some were telephone reviews. Most patients **(45.1%) were seen for follow up appointments.**

29 children **(55.8%) were reported to have a limited food intake** at the time of being seen in the clinic and in the remaining 23 children, 3 of them were recorded as being "picky" or "fussy" eaters but not to the extent of having limited intake.

When isolating those 29 children and investigating further, how restricted their intake was, **10.71% ate less than five foods** and **32.14% ate between five and ten foods.**

When looking at the relationship between age and restricted intake, and testing whether they are associated with each other there was no association across any of the groups. When testing this statistically, with the Chi square - Fisher Freeman Halton exact test, the score was 2.306, p value 0.566 and the Phi value was 0.216. Using the same statistical tests to look at whether age was associated with how restricted the CYP intake was again there was not a clear pattern to suggest a relationship. The Fisher-Freeman-Halton Exact Test value was 33.98 with a p. value of 0.184 and a Cramer's V value of 0.606.

When looking at how often centiles are being checked for the height and weight of the children during their clinic, **44.2% patients did not have their height measured** and **42.3% did not have their weight measured.** Isolating the children who had limited intake only, **bloodwork was not organised 58.6% of the time.**

Study Design/Aims

- To look at how many children with autism or possible autism had sensory eating issues
- To check whether growth/centiles were being checked
- To prospectively look at how often bloods for nutritional status were being sent.
- To create evidence to support the need for a local service to be commissioned for children with sensory eating issues
- To consider the impact of the current pathway on both the children and clinicians

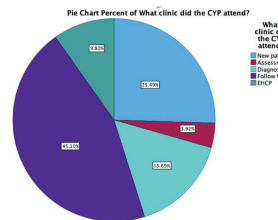


Fig. 1 A pie chart showing categorized percentages of the type of clinic that the CYP attended

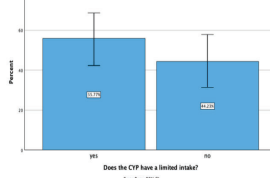


Fig. 2 Bar graph showing the percentage of CYP that were identified as having a restricted food intake. 55.8% (95% confidence interval error bars = 41.3-69.5%)

Why did I care about this?

Meet Fray. My 16 year old child, who was about 8 in this photo. (consent given for photo use, via teenage grunts)

- Born in 2007, at term on 50th centile, 91st HC
 - BMI 14 in this photo
 - Pyloric stenosis repaired at 2/52
 - Failure to thrive for most of life
 - Excluded from physical activity at school
 - Difficulty with solid food/Oral dyspraxia
 - Recurrent infections
 - General terrible relationship with food
- Would only eat foods that were orange



METHODS

Prospective data was retrieved from a local, Sussex based, child development centre, between November 2023 and February 2024.

A proforma was filled in prospectively, by clinicians seeing children at various points along the autism assessment pathway,

An update on Fray.

"I wouldn't say I'm better. Like so much of my life, eating carries a huge mental load. It's a continuous conscious effort. I'm old enough now to be able to choose my own plate instead of crying inside at the plate that is too squeaky or make foods myself rather than deal with the uncertainty of what texture will be inside that sandwich. I try to be adventurous with food, but that is me challenging myself and it comes at a cost. I will still never eat gravy on mashed potato."



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How do specialist play and leisure activities impact the wellbeing of children with continuing care packages due to disability?

sparkle
 helpu plant arbennig i ddisgleirio
 helping special children shine

Bethan Collins MSc, Sparkle (South Wales); Michael Charles, Aneurin Bevan University Health Board; Dr Charlotte Montgomery, Aneurin Bevan University Health Board; Dr Sabine Maguire, Cardiff University and Sparkle (South Wales)

Introduction

- Children, up to 18 years, who have complex healthcare needs resulting from disability may require a continuing care package from their local health board [1].
- There is limited previous research on the impact of leisure activities for these children [2,3], particularly leisure activities that are not home-based or facilitated by family-carers [3,4].
- We aimed to explore the experiences of children accessing Sparkle's* continuing care leisure club to understand the impact of such a provision on their wellbeing.

Methods

Qualitative case studies, including observations, semi-structured interviews with family-carers, surveys with Leisure Support Staff, and an interview-style activity with children, were conducted between June and October 2023. Data were analysed using coding reliability thematic analysis [5].

Sparkle's Continuing Care Club



Fortnightly on Saturdays at Serennu Children's Centre



2 hours for 5-11 years olds
4 hours for 12-17 year olds



Child-led play



Fully accessible facilities



Accessed independently of family-carers



Enrichment activities

FIND OUT MORE



*Sparkle is a charity in South Wales supporting children with disabilities



Results

- 4 children, 3 female and 1 male, aged 8-14 years
- Cerebral palsy, rare genetic disorders, epilepsy and/or autism
- All wheelchair users; 3 communicated non-verbally; 2 required specialist feeding
- 3 themes generated:

Individuality and independence

Leisure activities *independent* of family-carers allowed the children to explore their personal identities.

"She's just been able to become more [herself] than she might of if she'd not had the opportunity to have the independence of going somewhere without us." (Parent, Case Study B)

Social development

Children developed social skills *at their own pace* and benefited from interaction with peers and staff.

"Staff talked to her whilst on the trampoline, she used eye contact and expressions to join in with the conversations" (Researcher observation, Case Study A)

Access and benefits of leisure

Taking part in engaging activities that were *not* passive, home-based or required family-carer support *positively* impacted wellbeing.

"Life moves quickly, and when we're at home there's stuff that always needs doing, cooking and cleaning, so it's really difficult to try and stimulate him all the time, so when he's going to club [...] he's being stimulated which has a major impact on things like sleep." (Parent, Case Study C)

Conclusion

With little previous research into the wellbeing of this group of children, findings from this evaluation add valuable insight into their world. It is clear that while a provision of this type requires high staffing levels and appropriate training, it can make a positive impact on wellbeing for children with continuing care packages due to disability.

Find out more about Sparkle's research work:

<https://www.sparkleappeal.org/research/published-research>



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Improving parental health literacy at a special school in Lambeth

Kathryn Moore¹, Javairia Yakoob¹, Jin Han Khaw¹, Hemavathy Palanyiaya¹, Sarah Thomas²



Background

Research shows that low levels of health literacy in adults lead to poorer health outcomes^{1,2}. Additionally, it has been found that low health literacy in parents is associated with poor health outcomes in children, especially in those with complex medical needs and from poorer socioeconomic backgrounds^{3,4}. This is due to:

-  insufficient engagement with preventative services
-  poor disease control
-  poor medication adherence
-  dosing errors
-  increased hospitalisation and emergency services use

Aims



To explore how teaching workshops can enhance parental understanding of the services available to their child, and inform them of strategies to manage their child's health needs more effectively.



Methods

- Parents were consulted for ideas for topics they would like to be taught about. Following a brainstorming session with the team, suitable specialist topics were selected.
- Specialist services were contacted to deliver talks on their areas of expertise.
- Parents were informed about the workshop via a poster, Twitter, coffee mornings, and the parent WhatsApp group and reminder phone calls.

The topics chosen were:

Topic	Presenters
Puberty and sexual development	Positive support group
Communication difficulties	Speech and Language Therapist
Bladder and bowel difficulties	Continence team
Issues with hand functioning	Occupational therapy
Challenging behaviour	Autism support group
Alternative feeding methods	HEN dietician
Mobility issues	Physiotherapy
Seizures	Complex needs nurse
Sleeping difficulties	Community paediatrician

On the day:

Parents arrived and chose 4 of the morning topics, and 2 of the afternoon topics

Specialists then independently held 20-minute interactive sessions with small groups of parents

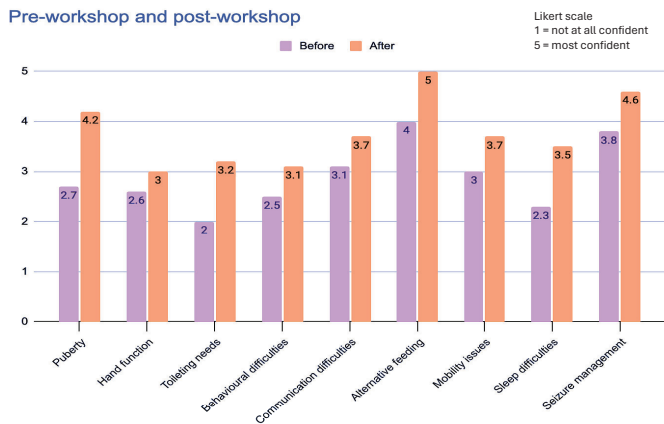
We gathered data via self-reported survey before and after the event, to determine levels of understanding

Results



- Prior to the event, **100%** of parents voted to affirm it would be helpful to have teaching on their child's health needs.
- **92.3%** of parents found that the workshop met their expectations with an overall average rating of **9.1/10**
- Confidence in **all** topics **increased**
- The biggest increases were for teaching on: **pubertal changes** (2.7 to 4.2), **toileting needs** (2 to 3.2) and **sleep difficulties** (2.3 to 3.5).
- Feedback from parents for future events included: longer sessions, spread out over multiple days and increased advertising of event.

Pre-workshop and post-workshop



Discussion

- Our intervention significantly improved immediate general health literacy among parents of children with complex health needs.
- Sustaining improvements is crucial for enhancing health outcomes and quality of life, leading to reduced social and financial burdens for families and NHS.
- Collaboration between MDT and parents was essential in gaining cooperation.
- Turnout was low however, with only 13 parents attending, so this hindered achieving greater statistical power.

Future events

- Improving scalability by exploring alternative educational formats (in-person talks/online webinars) while minimising costs.
- Assess long-term impact through follow-up surveys.
- Consider extraneous confounding variables, such as socio-economic background and ethnicity.
- Develop a framework that can be implemented nationally and worldwide

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Improving the transition from paediatric to adult care at a special school in Lambeth

Kathryn Moore¹, Javairia Yakoob¹, Jin Han Khaw¹, Dr Hemavathy Palanyiaya¹, Dr Sarah Thomas², Dr Hannah Zhu², Dr May Yip²

Background

The transition period for young adults from paediatric to adult care is often reported by parents and young people (YP) as a stressful and poorly resourced area of healthcare.

NICE guidelines on "Transition from children's to adults' services"

sets out 8 recommended features to improve transition, including:

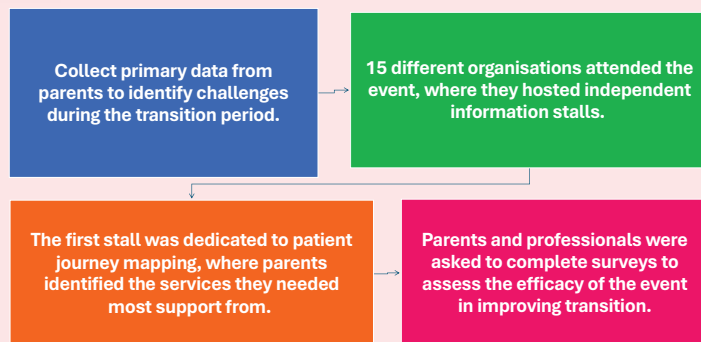
- Opportunities for parents and YP to meet the adult team before transfer of care
- Encouragement of appropriate parent involvement

Evidence also suggests that poor transitions are improved with transitional care programs.

Aims

To improve the transition period for families and YP through a multidisciplinary information event by incorporating NICE-recommended features listed above.

Methods



List of stalls:

• Patient Journey Mapping	• Special Educational Needs Team
• Autism Support Services	• Patient Advocacy Organisation
• Local Specialist Colleges	• Financial Aid Charity
• Assistive Communication Services	• Mental Health with Learning Disability Team
• Adult High Enteral Nutrition Team	• Adult Social Care
• Adults with Learning Disabilities Team	• Educational Support and Rights Advisory Organisation
• Adult Continence Support	• Parental Support Group

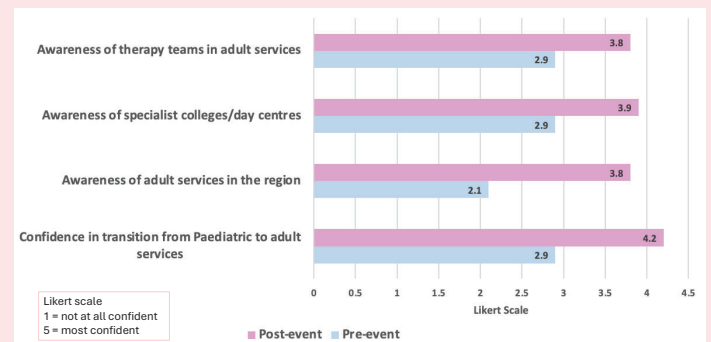
Results

18 parental and 19 professional responses were received:

- Post-event, 100%** reported that the event met their expectations and that the information provided was useful.
- 100%** of the representatives would recommend the event to other parents and colleagues.

Likert scale scores (1-5) before and after transition information event revealed improved awareness in the areas below:

	Therapy Services	Specialist colleges and day centres	Adult Services	Overall Transition Process
Pre-event average	2.93	2.88	2.13	2.94
Post-event average	3.82	3.88	3.76	4.22



Conclusion & Discussion

- Our intervention significantly improved health literacy on transition amongst parents of YP with complex health needs.
- Sustainable improvements in the transition process are crucial for enhancing YP's health outcomes to reduce the social and financial burden for families and NHS.

Discussion:

- Collaboration between professionals from health, education, social care and parents was essential in gaining buy-in and cooperation.
- Limited parental participation hindered achieving greater statistical power.

Future Events:

- Improve scalability by exploring alternative educational formats (in-person talks/online webinars) while minimising costs.
- Consider extraneous confounding variables, such as socio-economic background and ethnicity.
- Develop a framework that can be implemented nationally and worldwide.

Background

Childhood injuries are a **significant public health burden** globally and even more so in developing countries.

The global incidence of Traumatic Brain Injury (TBI) in children varies greatly country by country but the reported range is between **47 – 280 per 100,000 children** [1]. Unfortunately, **over 95%** of all paediatric deaths related to injury occur in Low- and Middle-Income Countries (LMICs) [2][3].

Strategy

Integration of road safety in the school curriculum.

Discussion

Lack of education

Education is crucial for child development and successful transition into adulthood. Kumar et al illustrated that children in India displayed poor hazard identification skills due to inadequate road safety education [4].

Their systematic review used two independent authors to screen studies, reducing selection bias and improving reliability. The Newcastle-Ottawa scale assessed study quality, revealing that 33.3% were high quality, 24.2% moderate, 6.1% low, and 36.4% could not be assessed.

The limited number of high-quality studies potentially challenges data validity and reliability. Additionally, the review did not mention result heterogeneity, further questioning reliability. Data was restricted to PubMed and English articles only.

Which areas are affected the most?

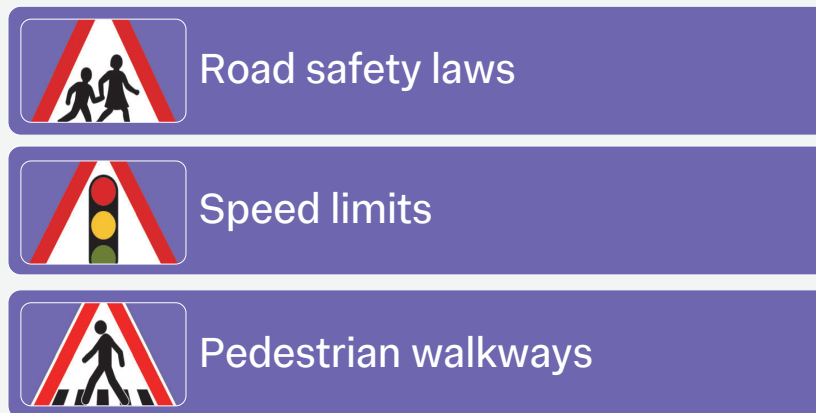
Dewan et al concluded that pedestrians are the most common RTA victims in Africa and Asia, highlighting the urgent need for road safety education, especially for children, to improve public health in developing countries [5].

Despite a comprehensive search, significant study heterogeneity questions the validity of Dewan et al's findings. The studies were restricted to English, indicating potential publication bias. The Newcastle-Ottawa scale and two review authors were used to assess data reliability and quality.

Primary prevention

Using Haddon's Matrix, educating children in LMICs could be a successful primary prevention intervention to improve public health and reduce RTAs and TBIs.

Factors which can help reduce TBIs in children include:



However, implementing these measures may be more challenging and time-consuming than educating children on road safety.

Factors affecting education

Integrating road safety into the education system is urged in India, which is a positive step. However, not all children in developing countries like India have access to school due to factors like financial constraints. Thus, educating all or most children in the country poses a real challenge. Additionally, no current data supports that this intervention can reduce fatalities, which may hinder its implementation.

CONCLUSION



Childhood injuries, particularly TBIs, are a significant global public health burden, especially in LMICs where over 95% of paediatric injury-related deaths occur. Integrating road safety into school curriculums could be crucial to addressing this issue.



Despite the potential benefits, challenges such as financial constraints and lack of access to education in LMICs may impede the widespread implementation and effectiveness of this intervention.



Therefore, while integrating road safety education is a positive move, additional measures and support are necessary to ensure its success and impact on reducing childhood injury fatalities.

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“You can’t manage what you don’t measure”: Learning Disability and the Annual Health Check – Improving Recognition of Learning Disability and Health Outcomes in Newham, East London

Raya Shpilberg¹, Jala Vally Mamode², Jill Ellis², Michelle Heys^{2,3}

Affiliations: 1) Royal Free London NHS Foundation Trust, 2) East London NHS Foundation Trust, 3) UCL Great Ormond Street Institute of Child Health

Contact details: Dr Raya Shpilberg, r.shpilberg@nhs.net

Background

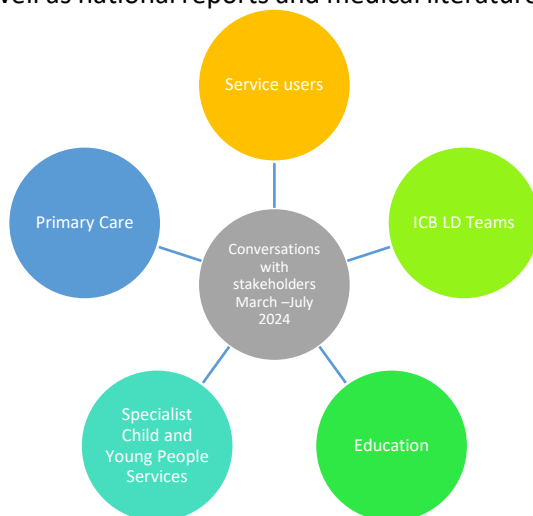
- People with Learning Disability (LD) have increased risk of health problems and shorter life expectancy.
- The NHS Long Term Plan in England (2019) recommends that at least 75% of people aged 14+ with LD have an Annual Health Check with their GP.
- Without accurate systems of measurement and recording of LD for the denominator, a focus on the recorded caseload may create unintended unmet need.

Aims

- Map the current situation for young people (YP) aged 14-17 years old with LD in Newham.
- Highlight areas of good practice and barriers to healthcare provision.
- Recommend improvements to promote health in YP with LD and reduce health inequalities.

Methods

- Accessed available data sets from the Community Child Health caseload, Primary Care dashboards and a recent LD Health Needs Assessment Report, as well as national reports and medical literature.



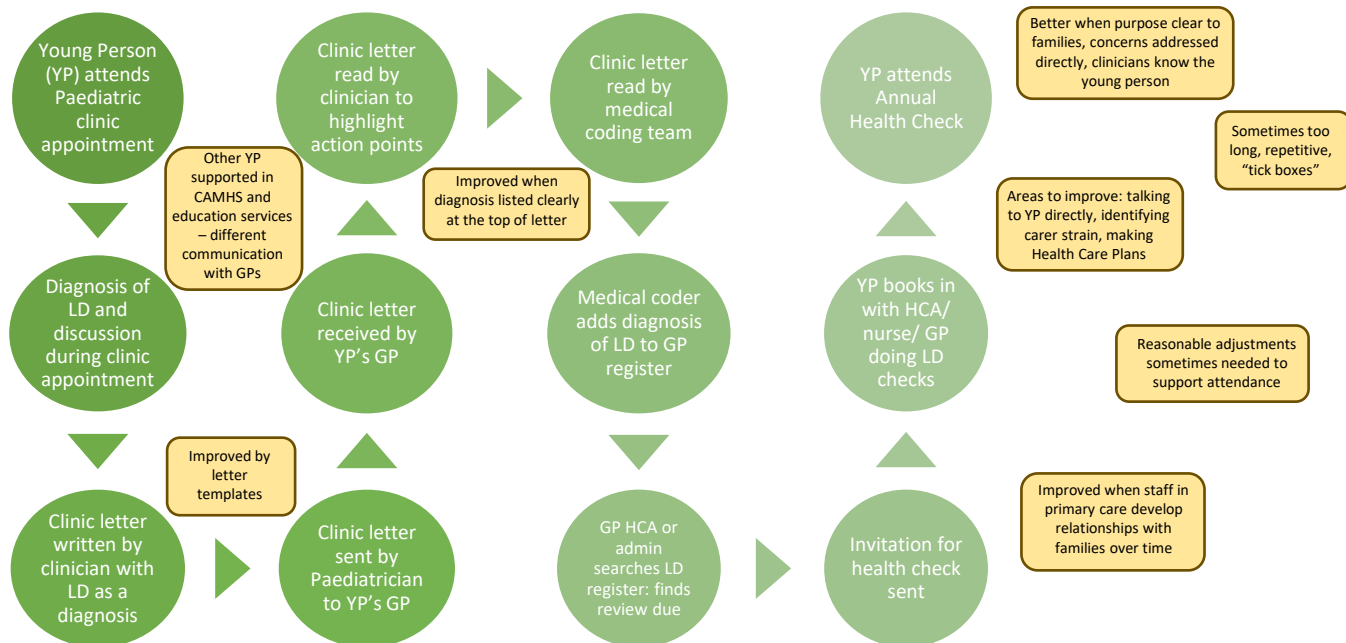
Results

21,596 14-17 year olds registered with Newham GP

172 14-17 year olds on GP LD register April 2023 – April 2024

138 (80.2%) Annual Health checks completed, April 2024

Using a conservative estimated prevalence of LD in the population as 2.5%, we would expect **540** 14-17 year olds on the GP LD register. Currently identified 172/540 = **32% of expected numbers**



Conclusions

- Newham offers Annual Health Checks to **80%** of young people aged 14-17 on GP LD registers. **Less than a third** of estimated numbers of this population are entered on GP LD registers, underestimating true population need.

- **Diagnosis/recognition of LD** in health services and stating LD as a diagnosis in **communication with GPs** are crucial steps in improving LD register accuracy. Consolidating existing data-sets through multi-agency working could also improve recognition of LD.

- There is **variation** in how Annual Health Checks are conducted and their perceived effectiveness, suggesting the quality of LD reviews requires improvement.

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Monitoring Growth in Community Paediatrics: the scale of practice

B Davies, B Bielinski

Hereford and Worcestershire Health and Care NHS Trust

Background

Monitoring growth in children identifies nutritional concerns, neglect, medication side effects, illnesses and more. There is no standardised practice on when to measure children. A previous audit in 2019 in a community trust showed only 80% of children in clinics had their weight and height measured.

Aim

This was a re-audit to evaluate any improvements in measuring children and identify factors affecting this being completed.

Methods

Children were randomly selected retrospectively from clinics in September 2023. Each case was reviewed for measurement and centile calculation of height, weight, occipital frontal circumference (OFC) and BMI. They were also examined for any factors affecting the measurement being carried out.

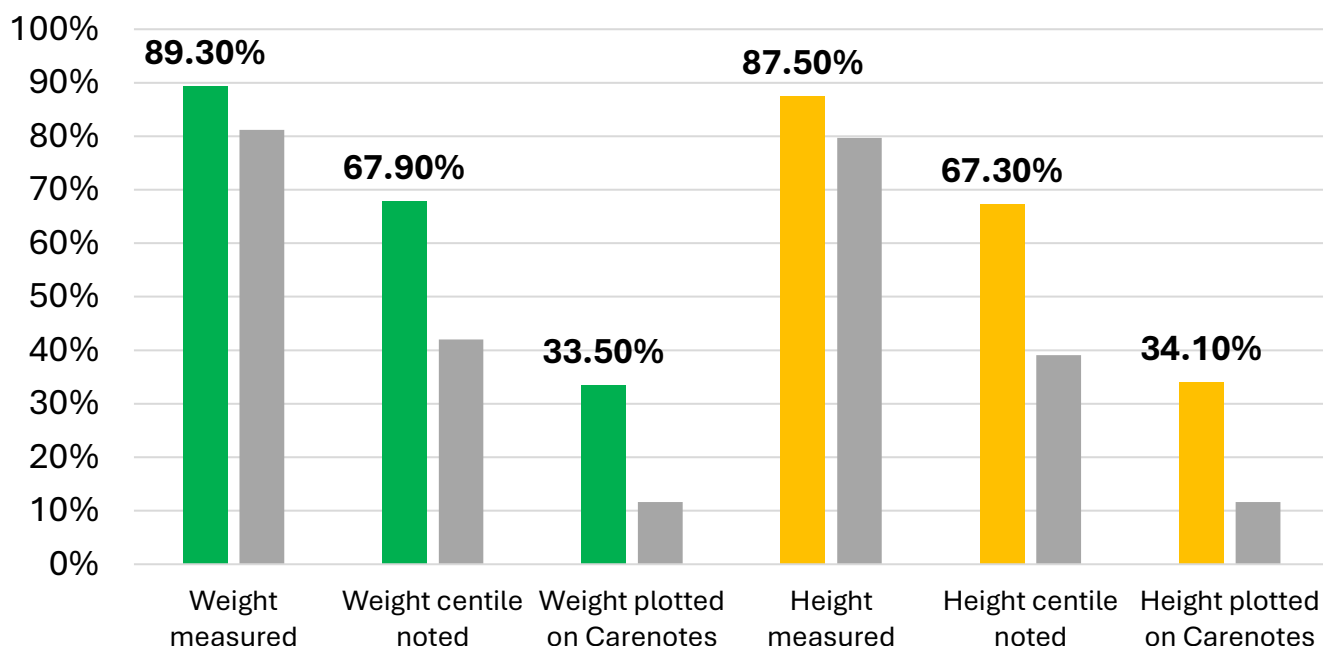
Results

158 children were included. Measuring weight and height increased to 89.3% and 87.5% respectively. Noting centiles also improved for weight and height (Figure 1). In children under 5-years-old, measurement decreased though centile recording improved. OFC measurement increased to 40%, and OFC centile plotting improved from 0% to 26.3%. Reasons for not measuring included an intention to weigh later or the child was distressed.

Conclusion

Overall, there were improvements in many areas. Nevertheless, many children's nutritional status remained inadequately assessed, and some aspects were inferior especially in the under 5s group. Moving forwards, further education is planned, with a proposal to add in specific growth chats on the electronic patient records for example those with Trisomy 21).

Figure 1: Comparing 2024 data (in colour) to that of 2019 (grey)



Prevalence of Oral Health Conditions in Asylum-Seeking Children

Background

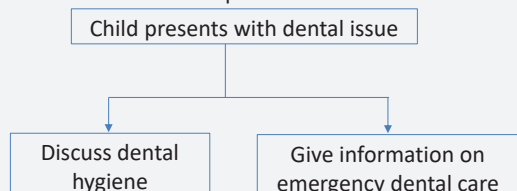
While oral health is an essential part of improving quality of life, there is limited data on the prevalence of oral health conditions in the UK, and therefore the services required to meet these needs.

Impacts of poor oral health on children¹:

Physical	Psychological
<ul style="list-style-type: none"> Pain and discomfort Malnutrition 	<ul style="list-style-type: none"> Self-esteem Mental health.
Social	Long-term
<ul style="list-style-type: none"> School attendance and performance Social interactions 	<ul style="list-style-type: none"> Chronic health conditions, such as gum disease, oral cancers.

In a Bristol clinic that carries out initial health assessments for asylum-seeking children, there is **no referral pathway** for oral health conditions

The two current treatment options:



Method

- 100 retrospectively consecutive asylum-seeking children who presented to a Bristol clinic between November-May 2024 were reviewed.
- A literature review was completed searching Medline (Pub Med)

Search strategy

oral health OR dental health OR
dental caries OR health needs
AND
asylum-seek child OR child refugee

Exclusion criteria

- Systemic review or qualitative studies.
- Adults involved in study.
- Published before 2000.

Results – Literature Review

Below is a table demonstrating the 9 papers identified in the literature review:

Year	Country	Prevalence of children with dental problems
2023	UK	6.40%
2023	UK	23%
2021	Netherlands	42% -57%
2019	UK	87.80%
2017	UK	36%
2016	UK	65%
2014	UK	46%
2012	UK	58.30%
2004	US	51.30%

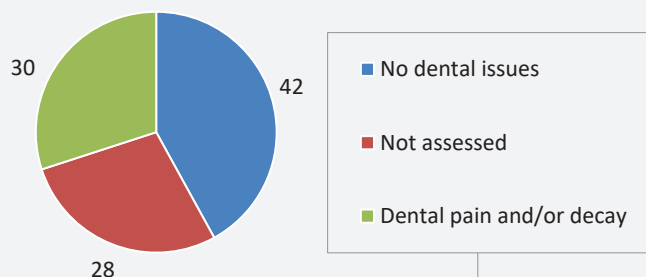
Results across the 9 papers showed a high prevalence of asylum-seeking children with dental problems, with a mean of 47.28%.

Results ranged from 6.4% to 87.8%, with a median of 48.5%.

Results - Bristol clinic findings

100 asylum-seeking children were reviewed, ranging from 5-17 years old.

Prevalence of dental pain and/or decay



Of the children presenting with dental problems:

- 5 presented with just pain
- 9 presented with just decay
- 16 presented with both pain and decay

Discussion

This high prevalence of dental issues in asylum-seeking children seen in the Bristol clinic was reflected in the limited literature identified on pubmed. This review suggests the need for two critical actions:

1. Targeted oral health interventions and policies

This may include:

Oral health screening and provision of oral hygiene adjuncts during initial health assessment

Translated leaflets on preventative care such as toothbrushing and signposting

Agreed referral pathway amongst HCPs

Notably, 28 of children were not assessed while a significant proportion of children had severe decay with no pain. This provides supporting evidence that HCPs should be encouraged to carry out dental screening in all initial health care assessments.

2. Further research into dental caries in ASC

The literature review highlighted the lack of literature on the subject, where further research is crucial in identifying the prevalence of asylum-seeking children with dental caries, and treating them effectively.

Conclusion

Paediatric initial health encounters provide an opportunity to identify dental needs, promote oral hygiene and signpost to services. There is a critical need for targeted oral health interventions in specialist clinics that complete initial health assessments for asylum-seeking children, as these play a large role in the both the prevention and treatment of dental caries.

References

- (1) Oral diseases: a global public health challenge, Peres, Marco A et al., The Lancet, Volume 394, Issue 10194, 249 – 260.

How well are we screening and assessing pain in our special school population?

Dr Nick Bates, Dr Tamsin Woodbridge

Background

Children with intellectual and developmental disabilities experience more pain than children without disabilities. The nature of these disabilities makes treatment especially difficult due to limited communication skills, multiple complex sources of pain and challenges in concordance to analgesic therapy.

Pain identification, assessment and management is a crucial part of working with this population. Are we doing this regularly and effectively when given the opportunity in special school clinics?

Method

The starting point of this study was to review the literature on pain assessment and management in children with intellectual or developmental disabilities, including the prevalence of different sources of pain for these children.

The authors randomly selected 20 patients who had been reviewed in school clinics in the last two years and reviewed their notes.

The authors then reviewed the management of two patients known to have chronic pain of unknown origin (CPUO) to review how this had been investigated and managed.

Aims

1. How often community paediatricians are assessing for pain in routine school clinic appointments
2. How do we identify pain for each child
3. How the cause of pain is identified
4. What strategies are used to identify the origin of chronic or non-localising pain
5. How inadequately-managed pain is escalated to other services

Results

These patients had been reviewed 31 times in 2 years by eight different clinicians. The majority had GMFCS V cerebral palsy. Clinicians recorded an answer about pain in 25/31 cases, with pain identified in 14/25. Difficulty in recognising pain highlighted, with 4/25 documenting what pain looks like for that child. One documentation of change in pain – “improving”. A single cause was identified in 8/14, multiple causes for 3/14, and no cause suggested for 3/14. In 70% of these patients, musculoskeletal or incorrect positioning was identified as the cause. For the patients with CPUO, multiple causes were considered with significant involvement of specialist services.

Conclusions

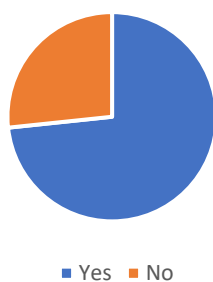
We are not always asking about pain in school clinics

We do not always know what pain looks like or how each child demonstrates this

We do not objectively assess severity of pain, making evaluation over time difficult

For CPUO, appropriate and thorough investigations and therapies are trialled

Was the cause of the pain assessed?



Cause of pain considered

