

UNCRC in Clinical Practise Friday 3rd November 2023 Stirling Enterprise Park (STEP)



Stirling Enterprise Park (STEP)
John Player Building, Players Road, Stirling, FK7 7RP

	Public Health Scotland and NHS National Services Scotland	
1515-1545	Improving national data on children with disabilities to support rights and reduce inequalities	Kerry McCallum Lynda Fenton
1445-1515	Supporting the child's right to be heard The Scottish Child Interview Model team	Jennifer Morrison Lauren Craig
	Refreshments	
1400-1445	Alina goes to the doctor" (Workshop) In-person & virtual Childrens Health Scotland	Michelle Wilson Anne Wilson
	Physical injury in children with disability – a review of child protection medical assessments Why do Non-Urgent Patients Present to the Paediatric Emergency Department?	Frances Wardle Jennifer Veitch,
	Down's Syndrome: Thyroid Failings	Dr Andrew Tester,
1300-1400	Abstracts Are we protecting the protectors? Chaperone use in child protection medical examinations	Dr Seremma Parsons
1200-1300	Lunch Posters & stalls SACCH AGM 1200-1220	
1130-1200	Including young people's voice in health research Generation Scotland, University of Edinburgh	Sarah Robertson Lorna Caddick Eva Drummond Ava Marshall
	Signalong - Practical session: In-person and virtual NHS Lothian Specialist Speech and Language therapy team	Karen Marshal Annie Welsh
1045-1100	Refreshments	
	role to play Play Scotland	Blair
1015-1045	Respecting the rights of children who come into conflict with the law Children's and Young Peoples Centre for Justice The right to play supports children's optimal development and we all have a	Marguerite Hunter
0915-0945	Children and Young People's Health Rights Children's Health Scotland	Anne Wilson Michelle Wilson Carole Murphy
0905-0915	Introduction and housekeeping	Shiuli Russell Alison McLuckie
0830-0905	Registration and Refreshments	



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Biographies



Children's Health Scotland, the health and wellbeing of children and young people (CYP), and those who love and care for them, lies at the heart of our charitable work. We are the leading children's health charity in

Scotland and the only charity dedicated to informing, promoting, and campaigning on behalf of the needs of all CYP within our healthcare system. The UNCRC and the EACH Charter underpin all of our work which includes our 4 main services CYP Health Rights Service, CYP Health and Wellbeing Service, Care Experienced CYP Service and Corporate Services. We work closely in partnership with many other organisations both statutory and third sector to help us ensure that all CYP across Scotland have access to the best healthcare possible. For more information on what we do please see:

Website: https://www.childrenshealthscotland.org/
Annual Review and Impact Report: https://www.childrenshealthscotland.org/wp-content/uploads/2023/09/230912-CHS-A2-poster-FINAL.pdf



The Children's and Young People's Centre for Justice (CYCJ) works towards ensuring that Scotland's approach to children and young people in conflict with the law is <u>rights-respecting</u>, contributing to better outcomes for our children, young people and communities. Based at the University of Strathclyde, we produce robust internationally ground-breaking work, bringing together children and young people's contributions, research evidence, practice wisdom and system know-how to operate as a leader for child and youth justice thinking in Scotland and beyond

Our general website - https://www.cycj.org.uk/
And our website for children and young people - https://justtherightspace.org/



Play Scotland is the national organisation driving the play agenda in Scotland, working strategically with partners to ensure that children's right to play is fully realised. Play Scotland's vision is for Scotland to be a playful nation. Our Mission: To enable all children and young people in Scotland to have equal opportunities to participate in diverse and quality play experiences that meet

their individual need.

We strongly believe that children's voices should be listened to, taken seriously, and included in consultations and actions.

Marguerite Hunter Blair is Chief Executive of Play Scotland the national expert in play for parents, providers, the play profession, and policy makers. She established the Scottish Play Commission (2008) and led the campaigns for Scotland's Play Strategy (2013) and a statutory duty for Play in the Planning Act (2019).

Marguerite is Chair of the Play Strategy Refresh Group and is a vice-Chair of Planning Aid Scotland, and Secretary of IPA Scotland. She is a member of SW/65 – BSI committee for children's playgrounds standards (EN 1176 series) and Scotland's representative on UK Play Safety Forum and UK Children's Play Policy Forum. Recent publication contributions include, 'Play is The Way' edited Sue Palmer (2019), 'Nature-based Play: Fostering connections for children's wellbeing and climate resilience' ARUP(2022), 'The Health & Wellbeing of Children in the Early Years 'report by Children's Alliance (2022), 'Inspirationally Playful: People, papers and practices that have inspired play practitioners and researchers' edited Professor John McKendrick (2023), and the Practice Information Note for RIAS (June 2023) on the importance of play, and how it relates to planning, places and health and wellbeing.

Signalong is a formal sign support system which is used to support the understanding and communication of children and adults with intellectual disabilities and/or communication difficulties. It is recommended that for children and young people who are deaf or are hard of hearing, advice is sought from the appropriate organisations regarding the use of BSL.

Karen Marshall is the clinical lead speech and language therapist for complex needs in the Children and Young People's Speech and Language Therapy Department for NHS Lothian. She oversees the service delivered to special schools and children in mainstream with complex needs and also preschool aged children with complex needs. She has also been a qualified Signalong tutor for 18 years and regularly runs Signalong courses.



Generation Scotland is a research study looking at the health and well-being of volunteers and their families. They invite volunteers to answer questionnaires and provide samples for genetic testing. This is combined with NHS health records and innovative laboratory science to create a rich evidence base for understanding health. Through this rigorous, ethical and safe approach to

research, Generation Scotland seek to enable meaningful change in public health. Generation Scotland was established in 2006 and have 7,000 families and over 30,000 members and for the first time ever young people over the age of 12 are able to join. Since 2023, they have been working with young advisors to improve the way that young people sign up to the study. GS volunteers have helped support research into diseases, including COVID-19, cancer, heart disease, diabetes, depression, dementia and much more.



Scottish Child Interview Model. protection and justice partners are working in partnership with the Scottish Government to take forward recommendations of the <u>Evidence and Procedure Review</u> to improve the quality and consistency of Joint Investigative Interviews (JIIs) of children. The aim is that JII statements are of a sufficiently high standard that they can be used as Evidence in Chief and contribute to the range of improvements being made to remove the need for children to give evidence in court and so reduce the potential of further trauma for child victims and witnesses. This

work is being led by local authorities and Police Scotland who both have statutory responsibility for the investigation of concerns about children.

A National JII Project Team, made up of experienced social workers and police officers, was set up in November 2017 to develop a new approach to JII's in Scotland, drawing on national and international research and best practice. This led to the development of the Scottish Child Interview Model for joint investigative interviewing and to a new, comprehensive training programme for child interviewers. This new model is now being implemented across all areas in Scotland. The National Team are responsible for training, delivery and on-going practice development for practitioners involved in forensic interviews with children. Embedding those changes requires the team to be involved in the evaluation of practice and development of interviewer's skills beyond initial training, drawing on messages from research about this crucial shift in focus to viewing joint investigative interviewing as a specialist skill.

Jennifer Morrison, Project Lead Social Work.

Jennifer joined Social Work Scotland in October 2017, having had a career in social work for 14 years, as a front-line child protection social worker and manager within a local authority setting. Jennifer's passion for the subject of forensic interviewing of children was central to her continued involvement in the development of the Scottish Child Interview Model and in 2021 Jennifer took up the post of project lead within the National Joint Investigative Interviewing Practice and Training Development team. Jennifer continues to lead on the roll out of the new training and policy and practice developments for social workers and police officers across Scotland who undertake joint investigative interviews.



NHS National Services Scotland (NSS) provides national infrastructure services and digital solutions which are integral to the delivery of health and care services in Scotland. We create and manage digital platforms across many areas of healthcare to realise benefits and improvements locally and nationally.





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Oral Presentations Abstracts

Are we protecting the protectors? Chaperone use in child protection medical examinations <u>Dr Seremma Parsons</u>, Lorraine Mulvey, Dr Shashwat Saran - University Hospital North Tees

Objective Standard 6 of the landmark document from RCPCH 'Child protection service delivery standards' states that 'Child protection (CP) medical assessments are carried out with the support of an appropriate chaperone". This document also says that:

A named chaperone is present as a witness and to support the child and clinician.

The chaperone should be trained, a qualified health professional and should not be a student

We wanted to ascertain the national picture regarding the use of chaperones in Child Protection medical assessments.

Methodology We conducted a survey, using the 'Survey Monkey' tool to understand what the current practices are regarding using chaperones in various parts of the country. An enthusiastic foundation trainee, in consultation with the Safeguarding team of our trust, designed survey questionnaires. Subsequently, the Named Doctor requested members of the National Named professional forum via email to respond to this survey.

Results Our preliminary results are based on thirty-one responses received so far.

- Eighty-four percent of respondents were Doctors and sixteen percent were Nurses.
- 2. All the respondents are based in England.
- 3. Sixty percent report that their NHS Trust does not have a dedicated chaperone policy for CP assessments.
- 4. Eighty-four percent reported that in their organisation Chaperone is routinely offered for CP medical assessments.
- 5. Eighty percent report that their organisation does not offer any formal training to the chaperones.
- 6. Twenty percent report that their organisation offers informal training to the chaperones.
- 7. Sixty-three percent report that it is acceptable in their organisation to have a family member, Social Worker, Police officer or Medical Student act as a chaperone.
- 8. The overwhelming majority (Eighty-five percent) of respondents are interested in the Child Protection chaperone training e-module developed by our organisation.

Conclusion Our survey highlights that neither the Clifford Ayling enquiry nor the Lampard Report recommendations about the safe use of chaperones, especially in the context of Child protection medical assessments are implemented in the UK (England). As child protection assessment is sensitive, having no/untrained chaperones exposes our patients and staff to serious risk.

The author feels a pressing need to improve the use of chaperones to support both the child, their family and the clinicians against any false allegations.

Down's Syndrome: Thyroid Failings Dr Andrew Tester, Dr Shubhangi Shewale, Mr Steven Strachan, Wishaw General Hospital

Down's syndrome (DS) is the commonest chromosomal disorder with an incidence of 1:1000 live births. Children with DS have a higher predisposition to develop hypothyroidism and symptoms may go unnoticed, due to overlap with other features of the syndrome. If left unrecognised, hypothyroidism causes preventable neurodevelopmental and physical manifestations. The Down's syndrome Medical Interest Group (DSMIG) suggest that all young people with DS be screened for thyroid disease at 4-6 months of life, 12 months and then annually lifelong. Screening is performed using finger prick samples of dried blood. The aim of our audit was to assess whether we were meeting DSMIG guidelines for thyroid screening in this cohort.

Our Lanarkshire DS patient register was used to identify patients; this register consists of all children from birth to 16 years living with DS in Lanarkshire. 10 patients under the age of 4 years were identified; 9 were eligible for screening (one patient already had hypothyroidism so was excluded). Of the resulting 9 patients, 9/9 (100%) had neonatal blood spot cards completed but only 2/9 (22%) had been screened appropriately for thyroid disease following the neonatal period. Of the 7/9 (78%) patients suboptimally screened, 5/7 (71%) had late screens and 6/7 (86%) had screening opportunities completely missed. Of the 2 patients with late screens, they were on average three months late. We presented this data locally to members of the multidisciplinary team caring for children with Down's syndrome and discussed strategies to improve screening.

Consequently, we aim to introduce several methods to mitigate the risk to our patients:

- 1. Designing a simple to follow DS thyroid screening flowchart and a new information document issued to health visitors, GPs and parents to act as a prompt for thyroid screening.
- 2. Creating alerts on our patient register to prompt distribution of screening packs one month before tests are due.

- 3. DS co-ordinator to contact health visitors/school if no sample has been submitted within a month of the annual checkpoint.
- 4. Increased frequency of DS team meetings to discuss challenges and strategies

We aim to reaudit our data in one year to assess our improvements

Physical injury in children with disability – a review of child protection medical assessments <u>Frances Wardle</u>, Owen Forbes. NHS GG&C

Background: Children with disability are likely to have multiple vulnerabilities that increase their risk of abuse.[1] They are also at a greater risk of un-intentional injury.[2] This may lead to an increased number of children with disability undergoing the child protection process due to concerns about physical injury.

Objectives: To find the proportion of child protection medical assessments for physical injury done by the Child Protection Service in Glasgow between January 2020 and December 2022 that were for children who had a disability, and to describe the outcomes of these assessments.

Method: A descriptive survey using retrospective data. The study population was all children aged from birth to 15 years 11 months with a disability who underwent a child protection medical assessment with the Greater Glasgow and Clyde (GG&C) Child Protection Service between 1st January 2020 and 31st December 2021 due to concerns about physical abuse. Data was collected using information in the child's record on EMIS and Clinical Portal with specific reference to the medical report from the Child Protection Consultant. Baseline comparative data was taken from the statistics collected routinely by the GG&C Child Protection Service. Data has been analysed using descriptive statistics.

Results: Of all child protection medical assessments done in the study period, 47 were for children with a disability (12.2%). For assessments done for children with disability, the child was more likely to be male (34 male, 13 female, ratio 2.6:1), and average age was 7 years (IQ1: 3 years 11 months, IQ3: 10 years 9 months).

Over half of assessments for children with disability were for children with a diagnosis of autism confirmed or who had suspected autism (51.1%, n=24). The second most common disability was global developmental delay (n=11, 23.4%), followed by speech and language delay (n=8, 17.0%). More than one disability was recorded in 15 assessments (31.9%). Of all assessments done by the child protection team in the study period for physical injury, 4.2% (n=16) were for children with a diagnosis of autism.

Most assessments for children with disability were done due to concerns about bruising (n=36, 76.6%). The most likely conclusion of the child protection investigation was not abuse (n=33, 70.2%). Physical abuse was confirmed by the child protection investigation in 8 assessments (17.0%). Of those assessments where the conclusion was 'not abuse', 42.4% (n=14) were identified as needing additional support or lack of supervision, with concerns about neglect raised in 6 assessments (18.2%).

Conclusion: Amongst all child protection medical assessments for physical injury completed in the study period, 4.2% were for children with autism. This is compared to an estimated baseline rate of 1.76% of children in the UK.[3] This suggests that children with autism are over-represented amongst children referred for a child protection medical assessment for physical injury. Most assessments done for children with disability were due to bruising. 'Not Abuse' was the most likely outcome following child protection investigations for children with disability, with concerns about need for additional support or neglect raised in a large proportion.

Why do Non-Urgent Patients Present to the Paediatric Emergency Department? <u>Jennifer Veitch</u>, Jamie Bentley, The University of Edinburgh, NHS Lothian

Background and Aim: The United Nations Convention on the Rights of the Child (UNCRC) states that 'every child has the right to the best possible health'. This is reflected in the Scottish Government Policy 'Getting it Right for Every Child' (GIRFEC), which states that practitioners and organisations in collaboration with children and their families should ensure 'access to suitable healthcare'. The Scottish Government began a campaign during the COVID-19 pandemic to help enable patients to access 'the right care in the right place'. This unscheduled care policy provided easy- to-access information about the services that were available, thus empowering patients to make decisions about what service most suited their need. The utilisation and impact of this resource is important to understand, as if used correctly it helps allow patients to access the most suitable unscheduled care for their illness/iniury.

Non-urgent presentation to the paediatric emergency department (PED) is an underexplored area within context of the National Health Service (NHS) but could impact a child's ability to access suitable healthcare in a timely manner if non-urgent presentation is frequent. It has been found that non-urgent presentation to the PED can have a negative impact on the care of not only the non-urgent patient, but also the other patients within the department. The study aimed to evaluate the parents/carers awareness of the unscheduled care policy and the services available within NHS Lothian, and the reasons that they bring their child to the PED for non-urgent complaints.

Methods and Results: The study took place as a service evaluation at the Royal Hospital for Children and Young People (RHCYP) Edinburgh between the 20th and 28th of March 2023. An online survey was conducted and combined with patient data to establish a group of non-urgent patients. All surveyed parents/carers of children with non-urgent complaints were unaware of the unscheduled care policy, and 64.71% brought their child to the PED because they were advised to by a healthcare professional, and almost all of these patients had accessed their General Practice (GP) before their visit (90.91%).

Conclusions: There is a lack of awareness of the unscheduled care policy within parents/carers of children presenting to the RHCYP ED. However, there is a general awareness of other services that are available. This suggests that perhaps more information and guidance about when to use each service is necessary to help parents/carers access the most efficient and appropriate service for their child. It is particularly important that parents/carers of patients understand the role of other services within their community, such as pharmacy. More research is needed within this area to understand the motivators behind non-urgent referral from other services, particularly GP.



Poster Presentation Abstracts



WILLIAM MORRIS PRIZE WINNER 2022

Is fertility being discussed with paediatric cancer patients?

<u>David Hayburn</u>, Dr Kathleen Duffin, Edinburgh Medical School, Biomedical Sciences, University of Edinburgh

Objectives Treatment for childhood cancer can be detrimental to future fertility; therefore, it is recommended that fertility risk should be discussed at the point of diagnosis of paediatric cancer. Where appropriate, fertility preservation should be offered. The purpose of this audit is to assess whether these recommendations are being achieved in the care of paediatric cancer patients in South East Scotland.

Method Patients aged 0-16 years old who were treated in NHS Lothian and diagnosed with cancer from Jan 1st 2018-December 31st 2019 were included. Eligible patients were identified from the Scottish Cancer registry and data was retrieved retrospectively from electronic patient records. The following outcomes were gathered: age at diagnosis, gender, documented fertility discussion. Where fertility was discussed, further information was collected about who was present, whether written information was provided, and whether fertility preservation was discussed/offered.

Results 149 eligible patients were identified; three patients were excluded from the study as their electronic records were not available. Discussions about fertility were documented in 71/146 (48.6%) of cases. In 29/71 (40.8%) cases, the patient was noted to have been included in the discussion; this represents 19.8% of the total patient cohort. In 42/71 (59.2%) episodes, only the parents/guardians were included in the discussion. Written information was provided in 57/71 (80.3%) cases. Fertility preservation options were specifically discussed in 39/146 (26.7%). Of these, 22 patients were identified as low risk to fertility and therefore not eligible for fertility preservation; 16 patients underwent fertility preserving techniques; and 1 patient was identified as high risk but opted not to undergo fertility preservation. In the group of 32 patients with whom fertility but not specifically fertility preservation was discussed, 28 of these patients were documented as being low risk. In one patient, it was documented that progression to treatment was urgent and therefore fertility preservation was not discussed.

Conclusion This audit demonstrates that fertility is being discussed in less than half of childhood cancer diagnoses in South East Scotland, with fertility preservation being discussed in one quarter of cases. Furthermore, less than 20% of patients were included in such discussions. It is possible that, particularly in low risk cases, fertility is being discussed but not documented. However, this still highlights a need for increased awareness of the need to discuss and document fertility risks in this patient group, in line with national and international guidance, ensuring transparency and informed consent

Rare de novo mutation in the KLF7 gene in a child with global developmental delay and neuromuscular symptoms. Dr Katherine Gordon, Dr Ai Lin Lee. Dept Community Child Health, Aberdeen

The KLF7 (Krüppel-like factor 7) gene encodes a protein involved in cell proliferation and differentiation, with an important role in neuronal morphogenesis. Worldwide, only 6 cases of KLF7 missense mutations have been reported in humans. These cases share a common phenotype of intellectual disability and neuromuscular problems. There is also emerging evidence in animal models suggesting a link with autism spectrum disorder (ASD).

We present the case of a 7 year old boy with a complex neurodevelopmental disability, present since birth. Following trio-exome analysis, he was found to have a de novo missense mutation in the KLF-7 gene. His issues include Global Developmental Delay, dysmorphic features, hypoplastic corpus callosum, microcephaly, truncal and limb hypotonia with intermittent dystonic episodes, airway dystonia, unsafe swallow requiring gastrostomy feeding, profound cerebral visual impairment, epilepsy, previous large bowel infarction requiring extended right hemicolectomy and ileostomy, recurrent urinary tract infections, and kyphoscoliosis. Previous investigations were negative for Myotonic Dystrophy, Mowat Wilson syndrome, Opitz G/BBB syndrome, Spinal Muscular Atrophy, Prader-Willi Syndrome, Smith-Lemli-Opitz syndrome, Epilepsy gene panel. SNP micro array showed a normal male pattern. Metabolic studies were unremarkable. No cause was identified via the Scottish Genomes Project.

The genetic diagnosis is clinically relevant to this patient as the phenotype is known to predispose to ASD, which has prompted further assessment in this area. This case also highlights the use of diagnostic-exome sequencing to identify genetic mutations in patients with profound intellectual disability, where traditional testing has not found a genetic cause, and is important to raise awareness of the KLF7 mutation phenotype.

Not another jejunal tube: a retrospective audit of factors contributing to tube displacement' Nicola Britton Louise Gannon, NHS Tayside

Objective Jejunal tube feeding has become the standard of care for children where gastric feeding is insufficient to meet caloric needs and can be a highly effective feeding route. Jejunal tubes require scheduled replacement every three to nine months. However, there is a noticeable burden placed upon acute services when they are displaced and require unscheduled replacement. This audit aims to identify baseline characteristics of jejunally fed patients, the frequency of tube displacement and factors contributing to this.

Method Data was retrospectively collected for jejunally fed children who were admitted to the Paediatric department with tube displacement between April 2022 and April 2023. Information regarding patient factors and jejunal displacement was collated from patient notes and clinical systems.

Results A total of eighteen patients in NHS Tayside have jejunal tubes; 3/18 (17%) patients have a nasojejunal tube, 2/18 (11%) with surgical roux-en-Y jejunostomy and the remaining 13/18 (72%) have a gastrojejunal tubes. There were 16 presentations to the Paediatric ward during this time with admission required for 15 patients. Jejunal tubes were displaced for a variety of reasons; six due to vomiting or pulling tube out, one episode of intussusception, three episodes of tube migration into stomach, four episodes due to burst balloon and two blocked tubes. Three patients were disproportionally affected by tube displacement and accounted for 9/15 (60%) of admissions. All three children had complex neurodisability and multiple co-morbidities. Excluding surgical jejunostomy patients, 6/16 (38%) patients with jejunal tubes had no presentations with displacement. The time to replacement of jejunal tubes varied in length with four being replaced within 24 hours, five within 24-48 hours and seven over 48 hours.

Conclusion Jejunal displacement affects more than half of the patients with jejunal tube feeding. The burden placed on out of hours services and difficulty replacing tubes can lead to prolonged admissions. However, many patients have no issues with jejunal displacement and the majority are replaced within 48 hours. Further information will be sought at network and national level to improve outcomes for jejunally fed patients, especially those with recurrent tube displacement

Walk tall and look the world right in the eye: A service evaluation of a 4-week trial to assess if the Innowalk Pros could provide physical activity for children with complex neuro disabilities with GMFCS IV and V within a Special School.

Kath Brimlow, Jenni Coulter, Aida de La Torre Romero, Georgina Farquhar, Craigalbert School

Background The new UK Government guidelines (2022)¹ recommendation is for disabled children to do 20 minutes of physical activity per day. Disabled children's activity levels decrease significantly, as they get older. Activity levels for disabled and non-disabled children are similar when they first start school, but the gap widens by the time they are 16 (Key Stage 4 - 52% vs 72%)² The Innowalk Pro is described as a Robotic motorised, dynamic standing frame³ that allows users with moderate to severe physical disabilities to stand and move.

Aim A retrospective service evaluation of a 4-week trial in November 2021 to assess if the Innowalk Pros could provide physical activity for children with complex neuro disabilities with GMFCS IV and V. UNCRC article 23 states that if a child has a disability, they have the right to special care and education, therefore, can the Innowalk Pro enable children with complex needs to take part in a walking activity within a special school⁴.

Methodology 10 children participated in the study: 8 girls and 2 boys, from 6-15.4 years, mean age 10.2 years. Two Innowalk PROs, full training, and ongoing support during the trial were provided by the "MadeforMovement" Team. Each child was timetabled to have 4 sessions per week of the trial.

For each child the total number of sessions, the distance achieved, and the duration of each session was recorded.

Ethics: The HRA decision-making tool confirmed the analysis that this Innowalk Pro study is a service evaluation and not research.

Results 2 children withdrew from the trial. One was due to absence through illness unrelated to the trial. The second child initially tolerated the Innowalk Pro well, but then during the third session the child indicated obvious discomfort and they were withdrawn from the trial.

The total number of sessions per child was 4 to 14 compared to our target which was 16 sessions.

The mean session duration for each child ranged from 13 minutes to 25 minutes, the mean was 19 minutes.

The mean session distance each child walked ranged from 0.5km to 1.5km, the mean was 0.95km.

Conclusions During the trial, the Innowalk Pros enabled 8 children out of 10 with a GMFCS classification IV and V to have access to a walking activity over a 4-week period. The mean session duration was 19 minutes so this can contribute to the UK Government's guidelines of physical activity for disabled children. The Innowalk Pro does enable children with complex needs to be able to take part in a walking activity within a special school. Most children (7 out of 8) achieved 2 to 3 sessions per week which was less than our target, but within the pilot scheme there was no time to reschedule Innowalk Pro sessions which were missed through illness or conflicting demands on the children's time

Teaching movement and communication skills through play Evaluating parental satisfaction of a pilot family led approach to a multi-professional weekend therapy Early Intervention Programme (EIP) Kath Brimlow, Alicia McKenzie, Alison Philips

Aim Service evaluation was to evaluate parental satisfaction with a parent-mediated weekend therapy programme for children 0 – 4 years with complex needs, (UNCRC article 23)¹, particularly, as parent mediated programmes can be viewed as burdensome by some parents as they are given more daily tasks to do with their child.

Methodology The programme was free to parents with self-referral. After a multi-professional assessment, their child was allocated to a small group of children with similar needs. Whole families were invited to attend the Early Intervention programme on 3 Saturdays per term and there was a sibling activity hub. The programme was planned and delivered by therapists and Early Years Practitioners. Pragmatic Organisation Dynamic Display (PODD)was integrated to support meaningful interactions, communication, and language development. In December 2022, the parents were sent an online Survey Monkey questionnaire, containing 13 items which recorded demographic information and collected information on the parents' experience of using the service. The questionnaire contained 7 closed questions which used both an 11-point rating scale and a Likert 5-point scale — with labelling. The comments from the 6 open questions were analysed using thematic analysis 3 The questionnaire was expected to be completed within 3 minutes.

Ethics: The HRA decision-making tool confirmed the analysis that this pilot EIP programme study is a service evaluation and not research.

Results Completed questionnaires were returned for 13 (35%) out of the 34 children attending the programme. These 13 children were 6 girls and 7 boys aged between 14 months and 3.5 years, mean 2.5 years. The children had attended between 2 and 7 sessions throughout the year, mean 3 sessions.

10 (77%) parents thought the programme was excellent (Rating score 9 -10) and 3 (23%) very good, (Rating score 7 - 8).

13 (100%) parents were extremely likely to recommend the programme to others.

Positive emergent themes for the open comments were:- 1) programme accessibility and inclusiveness, 2) multi-professional support for their child's condition, 3) parental empowerment, and 4) opportunity to use the Centre's facilities. Negative comments were that there was no time allocated (within the programme) to chat with other parents and the use of the hydrotherapy pool should always be included.

Conclusion Parent satisfaction was high for this Early Intervention Programme. The parents did not find the parent mediated intervention burdensome but appreciated being taught skills to improve their child's development, especially in the areas of communication and physical abilities. (UNCRC article 23). The authors are aware that while the 35% parents who returned the questionnaire, gave good feedback and suggestions, it does mean that there is some respondence bias.



With thanks to our sponsor and supporter