NOVEMBER 15TH 2016

healthwatch Greenwich

CHILDREN'S CONTINENCE CLINIC CLOSURE

IMPACT OF THE CLOSURE OF GREENWICH'S PAEDIATRIC ENURESIS SERVICE

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CHILDREN'S CONTINENCE CLINIC CLOSURE

INTRODUCTION

This report outlines the background and potential impact of the closure of Greenwich's Children's Continence Clinic. It draws on information provided by service users, specialist nurses, charities, Public Health (part of Royal Borough of Greenwich), and national guidance to identify the possible impact of the closure and make recommendations for future delivery.

BACKGROUND

Greenwich Children's Continence Clinic is a specialist nurse led provision delivering medical and emotional support and guidance to children and families around bladder and bowel continence issues – this includes children with learning difficulties, physical disabilities, late toilet trained children and children with continence issues for a range of other reasons. There were three half day clinics a week and four drop in sessions a month at children's centres around the borough.

Healthwatch Greenwich (HWG) were alerted to the possible closure of Greenwich Children's Continence Clinic by email, from a concerned member of the public on the 4th July 2016. HWG contacted the commissioning team at Greenwich CCG who provided information that the service was not going to be closed although the CCG were not the commissioners of the service. We have been unable to identify to whom we originally spoke. We notified the initial complainant by email that the clinic should remain open on the 18th July.

HWG subsequently received further emails from two different people on the 5th and 7th September stating they had tried to contact the clinic and had been informed that it had closed on the 31st August 2016. Service users had apparently not been notified until they contacted the clinic and were now being referred to their GP.

HWG contacted the CCG again on the 8th September to ask for clarification regarding the status of the clinic. On the 12th September, we were informed the clinic was operated by Oxleas NHS Foundation Trust

as part of their children's public health nursing services (previously funded by the provider arm of the then PCT), and were referred to Public Health in the Royal Borough of Greenwich (RBG). They forwarded our concerns and questions to Oxleas.

Public Health replied to HWG on the 16th September with information provided by Oxleas regarding the concerns:

- "HWG: The users of the service (approximately 700 clients across the borough) have not been informed that the clinic has been closed and are only now finding out when they call or try to visit.
    - Response: There are 302 clients on an activity care pathway for enuresis in Greenwich. There are 94 clients receiving products Unfortunately, Oxleas has not consistently contacted all clients' GPs – some GPs have been contacted. This is being remedied immediately.
- HWG: Service users are being referred to their GPs, but GPs also haven't been informed and are telling their patients they can't provide the supplies (nappies/pads etc.).
    - Response: As above, Oxleas will ensure that all GPs are informed. Oxleas will work with the CCG and ensure that all GPs are aware of the ordering process.
- HWG: Existing service users will continue to receive their items from NHS Supplies until they need a change in size or type – at which point they no longer have anyone to make arrangements for them.
    - Response: Practice nurses are able to measure for new products. Ordering information will be sent to GPs via the CCG.
- HWG: Has the provision been closed permanently?
    - Response: Yes, the clinic is no longer open.
- HWG: What alternative provision is in place to support existing and new service users?
    - Response: GP pathway. Clients already need to access their GP for hospital appointments (scans, etc.).
- HWG: What is the communication strategy to ensure all service users and GPs are informed of the closure and the alternative arrangements for ensuring they receive the supplies they need?
    - Response: Oxleas will work with the CCG and RBG to ensure that all clients and GPs are aware of the alternative arrangements.
- HWG: How much did the clinic cost to run?

- Response: 0.4-wte band 6 nurse to run three 3-hour clinics per week plus three hours per week to write up records over 39 weeks - £17929. 0.2-wte band 2 admin one day per week to arrange appointments, support sessions and send out GP letters - £4,871. Additional resources = approx £5,000. Total to run service - £27,801."

HEALTHWATCH GREENWICH ACTION

HWG subsequently made a public call for information and contacted other specialist clinics and charities to gather feedback regarding the provision of specialist continence clinics. However, we recognise that this is a particularly sensitive subject and people may not wish to talk about their or their child's experiences. To date we have received one direct call from a parent of a child who had accessed the service, further information from a friend of a parent, 2 responses to our anonymous online survey, information from a specialist nurse and a consultant paediatrician, detailed information from ERIC (a children's bowel and bladder charity), and from a similar clinic commissioned by Hackney CCG. We have also had detailed conversations with Public Health who have been open and transparent throughout. Both the CCG and RBG (via Public Health) have received draft copies of this report and were invited to check it for accuracy.

THE CLOSURE

The Children's Continence Clinic was one of several services provided by Oxleas commissioned by the former PCT, prior to novation of public health children's services to RBG (under Public Health) in October 2015. RBG undertook a procurement exercise this year for a new 0-19 children's service (integrating the public health nursing services, Health Visiting and School Nursing) based on the new national specifications. RBG is not responsible for commissioning children's continence services (NHS Commissioning Board, 2012), so it did not fall into the remit of the new specification. RBG was unaware at the time that the service was delivered by Oxleas public health nursing. It appears that Oxleas did not notify RBG about these arrangements until the new contract was awarded.

Oxleas didn't include the continence clinic in their bid during the procurement exercise because the service wasn't part of the specification.

Unfortunately, the service was closed by Oxleas without any notification to either service users or the GPs. After HWG raised the issue with Public Health, a letter was sent to GPs by Oxleas towards the end of September informing them of the situation (see Appendix 1). As of the 8th November, no direct communication had taken place with the more than 300 service users. HWG met with a GP on the 23rd September who confirmed that they had just received notice of the closure.

Public Health has subsequently agreed with Oxleas to provide additional funding to keep the specialist nurse in her current role until the end of October (following a restructure, the member of staff has been allocated another position) to help provide training and support to GP practices. Public Health is also in discussion with the CCG to look at future options for the service. At the time of publication, it has been agreed for the service to be recommissioned for a further 3 months, pending further discussions and a feasibility study.

FEEDBACK AND CONCERNS

Most of the feedback we have received so far agrees that whilst GPs are an integral part of the diagnostic process, there are real concerns regarding the capacity and skillset of GP practices to be able to manage a very specialist and sensitive area for parents and children. For example:

"A nurse led continence service works with a child and family over a period of time. Initially they will carry out a full continence assessment and depending on what comes out of that will provide information, advice, support along with the tools to solve or manage the difficulties. They will review progress and adapt to changing circumstances. This is not a role that a GP would or indeed should [do] *through the normal appointment system."*

Juliette Randall, CEO of ERIC – the children's bowel and bladder charity.

"There is definitely a need for a specialist service especially with the increasing number of SEN and disabled children who require the service, not to mention the many who will need assistance with day and night wetting, those who need toileting with an increasing number starting school not having achieved continence. The GP service can help but I don't imagine that they have the capacity to see first time and follow ups

regularly and routinely especially when it comes to those on toileting care plans who require multidisciplinary input from parents, schools, OT etc."

Karen Maughn-Smith, Paediatric Specialist Nurse – Continence. Homerton University Hospital NHS Foundation Trust.

"[Greenwich Children's Continence Clinic] *had a direct referral pathway to the Evelina Hospital bladder and bowel consultants and could identify those that needed referral and get it done quickly. Sad to say local paediatricians are not good at childhood continence. Many GPs are reluctant to refer on and try to manage locally, often with the wrong medication or doses. GPs do not have the facility or the training to review these children or make a continence assessment of children to decide which is the most appropriate product. They do not have NHS supply contracts or cost codes to be able to order products even if they knew how. A specialised continence assessment takes at least 20 minutes and there is a need to weigh and measure children to ensure good fit and that products will not leak. This client group are separate to the wetting and bowel client group."*

Anonymised.

"This a crucial service for children and for their development into adulthood. Lack of this service will increase issues of bullying for children at school it will affect their social skills and at home it will lead to abuse of children, [an] *example is the Victoria Climbié case who's bed wetting contributed to her death."*

Lola Kehinde, Lead Continence Nurse Specialist and Healthwatch Greenwich Board Member

"My friend's daughter used the clinic. She had been seeing her GP for a year and kept being told it would go away on its own. She was also told that they couldn't refer to the clinic until the child was 7. She was 6 then. I think it was her school nurse who referred her to the clinic, as they actually saw children from 5 years old. By then her GP had started medicine because my friend kept going back, but it wasn't working. My friend found out later it was completely wrong medicine for her type of wetting. When she saw the nurse at the clinic she knew exactly what it was. They did a bladder scan and started a

different type of medicine which did work. I remember how relieved my friend was because she had often been brought to tears over it [...] I remember it so well that's why I was so angry that they closed."
Anonymised, friend of a family who used the service.

"[The closure may cause] an increase in inappropriate and more expensive secondary and tertiary care referrals as childhood continence assessment lies largely outside of the average GPs area of expertise. The Evelina London children's hospital tertiary level Bladder clinic has received five referrals from Greenwich general practitioners in the last couple of weeks stating that the local service has been discontinued. These referrals are not appropriate for a tertiary setting and few general paediatric departments in secondary care have the expertise. Previously these referrals will have gone to the local Greenwich Children's Continence Clinic where they were very competently assessed and managed, including bladder scanning. Children who then required further more detailed assessment or who had failed treatment were then appropriately onwardly referred to our clinic by the clinic nurse.
Dr. Anne Wright. Consultant Paediatrician in charge of Evelina London Children's Bladder clinic. Member of clinical guideline development group for NICE nocturnal enuresis/quality standard. Chairman of Professional Advisory committee for ERIC. Secretary of International Children's Continence Society

"The nursing staff there are excellent. They know their stuff and offer excellent advice. Unlike my GP who told me my son soiling at 7 wasn't an issue and I should sit him regularly on the toilet!"
Anonymous survey respondent.

CASE STUDY

In addition to the above information, a parent of a child who had used the service also contacted us. This is their experience (names have been changed):

Jane first noticed that there was an issue when her daughter (Sarah) was 6 months old. Sarah had been suffering from persistent constipation that was causing her significant discomfort. Jane of course took Sarah to her GP, where she was prescribed some laxatives and advised to improve her diet. This did not clear up the problem and Jane returned to her GP. She was again prescribed laxatives and advised to improve Sarah's diet. This continued for a while with Sarah's problems getting worse. Sarah was eventually referred to a paediatrician, who again prescribed laxatives and advised Jane to improve her daughter's Diet. Sarah was a couple of years old at this point and the constipation was starting to create other continence issues. Jane was also beginning to feel as though she was being blamed because each time, the doctor would suggest that Sarah had a poor diet, which Jane didn't believe to be the case.

The problems persisted until Sarah was 6 years old. The persistent constipation and associated continence issues were becoming an increasingly serious problem for a child that was now at school. Eventually a school nurse referred Sarah to Greenwich Children's' Continence Clinic.

After their first visit to the clinic, Jane felt that it was the first time she had ever actually been listened to by a professional regarding Sarah's problems. The clinic helped them with medication choices and the use of a TENS machine to help manage the problem. The clinic referred them to a dietician to confirm that Sarah's diet was not the problem. In addition, the clinic provided a direct referral to Evelina Children's Hospital and Dr Wright, a bladder and bowel specialist. During their assessment, it was noticed that Sarah also suffered from hypermobility, which is known to be a contributing factor to bowel issues. Eventually Sarah was diagnosed with a megacolon. Both the diagnosis for hypermobility and the megacolon meant that Sarah could now receive the correct treatment for both.

Sarah is now 8 years old and in the words of Jane their quality of life is "100% better". Jane says "I hate to think where we would be without now without the Clinic". Jane felt she had not been listened to by any professional until she visited the clinic and was made to feel it was her fault that Sarah was suffering. Sarah is about to go on a school residential trip which Jane feels would have been impossible without the support and intervention of the Children's Continence Clinic.

CONCLUSION

Children's continence issues can cause a range of physical and emotional problems for children and their families, particularly when they're of school age. Children often suffer from bullying and can miss out on important social and educational opportunities as a result. Children with learning difficulties or physical disabilities are disproportionately affected and continence and bowel issues are often part of a more complex range of issues (for example Sarah in our case study, also having hypermobility causing her additional pain and discomfort).

The Paediatric Continence Forum (PCF) produced the 'Paediatric Continence Commissioning Guide' (2014), which has been accredited by NICE. In it they recommend that: *"All children and young people from birth to 19 years with bladder and bowel dysfunction […] including those with learning difficulties and physical disabilities should have access to an integrated community-based paediatric continence services: The Community Paediatric Continence Service (CPCS)."*

Public Health England (PHE) has recognised that problems with identification and referral of continence problems can inhibit children from reaching their potential. However, PHE goes on to goes on to state: *"…clinical support for enuresis or incontinence lies with NHS England".*

The All Party Parliamentary Group for Continence Care produced a report in 2011 stating: *"As a minimum, a high quality, cost-effective continence care service requires: an expert clinical leader responsible for strategy, service improvement, education, research and audit activities; one whole time equivalent specialist practitioner per 100,000 population, plus access to designated medical and surgical specialists, investigation and treatment facilities."* This includes adult continence.

Dr Anne Wright states that the closure of the clinic may result in: *"a waste of money in providing incontinence products (pads and nappies) instead of accurate continence assessment and prescribed strategies to attain continence. This is something that needs regular repeated assessment, particularly in children with special needs, as there is good evidence that most of these children are able to attain continence if bladder and bowel dysfunction are excluded and specialist toilet training is undertaken."*

In 2012, NHS England outlined the services CCGs, NHS England and Public Health (based in Local Authorities) were responsible for commissioning. The guidance states: *"Community health services (such as rehabilitation services, speech and language therapy, continence services, wheelchair services, and home oxygen services, but not public health services such as health visiting and family nursing)"* were the responsibility of CCGs (NHS Commissioning Board, 2012).

Based on the available information and conversations HWG have had with experts and members of the public, it is HWG's view that the Children's Continence Clinic is an essential specialist service. Whilst only impacting on a relatively small number of people (approximately 8% of the population – circa 900,000 children nationally), it can have a disproportionately negative impact on their lives and the lives of their families. HWG understands that a paediatric continence service is not a statutory provision, however it is our view, and the view of several families and clinicians, that the relative medical and emotional benefits to children combined with reassurance to families, gained from a service costing less than £30,000 a year is significant value for money and something that should be commissioned in Greenwich.

> "[The closure means] *the loss of a competent, well-run, valuable community continence service that may result in considerable delay and barriers to children and young people accessing the specialist care they need in Greenwich, with attendant consequences for them and their families.*"
>
> **Dr Anne Wright – Evelina Children's Hospital**

RECOMMENDATIONS

Healthwatch Greenwich make the following recommendations:

1 – COMMUNICATION: A) The CCG, Oxleas and RBG immediately notify all most recently registered users of the services of the closure and the interim arrangements. B) The CCG and RBG build into contracts (where possible and not already embedded) a requirement for providers to notify commissioners and engage with the public well in advance of any potential service closure (not restricted to the continence clinic), whether directly commissioned or otherwise.

2 – SERVICE USER ENGAGEMENT: The CCG and RBG seek the views of the most recent service users (more than 300 in Greenwich) and users of similar clinics in other boroughs. Emphasis should be placed on service user's experiences of accessing support elsewhere (such as their GP) and the length of time it took to receive appropriate treatment before and after accessing the clinic.

3 – IMPACT ASSESSMENT: The CCG undertake a full impact assessment of the continence clinic, including the impact of its current closure. The assessment should identify the knowledge and experience level of GP practices around diagnosing, referring and supporting paediatric enuresis within the borough, the understanding of referral routes for children to specialist paediatricians and dieticians as well as the available non-clinical support available to families (including counselling, professional advice, training for schools and youth professionals etc.).

4 – TEMPORARY PROVISION: The CCG, RBG and Oxleas have agreed to recommission the service for three months and carry out a feasibility study. This should be extended to at least six months, to give enough time for a full impact assessment to be completed, service user views to be more fully sought and explored and an appropriate long term provision to be identified, planned, recruited to, and implemented.

5 – LONG TERM PROVISION: The CCG and RBG (including Public Health) work together with providers to ensure that a high-quality specialist service is available and that other professionals such as GPs, school nurses and health visitors have the appropriate levels of training to be able to identify and refer children to the service as appropriate. The provision does not necessarily have to take the same form it in which was originally provided, but should remain a discrete, specialist paediatric continence service.

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REFERENCES

All Party Parliamentary Group (2011) *Cost-effect Commissioning for Continence Care*. http://www.appgcontinence.org.uk/pdfs/CommissioningGuideWEB.pdf

NHS England (2015) *Excellence in Continence Care; Practical guidance for commissioners, providers, health and social care staff and information for the public.* https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/11/EICC-guidance-final-document.pdf

Paediatric Continence Forum (2014) (Updated 2015) *Paediatric Continence Commissioning Guide: A handbook for the commissioning and running of paediatric continence services*. http://www.paediatriccontinenceforum.org/wp-content/uploads/2015/09/PaediatricContinence-Commissioning-Guide-2014-PCF.pdf

NHS Commissioning Board (2012) *Commissioning fact sheet for clinical commissioning groups.* https://www.england.nhs.uk/wp-content/uploads/2012/07/fs-ccg-respon.pdf

APPENDIX 1 – COPY OF LETTER SENT TO GP'S AFTER THE CLOSURE OF THE CLINIC

Dear Colleague

Re: Enuresis Clinic / Referrals

As you may know, we have recently launched a new integrated 0-19 Public Health Nursing Service and this will provide evidence-based advice and support to families, including addressing issues such as continence, bed wetting, and potty training, but will no longer provide the specialist health clinics such as the Children's Continence/Enuresis Clinic.

The changes to the specialist clinics should have little impact on your practice as they currently support only a small number of children. However, during this transition, to ensure that you and your practice team are fully briefed and supported in regard to the on-going management of enuresis and the alternative support available, a trained enuresis nurse will contact you to discuss any children or young people who have received services from the specialist clinic.

Continence support nurse:

Frances Adam can be contacted on:

Tel: 0208 319 9970

Email: Frances.Adam@oxleas.nhs.uk

We hope the following information (attached) will assist you, but please do not hesitate in calling me if you have any questions.

Yours sincerely

Helen Day Barnes

Service Manager, 0 to 19 Public Health Nursing Service

New 0-19 Public Health Nursing Service

We have designed a new model of service, which includes changing the way some services are delivered. Continence support will now be provided through our 'Universal Plus' service level. The offer includes the provision of additional, timely, expert and evidence-based advice and support to families when they need it on specific issues such as continence, bed wetting, and potty training. The offer also supports sleepless children, infant feeding (weaning, etc.), parenting support, etc. Interventions will be planned

and will include regular reviews to assess progress, measure outcomes achieved or escalate for additional support from General Practice, etc.

Our Child Health Clinics have also been re-shaped with greater focus on advice and empowering parents and carers in managing their health and linking in with existing community resources. The Child Health Clinics have been re-launched as 5 Health Advice Sessions that take place across the borough in Children's Centres each week (with one session taking place at Plumstead Health Centre with Children's Centre outreach support) these sessions are supported by a further 11 nursery nurse led drop in sessions across the borough again held in Children's Centres.

School nurses continue to offer services in schools and are available in every school to offer advice and support. School nurses liaise with young people, parents, school staff and SENCOs.

Prescriptions and monitoring progress

Please can you continue to issue prescriptions and monitor progress. Please note, clients should have a week's break from Desmopressin every three months to assess progress, and anti-cholinergics should be reassessed six monthly.

Further information can be found here:

http://www.evidence.nhs.uk/formulary/bnf/current/6-endocrine-system/65-hypothalamic-and-pituitary-hormones-and-anti-oestrogens/652-posterior-pituitary-hormones-and-antagonists/posterior-pituitary-hormones/desmopressin

Care pathway flowchart

The enclosed flow chart for the management of nocturnal enuresis is based on NICE guidance. We have advised this family that they will need to seek support from your practice for further review of enuresis.

Home Delivery Service – Continence products (NHS Supply Chain)

Freephone Healthcare Professionals Line: 0800 141 2255

This new line is only for professionals. It is available Monday to Friday between the hours of 08:30-15:00. If you call outside of these hours there will be an answer machine service; your message will be returned the following working day.

Should you have any enquiries, please contact Vicky Thomas on:

Tel: 0800 141 2255

E-mail: Home.Delivery@supplychain.nhs.uk

Or homedelivery@nhs.net

NICE Guidance

Further information about the management of enuresis can be found in NICE Guidance CG111
https://www.nice.org.uk/guidance/cg111?unlid=73774279201629161342

APPENDIX 2 – INFORMATION SENT TO GP PRACTICES BY CCG

Taken from article in Commissioning Voice (newsletter sent out by CCG to all GPs in Greenwich):

Enuresis Clinic / Referrals

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The changes to the specialist clinics should have little impact on your practice as they currently support only a small number of children. However, during this transition, to ensure that you and your practice team are fully briefed and supported in regard to the on-going management of enuresis and the alternative support available, a trained enuresis nurse will contact you to discuss any children or young people who have received services from the specialist clinic.

Continence support nurse Frances Adam can be contacted on 0208 319 9970 or frances.adam@oxleas.nhs.uk

Feedback on Article:

"The 0-19 service will not be providing specialist support for continence or bedwetting other than the standard tier 1 advice recently given to school nurses at a training day. After tier 1 advice has been given they are to be told to see their GP. Health Visitors will not be providing any specialist toilet training advice. They used to refer to the clinic as they [usually] *do not have specialist skills in this area. No training has been given to them on constipation or soiling, which is a huge issue in schools. Apart from clinic work* [the nurses] *attended schools to help draw up specialist continence care plans for managing in schools. School nurses are not going to be doing this either."*

Anonymised