

Report to Healthier Communities & Adult Social Care Committee 16th March 2022

Report of: Healthier Communities & Adult Social Care Scrutiny

Committee

Subject: Response to Scrutiny recommendations on Continence

Services.

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Summary:

On Tuesday 8th March 2022, the Healthier Communities and Adult Social Care Scrutiny Committee held an informal meeting with NHS Sheffield Clinical Commissioning Group, and Sheffield Teaching Hospitals NHS Foundation Trust to discuss their response to the Scrutiny Committee's report on Continence Services.

The NHS response to the report and its recommendations is appended, and the key points from the discussion are outlined for the Committee to formally note, and pick up in future discussions with the NHS on continence services.

The Scrutiny Committee is being asked to:

- Note the NHS response to the Committee's report on Continence Services
- Note the key points from the discussion held on the 8th March
- Request that the NHS returns to the appropriate Committee next Municipal year to give an update on progress.

Background Papers:

Minutes of the Healthier Communities and Adult Social Care Scrutiny Committee, October 2021.

Category of Report: OPEN/

Report of the Healthier Communities and Adult Social Care Scrutiny Committee.

Response to Scrutiny Recommendations on Continence Services.

1. Introduction

1.1 In 2019/20, the Healthier Communities and Adult Social Care Scrutiny Committee established a working group to look at Continence Services in Sheffield.

The Working Group made recommendations around 4 themes – prevention, inequality, a person-centred approach and communication – and these recommendations were agreed by the Scrutiny Committee at its meeting in October 2020 (report attached at appendix 1).

The report was then passed to the NHS for consideration and action.

2 March 2022 – NHS Response and discussion

The Committee met informally in March 2022 with representatives from Sheffield Teaching Hospitals NHS Foundation Trust, and NHS Sheffield Clinical Commissioning Group to receive an update on the Continence Service, and a response to the recommendations in the scrutiny report. This is attached at Appendix 2 for the Committee to note.

Committee members discussed the response, welcomed progress, and noted the impact of the pandemic on the Continence Service – and its ability to act on some of the recommendations. Committee members felt that it would be valuable for the appropriate Committee to receive an update at a future meeting – picking up progress on the original recommendations of the report, and the following points raised at the March meeting by Committee Members:

2.1 **Prevention**

Committee members recognised the impact of the pandemic in getting out into communities – pleased to see that progress can now be made and plans and projects are now in place. Keen to see holistic approach to pelvic floor education in schools – and how we can link into music and movement classes – pilates etc.

2.2 Inequalities

Committee members keen to see greater engagement with seldom heard voices as part of future service developments, and a commitment to put equality at heart of engagement.

2.3 A person- centred approach

Committee members expressed concern that there remains a fundamental tension between the service model – limits on continence products based on a technical understanding of product's absorbency –

and service user experience – with reports suggesting that some people feel they have to 'top up' their prescription or purchase alternative products. Concern that the increase in the cost of living will make this harder for many. Committee members keen to see this point explored in future engagement

Committee members keen for service users to be engaged and involved in service developments and improvements going forwards.

2.4 Communication

Keen to see a greater focus on services for men, and better information and signposting provided on discharge following prostate cancer treatment.

Consider the role of pharmacies in providing continence advice and products in communities.

2.5 **Other**

Sustainability – we should be working with the NHS Supply Chain on sustainability of continence products to get to our target of net zero by 2030.

Social isolation due to continence issues can be exacerbated by eg lack of public toilets, public transport etc – not just about health services.

3. Recommendation

The Scrutiny Committee is being asked to:

- Note the NHS response to the Committee's report on Continence Services
- Note the key points of the discussion held on the 8th March
- Request that the NHS returns to the appropriate Committee next Municipal year to give an update on progress.

Continence Services Scrutiny Working Group – Final Report

Report of the Healthier Communities and Adult Social Care Scrutiny Committee

March 2020

1 Introduction from the Chair

"Councillors come across a wide range of issues on the 'front - line', through casework, surgeries and campaigning. Several constituents have raised concerns with me about their experiences of living with incontinence. Most recently, I came across an elderly couple in crisis due to a combination of health issues. Once their health and social care needs had been assessed and addressed, they were still left with a problem of how to afford additional continence pads. This was a matter of concern because they were reliant on the state pension and they were distressed about it.

Other Councillors have had similar experiences. For us, living with incontinence is about promoting independence, social justice and dignity. This is why Scrutiny decided to look at the reasons why some service users do not feel that the service is meeting their needs. This report sets out our findings."

Cllr Cate McDonald, Chair, Healthier Communities and Adult Social Care Scrutiny Committee, Sheffield City Council.

2 Our approach

- 2.1 In October 2019, the Healthier Communities and Adult Social Care Scrutiny Committee established a working group to 'lift the lid' on Continence Services in Sheffield. The group set out to:
 - Consider how current continence services are commissioned and delivered, how people access services and how care pathways work.
 - Consider people's experience of incontinence and using continence services.
 - Consider how services promote independence, dignity and fairness; particularly the number and quality of continence pads provided.
 - Consider ways of improving prevention, and access to preventive services with particular reference to tackling health inequalities.

Our aim was to make recommendations that would improve outcomes for people using continence services, and put these recommendations to the NHS for a response.

- 2.2 We met with NHS Sheffield Clinical Commissioning Group, who commission continence services in Sheffield; and the Continence Advisory Service and Community Nursing Service from Sheffield Teaching Hospitals who deliver Continence Services, to understand how the service works.
- 2.3 We wanted to put people's stories at the heart of our work, to try and understand the experience that people using the service, and caring for people who use the service, have. This was a challenge continence is still not something people are comfortable talking about.
 - We set up an online questionnaire and invited people to contact us if they wanted to share their experiences. We had a very limited response, and so we approached organisations who work with people who use the service the Carers' Centre and Disability Sheffield advocates. They were able to give us an overview of the issues their clients have had with continence services, as well as specific case studies.
- 2.4 We spoke to a PhD student from Sheffield University who is researching continence, and also attended the Home Care Providers Forum, and the Care Home Managers Forum to gather views and experiences, and 'triangulate' the information we collected.
- 2.5 Links to the information we considered, and notes of our meetings are listed in appendix 1.

3 What We Learned

3.1 The Service

We wanted to start out by understanding how Continence Services work, so we invited NHS Sheffield CCG and the Continence Advisory Service in to explain how services work in Sheffield.

3.1.1 Continence Services in Sheffield are commissioned by NHS Sheffield Clinical Commissioning Group and are delivered by Sheffield Teaching Hospitals as part of the block contract for Community Services.

The aim of the service is to assess, treat and manage urinary and faecal incontinence in clinics across the city with specialist nurses and physiotherapists, and home visits for housebound users. The Community Nursing Service delivers continence assessments to housebound patients with other nursing needs. The stated focus of the service is on prevention: helping users to achieve continence, rather than on the supply of continence products. However at any given time there are around 8000 people using prescribed continence products in the city. Around 5500 are in their own homes, and 2500 in residential and nursing homes. Around 5500 of these are women - continence issues are more likely to affect women than men as having given birth is a significant factor in continence problems.

- 3.1.2 People are referred into the service by GPs and health professionals. They will have an assessment, treatment and, where ongoing management and continence products are required, reassessments are carried out on a 6 monthly or 12 monthly basis. Service users can also contact the Continence Advisory Service or Community Nurses to discuss continence issues at any point. The service operates within the National Institute of Health and Care Excellence guidelines.
- 3.1.3 The service delivers preventive 'new mum' classes monthly, targeting pelvic floor education at women who have recently given birth, as well as providing education and training for health and care professionals.
- 3.1.4 The budget for the service in 2019/20 was £533,334 for continence clinics, and £1,954,380 for continence products. To respond to the challenge of rising demand and rising product costs the service has:
 - Reduced the delivery cycle from 8 to 12 week for service users in their own homes, and from 4 to 8 weeks for residential and nursing homes.
 - Removed two of the light incontinence products for new patients
 - Limited the number of pull-up products to 2 per day for service users who fit the criteria
 - Reduced daily product allocation to 3 pads per day other than for those who meet the clinical exclusion criteria.
- 3.1.5 The service has done a lot of work with pad manufacturers and has told us that the pad technology is sufficient that is the prescribed number of pads should be enough to keep people dry and comfortable. The service explained that continence products

are allocated on the basis of 'clinical need'. In view of our focus on service user experience, we were keen to understand the way in which 'need' was defined. In this case, evidence about the effectiveness of continence products is the core component of clinical need, rather than lived experience.

3.2 Service User Feedback

We wanted to make sure that the experience of people using the service, and caring for people who use the service is at the heart of our work.

From the conversations we had, a range of issues emerged including:

- Mismatch between technical abilities of the product and lived experience some service users feel sitting in a wet pad compromises their dignity – regardless of technical properties of the pad
- Some service users go through more than 3 pads a day and families and carers are 'topping up' provision at their own expense as a result.
- Difficulties in managing 3 month supply especially where service users have multiple carers coming in daily, and complex conditions such as dementia. We were given an example of a service user suffering from dementia, who removed her pad every time she became aware of it – leading to significant top up costs for the family.
- Some service users feel that inflexible clinical criteria for some products reduces their choice, and doesn't help promote independence. We were given an example of a service user who can use pull ups independently, but is only permitted a limited number of these. As a solution, she has been offered ordinary pads, but she can't use these without help from a carer. It's important to the service user that she stays as independent as possible. She spends between £50 and £60 a month on extra products.
- Care Home and Home Care providers talked to us about difficulties around hospital discharge, with interim product provision not sufficient to cover the period between discharge and assessment.
- Difficulties in storing 3 months supply of products both in people's homes and residential settings.
- Disposal of continence waste remains a problem for some people.
- Positive feedback from Care Homes about the responsiveness of continence leads, and efficiency of the service in terms of timely delivery of products and responding to changes.

4 Our Findings and Recommendations

Our aim was to make recommendations on how we can improve outcomes for people using continence services in Sheffield. Whilst there is a lack of 'hard data' on this subject,

the qualitative evidence we gathered has led us towards four key themes— **Prevention**, **Inequality**, **Person-Centred approach** and **Communication**. The key finding for us, and one that we kept coming back to throughout the process is what we believe to be a fundamental tension between the service model – limits on continence products based on a technical understanding of product's absorbency – and service user experience. We have set out our recommendations below.

4.1 Prevention

- 4.1.1 'Promoting Prevention' lies at the heart of the Shaping Sheffield plan, signed up to by all health and social care partners in the city, recognising that prevention activity now will help to manage demand for services in the future.
- 4.1.2 The service was clear that its focus is on prevention, and that targeting pelvic floor education at teenagers and younger women, particularly new mums, is important in preventing continence issues post menopause, and in promoting the message that incontinence is not an inevitable part of getting older.
- 4.1.3 'New Mum' workshops are held in the city centre at Central Health Clinic, and advertised through flyers in discharge packs from Jessops, although take-up is variable across the city.

Recommendations

- 4.1.4 The Health Service should give consideration to taking continence prevention services out into communities, especially in areas where there is low take-up, and work with the Council and the VCF to develop approaches to delivering continence prevention services that are tailored to the needs of local communities.
- 4.1.5 The Health Service should ensure that consistent messages about continence prevention come from all parts of the health service that come into contact with new mums particularly health visitors and community midwives and that they are equipped to support and signpost people to the appropriate services.
- 4.1.6 The Health Service should consider how it could work to target pelvic floor education and raise continence awareness in schools by working with organisations such as Learn Sheffield, and Sheffield City Council.

4.2 Inequality

We recognise that health inequality is an important issue for the city - one that is not easily solved, but one that all organisations in Sheffield's health and care system are committed

to tackling - a focus on reducing health inequalities is a principle of the Shaping Sheffield plan.

The service told us that:

- prevalence of continence issues is higher in the north of the city, yet take up of continence services is lower than in other areas
- there are higher 'Did Not Attend' rates at the continence clinic amongst Black, Asian and Minority Ethnic communities
- there is lower take-up of the 'New Mum' classes in deprived communities.

We recognise that the reasons for this are complex and multi-faceted, but we believe that we need to understand and tackle this, and ensure that people across Sheffield are able to access continence services that are appropriate for them.

Recommendation

4.2.1 The Health Service should consider how it can address inequalities in accessing continence services for BAME and deprived communities, and look at how working with the Council and the VCF, as well as through the developing Primary Care Networks – who are experts in what works in their local areas - could help.

4.3 A Person Centred Approach

4.3.1 Through our scrutiny work, we consider many health and care services and issues, and something that we keep coming back to is the importance of a 'person centred' approach. A key priority of the CCG in its 2019/20 commissioning intentions was to commission health services that promote person centred approaches, and ensuring

- that the "what matters to you?" approach is embedded in care pathways. A 'holistic, person centred approach' is set out as a value in the Shaping Sheffield Plan.
- 4.3.2 We recognise that the assessments carried out by the service, and the resulting level of 'clinical need' and prescription of products, is based on the technical properties of those products. The service assures us that where 3 pads are prescribed, they should provide an appropriate level of containment for the service user. However, the stories we have heard suggest that, for some service users and care providers, the 'lived experience' of this is different. Some feel that their individual needs and preferences are not taken account of, and with strict criteria and limits on pads and products, the service model doesn't always feel personcentred.
- 4.3.3 The routine feedback the service receives through the Friends and Family Test is positive, and no formal complaints have been received about the provision of continence products. However, from the conversations we have had, it appears that there is a level of dissatisfaction amongst some service users. Understanding this better could be useful in informing service development. We have found our conversations with the Home Care Providers Forum and the Care Home Managers Forum to be very informative and valuable and no doubt there are other forums across the city that could provide useful intelligence and feedback for the service.

Recommendations

- 4.3.4 The Health Service should consider how it can resolve the tension between the medical service model which focusses on the clinical effectiveness of products, and the lived experience of service users, to ensure a person-centred approach.
- 4.3.5 The Health Service should consider how it could encourage better feedback from service users, and use existing forums to gather evidence and intelligence to inform service development.

4.4 Communication

4.4.1 The service highlighted that inappropriate pad usage can lead to service users going through products at a faster rate than their prescription allows. Training for carers and care providers on the use of continence products and barrier creams is available but not mandatory. Some of the care home managers we spoke to were

- not aware that this training was available, particularly in Learning Disability and Mental Health residential units.
- 4.4.2 Issues around hospital discharge were drawn to our attention by home care providers and care home managers. On discharge from hospital, service users are provided with continence products to last 7 days. At the time of writing, those service users were waiting an average of 2 weeks for a continence assessment, leaving a shortfall in products. Better communication between the hospital and the continence service could help to triage service users more effectively and ensure that the prescription of products on discharge is in line with likely waiting times for assessment.
- 4.4.3 There is still a lot of stigma attached to incontinence, and the service tells us that on average, people wait 5 years before seeking help. We recognise that awareness of incontinence is increasing for example through advertising of continence products. However whilst we need to break down stigma related to incontinence, we want to make sure that people do not view incontinence as an inevitable part of growing older, and encourage people to seek help when they need it.

Recommendations

- 4.4.4 The Health Service should consider how it can promote and incentivise take-up of continence product training amongst care providers.
- 4.4.5 The Health Service should consider how it could improve people's experience of waiting for a continence assessment after being discharged from a hospital stay.
- 4.4.6 The Health Service should consider what actions could be taken to tackle stigma, and raise awareness that incontinence is not an inevitable part of growing older.

5 Conclusion

We'd like to thank all of the people who have given their time and energy to help us carry

out this review – people who work for the NHS, voluntary sector organisations, care providers, service users and academic experts.

We have found it hugely interesting to get an insight into this issue that is rarely discussed, yet incredibly important. We hope that in doing this work, we will raise the profile of continence issues, get people talking about it, and start to break down some of the stigma surrounding it

We will formally put this report to the health service, and request a response to our recommendations within an appropriate timescale. We look forward to further discussions and seeing improved outcomes for the people of Sheffield.

Healthier Communities and Adult Social Care Scrutiny Committee

March 2020

Healthier Communities and Adult Social Care Scrutiny Committee Continence Services Working Group Evidence Gathering Sessions

Meeting 1 – 8th October 2019

Witnesses:

Sarah Burt, Deputy Director of Delivery, Care Outside of Hospital, NHS Sheffield CCG. Tracey Standerline, Head of Commissioning, Care Outside of Hospital, NHS Sheffield CCG Angela Stroughair, Continence Clinical Lead, Sheffield Teaching Hospitals Trust Paula Crosby, Head of Therapeutics and Palliative Care, Sheffield Teaching Hospitals Trust

Documents:

<u>Terms of Reference</u>
<u>Sheffield Continence Service Presentation</u>
<u>Meeting Notes</u>

Meeting 2 – 27th January 2020

Witnesses:

Rachel Morecroft, University of Sheffield

Documents:

Follow up information from Continence Service
Service User Feedback Summary Presentation
PhD research information
Meeting Notes

Meeting 3 - 2nd March 2020

Witnesses:

Tracey Standerline, Head of Commissioning, Care Outside of Hospital, NHS Sheffield CCG Angela Stroughair, Continence Clinical Lead, Sheffield Teaching Hospitals Trust Paula Crosby, Head of Therapeutics and Palliative Care, Sheffield Teaching Hospitals Trust Rachel Singh, Community Nursing Service, Sheffield Teaching Hospitals Trust

Documents:

Follow up information from January meeting
Feedback from Home Care Providers Forum and Care Home Managers Forum
Meeting Notes



Continence Services Scrutiny Working Group meeting

8 March 2022
Elaine Green Clinical Services Manager
City Wide services













The Continence Team

'Our ambition is to assess, manage and treat continence issues and develop a management plan'

- Male and female, 16 years upwards
 - Team Pelvic Health Physios & Registered Nurses, HCSW, Admin
- Paggel 20 Referrals come through Health Care Professionals (GPs)
 - Total Active Caseload for Continence Service is 7233
 - Clinical activity is in Clinics, Nursing homes, Patients homes, Schools, Day Centres









Criteria

Pelvic pain

Stress incontinence

Pelvic organ prolapse

Post-natal



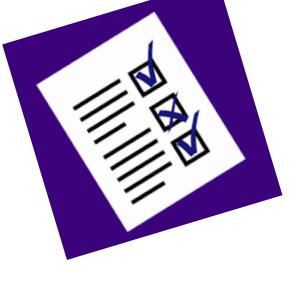
D Ava

Male stress incontinence/voiding dysfunction

Product reviews

Post void scans

Additional work during Pandemic – Supporting Urology with Trial Without Catheter (TWOC)













Our Approach during the Covid 19

Pandemic



PROUD TO MAKE A DIFFERENCE

- March 2020 Service stood down Community sites closed Staff redeployed to support Covid No face to face contact Staff and Patients shielding
- 2. Triage process implemented No access into nursing homes PPE, LFTs, Vaccinations
- 3. Sept 2020 NHS England advised to reinstate clinics
- 4. Dec 2020 Lockdown, Staff redeployed, Isolations, Staff and patient shielding
- April 2021 Clinical space available ARC Mapped service and commenced Service review
- 6. Dec 2021 New NICE guidelines and Pelvic floor report 2021

What We Learnt

- Flexible
- Adaptability
- Responsive
- Patient centred service provision
- Personalised approach
- Allowed service to review referral processes
- Telephone assessments for first assessment are well received by patients and are more effective/efficient
- Younger population more willing to attend face to face appointments
- Earlier engagement with patients promotes more efficient working
- Earlier implementation of treatment plans
- Improved DNA rates
- Quick to adapt and learn
- Resilient















Patient Story

23 year Male with LD/Autistic 56 year old female

- Presented in A&E with multisystem failure
- ITU malnutrition/neglect
- Reported to safeguarding/SYP/Social Care
- Crown Court evidence was given regarding Product usage/poor attendance. No fault with service
- Verdict Neglect, false imprisonment and sentenced Feb 2022
- Patient has recovered and is happy

- · Complex medical history
- Triaged
- Attended Face to face with Pelvic Health Physio
- Assessed
- Treatment plan devised

"I am very pleased with service provided, communication, accessibility and subsequent appointments made."













Patient Feedback

warm usefulinformation empathetic informative professional advised answeredmyquestions explainedeverything personalised knowledgeable beyondexpectations thank supportive













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How have we addressed the recommendations made in 2020?













Prevention



The Health Service should give consideration to taking continence prevention services out into communities, especially in areas where there is low take-up, and work with the Council and the VCF to develop approaches to delivering continence prevention services that are tailored to the needs of local communities

Identified the potential to develop a MDT clinic to include MSK, health visitors, dietetics with interpreters to provide education, support, advice



The Health Service should ensure that consistent messages about continence prevention come from all parts of the health service that come into contact with new mums – particularly health visitors and community midwives - and that they are equipped to support and signpost people to the appropriate services.

NHSE have developed a National project and STH is engaged and will be Fast-follower site for this National project. NHSE initiative supported by NHS long-term plan



The Health Service should consider how it could work to target pelvic floor education and raise continence awareness in schools by working with organisations such as Learn Sheffield, and Sheffield City Council.

Previously delivered pre-Covid. Schools now inviting us back













The Health Service should consider how it can address inequalities in accessing continence services for BAME and deprived communities, and look at how working with the Council and the VCF, as well as through the developing Primary Care Networks – who are experts in what works in their local areas - could help.

All these recommendations are relevant and as we move forward out of covid restrictions we can address

Plagger 28









A Person-Centred Approach



The Health Service should consider how it can resolve the tension between the medical service model which focusses on the clinical effectiveness of products, and the lived experience of service users, to ensure a person-centred approach.

Our aim is to always deliver a person-centred approach as we continue to focus on a timely assessment, treatment and future management plan



The Health Service should consider how it could encourage better feedback from service users, and use existing forums to gather evidence and intelligence to inform service development.

We have gathered STH Family and Friends feedback monthly – Ambition is now to commence engaging with stakeholders and patients/carers in 2022.

Service review being undertaken of the service to improve efficiency, effectiveness and plan for the future









Communication

The Health Service should consider how it can promote and incentivise take-up of continence product training amongst care providers

We have ongoing training available (online) for care homes and we are advocating this as care homes open up to services attending

The Health Service should consider how it could improve people's experience of waiting for a continence assessment after being discharged from a hospital stay

All patients on discharge receive a weeks supply of products

The Health Service should consider what actions could be taken to tackle stigma, and raise awareness that incontinence is not an inevitable part of growing older.

Education programmes and new NICE guidance to adhere to and raise the profile to reduce stigma and increase awareness









Our Next Steps

- Implementation of the NICE 2021 guidance
- Continue to develop collaborative relationships with Social Care and CCG
- Communicate future complaints to PALs and service lead
- Commence Stakeholder Engagement
- Work with CCG to develop refreshed service specification
- Identify potential to connections across Health and Social Care
- Page 325 Work with STH Estates to increase community venue space
 - Work with STH SPA to address a timely referral process
 - Promote education in schools (year 10 & 11) and care homes
 - Continue to raise safeguarding issues for patients with learning disabilities
 - Continue to link with Women's Health Team
 - Continue with triage process and review working processes
 - Review name of service to reduce stigma and increase awareness









Thank you for Listening















Any Questions













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