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 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, 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 person-centred.

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 need to break down this stigma, and help people to understand that incontinence is not an inevitable part of growing older.

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 raise awareness and tackle stigma around incontinence.

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:
Terms of Reference
Sheffield Continence Service Presentation
Meeting Notes

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

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