Wiltshire Council

Health Select Committee

6 May 2014

Report of the Continence Services Task Group

Background

- In January 2012 the Council and the NHS issued a new contract which brought together a number of services that had previously been fulfilled by a number of providers; this included the continence service. The contract was awarded to Medequip Assistive Technology Ltd (Medequip) and the specification included the introduction of the iDExpert range of continence products across the county (previously named Euron).
- In November 2012, the Wiltshire Carers' Action Group (WCAG) indicated its wish to bring a report to the Health Select Committee on continence services, following changes introduced under the new contract. The Committee agreed to receive a report at its meeting in January 2013.
- The WCAG report raised issues including the adequacy, range and number of continence products being offered under the contract and the failure of these to meet patients' needs, and also raised delivery and storage concerns.
- As a consequence of the issues being raised, the Committee agreed that it should conduct a rapid scrutiny exercise looking into continence services and this was duly carried out in February 2013.
- The rapid scrutiny exercise reported to the Committee in March 2013 and raised a number of issues of concern which it believed required further investigation. Consequently one of its recommendations was that the Committee establish a Task Group to look into the issues identified.
- There was a delay in the establishment of the Task Group due to Council elections and the need for the new Health Select Committee to agree its forward work programme, which included the Continence Services Task Group as a legacy item.

The Task Group

7 The Task Group had its first meeting in October 2013 with the following membership:

Cllr Jeff Osborn (Chairman)
Cllr Christine Crisp

Cllr Mary Champion
Mr Brian Warwick

- The Task Group agreed to adopt recommendations b) to f) below, made by the rapid scrutiny exercise, as its terms of reference with the addition to recommendation c) of looking at 'value for money'. It agreed that it would not look at the whole continence service, only those aspects that applied to the supply of continence products in the home setting.
 - b) The Task Group considers the assessment/re-assessment process, in particular the nature of it, the criteria involved and timescales around it.
 - c) The Task Group investigates the logistics of the service, with reference to Medequip and the options offered, in relation to the requirement for greater flexibility and client choice, and considers the monitoring of performance issues.
 - d) The Task Group looks at patient outcomes and requirements, including availability of appropriate continence products, frequency of supply, buffer stocks and flexibility.
 - e) The Task Group reviews Council's role, responsibilities and authority in continence care under its Health and Wellbeing remit.
 - f) The Task Group examines the terms and conditions of the Disability Living Allowance (DLA) and its applications.
- 9 The Task Group took evidence from:

Angela Billington, Lead for Continence Services (6 month contract), Clinical Commissioning Group (CCG);

Nicola Gregson, Head of Commissioning Care, Support and Accommodation; Chris Bull, Regional Area Manager, Medequip;

Tabitha Dawson, Customer Services (continence), Medequip;

Louise Rendle, Head of Network Services, Wiltshire and Swindon Users' Network (WSUN):

Sue Barnes, School Nurse, St Nicholas School, Chippenham (a school for children and young people, aged 3 - 19, with special needs, 40 - 50% of whom wear continence products);

Mr Tim Mason, carer and representative of the Carers' Support Group.

The Contract

The provision and delivery of continence products (CP) is undertaken by Medequip. This is one element of a larger contract which provides an integrated community equipment and support service (ICESS). It was

estimated that the continence element of the contract represents 20% of the contract costs. The contract began in January 2012 and was awarded for 5 years with the possibility of an extension of a further 2 years.

- The contract is jointly commissioned by the Council and the Clinical Commissioning Group (CCG). The CCG developed the service specification for the continence service, with the Council hosting the budget provided by the CCG. As the Council does not pay VAT, unlike the CCG, it allows maximum use of the budget. Joint commissioning also allows a more strategic approach to be adopted. It was suggested that the delivery costs for the continence service were high compared to other local authorities, but was acceptable across the whole contract.
- Medequip meet with the Council and CCG regularly and meet with the contract monitoring group every 6 weeks. The contract is built on volumes, whereby payment increases with the number using the service.
- The CCG appointed a lead for the continence service redesign (for 6 months) and also appointed a paediatric continence nurse in September 2013.
- 14 It is estimated that 3000 4000 patients in Wiltshire have continence products delivered.

The Service

Delivery

The delivery cycle of continence products to client's homes is 8 weeks. The delivery can be extended but not brought forward. After the initial delivery, the client is required to contact Medequip to re-order by either email or free phone. Clients can arrange for deliveries to be left if they are not likely to at home to receive them.

<u>Assessment/re-assessment</u>

- A copy of the assessment process is contained in Appendix 1. People can self-refer or may be referred by their GP. If a client encounters problems with the products they are using, this should trigger a reassessment which, it was suggested, should be carried out within 2 weeks, or sooner if it is an emergency. A district nurse is not authorised to change the products provided and would need to refer to a specialist nurse if a change is required.
- 17 Currently health and social care plans are separate. A social care plan can trigger a referral to the continence service, which would then undertake an

- investigation to see if there are any underlying causes for the continence that may need to be treated. Continence products may or may not be provided.
- The national target for 'referral to treatment' from an assessment service, which may result in an onward referral to a consultant-led service, is 18 weeks. It is for the NHS locally to decide how the waiting time rules are applied to individual patients, pathways and specialities, based on clinical judgements. The local target in Wiltshire is for 95% of cases to be treated within 18 weeks.
- In Wiltshire in 2013-14 there were 231 referrals to the continence service for children. The average waiting time was 14.8 days; 100% were seen in less than 18 weeks. In the same year, 2018 adults were referred. The average waiting time was 35 days; 99.9% were seen in less than 18 weeks. Figures for reassessments were not available at the time of production of this report.
- A copy of the eligibility criteria for the supply of continence pads is contained in Appendix 2.

Products

A range of products is provided from the iDExpert range (previously named Euron). Some clients have up to 3 types of product to address their needs. Clients are allowed a maximum of 4 products per 24 hours. The eligibility criteria state that 'exceptions will arise in certain clinical situations such as terminal illness, or where the individual's output exceeds the functional capacity of 4 pads. The Continence Nurse Specialist may approve exceptions determined by specialist clinical knowledge'. Pull-up pants (pull-ups) are not provided under the service. Clients can purchase additional and/or alternative products from Medequip. Medequip report that sales of continence products are rising month on month (including people not covered by the service).

Evidence from carers and service users

Deliverv

- There were significant problems with delivery when the new contract was introduced, with some people not being aware that the service had changed. Medequip reported that most problems were resolved within the first two cycles of deliveries (16 weeks) and currently there were few complaints about deliveries. This was confirmed by carers/users.
- However, some issues remain. A report was received of deliveries being left outside the home of a wheelchair user. This person was physically not able to

bring these into the house and had to ask a neighbour to assist, causing embarrassment. In addition, some delivery drivers were reported to have made inappropriate/insensitive comments.

Products

- The majority of the issues raised by carers/users related to the products provided under the contract introduced in January 2012, in particular the number supplied and their style, quality and size.
- 25 It was stated that 4 products per 24 hours were insufficient for many people. An example was given of a child with a condition that results in him having constant diarrhoea who was not granted additional products.
- The quality of the products offered in terms of absorbency was also an issue which impacted on people in several serious ways. The absorbency was so poor that some people were reluctant to go out. Other people reduced their fluid intake to try to cope. Many people, although they had been assessed as being entitled to receive products, chose to buy their own, more absorbent products, which in some cases resulted in significant financial hardship.
- The absorbency of one 'nappy-style' product provided was designed to hold 1600 mls of fluid. The weight of 1600 mls of water is 3.5lbs; it was suggested that the weight of this would be very unpleasant for the wearer.
- In addition to absorbency, it was reported that the odour control of the products provided was poor, resulting in embarrassment for the wearer.
- The quality of the products was such that St Nicholas School implemented toileting clinics, which aim to 'time train' some pupils, to manage the products. The support of the paediatric continence nurse in this, and other work, was praised by the school.
- Sizes of the products offered were a particular issue at the school. The children's sizes were too small and the adults' sizes too large for some of the young people. Also the products were not elasticated around the leg and as a result were prone to leaking. There had been issues with incorrect sizes being provided as the service had used out-of-date records of measurements for the children.
- A significant issue was the style of product offered; only pads and nappy-style products were provided, pull-ups were not provided. The care workers at many day centres are not required to offer support with personal care, which includes help with continence products. Therefore such day centres will only

- accept elderly people who wear pull-ups. People have to buy their own pull-ups if they wish to attend.
- An example was given of a family with 2 young people with Down's Syndrome who had previously been provided with pull-ups. When the contract changed the young people had to use a nappy-style product, the result of which was that they had regressed in their toileting behaviour and were no longer independent.
- Pull-ups were considered especially desirable for people with dementia, some of whom had difficulty identifying the nappy-style product as underwear. In addition those with arthritis had great difficulty peeling the protective layer off the sticky tabs that secured the product (2 on each side).

Storage

- An 8 week supply of products can be extremely bulky and require a large space for storage. This is a particular problem for many elderly people and especially those in sheltered accommodation. Many people have to distribute the products around their homes including in the living room, causing embarrassment and loss of dignity. There are also health and safety issues as the boxes are large with sharp corners. People can easily trip or knock their legs, possibly resulting in ulcers.
- Medequip indicated that they could look at the possibility of people collecting products from various locations if requested to do so by the commissioners.

Additional issues

- It was reported that there was a real lack of awareness of the continence service and a lack of literature on the service. People were not aware that they could self refer. Many people were not aware of the help available and delayed asking for help. This could mean that opportunities for using conservative measures for treatment were missed. The approach of some GPs to patients with continence problems was that patients would 'just have to live with it'.
- One witness who attended the Task Group undertook inspection with the Care Quality Commission (CQC) as an 'expert by experience'. The witness commented that 'with the products and numbers available, domiciliary carers had to function at a lower standard than the CQC would allow in a care home'.
- The eligibility criteria state that 'Children's product request forms have to be submitted by the Health Visitor or School Nursing Team. Subsequent

changes to requirements will be following updates from the child's parent/carer, who should contact the Salisbury Team'. The school nurse explained that some parents she worked with had needs of their own, including literacy issues, but she had been discouraged from helping such parents as the service maintains that it is the role of the parent to request changes.

The most common response to people when trying to obtain alternative products was that 'they are too expensive'.

Task Group findings/views

- The Task Group was focussed on the provision of continence products in the home setting. It did not interview staff from care providers who provide domiciliary care and acknowledges that this would have been another source of information.
- There was concern about the way the contract had been implemented.

 Although some staff had attended carers focus meetings to discuss the pending changes, many people were not aware of the changes and the new product range supplied did not meet the full range of needs of those requiring products.
- The Task Group had included in its remit, looking at 'value for money' in the contract, but was not able to do so. The software in use does not allow accurate figures to be provided and the breakdown between costs for delivery and products cannot be provided. The service itself is unsure of the numbers of people receiving continence products. This issue needs to be resolved if the service is to be able to make informed decisions and to monitor the performance of the contract for continuous improvement as required by the contract.
- People are assessed each year if no problems arise during the year. It was felt that a year between assessments could be too long for some people, such as those with learning difficulties. The waiting times for assessment were provided and they fall within the national guidelines, but the Task Group would be interested to know what the waiting times are for reassessment.
- Storage of 8 weeks' supply of products was clearly very difficult for some people, both physically and emotionally. Although the contract allows for deliveries on a 4 12 weekly cyclical basis, it is acknowledged that more frequent deliveries may be prohibitively expensive, but the option of collecting supplies could be investigated with the provider. This could be through the use of the existing network of peripheral stores currently in use for urgent provision or through the designated retail outlets referred to in the contract.

There should also be discussions with the housing associations and housing providers to establish what they can do to help resolve the problem.

- The maximum number of products available was insufficient for some people. Although the eligibility criteria state exceptions can be approved 'determined by specialist clinical knowledge', the Task Group found no example of when this had happened.
- The size range on offer for children and young people does not accommodate them all. A wider range of sizes needs to be sourced to ensure that the products fit correctly and ideally with elasticated legs to aid a good fit. Where necessary children should be measured to ensure they receive the correct size of product.
- The quality of product in terms of odour control and absorbency was insufficient for some people. The Task Group was concerned that some people reduced their fluid intake; this is contrary to the advice given to maintain good bladder health and could lead to infections and greater costs to the system. They also felt that if people were reluctant to go out because of the poor absorbency of the products, this would increase their social isolation, with its attendant problems.
- The Task Group was particularly concerned that the eligibility criteria stated 'pull-up pants would not be supplied', having heard about the impact of that decision on both adults and children. Although the draft Service Review for Continence Services indicates that pull-ups can be approved, again, the Task Group found no cases of this. The ability of children and young people to be able to use pull-ups represented a significant stage in their progress towards independence. Elderly people denied pull-ups risked not being able to attend day centres, and dementia sufferers in particular need a product they can cope with without support.
- Incontinence is a problem that affects a large number of people but it remains a taboo subject, causing great embarrassment to those afflicted, and the loss of dignity often suffered by people with incontinence should not be underestimated. There is a role for public health to raise the profile of incontinence to help break down this stigma. It is suggested that it could investigate linking to the national publicity campaign that sites posters in motorway services, highlighting potential bladder problems.
- The continence service itself also needs to increase awareness of the service and what it can provide. Some people do not wish to contact a third party so this information also needs to be made available in such a form that an individual can access it without the need to visit a clinician. Earlier

engagement with the service may mean that people can be helped through various therapies and treatments, so avoiding the need for expensive continence products.

- The Task Group was impressed by the support and commitment provided by carers, many of whom were family members, and were concerned to hear how long it took some families to obtain what they needed for their relative. Carers described how they were 'worn down' by the system and how many of them gave up trying and resorted to buying the products required. Some people were using their DLA to buy products, a benefit which is intended to provide care.
- The Task Group acknowledge that there were a number of problems when the contract was introduced and that some of those issues have now been resolved satisfactorily, but it is clear that there are significant problems for some people that have still not been addressed. Account should be taken of the distressing psychological and social effects of incontinence as well as the physical aspects. In addition, the physical and emotional impact this condition can have on carers needs to be recognised.
- The Task Group believes that the aspects of the continence service it has considered do not accord with the vision the Council is trying to achieve through the Health and Wellbeing Strategy and the Better Care Plan. It believes that a much more holistic approach needs to be adopted and that treatment should take account of individual needs and preferences (as required by the NHS Constitution for England).
- The Council is committed to ensuring that people can live independently for longer. Incontinence is second only to dementia as the main reason for entering a care home. For carers, incontinence can be the 'last straw' and is often the main reason for the breakdown of the caring relationship, leading to admission to residential care. Providing the most suitable continence products, including pull-ups, must be a priority in maintaining people in their own homes.
- As the elderly population grows in Wiltshire, so will the number of people requiring the continence service. The draft Review for Continence Services suggests that the total population who are likely to have urinary continence problems could be between 92,974 and 149,651. The budget for the home delivery service of products is currently significantly overspent. When carers' requests for alternative products are declined, expense is the reason usually given.

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¹ Good Practice in Incontinence Services, Department of Health, 2000

- The Task Group is mindful of the difficult economic climate and acknowledges that some products may appear to be expensive, but believes very strongly that the provision of poor quality products is a false economy. It believes also that, in considering the cost of the continence service, account needs to be taken of the potential wider costs to the Council and the NHS of not investing in it adequately.
- Lack of investment could result in more infections and the likelihood of people being admitted or re-admitted to hospital, increased numbers of people entering care/nursing homes, social isolation impacting further on physical and mental health and, importantly, loss of dignity for the people affected.
- By investing in the service and required products satisfactory outcomes for people will be achieved, complications such as infections are likely to be reduced, carers will be supported and the likelihood of those people needing to enter a care home early reduced. Using a product they can depend on with allow those people currently reluctant to go out, to do so, thereby increasing their activity, social interaction and engagement and quality of life.

Conclusion

- The Task Group considers that the number of products, quality and range currently provided under the contract do not meet the needs of everyone using the continence service. The contract allows alternative products to be sourced if those provided fall below acceptable performance levels.
- Awareness of continence as an issue and the continence service itself need to be promoted to the general public.
- The service needs to ensure that it has the necessary data, currently unavailable, to be able to make informed decisions.
- To support the aim of the Council of people living independently for longer, the continence service needs to take a more holistic view when assessing people for products to support people, and their carers, in the home. It needs to invest at this early stage in suitable products to reduce the number of people potentially going into care homes earlier than they might otherwise. In doing so, it needs to consider the wider costs to the Council and the NHS in not investing adequately in the continence service.

Recommendations

The Task Group makes the following recommendations:

- a) That the joint commissioners re-evaluate the home delivery service of incontinence products currently being offered, taking into consideration the issues raised above;
- b) That the Task Group meets with the Wiltshire Clinical Commissioning Group to discuss their findings;
- c) That the home delivery service of incontinence products is reviewed after 6 months to assess progress made.

Next steps

- To seek endorsement from the Health Select Committee of the report and its recommendations.
- To forward the report to the Cabinet member for Public Health, Protection Services, Adult Care and Housing and the Wiltshire Clinical Commissioning Group for written response.

Cllr Jeff Osborn, Chairman, Continence Services Task Group

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Appendices

- 1 Continence assessment and reassessment process
- 2 Eligibility criteria for supply of continence pads (NHS)

Background documents

- Wiltshire Council and Medeguip Assistive Technology Ltd Service Agreement
- Service User Consultation Report Continence Service, 23 May 2012 (Wiltshire Parent Carer Council)
- Draft Service Review for Continence Services 2013 2014 (CCG)