Improving continence services in Wales

A call to action
To the Welsh Government and Local Health Boards
From charities in Wales on behalf of their members, families and carers

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Introduction

There is a recognition and acknowledgement that there is some good practice within the continence services in Wales; good practice that should be held up as exemplars and models to be followed elsewhere as so many aspects of life are impacted upon if continence is not managed correctly.

However, evidence suggests that continence services in Wales are often inadequate, under-staffed and difficult to access.

This paper has therefore been prepared by charities in Wales¹,

- To highlight the consequences of poor continence service provision on older people and/or disabled people (of all ages), who live with continence issues
- To identify some of the contributing factors to the current state of continence services in Wales
- To propose recommendations for action to develop improved continence services for the benefit of the citizens in Wales who need access to, and support from, these services.

Our ‘call to action’ to the Welsh Assembly Government and Chief Executives of the Local Health Boards is outlined on page 9 of this paper.

Who are the people we are representing?
This information provided has been gathered through consultation and direct day-to-day contact with the following groups of people:

- People who were born with a neurological condition (e.g spina bifida) which physically affects bowel and bladder function;
- People who were born with a condition such as Down’s Syndrome, which will affect self-help and self-care skills and will may need support to learn to manage continence;
- People who develop a neurological condition (e.g multiple sclerosis) or serious health issues (e.g diabetes) which, by their very natures, will lead to continence issues;
- Older people;
- Parents and carers

¹ See appendix 1 for a full list of charities
What is the impact of living with continence issues?

Living with continence issues, whether bladder, bowel or both can be degrading, embarrassing and affect quality of life for an individual and his/her family. Continence issues and poor continence management impact negatively on many areas of an individual’s daily life, creating obstacles and barriers that contribute to the challenges of living with disability, illness or growing older.

Issues include:

**Health**
- On-going urinary infections and longer-term problems, such as kidney and renal tract damage
- Increased susceptibility to pressure sores, infections
- Severe constipation and low fluid intake
- Confusion over continuity of care at key transition stages
- Increased continence issues due to lack of care in hospital and community settings
- Limited or no access to specialist nurses
- Lack of awareness of the potential impact of continence mis-management on health and well-being
- Depression and anxiety

**Education**
- Children are often expected to be fully independent in terms of toileting needs when starting school – some simply are not.
- Lack of awareness, understanding and skill amongst school staff to deal with continence issues exacerbated through disability
- Lack of practical support for children – sometimes requiring specialist skills to assist with, or directly catheterise, a child
- Delays in beginning education, moving schools or starting college
- Embarrassment, isolation and non-inclusion
- Disruption to a child’s class timetable and his/her attendance at school

**Transition (from one school to another, school to college and the workplace)**
- Confusion over continuity of care, often leading to drop out from vital health and care services
- Reluctance to attend school, college or the workplace
- Frustration and social isolation

**Employment**
- Very little flexibility and understanding from many employers
- Fewer employment opportunities, or choice of opportunity
- Lack of facilities
- Increased sickness and time out of work place
- Inability to keep long-term employment
Dignity, respect and quality of life

- Social isolation and few friendships
- No personal relationship
- Lack of confidence
- Lack of independence and constant reliability on others
- Embarrassment and unease
- Living with, and managing continence issues, can affect an individual’s outlook on life, reducing enjoyment of, and access to, home, family and community life

Finances

- Increased financial burden due to the need to:
  - purchase better quality and/or greater quantities of continence products,
  - replace furniture, mattress and bedding on a more regular basis
- Greater expenses for laundry – energy bills, wear and tear on washing machines, replacement of specialist or ordinary clothing (including trousers, nightwear, underwear, shoes and socks!)
- Less likely to be in paid employment and living on welfare benefits.
- Cost of employing carers to assist with continence management
Continence services in the community – our concerns

This section outlines a number of issues that have been highlighted as areas for concern within continence services across Wales by service users and their families/carers. Interestingly, the same concerns are reflected in the specific findings and recommendations of the National Audit of Continence Care 2010.²

1. Lack of information and access to continence specialists

Whilst we acknowledge there is a willing network of continence advisers in Wales, concerns have been raised about the lack of a consistent approach to the delivery of these services, including:

- Not enough specialist advisers or nurses to deliver appropriate services or support others to do so.
- Service users experience services that are not transparent and easy to access, despite most community services having open access and self-referral opportunities.
- Inconsistencies in referral processes, leading to long waits to see a specialist. Individuals cannot always self-refer, despite many being the ‘expert’ in his/her condition and recognising the signs and the urgency for something to be addressed. They have to go through ‘other channels’ and this process can lead to long delays in treatment and an exacerbation of the continence issues.
- Difficulties in identifying who the specialist continence teams or individual staff are, and how to contact them.

In addition, it is apparent that many GPs lack knowledge of what tests, investigations and expertise is available in this field, and referrals are not always made to the experts when required.

However, there is also evidence that even when a referral is made, a consultant urologist (who may have a specific specialism) will not always have sufficient knowledge of other conditions and links to continence. This is a concern as a consultant’s lack of knowledge in relation to a particular condition can lead to incorrect advice and information being provided, and to the non-provision of the correct treatment/management required.

**Quote:** ‘The consultant told me that my continence issues were not related to my spina bifida. He said people with spina bifida who can walk do not have continence issues. He said my issues were caused by my diabetes … that’s why I don’t bother with appointments as no one understands my condition’.  Shine Cymru member, West Wales

Older people seem to accept that some degree of continence issues are inevitable as they age. They do not always seek advice and support, often due to the stigma and embarrassment that living with continence issues causes.

² National Audit of Continence Care. Royal College of Physicians. Sept 2010
There is a need for public health and social care services to raise greater awareness of continence issues and the availability of solutions to ease the symptoms.

2. Lack of awareness amongst other health and social care staff in Wales

There are varying degrees of continence, caused by a variety of different conditions, as highlighted in ‘the people we represent’ above. Some people will require more specialist advice, information and support than others.

However, there is also evidence that community-based staff who undertake continence assessments have little knowledge and training to deal with issues relating to continence.

Checklists are followed, ticked and the problem ‘solved’ by allocating continence supplies, without further investigation into, or preventative treatment of, the underlying causes of the continence issues.

There is acknowledgement amongst continence teams of the existence of the All Wales Bowel and Bladder pathway. However, through discussions with these teams, it is apparent that it is a tool that is not always used as it is out of date and staff need training to use it correctly. There seems to be no obligation to follow the pathway, with teams developing their own approaches and systems, which lead to an inconsistency of services for people in Wales.

Some people with on-going continence issues (e.g. a person with spina bifida) should have regular scans to identify issues and ensure preventative approaches to dealing with any issues. This does not happen as a matter of routine at present, yet such interventions could save the NHS large amounts of money in the long-term, by reducing health complications, curtailing long stays in hospital and contributing to greater well-being.

3. Lack of access to support at home

Individuals and families may struggle to identify the best strategies to teach independent toileting strategies to their child with Down’s syndrome, for example. They may not be aware that this skill is based on certain physical, psychological and developmental issues including a child’s understanding of their body, the environment around them, and their language and communication skills. Some of these families will need the support of specially trained continence advisors.

Similarly, adults with congenital or acquired disabilities or the elderly may need help with practical suggestions and solutions to managing their continence issues within the home and within the family. Individuals and families tell us there is a lack of support in the community to provide the services they need.

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3 All Wales Bowel and Bladder Care Pathway. July 2006
4. **Continuity and integration of continence service**

Individuals and their families are often left feeling unsupported through the transition phase from children to adult services because:

- They are confused about where the services are and how to access them, particularly if they have ‘fallen out’ of the system at transition or at some other stage in their lives.

- There is little evidence of the links between community-based continence services and hospital-based services.

- Most services operate a ‘problem-based’ service and do not retain cases as ‘active’ after the referring problem has been dealt with. For some continence issues, this is appropriate. However for others with conditions such as spina bifida or multiple sclerosis, continence issues can lead to kidney and renal tract damage (or worse, failure). People should have access to regular examination and scans to identify potential problems and protect renal function.

- There is a lack of follow up or continuation of treatment.

In some cases where other treatments have not worked satisfactorily, botox treatment for the bladder is sometimes offered. Individuals have reported that, whilst it has worked well for them, they have been unable to access follow-up treatment for a considerable amount of time. They have found themselves ‘returning to square one’, encountering increased complications and having to take long-term sickness leave from work.

5. **Supplies of continence products**

As mentioned previously, there is little faith in the assessment process amongst individuals, their families and the charities, as often the assessors (community nurses, health visitors etc…) appear to have little specialist knowledge or training, and simply follow a checklist to diagnose the issues and find solutions.

Unless assessments are carried out by trained staff, the current approach can lead to underlying issues being missed and not properly managed, which in the long term leads to greater health and social issues, as outlined previously.

Continence supplies are a particular area of concern, for both adults and children. In some areas, provision of continence products is subject to strict allocation rules, and can be limited to a single source of supply and/or the absolute minimum supplies provided, regardless of an individual’s needs (e.g. 4 pads a day, regardless of the individual’s needs and circumstances).
Put simply, the rationing of pads can lead to health issues such as infections and sores from not changing often enough, can lead to embarrassment and social isolation at school and in the workplace, and can lead to an individual losing their job, all of which have financial implications both on an individual, his/her family, the NHS and the State in general.

Individuals and families, who have to supplement their supplies with ones purchased from elsewhere, often do so at much greater expense than those supplied by the NHS.

Ironically, some individuals report an over-supply of continence products in one delivery or packs that consist of specific quantities of products unsuited to their needs e.g. too many night-time pads, but insufficient daytime pads etc. . . . This then leads to storage issues but more importantly, to wastage when un-opened products that have been issued are no longer required and cannot be returned to the supplier.

6. **Patient choice**

Some patients may opt to manage continence through use of continence pads, and do not want to consider any other method of continence management – this choice is sometimes due to awful experiences in childhood or early adult life. However, individuals tell us that they are often frowned upon, should they make this choice. Patients who choose this method of continence management should be treated in the same way as others and should be allocated sufficient products to enable them to lead a dignified and independent life. The standard allocation does not meet their needs.

7. **Public toilets**

The number of public toilets in Wales has steeply declined in recent years. Where they do exist, many are inadequate, inaccessible and in a poor state of repair to meet the needs of the general public. These inadequacies are confounded many times over for those who are disabled and who have continence issues. People are less likely to venture from home, for fear of exacerbating their continence issues and/or losing their pride and dignity because their facilities they need are not available.

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4 Age Cymru - evidence to Health and Social Care Committee’s Inquiry into public toilet provision in Wales. December 2011.
Continence care in hospitals – our concerns

‘It hardly needs stating that (in)continence requires conscientious attention and nursing care’ The Francis Report

Yet, individuals and families report degrading and unacceptable approaches to managing continence in some hospitals.

Generalist hospital staff do not appear to have enough awareness of continence issues and the varying approaches to managing continence for different conditions (e.g. the approach to managing urinary continence in an elderly patient is different to that of managing faecal continence in a young adult).

In the case of older people in Wales, these issues were widely reported in the Older People’s Commissioner for Wales review report ‘Dignified Care?’ The experiences of older people in hospital in Wales, 2011, which reported:

‘Privacy and independence in personal care are essential in helping people to maintain dignity. We are aware of many examples of inappropriate treatment, most of which centre around inadequate support to maintain independence and a lack of facilities and staff awareness to provide a satisfactory level of privacy.

The use of block treatments or going to the toilet by the clock rather than time of need is also unacceptable. Some older people have told us that whilst in hospital they have been told to wet the bed because of staff shortages. Unfortunately ‘forced continence’ is frequently reported with patients being made to use a commode or continence pads rather than receiving assistance to use the bathroom. Several older people complained that being asked to use bedpans or commodes in wards where bays are only separated by curtains is inappropriate and embarrassing.

This may have other dangerous impacts, such as where some older people have told us that they have limited their fluid intake whilst in hospital to avoid the potential for ‘accidents’. We have heard of patients being told off for having an ‘accident’ when they are incontinent, staff taking so long to bring bed pans that it is too late by the time they arrive, and forced catheterisation of patients when it is not required. One lady contacted us recently after visiting her older relative on a hospital ward; she shocked to discover that her fully continent relative had been catheterised, as had all the other older ladies on the ward, and suspected it was standard practice in many cases. Her relative suffered from infections after the catheter was removed and was no longer continent after she returned home’.

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5 Independent Inquiry into Care provided by Mid Staffordshire NHS Foundation Trust. Chapter 1-The patient experience. 2010
Call to Action

Despite the existence of an all-Wales Continence Care Pathway, this report has highlighted the issues and inconsistencies in the provision of continence services, and how the inadequacies of the services impact on the everyday lives of the estimated 150,000 people living with continence issues across Wales. This suggests that the Continence Care Pathway is not ‘fit for purpose’ and a review of policy and practice is required.

We request that the Welsh Government and Chief Executives of Local Health Boards establish a working group in 2013/14 to consider the issues highlighted in this report, and other referenced reports, to develop a programme for reform and improvement.

The group should consist of:

- Senior representatives from The Welsh Government
- A member of the Health and Social Care Committee
- Senior representatives from Welsh Health Specialised Services Committee (WHSSC), Local Health Boards and Local Authorities
- Members of the All Wales Continence Forum
- Regional practionners
- Patient representative organisations
- Service User representatives
- Other continence service providers (e.g. continence product suppliers).

We request that the group will consider and ensure implementation of ways in which to:

1. Place a greater focus on preventative measures to managing continence, and work with individuals to encourage their involvement in their own continence care;
2. Deliver well-resourced and easy-to-access continence services, with adequate staffing levels to meet demand;
3. Highlight the need not to ‘suffer in silence’ and encourage people to address their continence issues
4. Inform individuals and their families of the services and how to access them
5. Provide more specialist continence adviser/nurse posts to meet need across Wales
6. Ensure that specialist paediatric and adult continence teams (urologists, continence nurses and advisers etc.) are available to address continence issues for individuals within timescales that do not lead to exacerbation of continence-related issues

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6 All Wales Continence Forum. September 2011
7 Independent Inquiry into Care provided by Mid Staffordshire NHS Foundation Trust. 2010
National Audit of Continence Care. Royal College of Physicians. Sept 2010
7. Ensure generalist health and social care staff in the community and in hospitals are trained in continence assessment and care
8. Provide continuous professional development for generalist and specialist staff
9. Offer a smooth transfer at times of transition (from childhood to adulthood; from hospital to the community etc…)
10. Support schools, colleges and employers in understanding continence issues and helping them to address the barriers that so often inhibit individuals from progressing in life
11. Allow for patient choice and tailored approaches to addressing individual continence needs
12. Offer improvements in the choice and supply of continence products
13. Address the need for an improved access to clean and hygienic public toilet facilities for both disabled and non-disabled
14. Review and improve the All Wales Bowel and Bladder Care Pathway
15. Hold Local Health Boards to account for the delivery and improvement of these services through the establishment of minimum standards and key performance measures.
Appendix 1

Charities who have signed up to this ‘call to action’ are:

- Spina bifida • Hydrocephalus • Information • Networking • Equality – SHINE Cymru
- Downs Syndrome Association Wales
- Age Cymru
- MS Society Cymru