

Opening the Floodgates

Improving Continence Care for Learning Disabled People

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“ The severely mentally handicapped (formally idiots) are wholly dependant. They cannot be taught to keep themselves clean.....in practice they are less intelligent than domestic animals.”

(Stafford Clarke and Smith, 1978)



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Overview of Presentation

- Local context
- Literature search
- Two studies
- Implications for practice
- Implications for research / evaluation of practice
- Learning Disability Nurses role
- Training for Care Deliverers



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What does the literature say?

- Prevalence of incontinence increases the more profound the learning disability, however:
- There is little research in the area of continence and people with severe learning disabilities (Smith & Smith, 2000)
- Learning disabled people are often excluded from research and audit on the grounds that they have specific needs (Pyne & Stott, 1996)



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Literature Search - approaches to incontinence

- Symptoms led, either urinary or faecal incontinence - Assessment - Investigation - Treatment (e.g. Norton, 1996; Norton, 1997)
- Rehabilitation - Holistic Assessment - Investigation - Treatment - Continence Management Plan (e.g. Weeks et al, 2000)
- Learning Disability - Behavioural Training (e.g. Smith & Smith, 1998)



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Literature (3)

- More research needs to be done regarding the side effects of psychoactive medication given for epilepsy, mental health and to control behaviour, on bladder and bowel (de Silva et al, 1992)
- Symptoms of constipation and urinary infections can be fatal if not addressed (Jancar & Speller, 1994)



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Policy:

- *Good practice in Continence Services* (DoH,2000) states that urinalysis should be carried out as part of an initial assessment.
- *Valuing People* identifies continence as one of the 9 key health issues affecting learning disabled people
- *Essence of Care* (DoH, 2003)



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Study 1 – Continence Assessments

Aim:

- To explore the assessment process for learning disabled adults who receive continence products



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Method:

- Postal questionnaire Survey. Community nurses were asked to complete a questionnaire for each learning disabled person for whom products were re-ordered over a five month period.



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Key Findings:

- 79% of the sample appear to have never been assessed
- Urinalysis was rarely included when assessments occurred



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Implications for practice

- Establish a basic level of bladder and bowel care for all those receiving products
- Thorough continence assessments needed i.e. screening for urinary infections and constipation. This could form part of Health Action Plans
- A diagnosis of learning disability should not be used as a cause of incontinence
- Importance of partnership working between community nurses, Continence Advisors and Learning Disability Teams
- Importance of ongoing education, training and awareness-raising



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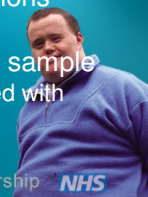
Study 2 – Urinalysis

Aims:

- To describe the prevalence of urinary tract infections and other conditions detectable through urinalysis
- To evaluate the utility of a urine sample collection product (previously used with children in a hospital setting)



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Methods:

- Learning disabled adults who receive continence products were invited to take part in the study and provided with Newcastle Ontex urine collection packs. Practice Nurses tested samples with a reagent strip, prior to samples being sent to microbiology labs. Participants (or carers) completed a questionnaire about using the pack, urinalysis results and follow-up treatment.



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Results

- 46 people offered additional support
- 33 people took part (72% response rate)
- 66% lived in supported housing, 33% lived with family
- 9 people had a UTI (27%)
- 1 person also had blood in urine
- All individuals with UTI followed up by research nurse



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Feedback on Urine Collection Pack.

- 13 people used the Ontex pad (40%) 10 female and 3 male. Other people used bowls or jugs
- 5 people who used the Ontex pad had a UTI (38%)
- 10 people who used the Ontex pad said they could not have obtained a sample with another method
- No problems reported re product other than need for sterile environment



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Conclusions.

- UTI detected in 27% of screened population, demonstrates importance of screening
- The Ontex pad provides a useful method of collecting a urine sample
- Replication of study in larger population would be beneficial
- People who are learning disabled and their carers require much greater support and awareness raising in terms of participating in research



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Implications for practice

Initial findings suggest:

- The pack will provide a means of collecting urine samples from learning disabled adults
- It is possible that people have undiagnosed UTI's



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Implications for research

- Lack of an evidence base
 - to guide practice
 - potential to develop an evidence-base
- Grey area between 'research' and 'evaluating practice'
- Consent



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Barriers for people with learning disabilities:

- Consent
- Expectations of parents and carer's
- Communication
- More likely to have continence issues
- Lack of knowledge
- Reliance on carers
- Lack of opportunities to learn skills
- Physical barriers



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Role of the Learning Disability Nurse in relation to continence:

- Provide training to care deliverers
- Health Promotion
- Assessment
- Monitoring
- Therapeutic input
- Multi- disciplinary working
- Research and service development.



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Training for Care Deliverers 'Continence Promotion':

Aim:

For the course participants to develop their knowledge regarding continence and in turn become more confident and efficient when supporting people



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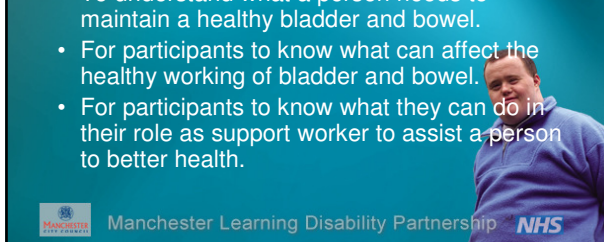


Objectives:

- For participants to understand what is meant by continence
- To understand what a person needs to maintain a healthy bladder and bowel.
- For participants to know what can affect the healthy working of bladder and bowel.
- For participants to know what they can do in their role as support worker to assist a person to better health.



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