Improving access to bowel screening for people with a learning disability

Peter Nash

South Tyneside NHS Foundation Trust
The lifetime risk of developing bowel cancer in the UK is 1 in 14 for men and 1 in 19 for women. It is 1 in 16 for people in the UK overall. Those with a learning disability are more at risk of bowel cancer since bowel cancer is associated with obesity, poor diet and lack of exercise (Read and Latham 2009, DOH 2013)
BOWEL CANCER

THE LONGER YOU LEAVE IT THE BIGGER IT GETS
I AM DIFFERENT

YES THAT’S TRUE

BUT IS MY LIFE

NOT WORTH THE SAME AS YOU?
Relative rates of screening for all four cancers were significantly lower for people with learning disability. Bowel Screening 57.8 per cent of total population; 28.1 per cent of people with Learning Disability (Tizard Learning Disability Review 2014)
Preventing Avoidable Deaths

Learning Disability Patient. Cause of death BOWEL CANCER
Pre Skills/Experience Analysis
56 staff

Pre findings

- Do you know what bowel screening is? Yes 54 No 2
- Have you supported someone with Bowel Screening before? Yes 4 No 52
- Do you know how bowel cancer occurs Yes 9 No 47
- Would you benefit from having training on bowel screening? Yes 56 No 0
- Are you aware of the national system for bowel screening and how it works Yes 0 No 56
- Are you aware of how to complete and support someone with a learning disability complete a bowel screening kit Yes 4 No 52
- Do you understand the barriers those with a learning disability face re bowel screening Yes 23 No 33
Arranged for the hospital screening department leads to do presentation to the team about the process when a person attend at the hospital due to occult bloods found in stool.

**Bowel cancer awareness and screening**

*South of Tyne Bowel Cancer Programme*

Mary Ritchie – Lead Specialist Screening Nurse
Julie Tucker – Health Improvement Practitioner
Factors relating to the individual

- Hearing
- Vision
- Physical and Mental Health
- Medication
- Time
- Comfort
- Understanding
- Expression

With all of us in mind
Factors relating to written information

- Many people with L.D. have very limited literacy skills
- High incidence of visual impairment (often undetected) amongst people with L.D.
- We use difficult words and jargon
- We use long complicated sentences
- Style and layout not helpful

With all of us in mind
Real object

Video information

Photos

Clip Art

Symbols

Change Pictures

Choose

South Tynedale NHS Foundation Trust
Invited a person with a learning disability who had completed the bowel screening process to speak to the team about their experience.
If you can’t explain it **simply**, you don’t understand it well enough.

– Albert Einstein
EQUAL TREATMENT – CLOSING THE GAP
The person, CLDT, carers and families were now more aware of the importance of bowel screening and how to support the person with a learning disability to undertake the test.

The Health Action Plan Database was updated.

A pathway now exist between GPs and the CLDT for non-responders.

CLDT are now trained in how to support someone with a learning disability to complete a bowel screening test.

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<thead>
<tr>
<th>Project outcome</th>
<th>Pre</th>
<th>Post</th>
<th>Increase</th>
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<tbody>
<tr>
<td>Had BS discussed</td>
<td>72</td>
<td>193</td>
<td>121</td>
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<tr>
<td>Completed BS test</td>
<td>34</td>
<td>117</td>
<td>83</td>
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<td>Followed up</td>
<td>0</td>
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<tr>
<td>RFA</td>
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