Bowel Health and Screening: A resource for people with Learning Disabilities and their carers

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Abstract

Introduction: A resource for people with learning disabilities (LD) designed using co-production and engagement approaches with key stakeholders and people with LD to inform them of the Scottish bowel screening programme and how to look after their digestive health. An accompanying training programme delivered to statutory and voluntary agencies, on how to use the resource to ensure patient centred care.

Aim: The aim of this project was to increase uptake of bowel screening in a population that had shown an inequality in access to the programme.

How we did it
January 2011: Bowel Cancer UK and NHS Greater Glasgow and Clyde (GGC) Health Improvement identified need for an adapted resource through training of LD service providers (carers)
September 2011: Multidisciplinary Project Group established, representation from Voluntary Sector, NHS, local authorities and people with LD
September 2011-May 2012: Project Group work together to develop resource and accompanying training
June 2012: Training session for carers piloted
July 2012: NHS Health Scotland support publication of resource
September 2012: Launched by Director of Public Health NHS GGC and people with LD
April 2013: Evaluation report published
May 2013: Project presented at European Commission colorectal screening conference
May 2013: Project finalist for UK Care Integration Award
April 2014: Project presented at the International Royal College of Nursing Conference
September 2014: Resource wins British Medical Association Patient Information Award

Highlights: The project group worked with carers and people with LD and harnessed their needs using engagement methods including focus groups, patient advocacy group, commissioning a local drama group of people with LD to write and perform a play and quantitative research with LD
staff from statutory and voluntary agencies. The result of this work is a quality resource that puts the patient at the centre of their care.

The training for carers of people with LD was designed to: provide attendees with the basic facts about bowel cancer and screening, and increase confidence in talking about good bowel health. This has been delivered across NHS GGC and has helped ensure that the resource is used to maximum effect.

Since the launch in September 2012, the uptake of bowel screening in people with LD has risen by 5% in NHS GGC. This surpasses the 2% increase in the general population.

**Sustainability & Transferability:** The resource’s sustainability relies on ongoing funding to continue development. Additional trainers would also benefit the project, allowing more carers to be informed of the resource and how to use it.

The project model of working collaboratively and in a participatory approach works, and could be transferred to other services.

**Lessons Learned:**
- Agree time commitment at outset of project as it improves engagement
- On-going evaluation works and helps a project move forward constructively learning and developing as it goes rather than at the end when it’s too late to change
- Involve the people most affected by the project from the start
- Involve senior management from the start

**Keywords**

engagement; coproduction; inequalities; inclusion; improvement

**PowerPoint presentation**

http://integratedcarefoundation.org/resource/icic15-presentations