

*J Laycock, ^J Clayton, "C Scott

*The Culgaith Clinic, Penrith, UK ^Research Fellow in Nursing, Sheffield Hallam University, UK "Research Assistant, Goulds Farm, Lingfield, UK

WHAT PATIENTS SAY ABOUT THE SERVICE THEY RECEIVE

Aims of study. The Association for Continence Advice (ACA) carried out a survey following a successful bid to the National Lottery Charities Board supported by Sanofi Synthelabo, to explore patients views and experiences of urinary incontinence with reference to their problems and the care they received

Method. An anonymous questionnaire was sent to over 15,000 people with urinary incontinence from the database of 3 organisations (Incontact, Research into Ageing and Simpla Continence Care) There were questions about - 1 Severity of symptoms, how these affected their day to day life and how these symptoms were treated or managed 2 When they had sought help and information, who and where from and what they had received 3 How satisfied they were with the outcomes 4 Demographic data

Results. The Organisations represented different populations and 1,915 questionnaires were returned (12.5%) Severity of symptoms varied from none at the time of the survey to no control at all or people who were catheterised Fear of discovery caused far more distress than the practical problem of managing the condition Men tended to seek help sooner than women, about half of men and a third of women sought help within 6 months but about 1 in 8 had not sought help for at least 5 years The most common types of information provided were leaflets, followed by information from organisations like The Parkinsons Disease Society One person in 8 had used a telephone help line Information was most commonly supplied by hospital specialists including doctors, physiotherapists and continence advisors, but surprisingly not by GPs or staff at health centres Nearly 1 in 8 respondents had received help from community pharmacists Generally a high level of satisfaction was reported with treatment and products, but lower levels with the information that was available Open questions produced comments on the inadequacy of public toilets, the need for better training for teachers dealing with incontinent children and unsympathetic treatment by GPs

Conclusions. This survey will help to take account of the patient perspective in planning future continence services

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