Out of the shadows

“Our voices aren’t going to go quietly into the dark anymore”
(Self-advocate)

A report of the sexual health and wellbeing of people with learning disabilities in Northern Ireland

By Audrey Simpson
Attracta Lafferty
and Roy McConkey

LOTTERY FUNDED

UNIVERSITY OF ULSTER
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Twenty years ago we wouldn’t have had a say. We would be sitting in wee corners in asylums with people making decisions for us, that wasn’t right. We have come a long way and all I am going to say is that our voices aren’t going to go quietly into the dark anymore.

(21-year-old young man)

Introduction

Background

In January 2000, fpa in Northern Ireland in partnership with the School of Social and Community Sciences at the University of Ulster began a pioneering Northern Ireland wide study into the sexual attitudes and lifestyles of young people under 25 years old. It was funded by the Research Grants programme of the Community Fund (now known as the Big Lottery Fund). The final report Towards Better Sexual Health was published in December 2002 (Schubotz, Simpson and Rolston, 2002) and since then has informed policy development and implementation of health and education strategies and service provision at both local and Northern Ireland wide level.

The Towards Better Sexual Health survey attempted to include young disabled people but the financial and methodological framework was not conducive for an effective inclusion of people with learning disabilities. In 2004, with funding again from the Research Grants programme of the Big Lottery Fund, fpa, in partnership with the School of Nursing at the University of Ulster, developed and implemented a research project which focussed specifically on the relationships and sexual wellbeing of people with learning disabilities in Northern Ireland. The research project became known as the SKY project (Sexual Knowledge and You) and a promotional leaflet was designed and disseminated widely to relevant organisations throughout Northern Ireland.

Rationale

There has been considerable social and legislative progress in tackling the barriers experienced by people with learning disabilities with regard to education, employment and housing issues. However, although in recent years the sexuality of people with learning disabilities has received increased attention from policy-makers (Department of Health and Home Office, 2000) and from self advocates (Williams and Shoultz, 1982), various commentators have drawn attention to a large gap between the needs
Personal growth and development

Male body parts

Interviewees were shown line drawings of the male body. As Figure 4 shows the majority were able to provide recognisable terms for the penis. Examples of misconceptions included the Adam’s apple, vagina and testicles. However, interviewees’ knowledge of the functions of the penis was less well developed. Many acknowledged that it is for ‘going to the toilet’ but displayed little or no knowledge of its sexual function.

There was less recognition of testicles and misconceptions included skin and intestine. Similarly there was little knowledge of the function of testicles and examples of misunderstanding included the testicles ‘fills up kidneys’ and ‘keeps the penis together’.
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In 2004, fpa, in partnership with the School of Nursing at the University of Ulster, developed and implemented research (the SKY project) which focussed specifically on the relationships and sexual wellbeing of people with learning disabilities in Northern Ireland. Out of the shadows is the report of that research.

Written and presented in a clear and user-friendly style this report will prove invaluable for a range of front-line staff and professionals whose work involves people with learning disabilities, and also family carers. It should also be essential reading for civil servants, policy makers and academics.

It presents findings from research with people with learning disabilities, family carers and front-line staff and professionals, and looks at the provision of relationships and sexuality education in Northern Ireland today. Conclusions and recommendations provide practical steps that can be taken by the key stake-holders involved in the research to move relationships and sexual wellbeing for people with learning disabilities out of the shadows.

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