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Editorial

Talking about sex, relationships and intimacy: new guidance and standards for nurses and other health and social care professionals working with young people with life-limiting and life-threatening conditions

Publication of *Sexuality Standards and Guidance for nurses and other health and social care professionals working with life-limited young adults, care staff and their families* (December 2015 and July 2016)

In 2013, The Open University Sexuality Alliance was established. This is a collaborative partnership which brings together young people and adults with Life-threatening and life-limiting conditions (LLTCs), representatives from the public and third sector, policy makers, doctors, lawyers, academics and nurses with particular expertise in addressing the sexuality of young people with an uncertain life-course. In partnership with Together for Short Lives, the UK charity for children and young people with LLTCs, the Alliance brought together a range of individuals and organisations, including Family Planning Association and Action Duchenne (the full membership is provided in Appendix 1). The primary focus for the Alliance was to develop Sexuality Guidance and Standards. These were published in December 2015 and a second edition is currently in press. The Sexuality Guidance provides important information about sex and sexuality for health, education and social care staff working with young people with LLTCs. The need for the Sexuality Guidance and Standards for people with LLTCs has been recognized by young people themselves, and practitioners in health, social care and education settings across the public and third sectors, particularly nurses.

Background

In 2012, a national conference: *Let's Get Back to Basics*, explored the legalities and practicalities of supporting young adults with their sexuality and concluded that there was an absence of specific and up to date sexuality

guidance and standards for people with LLTCs. It is widely recognised that guidance of this nature is vital to enable service managers and practitioners to effectively support people with LLTCs and their families/carers with issues relating to their sexuality.

Methods

The Open University Sexuality Alliance obtained Human Research Ethics approval to develop the Guidance and Standards and conducted a review of the literature in 2015. The review highlighted that while there was guidance about sexuality and disability, there was an absence of specific and recent guidance related to young adults with LLTCs (ACT 2009). Following consent, the contents and design of the guidance were discussed with four groups of young adults with LLTCs and some parents ($n = 25$), in Scotland and England. Key themes were analysed using NVIVO data analytical software to determine the issues of most importance to them. Anonymised quotes are used throughout the Guidance.

The Guidance

The guidance proposes underpinning principles and a set of eight standards for staff and four standards for organisational managers. It provides practical information for nurses and other health, social care and educational professionals on recognising, responding to and reviewing sexuality matters for young people with LLTCs throughout their lives. It provides guidance to support young people in developing their self-esteem, positive body image and self-confidence in relation to intimacy, sexuality and relationships. Crucially, it enables care staff supporting people with LLTCs to enhance their own knowledge and confidence in discussing relationships, intimacy and sexuality with people and their families and/or carers. It includes legal case histories to stimulate discussion, as well as useful resources including details of other organisations, websites and references. There is also a section for service managers which contains the key information that they need to know to ensure that staff are practising safely, legally and ethically.

The Standards: Underpinning Principles

All young people with LLCs should expect:

- To have the right to privacy, dignity and confidentiality
- To be treated in an age-appropriate way, regardless of their developmental stage and mental capacity
- To be able to address sexuality, intimacy and relationships with freedom from fear, guilt, shame and taboo
- To be appropriately supported from vulnerability to risk or harm
- To have the right to discuss, explore and receive relevant information about relationships, intimacy and sexuality, if that is their wish
- To have their individual needs and views at the centre of care and support, but with information and support provided to their families too
- To be able to approach professionals to discuss issues of sex, sexuality and intimacy without being judged
- To have support relating to sex, sexuality and intimacy throughout their life, including early discussions in childhood, as needs change and at the end of life. (Blackburn *et al.* 2016, p. 4)

Dissemination and impact

Since December 2015, the *Sexuality Guidance and Standards* have been available internationally to nursing, health and social care audiences. We launched the guidance at a seminar in London and have held a series of events and masterclasses since the launch to support their implementation. Young people and potential beneficiaries were invited to be part of the OU Sexuality Alliance to consult, design and develop the guidance and this factored into the project an overt element of user involvement, thereby building a group of stakeholders who are keen to promote the use of the guidance. For example, some of the young people involved have committed to writing a series of blogs for us on the OU Sexuality Alliance website. In addition, the RCN has endorsed the guidance and with the CQC have been engaged in the consultation and have supported its dissemination through their networks.

Measures have been put into place to assess impact and to identify if the guidance is making a difference. These include measuring website visits, referrals from other stakeholder sites, using a questionnaire to evaluate events and masterclasses, social media responses and feedback from speaking engagements, both in the UK and internationally.

Conclusion

We hope that the Guidance and Standards will significantly improve the understanding and knowledge of health, social and educational professionals in advising and supporting an increasing number of young people with LLCs who are now living into adulthood and want to know about their sexuality. The guidance and standards is freely available and is accessible in both hard copy from The Open University and online at: <http://www.open.ac.uk/health-and-social-care/main/research/research-themes/reproduction-sexualities-and-health/the-sexuality-alliance>.

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- Blackburn M.C., Chambers L., Earle S. & Raeburn D. (2016) Talking about sex, sexuality and relationships Guidance and Standards for those working with people with life-limiting or life-threatening conditions. ISBN 978-1-4730-0356-9.

Appendix 1

Members of The Open University Sexuality Alliance

Sharon Ballingall, Social Worker, Family Support Lead, Children's Hospice Association Scotland (CHAS)

Celine Barry, Takin' Charge Project Coordinator, Action Duchenne

Maddie Blackburn, PhD Student, and Chair of The Open University's Sexuality Alliance, Faculty of Health & Social Care, The Open University

Paul Casey, Training Manager, Family Planning Association

Lizzie Chambers, Development Director, Together for Short Lives and Executive Director of the UK Transition Taskforce

Mark Chapman, DMD Pathfinders

Alison Cooke, Director of Care Services, Rainbows, Children and Young People's Hospice

Claire de Than, Deputy Director of the Institute of Law, Jersey and Co-Director of the Centre for Law, Justice and Journalism, City University London

Tracie Dempster, Director of Care, Richard House Hospice
Dr Sarah Earle, Associate Dean Research,

Faculty of Health & Social Care, The Open University

Meena Enewalla, Transition Services Manager, Richard House and St Joseph's Hospices

Simon Hardcastle, Diana Team Leader, Clinical Lead for Transition, East Midlands Strategic Clinical Network & Senate, NHS England, Leicestershire Partnership NHS Trust

Sharon Harvey, Transition Support Worker, Demelza Hospice for Children

Hameed Jimoh (Junior) Young Avenger, Together for Short Lives and Expert by Experience Care Quality Commission

Laura Klepping, Nurse and Care Team Leader, Helen & Douglas House Hospice

Dr Susie Lapwood, Head of Research, Education and Professional Development, Helen & Douglas House Hospice

Dr Kirsty Liddiard, Post-Doctoral Research Associate & Disability Advocate, School of Education, University of Sheffield

David Raeburn, Public Legal Education and Pro Bono Specialist

Tracey Reed, Children's Palliative Care Assistant, Demelza Hospice for Children

Phillipa Sellar, Clinical Nurse Specialist and Young Adults Co-ordinator, St Christopher's (Hospice

Lucy Watts MBE, Young Avenger, Together for Short Lives, Global Youth Ambassador, the International Children's Palliative Care Network, Trustee, Pseudo Obstruction Research Trust, Ambassador, Dreams Come True, Blogger, Lucy's Light Community Champion, Scope.