

Sarah Earle: Briefing: 1/12/2015

Morning session

Good morning everyone, I would like to welcome you all to this very special day here at The Open University. Before I give some of the background to today, I just need to explain a few house-keeping arrangements.

Fire alarm testing

Lunch will be available at around 12.30 for everyone attending now and for those attending this afternoon's session on how to use the guidance, plus for all of you staying throughout the day. This is a self-service buffet which will be outside this door. If you feel like a breath of fresh, brisk and wet air, the terrace is open!

At lunchtime, please take time to view the exhibitions whilst networking. We are not expecting press to attend this meeting. However, Maddie Blackburn will be taking notes throughout the proceedings.

I would first like to welcome and thank Dame Elizabeth Fradd for taking the time and travelling to launch this resource here today. I should also like to welcome all the young people here today, in particular Junior, and young people from Helen and Douglas House, plus Mark for joining us by Skype. Junior and Mark will be addressing us soon. Lucy Watts sadly cannot be here today as she has another speaking engagement but she helped write the Foreword for this resource with Junior.

I am also delighted to welcome the Hall Family to the launch today and thank you for travelling such a long way to be with us. Very sadly, their son, Joshua, died in July this year. Joshua and many other young people around the UK contributed to the design, content, checking and re-checking of this guidance at every stage of its development. Without his and all the young people's huge input around the UK, we would not be here today. Joshua's input is testimony to his commitment to supporting young disabled people throughout his life... and in his absenceWe thank you, his family and Joshua, for his significant input to both the video and the guidance. You may wish to say a few words after Dame Elizabeth has launched the guidance before some of the contributions from the young people.

But first, some background to Talking about sex; the Guidance and Standards

In 2012, a conference entitled, *Let's Get Back to Basics* was hosted by two hospices in England. This event focused on the legalities and practicalities of supporting young people with LLTCs conditions with sex, sexuality and relationships. The conference concluded that there was a gap in information, services and support.

As a result of the conference, The Open University Sexuality Alliance was formed in 2013. Its main purpose was to develop sexuality guidance and standards for health, social care and

education staff who care for and support young people with LLTCs. The Alliance is a collaborative partnership. It brought together representatives from the public and charity sectors, service users and academics. Most of the 13 organisations who assisted in this very challenging piece of work are here today and some will be speaking later. On behalf of The Open University, I would like to say a huge thank you to all the Alliance members for their hard work and tenacity.

It is highly appropriate that Dame Elizabeth Fradd launches this resource. Not only is Dame Elizabeth a Patron of Together for Short Lives, our key partner in this work, but she has dedicated a significant amount of her working life to addressing vital issues which are important to both children and young people. She is currently an Honorary Professor at Nottingham University, was a former Deputy Chief Nurse in the Department of Health, England and was the Director of Clinical Governance and Inspections at the former Commission for Health Improvement. As a result of her significant contribution to the national children's and young people's agenda, she was invited to become a Dame of the British Empire in 2010. Liz, please can we invite you to launch these guidance and standards.

After Liz's speech:

I should now like to introduce Dr Kirsty Liddiard, Research Associate at the University of Sheffield and who has been a very active and supportive member of The Open University Sexuality Alliance. Kirsty will introduce the next session.

After the young adult session:

It is now lunchtime. For those attending this afternoon, please can you return promptly at 13.40. Enjoy your lunch. For those leaving, please can you complete the written evaluations in the pack.

Afternoon session, repeat of the morning, apologising to those who attended the morning session for any overlap in the proceedings. We need to briefly outline the contents. Lizzie and I can do that

Panel discussion- Liz Fradd has agreed to lead this and you have asked me to part of this.

Close of day

Thank you to everyone. **Completion of evaluations before departure please.**

