

Launch -“Talking about sex, sexuality and relationships: a guide for health, social care and education practitioners and organisations”.

December 1st 2015.

Thank you so much for inviting me to join you all today, I was delighted to be asked to formally launch the Sexuality Guidance and Standards. I am particularly pleased to be here because of their importance to the lives of an estimated 55,000 children and young adults with a life threatening or limiting condition in the UK aged 18 -40 years. I have no doubt that a number of the key elements of the document are transferable to other areas of professional practice – notably the underpinning principles and the five step framework for responding to young people’s questions.

The need for guidance and standards was brought to my attention recently when I read an article in a Sunday paper supplement about Mark Pollark, an extraordinary blind young man about to be married fell from a 2nd story window leaving him paralysed . He describes in the article how after being subjected to lengthy meetings with hospital clinicians about his multiple needs the matter of sexual function was eventually brought up. They discussed (and I quote)” in an awful mechanical way” that there would be no normal intimacy and fertility treatment would be the only option if he wanted a family. He confirmed that whilst some practicalities were discussed no psychosexual support was offered. Fundamental to successfully conducting conversations such as this is the importance of a culture that recognises the importance of respect and privacy.

Importantly and of relevance to today he also said that “there were 18 year olds on the ward with me and that’s how the truth of their injury is likely to be presented too. It’s really tough; it makes us feel vulnerable talking about it: nobody wants to talk about it”. But he went on to say that it is important we do talk, because we have to change the way people think about it and change the narrative around it. Marks story is powerful as are those embedded within the documents we are launching today. First-hand accounts ensure the text is richer and all the more meaningful, and they emphasise the need to be open and honest.

Marks views support the prime purpose of the Guidance and Standards which is - to help young people with a disability to understand their bodies and support them if they wish to enjoy intimate relationships. Professionals of all kinds find this topic difficult, especially when the young person has a life limiting or life threatening condition. Often staff avoids the issue by turning their attention to “more important matters” or hiding behind what they believe the law permits. The guidance is therefore successfully in my view, designed to help staff feel more comfortable and confident through the use of case studies, discussion points and quotes. Many young people themselves also don't find it easy either to talk with people or accept help from people whose assistance they may need. Particularly if this is offered from those they consider being of a different generation and maybe not entirely on their wave length. As Junior and Lucy say “they just don't get it”.

A key feature of the process taken to draft the document was the collaborative process that involved a wide range of individuals, who then formed the Sexuality Alliance. The Alliance was a forward thinking idea, and a great example of how working together can result in more meaningful outcomes for those we care about the most - the young people and their families.

Navigating ethics committee processes are never easy, but having the weight of so many different professional perspectives must have made a significant impact on those considering the application to undertake the work. The result is, I am certain, a high quality product which fills a significant gap in current knowledge and provides a guide not only for professionals but also for young people and their families too.

Well done to all those involved, you should be really proud of what you have achieved in a relatively short period of time and in a very difficult space. Thank you to those who participated in the focus groups which ensured the work was truly grounded in reality.

What you have collectively developed will help address the wishes of young people to live their lives like others , “to get out, meet people, have fun, shop and have relationships and stuff”. If you build the underpinning principles into the way you work and utilise the standards to help ensure your approaches are effective, I believe young people will be increasingly feel loved and desired as

they rightly should. There is a heartfelt plea in the foreword written by Junior and Lucy “please don’t ignore our needs”. It is incumbent on all organisations now to provide the regular training and opportunities for reflection needed for staff to be able to fulfil the new standards that are launched today.