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CONSULTATION

DEPARTMENT OF HEALTH AND SOCIAL CARE: LEARNING DISABILITY AND AUTISM TRAINING FOR HEALTH AND CARE STAFF

CoramBAAF is an independent membership organisation for professionals, foster carers and adopters. It is part of the Coram group of charities. Members include the majority of local authorities, agencies from across the voluntary and independent sector plus nearly 1,000 individuals. Together, the membership makes up the largest network of organisations and individuals involved with children in their journey through the care system.

CoramBAAF promotes the highest standards of practice in adoption, fostering and social work with children and families through support to social workers, health professionals and legal practitioners via resources, advice, training and publications. As an authoritative voice in the field of child care, we inform and influence policy makers and legislators.

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CoramBAAF welcomes the proposal to introduce mandatory training for health and social care staff in relation to learning disability and autism. We do have a concern that Foetal Alcohol Spectrum Disorder (FASD), a neurodevelopmental disorder with some parallels with autism is not also included. This risks failing a large number of service users – parents and their children and young people and those services that work with them.

FASD is a permanent, lifelong disability that results from exposure to alcohol during pregnancy. Children and adults with FASD often present with a bewildering complexity of symptoms and behaviours that mean they struggle with many or most aspects of daily life. This will have a

significant impact on those other people who are close to them. The most reliable prevalence study¹ suggests that FASD affects at least 6% of the children born in the UK. This compares with estimates of 1.1% of the population who are autistic.²

Children who become looked after and those that leave care through adoption are more likely to be affected than those in the general population, and studies in the UK³ and Canada⁴ suggest that at least one-third of looked after and adopted children will be affected by FASD. These prevalence figures indicate the reason we are raising this in our consultation response.

Feedback from service users and their families suggests that professionals in health, education, and social services have a low level of awareness about FASD and are not well trained. A report by the All Party Parliamentary Group on FASD in December 2015 recommended a significant investment in a FASD education programme for all professionals.

Increased professional knowledge and understanding is crucial for a responsible diagnosis and management of this disorder. Managing the challenges that are associated with FASD often requires an approach that is specific to that condition, and this is often at variance to approaches that might be helpful for people without the condition, or with other conditions. In some instances using non-specific approaches will make matters worse, impacting adversely on individuals and their families.

It is essential that FASD should be considered as a specific neurodevelopmental disorder alongside autism, not least because some people with FASD will otherwise be excluded from consideration. In our view, FASD should be identified within the scope of the revised document. In other respects, we are fully supportive of the proposal.

¹ McQuire C et al (2019) 'Screening prevalence of fetal alcohol spectrum disorders in a region of the United Kingdom: A population-based birth-cohort study' in *Preventive Medicine* 118 (2019) 344–351

² <https://www.autism.org.uk/about/what-is/myths-facts-stats.aspx>

³ Gregory G, Reddy V, and Young C (2015), Identifying children who are at risk of FASD in Peterborough: working in a community clinic without access to gold standard diagnosis, in *Adoption & Fostering* 2015, Vol. 39(3) 225–234

⁴ Ospina M, Dennett L (2013) Systematic Review on the Prevalence of Fetal Alcohol Spectrum Disorders, Institute of Health Economics, Edmonton, Canada