

Impact case study (REF3b)

Institution: Plymouth University
Unit of Assessment: 22 Social Work and Social Policy
Title of case study: Providing support and information during pregnancy – impact on policy and practice
<p>1. Summary of the impact (indicative maximum 100 words)</p> <p>A series of projects focusing on the medical, social, and emotional experience of pre-pregnancy, pregnancy, and early motherhood have been undertaken since 2006 at Plymouth University. The impact of these projects is wide ranging covering both policy and practice. The research has: changed the physical environment of the antenatal clinic specifically to suit the needs of pregnant women with pre-existing diabetes; developed an online leaflet for women with Polycystic Ovary Syndrome (PCOS); developed training programmes for health and social care professionals; provided baseline information to inform practitioners and patients involved in UK screening programmes; and, informed screening strategies for Downs Syndrome.</p>
<p>2. Underpinning research (indicative maximum 500 words)</p> <p>The body of research was undertaken by Professor Gayle Letherby (2008-present) and Adam Fisher (Research Assistant, 2005-present); Dr Lorna Bell (Senior Research Fellow, 2007-present); Dr Rebekah Southern (SERIO Director 2005-10). Letherby's initial research, prior to joining Plymouth, involved studies focusing on the experience of teenage pregnancy and young parenthood in the West Midlands. Her work highlighted the fact that this experience is characterised by multi-dimensional power relationships and that pregnant teenagers and young parents benefit from specialist services that need to be highlighted within the Teenage Pregnancy Strategy and for which health and social care professionals need training. This area of expertise links into research on risk assessment and screening undertaken by Prof. Wright and colleagues in Plymouth University Peninsula School of Medicine and Dentistry (Case study for UoA 1) and which has contributed to the reduction in the number of invasive diagnoses procedures in the UK.</p> <p>Since joining Plymouth, Letherby's research has expanded to include work on pregnancy, early motherhood and diabetes and Polycystic Ovary Syndrome (PCOS). The first project was a multidisciplinary qualitative exploration of mother/daughter relationships during pregnancy and the transition to motherhood of women with pre-existing diabetes (Letherby, et. al., 2012a). The research was undertaken by Letherby and Stenhouse (Associate Professor of Midwifery) 2008-09, and showed that pregnancy for those with pre-existing diabetes, however problematic, helps women feel 'normal'. Health professionals responses are important to women's sense of the progress of pregnancy and their feelings of bodily control and yet there is a lack of specialist knowledge. Professionals need to recognise the expertise of women and their significant others (in terms of diabetes management) (Letherby, et. al., 2012b). Following this, Letherby led the qualitative part of a multidisciplinary project focusing on improving the knowledge (particularly with reference to future risk of diabetes) of women with PCOS. The research, the result of a Queens Nurse Institute/Burdett Trust for Nursing award, took place in Cornwall between 2011-12 and highlighted the impact of PCOS on women's feminine, un/healthy and reproductive identity.</p> <p>Alongside Letherby's work, Bell et al undertook three projects relating to the management of screening women during pregnancy. Screening is an important tool in empowering people to take control of their health and make the most appropriate choices for their circumstances. The first project in 2006-07 applied systematic search and review techniques and for the first time in the UK collated data on ultrasound detection rates, false alarms and frequencies of 26 fetal anomalies (Bryant, Fisher and Vicente, 2007). The research confirmed that some anomalies remain very rare, and that ultrasound screening accuracy differs for individual conditions. The researchers conducted further research in 2008 focusing on biochemical serum screening at 8-10 weeks gestation for Down's syndrome. The resulting report (Bryant, Fisher and Southern, 2008), acted as a central hub of international data on the detection, false and screen positive rates for targeted</p>

Impact case study (REF3b)

serum markers. The final study in the research programme took place in 2009-10, and reviewed Down's syndrome screening strategies in the UK. The research found that gestational age continued to be vital in the efficacy of biochemical marker screening, and that triple-quadruple testing at 15-20 weeks gestation provided relatively high detection rates at lower risk-cut-off levels. This research specifically underwent critical peer-review according to the UK National Screening Committee review process, including an external review by international experts and a national consultation event.

3. References to the research (indicative maximum of six references)

Brown, G. Brady, G. and Letherby, G. (2011) 'Young mothers' experiences of domestic violence in their intimate and familial relationships' *Child Care in Practice* 17:4.

Child Care in Practice is a quarterly, peer-reviewed journal that provides an international forum for professionals working in all disciplines in the provision of children's services, from social care to health care, medicine to psychology, education, the police and probationary services, to solicitors and barristers.

Brady, G. Brown, G. Letherby, G. Bayley, J. Wallace, L. M. (2008) 'Young women's experience of termination and miscarriage: a qualitative study' *Human Fertility* 11:3.

Human Fertility is the official Journal of the British Fertility Society. It includes multi-disciplinary articles and is read by practitioners and academics Impact factor: 1.377.

Stenhouse, E. Letherby, G. Stephen, N. (2012a) 'Healthcare Needs for Pregnant Women with Pre-Existing Diabetes' *Midwifery*.

Midwifery publishes the latest peer reviewed international research to inform the safety, quality, outcomes and experiences of pregnancy, birth and maternity care for childbearing women, their babies and families. Impact factor: 1.777.

Letherby, G. Stephen, N. Stenhouse, E. (2012b) 'Pregnant Women with Pre-existing Diabetes: Family Support in Managing the Pregnancy Process' *Human Fertility* 15:4.

Human Fertility is the official Journal of the British Fertility Society. It includes multi-disciplinary articles and is read by practitioners and academics. Impact factor: 1.377

Bryant, L., Fisher, A., and Southern, R. (2008) *Literature Search: 8-10 Week Serum Screening for Down's Syndrome* (NHS Fetal Anomaly Screening Programme: Exeter)

Bryant, L., Clayden, J., and Bell, L. (2010) *Literature Survey for the Review of Down's Syndrome Screening Policy 2010* (NHS Fetal Anomaly Screening Programme: Exeter)

Both research reports underwent critical peer-review according to the UK National Screening Committee review process including an internal review by the UKNSC, peer review with international experts, a face to face panel review followed finally by a national consultation event.

4. Details of the impact (indicative maximum 750 words)

The research conducted by Letherby and Bell et al has impacted on the practice of care provided for pregnant women and mothers and has informed screening policy in the UK. Regarding healthcare practice, Letherby's work on the medical, social, and emotional experience of pre-pregnancy, pregnancy and early motherhood has resulted in changes in practice in the physical environment of the antenatal clinic at Derriford Hospital, Plymouth, which is now specifically geared to the needs of women with pre-existing diabetes. Furthermore, training programmes for health and social care professionals (e.g. midwives, healthcare assistants, social workers) have also been developed, with some being delivered by the research team alongside mothers, and some developed by a theatre group working with support from the research team (so far several hundreds of professionals have undergone this training since 2006). Letherby's work on PCOS has resulted in a patient information leaflet that has been sent to every GP practice in Cornwall and all

Impact case study (REF3b)

specialist gynaecology/infertility clinics in Cornwall and Plymouth by Public Health, Cornwall & Isles of Scilly PCT; and provided as a free downloadable PDF by the *Nursing Standard*.

Letherby's work has led to the commissioning/funding of further research including: an ESRC funded PhD focusing on the pregnancy and early motherhood experience of women with diabetes and obesity; a British Academy funded project focusing on social support accessed via the internet following perinatal loss; a Plymouth Hospital's funded project focusing on understanding and experiencing screening and diagnosis alongside associated issues of loss; and, a Cornwall and IOS NHS funded project focusing on patient-centred interventions to improve long term health and quality of life for women with PCOS. Following her research Letherby has been invited to talk with and provide teaching materials for health and social care practitioners throughout the UK (including training as mentioned above and commissioned writing for various Open University vocationally focused courses). This includes: a number of invited presentations at local, regional and national PCT/Social Services events; and, a plenary talk at the 2013 Diabetes UK conference (organised by the leading UK charity that cares for, connects with and campaigns on behalf of all people affected by diabetes, aimed at professionals working in the area and delivering information on the latest global developments in diabetes care and research). In addition, other impacts include the setting up of a young parent's forum and changes in the architecture of housing provision for young parents with private entrances (at the young women's request) to each flat replacing a communal entrance.

Bell's research has also led to improved information for women who are pregnant and where screening has revealed a fetal anomaly – this was the core purpose of SERIO's initial research in 2006-07. The impact of SERIO's further research has been more orientated towards policy review. Screening for Down's syndrome has been implemented as a Ministerial commitment since 2001 and is overseen by the Fetal Anomaly Screening Programme. Trusts have been expected to work towards improving their baseline programmes by improving the detection rate to 'greater than 75% with a false positive rate of less than 3%'. It was within this context that the previously stipulated detection rate goals were reviewed by the FASP using NHS NSC guidelines in 2010, based on the best research available at that time. As part of the first step of the review process, the evidence gathered in the research was reviewed by screening policy and health experts. Considering these research findings, alongside issues surrounding relevant governmental pressures, society/community concerns, media, maternal/parental experience and economic issues, the FASP recommended that Down's syndrome screening policy remains unchanged until the next triennial review in 2013. Work in this area has been recognised by senior level staff in the FASP, with its Director stating that SERIO *'have provided an extremely good service in undertaking literature reviews for us. These underpin the evidence required to support policy decisions and set standards which are necessary to ensure we have a quality screening service in England'*.

In delivering the review report to the NHS NSC, the National Project Officer for the NHS FASP reported to stakeholders of the Down's syndrome review process that... *'we anticipate that the UK NSC Group will see our policy as appropriate, safe, cost-effective and practical for those at point of delivery and receivership'*. The entire review process was also successfully submitted for NICE Evidence Accreditation. The Accreditation Programme recognises organisations that demonstrate high standards in producing health or social care guidance, assuring users of the accredited guidance that the information is of the highest quality. The new National policy has now been written and is currently open for public consultation.

5. Sources to corroborate the impact (indicative maximum of 10 references)

Factual statement of impact from Derriford Hospital staff

Leaflet on Polycystic Ovary Syndrome

Cornwall NHS news article outlining the importance of the PCOS leaflet

<http://www.webarchive.org.uk/wayback/archive/20130305163326/http://www.cornwallandislesofscilly.nhs.uk/CornwallAndIslesOfScillyPCT/MediaCentre/NewsArticles/091111projectdiabetesheartdis>

Impact case study (REF3b)

ease.aspx

Statement from the Director of the Down's syndrome National Screening Programme, NHS Fetal Anomaly Screening Programme, Innovation Centre, Rennes Drive, Exeter, Devon, EX4 4RN, tel: 0845 5277910

Impact on the policy review process is also referred to in the following documents:

NHS FASP (2011)

NHS FASP (2011) *Screening for Down's syndrome: UK NSC Policy recommendations 2011–2014 Model of Best Practice*, accessed at:

<http://fetalanomaly.screening.nhs.uk/getdata.php?id=11393>

NHS FASP (2010) *Adopting the UK NSC Policy Review Process to create new policy for Down's syndrome screening*, accessed at:

<http://fasp58.final.seedata.co.uk/pdf/AdoptingTheUKNSCPolicyReviewProcess.pdf>