Inside ‘Inside View’: Reflections on stimulating debate and engagement through a multimedia theatre production on the dilemmas and issues of pre-natal screening policy and practice

Gillian Lewando Hundt*, Claudette Bryanston**, Pam Lowe***, Saul Cross,**** Jane Sandall,***** Kevin Spencer******

* Professor of Social Sciences in Health, Institute of Health, School of Health and Social Studies, University of Warwick, UK
** Theatre Director, Associate Fellow, Institute of Health, School of Health and Social Studies, University of Warwick, UK
*** Lecturer in Sociology, Aston University, Birmingham UK
**** Media Technologist, Afikoman Media Productions
***** Professor of Midwifery and Women’s Health, King’s College, London
**** Director of Biochemistry, King George Hospital, Barking, Havering and Redbridge Hospital NHS Trust

Funding: Wellcome Trust

Corresponding Author

Professor Gillian Lewando Hundt
School of Health and Social Studies
University of Warwick,
Coventry CV4 7AL
Email: gillian.hundt@warwick.ac.uk

No conflicts of interest

Sources of funding: Wellcome Trust People Award for theatre production, ESRC for research study

Acknowledgements: We acknowledge the support of the Wellcome Trust through a People Award Number 075371/Z/04/Z and thank Kathy Joyce the actor and Tinch Minter, the writer. We acknowledge the support of the ESRC through grant number L21825042 on the Social and Organisational Implications of Genetic Prenatal Screening and the women and health professionals who took part in this.
Inside ‘Inside View’: Reflections on stimulating debate and engagement through a multimedia theatre production on the dilemmas and issues of prenatal screening policy and practice

Abstract
The role of applied theatre in engaging the public both lay and professional with debate on health policy and practice is an emergent field. This paper discusses the development, production performance and discussion of ‘Inside View’. The objectives were to produce applied theatre from research findings of a completed study on genetic prenatal screening exploring the dilemmas for women and health professionals of prenatal genetic screening, and to engage audiences in debate and reflection on the dilemmas of prenatal genetic screening. ‘Inside View’ was developed from a multidisciplinary research study through identification of emergent themes from qualitative interviews, and development of these by the writer, theatre producer and media technologist with input from the researchers. Inside View was performed in London and the Midlands to varied audiences with a panel discussion and evaluation post performance. The audiences were engaged in debate and found it relevant to them professionally and personally. Knowledge translation using applied theatre is an effective tool for engaging the public but the impact subsequently is unclear. There are ethical issues of unexpected disclosure during discussion post performance and the process of transforming research findings into applied theatre requires time, trust within the multidisciplinary team as well as adequate resourcing.
Inside ‘Inside View’: Reflections on stimulating debate and engagement through a multimedia live theatre production on the dilemmas and issues of pre-natal screening in policy and practice

Introduction

Developing public engagement with science is supported by charities, government and a range of policy makers and stakeholders including members of the public themselves. Its implementation utilises a number of different approaches that include café scientifiques, citizen juries (1), and performance (2,3). Each of these means of public engagement with science, technology and medicine have their own strengths and challenges in preparation and production although there is a paucity of evaluation in terms of reach and impact. Target audiences vary and due to the temporally limited nature of the activities it is hard to assess their legacy. By their very nature, science in society events involve multidisciplinary teams and this in itself presents its own challenges. Kerr et al (1) have argued, technical expertise is often deferred to, rather than challenged in these public debates limiting contestation. Applied theatre is however being used as a tool to engage people with complex issues and dilemmas both cognitively, morally and emotionally in many non-theatre settings (4).

This paper addresses the issues raised through the process of development, production, performance and discussion with the audience of an applied theatre production ‘Inside
View’ that sought to highlight for debate the complex issues and key dilemmas relating to the experiences of pregnant women and health care providers of pre-natal screening. The text and performance was informed by research findings of an ESRC funded study on women’s and health professionals’ experiences of first and second trimester pre – natal screening (5,6,7,).

Drama and theatre have been used widely in the field of health and social care, particularly internationally. It can be a powerful vehicle for health promotion knowledge transfer and awareness raising for example in relation to HIV/AIDS (8). Soaps on TV and radio can be designed deliberately for this purpose such as in Soul City in South Africa. This type of work has been called Theatre-in- Education - generally applied to work that takes place in schools in a classroom setting or Community Theatre, used to describe theatre performed by non-professional actors within a specific social context but the broader term ‘applied theatre’ allows a more inclusive approach.

Applied Theatre in health education and promotion often excels at conveying the complexity and dilemmas that are posed for individuals when faced with illness or health choices. For example a play on drug education aimed to inform primary school children about types of drugs also shows the different pressures and choices that are involved with drug use (9). Whilst the use of Applied Theatre in health education opens up issues, these types of activities usually have some essential ‘messages’ either to raise the empathetic awareness of the audience or to empower them to make more informed choices in the future.
As well as an educational agenda, Applied Theatre can be used to validate or disseminate research findings and to generate public debate and involvement. In a study in rural South Africa (10), a composite script was developed around the main findings on community understandings of stroke from rapid ethnographic assessment. The actors encouraged the audience as extended family members to participate in making decisions about the central character, a man who collapsed whilst working one day with stroke-like symptoms drawing on the use of the forum theatre approach of Boal (11). The study team found that as well as being able to validate and disseminate their findings, the involvement of the audience produced new insights and enabled individuals to voice their opinions. Following the performance the audience was asked how health services should develop in the future. Paget (12) has argued by using performance, findings of research can be portrayed in a much richer medium than in standard academic texts, and can ‘reawaken and recover the audience’s capacity to participate’ (1990:151).

One of the key ways in which Applied Theatre produces richer findings is through the inclusion of emotion. Although much social science research seeks to uncover informant’s experiences, traditional forms of dissemination transforms these into abstractions, flattening the emotions(12). Learning is often seen to need rationality rather than emotion, but feelings are a powerful channel towards understanding (13).

Nisker et al (3) argue that applied theatre is a way of emotionally engaging with an audience whilst opening up issues for debate that makes it a powerful method for public
consultation in the development of health policy. *Sarah’s Daughters* was developed to explore the issues surrounding living with the risk of hereditary breast cancer. Following the performances, the audience discussion was recorded and analysed. The researchers argue that the performances engaged the audience and allowed them to voice issues related to the development of health policy in relation genetic testing and the implications of testing on the lives of individuals and their families. They argue that performance can encourage informed opinion on health policy, and thus can be considered an effective way of consulting with the public providing it is done carefully and ethically.

The power of performance to raise questions about moral issues in a non-threatening way can make it particularly suitable as a learning experience (14). It allows the audience to identify with the characters, to ponder and debate moral choices and actions (15,16).

In order to assess its effectiveness, applied theatre needs to be evaluated. Evaluations of performances with an explicit health education or promotion remit, often focus on the extent to which the audience understood the key themes, and any change in attitude towards the ‘undesirable’ behaviour. Whilst evaluation is generally perceived as an essential component, it is more difficult in practice (13). Although understanding of themes and changes in attitude can be measured, it is less clear that they are real predictors of long-term behaviour. Moreover, evaluation can have conflicting aims between the need to assess if the theatre is ‘value for money’ or if it has enhanced learning.
Methods

Process of team work

This multidisciplinary team had some shared expectations – namely to deliver a piece of theatre that was derivative from and faithful to the research project findings but that would engage and involve the public in debate on the topic of prenatal genetic screening. The data-set included a survey of pregnant women’s views on prenatal screening, interviews with health providers in prenatal clinics and women and partners attending them, and ethnographic observation of clinic sessions (5,6,7). Three members of the research project team were members of the performance project, representing medical anthropology (GH), women’s health and midwifery (JS) and biochemistry (KS). They were joined by a theatre director (CB), media technologist (SC), a sociologist research fellow (PL) and later by a script writer (TM) and actor (KJ).

The research team members saw themselves as expert reference for the theatre director, media technologist and scriptwriter but recognised the need for dramatic interpretation as well as the time and space for the creative process. The theatre director proposed a vision to frame the shared expectations of the artistic team, the writer, media technologist and performer. The artistic team were presented with the challenge of developing a very short engaging performance (40 minutes) with artistic integrity that was a composite representation of the themes derived from the research data, which would present complex issues for diverse audiences.
The main themes from the data set were extrapolated and summarised by PL. These were based on an agreed set of criteria considered by CB PL and GH that would both be issues that would lend themselves to the theatre process, and those issues that were of prevalent concern for the woman and the health service providers. Regular discussions between PL and CB enabled CB to nurture the theatre making process with the writer and media technologist, the aims of which were to develop a text and a digitally designed environment for performance. CB PL and SC also made a site visit to one of the prenatal clinics. The script was developed from the summaries and the visual material was gathered and developed in consultation with, and utilising some material from the biochemist and the clinic site along with research material on the subject. The script was shared with the team as it was developed, undergoing several drafts both before and during the rehearsal period which was attended by some of the social scientists (GH, PL). The development of the performance was an iterative process involving adaptation of the script through a dialogue between the director, social scientists, and biochemist.

The performances of a one woman show performed by an actor portraying everywoman were followed by a panel discussion with different members of the multidisciplinary team responding to questions from the audiences in relation to both the policies, practices and ethical dilemmas of prenatal screening and also the transformation of research data into performance. Performances were held in non theatre spaces with one exception in Coventry and London to a range of audiences between October 2005 – January 2006. Audiences included young mothers, students of biomedical engineering, midwifery, nursing and medicine and a range of academics and policy makers. A summary of the
main findings of the research project were distributed along with the programme. Each of the six performancec lasted 35 minutes and was followed by 15 – 30 minute panel discussion with members of the project team who included a media technologist, theatre director, actor, writer, social scientists and a biochemist. The production can be accessed along with moderator notes and key research findings for use in teaching and training at http://www2.warwick.ac.uk/fac/cross_fac/healthatwarwick/research/pastresearch/inside_view.

Results and Discussion

Different discourses and disciplinary perspectives

Prenatal screening in pregnancy for anomalies such as Down’s syndrome, is an emotive and contested area. It is national policy in the UK to provide screening for Down’s syndrome for all pregnant women. The initial screening indicates the probability of this syndrome being present. The few women who are deemed to be at higher risk together with their partners may choose to have further diagnostic testing (chorionic villus sampling or an amniocentesis depending on the stage of the pregnancy) and this may lead to a choice concerning possible termination of the pregnancy if the presence of Down’s syndrome or other chromosomal anomalies are confirmed. Prenatal screening is offered to all women in pregnancy and they have to give their informed consent. The information is given by midwives and other health care providers and the need for clear information and communication to underpin these decisions is paramount and well recognised. New training materials have recently been developed. Nevertheless the information is complex and delivered within short routine consultations. Writers such as Kerr and Shakespeare
(17) have raised concerns about the potentially coercive nature of prenatal screening and eugenic agendas. The debate about pre-natal screening is one of complex cultural, moral and ethical dilemmas. The challenge for the director was to ensure that the passion for the debate remained vigorous and engaging throughout the performance without presenting a particular position. The medium of theatre allows for layered interpretation of material whatever text is chosen, so the challenge was considerable, yet alongside this for these very reasons it is a potent medium for exploring such debate.

In terms of content, the script was shared with the research team who read it and ensured that it was scientifically accurate and that it reflected the research data. For example the use of appropriate language by the different health professionals represented – sonographer, laboratory technician and midwife counsellor, the way in which higher risk was referred to and explained in the text. There were some hard decisions to take concerning how much information could be included, particularly scientific information within a short piece for such a wide audience. The storyline involved a pregnant woman attending a prenatal screening clinic, and followed her physical and emotional journey through the clinic. A decision was taken to leave both the woman and the audience with unresolved possibilities and outcomes as a way of focusing on every woman’s dilemma and choices.

A mini lecture on the biochemical processes of maternal serum screening was inserted to convey not only the information, but also to parallel the didactic nature of much of the
information giving to women and also was congruent with a performance that took place often in classrooms or lecture theatres.

Artistically, the theatre director had to broker these different perspectives on stage and this necessarily involved adapting and modifying the script with discussion between primarily the actor and writer with the media technologist. An artistic device of a favourite but flawed coffee mug was used to convey the possibility of valuing imperfection.

“Like this mug—here’s a print of the potter’s thumb. And here’s a bit of clay peeping through where the glaze didn’t stick— that’s why I brought it. It’s individual. Even the potter didn’t know for certain how the pot would come out... All the time it’s in the kiln, it changes, becomes more itself........” (excerpt from script)

Visual technology

Visual technology was important throughout framing the performance. At some point the audience would see a scanned foetus at 12 weeks, just as a pregnant woman on her first visit to the clinic would. There were a wide range of visuals developed to enhance and signify the content and dilemmas of this production. An opening sequence accompanied by music with a fetal heartbeat, showed a waterfall that then transforming into the double helix of DNA. The use and reference to time both in the script but also in the visuals and sound track enhanced this theme. Set into the digitally created backdrop of the waiting room there was an interactive clock that synchronised to the duration of the time spent by a pregnant woman in a one stop first trimester screening clinic. This was accompanied
by the sound of time ticking on in the sound track, and within the theatre piece were moments when time was suspended to allow the audience to have insight into the internal dialogue of the pregnant woman.

The media technologist used the analogy of a digitally created fruit machine as a central image to convey the idea of probability. The artistic team felt that this represented the feelings of a pregnant woman that the chances of having a healthy baby are part of a lottery or due to fate or chance. However, this image provoked debate within the team, as some members felt that this would convey that screening was inexact. When seen in the context of the performance, it was understood as a visual device that portrayed the ambiguity of both the powerlessness and the sense of nervous expectation experienced by women at this stage of their pregnancies.

Owing to performing this piece in non theatre spaces but mainly in lecture theatres without a stage to support a physically created space, the media technologist, developed film of different contexts. The film was projected onto a large purpose built screen to be in keeping with the nature of a lecture theatre yet to enable the back projection that was required. Images included a domestic kitchen, driving to the clinic, footage from the prenatal clinic to frame the scenes, visualisation of the maternal serum analysis using a desk top Kryptor analyser and clips of foetal ultrasound scans as well as a number of ironic still images melding the faces of two well known celebrities to illustrate the media term’ designer babies’. The visualisation of the foetus using an ultrasound scan was one the main motifs and informed the title.
Fig 1 Poster of Inside View

Differences in perspectives within the team were sometimes not easily resolvable. This was epitomised by the debate held concerning the image used for the poster and programme for the performance. This image was felt by the artistic team to be eye catching and provocative and the media technologist was particularly fond of the depiction of the foetus in the womb drawn by Leonardo de Vinci. However, the social scientists did not like the headless depiction of a pregnant woman, as she is absent as a person and disembodied with the womb focused on as a transparent vessel and herself as the passive carrier. Indeed they felt it was too provocative. For those with scientific training, the depiction of the foetus was too inaccurate. The poster did not feature this image for performances in some venues to accommodate these differences. This issue symbolised and signified the necessary and inevitable differences within a multidisciplinary team.

**Panel discussions**

The panel discussions held immediately after the performances were an integral part of the production and generally included the theatre director, actor, media technologist, scientist, and social scientist. The questions asked were diverse covering health care
provision, the ethics of screening, the scientific basis of screening, the experiences of pregnant women and their partners and the artistic process of transforming research into theatre, engaging with the personal, scientific, research, policy and practice and ethical dimensions of the topic. The discussions were tape recorded and transcribed. Members of the audience responded in different ways and the performance elicited reflection that was disclosed and shared spontaneously as resonating with personal experience:

‘It reminded me just how much I hated being pregnant on three occasions, the reason being that each time you were set up as having a test that you cannot really pass, you go there with all this joy because you are pregnant, and you are being put through a process, where people look worried and concerned and put all sorts of doubts into your head. I though that was one of the wonderful things that emerged from this piece’

(Audience participant Warwick Arts Centre)

There was some understanding that the research study and the performance were different and this was one of the areas that the panel emphasised. One member of the audience commented:

‘It works on a lot of different levels because it is a piece of theatre, not a piece of propaganda. It has come out of research but it is a piece of theatre and therefore it has a life of its own which may be something quite separate from the research or the things which you hoped and intended would come out of it’

(Audience participant – Warwick Art Centre)

The theatre director was able to describe to the audience the way of working from research to performance.
‘We worked if you like in a kind of reverse kind of play. Generally speaking, we think perhaps of the work we want to do and then we do the research and find out about it. Here we had the research and then we worked very hard to produce the piece…..Our chief aim has been to raise questions and debate.

Theatre Director – Warwick Arts Centre

Members of the audience also raised general ethical issues and sometimes there was inadvertent disclosure.

‘There is a limited debate about Downs Syndrome. Is it really that much of a problem that we need to abort these children? I am not talking from a religious point of view…. I have a niece who has Down’s syndrome. She has… these young people and their families have had a great deal of pleasure having these children and I think we need to have that debate’ Warwick Arts Centre

Health professionals in the audience also reflected on their own practice openly:

‘I spend most of my time performing prenatal diagnosis including CVS. … In actual fact, it is the whole spectrum of the population that has difficulty with screening whether you come from a very educated or poorly educated background. I think the one thing we mustn’t forget and I thought you brought this over beautifully, is that it is a pregnancy. As healthcare professionals, we must respect that and that is so important. It breaks my heart when I see fellow colleagues perhaps not addressing this in the manner that it should be addressed.’

Warwick Arts Centre – health professional

Some felt that the panel discussion was an essential part of the performance:
‘I think to do the play without the discussion would be wrong. But to have the discussion so that we can add things in..., by the audience is really important’

Church House- academic

Evaluation

Evaluation sheets were handed out and about 35% of the medical engineering and midwifery students who attended filled in the forms. As would be expected, the midwifery students and health professionals were more enthusiastic than the engineers.

Table 1 Evaluations of medical engineering and midwifery students and health professionals

There were a wealth of comments and the few below give a flavour of the range of responses. The midwifery and nursing students and health professionals who attended the performance at a major London teaching hospital and university, reflected on their practice.

Excellent idea, well produced and performed, thought-provoking and slightly disturbing in parts

I am a medical student and feel the performance raised issues we had previously come across but from the mother’s perspective which is very enlightening before we begin working with pregnant women.
It makes you sensitive regarding your routine work (bookings etc)

GP: I refer pregnant women automatically for screening – from now on, I will discuss it with them

Others reflected more on the constraints of routinized care in the clinic:

‘There have to be enough midwives to be able to see women as individuals and make it less of a ‘conveyor belt’ experience.’

Whereas others focused on the issues posed by new technologies:

‘To see the problems mirrored by a real person helps to identify and analyse issues of new technologies.’

The medical engineering students were less close to clinical practice but their comments reflected a realisation that medical engineering downstream affects women’s daily lives.

‘We all need more knowledge. Knowledge is power – ordinary women tend not to have this’

‘The presentation made me realize that my degree will affect people other than me’

‘There’s well too much stress for pregnant women!’

A teacher felt that ‘it would be excellent for pupils prior to conception’.

**Discussion**

On reflection, we underestimated the lack of the technical support available to present this performance in non theatre spaces. Technical support in academic institutions in
lecture spaces is not readily able to conform to the vigorous demands of theatre presentation and this resulted in the media technologist having to support all the performances. We also needed to adapt the script in an iterative way and this required more time than we had expected but was essential and valuable. The budget was unrealistically low and the time involved underestimated.

Some issues were difficult to negotiate owing to the different perspectives of the team members. The poster for the programme produced different reactions - for the artists it was polemical and representational, whilst for the scientist and social scientists it was physically inaccurate and socially problematic.

There are ethical issues that need to be faced when utilising applied theatre with public involvement through audience participation and discussion. The audience engaged cognitively and emotionally with the performances and in the discussions, there was disclosure of personal professional practice and experience of those present or members of their families that breached confidentiality and anonymity. On reflection, we were not prepared for this and in future would have taken a number of steps to contain this safely through provision of information pre performance and support post performance.

Applied theatre can be a transformative process for all those involved with it and it can be a ‘multidirectional engagement tool’ (3:266), It did elicit debate and engagement with health policy and practice post performance but the extent of the engagement and its lasting effects was not captured by the evaluation and is a methodological challenge.
There are some ethical concerns concerning disclosure during audience discussion and the personal impact of material presented (18). It is a tool for change (19) and in this case, was a way to engage a varied public in the policy implications of an important area of health care. There is growing interest in the use of applied theatre by social scientists and theatre practitioners owing to its effectiveness in stimulating debate and engagement but there remain challenges to be addressed.

Endnote
1. ‘Inside View’ can be seen on http://www2.warwick.ac.uk/fac/cross_fac/healthatwarwick/research/pastresearch/inside_view

References


19. Mienczakowski J. (1997) Theatre of Change, Research in Drama Education 2, (2) 159-171
<table>
<thead>
<tr>
<th>Performances</th>
<th>Location</th>
<th>Participants - Number</th>
<th>Audience</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Warwick University Arts Centre theatre</td>
<td>75-100</td>
<td>Medical students, Faculty, public</td>
</tr>
<tr>
<td>2</td>
<td>Warwick University Ramphal Lecture Theatre</td>
<td>??</td>
<td>Medical Engineering students</td>
</tr>
<tr>
<td>3</td>
<td>Kings College Lecture Theatre</td>
<td>100</td>
<td>Midwifery students and health professionals</td>
</tr>
<tr>
<td>4</td>
<td>Final conference Deans House, Dean’s Yard, ESRC Innovative Health Technologies Programme</td>
<td>100</td>
<td>Academics, Policy makers,</td>
</tr>
<tr>
<td>5</td>
<td>Sir Henry Parkes Primary School Coventry Sure Start Centre</td>
<td>15 + 5 staff</td>
<td>Young mothers group</td>
</tr>
<tr>
<td>6</td>
<td>Warwick University Avon Studio</td>
<td>9</td>
<td>Staff</td>
</tr>
</tbody>
</table>
Figure 1: Poster of Inside View performance
Table 2 - Responses of medical engineering and midwifery students and health professionals summarising % who responded with 4 or 5 on a scale of 1-5

<table>
<thead>
<tr>
<th>Questions</th>
<th>Medical Engineering students</th>
<th>Midwifery students and health professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you enjoy it?</td>
<td>69%</td>
<td>91%</td>
</tr>
<tr>
<td>Did it raise issues of new technologies in screening?</td>
<td>86%</td>
<td>80%</td>
</tr>
<tr>
<td>Did you feel it was relevant to your training or work?</td>
<td>56%</td>
<td>80%</td>
</tr>
<tr>
<td>Did it relate to experiences in your life?</td>
<td>31%</td>
<td>76%</td>
</tr>
</tbody>
</table>