

## WeLDNurses Non Invasive Prenatal Testing Consultation Easy Read

	<p>A new test has been developed that helps health professionals to identify the likelihood of a pregnant woman having a baby with Down Syndrome, Edwards Syndrome or Patau's Syndrome. This test is known as Non Invasive Prenatal Testing (NIPT).</p>
	<p>WeLDNurses hold two weekly twitter chats on subjects relating to people with learning disabilities and Learning Disability Nursing.</p>
	<p>Nuffield Bioethics are currently asking people's opinions on NIPT. WeLDNurses held a twitter chat on NIPT on 24<sup>th</sup> May 2016.</p>
	<p>42 people attended this chat. WeLDNurses looked at what people talked about, found 8 themes and made some recommendations.</p>
	<p><b>1. Value for women and families –</b></p> <ul style="list-style-type: none"> <li>• The test will give a clearer picture if the foetus has Down's syndrome, Edward's or Patau's syndrome.</li> <li>• The test is less risky than the current invasive tests.</li> <li>• The test will give women and families faster, more reliable information.</li> <li>• It is likely that this will increase the number of terminations of pregnancy.</li> </ul>
	<p><b>2. Economic –</b></p> <ul style="list-style-type: none"> <li>• A question was asked if this test provided more benefit for the money.</li> </ul>
	<p><b>3. Service and Practice Development –</b></p> <ul style="list-style-type: none"> <li>• Services providing NIPT ought to adjust their pathways to ensure women and families are able to make fully informed choices.</li> <li>• This should include support from those with a good knowledge of people with learning disability in society today.</li> </ul>
	<p><b>4. Affective –</b></p> <ul style="list-style-type: none"> <li>• Most people were sad the NIPT would likely increase the number of terminations of pregnancy.</li> </ul>

	<p><b>5. Ethical and Society Questions -</b></p> <ul style="list-style-type: none"> <li>• Many people talked about the value society places on people with learning disabilities and their families.</li> <li>• It was questioned as to what society might be like without people with Down's Syndrome?</li> <li>• It was questioned what might be tested for next?</li> </ul>
	<p><b>6. Language and use of words –</b></p> <ul style="list-style-type: none"> <li>• We talked a lot about how important using the right words is when helping people make decisions.</li> <li>• Using negative terms and not looking at the positive sides could encourage women to have terminations.</li> <li>• This is something that needs to be challenged</li> </ul>
	<p><b>7. Learning Disability Nurses –</b></p> <ul style="list-style-type: none"> <li>• Learning Disability Nurses have the knowledge skills and experience to support women to make choices about their pregnancy.</li> <li>• In 2013 it was recommended to government that Learning Disability Nurses should be involved in helping women make choices about their pregnancy.</li> <li>• There is no evidence of this having happened.</li> </ul>
	<p><b>8. Education –</b></p> <ul style="list-style-type: none"> <li>• Lots of good ideas were discussed to improve awareness and understanding for those in maternity services. These included:- <ul style="list-style-type: none"> <li>○ Families sharing their stories</li> <li>○ Involving people with learning disabilities and families in teaching.</li> <li>○ Developing education and training packages</li> </ul> </li> <li>• Further work to ensure that people with learning disabilities and their families can be seen regularly on TV and in the newspapers.</li> </ul>
	<p><b>Conclusion</b></p> <ul style="list-style-type: none"> <li>• WeLDNurses have made this report easy to read as we are not aware of people with learning disabilities have been asked their opinion about NIPT.</li> <li>• WeLDNurses has made recommendations for commissioners, providers, regulators, people with learning disabilities and their families to ensure this is carefully implemented.</li> <li>• For more details on this chat please go to <a href="http://www.wecomunities.org/tweet-chats/chat-details/2765">http://www.wecomunities.org/tweet-chats/chat-details/2765</a></li> </ul>
	<p><b>WeLDNurses are</b></p> <ul style="list-style-type: none"> <li>• Sally Wilson - @salsa442</li> <li>• Sam Abdulla - @samabdulla</li> <li>• Ross Wyatt - @ross_6479</li> <li>• Daniel Marsden - @dmarsden49</li> </ul>

## WeLDNurses Non Invasive Prenatal Testing (NIPT) Consultation submission

### **Preface**

WeLDNurses formed in summer 2012 and is run by four Learning Disability Nurses (LDN) Sally Wilson - @salsa442 Sam Abdulla - @samabdulla Ross Wyatt - @ross\_6479 and Daniel Marsden - @dmarsden49 to encourage LDN's around the world to utilise social media as creative space for professional development, networking, debate and problem solving. It is intended to offer LDN's a place to consider specialist subjects, LDN perspectives on mainstream topics and put these in the context of a wider community of stakeholders whose participation and contribution is actively encouraged.

WeLDNurses have previously been commissioned to run chats by Health Education Kent Surrey Sussex, NHS England, and the Department of Health, and have been contracted to provide social media & conference engagement consultative advice by RCNi, London South Bank University and Royal College of Nursing.

WeLDNurses run two weekly twitter chats using #weldns on prearranged topics from 8-30 until 9-30BST.

### **Introduction**

Since its inception WeLDNurses has had shared objectives with Positive Choices – a group that celebrates those that have chosen LDN as a career and hold a free annual student conference. Through this forum we became aware of Hayley Goleniowska – Downs Side Up and her and her family's journey in having a daughter with Down's syndrome. An instant connection was made, as we as LDN recognised our knowledge, skills and experiences could be of value to women and families who report the challenges of influenced by medical model maternity services.

WeLDNurses was interested to observe recommendation 10 of the All Parliamentary group's report on Abortion and Disability (Bruce, 2013) which read:-

*"There should be consideration of the expansion of the role and responsibilities of Learning Disability Liaison Nurses (LDLNs) to all disabling conditions so that they can support couples who discover their unborn child has a disability."*

We have – as yet – not heard of any specific good practice examples in this regard.

Since this time, mainstream media attention on this subject has ranged from the political sensationalism (Masters, 2012) to orthodox academic ethicism (Alexander, 2014), to medical

model triumphalism (Gallagher, 2016), while women, families and people with Down's syndrome and some professional groups have had some success in presenting the possibilities, contributions and the 'human face' of people with learning disabilities in UK society (BBC, 2012, Sanderson, 2012, Gordon, 2015).

As LDN, while we have an awareness of 'screening' as a concept and in some cases we had personal experiences of these pathways, we have little involvement and therefore lack the practical knowledge of systems, processes, support and outcomes. However, having the privilege of working with people with learning disabilities, their families and other stakeholders we posit we are a best placed to give an open and honest account of the possibilities for people with learning disabilities being born today and relish the opportunity to do so. We were also aware of the distinctions between Down's syndrome as a condition that has associated health issues compared to Edward's and Patau's syndromes that were significantly life limiting, and would be unlikely to live far into childhood, and the implications this might have on the process.

Conversations about a WeLDNurse chat on this subject started in 2015 with potential partners, however the recent interviews on BBC Radio 4 (2016) and publication of the Consultation papers from Nuffield Bioethics (2016) had this chat scheduled for 24<sup>th</sup> May 2016 from 8-30 -9-30BST using the #weldns hashtag. While there have been many influencing and supporting the development of the chat, WeLDNurses took the stance to lead this conversation, welcoming views of LDN's amongst all stakeholders.



## **Methods**

### **Having a WeLDNurses chat happen**

WeLDNurses invite stakeholders and partner organisations to submit 'Host a chat' form (WeCommunities, 2016) outlining the subject matter for the chat and consider its relevance for LDN and the wider community. The 'Host a chat' form provides a framework for hosts to prepare to engage participants in the topic, this includes pre chat reading, evidence,

references, and some questions for the chat. One of the WeLDNurses team coordinates the chat, publishing the pre chat reading on the WeCommunities site, engaging the community across platforms and will negotiate roles. The Chat Host – the person who asks the questions on chat night – is a significant role, and one which will be attributed to the appropriate person/account depending on the context and relevance of the topic and proposed outcomes of the host. Teams have previously hosted chats, in these situations, a little more planning and preparation is required to ensure the chat is coordinated.

### **Down's Syndrome Screening – The NIPT Debate**

Having been some time in development, this chat used a distinct model from above. An academic assignment was adapted and consulted upon by experts in the field, which elicited the complex ethical territory upon which this subject sits. For instance we became aware that the All Parliamentary report into Abortion and Disability (Bruce, 2013) website had recently been taken down, and that reference material contained therein had to be sought and referenced. We also became aware that previous debates have exposed significant support from those ethically opposed to termination, while we acknowledged their right to have their say we would contend the ethical issues associated with NIPT and the possible results are distinct from those associated with the strict pro-life perspective; the authors were also aware of the gender issues associated with this topic, and what some might perceive as a bias of views of those who work and live in the world of learning disabilities.

This last contention is worth consideration; researchers that draw upon critical social paradigm indicate the 'insider' facilitator is better able to move seamlessly between the context and the evidence. Costley et al (2010) observe the many advantages of the 'insider' facilitator, those of expertise, values and interest in the topic, the investment in local issues, their access to the relevant expert stakeholders; it is also suggested that insiders are less likely to encounter ambiguity, and more able to unravel the complexity involved in the subject.

As all WeLDNurses chat are public discussions as part of public record, consideration is always made for the safety of those joining the chat. Based on the above, this chat demanded particular scrutiny and reflection to ensure the Chat Host asked impartial questions, and encouraged responses, while not favouring a particular viewpoint, beyond that of the potential benefits of LDN being involved in this area of clinical work. As always WeLDNurses prefaced the chat with reference to the Nursing and Midwifery Council Social Media guidance (NMC, 2016).

In the days leading up to the chat we had the Nuffield Bioethics consultation papers shared with us, and extended the invitation to join the chat. Having viewed the Nuffield Bioethics papers, questions were selected that had synergy with the preparation WeLDNurses had completed. However re-wording and re-phrasing was undertaken for three particular reasons:-

- 1) The unusual and potentially biased and leading phrasing (“advantages” and “concerns”) of the Nuffield Bioethics consultation.
- 2) To fit in with the Twitter requirement of 140 characters
- 3) To have relevance and application to a WeLDNurses chat participants.

The WeLDNurses Chat questions can be found in Table 1.

**Table 1 Questions posed during WeLDNurses Chat**

- Q1 NIPT will be offered to women at a high risk of having a child with Down's. What are the advantages of having this test?
- Q2 What are your thoughts/feelings if [#nipt](#) led to an increase in terminations?
- Q3 What might be the disadvantages of having [#nipt](#) available in the UK?
- Q4 What information about [#nipt](#) & the conditions should be shared & by whom?
- Q5 What will the impact of [#NIPT](#) be for people with Down's, Edwards, Patau's syndrome, their families & our society?
- Q6 Do we think Learning Disability Nurses have a role in this area of work?

**Polls**

WeLDNurses used polls during this session for the first time, we thought the conversation would provide a lot of qualitative and lived experience data, the polls would help us to collect some quantitative data.

Participants engaged well in the method and it highlighted that as a quick and easy way to respond to closed questions. This has the potential to release time to explore the qualitative elements of topics discussed and to maybe build on and discuss some of the answers given in the polls. It also provided instant feedback as to participants context and opinions.

**Thematic analysis**

The WeLDNurses chat results including the full transcript (WeLDNurses, 2016) provided the basis for a thematic analysis (Paterson et al, 2001). Appendix 1 provides evidence as to how the below themes were arrived at. These themes are:-

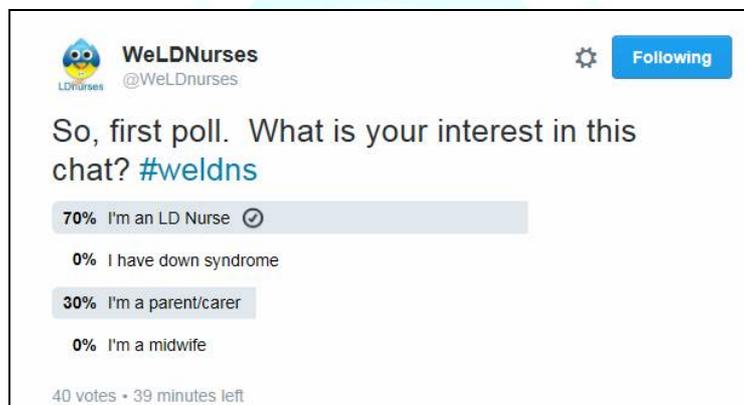
1. Value for women/ families

2. Economic
3. Service & practice development
4. Wider ethical and societal questions
5. Implications for Learning Disability Nurses/nursing
6. Affective
7. Language & discourse
8. Education

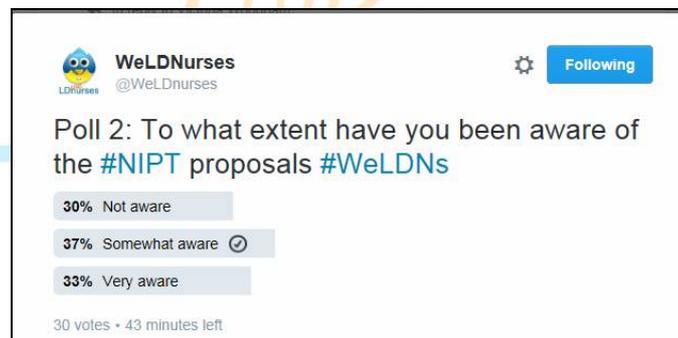
## Results

### Chat Stats & Poll Results

The chat attracted 42 contributors with a total reach of 312,035.



The first poll identified the split of parent/carers and professionals in the chat, although LDN appeared as the higher proportion, some of the LDN are also parent/carers and there is no way of differentiating which option people identified with on the poll, or if they chose an option at all. That said, it still proved to be encouraging to see a mix of nurses and parent carers giving us the opportunity to debate, reflect and identify new actions and activity.



This identified an even spread of knowledge, this was interesting because it gave good criticality to the debate as everyone wasn't coming from the same place in their understanding of the topic and during the chat people would have the opportunity to develop their thoughts and ideas, whilst those who were very aware would be able to support those

that weren't and reflect on the other participants' positions' in the debate. It is often useful to have people with little knowledge in the debate to ask the obvious or naïve questions that those who are deep in the topic may have not given thought for a while.



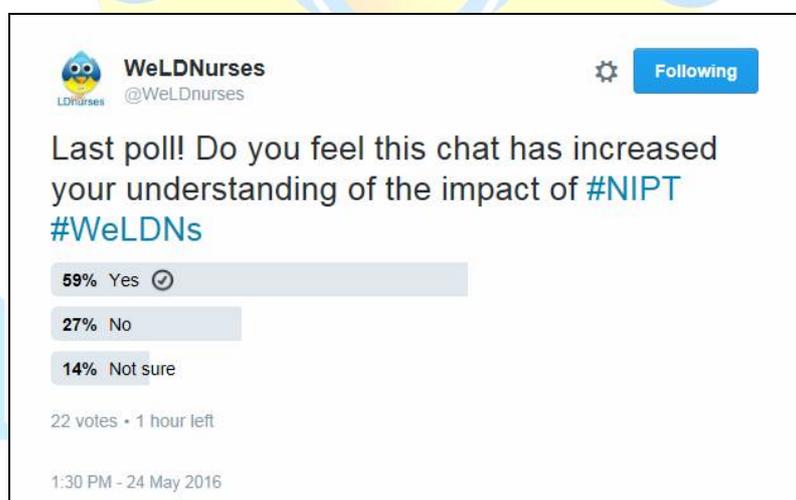
Interestingly there was a majority who felt that the test would impact the future population. Something that was explored further through the discussion was 'how' this would impact and 'who' would feel the impact. This sparked some interesting debates and some very appropriate points for consideration.



As is often the case with twitter chats, people's views may start one way and as a result of conversation, impact and reflection, can change leaving people with questions about the issue at hand and things they want to go away and consider further. This response identifies that there is still some degree of unrest about this test being placed in the screening process on the NHS with a greater number of people responding with 'no' and 'not sure' than agreeing that it should.



As learning disability nurses, we feel it is part of our role to advocate for the population which we care for and therefore naturally feel that this topic is close to our area of practice and something we want to be involved in. As there were a high proportion of LDN in the conversation you might think that this is the expected result, although the poll itself cannot determine who has selected which answer, the conversation around this would leave us thinking that it is more likely that more of the parent/carers answered yes with some LDN answering not sure. Nevertheless this is a large majority who believe that LDN should be involved.



As is always the case, these chats are intended to support people to explore an issue together and hopefully come away with something new, so it was reassuring that over 50% felt their understanding had increased. This supports the idea that many people need more information and knowledge before a decision can be made in this area. Considering the aim of this chat and the position we are in to feed into the consultation, this poll provides us with some evidence that there is a need to explore this further before any decisions are made.

Although the sample size is relatively small, the split of professionals vs parents/carers was useful and whilst this data is collected from the people who directly engaged in the chat there were many more people who accessed the information and will go on to access the information as the blog is published. The chat had a social reach of over 300,000 people, it would be interesting for further exploration to publish the polls again for a longer period of time and invite people to respond to allow the collection of a larger sample size.

## ***Thematic Analysis Results and Discussion***

### *Value for women/ families*

The chat commenced offering participants an opportunity to consider what might be the advantages for those experiencing this new service and how this might benefit newly pregnant women. While it was observed that the test is not sensitive or accurate enough to be referred to as a diagnostic, it was believed to offer a clearer indication of whether the foetus will have Down's, Edward's or Patau's syndrome without the risks associated with amniocentesis – although it was observed that only the later would offer irrefutable evidence of the condition being present. It was observed that greater information with reduced risks ought to both empower the women and family to plan their futures.

While informed decision making was seen as an advantage, family stories of receiving results of their tests were shared, including over the phone in the supermarket, and letters posted through the door. In this context transmission of results that women will use to make their decisions is as important as the information itself and particular attention should be paid to this element of the screening pathway.

Participants acknowledged that NIPT afforded women and families swifter and more reliable information with which to make choices, which would go some way to enable the necessary preparation for the arrival of their baby.

**Recommendation - NICE produce national practice guidance on the implementation and monitoring of NIPT.**

### *Economic*

It was also questioned whether NIPT is a more cost effective process and easier to regulate for the NHS compared to the identification processes currently in situ.

## **Recommendation – Economic assessment of NIPT to be completed.**

### *Service & practice development*

The above observed advantages were viewed in context with the service and practice developments that will be required, to include expert support and guidance through the identification processes, for professionals to retain the distinction between the value for the life and supporting women through the decision making process. Acknowledging the joys and challenges of becoming a parent, and in particular the commonalities and distinctions of having a child with Down's, Edward's or Patau's syndrome. Within this, it ought to be recognised that while people with Down's syndrome are prone to have several associated health conditions, those with Edwards and Patau's syndromes will have life limiting conditions, most of whom will not live beyond their first year, as such it is not always useful to conflate the three conditions.

Third sector organisations were mentioned here, in particular the challenges to obtain research funds currently to further develop our understanding of Downs' syndrome, while other charities self identified as being able to support women however they may choose. There were also questions posed as to whether terminations are available after a positive NIPT test, and by consequence how many false positive tests could lead to terminations of foetus's that were wrongly identified?

**Recommendation - Royal College of Midwives to review guidance, educational materials and competences for midwives relating to people with learning disabilities.**

**Recommendation - Royal College of Midwives & Royal College of Nursing to respond to Recommendation 10 from the Abortion & Disability report (Bruce, 2013).**

**Recommendation - NHS England to monitor impact of implementation of NIPT on termination rates.**

### *Affective*

A question about participants' feelings toward an increase to terminations as a result of the introduction of NIPT, elicited an overwhelming response of sadness and provided participants with an opportunity to reflect on their own values and beliefs as individuals and how these might align or contrast with those of a registered healthcare professional. These responses ought to be considered both by individual nurses and those considering involving LDN's in the

antenatal screening to enable processes to ensure individuals are supported to deliver the service sensitively and with compassion.

### *Wider ethical and societal questions*

Initial chat questions asked about the advantages of NIPT, which prompted broadening responses relating to context of the question and 'who' or 'what' might perceive NIPT as advantageous. This response set a specific theme that weaved its way throughout the chat, with participants questioning the value that society places on people with the aforementioned syndromes and their families, whether there is a wider understanding and appreciation of the contribution that people with learning disabilities can make to society. It was also observed that at a time of widening social integration with current generations having greater exposure and understanding of those with learning disabilities, the possibility of a UK population without the aforementioned groups of people based on their genetic make-up was a significant consideration.

The aforementioned pressures (Masters, 2012, Alexander, 2014) in the mainstream media also require consideration; the perceived 'burden' that is being brought into the world and the perceptions of irresponsibility of women to make these decisions is also a factor that impacts on choice making.

There were observations relating to the particular subcultures or communities of people with Down's syndrome and their families and supporters, with the implication that these would be significantly impacted by the reduction in the population and the associated isolation, exclusion and stigmatisation.

Questions were posed as to the short medium and longer term implications of this type of testing :-

- What will be the impact for people with the associated syndromes and their families and stakeholders?
- What will be the impact for women and families coming into contact with this testing procedure in the future? Will the smoothest route be toward testing and termination?
- What are the indicators of success of NIPT, and how will we know that these are being achieved?
- What conditions will be subject to further scrutiny and screening processes?

**Recommendation - Research funding to be made available to explore the impact for families and stakeholders of NIPT implementation.**

**Recommendation - National benchmarks to be published on the effective implementation and monitoring of NIPT for healthcare providers.**

**Recommendation - Health and Social Care Information Centre to publish retrospective and prospective annual reports on disability and termination of pregnancy.**

**Recommendation - Healthcare providers publish annual monitoring reports relating to disability and termination of pregnancy.**

### *Language & discourse*

The use of language for framing and describing this area of work was picked up on as significant. The use of words such as 'screening' and 'risk' and information providers observing foetuses as 'abnormal', along with professionals commencing the conversations with "I'm sorry...", or "It's bad news..." could be observed as an implicit indication of negativity, which – as is acknowledged by the consultation then be linked with termination. This type of discourse could be observed to be employing behavioural 'nudge' techniques within public health as observed by Voyer (2015) to encourage behaviour change and influence decision making based on liberal paternalism. Voyer (2015) goes onto observe the significance of the social environment in decision making, highlighting the importance of reciprocity, social norms and feedback all of which could be considered at play within the pathways of care within this area of work.

This discourse is also indicative of the pervasive medical model perspective through mainstream media. Best examples of this are Wikipedia (2016) and NHS Choices (2016) perspectives on Down's syndrome which outline the features, associated health needs and prognosis. What is absent from these reliable sources of data is how people with Down's syndrome might function and contribute in UK society today. Families continue to challenge this orthodoxy with publications, blogs and films (Goleniowska, 2014, Gordon, 2015) and ought to be supported to do so.

Autonomy and women's choice is very much dependant on the range of influencing factors, one parameter is the amount of time for decision making, while the information clarity, enabling this choice making is crucial. Following the chat, participants shared an American

public health film (Genetic Support Unit, 2016) that would be useful to contextualise to a UK audience.

Good examples of relatively non biased – but not developed for a UK audience -patient information (Lettercase, 2016) were also shared.

**Recommendation - The UK National Screening Committee recommendations non-invasive prenatal testing (2016) recommendations are reviewed, strengthened and reported on.**

**Recommendation - Research funding to be made available to provide an ethical inquiry into the discourse employed and its impact on decision making and autonomy.**

### *Implications for Learning Disability Nurses/nursing*

Participants acknowledged that while LDN's might be able to contribute to the antenatal screening process associated with Bruce's (2013) recommendation, it was observed that Learning Disability services would be unlikely to be engaged or commissioned to do so currently. Reference was made to contacts via the Royal College of Nursing where a good practice example might be found, however on investigation, while Learning Disability services in that area remained ready to welcome referrals for this type of work, none had been received.

It was observed that LDN's could offer an independent voice within the screening processes in a way that charities may find difficult in several different ways:-

- 1) Working with maternity services to plan the 'screening' pathways to identify points at which adjustments could be made.
- 2) Employing practice development methods to enable and empower maternity services to improve and provide adjusted pathways.
- 3) To provide and facilitate education and training opportunities to frontline maternity staff, relating to learning disabilities and reasonable adjustments.
- 4) To work alongside 'screening' services to support women to make informed choices.
- 5) To support and lead on transformational and inclusive research in this area.

It could be expected that these collaborative activities would have positive implications for women and families going through these screening processes while also providing support to midwives in supporting women with learning disabilities and learning difficulties using maternity services.

Along with these direct impacts LDN's were identified as ideally placed to support people with learning disabilities to advocate for themselves on this proposal, and could harness and translate the viewpoints and perspectives of families and other stakeholders to create consensus as the best way forward. On this point, it was of interest by all participants in the chat as to what reasonable adjustments under the Equality Act 2010 Nuffield Bioethics had made to the consultation process to enable people with learning disabilities and in particular the conditions to contribute.

WeLDNurses were pleased to welcome several charities to this chat, one of whom has a place on the UK National Screening Committee. WeLDNurses was pleased to be able to showcase the knowledge, skills, values and beliefs that LDN's could bring to this area of work, and we would encourage both those Charities and the UK National Screening Committee to consider how these knowledge and skills are represented and could be employed to improve care and support of women, families and people with learning disabilities across all services.

**Recommendation - Royal College of Nursing and Royal College of Midwives to produce guidance based on Bruce's (2013) recommendation.**

**Recommendation - Nuffield Bioethics to identify what adjustment made under the Equality Act have been made for people with learning disabilities to contribute to this consultation and outline this distinct in the final report.**

**Recommendation - For Improving Health & Lives to review and report on use of maternity services by people with learning disabilities in the England and Wales and 'screening' services.**

**Recommendation - For LDN's, local commissioners and stakeholder/partnership boards to review practices locally.**

**Recommendation - Charities & UK Screening Committee to consider how Learning Disability Nurses might contribute and influence the 'screening' advice and processes.**

### *Education and development of practice*

Participants were enthusiastic to identify creative, engaging, and experiential education opportunities to support and enable frontline staff to reflect on their values and beliefs while identifying adjustments and improvements to the care and support that all women and families might experience.

It was observed that personal testimony was the most powerful, and involving people with learning disabilities, family members and other stakeholders would be the recommended for local healthcare providers and higher education institutions.

Reusable Learning Objects (RLO) such as films and e-learning packages were considered also. Free online courses like UCL (2016) appears to be an important first step in this regard however these would benefit from greater input of people with learning disabilities and other stakeholders. The promotion, implementation and evaluation of the Down's Syndrome Association (2016) and Royal College of Midwives accredited 'Tell it Right' education programme would also offer some assurance of local activity.

Ethical and legal competences associated with this service and the client group would be beneficial for examination throughout the career pathway of all disciplines working with maternity services, similar to those referred to in Scotland.

In acknowledging that education in pregnancy is 'too late' participants refer to a latent societal preconception about disability, which also requires challenging in a number of ways:-

- 1) Further implicit and explicit presentation of people with learning disabilities in the mainstream media
- 2) NHS England to report regularly on the 5 year forward view action recommendation of employing people with learning disabilities.
- 3) Special Olympics to receive increased coverage in mainstream media.

**Recommendation - Healthcare Providers and High Education Institutions, and Regulators to review education opportunities and competences for healthcare professionals of all disciplines involved in Maternity services relating to people with learning disabilities.**

**Recommendation - Royal Society of Midwives to commission RLO's relating to 'screening' pathways, and identification and communication of disability along with the care of people with learning disabilities & families,**

**Recommendation - Transformational research and practice development be employed to consider how to implement, evaluate and educate all in NIPT's introduction.**

**Recommendation - Mainstream media consider further opportunities to have people with learning disabilities represented positively.**

**Recommendation - Statutory employers report regularly on the numbers of people with learning disabilities working 16 or more hours per week as a proportion of their workforce.**

## Conclusions

This report seeks to respond to the Nuffield Bioethics Consultation on the implementation of NIPT, by reviewing the WeLDNurse chat held on 24<sup>th</sup> May 2016. A thematic analysis of the transcript has highlighted seven areas for further consideration and several recommendations for individual's, healthcare professionals, local commissioners and national organisations.

These highlighted the contribution that Learning Disability Nurses could make in this ethically thorny area of practice, as advocates, enablers, facilitators and practice developers.

This analysis is based primarily on the implementation of NIPT to test for Down's, Edward's and Patau's syndromes, however it was acknowledged by participants in the chat that further discoveries in this technology will bring further significant ethical dilemmas that would be important to prepare for. WeLDNurses recommend that this preparation must begin with ensuring the implementation of NIPT is careful and thoughtful while transformational research methodologies are employed to ensure evaluation is considered from all perspectives.

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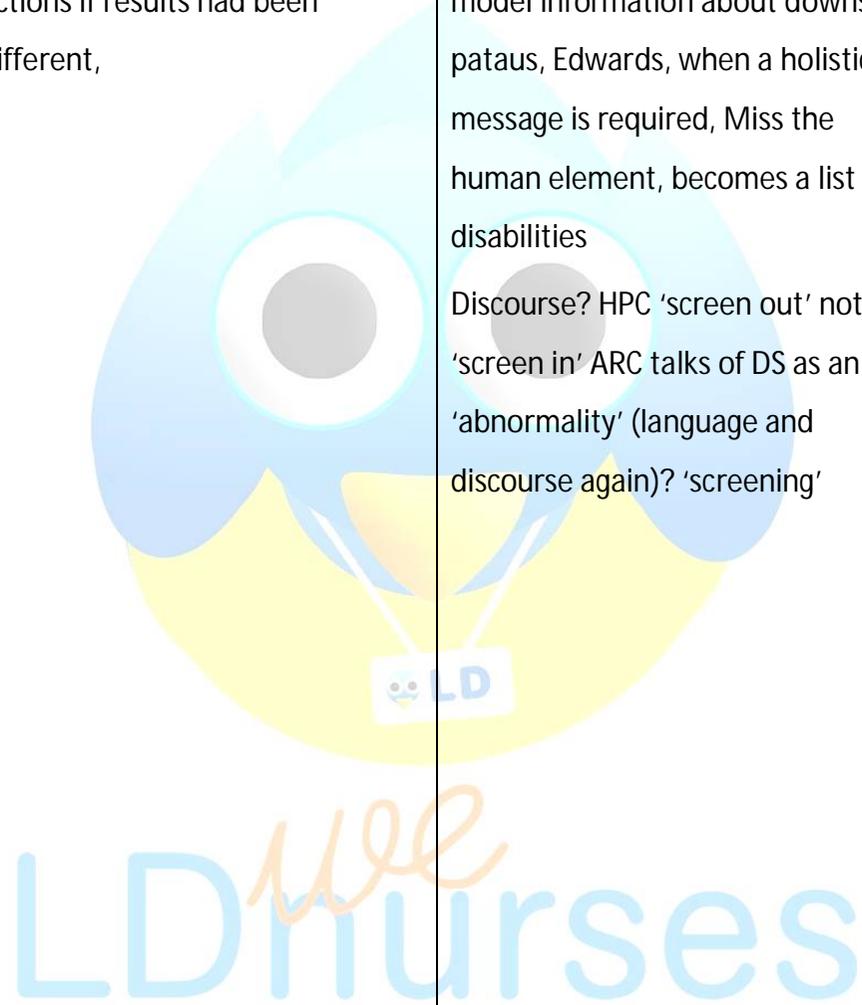
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## Appendix 1 Table evidencing NIPT chat themes

<p><i>Value for women/ families :better informed to make choices, , , hoping for balanced info for parents, preparation, value to women less invasive babies saved, less cause of miscarriage, More discrimination and grief for parents. Current diagnosis is delivered in a haphazard fashion, evidence of diagnosis being provided by phone, in the supermarket, notes through doors. Balanced information required.</i></p> <p><i>Reporting on what everyone is doing, Son sitting GCSE's this</i></p>	<p><i>Economic Finances NIPT not diagnostic, NIPT is cheaper?, 'NIPT reliability unknown' TOP not considered as significant in the studies more emphasis on miscarriages prevented, NHS should be able to regulate use of nipt better.</i></p>	<p><i>Service &amp; practice development: timely expert intervention balanced support through pathway, distinction between value of the life and support to the parents, joys and challenges of having a child with DS (commonalities and distinctions?) ARC provide support for women whatever their choice. Research funding will be more difficult to find DSE International research requires implementing how many terminations of non down's syndrome children will there be?</i></p>	<p><i>Wider ethical and societal questions: Questions as to who or what might be perceiving the advantage? as a population what part do people with learning disabilities and DS in this case play in our society?, if lives lost is measure then losing people with DS is a negative to everyone. Is there enough thought put into support for those who have a positive result? Impact of losing DS from our population? NIPT is not a</i></p>
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<p>week, not unique, but not significant in discussions with women at the time of choice.</p> <p>Road map to Holland</p>			<p>confirmation of diagnosis, Where will this level of 'screening' go next?</p> <p>Is Down's a sub culture of society in itself?</p> <p>Is the real question how do we show down's as integral to society value accordingly</p> <p>Ensuring there is a wider public platform for this debate</p> <p>What 'pressure' will be on women to select the test?</p> <p>Next generation will be more exposed</p>
<p><i>Implications for Learning</i></p>	<p><i>Affective : Sadx3, Sad for our</i></p>	<p><i>Language &amp; discourse and the</i></p>	<p><i>Education : Personal and parental</i></p>

<p><i>Disability Nurses/nursing</i> :Very unlikely LD Nurses would get the referral. LD Nurses are seen as less biased, in a way that the charities are not.</p> <p>Do learning disabilities nurses experience the same stigma as people with learning disabilities and DS? Are there any parallels in the population sizes?</p> <p>Current view = increase in TOP could LDN view change this?</p> <p>Helping to harness the voice of people with learning disabilities and other stakeholders</p> <p>LDNursing input pre and post identification</p> <p>LDnurses have VIP role, as there</p>	<p>society Reflection : questioning actions if results had been different,</p>	<p>impact on outcomes, medical model information about downs, pataus, Edwards, when a holistic message is required, Miss the human element, becomes a list of disabilities</p> <p>Discourse? HPC 'screen out' not 'screen in' ARC talks of DS as an 'abnormality' (language and discourse again)? 'screening'</p>	<p>testimony is powerful, Films?</p> <p>'Our lives have had more light and much less doom since G was born</p> <p>Rewrite the script and retell the story Are labels a bad thing? How do we instill value of people with disabilities in others?</p> <p>Ask wemidwives what support they receive to deliver this information</p> <p>Too late to educate in pregnancy?</p> <p>Schools</p> <p>@DSA Tell it right should be a core competency</p> <p>Embedding LD competencies in all undergraduate training in Scotland</p>
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<p>is a greater holistic understanding 'screening' becomes a stereotype leading to prejudice</p>			
<p><i>Specific conversation</i> Jane Fisher ARC – Robust defence of literature – claims of down's as a foetal anomaly. ARC provide booklets and signpost, but no peer councillors. Questions as to how many follow that route? If ARC supports all through pregnancy, does it have any LDNurses supporting and advising? Distinction between choice and informed choice, and a pathway</p>	<p>How will Nuffield Biotethics engage people with downs syndrome and people with learning disabilities in this conversation/consultation?*</p> <p>Volunteers for running consultations? Isn't that the Nuffield's job to arrange this?</p>	<p>*@dsrf_uk want help with consultation &amp; constructing questionnaires x2</p>	

that becomes normalised.			
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