AIMS For a better birth...

Decisions about our care are for us - the service user - to make. Yes, but ...

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By the AIMS Campaigns Team

Regular readers of this Journal need no reminder that we - maternity service users - have the right to make decisions about our own maternity care. These decisions are not to be 'shared' with healthcare professionals although we do expect their support as we come to make them, not least by helping us navigate the information we might require. In this article, we reflect on some AIMS work this year to improve maternity service performance in this key area. We also explore the constraints that service users continue to face in getting the care they decide is appropriate for them, and how we can, together, overcome these.

Why has this issue been on our agenda this year? Well, one reason is that we had the opportunity of influencing the new NICE guidance on this topic, during the stakeholder consultation that took place from December 2020 to February 2021. Back in 2017, NHS England had formally asked NICE (National Institute for Health and Care Excellence) to produce practical guidance for health and social care professionals on shared decision-making. Following consultation, this guidance was due to be finalised, four years after it had been requested, in June 2021. You can findour detailed response[1] here and the final guidance here[2].

As a starting point, the preference of the AIMS campaigns team was very much that the terminology of 'shared decision making' should be relegated to 'the back office' of the NHS. We understand that the term is meant to reflect the process by which clinicians and patients work together to ensure effective care, rather than being a comment on who takes the final decision, but we are concerned that its use in a patient-facing context is misleading. You can read morein our blog here[3].

Whilst this conversation was proceeding, we had been very pleased to seethe new maternity-specific guidance issued in England[4], which made absolutely clear that the role of the maternity services is to support informed decision making on the part of maternity service users. We are grateful to the two service user advocates who worked tirelessly on the relevant Maternity Transformation Programme group to achieve this outcome, Michelle Quashie and Natasha Smith. Thanks to the work of Michelle and Natasha, it is likely that more and more maternity professionals will get the message, over time, that the decisions of service users are legitimate and must be respected. However, there seems to be no rigorous

system in place for measuring the extent to which this translates to increased autonomy for service users. AIMS Volunteers will be looking to see that the guidance is reflected in the calls to our helpline, where we hear repeatedly from service users whose decisions haven't been respected - but will the new guidance be sufficient?

What we've learnt over the decades is that the broader culture of the NHS is always an important influencer of what happens in the maternity services. Because of this, AIMS has sought to work alongside others in the health services improvement community this year to highlight the dangers of a simplistic understanding of the idea of 'shared decision making'. We'd like it to be made crystal clear across the NHS, that service users have the legal right to make their own decisions about their care, and that they do not have to share these with anyone. We believe that this will be helpful in driving system-wide change.

That is why AIMS, along with others, tried hard to get NICE to recognise the difficulties with the term 'shared decision making', especially in a service user facing context. We made some inroads, but NICE made it very clear that the title of the guidance wasn't up for debate. This is particularly frustrating given that NICE guidance is intended to be service user facing, and that much time has passed since the original NHS England request for the guidance. We're not sure that NHS England would make exactly the same request today (especially given the progress made in maternity on this issue), but we live to fight another day, secure in the knowledge that national maternity services leaders at least understand that we - maternity service users - do not need to share our decisions with anyone. In discussions that went right to the wire, AIMS made sure that this maternity perspective was also adequately referenced in the final NICE guidance.

So that's an overview of recent AIMS campaigning work in this area; but where does this leave individual maternity service users and their ability to make decisions that are right for them and to have these respected? Despite this clear national maternity-care policy (indeed, law) that decisions are ours, and ours alone, to make, maternity service users will not always find that easy. Why is this?

It may sometimes feel that our right to decide is limited to what offers of care we can decline, and that those offers may be - for some of us - frustratingly narrow. AIMS has, of course, been working for 60 years to broaden the range of maternity care options available to all service users, and that work continues (including via NICE - see below), but realistically, our choices will always be constrained by the options available to us locally. AIMS is clear that postcode lotteries have no place in maternity services, for this simply does not meet the important principle - Leave No One Behind[5].

One key local constraint might be resources: perhaps your local service isn't properly resourced to be able to meet the legitimate requests of all local service users. This then can act as a constraint on any particular choice of an individual service user. It is really important that such experiences get fed back to local services, ideally via the Maternity Voices Partnership (MVP)[6]: these Partnerships are well placed to identify local barriers to high-quality care and to seek to resolve these for the benefit of their local service users. In some cases, this might require reminding local services of the national expectations for

high-quality services - including, importantly, those set out in NICE guidelines - as it can be the case that local policy has simply developed out-of-step with that and needs to be brought back into line. If the MVP can't help, the next tier up - your Local Maternity System (LMS)[7] - may be a useful place to raise concerns.

Another key constraint might be NICE guidelines. These represent the national level framework, to guide us all - service providers as well as service users - on what healthcare options should be available on the NHS. From this, it follows that not all options will necessarily be offered to all maternity service users. NICE is committed to base their guidance on a careful review of the available research evidence about 'what works'. In preparing this guidance, NICE involves lay representatives and also puts its work out to extensive stakeholder consultation. It is important to remember, however, that NICE guidance is only as good as the evidence on which it is based. So there is also a role for us all - service user advocates included - to flag up where such evidence might be missing, which can then lead to a future research recommendation.

From this, we can see that there is much work to be done, some at the local level and some at the national level, in order to understand, agree and improve the range of care options that should be available to maternity service users. For without those options in place, our decision-making ability will always be constrained. With your support, the AIMS Campaigns Team looks forward to continuing to work on this issue in the years ahead.

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[1] AIMS (2021) AIMS response to the NICE 'shared decision making' consultation process - https://www.aims.org.uk/assets/media/605/submissionnicesharedcareguideline2021feb.pdf

[2] NICE (2021) Shared Decision Making - https://www.nice.org.uk/guidance/ng197

[3] National Voices (2021) Improving healthcare: is it time to ditch the terminology of 'shared decision making'? https://www.gov.uk/government/organisations/nhs-commissioning-board

[4] NHS (2021) Personalised care and support planning guidance: Guidance for local maternity systems. https://www.england.nhs.uk/publication/personalised-care-and-support-planning-guidance-guidance-for-local-maternity-systems/

[5] UN Sustainable Development Group - Leave No One Behind - https://unsdg.un.org/2030-agenda/universal-values/leave-no-one-behind

[6] National Maternity Voices - Find and MVP - http://nationalmaternityvoices.org.uk/find-an-mvp/

[7] NHS England, Local Maternity System. https://www.england.nhs.uk/north-west/gmec-clinical-

networks/our-networks/maternity/local-maternity-system/