AIMS position

AIMS supports the rights of maternity service users to make decisions about the maternity care offered to them, including the right to decline any form of care, test or treatment.

AIMS believes that the role of midwives, doctors or other staff within the maternity services should be to respectfully support all service users to make their own informed decisions.

AIMS would like to see the confusing and potentially dangerous language of 'shared decision making' replaced by 'supported decision making' in order to make clear that the decision is for the maternity service user to make.

What is the issue?

Maternity service users have the right to make decisions about their own care, in line with UK laws on bodily autonomy and informed consent. This is a key element of the Better Births vision for the maternity services in England (2016). AIMS understands that there are some exceptions to this, for example when people lack the capacity to make those decisions and in some emergency situations, but notes that these are infrequent.

AIMS recognises that there are complex reasons why midwives and doctors do not always act in a way that facilitates the decision making of service users, and why the maternity services do not always respect the decisions service users make about their maternity care.

In our helpline work AIMS frequently comes across cases which suggest that many midwives and doctors do not understand the right of the service user to make their own decisions about their own care. This was also a theme that emerged in the National Maternity Review (2016), which "heard that many women are not being offered real choice in the services they can access, and are too often being told what to do, rather than being given information to make their own decisions" (ibid, p3). As a result service users:

- are not given the information they need
- are not informed of all their options
- are prevented from exercising their right to make decisions with which the midwife or doctor does not agree
- are coerced into doing what the midwife or doctor believes is 'best'

AIMS believes that the continued use of descriptive terms such as 'shared decision making' may be contributing to the failure to recognise the autonomy of the decision-maker. The concept of 'shared decision making'

- confuses the issue of who is the decision-maker
- obscures the requirement for midwives and doctors to offer service users high-quality and personalised information

In some cases the lack of availability of services such as birth centres or birthing pools, or restrictions on who is allowed to access these, is preventing service users exercising their right to make some decisions.

What is needed?

- AIMS calls, in line with Better Births vision, and recognising the UK's ambition to provide a world-class maternity service, for local maternity services to ensure:
 - that service users are well supported in their decision-making with personalised, up-to-date and evidencebased information
 - o that their decisions are respected and supported
 - o that a full range of services is available
 - o that access to services is based on a personalised care plan and is not limited by blanket restrictions
- AIMS calls for adequate training to be provided to all maternity staff about human rights and the UK's legal framework
 on the principle of informed consent, to ensure that they are confident in supporting service users to make decisions
 about their care.
- AIMS calls for the term 'shared decision making' to be replaced with 'supported decision making' in all guidelines, service-user information and other maternity service documentation to clarify who is the decision maker.

Why does AIMS believe this?

- Article 8 of the Human Rights Act¹ guarantees the 'Right to respect for private and family life' and the courts have
 interpreted this to include the 'principle of autonomy'. This means that every person, pregnant or otherwise, has the
 right to make decisions about their body for themselves. This right is also protected under the common law of England,
 Wales and Scotland.
- The Supreme Court of Human Rights' judgement in Montgomery v Lanarkshire Health Board² makes clear the requirement to obtain informed consent for procedures. "An adult person of sound mind is entitled to decide which, if any, of the available forms of treatment to undergo, and her consent must be obtained before treatment interfering with her bodily integrity is undertaken. The doctor is therefore under a duty to take reasonable care to ensure that the patient is aware of any material risks involved in any recommended treatment, and of any reasonable alternative or variant treatments." This underlines that there should be a sharing of information but that the decision must come from the patient.
- Some programmes and organisations have already made the shift in terminology to "supported decision making" including The Royal College of Surgeons of England³.

What is AIMS doing?

- AIMS supports all service users to make their own decisions regarding their maternity care. We provide evidence-based information in our Birth Information pages and books, and support to individuals through our Helpline.
- AIMS supports the full implementation of Better Births in England⁴, The Best Start in Scotland⁵, Maternity Care in Wales⁶ and the maternity improvement plans in Northern Ireland⁷.
- AIMS is campaigning for an end to the use of the term 'shared decision making' in the UK maternity services, by
 documenting and sharing our concerns, building alliances with others who have similar concerns, and identifying
 opportunities to open a change-focussed conversation⁸.

Call to action: what can you do?

- Share this Position Paper to raise awareness of this issue
- Share the AIMS Birth Information page Making Decisions about your Maternity Care (www.aims.org.uk/information/item/making-decisions) with maternity service users who need this information
- Consider making a complaint to your Trust/Board and/or the relevant professional body if you have not been supported to make an informed decision
- Write to your MVP/MSLC and/or your Trust/Board if you are concerned about the behaviour of staff and think there may be some who need a training refresher on the issues of informed consent and decision making.

References

- 1. Human Rights Act 1998, Article 8
- 2. Montgomery v Lanarkshire Health Board [2005]UKSC 11 para 87
- 3. Consent: Supported Decision-Making, The Royal College of Surgeons of England 2020
- 4. National Maternity Review Better Births. Improving outcome of Maternity Services in England
- 5. The best start: five-year plan for maternity and neonatal care
- 6. Maternity Care in Wales: a five year vision for the future (2019-2024)
- 7. Review of Strategy for Maternity Care in Northern Ireland, 2012-18, March 2017
- 8. Improving healthcare: is it time to ditch the terminology of 'shared decision making'?

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