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Book Reviews

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AIMS Journal, 2010, Vol 22 No 4

- Towards the Emancipation of Patients: patients' experiences and the patient movement by Charlotte Williamson; reviewed by Gill Boden

Towards the Emancipation of Patients: patients' experiences and the patient movement by Charlotte Williamson

The Policy Press, Bristol 2010
ISBN-10: 1847427448
ISBN-13: 978-1-84742-744-1
£22.99

image of Towards the Emancipation of Patients

Reviewed by
Gill Boden

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Charlotte Williamson argues that the patient movement is an emancipation movement. At first sight that seems odd; it is not how we tend to think of the worthy middle class woman who typified the Community Health Council member, but after reading with great interest her account of the rise of the patient movement from the late 50s, I am convinced by her arguments and pleased to feel myself part of this undoubtedly emancipatory movement.

She combines academic theory with empirical evidence and the two organisations she uses most to illustrate her arguments are NAWCH (The National Association for the Welfare of Children in Hospital) and AIMS. NAWCH campaigned to allow parents to visit their babies and children in hospital. Since the beginning of the 20th century parents had been prevented from visiting their children, sometimes for months at a time: in the 40s and 50s psychoanalytic insights led to an intellectual under standing of attachment which mothers had under stood intuitively. Government policy, in 1959, (following the Platt report) recommended that visiting to children be unrestricted; that mothers be admitted to hospital with their children and the training of doctors and nurses give them greater under standing of children's and families' emotional needs. After a TV screening, in 1961, of James Robertson's film A Two-year-old Goes

to Hospital, NAWCH was set up and between 1959 and 1991 the Ministry of Health issued five guidance circulars and NAWCH under took five national surveys. However, largely owing to obstruction by paediatricians, it took more than 30 years to put the agreed policy of unrestricted visiting into practice. It now seems like ancient history, but in 1983, when I accompanied my breastfeeding one-year-old into a burns unit, I was told by nurses that there was no need to sleep nearby as none of the children woke at night - experience of that night told me otherwise.

In maternity units in the 50s babies were routinely removed from their mothers after birth and put into nurseries; as Michel Odent put it recently, a mother chimpanzee would kill you if you tried to do that, but not one mother in his experience of many years of that practice ever refused her permission. Pressure groups have changed that and mothers are 'allowed' to keep their babies with them but at present mothers have no rights to have unrestricted access to family members while in hospital to give birth.

*'Being with someone to whom one is emotionally attached is the most direct and probably the most effective way of being supported at times of anxiety and stress provided that person wants the support.'*page 128

Flexible visiting by people of the patient's choice, at times that suit both patients and visitors, was officially recommended in 1976 but is not yet widely implemented in the UK. Pockets of serious resistance remain: some neonatal intensive care units limit parents' access to their babies even though babies tend to have better sleeping and breathing patterns when their parents touch them, and backslidings also occur so visiting times can be reduced. In my area, Cardiff, the University Hospital of Wales introduced severely restricted visiting times in the maternity unit last summer with the excuse of infection rates and extended these draconian limits to women in single rooms in the midwifery led unit; the reason given was equity i.e. if not every woman can have this privilege no woman can. After strong representation from childbirth organisations, mothers in the MLU were 'allowed' to keep their partners with them at mealtimes - we pointed out that new mothers would otherwise be alone holding their babies at mealtimes and occasionally not even fed, but they are not 'allowed' to invite their parents, for example, to visit them after the birth unless it coincides with visiting times.

Williamson discusses the nature of dominant interests; clinicians as dominant interest holders have considerable power to act in patients' interests or to harm them: clinicians in hospitals can successfully refuse the requests of managers - she cites the case of a manager in the A and E Department of Salford Hospital who asked a doctor to stop treating a seriously ill patient so that he could treat several less seriously ill patients in order to reach a target that no patient should remain in A and E for more than 4 hours (Healthcare Commission 2009). The doctor refused but he was worried that a more junior doctor might have felt compelled to comply. She introduces a diverse set of people known as corporate rationalists, who include officials in government health depar tments, executive managers in health service institutions and public health doctors. She argues that they have gained power relative to clinicians over the last few decades, becoming significant in the UK after 1984 with the government's introduction of General Management, so much so that they can now be said to be dominant interest holders too. Corporate rationalisers sometimes support the interest of patients against those of

clinicians though not necessarily for the same reasons as patient activists would.

Williamson distinguishes between radical and conservative patient groups and I'm sure that you will recognise both from her descriptions; she gives an example from her own experience of a Trust where all but two of the non-executive directors supported the executive director's recommendation that money should be spent on employing more obstetricians. As business men, she remarks, none knew anything about the maternity services: a health economist and she argued that money would be better spent on employing more midwives but their arguments failed. She uses AIMS as an example of an avowedly radical group which explicitly connects their oppression as women to their oppression as 'patients', and consciously takes a liberating stance.

Knowledge from social science can be helpful to patient groups. Williamson cites the successful campaign of NAWCH to implement unrestricted visiting for children and contrasts that with the attempt by RAGE, Radiotherapy Action Group Exposure, to argue for changes in clinical standards and clinical research so that effective non-toxic treatments for their potentially fatal disease will be developed.

She discusses overt and covert coercion: practices that threaten and affront patients' moral agency. On our helpline we hear constant reports of women being told that they are not allowed to behave as they wish and in meeting with health professionals I frequently hear expressed, mainly by paediatricians, the view that mothers should be forced to accept treatment advised by doctors for their babies, even where it is a prophylactic measure. In some ways covert coercion is more worrying: we have reports of mothers being told that if they co-sleep, breastfeed beyond a year, insist on a home birth or a physiological third stage, for example, they will be considered to be putting their baby at risk. This is now a phrase that will strike a chill into even the most confident well informed middle class mother - mothers with difficulties are often helpless in the face of such an implied threat.

Charlotte Williamson still describes much of maternity care as oppressive and quotes Sally Willington, founder of AIMS, in 1961:

'In hospital, as a matter of course presumably, mothers put up with loneliness, lack of sympathy, lack of privacy, lack of consideration, poor food, unlikely visiting hours, callousness, regimentation, lack of instruction, lack of rest, deprivation of the new baby, stupidly rigid routines, rudeness, a complete disregard of mental care or the personality of the mother.' page 48

Much has changed, government policy and most midwives want woman-centred care and a focus on normality in childbirth: reading this book has recharged my motivation to be part of the patient movement and not to give up yet.

'Some of today's standard should be as inconceivable as slavery or women's disenfranchisements are today. Different emancipation movements confront different issues; but the changes in moral and ethical sensibility required in order to lift repression and oppression are the same.' page 214