Weak and Strong Publics: Drawing on Nancy Fraser to Explore Parental Participation in Neonatal Networks

Andrew Gibson
Dr Loraine Blaxter
Professor Gillian Lewando Hundt

Institute of Health
University of Warwick
Introduction

• How do we theorise the process of patient and public involvement?
Drawing on Nancy Fraser’s Work

- Weak and Strong Publics
- Publics and the State
- Participatory Parity
Practice and Policy Context

- The Department of Health in 2003 recommended the development of managed clinical newborn networks.

- 2006-7 newborn network boards are at different stages with different strategies for parental involvement.
Aims of the Study

• Explore the development of user involvement and roles within neonatal networks locally and nationally

• Identify strategies for recruiting, supporting and training parents to be effective participants
Methods

National Survey of:
Parental involvement in all 23 network boards in England

5 Area Case Studies:
• Interviews with key professionals
• Observation of meetings and review of minutes
• Interviews with involved service users
Preliminary Findings

• Wide variation nationally in level and type of parental involvement

• Lack of diversity in parental board members
Recruitment of Parents

- Accessing people already involved in some way (e.g. via PPI groups or Maternity Services Liaison Committees)

- Contacting parents through the units in the network

- Parent selection of representatives
The Ideal-Type Parent Board Member

- Experience of neonatal services
- Enthusiastic about making a difference
- Be able to represent the views of other service users
- Sufficient time and interest to participate
- Able to work as part of a team
- ‘Ordinary’ people
Being a Parent Board Member

“Between this (setting up a parents’ group) and the network it is taking up a lot of time and effort. It is hard fitting it round home life, and I don’t want to spread myself too thinly.”

(Parent Board Member)
Culture and Organisation of Board Meetings

• Average number of parents on a board is 2 (6 boards), but 8 boards had no representation at this level

• Average neonatal board has 20-29 members
“I have to admit that I was terrified walking in that room today. I don’t know why, it wasn’t as if they were all going to quiz me or anything.”

(Parent Board Member on her first meeting)
Culture and Organisation of Board Meetings

- Some board members feel that having parents at board meetings might be tokenistic.

- Others feel that only parents who are “network minded” should be involved.

- Concern that parents will represent themselves rather than the broader view of parents: “wanting a level 3 neonatal unit on their doorstep.”
Modes of Parental Involvement

Parents as:

• consultants
  (experiential representation)
• a source of information
  (statistical representation)
• representing the views of other parents
  (democratic representation)
Parents as Representatives

Network Board

Network Parent Group

Unit Parent Group
Unit Parent Group
Unit Parent Group
Unit Parent Group
Discussion

• Participatory Parity:
  ‘social arrangements that permit members of society to interact with one another as peers.’

• Barriers to achieving participatory parity

• Parental participation within neonatal services: an example of a weak public.