

# Service User Experiences of Intensive Mental Health Care - What is it like and how do we know?

Deborah Wildgoose 8th September 2010



# Overview

An overview of the policy framework with regard to developing quality within the provision of healthcare

Identify some emerging key themes from the available literature

With one question:

So how **do** we gather service user experiences?



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# Quality and the Policy Framework

- A First Class Service (DH 1998)
- NSF (DH 1999)
- NHS plan (2000)
- Policy Implementation Guides (2001 – 2007)
- High quality care for all (2008)
- Liberating the NHS (2010)



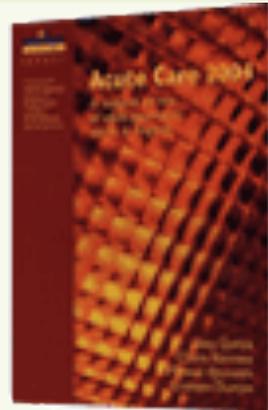
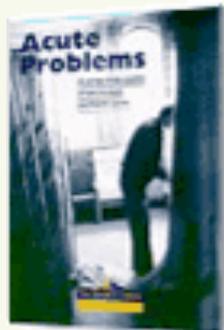
## Other Perspectives

Peter Carter (General secretary of the  
Royal College of Nursing)

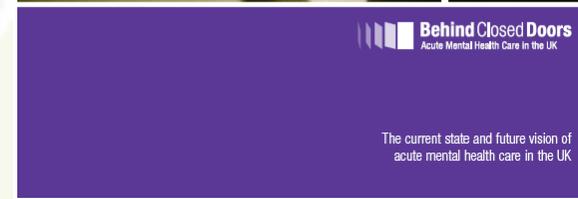
‘The overwhelming majority of NHS care is safe,  
but we believe the ambition now must be to drive up  
patients' experience from 'safe' to 'high quality'” (Carvel  
2008)



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# Other Perspectives



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# Key themes

1. Service users are unable to give valid feedback on the care they have received
2. Growing body of evidence reflecting care experienced on acute wards
3. Poor evidence of work to elicit service user satisfaction with PICU care
  - In the absence of evidence and evaluation about PICU's most studies have concentrated on the role, function, care and outcomes of PICU's with little focus given to service user satisfaction.



# Social Exclusion

‘It has long been recognised that adults with mental health problems are among the most excluded and disenfranchised groups in society’

Gale and Grove 2005

- Social status has a direct impact on mental health and vice versa.
- Those with mental health problems are at greatest risk of exclusion by and from society.
- Service users cared for within a PICU may experience the greatest exclusion and be those least likely to be heard - able to provide a view
- The necessity to protect the privacy and dignity of those being cared for within, has resulted in many PICU's being located away from the public gaze
- Paradoxically this also means that the services, care provide and the experiences of those within a PICU are out of sight



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## **Hopkins and Niemiec (2006)**

There is a history of the voices of mental health service users being 'less privileged' than others

## **Lovell (1995) Spencer (1996)**

There seems to have been a perception that they may be unable to give informed judgements or valid and reliable feedback about the services they receive



## Goodwin et al (1999)

Many reasons can be given for denying the users of mental health services a voice. These include the idea that, by definition, people with diagnoses of mental illness do not know their own minds, that service users are unsophisticated, or that they are unrepresentative, especially if articulate



## Shields et al 1988 in Goodwin (1999)

Suggests 3 reasons why we should seek service users views

- Vulnerable group – we have a moral obligation
- Service users can identify ways to provide cost effective treatments
- Ensure accountability by asking service users what they think of service provision

Language may have changed but the essence of the view has not



## Quirk and Lelliott (2001, 2004)

Extensive ethnographic work on acute admission wards, Identified that:

- Little is known about the quality of care that is provided on acute wards
- Sense that hospital care is a 'black box' - people admitted and discharged with little known about what happens whilst they are there
- Most studies used quantitative and questionnaire survey methods
- While useful in providing an overview, such (largely questionnaire survey-based) research barely scratches the surface of everyday life on acute wards
- offers only a limited insight into the world of the patient



# Care Within a PICU

- Literature review of PICUs carried out in 2008
- Only one study focused on service user satisfaction
- ‘The findings broadly indicated that discharged patients were satisfied with the care they received’ (*Bowers et al 2008*)



## *Wykes and Carroll 1993*

- Postal questionnaire sent up to 3 months following discharge
- It achieved a significant aim - that service users who have been cared for in PICU can provide feedback
- It did not capture service users perceptions and feedback either during or immediately following the conclusion of their care, therefore a richness was lost.
- Used a postal questionnaire and consequently did not allow service users freedom in reporting what they wished to be known – ***‘to make their world visible’***



# Questionnaires – how useful are they?

- Stallard (1996)
- Hopkins and Niemiec (2006)
- Carr-Hill et al (1989)
- Rapley (1995)
- Goodwin et al (1999)



# So what approach should we take?

- 'When given a choice of response it may limit the respondents' freedom of expression'

*(Stallard 1996, Northway 2000, Pollock 2002)*

- 'Why not seek to understand what is key and important to them, from their frame of reference'

*(Volante 2007)*

- Make their world visible from their own perspective

# Finally, How do we gather service user experiences?

- Firstly we need to understand what we want to know?
- The responses obtained is all about approach
- If we want their views on care we must give service users the freedom of expression – allow them to tell us what they want us to know



***‘Experience is not what happens to a man.  
It is what a man does with what  
happens to him’***

*(Huxley 1932)*



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