

Group Exercise II – Blue group

What are the obstacles that prevent full, active and visible engagement of carers?

OBSTACLES

1. Don't see carers as professionals. Carer neurologist unless are asked information as "gate keepers" – not carers themselves.
2. It's a hierarchy where patients are at the bottom of the ladder – even social workers are not consulted eg. on discharge, never mind carer's opinion.

Assessment of the ability to care

Obstacle is that NHS don't assess carers over a long period of time. If they do, they'll find out the carer's strengths – they don't do this, nor do they tot up the positive scores, because they're not prepared to see.

Non-challenging Boundaries

Scared to challenge our GP, "because he's been our GP for years."

Giving too much power to GP's.

Frightened to comment.

Understanding

Often devalued that carers can understand.

Often carers the only university educated person in the room.

"Mental Health" Label

If you're labeled as having a mental health problem, (sometimes only because you're being too vociferous"). This has very serious legal implications – for example in court, when evidence is discounted because of a carer's label.

Obstacles to full engagement

Basic Training

Not yet done around Carer's rights eg. to assessments not known about.

Social Assessments by GP's

Doctors are asked to do social assessments which need to be made.

Social assessments should be multi-disciplinary, as in hospital – not a single assessment – now done by GP alone – who often knows nothing about the social circumstances of the poorer communities.

GP's are reprimanded by their peers if they step out.

More than one carer

Only one carer usually consulted. If more than one carer, a clearer picture of the care package will emerge.

Obstacles to full engagement

Group Exercise II - Green group

What are the obstacles that prevent full, active and visible engagement of carers?

Lack of funding. False confidentiality.

Power-crazed elitist, paternalistic professionals “They don’t listen!!!”

Boundaries

Artificial professionals and system boundaries: services not built round patient/ carer needs.

Third Sector: Gaps in NHS provision filled by voluntary sector but not signposted and not carer focused.

Physical Accessibility

Services geographically inconvenient, “You have to go here, there and everywhere.”

The better you cope, the less you get:

“She’s partially-sighted but you’d never know it” – so I get no help at the destination.

Failure to Self-identify

I’m his wife, she’s my mum, just doing what you have to do.

Information

Lack of it. Access to it. No single source. Wrong information, wrong format.

“We didn’t know we could get help on NHS.”

Obstacles to full engagement

Group Exercise II - Orange

What are the obstacles that prevent full, active and visible engagement of carers?

Funding

‘Patients as people not units’

Nurses – ‘too clever to care’, nurses don’t want to do everyday things

Learning Disabilities eg. Nurses not trained to care.

Carers shouldn’t be seen as troublemakers just because they want the best for the person they are caring for.

Definition of care is problematic – more physical than psychological/ emotional.

Recognition of carer expertise.

Need to listen to carers.

Obstacles to full engagement

Group Exercise II – Pale blue

What are the obstacles that prevent full, active and visible engagement of carers?

Patients

Not knowing your rights.

Time pressure – not in control.

FEAR – of punishment!

Carers

Feeling of being unrecongnised/ unheard “system doesn’t take you seriously”

Inflexible options – time, place, parking, access

Fear of - “Rocking the boat”

- “Speaking out”

It might go against cared for.

NHS

Staff – communication between hospitals and GPs.

Listening isn’t a first principle.

Capacity of system – finding the gate/ reconnecting.

Group Exercise II – Pink group

What are the obstacles that prevent full, active and visible engagement of carers?

LACK OF TRUST/FAITH eg. Not being involved in crucial nursing assessments - secrecy.

NO SINGLE KEYWORKER

- Too many people involved
- Repeating story – groundhog day effect
- Power to trigger services right across the board
- No responsibility
- Facilitate communication
- Little coordination across services

NHS LED RESEARCH

- Need to include carers: no investment in time/ premises/ resources. (eg. 9-5 not ideal time)

ATTITUDE OF OFFICIALDOM

- ‘We know best’ therefore don’t listen.
- Institutional mindset: care at home of less worth than that in institutions.
- Resource-led, not needs-led thinking.

LIMITED UNDERSTANDING OF CARER’S ROLE AND FAMILY CULTURE

- Lack of person-centred care for carer. One size won’t fit all.
- Carers’ are all individuals; changing needs over time.
- No energy to spare for battles – eg. equipment.
- NHS needs to think ‘carer’.

Obstacles to full engagement

IMPROVERISHMENT

- Illness/ disability affects earning power of cared for and carer.
- Paucity of I.C.A.

UNEQUAL POWER RELATIONS

- Top down
- ‘Protecting’ professionals at expense of carers.

CARER’S DILEMMA:

- Fear of making waves in case of repercussions on patient care and carer’s relationship with professionals.
- Fear of moral judgement.
- “The Interfering relative”

Obstacles to full engagement

Group Exercise II – Red group

What are the obstacles that prevent full, active and visible engagement of carers?

Proper Funding

For carer voluntary organisations who are supplying what people need/ supporting carers well.

Ring fenced resources to help carers – otherwise low priority and miss out.

Lack of incentives with statutory authority to address carer's issues and problems ie. no targets/ objectives.

Cultural resistance to change from certain established interests in NHS, Department of Health, Social Services etc.

IMBALANCE OF POWER

- Carers don't feel empowered to speak out.
- Professionals don't recognize the powers they have even when trying to encourage dialogue.

Beware carers being needlessly overwhelmed with paperwork, meetings etc.

Learn from good practice where it exists and don't reinvent the wheel.

Obstacles to full engagement

Group Exercise II – Yellow

What are the obstacles that prevent full, active and visible engagement of carers?

Need to include in education and training of professionals, need for partnership working should be emphasized.

Need for national targets to reflect need for carer involvement (“all tokenism at present”)

Special issues of communication in multi-ethnic communities.

Bureaucracy (preventing inter-borough working)

Fear – of complaining, criticizing services (on saut patients/ carers.) Also voluntary bodies dependent on funding.

Major issues mental health services (ie. lack of continuity of services, engagement with carers).

“Doctors do not see carers as their issue” (GP/ chain patient) Nor NHS?

Mention – ‘Better healthcare closer together’ (consultation document)

No mention of carers at all!

“You have sympathy of management and that is all you have.” (Patient chain)

Lack of communication between carers and professionals (feeling in conflict – when really they are on the same side! Have same concerns.) Also, issues when help professionals constantly changing (eg patient had 9 psychiatrists in 9 years.)