



From joint planning to continuity of care – what about the outcomes?

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The research team

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- ◆ Project funded via NIHR SDO R&D programme

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Outline of presentation

- ◆ The issues
- ◆ Policy responses
- ◆ Existing evidence about how to achieve continuity of care and its effects
- ◆ Findings from review of evidence on outcomes for people with LTNCs
- ◆ Use of outcome measurement in practice

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Long-standing issues

- ◆ Problems *across* boundaries identified since the early 1950s
- ◆ Problems *within* service systems also evident
- ◆ Exacerbated with increased specialisation, technological advances and accelerated shifts in place of care



Policy responses

- ◆ Bridging a divide created in UK in 1948
- ◆ Attempts to achieve co-ordination and collaboration since mid-1970s
 - ◆ Strategic (macro or policy) level
 - ◆ Service planning and delivery (meso or structural) level
 - ◆ Individual practitioner and service user (micro) level

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Some examples from the last 30 years (1976-1983)

- ◆ Joint planning (1976)
- ◆ Priorities in Health and Social Services. The Way Forward (1977)
- ◆ Collaboration in Community Care – a Discussion Document (1978)
- ◆ Care in the Community: a Consultative Document on Moving Resources for Care in England (1981)
- ◆ Joint Finance circular (1983)

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Some examples from the last 30 years (1986-1998)

- ◆ Audit Commission report (1986)
- ◆ Griffiths Report (1988)
- ◆ White Paper 'Caring for People' (1989)
- ◆ NHS and Community Care Act (1990)
- ◆ Guidance on 'continuing care' (1995)
- ◆ The New NHS. Modern. Dependable (1997)
- ◆ Partnership in Action (1998)
- ◆ Modernising Social Services (1998)
- ◆ Better Services for Vulnerable People - Joint Investment Plans (1998)

Some examples from the last 30 years (1999-2008)

- ◆ Health Act (1999) – ‘flexibilities’
- ◆ NHS Plan (2000) – structural integration?
- ◆ Care Trusts (2001)
- ◆ Older people’s NSF and intermediate care (2001)
- ◆ Long Term Conditions Strategy (2005)
- ◆ Long Term (Neurological) Conditions NSF (2005)
- ◆ Our health, our care, our say: a new direction for community services (2006)
- ◆ Consultation on Green Paper on social care
- ◆ ‘Darzi review’ (2008)

Our health, our care, our say: a new direction for community services

One of our main aims for the future is to make sure that health and social services will **work together** and share information to give **'joined-up' care** to the people they work for. Services will **share information** about the people in their care so that health, housing, benefits and other needs are considered together. By 2008, anyone with long-term health and social care needs should have an **integrated Personal Health and Social Care Plan**, if they want one. All Primary Care Trusts and local authorities should have **joint health and social care managed networks and/or teams for people with complex needs**. We will also be building modern NHS community hospitals, which will offer **integrated health and social services**.

What helps or hinders at meso level?

Negatives

- ◆ Cost shifting
- ◆ Repeated restructuring
- ◆ Always starting at the beginning
- ◆ Organisational boundaries
- ◆ Professional and cultural boundaries

Positives

- ◆ High level of 'ownership'
- ◆ Trust, reciprocity and respect
- ◆ Right financial, institutional and legal structures
- ◆ Right accountability processes
- ◆ Appropriate leadership and management



What helps or hinders at micro level?

- ◆ Communication between primary and secondary health care
- ◆ Communication between long-term and short-term care systems
- ◆ Team working within single sectors
- ◆ Professional boundaries
- ◆ Systems for transition
- ◆ Care pathways for individual service users

Haggerty et al 2003

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But does any of it make any
difference to service users?

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Evidence on outcomes for service users

- ◆ Existing evidence base largely about integration of provision for older people
- ◆ Lots of information on process issues
- ◆ Tends to be about policy and structure issues
- ◆ Less on individual practice issues
- ◆ Little on outcomes for those on the receiving end

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Context of our research

- ◆ National service frameworks to improve care delivery in many different conditions
- ◆ Early NSFs for cancer and cardiac care
- ◆ Long-term neurological conditions were ‘latecomers’
- ◆ Standards in the NSF are ‘evidence-based’ but in places evidence was hard to find
- ◆ Programme of research to evaluate impact of NSF and to provide further evidence

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Why neurological conditions?

- ◆ Prevalence -10m people across the UK
- ◆ Impact – the most common cause of disability
- ◆ Account for up to 20 per cent of hospital admissions
- ◆ Third most common reason for people needing to see their GP
- ◆ Problems cut across boundaries

Defining and measuring integration

- ◆ Different experiences
 - ◆ Sudden onset
 - ◆ Intermittent and unpredictable
 - ◆ Progressive
 - ◆ Stable but with changing needs
- ◆ Very many possible boundaries – not just health and social care
- ◆ Continuity of care – framework for study

Freeman et al. (2001, 2003, 2007)

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Findings from our review of evidence

- ◆ 2,552 publications identified by electronic and other searches
- ◆ 5,733 selected as potentially relevant
- ◆ 114 of these looked like evaluations
- ◆ Read all these
- ◆ 68 publications included for review
- ◆ 50 separate studies
- ◆ 48 different models of integrated care

Outcomes reported

| | |
|---------------------------------------|----|
| Use of or contact with services | 21 |
| Patient's view of model of care | 18 |
| Disability/impairment | 17 |
| Clinical outcomes | 15 |
| Quality of life | 15 |
| Mental health | 11 |
| Impact on family/carers | 8 |
| Costs to health service | 8 |
| Hospital admission | 6 |
| Communication in team or with patient | 5 |
| Patient or carer expressed need | 4 |

| | |
|--|---|
| Knowledge of condition | 4 |
| Social outcome, e.g. education, employment | 3 |
| Staff views on model of care | 3 |
| Mortality | 3 |
| Costs to patients or families | 2 |
| Coping or stress | 1 |
| Costs to social care services | 0 |
| Other | 6 |

Access to or use of services

- ◆ A key outcome for integrated care?
- ◆ 21/50 studies reported this outcome
- ◆ Little consistency of outcomes
- ◆ Two good quality studies show no effect for patient information/education
- ◆ Other studies of multi-disciplinary teams, nurse specialists, and other forms of integrated care show small effects but these are not consistent across studies and tend to be short-lived

Service users' views

- ◆ 18/50 studies reported this outcome
- ◆ Only one of these offered any real comparison between integrated care and anything else
- ◆ Of four service user view 'domains' tested, only one was significantly different for those receiving this model of care (home-based vs hospital-based treatment)
- ◆ HOWEVER, this was continuity of care!
- ◆ Overall, service users are positive – but might this just be gratitude at getting *any* service?

Quality of life

- ◆ 15/50 studies reported this outcome
- ◆ 9 of these were RCTs
- ◆ So most robust evidence base so far
- ◆ 6 RCTs show no increase in quality of life for those receiving a model of integrated care
- ◆ 1 RCT of self-care advice for MS showed change in mental health and vitality
- ◆ 1 RCT of MD home care for MS showed change in overall mental and physical health-related quality of life
- ◆ 1 RCT of patient education and health promotion for PD showed change in 'self-efficacy'

But ...

- ◆ Poor studies
- ◆ Lack of measures before intervention
- ◆ Use of non-validated measures
- ◆ Inability to find data for study showing greatest effect

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So what is going on here?

- ◆ Anything is better than nothing?
- ◆ Small numbers and poorly designed studies?
- ◆ Is demonstration of 'conventional' impact essential?
- ◆ If not, then we at least need to say something about cost – almost totally missing from the evaluations
- ◆ Are we asking the wrong questions?
- ◆ Are we measuring the wrong outcomes?
- ◆ What about empowerment, sense of worth, ability to make sense of one's condition?



What do service users tell us?

- ◆ What they want
 - ◆ Prompt diagnosis
 - ◆ Information and support
 - ◆ Person-centred care & choice
 - ◆ Flexible responsive services
- ◆ Delivery of a 'seamless' service
- ◆ How do any of these relate to existing outcome measures?

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Is there a way forward?

- ◆ Better understanding of what *really* matters to service users
- ◆ Use that understanding to design outcome measures that are *appropriate*
- ◆ Implement those outcome measures at very first contact with service users and throughout
- ◆ ‘Unpicking’ what we think the service is *actually* achieving



Whose outcome is it anyway?

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Contact details

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