How do we integrate health & social care: lessons from research & practice

Martin Knapp
Personal Social Services Research Unit, London School of Economics & Political Science & NIHR School for Social Care Research

Green Templeton College, Oxford
18 October 2017
How do we integrate health & social care: lessons from research & practice

A. A simplified care system
B. NHS challenges
C. Social care challenges
D. Integration
E. What (else) could we do better?
F. Implement evidence
G. Do more research
H. Sort out financing
I. Raise awareness; take responsibility
A simplified care system
A simplified health/social care system

**REVENUE COLLECTION**
- Taxation
- Insurance
- Out-of-pocket

**PURCHASER BUDGETS**
- Health system
- Social care
- Education etc.

**PROVIDER BUDGETS**
- Hospitals
- Community care
- Care homes

**RESOURCE INPUTS**
- Professional staff
- Buildings
- Medications

**COSTS**
- ‘Formal’ care
- ‘Informal’ care

**NON-RESOURCE INPUTS**
- Social environment
- Staff attitudes
- Patient histories
- Personal resilience

**OUTCOMES**
- Fewer symptoms
- Quality of life
- Better functioning
- Independence
- Self-determination

**OUTPUTS**
- Surgical operations
- Treatment sessions
- Home care visits
- Care home stays

Person in need

Family
People with needs & assets

Health care: NHS
Social care: LAs
Housing: DCLG
Education: DfE
Crim justice: MoJ
Benefits: DWP
Employment: Firms
Social network: CVOs
Income: Indiv
Mortality: All

... impacting on potentially many budgets

Genes
Family
Income
Empty’t
Resilience
Trauma
Phys env
Events
Chance
NHS challenges
Public satisfaction 2016 (no significant changes from 2015):

- NHS overall 63%
- GP services 72%, highest in NHS
- Outpatient 68%
- Inpatient 60%
- A&E 54%
- Social care services 26%

From NatCen Survey 2016

Main reasons for overall satisfaction with the NHS:
1. quality of care,
2. NHS is free at the point of use
3. range of services available

Main reasons for overall dissatisfaction with the NHS:
1. long waiting times
2. staff shortages
3. lack of funding
1. We spend more on the NHS than ever before
2. A bigger proportion of public spending goes on health
3. Key A&E targets are being missed
4. The UK’s population is ageing
5. Care for older people costs much more
6. Increases in NHS spending have slowed
7. The UK spends a lower proportion on health than other EU countries
8. Demand for A&E is rising
9. Fewer older people are getting help with social care
10. Much more is spent on front-line healthcare than social care
He [Jeremy Corbyn] talks about delayed discharges. Some local authorities, which work with their health service locally, have virtually no delayed discharges. Some 50% - half of the delayed discharges - are in only 24 local authority areas. What does that tell us? It tells us that it is about not just funding, but best practice.

"Just 24 local authorities account for 50% of all the delayed discharges from the NHS"
A patient is ready for transfer when:
a. A clinical decision has been made that the patient is ready for transfer AND
b. A multidisciplinary team decision has been made that the patient is ready for transfer AND
c. The patient is safe to discharge/transfer.

DTOCs are obviously not the only challenge facing the NHS - but data are readily available and so this topic attracts disproportionate attention.
Causes of DTOCs (coded by NHS staff)

- Awaiting care package in own home
- Awaiting nursing home placement or availability
- Awaiting further non-acute NHS care
- Awaiting completion of assessment
- Patient or family choice
- Awaiting residential home placement or availability
- Awaiting community equipment and adaptations
- Housing not covered by NHS and Community Care Act
- Disputes
- Awaiting public funding

Biggest changes since November 2010 have been increases in the number of days delay due to patients waiting for a care package to be available either at home (172% increase) or in a nursing home (110% increase).

What's behind delayed transfers of care? Nuffield Trust February 2017
Proportion attributed to social care causes went from 32% (Aug 2010) to 24% (Feb 2014) to 37% (Dec 2016)
Social care challenges
1. Social care spending has stopped rising
2. Councils are prioritising care
3. The NHS is propping up care
4. No care means patients get stranded
5. Councils are looking after fewer old people
6. People are being left to fend for themselves
7. Self-funders appear to be subsidising councils
8. The care market could be at risk
9. The population is ageing
10. Council tax bills are rising to help councils cope.
Social care trends and challenges

- Population ageing & expansion of morbidity ... unequally distributed across the population
Ageing: implications for care needs

Projected numbers in E&W aged 80+ by interval-need dependency, 2010-2030

- 75% in care homes
- Main carer: child
- 33% in care homes
- Main carer: spouse (34%), child (31%)
- 4% in care homes
- Main carer: child (37%), no-one (18%)

People in E&W aged 80+ by interval-need dependency, 2010

Jagger et al, BMC Geriatrics 2011; slide borrowed from Carol Jagger
HLE & LE, men at age 65 by national deciles of area deprivation, England 2012-14

Foresight report 2016 - data from ONS (2016)
Projected public expenditure on health & long-term care as % of GDP, 2014/15 to 2064/65

Social care trends and challenges

- Population ageing & expansion of morbidity
- Funding cuts: LGA estimate a funding gap in social care of £5 billion by the end of the current Parliament.
Index of net current expenditure on adult social care relative to 2005/06

Real term figures calculated at 2014/15 prices (GDP deflator)
Source: HSCIC EX1 and ASC-FR annual returns (expenditure); ONS (mid-year population estimates) - courtesy of Jose-Luis Fernandez
Social care trends and challenges

- Population ageing & expansion of morbidity
- Funding cuts
- Dwindling numbers of people supported by local authorities; efforts & resources concentrated on ‘high-need cases’.
Proportion of older people (age 65+) receiving support

Number of service recipients

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- Residential and nursing care
- Community-based services

Source: LSE PSSRU
Social care trends and challenges

- Population ageing & expansion of morbidity
- Funding cuts
- Dwindling numbers of people supported by local authorities
- Almost complete disappearance of public sector services
Home care: local authority-supported contact hours and households (age 65+)

- Local authority providers
- Independent sector providers
- Households

Contact hours vs. Households

Slide from Jose-Luis Fernandez
Social care trends and challenges

- Population ageing & expansion of morbidity
- Funding cuts
- Dwindling numbers of people supported by local authorities
- Almost complete disappearance of public sector services
- Rapid growth in self-funders but no reliable data on how many people
- ... but social care workforce is growing.
Social care self-funders

- **Lots of them** - Up to 25% of home care hours are provided to self-funders; >40% of care home places paid for by self-funders (Baxter & Glendinning, 2015)
- **Reluctant to ask** - Self-funders often do not think to approach their local council for advice (Wright, 2000) or are deterred by perception of stigma associated with asking the council for help (Putting People First 2011)
- Self-funders are the **most disadvantaged & isolated** people in social care system: care arrangements often owe more to chance than active choice (Henwood and Hudson, 2008).
- Having sufficient financial resources to self-fund **does not guarantee greater control** over care (Putting People First 2011).
- 69% of self-funders did not feel well-informed about **financial implications of paying for long-term care** (NAO 2011).
Social care trends and challenges

- Population ageing & expansion of morbidity
- Funding cuts
- Dwindling numbers of people supported by local authorities
- Almost complete disappearance of public sector services
- Rapid growth in self-funders but no reliable data on how many people
- ... but social care workforce is growing.
- Growing gap between need for and supply of unpaid care
Sources of social care

Where older people in England with care needs get help

- Family & friends: 37.5%
- Council help: 21%
- Pay for help: 12.5%
- No help / little help: 30%

Source: Age UK, Laing Buisson, NHS Digital, Carers UK
Projected demand for, and supply of unpaid care for older people in England

- **Demand, base case**
- **Demand, if formal care falls by 10%**
- **Supply, base case**
- **Supply, 1% pa decline in caring rate for younger carers**
- **Supply, 1% pa rise in caring rate for younger carers**

Other challenges currently facing social care

- **Deprivation of Liberty Safeguards (DOLS)** assessments - demanding on time and money
- **Market management** - perennial challenge
- **National Living Wage** - low profit margins already
- Each new cohort of social care users has **higher aspirations** for their care
- More **young adults with complex needs** are surviving into adulthood - many require intensive, high-cost support
- **Workforce** - **recruitment difficult** (especially for home care); high staff turnover rates
- **Brexit** - non-British EU workers account for 7% of the UK social care workforce of 1.34 million people
- **Technology** - has uptake been too slow or too fast?
- The overall **financing model** is seen as ‘broken’. Dilnot recommendations accepted but never implemented - see later
Social care for older people is under massive pressure; increasing numbers of people are not receiving the help they need, which in turn puts a strain on carers.

Access to care depends increasingly on what people can afford - and where they live - rather than on what they need.

Under-investment in primary and community NHS services is undermining the policy objective of keeping people independent and out of residential care. The Care Act 2014 has created new demands and expectations but funding has not kept pace. Local authorities have little room to make further savings, and most will soon be unable to meet basic statutory duties.
Integration
But the issues go much wider ...
What is the question to which integration is the answer?

REVENUE COLLECTION
• Taxation
• Insurance
• Out-of-pocket

PURCHASER BUDGETS
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• Social care
• Education etc.

PROVIDER BUDGETS
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Person in need

Family

RESOURCE INPUTS
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COSTS
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• Personal resilience

OUTCOMES
• Fewer symptoms
• Quality of life
• Better functioning
• Independence
• Self-determination

OUTPUTS
• Surgical operations
• Treatment sessions
• Home care visits
• Care home stays

What is the question to which integration is the answer?
Presumably ... how can we achieve ...?

**REVENUE COLLECTION**
- Taxation

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**OUTCOMES**
- Fewer symptoms
- Quality of life
- Better functioning
- Independence
- Self-determination

**OUTCOMES**
- Better assessment of needs, assets & preferences - more holistic, continuous ...

**NON-RESOURCE INPUTS**
- Social environment
- Staff attitudes
- Patient histories
- Personal resilience

**OUTPUTS**
... more flexible & personalised responses to needs & assets

**RESOURCE INPUTS**
- Professional staff
- Buildings
- Medications

**OUTCOMES**
... better coordinated & hence more efficient commissioning

**OUTCOMES**
... better access to services; more holistic, continuous ...

... improved cost-effectiveness of care

... avoidance of wasteful duplication & damaging gaps in service provision

... better outcomes for individuals & families
## Integration: governance or service organisation?

### Dimensions
- Horizontal or vertical within systems (health or other)
- Across systems - health, social care, housing, etc.
- Across sectors (public, for-profit, third sector ...)

### Scope
- The whole of (e.g.) health & social care, or hospital and community care systems
- Parts of these systems, e.g. integrated teams/professions
- Integrated care pathways
- Acute and long-term services

### From individual perspective:
- Strategies that map journeys through services (integrated care pathways)
- Strategies that support individuals in negotiation with (and access to) services

### Examples of service integr’n:
- Case & care management
- Intermediate care
- Joint needs assessment; joint care planning
- Personal budgets
- Multidisciplinary teams
- Shared guidelines/protocols
Progress reported by Integration Pioneers

% of leads reporting “some” or “substantial” progress

Patients/service users experience services that are more joined-up (91%)
Quality of care for patients/service users has improved (91%)
Services are now more accessible to patients/service users (91%)
Quality of life for patients/service users has improved (86%)
Patients/service users now able to continue living independently for longer (82%)
Experience of carers has improved (82%)
Patients/service users now have a greater say in the care they receive (82%)
Patients/service users now better able to manage their own care & health (77%)
Patients/services users now have greater awareness of services available (77%)
GPs now at centre of organising and coordinating patient/service user care (77%)
Service providers now able to respond more quickly to patient/service user (changing) needs (73%)
Number of readmissions to hospital have reduced (68%)
Unplanned admissions have reduced (64%)

Erens et al Journal of Integrated Care 2017
## Barriers identified by Integration Pioneers

<table>
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<tr>
<th>% “very” significant by Wave of Integration Pioneer</th>
<th>Wave 1</th>
<th>Wave 2</th>
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<tr>
<td>Significant <em>financial constraints</em> within the local health and social care economy</td>
<td>63</td>
<td>49</td>
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<td>Incompatible <em>IT systems</em> make it difficult to share patient/service user information</td>
<td>38</td>
<td>64</td>
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<td>Conflicting <em>central government policy</em> or priorities</td>
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<td><em>Lack of additional funding</em> makes it difficult to try out innovative services</td>
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<tr>
<td><em>Information governance regulations</em> making it difficult to share patient/service user information</td>
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<td>Too many <em>competing demands for time or resources</em> reducing the focus on working together</td>
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<td>Shortages of <em>frontline staff</em> with the right skills</td>
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<td><em>Increased demand</em> for existing services</td>
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<td>Working out <em>realistic savings</em> that could be achieved</td>
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<tr>
<td>The different <em>cultures of partner organisations</em></td>
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Erens et al *Journal of Integrated Care* 2017
What (else?) could we do better?
More money would be helpful, yes, but clearly we need to think carefully about whose money and how to use it.
What (else) could we do better?

• Where there is robust evidence then learn from it and implement if relevant

• Generate more research evidence to inform policy discussion & practice development

• Take a sustainable decision on how social care is to be financed

• Raise awareness of social care needs, how they arise, and ways to address them
Implement evidence
Child abuse and neglect NG76 October 2017
Intermediate care including reablement NG74 September 2017
Transition between inpatient mental health settings and community or care home settings NG53 August 2016
Transition from children’s to adults’ services for young people using health or social care services NG43 February 2016
Transition between inpatient hospital settings and community or care home settings for adults with social care needs NG27 December 2015
Older people with social care needs and multiple long-term conditions NG22 November 2015
Home care: delivering personal care and practical support to older people living in their own homes NG21 September 2015
Managing medicines in care homes SC1 March 2014
Personalisation of social care has been a strong policy theme for 20 years – to promote choice & control.

Individual (personal) budgets have positive effects on quality of life, social care outcomes, satisfaction.

But outcomes much less positive for older people:
- Concerns about managing budgets
- Need more support

Level of support influences outcomes achieved.

Cost-effective Support arrangements are key to success.

Glendinning et al IBSEN report 2008
Evidence on four main types of intervention:
- services aimed at the care-recipient (benefits in kind)
- services aimed directly at the carer
- work conditions
- cash benefits.

What impacts on:
- Employment (carer)
- Health, wellbeing and quality of life (carer & recipient)
- Income, wealth and poverty
- Changes in supply of unpaid care.

Robust, quantifiable evidence used in our modelling of economic impacts:
- **Statutory care leave** - potentially increases unpaid care provision and increases employment, possibly combined with other interventions.
- **Flexible working arrangements** - improve carer employment outcomes.
- **Formal care** - increases supply of low-intensity unpaid care & decreases higher-intensity caring that is less compatible with employment. Home care, PA support, day care most effective for those caring 10+ hrs per week.

START: a carer support programme

Caring can be enormously stressful; 40% of family carers for people with dementia have depression or anxiety

START: individual programme (8 sessions; 8-14 weeks, delivered by psychology graduates + manual); carers given techniques to:

- understand behaviours of person they care for
- manage behaviour
- change unhelpful thoughts
- promote acceptance
- improve communication
- plan for the future
- relax
- engage in meaningful, enjoyable activities.

Evaluation of START over a 72-month period

**Carer health & QOL**
Mental health gains at 8 & 24 months
QALY gains at 8 & 24 months

**Patient health & QOL**
No differences in health or QOL
Delayed care home admission *not sig.*

**Costs (not significant)**
Increased carer costs at 8m
Reduced total service costs at 24 mths

**Cost-effectiveness**
£118 per 1-point change on HADS-total; £6000 per QALY at 8 months
START dominates usual care at 24 mths

Pragmatic trial: START vs usual support.
n=260 family carers of people with dementia, in North London area.
Analyses at 8, 24, 72 months after end of intervention.

Now analysing carer mental health, care home admission, costs & cost-effectiveness at 72 months ...
... the results look encouraging!
Telecare

- Telecare did not reduce service use over 12 months (n=2600)
- Does not transform lives but may have small benefits on some psychological & HRQOL outcomes (n=1189)
- Not cost-effective

Do more research
Far less social care research than health services research...

... and much is of modest quality. Too many small, local, short-term, uncontrolled studies, using invalid measures.

There are capacity problems in doing research ...

... but especially in using research: insufficient commitment to participate in, and then implement robust research.

NICE guidelines: 183 clinical, 63 public health, 4 medicines practice, 2 safe staffing guidelines (= 252 in total) ...

... but only 6 social care guidelines so far.

NICE has been unpleasantly surprised by the paucity of social care research evidence
Why is the social care evidence base weak?
Some or all of these might be true

- Research funding limited compared to other areas (e.g. health)?
- Methodology limitations in design, data utilisation & analysis, ambition?
- Researcher capacity is constrained: attractiveness? Too few practitioner-researchers?
- Low sense of ‘community’ among researchers?
- Increasingly difficult to get local authorities/providers to participate?
- Increasingly difficult, too, to get research messages through?
- Support costs for research too low?
Mission: “to develop the evidence base for adult social care practice in England by commissioning and conducting world-class research.”

Funded by the National Institute for Health Research

Phase 1

- 2009-14; budget of £15m;
- LSE, KCL, Universities of Kent, Manchester & York
- 70 primary research projects; 28 Methods & Scoping Reviews

Phase 2

- 2014-19; further budget of £15m
- LSE, Universities of Bristol, Kent, Manchester & York
- 60 primary research projects; some Reviews underway
Sort out financing
Projected lifetime LTC costs at age 65

Costs paid by users until their funds run out:
- unfair
- disincentive to save
- expensive for govt

Small minority of people with ‘catastrophic’ costs

A minority of people with no LTC costs

England
Dilnot (2011) and Care Act (2014)

Current situation: awaiting consultation ...

Dilnot: cap on individual care costs set at £35,000
Care Act: cap on individual care costs set at £72,000

Lifetime cost vs. Percentage of population

- Dilnot: cap on individual care costs set at £35,000
- Care Act: cap on individual care costs set at £72,000
“In theory, the significant financial uncertainties in terms of potential need, intensity and duration of long-term care provide a powerful rationale for sharing this risk across individuals” (OECD 2011 p253).

In reality, private LTC insurance coverage is very low.

Why?
Asymmetric information (adverse selection, moral hazard) → insurers protect themselves by limiting access to coverage

Insurers face significant uncertainty re. future costs: individuals’ future needs are uncertain & a long way off; also LTC systems (& eligibility) could change

Insurers therefore unable to control what LTC risks they will cover → premium volatility

Individual myopia in planning for financial risks associated with LTC needs

Competing financial obligations & priorities in earlier adulthood (education, mortgage...)

Availability of potential substitutes e.g. public cover
Raise awareness & take responsibility
Preparing to pay for social care

62% of the public have *hardly or not at all thought* about preparing financially to pay for social care they might need when they are older (% unchanged since 2011)

28% have actually started to prepare to pay for social care services they might need when they are older (% unchanged since 2011)

- Younger people are less likely to have started preparing financially
- People in social grades AB are more likely to have started preparing financially

Concern about meeting the costs

46% of the public are concerned about meeting cost of social care services they might need when they are older

Following Care Act 2014, proportion concerned about meeting social care costs fell (from 59% in 2014 to 44% in 2015), and this was maintained in 2016

- Younger people are much less likely to be concerned about meeting cost of social care services they might need in future

Responsibility for saving

45% agree it is their responsibility to save so that they can pay towards their care when they are old; 32% do not think it is their responsibility, 22% have no opinion
Dementia risks

Prevalence: 850,000 in 2015 (UK); >2,000,000 by 2051.
There is no known cure.
Costs (UK) are already almost £30 billion annually.

Risk factors for dementia:
- Genes (at birth)
- Education (early life +)
- Hearing loss, hypertension, obesity (mid-life)
- Smoking, depression, physical inactivity, social isolation, diabetes (late-life)

Population-attributable risk is 35%

Livingston et al Lancet 2017
Some of the work presented here was supported from:

- Department of Health (DH) for England
- National Institute for Health Research (NIHR)
- NIHR School for Social Care Research
- Economic and Social Research Council (ESRC)
- Alzheimer’s Society.

All views expressed in this presentation are those of the presenter, and are not necessarily those of the DH, NIHR, ESRC or Alzheimer’s Society.

I have no conflicts of interest to report that are relevant to this presentation.

Thank you

m.knapp@lse.ac.uk