Health, social services and third sector research in the United Kingdom -

An economic perspective

Guest lecture, Masaryk University, Faculty of Economics and Administration, Academic Club

Annette Bauer

PSSRU, Social Policy Department
London School of Economics and Political Science
Todays’ agenda

1. Brief introduction of PSSRU

2. Research studies and methods employed by PSSRU in health and social care

3. Economics in third sector research
Acknowledgement: I want to express special gratitude to PSSRU colleagues in particular Martin Knapp and Adelina Comas-Herrera who generously provided slides to this presentation.
A Brief introduction to PSSRU
PSSRU (Personal Social Services Research Unit); part of LSE Health and Social Care
PSSRU
40 YEARS OF RESEARCH ON HEALTH AND SOCIAL CARE
Who we are

PSSRU - Est 1974; at LSE since 1996

LSE Health – Est in 1993 at LSE

Came together in 2000 to form LSEHSC

Joined by
- European Observatory on Health Systems and Policies
- NIHR School for Social Care Research

Mission: “the production and dissemination of high-quality research and policy analysis in health and social care”
PSSRU @ LSE

Research areas

• Social care service evaluation
• Modelling needs, funding & LTC
• Systems / policy evaluation
• Mental health economics & policy

• Dementia
• Outcomes / performance meas’t
• Children & YP’s services
• Unpaid care

Overarching emphases/aims

• Improving user, carer involvement
• Supporting staff development
• Impact & knowledge exchange

• Policy engagement
• Practice relevance
• Academic contributions
• International collaboration
Some basic numbers

- 88 FTE staff members

Since 2009:

- Over 260 new grants secured
- £31 million awarded
- c. 822 papers in peer-review journals
- c. 241 chapters in edited volumes, monographs and books, and publicly available discussion papers
- Over 700 presentations
PSSRU Research

- Care, support and treatment
  - Unit costs of health and social care
  - Resource allocation formulae
- Intellectual disability
- Depression
- Dementia
- Social isolation
- Commissioning
- ASCOT
- Shared Lives
- Disability
- Eligibility thresholds
- Community development
- Production of welfare framework
- Personal budgets
- Care management
- Literature reviews
- Mental health
- Personalisation
- Direct payments
- Unpaid carers
- Health and social care integration
- Quality and performance
- Long-term conditions
- Long-term care financing
- Suicide prevention
- Care home quality indicators
- Children and young people
- Telecare
- FACS
- Cost-effectiveness analysis
- Residential care and housing
- Knowledge exchange
- Instrument development
- Unpaid care and employment
Eligibility criteria – to DH
• Funding of long-term care – Dilnot Commission
• Projections models – EC Ageing Report; local authorities; DH
• Carers and employment – HM Treasury & others
• Dementia economics – World Dementia Council; Prime Minister’s Challenge; DH/BIS for PM
• Suicide – Scottish Government policy
• Mental health – national mental health strategy
• Prevention – Local authorities
• Regulation – Care Quality Commission
• Building community capacity – social care policy
• Autism – Scottish policy; international debates

Inputs into Government Green and White Papers, Parliamentary debates, Select Committees
Number of large programmes:
• Modelling the costs and outcomes of dementia
• Unpaid care and employment (longitudinal)
• Developing and testing a preventions evaluation framework
• Economic analysis of the Better Start programme (Big Lottery)
• Understanding the interactions between state pension and long-term care funding
• Evaluating direct payments in residential care

And initiatives
• International Long-term Care Network & development of Journal of Long-term Care
• Ongoing work on understanding knowledge exchange and impact in social care and “evidence-based practice”
• Social Care Elf
Research topics and methods by PSSRU
B1 Personal budgets health and social care/ Economic evaluation
B2 Perinatal mental health/ Cost of illness
B3 Advocacy for parents with learning disability/ case study approach
B4 Long-term care finance/ macro-simulation
B5 Building community capacity/ decision modelling
B.1

**Topic:** Personal budgets in health and social care

**Method:** Economic evaluation of personal budgets
B.1

- Principles and methods of economic evaluation
- Background to personal budgets in the UK
- PSSRU research: Economic evaluation of personal budgets
Economic evaluation: what does it mean?

If the policy/practice question is: ‘Does this intervention work?’

Then the economic question is: ‘Is it worth it?’

Which requires us to define what we mean by ‘work’ and by ‘worth’ – hence what outcomes and costs.

Which then usually requires difficult and maybe controversial trade-offs.
Imagine that you have an idea for a new service (call it ‘Service 2’)

You want to sell/recommend it so that it replaces today’s usual service (call it ‘Service 1’)

The decision-maker has a limited budget. What will s/he want to know before deciding whether to purchase the new service?
Is it more cost-effective?

Service 2
Effects - on a user’s needs, social functioning, quality of life

Costs - cost of the service, costs of other services used, effect on employment

Service 1
Effects - on a user’s needs, social functioning, quality of life

Costs - cost of the service, costs of other services used, effect on employment

An economic evaluation needs all 4 elements
Possible CEA results

- New service less effective and more costly: $C_2 > C_1$ and $E_2 < E_1$
- New service more effective but also more costly: $C_2 > C_1$ and $E_2 > E_1$
- New service less effective but less costly: $C_2 < C_1$ and $E_2 < E_1$
- New service more effective and also less costly: $C_2 < C_1$ and $E_2 > E_1$

$C = \text{costs}$
$E = \text{effects}$
$1 = \text{old service}$
$2 = \text{new service}$
Possible CEA results

C_2 > C_1

E_2 < E_1

C_2 < C_1

E_2 > E_1

C = costs
E = effects
1 = old service
2 = new service
If you are trying to sell Service 2 ...

How are the outcomes traded-off against the costs?

How are the costs traded-off against the outcomes?
Trade-offs … is it worth it?

If an intervention is more effective and also more costly, then calculate the cost per unit gain in effectiveness.

So we first need to calculate the cost-effectiveness ratio, which is ...

\[
\text{ICER} = \frac{(C_2 - C_1)}{(E_2 - E_1)}
\]

= the cost of achieving an incremental improvement in an outcome measure
Trade-offs ... is it worth it?

With the ICER we then have the following options:

- Show the decision-maker the cost-effectiveness of different ways to spend their money and get them to choose
- Or ask them how much they are willing to pay
- Or set a threshold, rigidly or as a guide (cf. NICE)

But then we need some way to compare across different ‘areas’ (e.g. across different need groups)

- Hence QALYs in health; and ASCOT in social care.
Cost-utility in *Health*

Quality Adjusted Life Years (QALYs)

- Incorporate quality and quantity of life.
- Calculated by multiplying the duration of a time spent in a health state by the Health Related Quality of Life weight (=utility score).
- HRQoL are preference weights that reflect desirability measured on a cardinal scale from 0-1.

Example: An individual spent 10 additional life years in health state associated with utility 0.6. How many QALYs are gained? What needs to be considered?
# Utility weights for the EQ-5D

<table>
<thead>
<tr>
<th>EQ-5D score</th>
<th>Description</th>
<th>Utility weight</th>
</tr>
</thead>
<tbody>
<tr>
<td>11111</td>
<td>Mobility – no problems, Self-care – no problems, Usual activities – no problems, Pain/discomfort – no problems, Anxiety depression – no problems</td>
<td>1.000</td>
</tr>
<tr>
<td>21121</td>
<td>Mobility – some problems, Self-care – no problems, Usual activities – no problems, Pain/discomfort – some problems, Anxiety depression – no problems</td>
<td>0.727</td>
</tr>
<tr>
<td>11223</td>
<td>Mobility – no problems, Self-care – no problems, Usual activities – some problems, Pain/discomfort – some problems, Anxiety depression – major problems</td>
<td>0.255</td>
</tr>
<tr>
<td>23323</td>
<td>Mobility – some problems, Self-care – major problems, Usual activities – major problems, Pain/discomfort – some problems, Anxiety depression – major problems</td>
<td>-0.086</td>
</tr>
<tr>
<td>Domain</td>
<td>Definition</td>
<td></td>
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<tr>
<td>------------------------------------</td>
<td>---------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Control over daily life</td>
<td>The service user can choose what to do and when to do having control over his/her daily life and activities</td>
<td></td>
</tr>
<tr>
<td>Personal cleanliness and comfort</td>
<td>The service user feels he/she is personally clean and comfortable and looks presentable or, at best, is dressed groomed in a way that reflects his/her personal preferences</td>
<td></td>
</tr>
<tr>
<td>Food and drink</td>
<td>The service user feels he/she has a nutritious, varied and culturally appropriate diet with enough food and drink he/she enjoys at regular and timely intervals</td>
<td></td>
</tr>
<tr>
<td>Personal safety</td>
<td>The service user feels safe and secure. This means being free from fear of abuse, falling or other physical harm and of being attacked or robbed</td>
<td></td>
</tr>
<tr>
<td>Social participation and involvement</td>
<td>The service user is content with their social situation, where social situation is taken to mean the sustenance of meaningful relationships with friends and family, and feel involved or part of a community, should this be important to the service user</td>
<td></td>
</tr>
<tr>
<td>Occupation</td>
<td>The service user is sufficiently occupied in a range of meaningful activities whether it be formal employment, unpaid work, caring for others or leisure activities</td>
<td></td>
</tr>
<tr>
<td>Accommodation cleanliness and comfort</td>
<td>The service user feels their home environment, including the rooms, is clean and comfortable</td>
<td></td>
</tr>
<tr>
<td>Dignity</td>
<td>The negative and positive psychological impact of support and care on the service user’s personal sense of significance</td>
<td></td>
</tr>
</tbody>
</table>
Utility weights (1)...

<table>
<thead>
<tr>
<th>Best (mark &quot;X&quot;)</th>
<th>Aspect of life</th>
<th>Worst (mark &quot;X&quot;)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I can get all the food and drink I need</td>
<td></td>
</tr>
<tr>
<td></td>
<td>I have poor personal hygiene, so I don't feel at all clean or presentable</td>
<td></td>
</tr>
<tr>
<td></td>
<td>My home is as clean and comfortable as I want</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sometimes I don't feel safe enough</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sometimes I feel lonely, but have some contact with people I like</td>
<td></td>
</tr>
<tr>
<td></td>
<td>I spend my time as I want, doing things I value or enjoy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>I have adequate control over my daily life</td>
<td></td>
</tr>
<tr>
<td></td>
<td>The way I'm helped undermines the way I think and feel about myself</td>
<td></td>
</tr>
<tr>
<td></td>
<td>And I am living in my own home</td>
<td></td>
</tr>
</tbody>
</table>
Utility weights (2)...

Would you prefer:
to die immediately
or
Life B for 10 years followed by immediate death
or
are they the same?

- I have no control over my daily life
- I have some social contact with people, but not enough
- I don’t always get adequate or timely food and drink
- I’m able to do enough of the things I value or enjoy with my time
- I feel less than adequately clean or presentable
- I feel less than adequately safe
- My home is as clean and comfortable as I want
- The way I’m helped and treated sometimes undermines the way I think and feel about myself
Personalisation in practice: social care

- Services tailored to the **needs** of the individual, rather than ‘one size fits all’
- Services tailored to the **preferences** of the individual

Hence actions could include:
- Better information & advice on care & support
- Promotion of independence & self-reliance among individuals & communities (includes social capital)
- Prevention / risk-reduction strategies that emphasise personal strengths & responsibilities
- Direct payments and personal budgets (with brokerage & support as needed)
Personalisation in practice: health care

- Treatment tailored to individual **needs** (e.g. symptoms & functioning)
- Treatment responsive to individual **preferences** (e.g. therapy type, location, timing, professional)
- Prevention / treatment strategy responsive to individual **circumstances** (e.g. genes, income, culture, resilience, age, …)

Hence actions could include:
- Better information & advice on care & support
- Promotion of self responsibility for health
- Encouragement of communities (social capital)
- Personalized medicine
- Personal health budgets (with brokerage etc)
Social care

“Every person who receives support, whether provided by statutory services or funded by themselves, will have choice and control over the shape of that support in all care settings” (Department of Health 2010).

Health care

Patients must be given “real power to shape their own care ... We need to stop treating people as a collection of health problems or treatments. We need to treat to them as individuals whose needs and preferences should be seen in the round and whose choices shape services, not the other way round.” (Simon Stevens, CEO of the NHS, 2014).
Why this policy/practice emphasis? (1)

• Long-standing social work commitment to **self-determination** for (under-privileged) individuals and families – i.e. empowerment ...

• To encourage **personal health responsibility** e.g. for lifestyle, diet, tobacco, alcohol consumption, ...

• Empowerment could encourage services to be more **responsive to individual needs & preferences**.

• Social care, public health (and health care?) emphases on **roles of families & communities** ...

• ... particularly the benefits of **social capital**

• And the over-arching beliefs that individual, family & social **outcomes** will be better; and/or costs will be lower
Why this policy/practice emphasis? (2)

- **The citizenship agenda** – ground-level politics
- **Rights-based advocacy** by/for service users
- **Flexibility**: personalisation potentially offers different levels of independence & control
- `Collectivization of welfare` – encourages informal pooling of budgets.
- **Political support:**
  - from the **Right** – encourages personal responsibility; accountability; market-like allocations (e.g. with personal budgets)
  - from the **Centre Left** – encourages public confidence, social inclusion, personal rights
## Individual / personal budgets

<table>
<thead>
<tr>
<th></th>
<th>Public sector</th>
<th>Voluntary</th>
<th>Private</th>
<th>Informal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public</td>
<td>Hierarchy &amp; quasi-mkts</td>
<td>‘Out-sourcing’ or contracting out</td>
<td>Support for carers</td>
<td></td>
</tr>
<tr>
<td>Charitable</td>
<td>Foundation support</td>
<td></td>
<td>Community grants</td>
<td></td>
</tr>
<tr>
<td>Corporate</td>
<td></td>
<td></td>
<td>Paid leave for carers</td>
<td></td>
</tr>
<tr>
<td>Individual – own use</td>
<td>Individual / personal budgets</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individual transfers</td>
<td>Donations to the state</td>
<td></td>
<td>Support for neighbours</td>
<td></td>
</tr>
</tbody>
</table>

Individual budgets (IBs) & personal budgets (PBs)

- Central to Labour Government’s ambition to ‘modernise’ social care ...
- ... at the heart of its ‘personalisation’ agenda
- ... to promote choice
- Pilot programme set up 2005 – evaluated in the IBSEN study (see later)
- PBs are more or less the same as IBs
- Putting People First (White Paper, 2007) proposed that ‘all people who are eligible for social care and support should have access to a personal budget, including the direct payment option, with the intention that they could use it to exercise choice and control in meeting their agreed social care outcomes’ (SCIE Rough Guide).
Personal budgets - elements

- Give clear, early understanding of amount (£) available to the individual, so that they can influence or control how it is spent, in a way which helps them best meet their needs.
- Focus on providing for ongoing support and care needs.
- Implemented within self-directed support framework: self-directed assessment; ‘up-front’ allocation of funds; support planning to promote maximum choice and control.
- Include sufficient funding to cover costs in employing personal assistants directly, and contingency funding for emergency cover.
Personal budgets - how?

- As a **direct (cash) payment**, held by the service user or, where there is a lack of capacity, by a ‘suitable person’.

- An ‘account’ held / managed by **local authority** in line with user’s wishes, to pay for community care services commissioned by the LA.

- An account with a **third party** (provider), 'spent' by user in direct negotiation with the provider. This ‘managed option’ allows the individual to draw on existing or new contracts to suit their needs without taking on direct budget management responsibilities.

Or some mix of the above.
The IBSEN evaluation

**CORE QUESTION** → Do individual budgets offer a **better way to support** disabled adults and older people than conventional methods of resource allocation and service delivery?

If so, **which models work best** and for whom?

### Evaluation dimensions

- **User experience**
- **Carer impact**
- **Workforce**
- **Care management**
- **Provider impact**

- **Risk & protection**
- **Commissioning**
- **Outcomes**
- **Costs**
- **Cost-effectiveness**
IBSEN - design

- **Randomised trial** – IB and comparison groups (but lots of flexibility within those groups re deployment)
- Follow-up interviews after 6 months → some challenges (logistical, instrumentation, interviewee exhaustion, proxy respondents ...)
- In-depth interviews with 20% of users – assessment and support planning
- Interviews with lead officers (in local authorities), providers, commissioners, other managers, Adult Protection, ... ...
- Interviews and diaries – care managers, team leaders
- Add-on study of impact of IBs on *carers*

Considerable local and individual flexibility:

- Cash direct payment [67%]
- Care manager-held ‘virtual budget’ [20%]
- Service provider-held ‘individual service account’ [<1%]
- Third-party individuals and trusts [13%]
## IBSEN - patterns of spending

<table>
<thead>
<tr>
<th></th>
<th>IB as direct payments</th>
<th>IB as care-managed budget</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>Mean annual expenditure</td>
</tr>
<tr>
<td>Personal assistant</td>
<td>64</td>
<td>£8,940</td>
</tr>
<tr>
<td>Home care</td>
<td>20</td>
<td>£7,140</td>
</tr>
<tr>
<td>Leisure activities</td>
<td>43</td>
<td>£2,020</td>
</tr>
<tr>
<td>Planned short breaks</td>
<td>24</td>
<td>£1,750</td>
</tr>
<tr>
<td>Other</td>
<td>23</td>
<td>£930</td>
</tr>
</tbody>
</table>
## Personal budgets bought ‘new’ services

<table>
<thead>
<tr>
<th>Accommodation</th>
<th>Employment and occupation</th>
<th>Health-related</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cleaning service</td>
<td>Going out: trips/cinema etc.</td>
<td>Private health care</td>
</tr>
<tr>
<td>Decorating service</td>
<td>Classes/arts and crafts</td>
<td>Massage for carer</td>
</tr>
<tr>
<td>Gardening service</td>
<td>Gym membership/swimming</td>
<td>Alternative therapy</td>
</tr>
<tr>
<td></td>
<td>Computer maintenance</td>
<td>... Dating agency</td>
</tr>
<tr>
<td></td>
<td>Admission fees for service user and PA</td>
<td></td>
</tr>
</tbody>
</table>
The views of personal budget holders (1)

Comment on standard care:
“That’s all they recognise, just your personal care, being washed and all that. And you know, other things are so much more important to your well-being.” (Older person)

Personalisation – benefit:
“It’s given me more say and I can do more.”
(A woman with physical disability able to go on holiday, employing her sister as her carer)
Reluctance to take responsibility:
“"I don’t want to be dealing with that sort of thing at my age, dear." [I.e. the ‘hassle costs’ of choice]

Anxiety or unwillingness to manage money
“Carers are all laid on for me at the moment and I haven’t got the time and I haven’t got the brain really to work out financial details or anything like that, and I’m quite happy with the arrangement I’ve got.”

Able and willing to handle finances without stress
“So I thought, right, I can do this cheaper myself so ... I went to a smaller, cheaper and far superior agency.”
# Outcomes and costs (IBSEN evaluation)

<table>
<thead>
<tr>
<th>Domain</th>
<th>Pooled sample</th>
<th>Subgroup differences?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of life</td>
<td>No difference</td>
<td>IBs better for mental health subgroup</td>
</tr>
<tr>
<td>Psychological well-being</td>
<td>No difference</td>
<td>IBs worse for older people</td>
</tr>
<tr>
<td>Social care outcomes</td>
<td>No difference*</td>
<td>No difference*</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>IB better</td>
<td>IBs better for physical/sensory disability group</td>
</tr>
<tr>
<td>Costs</td>
<td>IB lower (small diff)</td>
<td>No difference</td>
</tr>
</tbody>
</table>

*IBs offered more ‘felt control’ when analysed for the overall sample and the learning disability group*
Overall conclusions from IBSEN

- **Positive effects of IBs**
  - Quality of life, social care outcomes and satisfaction
- But much less positive for **older people**
  - Concerns about managing budgets
  - Early stages in the process, however
- **Levels of support** were found to influence the outcomes achieved ...
- ... with implications for **cost-effectiveness**.

But ... Government didn’t wait for IBSEN results before proceeding with the national roll-out of Personal Budgets (short-term political imperative?)
Interest stimulated by UK experience in social care, particularly for people with both social care & long-term health needs.

Patients often interested in involvement in managing their condition.

PHBs won’t work across all areas, particularly where needs are unpredictable or where treatments are complex (cf. market failure).

But where health and social care needs overlap, and service responses could also overlap, it makes sense to explore PHBs. She proposed 4 criteria to determine eligibility for PHBs:

• reasonably stable and predictable needs
• individuals have unique knowledge about their needs and how they can best be met
• genuine alternatives exist for meeting their needs
• alternative sources of supply exist or can be developed outside of local authority or NHS services.
Relative to the control group:

- Significant improvement in **care-related quality of life** and **psychological wellbeing**. Health status stayed the same.
- Benefits more marked for people with **greater need**.
- Worked better where people given **more choice and control** (over what they bought & how they received budget).
- No differences by **gender, ethnicity or income**.
- Positive impacts for budget-holders & **other family members**. Also changed relationships with **healthcare professionals**.
- **Family carers** - better quality of life and perceived health
- PHBs were **cost-effective**, particularly for people who get NHS Continuing Healthcare and those who use mental health services.
- People chose to **meet health needs in different ways that cost less** (e.g. training their care staff to change dressings).
- **In-patient costs** fell for people with a personal health budget
PHBs - policy roll-out in England

- PHBs introduced in England in April 2014 for 56,000 people with highly complex, long-term health needs eligible for NHS continuing healthcare (if they want to take them).
- In 2015 it is expected that PHBs will be extended to anyone with a long-term condition who could benefit from one.

**Future success will depend on:**

- Culture change and a shift in the relationship between health professionals and patients
- Giving people the right support, including clear information.

But PHBs could be a vehicle to promote integration of social care and health care
Topic: Perinatal mental health
Method: Cost of illness, decision modelling
Background

- Large proportion of women suffer: up to 1 in 5
- Children suffer too: Via genetic and environmental factors starting in the womb (e.g. .. cortisol levels produced when mother is stressed reach the fetus; mother less likely to be able to provide sensitive attachment after birth; ...)
- Negative consequences for children throughout life-time
- Evidence comes from cohort studies (e.g. ALSPAC, Millennium Cohort, South London Development Study)
- Service provision is highly patchy, treatment often inadequate: Less than 15% of localities provide specialist services at level recommended in NICE guidelines and 40% provide no services at all
Initial economic work: Postnatal & perinatal depression

A small **cost-effectiveness** modelling study of *health visiting* based on published trials data (and other sets of evidence):

- Considered the **short-term health outcomes and costs** (health and social care expenditure);
- Intervention was likely to be cost-effective but not cost saving (in the short-term);
- Did not include long-term impact on mothers and children.

Initial economic work: Postnatal & perinatal depression

Modelling study of long-term costs of the impact on children based on primary data from the South London Development Study (Susan Pawlby and colleagues from King’s College)

Step 1: Logistic regression of effects of perinatal depression on child development outcomes at 11 and 16yrs

Step 2: Evidence reviews of studies of epidemiology, health-related quality of life, public sector costs and employment

Step 3: Modelling cost consequences of adverse outcomes over life-time (where possible)
Findings

• Indicated potential for large financial gains of investing into this area: For each child exposed to perinatal depression, public sector costs exceeded £3,030, costs due to reduced earnings were £1,400 and health-related quality of life loss was valued at £3,760.

Limitations

• Subset of adverse outcomes and economic consequences; small study sample; perinatal depression only

Collaborative research

- Commissioned by the Maternal Mental Health Alliance
- Part of Everyone’s Business Campaign
- Funded by Comic Relief
- In partnership with the Centre for Mental Health
- In consultation with an expert reference group
- NICE clinical guideline updated at the same time
- Presented to Parliament in Oct. 2014
Cost of illness study: Aims

General: To produce estimates of the overall costs of maternal perinatal mental health problems.

More specifically:... To investigate

• The distribution of costs between groups i.e. mothers & children; for different perinatal conditions;

• Life time costs at present value per case and per birth;

• Perspective of government: expenditure for public services in health and social care, education and criminal justice) and

• Perspective of wider society: government plus value for life years lost, health-related quality of life impairments and productivity losses).
Cost of illness study: Method

Decision modelling approach - *rationale*

Allows to

- Synthesise data from a variety of sources following principles of meta-analysis;
- Utilise information from a wide range of different cohort studies;
- Extrapolate data beyond endpoints of relevant studies and model life-time economic consequences;
- Link intermediate to final outcomes such as quality of life and productivity losses;
- Incorporate uncertainty around parameters;

... and avoids having to carry out primary data collection or analysis and to rely on single source.
Method: Steps involved

- Designing the pathway (model structure) based on initial evidence of adverse outcome
- In depth literature review of adverse outcomes
- Selection of studies, appraisal and information extraction
- Additional data searches
- Adaptions of model structure based on data, defining time periods
- Calculating additional risk (risk differences)
- Calculating annual cost of adverse outcome for identified time periods
- Calculating net present values
Method: Literature review

1. Cohort (and other types of) studies of **resource use or costs** linked to perinatal mental health problems
2. Cohort (and other types of) studies which measured the relationship between perinatal maternal mental health problems and mothers’ and child’s health and wellbeing outcomes
3. Systematic reviews and meta-analyses on prevalence and natural course of mental health conditions
4. Cohort (and other types of) studies which quantified resource use or costs linked to adverse child outcomes
5. Unit cost data, national statistics

**Searches needed to be pragmatic! Quality not formally assessed; instead we applied certain criteria to prioritise e.g. large cohort studies from UK, published in peer reviewed journals**
Method: Decision modelling

**Incremental** approach: additional costs associated with perinatal mental health problems;
- Directly or from additional data sets (national averages)

*Principles and standards* of attaching monetary values (recommended by the National Institute for Health and Care Excellence (NICE) and other government bodies)
- **Unit costs attached to public service use** from PSSRU Unit cost book for health and social care and NHS Reference costs
- **Mean weekly wage rates** from Office for National Statistics
- **Willingness-to-pay value** for a health-related quality adjusted life year gained
- **Value of prevented fatality** for whole life lost (suicide or infanticide)
- **Discount rate** of 3.5%; average growth of earnings of 2%
Method: Decision modelling

Assumptions

• *Remission* of an episode of mental illness occurring during the perinatal period => cut-off point at 10 years
• *Average age of women at childbirth* of 32 years
• *Average remaining life expectancy* of 44yrs (based on an average life expectancy for women of 76 years)
• *Retirement age* of 65yrs
MOTHER, cost of perinatal depression or anxiety

**Step (1)**
7.4%

Prevalence and remission 10yrs

**Perinatal period**
= Pregnancy until 1yr after birth

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<th>7th</th>
<th>8th</th>
<th>9th</th>
<th>10th</th>
</tr>
</thead>
</table>

**Step (2)**
Additional costs of perinatal mental illness, annual costs of mental illness

£, perinatal period
Const. £ p.a.

**Step (3)**
Present value = \( \sum_{t=0}^{10} \) Mean prevalence\(_t\) \( \times \) Costs\(_t\) \( \times (1 + i)^{-t} \)
Impact on CHILD, Example outcome: depression

- 9.4% (postnatal depression)

Prevalence and remission 10yrs

Risk differences for child emotional problems

0.05pp

0.009pp

Step (1)
Birth ...

5th yr ...

10th yr ...

16th yr ...

... 65th yr

Step (2)
Additional costs of depression in child- and adulthood

Const. £, p.a., childhood

Const. £, p.a., adulthood, based on mean duration of condition and costs distributed over life time

Step (3)
Present value = \sum_{t=5}^{65} \text{Mean prevalence}_t \times \text{Costs}_t \times (1 + i)^{-t}
Key findings

**Known costs of perinatal mental health problems per year's births in the UK, total: £8.1 billion**

- Health and social care
- Other public sector
- Wider society

- £0.5 billion
- £1.2 billion
- £6.4 billion

**Of these costs**
- 28% relate to the mother
- 72% relate to the child

**Up to 20% of women develop a mental health problem during pregnancy or within a year of giving birth**

**Women in around half the UK have NO access to specialist perinatal mental health services**

**Suicide is a leading cause of death for women during pregnancy and in the year after giving birth**

**Costs vs improvement**
- The cost to the public sector of perinatal mental health problems is 5 times the cost of improving services.
Key findings

Average cost to society of one case of *perinatal depression* £74,000, of which £23,000 relates to mother and £51,000 relates to child.

*Perinatal anxiety* (when it exists alone and is not co-morbid with depression) costs about £35,000 per case, of which £21,000 relates mother and £14,000 to the child.

*Perinatal psychosis* costs around £53,000 per case, of which about £47,000 relates to mother and £6,000 to child (= lack of evidence of longer term impact on child).
...a lot of media attention
Topic: Advocacy for parents with learning disabilities
Method: Case study approach
Parents with learning disabilities

• At much higher risk of losing their children into care
• More likely to be involved in child protection cases: 15% to 22% of parents involved in child protection conferences and care proceedings have LD (Brandon et al 2009)
• Learning disability can be the main reason for child welfare issues but often not identified
• Less likely to seek help (Cleaver & Nicholson 2008)
• Additional support and responsive mainstream services needed
• Evidence shows that it is better to intervene early (e.g. Allen 2011)
Our research: ‘Investing in advocacy for parents with learning disabilities’

Method

• 2 workshops and a small survey with 4 advocacy projects working in England
• Information on case studies and organisation collected via semi-structured questionnaire
• Evidence reviews
• Simple decision modelling

We received information on 17 case studies
Our research: ‘Investing in advocacy for parents with learning disabilities’

Findings

Example 1 of a case study (in summary form)

Helen, a survivor of domestic violence, was referred to an advocate one week before the final hearing in child care proceedings for six of her children. She had felt unsupported by council staff during prior processes of assessment and case conferences. In turn, social services were concerned that she did not understand the process and its implications. With the advocate’s help, Helen started to engage with social services and was able to keep her youngest child under a supervision order which was later lifted; she also improved contact with her children in foster care. Helen is now engaged with the school and a wide range of support groups, due she thinks to her increased knowledge and self-confidence. She also reports feeling less isolated, anxious and depressed.

When Helen understood that she had rights, too, this changed the way she interacted with social services. Helen also used the advocate to speak on her behalf in meetings when she felt too emotional to participate effectively.
Our research: ‘Investing in advocacy for parents with learning disabilities’

Findings

Example 2 of a case study (in summary form)

The birth of Serena’s first child was imminent when advocacy became involved in her accommodation and financial difficulties. A young person and a child in need plan was in place because her professional workers were concerned about her ability to parent. She was referred to advocacy to prevent escalation to child protection status. The advocate supported Serena to access early interventions including parenting classes, peer support groups, financial advice, and housing. The advocate also ensured she received counselling for symptoms of postnatal depression. When the advocacy intervention ended (after 15 meetings over an 8 months period), social services were no longer concerned about Serena’s ability to parent. When she became pregnant again no further involvement was considered necessary.

In Serena’s case the referral was made at an early point so that many more intensive and expensive interventions could be prevented including case conferences, court hearings and parenting assessments. Good multi-agency was reported to have been in place locally in particular between housing and benefit services.
Our research: ‘Investing in advocacy for parents with learning disabilities’

Findings

Project leads identified factors that constituted good practice and positively influenced outcomes:

- Early referral: Good practice meant receiving a referral no later than the initiation of a Section 47 enquiry.
- LD (and associated communication and understanding difficulties, fears and defensive behaviours) as main reason for parents’ disengagement from child safeguarding process;

Advocacy was also considered able to change professionals’ awareness and attitudes and improve joint working with parents; an advocate’s involvement could mean more time spent considering options and evaluating possible decisions. It could also lead to better interagency working around parents’ needs.
Our research: ‘Investing in advocacy for parents with learning disabilities’

Findings

• Possible reduction in safeguarding activities, care proceedings and arrangements, worth £720 per parent
• Possible economic benefits linked to increased access to early interventions, worth £3,130
• Costs of advocacy: £32 per hour, mean length of intervention 95hrs
• Wide range of outcomes: mental wellbeing, placement stability, better relationships with children who had been previously removed, school attendance and performance

Our research: ‘Investing in advocacy for parents with learning disabilities’

Full standard child safeguarding process under continuing difficulties, concerns and a lack of parents’ engagement.

<table>
<thead>
<tr>
<th>Child in need</th>
<th>Child protection plan</th>
<th>Care proceedings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessment</td>
<td>Meetings</td>
<td></td>
</tr>
<tr>
<td>Strategy meeting/discussion, police referral</td>
<td>Section 47 enquiry* started, core assessment</td>
<td>Initial child protection conference</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Case conferences, core group meetings</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Review conference (Child protection plan Y/N)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Application for care proceedings, pre-proceeding meeting</td>
</tr>
<tr>
<td></td>
<td></td>
<td>First Appointment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Case Conference</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Issues Resolution hearing</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Care order</td>
</tr>
</tbody>
</table>

Assessments (e.g. psychological, psychiatric, learning disabilities, parenting, etc.)
B.4

**Topic:** Long-term care finance

**Method:** Macro-simulation
What is long-term care?

• Aims to:
  – reduce, lessen consequences of, or compensate for disability, cognitive impairment and loneliness; improve quality of life.

• Services are delivered in:
  – peoples’ own homes (home help, meals, nursing care)
  – or in substitute care settings (residential care homes, nursing homes, hospitals)
What is Long-Term Care (cont.)?

• Support is provided by:
  – Unpaid carers and formal care providers (public, private and voluntary sector), largely unskilled

• Support is provided in:
  – everyday tasks, including dressing, bathing, shopping, cooking, cleaning, therapy

• Main client group: older people
Health Care vs. Long-Term Care

- Most people will need health care, and at more than one point of their life.

- Health care costs are mostly covered by public system, considered public responsibility.

- Health care is mostly delivered by highly specialised professionals.

- 1 in 3 people will need long-term care (usually at the end of their life), many will not need it at all.

- LTC is a result of health problems, but financed differently than health care => sense of unfairness.

- Most LTC is provided by unpaid carers. Substitution between formal and informal care.
Public spending on LTC as % of GDP, 2010-2060. Base case (demography-led) scenario

Source: The 2012 Ageing Report: Economic and budgetary projections for the EU27 Member States (2010-2060). European Commission
Financing long-term care

• All developed countries, unless there is a major breakthrough in the prevention or treatment of disabling conditions associated with old age, will need to devote a larger share of resources to LTC than they do currently.

• Relying on informal care or private savings to meet this additional costs would be inefficient and inequitable.

• Resistance to higher taxation suggests that a possible solution may lie in new public/private financing partnerships, with a potential role for compulsory insurance (public or private).

• The state’s role could be to guarantee universal coverage and redistribution mechanisms to guarantee equity.
Policy reform, DILNOT report ‘Limited liability model of social insurance’; majorly informed by PSSRU projection modelling

- Costs of care in later life are shared between the individuals and the state
- Individuals pay for their own care until they reach a cap after which the state pays for their care (suggested cap was between £25,000 and £50,000, implemented cap was much higher at £75,000)
- Raised means test for residential care from £23,250 to £123,000 i.e. people entering a care home with less than £123,000, including the value of their home, will not have to pay the full cost of their care
Modelling approaches and challenges

- Modelling future dementia care needs and associated expenditure presents two major challenges:
  - Capturing complexity
  - Data limitations
- Capturing complexity: there are many variables involved, some not easily quantifiable
- The ideal dataset on which to base a model (longitudinal, sufficient numbers of people with dementia and care users… with all the relevant variables) is rarely available, so creative data-linking and bridging is required.
Health and Social care: funding divide vs. integration

• Health care is **free** at the point of use, whereas social care is often **means-tested** or attracts co-payment.

• The **boundaries between health and social care are unclear** and there is both opportunities and incentives for cost-shifting

• Different professional traditions and organisational structures make integration of health and social care very challenging.
  
  – Lack of integration results in less prevention than would be optimal:
    • Better management of chronic conditions by health sector => less need for LTC
    • Better social care can prevent costly hospital admissions.
Algorithms assigning needs to benefits vs. care management

- **Social insurance systems** tend to have algorithms that assign pre-defined benefits to particular levels of need.

- In **tax-based systems** (traditionally) care managers assess individual needs and assign personal packages of care.

- Algorithms are clear and transparent, but may lack flexibility in the way resources are allocated, in particular difficulties reflecting needs arising from cognitive impairment.
Simulation modelling

The projections model is an aggregate or “cell-based” model. This means we look at groups of people rather than individuals. The model categorises the older population using a series of variables such as age, gender, household composition, level of disability, and housing tenure. We end up with about 400 different groups of older people, and, using official population projections and other data, we estimate how many people will be in each group in the baseline and future years, e.g. 2010, 2020, 2030, 2040. We conduct analyses of various sources of data to estimate the proportion of people in each group who receive different types of care. We then assume in our baseline projections of future demand and costs that these proportions will remain constant for each group. These are projections not forecasts: we make a number of assumptions – for example about future population growth, annual increases in the costs of care, and disability levels by age and gender – and conditional on these assumptions we can then say expenditure is projected to rise from £X billion to £Y billion over a specified time period.
The PSSRU LTC CI model

- Based on the England PSSRU aggregate LTC model
- Data from MRC-CFAS and PSSRU surveys of residents in care homes is used to estimate the prevalence of CI and the proportion of care users who have CI.
- Older people and users of services are divided into four disability groups:
  - No CI or functional disability (FD)
  - FD but no CI
  - CI only (used as proxy for mild stages of dementia)
  - CI and FD (proxy for moderate/severe dementia)
- Simulates the impact on demand of specified changes in demand drivers, or specified changes in patterns of care.
- Makes projections on the basis of specific assumptions about future trends.

See, for example, Comas-Herrera et al., 2007
Probability of being in an institution for people aged 75 to 84, by gender, household type and dependency group.

<table>
<thead>
<tr>
<th></th>
<th>Group probability of being in an institution</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>CI only</td>
</tr>
<tr>
<td><strong>75-84 male</strong></td>
<td></td>
</tr>
<tr>
<td>Alone</td>
<td>27</td>
</tr>
<tr>
<td>With others</td>
<td>37</td>
</tr>
<tr>
<td>Married</td>
<td>8</td>
</tr>
<tr>
<td><strong>75-84 female</strong></td>
<td></td>
</tr>
<tr>
<td>Alone</td>
<td>9</td>
</tr>
<tr>
<td>With others</td>
<td>13</td>
</tr>
<tr>
<td>Married</td>
<td>4</td>
</tr>
</tbody>
</table>

Source: PSSRU CI LTC model estimates (using MRC CFAS data).
Expenditure projections for people with dementia 2002 to 2031

Projected total LTC expenditure, at 2002 prices

LTC expenditure as % of Gross Domestic Product

Red – older people with cognitive impairment; Blue - not

Comas-Herrera et al, IJGP 2007

<table>
<thead>
<tr>
<th></th>
<th>2007</th>
<th>2032</th>
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<tbody>
<tr>
<td></td>
<td>Constant Disability prevalence</td>
<td>Hypothetical “Brookings” scenario</td>
</tr>
<tr>
<td>Home care</td>
<td>298,000</td>
<td>514,000</td>
</tr>
<tr>
<td>Institutional care</td>
<td>332,000</td>
<td>609,000</td>
</tr>
<tr>
<td>Total LTC Expenditure (£billion)</td>
<td>17.5</td>
<td>49.8</td>
</tr>
<tr>
<td>LTC Expenditure as% of GDP</td>
<td>1.4%</td>
<td>2.7%</td>
</tr>
</tbody>
</table>
Assumptions about future disability when projecting future LTC expenditure:

1. Assuming unchanged disability rates
2. Extrapolating from past trends
3. Projections based on hypotheses linked to changes in life expectancy (for example Brookings scenario).
4. Asking the experts for their views about the future.
5. Linking with epidemiological models of chronic conditions and their mortality and disabling outcomes.
Assumptions about future disability when projecting future LTC expenditure:

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4. Asking the experts for their views about the future.
5. Linking with epidemiological models of chronic conditions and their mortality and disabling outcomes.
B.5

**Topic:** Building community capacity

**Method:** Decision modelling
Decision modelling
A method that can combat some of the challenges of trial-based economic evaluations

Instead of collecting new data over time ...

1. Use previous studies and routine data collections to simulate the impacts of an intervention.
2. Trace ‘pathways’ through a care system or a life-course
3. Estimate the associated outcomes and costs

Advantages of this method are that it allows

- To use synthesised data,
- To combine different sets of evidence,
- To link intermediate to final outcomes and
- To extrapolate beyond the observed time period.
Simple decision tree: suitable to model a limited number of events which happen in a short time period with no continuous risk (= follow-on events)

Parameters:
• Probability of fall for an ‘average’ person who received/ did not receive falls prevention
• Cost of the falls prevention intervention
• Consequences: Quality-of-life, resource implications of a fall (e.g. average cost of treating a fall)
State transition model (>Markov):

- Represent continuous risk in the form of repeating events over a long time horizon
- Events are modelled as transitions from one state to another

Parameters:

- Transition probabilities
- Cost of the intervention
- Consequences: e.g. quality-of-life associated with death, hospitalisation, care home admission; resource implications linked to these events
Model parameters

- Effects of intervention and routine care
  - From studies with comparison group or – if not available – from information about likely effect in routine care

- Willingness-to-pay

- Resource use

- Cost of interventions (or - if not available - descriptions of interventions)

- Unit costs

- Sociological data
Building community capacity

Different names at different times, and supported by governments under different political agendas

- Active citizenship
- Prevention
- Local democracy
- Personalisation
- Decentralisation
- Integration
- ... budget control
What is Community capacity-building -1-

Definition

An asset-based, developmental approach which aims to:

- Combat obstacles that prevent people (and organisations) from **achieving their goals**
- **Empower** local people and neighbourhoods to initiate action themselves
- Lead to **measurable and sustainable** results at an individual, community, societal level
- Generate **social capital**
“[...] social capital refers to the networks of social relations that provide access to needed resources and supports …

Any study of social capital should encompass the investments that people make [...] and the returns to those investments in the form of economic, social and health outcomes for individuals, communities and societies.”

Policy Research Initiative (2003), Social capital: Building on a Network Based Approach, Canada, October 2003
Some exploratory study

We looked at three examples of community capacity building.
Why measuring the economic value of community capacity-building?

In a world of scarce resources we need to know: Is it good *value for money*?

- Can it stop needs before they arise, does it meet them when they do and is there active participation?
- Does greater community capacity and governance reduce the demand on the welfare system?
Barriers towards building community capacity ...

Evidence is mainly qualitative, difficult to demonstrate value for money

Traditional evaluation designs are often not able to capture the wide range of long-term benefits

Many benefits are long-term (whilst commissioning cycles are typically short-term)

Benefits to wide range of public service sector (whilst costs often carried by a single commissioner)

=> Requires pooling of resources across public service sectors and long-term commissioning vehicles
What the evidence tells us -1-

**social capital** -> better health, reduced level of (perceived) crime, higher educational achievement, economic growth (for example *The Hidden Wealth of Nations* by David Halpern 2009)

**volunteering** -> intrinsic motivation and benefits, health and wellbeing, pathway to employment (Ironmonger D 2006)

**social support** -> reduced social isolation, loneliness and depression (for example Steptoe A et al 2013)

**early intervention** -> preventing use of more intensive services, improved health and wellbeing (Allen G 2011)

**co-production** -> adaption of behaviours that improve individual’s and service outcomes (*Engaging public sector clients* by John Alford 2009)

**independent living** -> improved functioning and prevented or delayed need for institutionalisation (Beswick AD et al 2010)

**personalisation** (personal budgets) -> improved health and wellbeing (Forder et al 2013, Glendinning et al 2008)
What the evidence tells us -2-

Time banks

= Exchange of skills and help measured in hours of time rather than in £

• Social inclusion, self-esteem and confidence, reduced social isolation, wellbeing, increased access to assets, improved employment prospects, reduced reliance on services

What the evidence tells us -3-

Befriending, older people

= Befriender (usually volunteer) offers emotional and social support to older person through regular visits or phone contacts

• Reduction in social isolation, loneliness and depression

• Additional benefits if schemes have particular focus on certain groups e.g. hospital discharge

Charlesworth G et al. 2008, Windle K et al 2009, Mead N et al 2010
What the evidence tells us -4-

Community navigator

= Helps people to access the ‘right’ services and support; has networks & knowledge of community and public services

• Earlier and more appropriate use of services (Anderson & Larke, 2009)

• Evidence of early intervention such as housing support (Porteus et al 2011) and debt advice (Knapp et al 2011)
Example: Befriending

- Intervention which “introduces the client to one or more individuals whose aim is to provide the client with additional social support” (Mead et al. 2010)

- Key elements: emotion focused, highly personalised, non-directive

- Belongs to a category of social interventions which are complex and difficult to evaluate; often linked to other interventions (including practical and technological support)

- Low cost (lay led schemes)
The role of social relationships in Older Adults

- Aged > 65yrs: loneliness and social isolation (5-16%), Windle et al. 2011

..defined and measured..

- **Social support** - (real) availability of social resources approx. by: living with spouse, no. contacts with a confidant, involvement in social activities

- **Loneliness** - individual’s experienced dissatisfaction with the quality or frequency of social contacts

- Significant influence on mental and physical illness and on mortality (Hold-Lunstad et al. 2010; Steptoe et al. 2013)
Evidence: Social relationships in older people

- Estimated prevalence of loneliness and social isolation in older people above 65yrs: 5-16%, e.g. Windle et al. 2011

How is it defined and measured?...

- **Loneliness** - individual’s experienced dissatisfaction with the quality or frequency of social contacts (=subjective)

- **Social support** - (real) availability of social resources approx. by: living with spouse, no. contacts with a confidant, involvement in social activities (=objective)

=> Significant influence on **mental and physical health** including mortality (Hold-Lunstad et al. 2010; Steptoe et al. 2013)
Evidence: Effectiveness of Befriending

Modest but significant effect on depressive symptoms found in meta-analysis of RCTs by Mead et al., 2010

..but size of effect strongly depends on study group, outcome (measures) and evaluation design:

For example, RCT with dementia clients found effect only in a particular group of carers (Charlesworth 2008)

Larger effects if (1) social isolation measured on complex scale versus one-dimensional; (2) study design is ‘weaker’ i.e. without control group or non-randomised control group (Masi et al. 2011)
Are befriending interventions cost-effective...?

And are there potential cost savings to the public sector and benefits to wider society?

Our modelling method

- **Data/ information from** literature & expert opinion

- **Costs** estimated based on mean length and number of sessions typically provided per person-year and minimum cost per hour from data on resources required to support volunteers (conservative, this did not include opportunity costs)

- **Effectiveness** estimated based on reduced loneliness and reduction in depression and expected use of health services
Modelling means building a pathway of events based on logic and evidence.

**Befriending Interventions to Older People**

*The Evidence on Economic Consequences*

1. **Social isolation/Loneliness** ↓
   - Wilson et al., 2007; Cacioppo et al., 2006; Stevens, 2001; Prince et al., 1997

2. **Depression** ↓
   - McCrone et al., 2004; Beecham et al., 2007; Beekman, 1997

3. **Access to services** ↑ (£)
   - Quality of life ↑ (£)
   - Crises, home services, hospital ↓ (£)
Our initial findings…

**Time banks**
- Cost per time bank member = £607 p.a.
- Economic pay-offs = c.£1300 per member
- … of which £187 = short-term cashable to govt.

**Befriending**
- Cost per older person = £90 over 12 weeks
- Economic pay-offs = £490 including QOL gains
- … of which £38 = short-term cashable to govt.

**Community navigators (benefit & debt advice)**
- Cost per ‘hard-to-reach’ person = £611
- Economic pay-offs = £360 (or £1200 including QOL gains)
**Help@home, Age UK Shropshire**

**Aims** to enable older people to live independently at home, reduce loneliness and isolation, improve mental and physical health;

**Targeted at** older people in Telford and Wrekin who do meet the formal eligibility threshold for publicly funded care

- **Volunteer-run befriending scheme**, free-of-charge, via telephone or personal visits;
- **Practical help** with gardening, shopping etc., for which older person is charged;
- **Benefits advice** service provided alongside;
- **Referral to personal care** if needed (not provided by scheme).
Evaluating costs and outcomes – Research method

- **Exploratory phase**: expected outcomes, existing data, data that are readily available, capacity for data collection, expectations and (2) **Evaluative phase**: data collection and analysis phase (including literature review)

- Sources for **outcome** data: (1) ASCOT, n=40, applied when people started using the projects and follow up at about 6 months; (2) PSSRU questionnaire for survey with about 1,000 existing service users (plus 40 new service users at assessment stage); (3) project data from satisfaction surveys, volunteers, benefit claims

- Sources for **cost** data: (1) PSSRU questionnaire (as for outcomes), (2) budget and activity data (from which evaluated the costs of the scheme)

- Data from the literature for parameters required to establish monetary values and long-term consequences
Outcomes -2-: Health-related quality of life

(1) **Self-perceived quality of life** (physical and mental) from PSSRU before/after questionnaire

Utility scores applied to health states from the literature:

- Mean health utility of UK population (>85yrs) for physically and mentally ‘well’ state (Kind 1998);
- Utility of older people with high reablement needs for ‘physically unwell’ state (Glendinning et al 2008);
- Mean health utility of older people with anxiety and depression (Ara and Brazier 2011)

(2) **Social support** (measured in number of social contacts) from PSSRU before/after questionnaire

- Based on additional annual risk of death among socially isolated individuals of 4.3% (derived from Steptoe et al 2013)

NICE willingness-to-pay threshold of £20,000 for one year in full health (=conservative)
Costs: Resource use

Data collection

• Established health and social care service use over period of 6 months before older people engaged with the project (n=40) and after (n= circa 1,000);

• Also covered unpaid care; perceived risk of care home admission (asked as hypothetical question);

Data analysis

• Logistic regression analysis to adjust for differences in age, gender, living status between ‘before’ and ‘after’ groups;

• Change in annual service use costs an unpaid care (valued with home care rate following replacement cost approach);

• Annual savings linked to prevented care home stay based on average length of stay with the scheme, discount rate of 3.5%
2 additional elements of the scheme

Volunteering

Costs included in budget data for the overall scheme;

We originally had planned to collect quality of life data from volunteers but time constraints prevented this;

Data were available on volunteers leaving into employment; valued with mean wage rate of people who move from Job Seeker’s Allowance into employment (Adams et al 2013).

Benefit advice

A ‘good’ cost to the government and what we call zero-sum exchange of money from a society perspective;

Potential health and wellbeing improvements but lack of appropriate quantitative data.
## Annual economic pay-offs

<table>
<thead>
<tr>
<th></th>
<th>Government</th>
<th>Individual</th>
<th>Societal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Volunteers into employment</td>
<td>184</td>
<td>565</td>
<td>749</td>
</tr>
<tr>
<td>Health-related quality of life (physical and mental)</td>
<td>-</td>
<td>1023</td>
<td>1023</td>
</tr>
<tr>
<td>Service use</td>
<td>2026</td>
<td>1265</td>
<td>3291</td>
</tr>
<tr>
<td>Care home admission (service users and spouses)</td>
<td>330</td>
<td>1378</td>
<td>1708</td>
</tr>
<tr>
<td>Unpaid care</td>
<td>-</td>
<td>-45</td>
<td>-45</td>
</tr>
<tr>
<td>Cost of the scheme</td>
<td>-791</td>
<td>-325</td>
<td>-1116</td>
</tr>
</tbody>
</table>

### Local government

- **Net benefit per service user**: 1565
- **Net benefit per volunteer**: 184

### Central government

- **Benefit payments**: -1752
- **Net benefit per service user**: -187

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Addition of values:

- Net benefit per service user (Government + Central Government): 1565 + (-187) = 1378
- Net benefit per service user (Individual + Central Government): 3296 + 1752 = 5048
- Net benefit per service user (Societal): 4861
Potentially cost savings linked to the scheme were £1.3 million (local government perspective); with wider benefits from a societal perspective of £3.9 million.

In particular:

- **Physical health** improvements (or avoidance of worsening physical health);
- Reduction in **health services**, in particular hospital and district nurse;
- Reduced **social isolation**;
- **Mental health** improvements;
- Helping volunteers on their pathway into **employment**.
In addition...

- The scheme helped to re-distribute **£1.5 million** of central government resources (which has been found to be difficult for older people, Wiggan and Talbot 2006); problematically, older people had **increased financial worries** despite the financial support.

- And to increase social care-related quality of life by on average **0.06 units on ASCOT** (based on sample of n=24); this is relatively strong increase considering that change in study that evaluated home care was on average 0.07 (Caiels et al 2010).

- Satisfaction data showed that older people felt **very positive** about staff and volunteers; and they believed it helped them remain living in their own home and to improve their quality of life.
We faced many **challenges and barriers** that are typical for evaluations of this type of relatively small scale, personalised and empowerment-based projects, in particular:

- Finding a suitable comparison group;
- Following individuals over time;
- Asking sensitive or difficult questions;
- Getting data.
Economics and third sector research
... economic theory provide a possible explanation as to why the third sector exists ...

- Market failure and externalities: leaves most third sector activity unpriced or with prices that do not reflect full societal costs
- Rare conditions, small or heterogeneous groups: not enough demand for market or efficient government provision (lack of economies of scale)
- Information asymmetries and transaction costs: Trust/experience goods
- Low start up and entry costs
- Vulnerable users or beneficiaries at risk of exploitation: possibly limited ability to exercise voice or exit rights
- Stigmatized groups for which public mainstream provision has failed
- Perception that third sector provides higher quality and/or lower costs, and ensures greater equity, is more innovative
Examples of economic concepts, methods and approaches

Production of Welfare Framework (Davies and Knapp 1981)

=> Foundation for performance evaluation

• Costs: include costs of resource inputs, total budget of the agency, opportunity costs (expressed in monetary terms)
• Resource inputs: e.g. staff, volunteers, members and capital
• Non-resource inputs: no-identifiable price but influence the achievement of outcomes. E.g. opinions, attitudes, ideologies which shape the contextual environment
• Intermediate outputs: volumes of service output (quality dimension)
• Final outcomes: changes in welfare, quality of life and field-specific status; externality effects- influenced by the volume and quality of services provided (user and carer satisfaction)
Examples of economic concepts, methods and approaches

- **EFFICIENCY**
  - Costs or budget
  - Resource inputs
  - Intermediate outputs

- **ECONOMY**
  - Non-resource inputs
  - Final outcomes

- **EFFECTIVENESS** (intermediate)
- **EQUITY** (intermediate)

- **EFFECTIVENESS** (final)
- **EQUITY** (final)
Application of economic evaluation in a performance management context

Economics can contribute to all stages of the evaluation process:

- Clarifying objectives
- Convert objectives into measurable outcomes
- Distinguish between inputs, outputs, process and outcomes
- More systematic and rigorous assessment of outcomes, in particular causality
- Comprehensiveness, opportunity cost principle, societal and multiple perspective

Types of economic evaluations

**Cost-effectiveness:** consequences measured using single outcome in natural units e.g. life years gained

**Cost-utility:** consequences measured using a single outcome in terms of utility e.g. QALY (in health care) and social care QALY

**Cost-consequences:** consequences measured using multiple outcomes, one by one

**Cost-benefit:** consequences measured in £ i.e. assigning £ values to outcomes
Cost benefit vs. social return on investment analysis (SROI)

• Both have in common that they aim to translate outcomes into monetary values
• Cost benefit analysis often focused on consequences that translate directly into savings (e.g. reduction in hospital admission)
• SROI has specific focus on involving stakeholders
• SROI uses method. non-validated proxy indicators with the aim to value all benefits including intangible
• SROI easier subject to manipulation and bias
Economic evaluation of third sector projects:  
*Measuring outcomes*

- Outcomes often not clearly defined at the beginning of the intervention because of its personalised process-focused nature
- Many groups of beneficiaries: users, their families, volunteers, unpaid carers, community members
- Not one single outcome measure that is sensitive to capture all changes even for one group
- Many benefits occur only long-term
- Ideally all perspectives would need to be captured through different outcomes measures and over sufficiently long time periods to evaluate the full value or impact

...impractical/impossible, instead:
- Iterative process in consultation with key stakeholders
- Defining the most important objectives and tracing pathways between outputs, intermediate and final outcomes
- Utilise evidence from the literature and other sources to link outputs or intermediate to final outcomes and extrapolate outcomes beyond observed time periods

=> Decision modelling
Economic evaluation of third sector projects: *Measuring costs*

- Multiple funding bodies
- Different government budgets but usually perspective only taken from the government department that is responsible for funding the intervention (and commissioning the study)
- Multiple needs (co-morbidities): costs hard to disentangle
- Intangible costs such as volunteer’s time, parent’s time, carers’ time
- Out-of-pocket expenditure
- Costs to communities
- Costs can persist for long periods
- Many costs are hidden from view
Economic evaluation of third sector projects: *Identifying the counterfactual*

- No alternative provision by definition (... according to economic theory)
- So counterfactual is ‘doing nothing’
- Ethical implications for study design
- Consideration of other sources that provide information about expected scenarios of what would have happened in the absence of the projects (e.g. neighbourhood statistics)

=> Can be used also in decision modelling
Performance indicators for third sector project, derived from Kendall and Knapp 2000

By dimensions measured

EFFICIENCY
• Resource inputs (by activity), expenditure, average costs; Number of volunteers and hours volunteered; Volume for example events organised, users seen
⇒ essential but narrow view on performance, many resource inputs without formal market price

EFFECTIVENESS
• Comparative impact on outcomes; Satisfaction ratings; Subjective measures of opportunity of impact; Quality; Outputs/ volume
⇒ Often difficult to conceptualise; subjective; can be manipulated

EQUITY
• Market concentration index; Service targeting, Accessibility, Redistributive policy consistency; Benefit/burden ratio
⇒ Subject to manipulation and difficult to conceptualise