Shared Lives as a potential option for older people: lessons learned and future prospects

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**Shared Lives as a potential option for older people: lessons learned and future prospects**

**April 25th 2014**

**Tower 2, LSE**

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Aims of today

- Context and aims of the study
- Findings
- Maximising impact
- What next?
Disclaimer

This presentation reports on independent research funded by the NIHR School for Social Care Research. The views expressed in this presentation are those of the authors and not necessarily those of the NIHR School for Social Care Research or the Department of Health/NIHR.

NIHR School for Social Care Research

- Established 2009
- SSCR ... “will give researchers the time and funding to ask the important questions and improve our understanding of what works, what doesn't work and why. This new School will provide considerable benefit to the health and well-being of the population through the new knowledge gained” (Dame Sally Davies, Director General of Research and Development at the DH).
- Five year contract
- PSSRU Kent one of five ‘core’ members
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Mission and activities

- to develop the evidence base for adult social care practice in England by commissioning and conducting world-class research

- **Conduct** high-quality research
- **Commission** high-quality research
- Provide **focus** for and promote social care research
- Develop **methodological** rigour and widen repertoire
- **Consult** widely on research priorities
- Contribute to wider efforts to build social care research **capacity** and improve research **awareness**
- Support a wide range of **knowledge transfer** activities -maximise **impact**

Policy and practice context

- Personalisation policy
  - Targets for personal budgets
  - Wider emphasis on personalisation of support
  - Emphasis on outcomes
- Lack of evidence for services about
  - ‘What works’
  - Cost-effectiveness
Personalisation of Services Scoping Study

• Aim
  • To identify type of research evidence needed to support social care practice
• Key finding
  • Financial resources critical issue; need for personalised services that deliver good outcomes at low cost (Brookes et al 2013)
  • Shared Lives potential with older people

What is Shared Lives?

• Family-based support; inclusion in SL carer’s family and community life; SL carer’s family home used as resource
• Types of arrangement:
  – Residential or long-term
  – Respite or short breaks
  – Day support
  – Rehabilitative or intermediate
  – Outreach or ‘kinship support’
• Careful matching of SL carer and person needing support
• SL schemes approve and train SL carers, conduct matching process, monitor SL arrangements
• Established but small service, under-researched
Outcomes, processes and costs of Shared Lives

- January 2012 - April 2014
- Overall objective: to generate evidence about the potential of Shared Lives for older people
- Evidence on:
  - Outcomes and experiences
  - Costs
  - Demand
  - Issues for expansion

Methods

- Multi-method approach developed with SL and councils
- Stage 1 Development
  - User and practitioner involvement
  - Local fieldworker recruitment
  - Setting up and refinement of methods with 3 councils
  - Scoping survey of SL schemes
- Stage 2 Evaluation
Outcome and experiences

• Survey of older users and carers
• Comparison with other service users
  • Adult Social Care Survey
• Characteristics
• Quality of life
• Views of Shared Lives

Costs and demand

• Costs
  – Scoping survey information on charges and payments
  – In-depth questionnaire for 4 schemes
• Demand
  – Challenging to identify
  – Delphi approach
Case Studies

• Three councils
  – Different starting points
  – All interested in developing SL service for older people
• Local user, carer and practitioner groups
• Interviews with variety of stakeholders
• Plans, processes, facilitators and barriers

DEVELOPMENT STAGE
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Development stage

- January to August 2012
- Development work with 3 local authority schemes – evaluation approaches
- Initial interviews with scheme manager, social worker & commissioner
- Recruitment of local fieldworkers
- Establishing project advisory groups
- Scoping survey of SL schemes with a focus on provision for older people

Development stage - scoping survey (1)

- Web-based
- Invitation email through SLP
- Background information; who scheme supports; staffing; SL and older people; costs
- Descriptive statistics & answers to open questions charted
Development stage - scoping survey (2)

- 43 schemes responded (approximately 32%)
- 19 out of 34 had plans to increase provision for older people
- 4 out of 11 who had recently tried to increase had been successful
- Problems due to lack of funding/awareness/commitment from management, suitable accommodation

Shared Lives scheme sample & older people supported

<table>
<thead>
<tr>
<th>Type of arrangement</th>
<th>No. of schemes</th>
<th>Older people</th>
</tr>
</thead>
<tbody>
<tr>
<td>Long-term residential</td>
<td>26</td>
<td>24%</td>
</tr>
<tr>
<td>Day time arrangements</td>
<td>15</td>
<td>31%</td>
</tr>
<tr>
<td>Respite/short breaks</td>
<td>15</td>
<td>14%</td>
</tr>
<tr>
<td>Outreach/kinship support</td>
<td>3</td>
<td>30%</td>
</tr>
<tr>
<td>Total number</td>
<td>780</td>
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What does this tell us?

- SL already supporting a number of older people
- May require building on existing provision
- There is support for expansion
- Need for access to suitable carers to support older people
- Out-sourcing may play a larger role as the social care landscape changes
National survey of older people & carers using SL

• Aims:
  – Identify experiences of Shared Lives
  – Identify outcomes for older people and their carers using SL
  – Compare to older people & carers using other social care services

• Recruitment through scoping survey & follow-up

Content of questionnaire for older people (1)

• Demographic information
• Health and dependency
  – Self-perceived health: single item, 5 point scale
  – Activities of daily living (ADLs): 8 items, overall score
  – Experience of pain & discomfort (EQ5D)
  – Experience of anxiety & depression (EQ5D)
• Use of health & social care services
• Experiences of Shared Lives (open questions)
Content of questionnaire for older people (2)

- Outcomes
  - Satisfaction with care & support
  - Overall QoL (single item)
  - Social care-related QoL (ASCOT): 8 domains - accommodation cleanliness & comfort, personal cleanliness and comfort, food & drink, personal safety, social participation, occupation, control over daily life, dignity
  - Scoring: Ideal state, no needs, some needs, high needs; summed to represent overall SCRQoL (range -0.17-1.00)

Sample of older users of SL

- 150 responses, 10 schemes
- 4 ‘types’ of SL represented: long term, day support, short breaks/ respite, outreach in individual’s own home
- 40 people completed ‘easy read’ version of questionnaire – reduced question set
Sample by type of SL arrangement

<table>
<thead>
<tr>
<th>Type of arrangement</th>
<th>No. of schemes</th>
<th>% of sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Long-term residential</td>
<td>8</td>
<td>53 (35%)</td>
</tr>
<tr>
<td>Day time arrangements</td>
<td>2</td>
<td>35 (23%)</td>
</tr>
<tr>
<td>Respite/short breaks</td>
<td>3</td>
<td>8 (5%)</td>
</tr>
<tr>
<td>Outreach/kinship support</td>
<td>1</td>
<td>55 (37%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td><strong>150</strong></td>
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Characteristics of sample

- 50% female, 50% male
- Age range 65-102, average age 77
- 98% white British (1 person Asian, 2 people Black)
- Differences in characteristics of users of different types of SL:
  - Long-term residential: younger, less dependent, in better health
  - Outreach: Older, more dependent, poorer health
  - Respite/short breaks & day support: broadly similar in characteristics
  
→ Cannot treat SL users as homogenous group for analysis
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Outcomes – users of Shared Lives

- Full sample:
  - 74% rated QoL as good or very good; 22% as alright; 4% as bad or very bad
  - Average SCRQoL score: 0.84 (range 0.22-1.00)
- People using long-term residential SL rate overall QoL more highly than those using other types of SL & have better SCRQoL (see poster)
- Regression model predicting SCRQoL from gender, age, dependency, health, pain & discomfort, anxiety & depression, type of SL – enables assessment of unique effect of each variable on SCRQoL
- Better SCRQoL related to being female, being younger, experiencing less pain & discomfort and experiencing less depression & anxiety
- Once background differences are controlled for in analysis, no difference in outcomes between different types of SL support

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Outcomes – compared to other services (1)

- Comparison group drawn from Adult Social Care Survey (ASCS) from 2012
- Excluded those under 65, receiving nursing care, in receipt of equipment only: n=30,000
- SL and ASCS samples differ in terms of age, gender balance, dependency, health, pain experienced
- To adjust for these imbalances, used propensity score matching (PSM):
  - Generates ‘control group’ from ASCS sample whose characteristics are similar to SL sample
  - Facilitates un-biased comparison of outcomes
  - Resulted in 121 ‘matched pairs’ with similar characteristics
  - ASCS sample included a mix of people using home care, day support & residential care
Outcomes – compared to other services (2)

• Findings:
  – No significant difference in overall SCRQoL (SL=0.84, ASCS=0.82)
  – Domains of SCRQoL – differences generally in direction anticipated, but not statistically significant
  – SL better overall QoL (small but statistically significant difference)

• Caveats:
  – Limited variables from which to generate matched sample – unmeasured difference?
  – Small sample size
  – Complex sample

Survey questions about Shared Lives

• What support do you/does the person you care for get from Shared Lives?

• Has Shared Lives changed your life in any way? If yes, please could you tell us in what ways?

• What are the good things about Shared Lives?

• What are the not so good things about Shared Lives?
Service User responses:

Company and friendship
“I am well cared for by friends”
“Being made to feel part of a family gives me confidence and a feeling of being wanted and not alone”

Occupation
“I go out and have lots of new activities and been able to start my sewing again which was my hobby years ago”
“[Shared Lives] gives me something to look forward to and a purpose in life”

Feeling secure
“Feeling safe and not having to worry about anything”
“Sense of well being and feel more secure both on and off the premises”

Service User responses (cont):

Support
“I’ve been able to come out about being gay since living in Shared Lives”
“Living with a couple in Shared Lives keeps me out of hospital (psychiatric). If I am troubled with anything I can talk about it with my carer who encourages me and completely supports me”
“It’s a lifeline - it’s contact - it’s help to live - it’s support and very valuable”

Lifestyle
“Able to live with a family instead of going into a home”
“Allows me to live in my own home and be as independent as I can”
Service User responses (cont):

Attitudes to SL carers

“[my SL carer] is very good, very professional and she listens to what I have to say carefully - my speech is affected by a stroke and I'm tired when she comes but she listens patiently to everything I say”

“I have been matched with someone that I get on really well with”

Attitudes to SL service

“Can't think of any [not so good things] at the moment apart from having to pay for the service in future”

“Not long or often enough”

Family carer responses:

Carer quality of life

“2x 4 hour slots per week to enable me to get out of the bl....dy house. Invaluable!!”

“Allows me to sleep and work 2 days per week: Thus, I pay my mortgage and see my husband/friends as a direct consequence of having a (wonderful) Shared Lives person”

“Brings some normality into an otherwise tedious, tiring and depressing lifestyle”

Service user quality of life

“The same person always visits- really important for my relative with Alzheimer’s”

“Mum has someone who has come especially to chat to her rather than for another reason like delivering a meal or doing housework.”
Family carer responses (cont):

Attitudes towards SL carer and the service

“I do not have any "not good things" regarding Shared Lives, without their help I would find life very hard to cope with”

“I suppose it would be possible for the person being cared for to be incompatible with a sitter, but the [LA] Social staff have been very keen, and very good at, avoiding this before an arrangement is made”

Problems

“All good, but could maybe do with more than just the one visit per week”

“Maybe a nice flexible day and time would be helpful sometimes. I was told I needed to agree to a set day and time each week”

What does this tell us?

• SL clearly valued
• Some evidence that SL can have good outcomes for older people – a starting point
• Cannot be confident in comparison due to limitations outlined above
• SL can only do so much – day support, respite/ short breaks, outreach all offer relatively small amounts of support
• Difficulty in capturing outcomes for SL users
• Need more information about those using SL in order to select most appropriate comparison group
COSTS AND DEMAND

Costs - scoping survey & cost questionnaire (32 schemes)

- Numbers and types of placements
- Numbers of SL carers and vacancies
- Numbers of scheme staff by type
- Rent and living costs paid to SL carers
- Payments to SL carers
- Paid breaks or respite
- Scheme management charges
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Costs - cost questionnaire (4 schemes)

• Breakdown of scheme staffing & salary costs
• Summary of service provided by staff
• Additional costs relating to service users (& who pays for them)
• Rent and living costs paid to SL carers
• ‘Hidden’ costs
• Annual operating cost of scheme
• Other related expenses (added to cost of scheme staff)
• Premises
• Management costs
• Income

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Costs - Shared Lives carers

• Number of SL carers ranged from 16 to 225, with a median vacancy rate of around 10%
• Payments to SL carers ranged from £150 to £1000 per week
• These amounts often depended on level of need, client group or ‘banding’ (between 3 and 5 bands)
• 27 schemes offered paid breaks or respite, most often reported was 28 days per year
Costs - Shared Lives schemes

- Staff teams ranged from 2 to 8, majority having a full-time manager or co-ordinator plus SL workers/officers and support staff
- Across 4 schemes between 12 and 80 staff hours spent on carer recruitment, 60 and 100 hours on matching & 100 hours on supporting placements
- Between £310 and £460,000 annual expenditure on scheme staff
- Around £15,000 for other related expenses such as advertising, recruitment and carer training

Demand - the Delphi process

- Key features – anonymity, structured flow of information, regular feedback, ‘moderator’
- Panel of ‘experts’
- 3 rounds of questions by email
- Broad descriptive analysis, possibility of analytical review of likely potential future scenarios
Demand – national estimates

• Round 1 – panel were asked to estimate the number of older people who might benefit from a SL placement, ranged from 20,000 to 100,000 with a median of 50,000
• Round 2 – answers ranged from 25,000 to 50,000, based on growing demand for: good quality care services; alternatives to care homes; older adults with LD; self-funders; but not suitable for everyone

Demand – type of placements

• Round 1 – panel asked to rank which types of SL placement they think would be most/least demand for, indicated most for respite/short breaks and day support followed by rehabilitative/intermediate care support, residential/long-term and outreach/kinship support
• Round 2 – answers very similar to Round 1, based on the assumption that older people would generally prefer to live in their own home, short breaks and day support seen as most acceptable means of meeting needs of service user & carer
CASE STUDIES

Case study methods

- Local user, carer and practitioner groups
- Interviews with scheme managers, SL workers, social workers and commissioners (& small number of older people and carers)
- Interviews with scheme manager at outset, wider group 12 months later
- Interviews with scheme staff covered: provision for older people, the placement process, expansion plans, potential demand, barriers & facilitators, future plans
- Interviews with social workers and commissioners covered: local authority context, awareness of SL, potential demand, views on use with older people, barriers
Case study 1: Oxfordshire - description of the scheme

- Covers the whole of Oxfordshire
- Existing scheme supporting range of client groups, small number of older people
- Offers day support, respite & short breaks, and long-term arrangements
- 3 levels of banding depending on person's support needs
- Role of SL officers - Recruiting and training SL carers, matching and placing older people, advising and helping to arrange benefits, monitoring placements and offering ongoing support
Case study 1: Expansion of services for older people

Prior to research:
- 2007/8- Older People Partnership Project- to increase numbers of older people within the scheme
  - Dedicated funding and staffing
  - Adaptation of the referral process
  - SL carers availability made known on weekly basis to care teams
  - Resulted in an increase of referrals and placements- 21 new placements in first 10 months- majority respite/short breaks

Ongoing attempts to expand service:
- Raising awareness
  - Radio, newspapers, open evenings, adverts on council broadcasts
- SL week
- New advertising material including pictures of older people as potential users of the SL service
- Communication with different teams to raise awareness- Social work teams, carer centres
- Dementia specific training- Dementia training pack from SL plus
- New database with live records of client information
- Introduce a friend incentive scheme
Case study 1: Expansion of services for older people

Challenges encountered
- Difficulties in getting locality teams to refer
- Inappropriate referrals - i.e. Individuals requiring 24hr care
- People being referred too late - i.e. when dementia is too progressed for them to settle into new home
- Incomplete service user needs information given - either by family carer or social worker

Plans going forward
- Aim to provide a more preventative service, accepting people in early stages of dementia who don’t currently meet the eligibility criteria
- Also want to include self funders

Case study 1: Barriers to expansion
- Lack of awareness from potential users & carers, social workers, wider council; perceptions of SL
- Lack of availability of carers with appropriate accommodation/skills
- Familiarity with other services
- Contextual factors
  - major restructuring of council
  - eligibility criteria: focus on high needs
  - funding mechanisms
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Case study 1: Facilitators for expansion

- Active promotion of Shared Lives
  - Shared Lives week
  - Presentations at social work team meetings; build relationships; encourage sharing of positive experiences
- Funding for advertising
- Training for SL carers to support people with more complex needs—specifically dementia
- Dedicated project/worker for expansion
- Policy changes—eligibility criteria

CASE STUDY 2 - LEEDS
Case study 2: Leeds – description of the scheme

- Existing scheme supporting range of client groups including older people
- Day support, respite & short breaks: some older people supported
- Outreach service: carer supports individual in their own home, mainly used by older people
- Long-term residential arrangements provided by third-sector scheme
- Referrals to scheme through care management process

Starting point:
- Expected continued demand for outreach service
- Wanted to expand respite & day support service for older people
- Need to recruit more carers, train existing carers to support older people
- Uncertainty around outsourcing

Case study 2: Expansion of services for older people

What happened?
- Small number of new referrals over 12 month period
- Social enterprise development exercise
  - Decision not to spin out, but useful lessons
  - Staff resources not available for SL carer recruitment etc.
- Ongoing activities to raise awareness

Plans for the future
- Expand short breaks/respite and day services for older people, including those with early stage dementia; continued role of outreach service
- Link with modernisation programme for older people’s services
  - SL as ‘alternative provider’
  - Potential SL carers
- Ongoing development following social enterprise exercise
Case study 2: Barriers to expansion

- Contextual issues
  - Move to flexible working/hot-desking for social workers, lack of opportunities for knowledge-sharing
  - Pressures on assessment teams, need for ‘quick fix’
  - Budget structures
  - Eligibility criteria
- Lack of awareness from potential users & carers, social workers, contact centre; perceptions of SL
- Lack of potential carers with appropriate accommodation/ skills

Case study 2: Facilitators for expansion

- Link in to induction/ training for new social workers; understanding of matching process; encourage to share experiences;
- Dedicated project/ worker
- Clear direction from senior management
- Modernisation of budget structures
- Taking advantage of opportunities
  - Care Bill (support for carers, prevention, personalisation)
  - Modernisation/closure of existing services, redundancies
  - Meeting a need (e.g. outreach in people’s own homes)
- Being able to evidence preventative benefits of SL
CASE STUDY 3 - KENT

Case study 3: Kent - description of the scheme

- Main service long-term placements & short breaks for people with LD
- 2012 started to promote service for older people
- Support from local authority to develop service for people living with dementia
- NHS South of England Dementia Challenge 2012 funding for project
- Resources for case manager post, started in post June 2013
Case study 3: Kent - evaluation approach

- Formative evaluation was chosen as the most appropriate design
- Focus on relationships, processes, organisational context, change processes and management
- Provide constructive feedback to assist staff to make decisions to continuously improve the service
- Documentary review, key informant interviews (15) & analysis of administrative data

Case study 3: Kent - barriers to introducing the new service

- Project separate from main service
- Focus on dementia
- Lack of awareness & shared understanding aims, expected benefits
- Perceptions of safety & acceptability
- Context – restructuring, management structures, local authority ‘knowledge creep’ unhelpful
Case study 3: Kent - facilitators to introducing the new service

- Project separate from main service
- Focus on dementia
- Key individual to drive it forward
- Management support
- Seen generally as ‘good idea’

Case study 3: Kent - where are they now?

- After 6 months steps to gaining collective buy-in for the project
- Referrals starting to come through
- SL hosts in place
- Lots of links with organisations ‘on the ground’
- Mobile telecare to support carers
- Focus on LD teams
- Focus on day support element of service
MAXIMISING IMPACT

Maximising impact

- Roundtable - Shared Lives supporting older adults, lessons from research (February 2014)
- Journal article – What next for Shared Lives? Family-based support as a potential option for older people (accepted with minor revisions April 2014)
- 5 further articles planned plus 1 on costs for Unit Costs of Health & Social Care (by the end of 2014)
- Shared Lives research web page (June 2014)
SUMMARY AND DISCUSSION

Summary

- Key finding of study
  - Not straightforward to develop/expand service with older people
- The study contributes evidence on
  - Experience and outcome
  - Demand and costs
  - Barriers and facilitators
- Aim to create resource and contribute from this work
- Ideas always welcome!
References

Shared Lives: Practitioner views
The interviews – what did we ask about?

- Provision for older people
- Placement process
- Expansion plans
- Future plans
- Shared Lives scheme staff
- Barriers & facilitators to expansion
- Potential demand

- Context
- Encouraging wider use
- Awareness of Shared Lives
- Social workers & commissioners
- Views on wider use for older people
- Barriers to use for older people
- Potential demand
Shared Lives: Outcomes & experiences
The survey – what did we ask about?
Quality of life for older users of Shared Lives

The main outcome measure used in the survey was the Adult Social Care Outcomes Toolkit (ASCOT), which is designed to capture information about an individual’s social care-related quality of life. The measure aims to be applicable across as wide a range of user groups and care and support settings as possible (see http://www.pssru.ac.uk/ascot).

A single item measuring overall quality of life was also used, with 5 response categories ranging from very good to very bad (Bowling, 1995)

Domains of social care-related quality of life:
Accommodation cleanliness & comfort; Personal cleanliness & comfort; food & drink; Safety; Social participation & involvement; Occupation; Control over daily life; Dignity

Example question:
Which of the following best describes how much control you have over your daily life?
• I have as much control over my daily life as I want [ideal situation]
• I have adequate control over my daily life [no needs]
• I have some control over my daily life but not enough [some needs]
• I have no control over my daily life [high needs]
Service Users’ Responses
Carers’ Responses
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Coming soon…

Shared Lives Research Webpage

Please e-mail Grace Collins at g.collins@kent.ac.uk for any enquiries