Barriers to Receipt of Social Care Services for Working Carers and the People they Care for in Times of Austerity

Nicola Brimblecombe
Context of research: policy

‘…represents the most significant reform of care and support in more than 60 years, putting people and their carers in control of their care and support’

Norman Lamb 2014

BUT…
chronic underfunding led to barriers to provision and receipt of social care

- Since 2009/10 unprecedented levels of cuts to adult social care funding and provision (Fernandez 2013)

- Issues around social care workforce

- Increasing need for care
• unmet need for social care services  
  (e.g. HSE, 2016; Burchardt et al. 2018; Brimblecombe et al 2016; Children’s Commissioner 2017)

• increasing reliance on unpaid carers (to some extent)  
  (Burchardt et al., 2015; Scheil Adlung, 2015; Pickard et al., 2015)

Inequalities in who has care needs and if/how they are met  
(eg HSE, 2016; Burchardt et al., 2018)
Theresa May under pressure over 'dementia tax' social care shakeup

Plan to make elderly people pay for care in their own home going down badly on doorstep say Conservative candidates

Labour would introduce national care service

Press release

Government to set out proposals to reform care and support

First Secretary Damian Green has announced that the government will publish a green paper on care and support for older people by summer 2018.
What is meant by unmet need?

1. Unmet need for help with Activities of Daily Living (ADLs) and/or Instrumental Activities of Daily Living (IADLs) can vary from no help to insufficient help.

2. Care Act definition covers no care, insufficient care AND care provided by unpaid carer being intensive (and so having potential for impact on carer wellbeing).

3. Dual perspective on unmet need: for whom: person with care needs? carer? both?
   - Most older adults (65-74%) who had received help, had received this from unpaid helpers only (HSE, 2016)
   - Views sometimes differ (e.g., Brimblecombe et al., 2016)

4. Right-based approach

5. Individual views, preferences, priorities, needs

6. What we mean by it in our research
Our research

Longitudinal mixed-methods study of working carers in England:

• Services received and needed
• Dual perspective: carer and person with care needs
• Working age carers
  (+ current research on young adults aged 16 to 25)

Study coincided with period of fiscal austerity introduced by the Coalition Government in 2010 and ongoing cuts to social care service funding

Research team (working age carers): Linda Pickard (PI); Nic Brimblecombe; Derek King; Martin Knapp

Research team (young adult carers): Nic Brimblecombe (PI); Derek King; Martin Knapp, Madeleine Stevens

Funder: NIHR SSCR
Methods

Baseline (2013)
- data collected from sample of unpaid carers in paid employment (N=384) and person with care needs they support (N=165)
- self-completion questionnaires

Follow-on (2015)
- carers completing questionnaire at baseline invited to complete follow-on questionnaire (N=248 did so)
- semi-structured telephone interviews with sub-sample of carers completing questionnaire in 2015 (N=40)
Unmet need for social care services

• Expressed need for more services for self (care-recipient)
  » 47% (2013)

• Expressed need for more services for care-recipient (carer)
  » 65% (2013)
  » 69% (2015)
Unmet need for social care services

- Unmet need high in both 2013 and 2015
- Not surprising
  - our study coincided with particularly deep cuts to social care
  - accompanied by an increase in need for care
    (Fernandez et al., 2013; Burchardt et al. 2015; ADASS, 2016)
- Shortfalls may be being met, in part, by self-funding and/or increased unpaid care
- Despite this, unmet need was still high in our and other studies over the period
Factors associated with unmet need for services (2013)

<table>
<thead>
<tr>
<th>Carer</th>
<th>Odds ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care-recipient has ADL-needs compared to no ADL-needs</td>
<td>2.6</td>
</tr>
<tr>
<td>Care-recipient is parent/in-law of carer compared to care-recipient is other than parent/in-law</td>
<td>3.3</td>
</tr>
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Factors associated with unmet need for services (2013)

<table>
<thead>
<tr>
<th>Care-recipient</th>
<th>Odds ratio</th>
</tr>
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<tbody>
<tr>
<td>Unpaid care provision</td>
<td>4.0</td>
</tr>
<tr>
<td>10+ hours a week compared to &lt;10 hours a week</td>
<td></td>
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<tr>
<td>Carer’s health</td>
<td>2.2</td>
</tr>
<tr>
<td>Fair, bad or very bad compared to very good or good</td>
<td></td>
</tr>
<tr>
<td>Carer’s employment status</td>
<td>4.2</td>
</tr>
<tr>
<td>Part-time compared to full-time</td>
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</table>
Experiences of unmet need for social care
Experiences of unmet need for social care

Carer: ‘They did this assessment...and the social worker came and she said ‘well we’re offering you eight hours’ and I just, I went hysterical. I went absolutely hysterical. I was screaming.... I couldn’t believe it, in my wildest nightmares, I couldn’t believe they’d go from fifty-five hours to eight. I couldn’t, I just ... it was unbelievable. Even now, I’m gob-smacked. I got to the point and I just said ‘I can’t do it. I cannot do it...., I cannot not sleep, I can’t never have a night’s sleep’.... So [social worker] went away and then a couple of days later ... by this time I was in the worst depression, and you know, I had been going through a really bad time. Everyone wanted to put me on tablets....and I’m saying ‘no, ...I’m not depressed because I’m depressed, I’m depressed because I can’t fix this situation. And giving me tablets isn’t going to fix this situation’. You know, so it was really a horrendous time.... ‘
Experiences of unmet need for social care

Carer, talking about lack of transport-related services for disabled son:

‘It’s causing me a lot of stress if I’m honest. I feel really – I feel actually quite ill because the thought of – I mean yeah I can take him and do it, but the thought of in September having to send him on his own [to a new college] I don’t even know if I can – I don’t even know if I can do that, I – I’ll have a go, I’ll, you know, I’ll try. [Son shouting in background]. He’s saying no!’
Experiences of unmet need for social care

Following a telephone review assessment, care was completely withdrawn from a woman who was unable to cook or bathe without help and had limited mobility.

Her daughter said:

‘within a fortnight – that was it – she was in pieces – you know - she was in a terrible state’
Other research on unmet need in similar time period

Blake et al., 2017

- Over half (53%-78%) of older people with care needs had some unmet need

- In interviews, found that participants often did not report unmet need in survey but
  - carrying out activities without help often led to significant pain and exhaustion
  - where support was available, it was often precarious, not sustainable in long-term
  - needs were hidden: in particular unmet need for social contact, hobbies, being able to get out of the house

-> loneliness and isolation

Picture for some = ‘daily struggle to meet their basic needs’
Other research on unmet need in similar time period

Health Survey for England, 2017
- 20% of men and 27% of women had some unmet need with at least one ADL, and 12% and 16% respectively had some unmet need with at least one IADL
- People in most deprived areas around twice as likely to have unmet need for help with at least one ADL compared with those in least deprived areas

Humphries et al., 2016 (Kings Fund)
- Million+ people who had difficulties with basic activities of daily living received no formal or informal help at all
  - increase of 100,000 in one year alone

Burchardt et al., 2015
- Half of 60-74 year olds and one third of 75+ year olds with four or more areas of substantial difficulty, reported receiving no formal or unpaid support
- Without adequate support ‘must lead more restricted lives’ (p53)
Barriers to receipt of services
Non-availability

- Services such as day centres and meals-on-wheels had closed in local area
- Reduced availability of supported employment and community transport
- Funding cuts

Carer: ‘Well, the thing is, whether you’d like it or not, the local authorities haven’t got it to give any longer have they? With all the budgets and the way things are’
Non-availability

Carer: ‘And, unfortunately, with the situation the way it is, there are fewer and fewer nursing homes, residential homes, whatever. So you know, somebody – I defy anyone to walk away from their elderly parents and not care for them.’

Interviewer: ‘You said that the home care was withdrawn and then she’d got a lot worse …’

Carer: ‘Yeah. Oh, I mean that was really, really sad and so frustrating. It should never have happened….but you know, that looks as if it’s gone forever now, doesn’t it?…. I feel it is. Because if – you know – they’re talking about [council name] have got to find another twenty million in cuts – where’s it all going to come from?...So, it’s not going to get better is it?…. I mean they’re closing so many homes, it’s frightening….’
Non-availability

- Another reason for non-availability was ineligibility
- Some interviewees had direct experience of service non-availability/ineligibility
  - i.e. tried but could not get any
- Others assumed these things because of the climate of cuts generally or from what they observed
  - carers did not consider or seek services

Private funding

- many carers or care-recipients could not afford to pay, or to pay for enough, or to pay much beyond the short-term
- concerns about committing to pay for something that they would not be able to sustain
Non-availability

- If services are not available, are unaffordable or the care-recipient is not eligible, care needs have to be met in other ways, or not met at all
- If needs are met, in whole or in part by unpaid carers -> difficulty balancing employment and care
  - may leave employment (King and Pickard, 2013)
  - may make other accommodations to their working lives: taking less well-paid work to be nearer the person they care for or for more flexible working conditions; reducing hours of work (Arksey et al., 2005; Colombo et al., 2011)
- Impact on care-recipient of non-availability as seen earlier
Lack of information

Difficult to get information on what services were available, how to access them and eligibility including financial eligibility

- Overworked, and reduced numbers of social and support workers; lack of coordination between relevant services = contributory factors

- System could be complicated and difficult to understand

- Carers could become ‘lost in the system’
Characteristics of services: quality

Carer: ‘We agreed a time for him to come in the morning [so carer could go to work] [but]...they were coming later and later and later... so obviously my dad was already trying to get up, trying to wander, he was wandering around the house...there were days when they’d come, they’d sort of ask him if he wanted to get ready...to get up or get washed or dressed, he’d say no so of course then they’d just leave him.... then he was left for...four or five hours ‘til lunchtime, so he’d be wandering around the house in just his bed clothes, he wouldn’t have had breakfast or anything like that. ...The foods that he was being given, he was given a cold mashed potato sandwich one day...and if he was given fruit or something like that the fruit would just be left in front of him so he’d just have a banana put in front of him or an orange. Well my dad with dementia he didn’t know how to peel an orange or peel a banana or anything like that, so every day I used to come home at lunchtime and he had – he literally hadn’t eaten.’
Characteristics of services: quality

Quality of the service or agency: unreliability, poor organisation, visits being too short, a lack of continuity of care or carers not being paid enough

Carer: It’s not necessarily the carers themselves – their fault, but they’ve probably got, you know, ten people to get up in the morning or whatever and.. they’ve been allocated three quarters of an hour to get that person.. up, washed, dressed, fed, and – and everything and, you know, three quarters of an hour is not – it’s not sufficient.
Quality of services and social care workforce

UK social care sector in crisis due to staff shortages

A lack of qualified people is hitting many public services hard – and the majority of employees are women. Why do so many want to leave?

Issues with pay, training, workload and other working conditions (Colombo et al., 2011; SCIE, 2013) - 27.8% turnover rate 2016-17 (NAO, 2018) - £7.50 median pay per hour for a care worker 2016-17 (NAO, 2018)

Careworkers’ working conditions can have a direct impact on service quality, and on careworkers themselves (CQC, 2010)

Austerity -> increasing challenges for social care workforce
Characteristics of services: quality

- Unreliability, bad organisation, too-short visits, or lack of continuity of care
  - Unmet need for care
  - Impact on people with care needs
  - Impact on working carers
    - Carers need good quality, suitable, convenient, appropriate, reliable and trustworthy services to be able to balance work and care
    - Problems with received services had other impacts on working lives, such as disruption at work, need to care-manage whilst at work, absenteeism, or stress and anxiety
Characteristics of services: quality

• Meant that, despite services being received, needs were not being adequately met

• + past experiences of poor quality services could result in carers or care-recipients not seeking or ceasing receipt of services

• + indirect experience resulted in fears and concerns about quality of care and thus as barriers to seeking care

• Poor quality care was one of the reasons given by some carers or care-recipients for not wanting services
Characteristics of services: process

Process of obtaining services and support could act as another barrier: could be unpleasant, traumatic, stressful, bureaucratic and time-consuming.

Carer: ‘I don’t think they realise how much pressure they put on people, and how much the cuts – and I know – I understand that the cuts have had to happen in a lot of areas – but I think the cuts on disabled people are far too big, far too fast, for people who are genuinely disabled. They put too much pressure on people that are disabled and they can feel belittled for being disabled…. the pressure on him [disabled partner] because he has a disability, it doesn’t help. For somebody who’s lost their self-esteem anyway….. and you’ve got to keep reliving something that’s happened to you…. the medicals and stuff. Cos if it hadn’t been such – I don’t know – like torment for him to keep doing it like, emotionally hard for him, I think he might have even gone on to do something maybe two or three years ago’.
Characteristics of services: process

Interviewer: ‘Why do you think he’s not getting the services he needs?’

Carer: ‘Partly because he’s – he went to so many appointments….and I think that got too much for him. So he got to the point where... he’d had enough. So partly because of that and partly because whenever we’ve tried to get anything he just never seems to meet the criteria’
Characteristics of services: suitability, appropriateness

No suitable or appropriate services available or received services were inappropriate to needs

(i) not age-appropriate, particularly for young adults

(ii) not need-appropriate, especially for people with dementia but also for young adults with learning disabilities

(iii) not culturally appropriate

(iv) not provided at convenient or suitable times for person’s needs
Attitudes of carer towards services

Characteristics of services
- did not want services because they were perceived as unsuitable, not appropriate to needs or not available at convenient times

Embeddedness of caring
- carer had always provided care, and so had not considered other forms of provision of care

Being able to manage
  Carer: ‘I don’t think there’s anything else we really could do [with] because I do everything really’.
  - Some managed even though ‘it was a struggle at times’
  - Other information sometimes suggested they were ‘managing’ only with great difficulty e.g. caring for long hours and/or with impacts on their work, health and wellbeing
Attitudes of carer towards services

Carer sometimes expressed conflict about receipt of services:

Carer: ‘I think it would lessen the guilt but then maybe it might increase it because I’ve have this – personally I’ve got this desire to want to do things, because I can. So, maybe it might – I don’t know – I’m not sure – I’m not sure how I’d feel about that, because on the one hand it would – I’d think oh, right it’s okay, cos somebody’s with me mum, so that would release me. But then at the same time, somebody else would be doing that I feel I should be doing. So I’m not sure how that would – how I would feel about that’.

But other carers very clear that they did not want services
Attitudes of carer towards services

Wishes of care-recipient

- One reason some carers gave for not wanting services was because the care-recipient did not want anyone other than them providing care.

- Sometimes carer agreed with this - wanted to be the only person providing care. Sometimes they did not, or did not exclusively.

<table>
<thead>
<tr>
<th>Agreement on need for more services (2013) (N=150 dyads)</th>
<th>%</th>
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<tbody>
<tr>
<td>Carer and care-recipient agreed do not need more services</td>
<td>26.7%</td>
</tr>
<tr>
<td>Carer and care-recipient agreed need more</td>
<td>40.0%</td>
</tr>
<tr>
<td>Carer perceived needs more, care-recipient did not</td>
<td>26.0%</td>
</tr>
<tr>
<td>Care-recipient perceived needs more, carer did not</td>
<td>7.3%</td>
</tr>
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Attitudes of care-recipient towards services

Characteristics of services
- in particular, concerns about quality or perceived quality of services
- negative past experience or concerns about unsuitable services, especially residential care
- process = off-putting

Privacy
- Did not want ‘strangers’ coming into the house
- Several described this as ‘intrusion’
- In some cases this was related to fears about formal services
Attitudes of care-recipient towards services

Pride, reluctance to admit needing help/accepting help

Carer: ‘They don’t like to admit that they can’t do things.’

Carer: ‘Sometimes elderly people feel ashamed having to admit to a third party that I am not being looked after by my own children.’

Interviewer: ‘And have you considered asking social services to assess your mother’s needs?’

Carer: ‘No I haven’t, for this reason: she’s mortified at the thought of having help from anybody.’
Attitudes of care-recipient towards services

Similarly to carers, although some care-recipients expressed not needing help, other information suggested differently.

Carer: ‘She turned all this down, oh, two years ago.... She said ‘no, we’ll manage’.... Very proud people, they didn’t want it. Mum said ‘no, I’m alright’. But she wasn’t alright.’
Barriers and unmet need during time of austerity

- Our study illustrates significant barriers faced by working carers and the people they care for during a time of decreased and decreasing service provision.

- Cannot say definitively what impact of cuts to services had been on non-receipt of services and barriers to services.

- But cuts likely to have at least played a part:
  - context: £4.6 billion cuts over five years in adult social care budgets in real terms (ADASS, 2016); 26% reduction in the number of recipients of care services 2005/06-2012/13 (Fernandez et al., 2013)
  - many carers interviewed spontaneously mentioned cuts
  - context of cuts to social care interacted with or underlay expressed barriers
  - cuts impacted on carers and care-recipients in multiple ways

Austerity cuts = large part of context of caring over the period
Summary and conclusions

Past, current and planned cuts combined with increasing need

- Unmet need for services
- Inequalities in unmet need

Lived experience of unmet need starkly illustrated in our study

High level of unmet need for services

- More restricted and difficult lives for person with care needs
- Difficulties for carer including restrictions to their lives (employment, education, health, social participation)
  - e.g. lack of services for person with care needs associated with higher likelihood carer leaving paid employment (Pickard et al., 2015; 2017)
  - looking at working age carers here but difficulties for other groups e.g. older carers, young adults
Impact of caring responsibilities: young adults

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<th>%</th>
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<tbody>
<tr>
<td>N=189</td>
<td></td>
</tr>
<tr>
<td>Employment affected by caring¹</td>
<td>68.6</td>
</tr>
<tr>
<td>Education affected by caring¹</td>
<td>75.2</td>
</tr>
<tr>
<td>Health affected by caring</td>
<td>89.1</td>
</tr>
<tr>
<td>Social life affected by caring</td>
<td>87.4</td>
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</table>

¹ Excludes not applicable

Source: PSSRU Young Adult Carer Survey, 2017
## Sufficiency of services and young adult carers’ outcomes

<table>
<thead>
<tr>
<th>N=189</th>
<th>Care-recipient has right amount of services?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td>Employment affected by caring (%)</td>
<td>72.0</td>
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<tr>
<td>Education affected by caring (%)</td>
<td>83.6</td>
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<tr>
<td>Health affected by caring (%)</td>
<td>93.3</td>
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<tr>
<td>Social life affected by caring (%)</td>
<td>91.9</td>
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<tr>
<td>Health bad, very bad (%)</td>
<td>23.0</td>
</tr>
<tr>
<td>Depression/anxiety symptoms (PHQ score; mean)</td>
<td>5.5</td>
</tr>
<tr>
<td>Positive aspects of caregiving (PACE score; mean)</td>
<td>30.8</td>
</tr>
<tr>
<td>Wellbeing (WEMWBS score; mean)</td>
<td>22.0</td>
</tr>
</tbody>
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Source: PSSRU Young Adult Carer Survey, 2017
The future

Indications this is going to get worse

• Further cuts planned to Local Authority budgets and increasing pressure on NHS
• Increasing gap between resources and needs
• Welfare benefit changes: disability benefits; housing benefits; Universal Credit

Carer [quoted earlier]...’you know, that looks as if it’s gone forever now, doesn’t it?.... I feel it is. Because if – you know – they’re talking about [council name] have got to find another twenty million in cuts...So, it’s not going to get better is it?.... it’s frightening....’
What can be done? Implications for policy

Unmet need for formal care not cost-free for government

• Costs to state of carers leaving employment in England estimated £2.9 billion a year (Pickard et al., 2017)
• Costs of hospitalisation of person with care needs; poorer carer health

Need for greater public investment in social care

Social care workforce training and working conditions
What can be done? Implications for policy

Not just social care

• In our research, carers spoke about, for example, importance of welfare benefits, employment, leisure activities, neighbourhood and community for care-recipient and themselves

• Blake et al., 2017: importance of affordable public transport; warm and secure housing; access to benefits for older people with care needs

• Importance of factors such as flexible working conditions for working-age carers (Brimblecombe et al., forthcoming)

       .....etc etc
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References


References


