



volume 31: number 3: 2016

Research, Policy and Planning

The Journal of the Social Services Research Group

www.ssrg.org.uk



Research, Policy and Planning

The Journal of the Social Services Research Group

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Research, Policy and Planning is usually published up to three times a year - by the SSRG, and distributed free to members.

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Editorial

Welcome to the 3rd edition of volume 31 of Research, Policy and Planning. In this edition we have four papers, each reflecting different topical issues within the field of social work and social care. Three of these are based on literature reviews: two scoping reviews, one systematic review, and a fourth offers a review of policy.

The first paper, by **Jill Manthorpe and Ann Bowling**, is concerned with how to measure the quality of life of those who care for people living with dementia. Drawing on a scoping review for the Medical Research Council to determine 'state of the art' ways of measuring the quality of life of carers, they suggest there is both a dearth of carer-reported quality of life measures (compared with the large number of proxy measures to assess the quality of life of the person with dementia) and a lack of consensus about *what* to measure and *how* for carers of people with dementia, which is not helpful for practitioners or those responsible for funding services.

The second paper, from **Kate Baxter**, is also based on a scoping review of research evidence about adults in England who self-fund their own care. Self-funders have been largely overlooked by researchers even though (as the paper itself observes) both the number and proportion of self-funders is increasing, partly as a result of tightening eligibility criteria. Baxter's paper, based on a review of 76 studies that met the review criteria, offers a useful synthesis of what is currently known. It highlights challenges facing local authority adult social care departments after the 2014 Care Act, in providing appropriate advice to this group and in market 'shaping' to respond to the needs of self-funders. This paper offers valuable insights for local authority and other staff working in the fields of communications and those responsible for commissioning and planning services.

The third paper is based on another literature review: a systematic review of literature in an (arguably) even less well researched field: the factors influencing decision making by children aged between 8-12 in child and adolescent mental health services (CAMHS). This paper, by **Ann Cox, Chris Brannigan, Martyn Harling and Michael Townend**, focuses on an important gap in evidence to inform practice. Though there is significant legal guidance and case law to support and guide clinicians and practitioners in assessing whether young people aged over 13 are able to make informed decisions about their own healthcare, for younger children the guidance is unclear; and as the authors point out, this can lead to professional anxiety and a tendency to 'default to parental consent'. To remedy this, they review 12 studies to suggest six factors that influence the process of assessing the competence of younger children to make decisions: consent competence and capacity, best interests, communication, risks and conflicts, legal frameworks and the parental role. The authors conclude that though in law children are not allowed to refuse treatment, involving them in decision making where possible is 'good practice', and supports the child's empowerment and participation. The authors conclude by calling for a better understanding of the training requirements that would support the skills of clinicians working with children in this age group. This paper would be of particular interest to social work, nursing, or allied clinical professionals working in the field of child mental health.

The fourth and final paper is from **Michelle Cornes, Helen Mathie, Martin Whiteford, Jill Manthorpe and Mike Clark**. Their paper, originally written as a briefing report for homelessness organisations and subsequently developed into a journal article, focuses on the implications of the 2014 Care Act for homeless people. The paper argues that prior to the 2014 Act, homeless people were deemed ineligible for publicly funded care and support: a situation that contributed to the creation of the *Supporting People* programme and the provision of 'housing related support'. Though *Supporting People* has been one of the casualties of the Government's public sector austerity policies, the paper draws attention both to opportunities

for using Care Act legislation to obtain services for homeless people, whilst at the same time offering a critical analysis of barriers – some more apparent than real – to using the Care Act to support the needs of this group. Cornes *et al.* call for homelessness organisations to develop closer working relationships with local authority care managers and social workers, and to be more actively involved at local levels in the Act's implementation. This paper will be interesting and useful particularly for local and independent sector workers working with homeless people.

These four papers are followed by the three reviews. The first, by Serge Paul, considers two recently published books which form part of the Critical and Radical Debates in Social Work series edited by Ian Ferguson and Michael Lavalette: *Poverty and Inequality* by Chris Jones & Tony Novak and *Children and Families* by Paul Michael Garrett. (The other four volumes in this series, on Personalisation, Mental Health, Adult Social Care and Ethics have been reviewed in previous editions of RPP). Reviews of two other books: *Social Work with Troubled Families* (editor Keith Davies, 2015) and *Vulnerability and Young People: Care and Social Control in Policy and Practice* (Kate Brown, 2015) by Andy Pithouse are also included.

Finally, Editors would like to express our grateful thanks to Dr Chris Rainey for his wise counsel over the past several years on RPP's Editorial Board. Chris retired recently and has resigned from the Board. We will also miss Colin Kelsey, another long-standing Editorial Board member, who died suddenly earlier in the year.

John Woolham

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Quality of life measures for carers for people with dementia: measurement issues, gaps in research and promising paths

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Abstract

Background: providing support to a family member with dementia often comes at a cost to the quality of life (QoL) of the carer (caregiver), giving rise to current and future unmet needs for health and social care and support themselves. These have important implications for cost-effective health and social care support services and pathways. This article summarises the findings of a scoping review of the literature on QoL measures for carers of people with dementia that was commissioned by the Medical Research Council to address what is 'state of the art' in measurement and identification, any gaps in the evidence base, and challenges for further research.

Method: a scope of the literature using Medline and Psychlit (all years) as these are particularly relevant to health psychology was undertaken in March 2013, using combinations of the following keywords: quality of life, measure, scale, caregiver (including carer), chronic illness (the term long-term condition is generally captured under this phrase), dementia, cognitive impairment, Alzheimer's disease.

Results: there is a dearth of carer-reported QoL measures, in contrast to the existence of proxy scales for carers which are used to measure the patient's/client's QoL (prevalent in relation to dementia). Several methodological challenges were identified.

Conclusion: caring for people with dementia often has both negative and positive consequences which need inclusion in measures but these may vary by individual and over time. The lack of consensus about what to measure and how in QoL of carers of people with dementia does not help practitioners or service funders. Measures need to be appropriate for younger and older carers, type of carer and caring tasks, and be sensitive to cultural and socio-demographic differences.

Keywords: dementia, carers, quality of life, health care, social care, measurement, questionnaire, psychometrics

Background

There is international interest in finding out the most effective ways of supporting family carers of people with long-term conditions and disabilities (Parker, Arksey & Harden, 2010) and concern that the numbers of carers will be insufficient to meet the needs of people requiring care and support leading to a possible 'care gap' (Pickard, 2015). The United Kingdom (UK) Coalition Government's action plan - '*Recognised, valued and supported: Next steps for the Carers Strategy*' (HM Government, 2015) - expressed a commitment to '*reciprocate the support carers show with measures that ease the responsibility of caring*' (p.3). It emphasised that supporting carers to remain mentally and physically well should be a key component of prevention and requires a public health approach (HM Government, 2015). In England, all carers were given new legal rights to assessments of their needs under the Care Act 2014 and campaigning groups for carers are active in the policy sphere (Carers UK, 2013; Carers Trust, 2015).

Of the 5.8 million adult carers in England and Wales (White, 2013) there are an estimated 550,000 carers of people with dementia in England. While the costs of dementia are calculated at £19 billion a year (DH, 2013), their carers are estimated to save £8 billion a year in public expenditure and societal costs (Alzheimer's Society, 2012). As with many other carers of

people with long-term conditions, including dementia, carers provide a wide range of practical and emotional support, social care, home nursing, and help with many aspects of daily living. Tasks can include help with personal care, managing finances and legal affairs, provision and assistance with consumption of food and drink, social activities, mobility, emotional support, administering and coordinating medication. Support may be substantial and regular or low level and fluctuating, however, people with dementia generally need higher levels of care as their symptoms progress (Brodaty & Donkin, 2009). There is also increasing recognition of the diversity of carers and Moriarty *et al.* (2011) note that, as the population of Black and Minority Ethnic (BME) people with dementia and their carers becomes more diverse in England, access to support tailored to their own individual circumstances will need to be assured.

Maintaining carers' quality of life (QoL), including mental and physical functioning and their economic wellbeing, is therefore important at several levels. First there is a need to ensure that the person with dementia can 'live well' (DH, 2009) and that their care and support up to death meets their needs and wishes. Second, there is a need to minimise the risks to carers of adopting this role, for their own benefit physically, mentally and economically, and also socially to enable them to stay in or return to employment (King & Pickard, 2013). Potentially the QoL of one affects that of the other, whether or not they live together. However, it is increasingly acknowledged that providing support to a family member with dementia often comes at a cost to the QoL of the carer, potentially giving rise to current and future unmet needs for health and social care and support themselves. These have important implications for cost-effective health and social care support services and pathways, and the QoL of the carer requires understanding, accurate measurement and identification and a tailored, sensitive and timely response from practitioners and the wider community.

Aim and method

This article summarises the findings of a scoping review of the literature on quality of life (QoL) measures for carers of people with dementia that was commissioned by the Medical Research Council to address three key questions: 1) What is the 'state of the art' regarding QoL measurements for carers, specifically of people with dementia and living at home?; 2) What topics require further investigation?; and 3) What are the possible and predictable challenges of such research that will need to be addressed?

A scope of the literature on this topic using Medline and Psychlit (all years) was undertaken in March 2013 using combinations of the following keywords: quality of life, measure, scale, caregiver, chronic illness, dementia, cognitive impairment, Alzheimer's disease.

Scoping reviews are of value in identifying research gaps, and are increasingly used for such purposes (Arksey & O'Malley, 2005). A summary of the findings, with gaps in research identified, is presented next (for full details of the review please contact the authors) with discussion focusing on England in particular. While various terms are used in the literature (caregivers, family carers, informal carers), we use the term 'carer' to reflect the choices of the main carers' organisations, and policy and legislation in England. Similarly, the term 'dementia' is used as an overarching term, although the term 'Alzheimer's disease' is referred to even though it is not necessarily being used in a diagnostic sense. In this review, we use 'dementia' to cover different types of diagnosed or recognised cognitive impairment.

Findings

Concepts of QoL, and in dementia: the state of art

With the increasing emphasis on evidence-based, or evidence informed, policy and practice (DH, 2014) inclusion of patient- or user-reported outcome measures of generic health-status, health-related and/or disease-specific QoL, are generally used in evaluations of care.

The information they yield has a key role in policy-making. Thus, the US Food and Drug Administration and the European Medicines Agency have released guidelines specifying minimum criteria for the scientific adequacy of scales used in clinical trials, although controversies remain (Bottomley *et al.*, 2009). The quality of research inferences is inevitably influenced by the appropriateness and robustness of the measurement scale used.

In England there has been great interest in developing carer outcomes to be used in parallel with outcome measures for users of social care services; 2012-13 was the first year in which the ASCOF measures, based on the Personal Social Services Survey of Adult Carers in England (Carers' Survey), were included in a national survey of whether social care users and carers feel that the social care they receive is leading to better outcomes (HSCIC, 2013). This carer-reported QoL score has an optimal positive score of 12; in 2012-2013, the average score was 8.1, interpreted as meaning that 42.7 per cent of carers reported themselves as extremely or very satisfied with social care services (arranged, provided or funded by local councils) (HSCIC, 2013, p.18). The ASCOF quality of life score was based on responses to six questions; one of which was satisfaction with care services (see Netten, 2011 for a helpful overview of ASCOF).

Quality of life (QoL) is an increasingly important measure in evaluations of health and social care more generally (Bowling, 2014a). Aside from the ASCOF Users and Carers Survey (see above), models and measures of QoL used to evaluate health and social care interventions are primarily health-related, with a heavy emphasis on physical and mental functioning. In contrast, carers themselves often identify a wider range of life areas as important to them, although, not surprisingly, these may be affected by health conditions (Bowling *et al.*, 2014). The concept of QoL is relative, and the perspectives of people with dementia – as well as their carers, and carers generally – were neglected in its early developments. Where a condition can affect life overall, broader QoL measurement is required, in addition to capturing elements specific to the caring circumstances. For policy outcomes to be relevant to carers, measures of QoL need to have social, as well as policy, relevance, and conceptual strength. QoL is a subjective concept, and thus measures need to be socially relevant and need the participation of the population concerned in their development. Few investigators developed their measures 'bottom-up' with the population of interest, and tended to focus instead on 'expert opinions'. Thus, most measures have unknown social relevance, and there is no certainty about whether they are measuring the right things.

Definitions of QoL often vary by discipline of the investigator and by the population group being focused upon. Some dementia-specific measures of QoL (e.g. the Quality of Life in Alzheimer's Disease (QOL-AD & QOLAD-Carer proxy version; Logsdon *et al.*, 1999) claim to be conceptually based, but most have no conceptual underpinning, or are domain-specific or health-related. Overall, there is no consensus about QoL in dementia, and different investigators have developed frameworks and measures based on different domains and methodologies. Moreover, most measures of QoL or health-related QoL that are used with people with dementia and their carers (for proxy assessments of the former) have questionable reliability and validity, some require observations which are time consuming and expensive, or, more recently, rely on questioning the person with dementia themselves, which is possible with people with mild-moderate dementia (Smith *et al.*, 2005; Trigg *et al.*, 2007; Bowling *et al.*, 2014a), but is increasingly difficult as communication deteriorates as dementia progresses.

Scale development has been even slower in relation to carers' assessments of their own QoL, as opposed to their proxy assessments of the QoL of the person they are caring for. Lim and Zebrack (2004) defined QoL as multidimensional, both generically and in relation to people with chronic conditions and family care-giving. They acknowledged that, while there is no consensus on specific elements, it encompasses physical health and functioning, socio-economic status, psychological, emotional, and social wellbeing, although for carers there are additional elements. These were said to include: burden and family functioning, as well as life satisfaction, adaptation, health, and distress. Given the lack of agreement on concepts or optimal

measurement instruments, researchers commonly use broader health status scales as proxy measures of quality of life, or health-related quality of life. These types of measures are sometimes combined with disease-specific measures of symptoms, mental and/or physical functioning, generic and disease-specific 'quality of life', and wellbeing. The wide range of diverse measures used, and their varying or overlapping emphases, stimulated adoption of the term 'patient based outcome measures' (PROMS) (HSCIC, no date).

Outcome measurement: the 'state of art' specific to carers

Outcome measurement among carers, including those of people with dementia, relies heavily on the use of different measures. The reported negative effects of caring on the carer include high rates of burden, stress, exhaustion, anxiety and depression, use of psychotropic medication, social isolation and impaired family life, low life satisfaction, impaired sex life, fatigue/sleep deprivation, physical ill-health, financial difficulties, and partners feeling in marital limbo, fears for the future (Guerriero-Austrom & Hendrie, 1992; Jones & Peters, 1992; Rees *et al.*, 2001; Lim & Zebrack, 2004). Lim and Zebrack's (2004) review documented how caring for chronically ill family members, or 'significant others' at home influences multiple aspects of carers' lives (including worsened physical health, impaired social and family life, increased stress, anxiety and depression). Coen *et al.* (1997) - in a review of carers' QoL and that of people with Alzheimer's Disease - concluded that the level of burden and its impact on the QoL of carers must be taken into account when examining commonly used proxy assessments of the QoL of people with Alzheimer's. The negative aspects of caring for people with dementia tend to receive most attention in this research, but caring has also been associated with positive feelings and outcomes (Coen *et al.*, 2002), which are relevant for the assessment of QoL. Positive experiences include closeness, reciprocity, spiritual growth, increased self-esteem and mastery. Socio-demographic factors can also influence carers' perceptions of their roles. Positive perceptions have been associated with lower education and socio-economic status, greater satisfaction with social participation, better physical health status, being 'non-Caucasian', and being older (Haley *et al.*, 1996; Kramer, 1997; Rees *et al.*, 2001; Rapp & Chao, 2000).

Lim and Zebrack's (2004) review concluded that studies used diverse positive and/or negative outcomes and models to indicate carers' QoL (psychosocial: adaptation, mental health, life satisfaction, stress, emotional distress, health, caregiver burden, and depression). Of the 19 articles they reviewed, only one used a single measure of QoL for carers *per se*: the Caregiver Quality of Life Index, containing items related to physical, emotional, social, and financial wellbeing. This had been developed specifically for carers of cancer patients (Weitzner *et al.*, 1999). The remaining papers used modified measures, single or composite measures of selected QoL concepts (e.g. burden, mood, health status). Rees *et al.*'s (2001) earlier overview also reported that burden of care detracts from carers' QoL, but again QoL was measured by different batteries of domains, or modified measures; leading them to conclude that very few instruments had been developed specifically to measure carer QoL.

Most research, while purporting to measure QoL of carers, focuses mainly on specific domains, or uses batteries of several different measures [burden depression, anxiety depression, social support (Charlesworth *et al.*, 2008), stress and burden (Vitaliano *et al.*, 1991), brief QoL utility measures (EQ-5D, by Spijker *et al.*, 2009), or adaptations of patient-reported dementia-QoL measures, based on the untested assumption that they are relevant and tap pertinent domains for carers (e.g. Dementia QoL questionnaire (DQoL), by Graff *et al.*, 2007); adapted Alzheimer's Disease related QoL (ADRQL), Thomas *et al.*, 2006]. For example, Bruvik *et al.* (2012), in their study of 230 dyads of people with dementia and their family carers, adapted the QoL-Alzheimer's Disease scale (QoL-AD) (Logsdon *et al.*, 1999) to assess the QoL of the carer, and also used it for carers' assessments of the QoL of the person with dementia. They justified this with reference to the fact that the QoL-AD had been used to measure carers' QoL in two previous studies, while acknowledging that this scale had not been validated for assessments of carers' own QoL (Shin *et al.*, 2005; Rosness *et al.*, 2011).

The lack of validated carer-specific QoL measures has also led to the use of generic health status measures as proxies, as they tap some overlapping QoL domains, for example, the Short-Form 36 Health Survey Questionnaire (SF-36) (Ware, 1993). Argimon *et al.* (2004) aimed to assess the health-related QoL of carers of people with dementia, compared with an age- and gender-matched sample from the general population using the SF-36. This instrument includes sub-scales of physical, mental and social functioning, and was designed to measure broader health status. Argimon *et al.* (2004) used it with the implicit assumption that it is the same concept as health-related QoL, and appropriate for carers. They noted, however, that the SF-36 had not been validated in respect of the carers of people with dementia. Arango-Lasprilla *et al.* (2010) also used the SF-36 to measure the HR-QoL of carers of people with dementia in Colombia, although uncritically.

However, a condition specific measure of the QoL of carers of people with dementia was developed from studies of the difficulties of carers of people with dementia being cared for at home, and has been validated in France (Thomas *et al.*, 2002; 2006). This was based on the generic WHOQUAL Group (1993) concept of QoL as ‘the individual perception of a human being’s position about life, cultural background, considering his (sic) value in relation to his objectives, goals, and standards’, and on their research on carers’ complaints, interrelationships and what causes them – rather than quality of life *per se*. This measure includes 20 items spanning several areas of a carer’s life. Four main domains of observation were addressed: behavioural capacities to face difficulties generated by the person with dementia (A), relation with the environment (B), psychological perception of the situation (C), perception of a possible distress (D). These are summed to create an overall score of a carer’s QoL and represented as a percentage. A score of zero (0) indicates poor QoL, a score of 100 indicates good QoL. Validity was supported by correlations with socio-demographic characteristics of the people with dementia and their carers, a proxy measure of QoL of people with dementia that was administered to physicians and carers (Rabins *et al.*’s (1999) ADRQL (Alzheimer’s Disease Related Quality Life)), and neuropsychology assessments of behavioural and psychological symptoms of dementia; associations were weaker with duration of dementia (Thomas *et al.*, 2006). The measure still requires thorough testing, and addresses only a limited number of potential QoL domains.

One of the few ‘bottom-up’ studies of QoL of carers was a qualitative study of carers of people with dementia living in Sardinia, which asked carers themselves to identify the components of their QoL (Vellone *et al.*, 2012). Questions asked of carers included the following:

1. *Considering the fact that you take care of a person affected by Alzheimer’s disease, what do you think QoL is?*
2. *Which factors do you think improve your QoL?*
3. *Which factors do you think worsen your QoL?*

The themes identified from their phenomenological analysis of what constitutes QoL are presented in **Box 1** and illustrate the range of potential views. These may be useful areas around which to base evaluations and engagement.

Finally, the matter of a ‘condition-specific’ QoL measurement for carers is indicated by studies of carers that have reported different stresses by type of condition. Some studies have reported that caring for a person with dementia is more burdensome and stressful than caring for a person with a physical disability (Schulz *et al.*, 1990; Mohide *et al.*, 1998; Ory *et al.*, 1999). This suggests that condition-specific measures may be needed for carers. While using generic measures has the advantage of being able to compare different groups (see HSCIC, 2013), they may fail to capture areas that are carer- and disease/condition-specific. Thus the exploration of condition-specific QoL measurement among carers, with generic cores, merits attention, as does detailed analysis of existing data where such information can be compared and models of understanding developed.

Box 1. Summary of themes identified by Vellone *et al.*, 2012.

Overall components

Unity and cooperation in the family

Freedom, independence, having time for themselves

Serenity/tranquility

Wellbeing and health

Factors worsening QoL

Fear for the future: for the care needed and for the illness worsening

Continuous care of the patients, not having time for themselves

Factors improving QoL

No worsening of the illness

Help and support from family

Help from formal services

Satisfaction and reward from giving care

Financial support for paying other assistants

More free time

More public sensitization (awareness) about Alzheimer's Disease

What topics require further investigation?

Notions of carer stress are the most prevalent in the literature on the impact of caring on carers. Several factors contribute to stress, as summarised by Brodaty and Donkin (2009), these include: background factors (level of support received and impact of other life events), primary stressors of the illness (such as the level of help required, behavioural and psychological problems), secondary role strains (such as family conflict and social life), and intra-psychic strains (personality, competence, and role captivity of the caregiver such as feelings of being “trapped” in their caring role), as well as carer overload (e.g. fatigue and burnout). However, research findings are inconsistent on the impact on carers of the duration of caring. Explanatory models included suggestions that caring for someone with dementia leads to burden and strain that can be exacerbated (e.g. by behavioural disturbance, physical or psychological ill-health) or ameliorated (e.g. by support, mature coping mechanisms) (Poulshock & Deimling, 1984).

Three theories have been proposed to explain carer stress. The ‘adaptation hypothesis’ suggests that over time carers adapt to the demands of their role (Rabins *et al.*, 1990); the ‘wear and tear’ hypothesis proposes that the longer a carer remains in his or her role, the more likely negative outcomes are to occur (Townsend *et al.*, 1989; Zarit *et al.*, 1986); the ‘sequestration hypothesis’, proposes that people with dementia are more likely to move to long-term care where their carers are experiencing greater stress, thus removing them from population research samples (Brodaty *et al.*, 2005).

Other models focus on the consequences of reduced social support. Charlesworth *et al.* (2008) summarised the literature on the impact of caring on carers’ wellbeing. They found reductions in their social interactions and friendships, and increases in family role conflicts, owing to a lack of opportunities to socialise and/or the stigma associated with the condition. They reported that carers who are socially isolated are more vulnerable to the negative impacts of caring, including risks of loneliness and its reported associations with increased mortality and morbidity, including psychiatric morbidity. There is an established literature on the associations between low levels of social networking and increased morbidity and mortality. Theoretical models underpinning this literature focus on both the direct (e.g. information giving, instrumental and emotional support) and indirect effects (e.g. stress buffering model) of social support on health and mortality (see Holt-Lunstad *et al.*, 2010).

Lim and Zebrack (2004) argued that family stress theory has potential for the greater understanding of carers’ experiences and behavioural outcomes, by examining how multiple aspects of carers’ QoL may be partly influenced by other existing environmental stressors, stress appraisal, coping methods and social support: the family is seen as facing and dealing with challenges as a normal part of family life. Studies of variables influencing carers’ QoL were also summarized in their review (patient/user characteristics, carer characteristics, stressors, stress appraisal, stress coping methods, and social support).

What are the possible and predictable research challenges?

Psychometrics is a well-established scientific field that is concerned with the measurement of subjective judgements using numerical scales and the evaluation of the measurement properties of such scales (e.g. reliability, validity, responsiveness). The literature, when synthesised, suggests that these are possible steps to be followed for the development of a QoL measure (see **Box 2**). Psychometric properties would then be examined using both classic (or ‘traditional’) and modern psychometric methods: these include acceptability (including data quality), scaling assumptions, reliability (e.g. internal consistency and test-retest reproducibility); validity (e.g. convergent and discriminant validity); and responsiveness. These underpin the US Food and Drug Administration (FDA) recommendations for patient-reported outcome instrument evaluation (see FDA, 2006).

Box 2. Summary of classic psychometric methods (Bowling, 2014a, summarised from Cano *et al.* (2012), Tables 1 and 8, and Bowling (2009), see sources for references to criteria).

Psychometric property	Criteria
Item generation and reduction	<p>Potential questionnaire items should be generated from face-to-face interviews with a small sample of the target group, then the pool of items is examined conceptually, and by experts, and reduced using standard psychometric approaches.</p> <p>The generation of the item pool from a sample of the target group should be conducted alongside literature reviews and consultations with users and with expert groups. The latter should not be used as a substitute for this exercise.</p> <p>Redundant items and those with weak measurement properties and high levels of missing data can then be removed, and the resulting items grouped into scales using factor analysis, and then refined to form the intended measurement scale for testing for acceptability, reliability and validity, in a larger survey, before final refinement and final testing.</p>
Acceptability	<p>Assessed by data quality and targeting. Data quality: the completeness of item- and scale-level data, assessed by data completeness; criterion for missing data <10%. Targeting: the extent to which the range of the variable measured by a scale matches the range of that variable in the study sample; assessed by maximum endorsement frequencies <80%, aggregate endorsement frequencies >10%, skewness statistic -1 to +1, proximity of scale mean score to scale mid-point (closer matches = better), acceptable distribution of scores (closer to 100% indicates better targeting).</p>
Scaling assumptions	<p>Assessed by the extent to which it is legitimate to sum a set of items, without weighting or standardisation, to produce a single total score. Criterion is satisfied when items have adequate corrected-item total correlations ≥ 0.30, and grouping of items in subscales is correct. Assessed by principal components analysis (factor loadings >0.30, cross-loadings <0.20), item convergent and discriminant validity (item-own scale correlations >0.30, magnitude >2 standard errors than other scales).</p>
Reliability	<p>Reliability: the extent to which scale scores are not associated with random error.</p>
Internal consistency reliability	<p>Precision of the scale based on the homogeneity (inter-correlations) of items at one point in time. Assessed by testing whether items are inter-correlated, using tests of internal consistency (e.g. Cronbach's coefficient alpha ≥ 0.70; some use ≥ 0.80), mean item-item correlations (homogeneity coefficient) ≥ 0.30, and item-total correlations ≥ 0.30</p>
Test-retest reproducibility and inter-interviewer reliability	<p>The agreement between respondents' scores at two short time intervals, where they are expected to be stable; it estimates the stability of scales. Scale-level intra-class correlation coefficients ≥ 0.80, item-level intra-class correlation coefficients ≥ 0.50, should be achieved. Inter-interviewer reliability: the reproducibility of the scale when administered to the same respondent by different interviewers.</p>
Validity	<p>Validity: the extent to which a scale measures the construct that it purports to measure.</p>

Psychometric property	Criteria
Face validity	An estimate of whether a test appears to measure a certain criterion
Content-related validity	The ability of the measure to reflect what is predicted by the conceptual framework for the measure – this can include tests for discriminant, convergent and known-groups validity (see later).
Validity (within scale)	Evidence that a scale measures a single construct, and that scale items can be combined to form a summary score. Assessed using internal consistency reliability (Cronbach's $\alpha \geq 0.70$, again ≥ 0.80 is used by some) and factor analysis (factor loadings > 0.30 , cross-loadings < 0.20)
Validity (correlations between scales)	Correlations between scales: moderate correlations (0.30–0.70) expected.
Discriminant validity	Evidence that a scale is not correlated with other measures of different constructs, hypothesised as not expected to be correlated with the scale.
Known-groups validity testing/hypothesis testing	Ability of a scale to detect hypothesised differences between known sub-groups.

Discussion

This review focused on three key questions. We found that QoL outcome measures for carers are emerging and some are condition specific to dementia. They are even beginning to be used in practice or commissioning. However, several methodological challenges remain. For example, most studies assessing the impact of long-term conditions on carers are cross-sectional. There is a dearth of carer-reported QoL measures, in contrast to the existence of proxy scales for carers which are used to measure the patient's/client's QoL (these are prevalent in relation to dementia). This is important as the research community is becoming more aware that the carer's perceptions of the QoL of their relative or friend with dementia may be influenced by their own interests and stressors. Such a point is often made by practitioners in our experience. Similarly, generic versus condition-specific QoL measures for carers require assessment but there is also the complexity that most people with dementia have multiple long-term disabilities and/or impairments and that these are interrelated (Melis *et al.*, 2013). A particular challenge in outcomes research and in outcome measurement in local services is that people's values may change over time as they adjust to their circumstances. This has enormous implications for the assessment of QoL, the interpretation of change, and in shedding light on the paradoxical findings so often obtained.

As noted, caring for a person with dementia often has both negative and positive consequences which require inclusion in measures but these may vary by individual and over time. Measures need to be appropriate for younger and older people, type of carer, and be sensitive to cultural and class differences. For example, partners may respond differently to other family carers

such as adult children, and sons differently from daughters – so measures overall need to ensure relevance. Thus a broader approach to measuring the QoL of carers is needed and one that goes beyond health- and care-related items because caring can affect life as a whole, both currently and in the future. Scale development needs to start ‘bottom-up’ by eliciting the perspectives of the target group (e.g. carers); only through their rigorous and sensitive involvement can outcome measures be developed which have social relevance.

A great deal has been learnt from decades of work on QoL and from studies of carers. First, that scientific rigour is required in the development and testing of relevant carer QoL outcome measurement, in order to make their use worthwhile. Tools such as ASCOF have received substantial resource, much investment in terms of practitioner time and effort, and are continuing to be further evidence based, especially around intervention effects (Sutcliffe *et al.*, 2012) since the carers surveyed are in receipt (or the person they care for) of publically funded social care services (the intervention). Rand *et al.* (2015) recently reported following their interviews with 387 carers collecting data on variables hypothesised to be related to SCRQoL (e.g. characteristics of the carer, cared-for person and care situation) and measures of carer experience, strain, health-related quality of life and overall QoL, that:

The results provide evidence to support the construct validity, factor structure, internal reliability and feasibility of the ASCOT-Carer INT4 as an instrument for measuring social care-related quality of life of unpaid carers who care for adults with a variety of long-term conditions, disability or problems related to old age.

As the DH (2012, p.10) notes, the Carers’ Survey (on which ASCOF draws) is close to being the ‘carers’ equivalent of the overarching social care-related quality of life measure’. The present ASCOF Carers’ Survey is biennial, but may become an annual collection if the effort and expense of undertaking the survey can be substantially reduced, subject to local government agreements and national agreements about resourcing and data requirements. The results will likely be valuable to carers, practitioners and funders and when it is possible to cross-tabulate the findings related to carers of people with and without dementia then services and support may become more personalised and effective.

Second, wider assessments of carers’ QoL may benefit from development or refinement of a clearer conceptual basis underpinning the measure(s). Rigor in the research methods used to develop and assess the measure will be needed but so too is the need for these measures to be relevant to outcomes. Such work needs more engagement with diverse current and former carers from the outset, to ensure social significance, as well as experts and practitioners to ensure policy and practice relevance. Use of adequate and generalisable sample sizes, coverage and types for psychometric testing are also needed. We have proposed above that the use of gold-standard psychometric testing is required, using classic (traditional) and modern methods. These need to include assessment of predictive validity over time, responsiveness to changes in outcomes, interpretability, and use in decision-making.

There are wider implications in relation to the measurement of QoL. For example, dementia caring might be combined with other forms of care-giving (sometimes termed ‘sandwich’ caring when it involves care for children and for ageing parents), and some carers will have cared for more than one relative – with accumulating experiences. Investigators should consider using a core generic QoL measure (for generalisability across carers by condition of the person cared for), as well as relevant condition-specific modules (e.g. for carers of people with dementia or carers supporting people with severe learning disabilities). This also needs to take into account the trade-offs between scale length and levels of psychometric acceptability and the growing emphasis in practice on personalised support and funding for people with dementia and for their carers, amongst others (Glendinning *et al.*, 2013; Newbrunner *et al.*, 2013). Changes in social care and health services between the different countries of the UK will make it all the more important to be able to have confidence that impacts on the carers of people with dementia (amongst others) are being accurately measured so that any comparisons are valid.

It should be cautioned that this overview does not claim to be comprehensive, and is limited to results from a scoping review rather than a systematically conducted review of the literature. Thus our conclusions are tentative. However, scoping reviews are of particular value with neglected topics, and in identifying research gaps (Arksey & O'Malley, 2005). Following our review the MRC subsequently commissioned a major study, DECIDE (Dementia Carers Instrument Development) (see <http://gtr.rcuk.ac.uk/projects?ref=MR/M025179/1>) (contact Penny Wright at the University of Leeds, e.p.wright@leeds.ac.uk). This study acknowledges that having an accurate and meaningful way of measuring carer quality of life is needed in three distinct areas and will focus on:

1. Individual carer assessment: to identify carers most at need,
2. Service development and evaluation,
3. Informing policy-making and decision-making around government spending.

In addition to this, the work of the DH's Policy Research Programme's Quality and Outcomes of Person-centred Care Policy Research Unit (QURU-<http://www.qoru.ac.uk/>) continues to add to the evidence base (most pertinently to this present paper, see Rand *et al.*, 2015).

Conclusion

There is great political and policy interest in promoting research in dementia (DH, 2013). This present overview has concluded that methodological development in the measurement of QoL outcomes is still needed. Few conceptual models have been developed specifically to measure carer QoL, including carers of people with dementia, and measurement has thus suffered accordingly. Rigorously conducted conceptual and methodological research, using gold standard psychometric techniques, and based on a participatory, 'bottom-up' model with carers, as well as policy makers and frontline practitioners, is needed to address this gap. Policy initiatives, as well as care and support more generally for carers of people with dementia can then be evaluated, modified and bolstered from this evidence.

Acknowledgements and disclaimer

We are grateful to the Medical Research Council (MRC) for commissioning this review. The views expressed are those of the authors and should not be interpreted as those of the MRC or the Department of Health.

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Self-funders and social care: findings from a scoping review

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Abstract

This paper draws on a scoping review of the evidence base about adults in England who purchase social care services and support using their own money. It presents a selection of the review's findings relevant to self-funders and key aspects of the Care Act 2014.

The review covers the years 2000 to 2015. Searches of electronic databases were complemented by a focused search of the websites of key organisations. After applying inclusion/exclusion criteria, and removing duplicates, details were extracted from 76 references. The majority focused on residential care (33), domiciliary care (12), or both (23). Studies used a range of research methods.

The overall numbers and percentages of self-funders of home care and care home places have increased. There are variations across regions but limited evidence about demographic or socio-economic characteristics of self-funders. Self-funders feel they lack advice from local authorities; local authorities have limited knowledge of self-funders in their areas. People struggle to understand fees and the financial implications of long-term care. Providers are beginning to realise the potential of the self-funding market but full use is not yet being made of e-marketplaces.

Key gaps in knowledge remain at a time when the number and importance of self-funders is increasing.

Keywords: self-funders, social care, literature review, adults, older people, England

Background

People who purchase social care services and support using their own funds are often referred to as self-funders. Self-funders are different to people receiving a cash payment from the state. Many countries employ some form of 'cash for care' system, whereby eligible people are given cash payments to pay for social care which they arrange themselves (Glendinning & Kemp, 2006). Some countries also compensate family carers financially for the informal care they provide (Lundsgaard, 2005). There are undoubtedly similarities between people spending their own resources on care and those spending resources provided by the state. However, self-funders are distinct from people who purchase services and support through cash for care schemes because they do not necessarily have any contact with social services or other relevant bodies that may offer help and advice; they often have to navigate the care system alone.

Self-funders in England are people who have care needs below a national eligibility threshold or who have financial assets above a threshold. Under the previous FACS (Fair Access to Care Services) system, 87 per cent of English councils in 2012/13 restricted eligibility to people with needs deemed to be substantial or critical, an increase from 47 per cent in 2005/6 (ADASS, 2012). High eligibility thresholds, coupled with continuing restrictions on local authority expenditure and population ageing, mean the number of self-funders is set to increase.

In 2014, the Care Act (Great Britain, 2014) received royal assent. Described as 'the most comprehensive overhaul of social care since 1948' (Department of Health, 2014), it brings together existing laws and new responsibilities. Some elements of the Act came into being in April 2015; others were due to take effect from April 2016 but have been delayed until 2020. Many areas of the Act are relevant to self-funders. These are described as follows:

National eligibility criteria

The Act introduced a national minimum threshold for eligibility for social care. Previously, local councils set their own thresholds using the FACS criteria of low, moderate, substantial and critical. Most councils set eligibility levels at substantial. The new national minimum threshold has been selected to broadly reflect this level. The national minimum threshold means that there may be some changes in eligibility at the margins.

Information and advice services

Councils have been urged to develop information and advice services for all residents for several years through the *Putting People First* concordat (HM Government, 2008) and the *Vision for Adult Social Care* (Department of Health, 2010).

The Care Act made it a duty from April 2015 for local councils to establish and maintain information and advice services relating to care and support for all people in their areas, not just those in receipt of services or otherwise known to the council. Among these people are self-funders. Specifically, councils must provide information on: the types and range of care and support available locally; the process of accessing care and support; where to find and how to access independent financial advice; and how to raise concerns about the safety and wellbeing of someone who receives care.

Independent financial advice

As part of the new requirement to establish and maintain an information and advice service, councils must ensure that people are helped to understand how to access independent financial advice. Local council staff, including frontline staff, should have the knowledge to direct people to independent financial advice, and to explain the pros and cons of regulated versus non-regulated advice services.

Market shaping and commissioning

The Care Act places a duty on councils to facilitate and shape the care market so that it is able to meet the needs of local residents who need care, whether or not the council pays for that care. The aim is to help develop a sustainable and diverse range of providers and care from which people can choose.

Business failure and continuity of services

Councils have a temporary duty to meet people's needs if their provider (of residential or domiciliary care) is no longer able to do so because of business failure. This duty applies to any failed provider that was meeting needs in the local council area, irrespective of whether the council had a contract with the provider or who was paying for the care. This means that self-funders are included in this duty.

Originally from 2016, but now delayed to 2020, phase two of the Act introduces financial changes for self-funders (and others), specifically:

Care accounts and the cap on costs

The care costs cap of £72,000 (2015 prices) is the maximum amount anyone will have to pay for their care over their lifetime. Personal care and support costs of domiciliary and residential care are included in the cap, but not the 'hotel' costs associated with residential care. Progress towards this cap will be based on the costs to the local council of meeting a person's care. Crucially, this means that self-funders must have a needs assessment before any costs can be added to their care account.

Increase in financial eligibility thresholds

Lower and upper limits will be increased. For example, the upper limit for people whose housing assets are not disregarded will be increased to £118,000. Therefore, assets of between £17,000 and £118,000 will be included in means-testing through a standard formula which converts each £250 of assets into a weekly income of £1 (known as tariff income). This means someone with £118,000 of assets will be assumed to have an additional weekly income of £404 (Age UK, 2015).

This paper draws on a scoping review of the evidence base about adults in England who purchase social care services and support using their own money (see Baxter & Glendinning, 2015). It presents a selection of the review's findings that are relevant to these aspects of the Care Act 2014.

Methods

The purpose of a scoping review is to map current knowledge about a subject and identify gaps in that knowledge (Arksey & O'Malley, 2005). The review was undertaken between January and March 2014 and updated in August 2015. It aimed to identify evidence from published literature about people who fund their own social care in England, specifically:

- the size of the evidence base;
- the size and characteristics of the self-funding population in England;
- the information, advice and other forms of help needed, sought by and available to those currently funding their own social care support, or expecting to have to do so in the future; and,
- care providers' experiences of people funding their own social care support.

For the purposes of the review, we defined a self-funder as someone who pays for all of their social care or support from their own private resources, or 'tops up' their local authority residential care funding with additional private spending. People who make a required means-tested contribution to their local authority funding were not included as self-funders. We defined social care as care homes (both with and without nursing), domiciliary care, day care and care received as part of extra-care housing.

Searches covered research evidence published between 2000 and 2015. Relevant articles and reports were identified through searches of the following electronic databases: ASSIA (Applied Social Science Index and Abstracts); Scopus; Social Services Abstracts; Social Policy and Practice; and Social Care Online. **Box 1** (p.182) gives an example search strategy. This was augmented by searches of the websites of selected organisations known to have undertaken research about self-funders.

The original search identified 164 potentially relevant references from the electronic databases and 21 from searches of websites. All 185 references were downloaded to a reference management software package. **Table 1** (p.182) details the process of reading abstracts and full texts, removing duplicates and excluding references that were not relevant, and the numbers remaining at each stage. **Box 2** (p.183) gives the inclusion and exclusion criteria. Data were extracted from 71 references. The update in 2015 identified a further 44 potentially relevant references; after removing duplicates, and references that were not relevant, data were extracted from five references. Some references reported different aspects of the same studies therefore the number of studies is less than the number of references.

The review was deliberately inclusive in nature and made no attempt to assess the quality of articles using a formal hierarchy of evidence (see Petticrew & Roberts, 2003). Had we done so, data would have been extracted from far fewer studies. Instead, a wide range of relevant studies was included.

Box 1. Search terms and strategy.

The following search terms/strategy was used in searching ASSIA, then amended for other databases according to their specific search requirements.

1. ab("social care") OR ti ("social care")
2. ab("social service*") OR ti ("social service*")
3. ab("social support") OR ti ("social support")
4. s1 OR s2 OR s3
5. ab("self fund*") OR ti ("self fund*")
6. ab("top* up") OR ti ("top* up")
7. ab("private* purchas*") OR ti ("private* purchas*")
8. ab("private spend*") OR ti ("private spend*")
9. ab("personal fund*") OR ti ("personal fund*")
10. ab(private* NEAR/3 fund*) OR ti (private* NEAR/3 fund*)
11. ab(private* NEAR/3 pay*) OR ti (private* NEAR/3 pay*)
12. ab("private expenditure") OR ti ("private expenditure")
13. ab("pay for care") OR ti ("pay for care")
14. ab("self financ*") OR ti ("self financ*")
15. ab("paid for") OR ti ("paid for")
16. s5 OR s6 OR s7 OR s8 OR s9 OR s10 OR s11 OR s12 OR s13 OR s14
17. ab("residential care") OR ti ("residential care")
18. ab(care NEAR/3 home*) OR ti (care NEAR/3 home*)
19. ab("domiciliary care") OR ti ("domiciliary care")
20. ab("non-residential care") OR ti ("non-residential care")
21. ab("day care") OR ti ("day care")
22. ab("extra care housing") OR ti ("extra care housing")
23. ab("housing with care") OR ti ("housing with care")
24. s17 OR s18 OR s19 OR s20 OR s21 OR s22 OR s23
25. s4 OR s24
26. s16 AND s25

Limits applied to each search:

Date: After 01 January 2000
 Type: Scholarly journals
 Language: English

Table 1. Number of references identified and read.

	Number of references	
	Original search (2000-2014)	Updated search (2014-2015)
References identified through database searches	164	44
References identified through targeted webpage searches	21	0
Duplicates removed	49	19
Abstracts read	136	23
References excluded	26	13
Duplicates removed	19	0
Full references read	91	10
References excluded	18	5
Duplicates removed	7	0
New references added	5	0
References from which data extracted	71	5

Box 2. Inclusion and exclusion criteria.**Inclusion criteria:**

- empirical research (all methods)
- reviews of empirical research
- secondary analysis of existing data
- models/simulations using existing data

Exclusion criteria:

- debates, viewpoints or think pieces
- policy documents
- guidance documents
- focus not on England
- not about social care
- not about self-funders

Findings***Characteristics of the evidence base***

The studies used a wide range of research methods, often in combination, including surveys, interviews, focus groups and secondary analysis of existing data. Other commonly used methods were mystery shopper exercises and routinely collected evidence from regulatory inspections.

We did not undertake any formal assessment of the generalisability of the publications or research studies on which they were based. However, approximately one-third of the studies were based on national or multi-regional research and used large scale quantitative surveys or mixed methods. About a quarter of studies were also based on national or multi-regional data but used predominantly qualitative methods. A further quarter of studies were small scale or locally-based, for example, research in a single local authority. Thus, the findings from the majority of studies might be considered generalisable in the sense that they report on data from a wide range of the relevant population and the social care services available to them.

Table 2 (p.184) shows the types and focus of the references.

Numbers and geographical variations

The evidence provides no definitive figure for the number of people funding their own domiciliary care in England. However, numbers appear to have increased from around 150,000 in 2006 to 170,000 in 2011 (Commission for Social Care Inspection, 2008; Henwood & Hudson, 2008; National Audit Office, 2011; Putting People First Consortium *et al.*, 2011) and account for around 20 to 25 per cent of the home care market (Poole, 2006; Putting People First Consortium *et al.*, 2011).

In residential care, 118,000 older people self-funded in 2006 (Commission for Social Care Inspection, 2008) increasing to 170,000 by 2011 (National Audit Office, 2011; Putting People First Consortium *et al.*, 2011). Around a third of care home places were self-funded in the period 2002-2005 (Williams & Netten, 2005; Commission for Social Care Inspection, 2006; Wanless, 2006). More recent estimates suggest 43 to 45 per cent self-funded in 2010-2012 (GHK Consulting Ltd., 2011; Putting People First Consortium, 2011; Laing & Buisson cited in Carr-West & Thraves, 2013). It is clear that, whatever the discrepancies in the estimates, trends appear to be upwards.

Table 2. Characteristics of the evidence base.

	Number of references	
	Original search (2000-2014)	Updated search (2014-2015)
<i>Type of reference</i>		
Peer reviewed journal article	16	1
Report	51	4
Magazine-style journal	3	0
Press release	1	0
<i>Focus of reference</i>		
Residential care only	30	3
Domiciliary care only	12	0
Residential and domiciliary care	22	1
General social care including residential or domiciliary care	5	1
Housing with care	2	0
Day care	0	0
Total	71	5

There are also regional variations. A higher percentage of people in the South East and South West of England self-fund care home places (48 per cent and 43 per cent, respectively) than in the North East (less than 20 per cent) (Care Quality Commission, 2013a). Think Local Act Personal Partnership (2012) found the percentage of self-funders in care homes varied by local council (for example, 15 per cent in Hartlepool and 57 per cent in Hampshire). Payment of top ups also varied; in Hartlepool, the maximum percentage paying top ups in any single care home was one per cent of council-funded residents whereas in Bradford it was 31 per cent. The picture was comparable for domiciliary care with 14 per cent self-funding in London Borough of Kensington and Chelsea and 64 per cent in Hampshire.

Knowledge about self-funders

There was a very clear gap in the evidence about the characteristics of self-funders, with no reliable data on their socio-economic make-up, age, gender or ethnicity. However, there was some suggestion that self-funders had lower dependency levels in residential care than those who were publicly funded (Challis *et al.*, 2000; Netten *et al.*, 2001a, 2001b, 2003); some were still able to undertake numerous activities of daily living and/or gardening before admission (Wright, 2002, 2003).

In addition to there being little evidence of their characteristics, in 2011, 60 per cent of local authorities did not know how many people in their area funded their own care home places; only 39 per cent knew how many people qualified for state funding after spending their assets (National Audit Office, 2011). Carr-West & Thraves (2013) estimated that 24 per cent of self-funders in care homes eventually fell back on state support. In addition, 40 per cent of local authorities suspected that more top up fees were being paid than they were aware of (Office of Fair Trading, 2005a, 2005b).

In relation to domiciliary care, a number of studies raised the issue of people being ineligible for public funding but unable to afford to pay for their own care (McCliment & Grove, 2004; Commission for Social Care Inspection, 2008; Henwood & Hudson, 2008). These people were described as 'lost to the system', that is, not known by local authorities (Henwood & Hudson, 2008).

Advice from local authorities

Advice from local authorities appeared to be limited. A survey of older people in Hampshire (Institute of Public Care, 2010) revealed that a significant proportion of those who were self-funders of domiciliary care had not had any contact with, and thus no information from, the local authority. Forty-seven per cent chose not to make contact, preferring to manage their affairs independently or believing they would not be eligible for public funding.

When contacting local authority telephone advice services, self-funders and their relatives felt disadvantaged by the unwillingness of statutory services to help them with exploring options (Thornber, 2008; Commission for Social Care Inspection, 2008; Henwood & Hudson, 2008; Hudson & Henwood, 2008). Henwood & Hudson (2008) also found that self-funders who believed they had significant needs were steered towards residential care before other options had been explored fully.

Not all self-funding residents received a local authority assessment of their needs or advice on their placement before entering a home (Netten *et al.*, 2001b; Challis *et al.*, 2000). The Commission for Social Care Inspection (2007) found that the availability of assessments was not well publicised to people likely to fund their own care. Moreover, little was offered other than a list of care homes following any assessments given. Dalley & Mandelstam (2008) and Henwood (2009) also found local authorities failed to assess the needs of people they expected to be self-funders or to separate needs assessments from financial assessments; furthermore, they failed to help self-funding residents when their funds ran low (Dalley & Mandelstam, 2008). There is widespread interest by councils in online self-assessments; these may be useful to self-funders in the future (Ayling & Marsh, 2014).

Self-funders were also disadvantaged once they had entered residential care. Williams & Netten (2005) found self-funders lacked advice and assessment when care homes closed. Only about a third of local authority closure protocols mentioned self-funders, with half of these stating that they treated all residents the same regardless of funding, and the other half that self-funders would only be given information and advice about closures if they requested it or had no relatives.

Financial advice and implications

Financial implications of long-term care

Self-funders did not feel well informed about the financial implications of long-term care (National Audit Office, 2011). Many care home residents were concerned about what would happen to them when they ran out of money, particularly whether they would have to move to a cheaper home (Netten *et al.*, 2001b; Wright, 2002, 2003). They were not usually warned about this (Commission for Social Care Inspection, 2008; Henwood & Hudson, 2008) or that they may have to move to a more suitable home if their needs increased (Commission for Social Care Inspection, 2007; Wild *et al.*, 2010).

There was also confusion about selling houses to pay for care (Wright, 2003). Henwood (2006) estimated that approximately 40,000 houses were sold per year to pay for care home places, with between 120 and 640 possibly sold unnecessarily as people may have been eligible for NHS Continuing Healthcare. A London-based study (Robinson & Banks, 2005) found that around half of older Londoners owned their own homes and so had to pay the costs of their care home places. This resulted in many choosing a cheaper home outside London, moving away from family, friends and familiar surroundings. In addition, while finances were tied up in housing, people found it hard to find the money to buy the support which would enable them to remain in their own homes.

Care home fees and topping up

Self-funders pay more than publicly-funded residents and top up fees are common (Wright, 2002; Ball *et al.*, 2005). Self-funders in nursing homes have been found to pay about 30 per cent more than the fees paid for local authority-funded residents (Garvican & Bickler, 2002) and 40 per cent more, on a 'like for like' basis, in care homes across 12 councils surveyed (County Councils Network & LaingBuisson, 2015).

A study by the Office of Fair Trading (2005a, 2005b) looked at the care home market for people aged over 65. It showed that 30 per cent of residents were self-funders, with an additional 15 per cent making top up contributions. Ten years later, County Councils Network & LaingBuisson (2015) found 55 per cent of residents in care homes without nursing were self-funders, and 12 per cent paid top ups to local authority funded places. The proportion of people who top up local authority funded care home places has increased for all age groups (Care Quality Commission, 2013b; Office of Fair Trading, 2005a, 2005b).

Care home fee contracts for self-funders can be confusing. For example, the Office of Fair Trading (2004) found that contracts for self-funders or those topping up care home places were not clear and prices not transparent. The difficulty in obtaining sufficient information about prices was seen as particularly important if older people or their relatives were under pressure to choose a home quickly or if they were making a one-off choice (that is, for a permanent rather than temporary home). Local authorities are not usually involved in top up fee contracts, which has raised concerns that the fees might be unjustified (Office of Fair Trading, 2005a).

Financial advice and products

Few people use financial products to help pay for their care. Only four per cent of self-funders in residential care had an Immediate Needs Annuity (INA) in 2011 (Lloyd, 2011). The obligation to obtain independent financial advice can deter people from purchasing financial products (Lloyd, 2011). Carr-West & Thraves (2011, 2013) found that 40 per cent of people in care homes would benefit from an existing financial product but only three per cent of councils provided a list of independent financial advisors who could give advice about these products.

On the whole, key national organisations were not confident in giving advice about finances (Hudson & Henwood, 2009), despite a third of calls to a national advice line being about finances, and the most requested information guides being about care home fees and third party top ups (Independent Age, 2012). Ayling & Marsh (2014) report practice examples from two councils signposting independent financial advice through their websites and customer contact centres, but also point out that reluctance by some councils and their voluntary sector partners to promote self-employed financial advisers (whose income is related to the products they sell) is hampering progress.

The developing market for self-funders

The evidence base on provider experiences and the market for social care for self-funders is limited. There is some evidence that domiciliary care providers previously prioritised large local authority contracts, thus limiting self-funders' choice of agency (Patmore, 2003; Putting People First Consortium, 2011). Baxter and colleagues (2008) also found that home care agencies did not advertise specifically to self-funders, but used information aimed at council-funded clients (eligible only for personal care services); thus self-funders had no information about the wider range of services available to them (for example, help with shopping, trips out or companionship).

However, large local authority contracts are no longer typical. More recently, evidence suggests that although managers of home care agencies lack good information about the local market of self-funders, they recognise the advantages of accepting self-funders seeking modest help as

their needs are likely to increase over time (Putting People First Consortium *et al.*, 2011; IPC Market Analysis Centre, 2012). Providers expect the size of the market for self-funders to continue to increase as eligibility thresholds rise and, if the level of personal budgets falls, more people top up their local authority-funded care (Laing & Buisson, 2013).

In terms of advertising services to potential clients, 25 per cent of councils now have 'e-marketplaces' – digital platforms that enable people to find out about local services (Roberts, 2015). These increase the exposure of services (both domiciliary/regulated care and unregulated services such as handyman schemes) to clients, although many providers do not advertise prices and many sites are merely directories of services, rather than interactive sites through which people can purchase services; residential homes are reluctant to advertise prices as these are usually negotiated individually and prices for self-funders are higher than for council-funded clients (Roberts, 2015). There are some concerns that cross-subsidization, with self-funders' fees compensating for the low prices paid by local authorities, has reached unsustainable levels and may result in more care homes in the future being for self-funders only (Birley *et al.*, 2015; County Councils Network & LaingBuisson, 2015).

Discussion

This discussion summarises the main findings and the strengths and limitations of the research. It then gives implications for policy and practice, including issues around information and financial advice, market shaping and cross-subsidization. The final section suggests areas for further research.

Summary of main findings

This paper has reported selected findings from a scoping review commissioned by the NIHR School for Social Care Research to determine the size and scope of the research evidence base about people who fund their own social care in England (Baxter & Glendinning, 2015). It has reported evidence that a substantial percentage of people fund their own care both at home and in care homes; there are large variations in these proportions at regional and local levels. Very little is known about the characteristics of self-funders, and local councils are often not aware how many people fund their own home care or residential care in their areas. Advice and information offered by councils to self-funders has been perceived as poor. The financial implications of long-term care, fees and the availability of financial products are all poorly understood and explained. The market for self-funders is developing, with the introduction of e-marketplaces and the realisation by home care providers that demand is growing. The issue of cross-subsidization in the residential care sector is a current issue.

Strengths and limitations

The research evidence presented is limited in that it focuses on self-funders in England only. However, the findings are pertinent in other parts of the UK where people ostensibly receive free personal care. For example, personal care at home is free for people aged 65 or over in Scotland, but these free services are not provided to everyone; people's needs are still assessed and those with needs lower than the eligibility threshold are required to fund their own care.

The review has a number of strengths. First, the inclusive design permitted a wide range of published research to be reviewed, which illustrated the overall weakness of the evidence base. Second, the review's inclusion of both quantitative and qualitative evidence enabled the presentation of generalizable evidence alongside more nuanced data. Finally, the review is strengthened by its focus on self-funders as a defined group, distinct from people purchasing care using funds provided through cash for care schemes.

Implications for policy and practice

Importantly, the Care Act has addressed some of the issues highlighted by the evidence. Specifically, the research evidence shows that self-funders lacked information about care home closures. The Care Act states that councils have a temporary duty to ensure that people's needs continue to be met if their care home or home care provider fails – this duty covers all people however funded. In addition, the lack of information more generally to self-funders is to be addressed, with the Care Act requiring councils to establish and maintain services to provide advice, including how to access independent financial advice, to all people in their areas.

The requirement that councils ensure everyone, including self-funders, has information about care and, when appropriate, care accounts, is important. The evidence to date suggests that not all self-funders receive information from councils, and for those who do it can be limited. The new requirements are likely to involve substantial increases in workloads for councils, both in identifying current and potential self-funders, and in ensuring services offering information and assessments are available. An important part of this process will be to publicise to self-funders their rights to these services. A particular challenge will be how to reach people who, according to evidence, choose to be self-funding because they do not want to share financial details with the council or prefer to manage their own affairs.

The Care Act states that councils must ensure that people are enabled to access independent financial advice. This duty should mean all councils, rather than the current three per cent suggested by the evidence (Carr-West & Thraves, 2011), provide accessible details of independent financial advisers. Part of this advice should relate to top ups, property disregards and deferred payments. These are all issues that the evidence suggests are priorities for people seeking information. However, ways of overcoming the reluctance of self-funders to receive financial advice and councils to promote self-employed advisers will need to be found.

There is evidence that people with low to moderate care needs are often 'lost to the system' (Henwood & Hudson, 2008). Although care accounts have been delayed, in the immediate future it is important that self-funders know that they have a right to an assessment; councils need to have the capacity to undertake assessments and subsequently offer appropriate support and advice for arranging care. In the longer term, it is important that people have their needs assessed regularly so that a care account can be set up as soon as they reach the eligibility threshold. Failure to do so will mean that eligible expenditure on care may not contribute to people's care accounts.

We found no evidence about the impacts on self-funders of market shaping and commissioning, but some early signs that councils were hosting e-marketplaces to enable advertising of a diverse range of services. It is essential that, in addition to personal care, low level support and preventive services are available and that self-funders are aware of them. Local wellbeing initiatives, for example, might help prevent, reduce or delay self-funders' needs for more intensive social care (and potentially, in the longer term, financial demands on local councils). Given the evidence that the size of the self-funding market varies across regions and councils, the design and impact of any initiatives will need to differ according to a council's geographic location and their previous involvement with supporting self-funders.

The very recent literature shows that cross-subsidization is an important area for commissioners in shaping markets, particularly residential care markets. Self-funders often pay substantially more than council-funded residents for similar services. When phase two of the Care Act is implemented, self-funders moving into residential care will be given the right to ask councils to arrange care on their behalf. (They already have this right for domiciliary care.) This means self-funders will be able to pay the lower fees that councils are charged (plus an arrangement fee) rather than the higher self-funding fees. As Birley *et al.* (2015) and County Councils Network & LaingBuisson (2015) discuss, shrewd self-funders (perhaps following independent financial advice) will use this system when they realise the savings they can make.

This will, ultimately, leave care homes with lower fee income as the ratio of self-funding fees to council fees falls. To maintain income levels, care homes may have to increase fees charged to already financially stretched councils.

Implications for research

This paper has shown that the evidence base about self-funders is weak. Most studies identified for the scoping review were descriptive rather than evaluative. It was not clear whether or not many references had been peer reviewed. Given the number of self-funders, this level of evidence is disappointing and has clear implications for research, not least in filling some of the gaps in knowledge.

One noticeable gap is the lack of research evidence about the characteristics of self-funders. If providers, especially home care providers, are to diversify to meet the demands of the self-funding market, they need a thorough understanding of who their purchasers are, as well as the types of services they want to purchase. These services will not necessarily be the same as those commissioned by local authorities on behalf of personal budget users.

Phase one of the Care Act provides opportunities to evaluate the relative success of different methods of establishing and maintaining information and advice services, including e-marketplaces. Think Local Act Personal offer useful examples of current practice (see Ayling & Marsh, 2014), but independent evaluations of what works, for whom and why, would be important contributions.

The evidence also suggested that home care providers are becoming more aware of the importance of the self-funding market. However, we do not know how an increase in the number of self-funders, and potentially an increase in their average needs resulting from increased eligibility thresholds, will impact on providers or their care workforce, nor what challenges and opportunities arise in providing care to self-funders compared to people receiving public funding in either home care or care homes.

Conclusion

There is a body of research evidence about self-funders of adult social care in England, but key gaps in knowledge remain at a time when the number and importance of self-funders is increasing.

Acknowledgements

Thank you to Caroline Glendinning for her contribution to the scoping review and the report on which this paper is based.

This report presents independent research commissioned by the NIHR School for Social Care Research. The views expressed in this publication are those of the author and not necessarily those of the NIHR School for Social Care Research or the Department of Health, NIHR or NHS.

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Factors that influence decision making by 8-12 year olds in child and adolescent mental health services (CAMHS): a systematic review

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Abstract

There is significant legal guidance and case law available to support clinicians in assessing whether young people aged over 13 years are able to make informed decisions about their own healthcare; however when working with children aged 8-12 years, the guidance is unclear. In order to assess whether 8-12 year olds are able to make decisions in their own healthcare, we first need to understand the factors that influence this process.

A systematic literature review of five electronic databases (PsycINFO, EBSCO, Science Direct, Science Full Text, Web of Science All Databases) was conducted. The search identified 12 studies and one piece of government guidance. The studies were identified from a variety of health and social research journals. The six factors that were identified were: 1) consent, competence and capacity, 2) best interests, 3) communication, 4) risks and conflicts, 5) legal frameworks, and, 6) parental role.

The review concludes that it is possible for some children 8-12 years of age to make decisions regarding their own healthcare. The necessary conditions are that age specific language is used through a variety of mediums which will include risks, benefits and options for the proposed interventions. Clinicians need to be skilled in the assessment of the child's ability to make decisions and be effective communicators with a commitment to children's involvement. Further research in both these areas is needed.

Key practitioner messages:

- There is a legal requirement that a child's voice is heard
- All children's views should be given due weight
- Clinicians need to be skilled in order to assess competence and capacity
- Children aged 8-12 can make informed decisions about their own healthcare when supported with appropriate age related information

Keywords: children, mental health, decision making, empowerment

Introduction

There is a legal requirement to ensure children's views are taken into consideration within health and social care decision making processes (Children Act, 1989, Section 17.4a; United Nations Convention on the Rights of the Child (UNCRC), 1989, Article 12, p.5). What is less clear is when this involvement should take place; how should it take place and what conditions need to exist for the involvement to be both appropriate and effective. This includes the age of the child and their capacity to make decisions.

International law, UK legislation, British Government policy and case law all influence and offer guidance in this respect (e.g. Human Rights Act (HRA), 1998; Mental Health Act (MHA), 1983; Gillick v Norfolk and Wisbech Health Authority, 1985). Each of these areas will be briefly introduced in order to support the need for a systematic review.

The UNCRC (1989) (Article 12, p.5) states 'parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the

child, the views of the child being given due weight in accordance with the age and maturity of the child'. The Human Rights Act (1998) further supports this in its declaration in that if a person's rights, which include those of a child, are infringed by a public body, then they would have the right to seek legal redress within their legal jurisdiction. This important legal position and imperative to involve children in decision making was subsequently included as one of the essential positions within the Robbins Report (Robbins, 1999).

In the UK, the Children Act (1989) also recognised the imperative to involve children in decisions about their own welfare; in doing so the issues of the capacity of children to participate in decision making is explicit but in the context of their age and ability to understand the implications of their decisions. The National Service Framework for Children (NSF) (DH, 2003), and the CAMHS review (CAMHS, 2008) also strongly emphasised notions of involvement within decision making: 'seeing the world through the child's eyes' (DH, 2003, p.4, para.1.7) and 'patient being the centre of care' (CAMHS, 2008, p.11) as their key policy and practice objectives.

Case law regarding consent has influenced practice within all aspects of health. One such was *Bolam v Friern Hospital Management Committee* (1957) from which a four stage test (*The Bolam Test*) was developed to establish whether harm to a patient was negligent or whether it was what any 'competent' practitioner would do. *The Bolam Test* is still used by courts to establish whether reasonable practice has taken place (*Sidaway v Board of Governors of the Bethlem Royal Hospital*, 1985; *Simms v Simms*, 2003; DH, 2009a). *R v Bournemouth Community and Mental Health NHS Trust* (1997) concluded that the Trust had treated a patient on false premise of consent as the patient did not dissent although this case was in relation to a patient that was severely learning disabled. *Bolitho v City and Hackney Health Authority* (1997) considered 'reasonable practice' with regards to whether a child should have been intubated (the insertion of a tube through the mouth or nose into the larynx to aid ventilation, (Marcovitch, 2010)) or not, to which it concluded that the courts should decide 'reasonable practice' and not professionals. Though case law is helpful in contributing to the development of better practice, there have also been many criticisms of particular case laws when newer, more appropriate cases pass through the legal system, thus creating constantly evolving fields of practice.

From a legal field perspective it is important to consider the age of criminal responsibility, which currently stands at 10 years of age (Children and Young Persons Act, 1963). Children aged 10 years and over are considered capable of intending to commit a crime. One of the most noted cases is that of James Bulger where two children, Jon Venables and Robert Thompson, both 10 years old at the time, abducted, tortured and murdered 2½ year old James. The prosecuting QC argued that Venables and Thompson understood that what they did was wrong and had understanding of the consequences of their actions (*T v United Kingdom*, 1999; *V v United Kingdom*, 1999). If children aged 10 years can understand the consequences and gravity of torture and murder, and be held legally accountable, then it is arguable that competency for the purpose of treatment decisions, which would be of less gravity – for example, decisions made as out-patients in CAMHS – is possible; despite the outcomes of treatment being dependent on variables including the therapeutic relationship, systemic considerations and clinician proficiency (Shirk & Karver, 2003).

The case law which has largely influenced CAMHS practice with regard to consent is that of *Gillick v Norwich and Wisbech Health Authority* (1985). Lord Fraser further reviewed the *Gillick* case, and deemed that a young person had the ability and right to consent to contraceptive treatment. The child had to show understanding for that specific decision at that specific time, with an understanding of the risks, benefits and options. The term 'Fraser competent' was established from this ruling but only referred to the ruling regarding the advice and treatment of contraceptives. Fraser competence is classified as a guideline and is not statute law. 'Gillick competence', however, has been generalised in healthcare to refer to any young person who is deemed as having capacity to understand the options, including the risks and benefits of a particular treatment. This terminology is now used within best practice guidance and legal

frameworks (e.g. Department of Health & National Institute for Mental Health in England, 2009b; Mental Capacity Act (MCA), 2005).

Although the Gillick Framework is helpful when working with young people, it does not make clear how or when this can be applied to younger children. Plans to improve access of children and young people to psychological therapies (CYP-IAPT) is planned for full implementation within CAMH services in the UK by 2018-2019 (Her Majesty's Treasury, 2015, p.59). CYP-IAPT is a service transformation of existing children's mental health services into collaborative partnerships within the community that will include all services from the National Health Service (NHS) to 3rd sector agencies and local authorities. Embedded in this transformation is outcome monitoring, access to evidence based therapies and participation. There are 9 participation priorities which embed the involvement of children and young people in all aspects of their care and CAMH service development (DH, 2012). With these developments in mind, it is important for all clinicians to understand the factors that influence decision making by children aged 8-12 years in order to fully empower and legally address their rights, whilst they receive care from CAMH services.

Methodology

A systematic search of five electronic databases was undertaken in order to gain an insight into the factors that are necessary for children aged 8-12 years to make decisions. PsycINFO, EBSCO, Science Direct, Science Full Text and Web of Science All Databases were accessed for the search. The rationale for using these databases was to ensure the search remained within the health and social science field. The search was conducted on the 12 July 2014. The keywords used were 'child* + legal* + decision making', 'child* + legal* + consent*' and 'child* + legal* + capacity'. The parameters were set so the search extracted information from 2004 onwards in line with the NSF (DH, 2004). Although legal frameworks developed before 2004 have relevance, these would still be apparent in the studies identified. The search was restricted to journals published in the English language and the review included only papers which were focused on English and Welsh law, due to the differences in the law in other parts of the UK and other countries. The search excluded literature in other languages.

The primary search results generated 523 pieces of literature; all were assessed by title, abstract and conclusion to determine relevance to the review using a data extraction form (Jones, 2007, p.44) (see **Appendix 1**, p.209). Literature was excluded if it did not discuss children aged 8-12 years or it was outside of the health and social care field. This excluded almost all of the studies identified in the initial electronic search and left 12 articles and one piece of government guidance. The full text of each of these was read and all were included in the review. The exclusion of the 510 pieces of literature through this process suggests a lack of published research focused specifically on this age group.

The data extraction form (Jones, 2007, p.44) was used to elicit data from the 13 pieces of literature. Keywords, definitions, conceptual frameworks and findings from the data extraction form were depicted in diagrammatic form, in order to define categories. The categories were then drawn together under themes. This method is somewhat similar in structure to the constant comparative method as defined by Glaser & Strauss (1967).

Results

The articles identified were deemed to have content relevant information to 8-12 year olds or discussions that focused on children aged under 13 and aspects of decision making. Through the process of extracting the information from the literature, 6 main themes were identified through the use of the extraction tool. These were: 1) consent, capacity and competence, 2) best interests, 3) communication, 4) risks and conflicts, 5) legal frameworks, and, 6) parental role. A summary of the content of these studies can be found in **Table 1** (p.198). The following discussion will consider each of the 6 main themes in turn.

Table 1. Summary of studies, themes and conclusions.

Reference	Age related discussion	Themes elicited	Conclusions
Alderson (2007)	12 years and under considered in several different areas	Consent to healthcare treatment and research, decision making, legal influences, competence, assessment, risk, capacity, ethical influences, parental role, research with minors, communication, cognitive development, social and emotional influences	Basic principles for consent to healthcare and research need to be more clearly agreed. Assessment and communication around competency with children needs to be improved
Al-Samsam (2008)	Under 16s in general	Consent in physical healthcare, capacity, legal influences, ethical influences, parental role, conflict	Both statute and case law provide a framework for healthcare workers; doctors are receding in enjoying treating children due to the presence of unresolved conflicts between parties decision making
Birchley (2010)	School age children in relation to genetic disorders	Parental role, best interests, conflict, legal influences, decision making, consent	We need a best interest standard that proportions value to each individual viewpoint; it needs to be more transparent and transformed into an accountable measure
Bowers & Dubicka (2009)	12 years (inpatient)	Capacity, cognitive development, parental role, legal influences, consent, risks, communication, best interests, ethical influences	We need a single comprehensive guide to the legal framework for the protection of rights of children. Clinicians must increase their knowledge of this area
Boylan & Braye (2006)	Research of children's participation on 8 years and over	Participation and decision making for looked after children in statutory reviews, competency, legal influences, role of advocacy, confidentiality, best interests, professional practices and attitudes	A need to broaden the legal and policy framework scope to include peer, self and citizen advocacy models
Didcock (2007)	Research including 8 & 9 year olds. Under 13 (contraception) 12 years (inpatient)	Consent, competency, decision making, best interests, conflict, cognitive and social development, family influences, legal influences, parental responsibility, confidentiality	Doctors need to keep up to date and seek guidance from experts and clearly document decision making
Donnelly (2010)	6 year old children. Under 16 generally	Participation by children in public law proceedings, decision making communication, legal influences, competence, capacity	There is a need for professionals to develop various engagement strategies to help children to participate. A comprehensive legal framework is needed
Larcher & Hutchinson (2009)	Case studies referring to 5 & 10 year olds. Research relating to 9 years	Consent, decision making, competence, cognitive development, theoretical basis for development of competence, assessment, legal and ethical influences, communication, risks, exploration of systemic influences	There is no single test for competence, need to be clear about what competence is and is not

National institute for Mental Health in England (2009b)	Case study 12 years old. Under 16 generally	Considers admission to hospital or treatment of children, decision making, consent, capacity, competence, cognitive development, parental role, confidentiality	Consider views of patient; is there a way of doing things differently (rather than admission to hospital or something less restrictive)?
Parekh (2006)	5 years; under 12 years	Consent, competency, decision making, cognitive development, legal influences, best interests, parental role, ethical, moral and social influences	Calls for a holistic approach to assessing competence. Consideration to include sociologists, clergymen and a multi-disciplinary team. Current state of the law needs to change
Tan & Fegert (2004)	9 years old and competence	Capacity, competence, decision making, cognitive development, legal influences, capacity, parental role, best interests, family influences, communication, emotional and social influences	We should consider children's competence differently in mental health rather than using an adult adapted model. Children find making decisions difficult due to the failings of their families
Tan, Passerini & Stewart (2007)	Case studies of a 7 & 9 year old; 9 year old capacity in research studies	Consent, confidentiality, decision making, legal and ethical influences, best interests, conflict, competence, capacity, parental role, cognitive development, communication, considers an algorithm, family influences	Ethical, legal, developmental influences and the evidence base, clinical context and evidence base all need to be taken into consideration when discussing formulating an idiosyncratic treatment plan
Wellesley & Jenkins (2009)	Under 16 in general	Consent in research and organ donation, decision making; assessment, competency and capacity, legal influences; parental responsibility, best interests, conflict	Defines the law in these areas. Does not offer any advice for academic or clinical practice

Discussion and findings

For all human beings, it is a fundamental right for each of us to determine what happens to our own bodies (Didcock, 2007) and therefore consent to have any form of treatment is a generally accepted principle. Consent, competence and capacity are examined together as these three facets are reliant on each other in order for an informed decision to be made (DH & National Institute for Mental Health in England (NIMHE), 2009b; Wellesley & Jenkins, 2009). Whilst consent and capacity are static in definition, although capacity is fixed for a particular decision at a particular time, competency is posited to be more fluid (Tan *et al.*, 2007).

Consent

Informed consent requires three main components: information on benefits and risks of all treatment options, the absence of coercion; and for capacity to be present (Tan *et al.*, 2007; Wellesley & Jenkins, 2009). The two latter components depend on the skills, communication and competence of the person facilitating the discussion (Alderson, 2007; Boyden, 2005; Boylan & Braye, 2006; Donnelly, 2010; Tan & Fegert, 2004; Tan *et al.*, 2007). Donnelly (2010); Larcher & Hutchinson (2009) and Tan & Fegert (2004) each state that specific skills are necessary to support children when having discussions that involve the child in making a decision. Since the literature and guidance about children making decisions is unclear (Alderson, 2007), clinicians can 'default' to parental consent (Bowers & Dubicka, 2009). Tan *et*

al. (2007) additionally suggest that the emphasis on autonomy and consent for legal minors can lead to anxiety amongst professionals when frameworks and guidance are absent. Clinicians need to be aware of their own assumptions and understand their competencies in relation to gaining consent and how these are socially constructed (Alderson, 2007; James & Prout, 1997) in order to avoid the possibility of demoralising children participating in decisions that affect them (Donnelly, 2010).

A contentious area of consent for children under the age of 16 is that they can consent to treatment but cannot refuse treatment (Parekh, 2006); this has been debated and has caused considerable confusion amongst practitioners. For example, Al-Samsam (2008) has argued that if children can only agree to treatment and not refuse it they do not really have full consent. Tan *et al.* (2007) also raised concerns that clinicians may use consent to protect themselves rather than purposefully using consent to improve clinical practice and enhance the therapeutic relationship and alliance.

Competence

Wellesley & Jenkins (2009) state that competence is a defined set of abilities needed for a specific task and Tan *et al.* (2007) propose that competence is developed and defined through shared usage within a healthcare setting; however, the level of the shared usage would be dependent on each individual's service and how much the service in question valued and considered the child's participation. If a service defaults to parental consent without consideration of the child, then the shared usage may be very underdeveloped.

The law does not specify any age for which a child can be considered competent (Parekh, 2006). Parekh (2006) recommended that there should be a wide range of professionals involved in assessing competence including clergymen, psychologists and sociologists, and that medical staff should have competence assessment specifically included within their training. However, it seems unlikely that organisations would be able to facilitate an assessment of competence inclusive of all of the suggested professionals on a regular and recurrent basis. The impact of such an assessment on the child would also need to be considered. Being assessed by different professionals could hinder the decision making process for the child. The child might feel intimidated by so many assessments and ongoing questioning. The process could cause significant delay in decision making and a delay in treatment in some contexts which could be expected to have a negative impact on the child.

Competence will also rely on some extent in the child being assured in their own ability and understanding (Donnelly, 2010). Maturity and appropriate levels of cognitive development will be necessary for children to understand the risks, benefits, options and ethical and moral aspects of their decisions (Parekh, 2006). Such understanding is structured through many aspects of a young person's life. These include age, cognitive and social development, emotional factors, health status and family relationships (Didcock, 2007). Alderson (2007) and Larcher & Hutchinson (2009) suggested that the framing of competency has moved towards considering an individual's experience, learning and understanding and away from exclusively being defined according to age. Tan & Fegert (2004) explained that children who are raised in a warm and trusting environment are more likely to be able to make a decision from an early age. By contrast Tan *et al.* (2007) found that if there are attachment difficulties for the child or difficulties within the home then this will directly impact on the child's ability to form independent views and make autonomous decisions. Acknowledging the relationship between family difficulties and child mental health (Green *et al.*, 2005), further consideration is needed on the impact of mental health on declining cognitive abilities (Billick *et al.*, 1998; DH & NIMHE, 2009b) and subsequent decision making.

Several discussions have taken place about the level of cognitive ability of the child and the impact that this has on decision making (Alderson, 2007; Didcock, 2007; Donnelly, 2010; Larcher & Hutchinson, 2009; Parekh, 2006; Tan & Fegert, 2004 and Tan *et al.*, 2007). In 1956

Piaget & Inhelder undertook an experiment to ascertain whether children could consider reasoning from another person's perspective. When considering a platform that projected three mountains with different colours and markings, the child was asked to consider relational viewpoints. Piaget & Inhelder found that only children aged 7 years or over could do this (Piaget & Inhelder, 1956/1971). Donaldson (1978) refuted this finding when she conducted an experiment and suggested that children as young as 3 could complete harder geometric puzzles. Weithorne & Campbell (1982) experimented with giving hypothetical questions to different age groups and found that 9 year olds answered similarly to 14 year olds; however, Brazier (1992) suggested that only children aged 13 years or over possessed capacity. Such disagreements simply strengthen the need for competency to be assessed on an individual basis.

Capacity

Mental capacity is where an assessment is made to determine whether someone with a mental illness has the ability to make specific decisions (Letts, 2010; Tan *et al.*, 2007) and refers to the legal power given to a person by law (Wellesley & Jenkins, 2009). The MCA (2005) only includes guidance for young people aged 16 years and above. The concept of mental capacity can be considered for younger children. Children under the age of 16 are presumed to lack capacity until proven otherwise (Alderson, 2007; Larcher & Hutchinson, 2009; Wellesley & Jenkins, 2009). This was considered by Alderson (2007) as a double disadvantage because children would always be starting from a negative position. Alderson & Montgomery (1996) suggested that by the age of 5 years, children have a good solid understanding of the world and its concepts and children at this age should be presumed to have capacity. Tan & Fegert (2004) suggested that the notion of capacity, based predominantly on intellectual acumen, is open to challenge, and that capacity should not be determined by any judicial fixed age limit (Al-Samsam, 2008).

Best interests

If a child is assessed as unable to make an informed decision, parents and professionals make the decision, which is limited to the child's best interests. The statutory and professional guidance examines best interests to support professionals in this process (Children Act, 1989; MHA, 1983; DH, 2001a; General Medical Council (GMC), 2013; Nursing and Midwifery Council (NMC), 2013). Birchley (2010) suggested that best interests should be an amalgamation of the views of law professionals, doctors, parents and children themselves. Boylan & Braye (2006) further advocated that best interests should be seen as a process of promoting the child's voice and providing a co-extensive culture in which this voice can be heard. By contrast Birchley (2010) argued that defining best interests is almost impossible and is open to subjective interpretation, it is therefore unreliable and could be solely defined on the basis of one medical opinion. Birchley (*op cit.*) also recognised that it is a demanding standard: it is not in a child's best interests to eat fatty foods or be around smokers and yet children regularly are. Bowers & Dubicka (2009) acknowledged that all parents may not act in the child's best interests and parents' understanding of the child's best interests may vary.

Professionals also need to be mindful that parents may not always have capacity (Al-Samsam, 2008; MCA, 2005). If this is the case then these decisions would fall out of the Zone of Parental Control (ZPC) and professionals would need to make the decision on behalf of the child (DH, 2008, paragraphs 36.9-36.15).

Communication

The quality of the information elicited from a child is highly dependent on professional practice, attitudes and communication skills (Boylan & Braye, 2006) alongside the level of cognitive development of the child (Taylor, Tapp & Henaghan, 2007). Clinicians need to be skilled in delivering the correct information in the most appropriate way to the child and understand the

child in a medical and social context (Larcher & Hutchinson, 2009); and this should not be undertaken by unskilled staff (Wellesley & Jenkins, 2009). Children should be given information that is complementary to their learning and understanding; which could include toys, videos, leaflets, worksheets, both verbal and written communication, over a period of time and hold discussions with one or more clinicians (Alderson, 2007; Al-Samsam, 2008; Bowers & Dubicka, 2009; DH, 2001a; GMC, 2013; Taylor *et al.*, 2007). The child should understand general and specific information about their disorder and treatment options (Tan & Fegert, 2004). Larcher & Hutchinson (2009) state that clinicians should improve the child's skills for competence and consider increasing the child's level of experience, which is a contributory factor in competence and capacity (Tan & Fegert, 2004), however, there is a lack of guidance about how this should be implemented. Furthermore, Rushford (1999) suggests that this is an ethical responsibility.

Risks and conflicts

The law does not recognise that giving too much information may be more harmful than useful (Wellesley & Jenkins, 2009). However, the provision of information alone is inadequate. Other considerations are that decisions which carry significant weight may be burdensome and can result in 'significant harm' to children (Alderson & Montgomery, 1996). Cantwell & Scott (1995) suggested that 'children are harmed' by the burden of saying what they want within an environment where family members might be present, thus making competence an area of debate (Alderson & Montgomery, 1996; Billick *et al.*, 1998). A child should only make a decision if the weight of that decision will not burden the child (Alderson & Montgomery, 1996). The decisions made in CAMHS for this age group will not, arguably, be of a life threatening severity and therefore will carry less weight.

The literature has shown that children who do participate more in their decisions and care have significantly more motivation throughout their treatment; this may not always be a fully informed decision by the child but a child who has had their views heard and treated as important (Tan *et al.*, 2007). There is a clear message from children of the importance that their rights regarding decision making are supported within a therapeutic relationship (Boylan & Braye, 2006).

Consideration needs to be given to whether parents have capacity to make decisions too. Safeguarding of the child is always of paramount importance - a child may be put at risk by making an informed decision if the parents do not agree with the decision. This could increase the risk to the child at home through parental retribution.

The legal framework

The legal framework (Children Act, 1989; Gillick v Norfolk & Wisbech Health Authority, 1985; HRA, 1998; MHA, 1983; UNCRC, 1989) and government guidance (CAMHS review, 2008; DH, 2003; DH, 2004; DH & NIMHE, 2009b; Robbins, 1999) that directly impact on decision making in 8-12 year olds, has been previously explored in this review. The legal framework can be contradictory at times, for example, children can be prescribed contraceptives, whilst it is illegal for a child under the age of 16 to have sexual intercourse (Didcock, 2007; Parekh, 2006). Other contradictions arise from guidance and case reviews. For example, whilst there is increased pressure to ensure patient autonomy, choice and confidentiality (DH, 2001a, 2001b), there has been an emphasis in ensuring information is shared between all parties to ensure that children remain safe. In the *Bichard Inquiry Report*, Lord Laming felt that the lack of communication and sharing of information led to the failure to protect children, which left professionals working in this area feeling confused about when information should be shared (Bichard Inquiry Report, 2004). Such conflicts highlight the difficulties that clinicians struggle with in practice. Likewise these contradictory notions can be consistent with the themes of risk and conflict within clinical practice. One of the major challenges in this area is to provide a consistent and united approach (Donnelly, 2010) throughout children's services.

Parental role

Parents do have to be involved (Tan *et al.*, 2007) and have continued responsibility for their children in concordance with the Children Act (1989). Boylan & Braye (2006) suggested that children's participation can be hindered by clinicians having a more dominant commitment to parental consent. In this regard Paul, Foreman & Kent (2000) found that a high proportion of children and young people attending outpatients appointments had not consented to attend. Clinicians play an important role in balancing the views of children and parents.

Conclusion

This paper has considered factors that were identified through the use of a data extraction form (Jones, 2007, p.44) from selected literature of a systematic review. These are 'consent, competence and capacity', best interests, communication, risks and conflicts, legal frameworks and parental role, each of which influence decision making by 8-12 year olds.

The limitations for this review are that information may be relevant for this age group outside of the health and social care field. Further results may be generated by widening the lower age range in the inclusion criteria. Finally, consideration needs to be given in identifying government and public health policy through literature searching; as it is likely that some documentation has not been captured through the defined search process.

The review has evidenced that it is legally possible for children to make decisions should they have capacity to do so; however, the differences between adult capacity and children's capacity is significant with children's rights remaining limited. Children are always presumed to lack competence and children are not allowed to refuse treatment, only accept it.

One of CAMHS' underpinning philosophies is the family orientated approach (CAMHS Review, 2008) which can mean that information is shared with the family during the course of the child's assessment and treatment process. Only offering the option of a discussion in a family setting of the child's mental health can potentially disempower the child and can decrease the opportunity for them to make their own decision without the expectations of others in the process (Tan *et al.*, 2007). Plans and guidance need to be in place in order to support clinicians and children as to how these situations can be best managed and all views can be heard.

Through the review of the literature there are areas that need clarity around the involvement of children in their own healthcare. Consideration needs to be given when involvement should take place; in line with legal obligations, in that clinicians have a duty to ensure that the involvement of children in their own healthcare should be facilitated in all situations. The level of involvement may vary dependent on whether the child should be supported to make a fully informed decision, therefore giving informed consent, or whether they should be part of the decision making process in a different way – perhaps ensuring their voice is carefully heard and fully taken into account. The review determines that decision making will be dependent on factors, including competency, cognitive ability, severity of mental health difficulty, environmental factors, such as the home situation and whether the child will be put at risk through making a specific decision. It was identified that the terms and conditions that need to exist for involvement to be appropriate and effective will include all of those factors identified above. It will also include factors around the clinician's skills and abilities to have the discussion using the variety of media with the child, a developed therapeutic relationship and an organisational philosophy that supports and values child empowerment and participation.

Though clinicians need to identify how we improve skills for clinical competence, the review was unclear about how they should do this. It was, though, evident within the literature that experience of a situation is important for understanding, so including children in decision making will improve their competency and confidence.

Implications for both academic and clinical practice

A framework needs to be developed as to how the child can lead in their treatment choices; with attention given to the families' involvement and rights. The family orientated approach in CAMHS needs to consider how services can best deliver holistic and family orientated care whilst empowering the child to have autonomy to make decisions and cautiously assessing any possible risks to the child making decisions within the family setting.

A key component of facilitating the child's involvement is understanding what the training requirements are that are needed to develop the skills of clinicians in this area. Communication, skills and training of professionals have been highlighted as important factors when giving information to children; however, there were no suggestions as to what this training might involve or how someone might be trained. There is a need to help clarify the legal position for clinicians and the child, as the absence of legal and competency frameworks leaves this area of practice open to interpretation and subjectivism. This is further compounded by the absence of NICE (National Institute of Health and Care Excellence) guidance in this area. The development of guidance and a legal framework would support clinicians and children in this area. It is important that CAMH services have a well developed understanding of their legal position when working with children aged 8-12 and imperative to ensure children's decision making is empowered and is at the heart of organisational philosophy and policy. The factors considered in this paper are clearly discussed in the identified literature, however, there is a significant absence of the necessary conditions needed for decision making from the child's perspective and the child's voice has yet to be heard; this needs to be addressed in further research.

Acknowledgements

The authors do not declare any personal or financial conflicts of interests.

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Appendix 1: Data extraction form

Article no:		Review date:		
Title:				
Author(s):		Publication date:		
Publisher:		Place of publication:		
Journal:		Volume:	Number:	Page no:
Keywords/ definitions:				
Conceptual framework:				
Findings/ argument:				
Author conclusions:				
Own notes:				
Rating: quality of research		Rating: relevance to study		
A	High quality	1	Extremely relevant	
B	Medium quality	2	Quite relevant	
C	Low quality	3	Marginal relevance	

Taken from: Jones, 2007, p.44

The Care Act 2014, personalisation and the new eligibility regulations: implications for homeless people

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Abstract

As government funding for housing related support (formerly Supporting People) services continues to shrink, it is timely to revisit the question as to whether 'homeless people' are eligible for publically funded care and support, including personal budgets, organised through the local authority. The Care Act 2014 which was implemented in England on April 1st 2015 may serve to provide greater entitlement to this source of funds which has rarely been used in support of 'homeless people'. However, there are questions as to how far these changes will be embraced and actively implemented on the ground. On the one hand, social workers may be reluctant to extend their reach because there is already a shortage of resources to meet the needs of existing service users. On the other hand, there is uncertainty inside homeless organisations as to the benefits of personal budgets which may lead to a reluctance to refer 'homeless people' for assessment under the Care Act 2014. We outline suggestions as to how these mutually reinforcing barriers might be overcome to ensure adult social care becomes more inclusive.

Keywords: homelessness, severe and multiple disadvantage, social inclusion, housing related support, eligibility, personal budgets

Introduction

The Care Act 2014 is the most significant reform of publicly funded care and support in England in 60 years. It fundamentally reframes local authorities' statutory duties from one of providing or commissioning services for specific user groups to promoting wellbeing. It places personalisation on a statutory footing for the first time providing those who are eligible with a legal entitlement to a personal budget. It rescinds former legislation, including the NHS and Community Act 1990, with the aim of creating a single consistent route to establishing entitlement to publically funded care and support:

To make the law fair and consistent, we want to remove many anomalies, which treat particular groups of people differently. We do not want people to be dealt with differently based on the type of service they need or where they receive it.

(Department of Health, 2013, p.1)

This paper explores the implications of the Care Act 2014 for 'homeless people', a group that was defined as 'ineligible' for publically funded care and support under the previous community care legislation. In the first section of the paper, we describe how the *Supporting People Programme* evolved to fill this gap, providing what was termed 'housing related support' to meet the needs of homeless people and other excluded groups. We then describe how the austerity measures have eroded this support, and the evidence for a retrenchment of the welfare state. In the second part of the paper, we explore the changes that have been introduced as a result of the Care Act 2014 and in what circumstances they might be used to access personalised support for 'homeless people' (including housing related support). We draw attention to the epidemiological evidence that necessitates a reconceptualisation of homelessness as a 'health risk' that extends beyond the low level preventative agenda making the case that many

'homeless people' will now fulfil the new eligibility criteria for publically funded care and support. In the second half of the paper, we turn our attention to the barriers which may hinder awareness raising and the implementation of these changes thereby limiting opportunities to enhance choice and control for some of the most severely and multiply disadvantaged people in England.

This paper was originally prepared as a briefing document on the Care Act 2014 for homelessness organisations. It was presented and discussed at a series of regional events in London, Manchester and Birmingham in 2015. The events were organised by Homeless Link (the national umbrella organisation for homelessness organisations). This updated version of the paper draws on the original review of the Care Act 2014 and associated literature, and incorporates some of the discussion arising from these regional events.

Assimilating the Supporting People Programme within adult social care

In England, support services for people who are homeless have been developed largely in isolation from local authority adult social care services and social work provision. The *Supporting People Programme* (Department of Social Security, 1998) provided separate management arrangements and 'ringfenced' or protected funding from 2003 onwards for a range of services designed to act as a bridge between general housing services and local authority social services (formerly personal social services). Whilst social services departments refocused their resources on crises intervention and on meeting high level needs (mostly for personal care), with population ageing being a prime reason, housing providers met the needs of tenants requiring lower levels of support (Foord, 2005). *Supporting People* services were termed 'Housing Related Support' (HRS) and encompassed wide ranging activities linked to helping people to obtain suitable housing, sustain their tenancy, and gain skills and confidence. A key stipulation of the *Supporting People Programme* was that funding should not be used to provide direct 'care' but should focus on prevention and enabling people to maintain their independence.

Because the *Supporting People Programme* was positioned outside community care legislation (NHS and Community Care Act 1990) this enabled many new individuals who were not previously eligible for statutory support to receive some form of assistance (in addition to income related benefits and the universal National Health Service). A defining feature of the *Supporting People Programme* was the proliferation of many innovative schemes and local services designed to meet the needs of homeless people, people with substance misuse issues, ex-offenders, lone teenage parents, asylum seekers, refugees, gypsies and travellers, and other socially excluded or 'unpopular groups' (Foord, 2005, p.6). Although many of these schemes were constructed by local funders or commissioners as providing preventative or lower levels of support, they often addressed multiple needs and complex social issues linked to mental health issues and drug and alcohol dependencies. In the homelessness sector, this complexity became characterised as 'multiple exclusion homelessness' (Fitzpatrick et al., 2011; Cornes et al., 2011).

The end of the *Supporting People Programme* was signalled by the removal of the funding 'ringfence' in April 2009. This was justified on the grounds of enabling local authorities to decide where best to target resources to enable efficiency savings (Chartered Institute of Housing & Local Government Association, 2010). Assessing the risks associated with this devolution, the Department for Communities and Local Government (DCLG, 2008) noted the concerns of local commissioners that the *Supporting People Programme* might be absorbed and then 'dissolved' within wider strategic planning and commissioning structures. In a recent survey of 83 commissioners from different areas across England, 45 reported that their dedicated *Supporting People* commissioning and procurement teams 'have either dispersed or integrated into the adult social care commissioning teams, or have physically moved into closer geographical proximity within the same building' (SITRA, 2014, p.22).

Retrenchment of welfare provision for homeless people

Following the removal of the *Supporting People* 'ringfence', homelessness and other housing related support services have been subject to funding cuts (House of Commons Library, 2012). The most recent estimate based on a forthcoming Joseph Rowntree Foundation study by Hastings *et al.* suggests that the sums committed to the *Supporting People* overall spending budget by local government in England reduced by nearly half (48.8%) in real terms between 2010/11 (original budget) and 2014/15 (cited in Bramley & Fitzpatrick, 2015).

The homelessness sector advocacy group, SITRA, has voiced concerns that housing related support funding in some areas may be engulfed:

[Supporting People] commissioners reported facing round after round of funding cuts to [housing related support] services, resulting in energy and attention being solely directed to sustaining some level of housing related support activity. (SITRA, 2014, p.3)

The impact of these changes on the homelessness sector was investigated by Homeless Link in an annual survey of providers. Homeless Link (2014) reported that although many accommodation projects had experienced a reduction in funding, the number of 'beds' provided had not dramatically reduced. The main changes resulting from funding reductions appeared to be reductions in the range of services offered and the level of support available. About one fifth (19%) of projects with less funding reported reducing 'key working' and a third (33%) reported reductions of 'meaningful' activities. Half (48%) of the projects receiving less funding had reduced the numbers of their frontline staff, while 41% had cut back office or administrative support. These changes suggest that projects are operating with fewer staff to support the same number of service users. This finding mirrored that of an earlier survey in which 40% of respondents reported handling the same number of cases with fewer staff (McCabe, 2012).

One important consequence of this reduced capacity may be the tightening of access criteria for housing related support services. Three quarters (74% compared to 63% in the previous year) of accommodation providers reported 'turning away' people whose needs were perceived as too high for them to manage. This is often referred to as the 'inverse care law' (Keene, 2001), whereby:

Those who need support the most are at greatest risk of not being able to access this.
(Homeless Link, 2014, p.52)

While these findings may suggest that homelessness services have made significant efficiencies, Homeless Link (2014) cautioned that there will be a limit as to how much further this can happen before core services are affected. It concluded that localised funding decisions have left homelessness services vulnerable and argued for a nationally coordinated, long-term homelessness strategy with accompanying investment and secure funding base (Homeless Link, 2014). According to Whiteford this may be justified on the grounds that:

Supporting People has been shown to have produced savings of more than 3.4 billion for the Treasury by intervening early to prevent more severe problems from developing... These significant and substantive gains were guided by the powerful locomotive of record funding levels to local authorities, charitable organisations and social enterprises.
(Whiteford, 2013, p.14)

Future strategic management of homelessness and housing related support services

While the cuts to homelessness and housing related support services are part of the reductions in public expenditure made by the Coalition and Conservative governments, they are taking place in the context of changes in the commissioning and delivery of adult social care. From

2007 onwards, the policy of personalisation has been pursued by successive governments (DH, 2007) especially in England. While its meaning is contested, it has come to be most strongly associated with the devolution of budgets down to the individual or a nominated budget holder (Needham, 2011) or management of a known 'budget' by the local authority or a social care provider. In England, 'personal budgets' are designed to facilitate micro or individualised commissioning and to enable people to have greater choice and control over their care and support. Personal budgets encompass direct payments (cash for care) and a range of managed options, including Individual Service Funds (ISFs) (Miller & Sanderson, 2014) or Managed Personal Budgets. ISFs enable people to nominate a provider of their choice to manage their personal budget on their behalf. Providers can then make a charge for both the support they provide and, subject to the discretion of the individual local authority, for managing the personal budget itself.

To facilitate increases in the purchasing of care and support by individual personal budget holders the bulk purchasing of services by local authorities and the use of block contracts, such as those associated with the former *Supporting People Programme*, are declining. As confirmed in the Care Act Guidance (DH, 2014) social care and support commissioning are to become a force for 'market shaping' ensuring that users and carers will have choice of support and provider and can be assured of quality. In many areas this is being achieved through the development of Framework Agreements, whereby local authorities establish a list of 'preferred providers' and set prices but do not give providers any guarantee of hours or custom, unlike block contracts where these elements were often guaranteed and service user choice limited to these providers (Rabiee, Glendinning & Baxter, 2013).

Significantly, the Care Act guidance (DH, 2014) confirms that adult social care in England is to have a broad 'care **and support**' function (and should not be confined to the provision of personal care services). This encompasses meeting needs relating to 'housing related support'. While a clear boundary is to be maintained between the local authorities' 'care and support function' and their 'housing function' (e.g. to meet accommodation needs under the Housing Act 1996):

There is nothing to stop local authorities in the care and support role from providing more specific services such as housing adaptations. (DH, 2014, p.295, s15.52)

The 'care and support' function is also envisaged as encompassing many of the activities which were once in the domain of the *Supporting People Programme*, for example:

Enabling individuals to recognise their own skills, ambitions and priorities and developing personal and community connections in relation to housing needs. (DH, 2014, p.295, s15.55)

Under the Care Act 2014 it is envisaged that 'housing related support' will be integrated with other forms of care and support as part of a personalised support plan. In Scotland, where 'cash for care' schemes have been implemented as part of the policy of 'Self-Directed Support' (SDS), Rosengard, Ridley & Manthorpe (2013) report that in 2011-2012, while personal care was the main form of support purchased through individualised SDS budgets in Scotland, 11% of packages also included the purchase of housing related support services.

Indeed, one of the benefits of using a personal budget is the potential for greater flexibility and integration of support. One major disadvantage of the *Supporting People Programme* was that, in creating an artificial split between 'care' and 'support', it contributed to systemic problems which were not conducive to seamless services (Foord, 2005; Cornes et al., 2011). For example, older homeless people were often reported as falling through the 'cracks' in provision as their needs straddled both Adult Social Care and *Supporting People*, leading to disputes between agencies as to who was responsible (Crane & Warnes, 2001). Personal budgets have the potential to overcome these problems by removing some of the artificial barriers imposed by

services. For example, where a person employs their own worker (a 'Personal Assistant' [PA]) they can expect integrated care in the sense that a PA can carry out both personal care and other support tasks such as assistance with management of household finances so long as this meets the outcomes agreed with the local authority.

Discussing what these changes are likely to mean for homeless people and other former *Supporting People* service users in England, SITRA observe that:

For those who are eligible [for personal budgets organised through adult social care], care packages can still address many of the different [housing related support] needs of individuals and can be personalised. However, for service users, who do not fit the criteria, there is not any plan [in the five local authority areas they studied] to deliver any direct support services, let alone personalised services. (SITRA, 2014, p.24)

The new eligibility regulations

To summarise so far, policies impinging on care and support for homeless people are at a critical juncture. On the one hand, there is evidence that the end of the *Supporting People Programme* has signalled a retrenchment of the welfare state and the withdrawal of support from 'unpopular groups':

If you are homeless, with a drug and alcohol problem and a criminal past, your chances of finding help are becoming much slimmer. As homeless services continue to experience savage funding cuts they are increasingly being forced to turn away the most vulnerable. (Twinch, 2014, p.1)

On the other hand, the Care Act 2014 opens up new opportunities for increased choice and control through personal budgets, including integration of supports that were previously provided in parallel. However, these benefits will only be accrued for those assessed as eligible for publically funded care and support under the Care Act 2014. We now turn our attention to the question of eligibility and how 'homeless people' are likely to fare under new regulations.

The Care Act 2014 introduced a new set of regulations about eligibility with effect from April 2015 (see SCIE, 2015: <http://www.scie.org.uk/care-act-2014/assessment-and-eligibility/eligibility/outcomes-care-support-needs.asp>). These regulations replaced the previous eligibility criteria and guidance, often referred to as 'FACS' (Fair Access to Care Services) (DH, 2010). The new regulations are designed to be more inclusive in that they remove reference to 'eligible' and 'ineligible groups' so that any adult with any level of need will have a right to an assessment (DH, 2013, 1.9). In the previous legislation (under the 1990 NHS and Community Care Act) people's eligibility for help depended first on them falling within a defined category such as disability, age or mental disorder. Removing reference to particular groups was a specific recommendation of the Law Commission (Law Commission, 2011) on the grounds that this would make it easier to understand when the duty of assessment was triggered. As a result:

It also follows that the ambit of the [Care Act] legislation will be in principle wider than that of the [previous] legislation. This might mean that certain vulnerable adults [e.g. homeless people] who previously have been passed over by social services – on the grounds that they did not come within a certain user group defined in legislation – will in future not be excluded. (Mandelstam, 2013, p.80)

Under the Care Act 2014 determining eligibility now hinges on 'identifying how a person's needs affect their ability to achieve relevant outcomes, and how this impacts on their wellbeing' (DH, 2014, p.96). Indeed, it is difficult to think of a situation in which being homeless would not have a significantly negative impact on a person's wellbeing. However, the regulations are specific and nuanced, and for advocacy purposes, what counts is not the fact of being

'homeless' *per se*. but the associated consequences which might give rise to physical and/or mental impairments. To access publically funded care and support (i.e. a personal budget), the new eligibility regulations put in place three hurdles. [1] The first is that 'the adult's needs must arise from or be related to physical or mental impairment or illness' (DH, 2014, 2(1)a). Helpfully, for many homeless people, the Care Act guidance (DH, 2014) then makes it clear that relevant conditions include 'substance misuse' (2014, p.96) and with regard to mental impairment that, 'a formal diagnosis of the condition should not be required' (2014, p.96). This latter point is especially relevant to people who are homeless and who may be experiencing 'complex trauma' or 'personality disorder' since some may have been excluded from treatment and support on the grounds that they do not have a formal diagnosis (St Mungo's, 2009).

[2] Once a physical or mental impairment has been identified, the second hurdle is to determine if as a result of this, the person is unable to achieve two or more of the outcomes listed in the regulations. There are ten specified outcomes and these lie across a broad spectrum encompassing personal care, inclusion and housing related support. Specified outcomes include 'maintaining a habitable home environment' and 'accessing and engaging in work, training, education and volunteering'. In the guidance, maintaining a habitable home environment encompasses tasks that will be familiar to many homelessness workers including 'support to sustain occupancy of the home and to maintain amenities, such as water, electricity and gas' (DH, 2014, p.98). [3] Finally, the third hurdle involves the local authority making a decision as to whether the adult's needs and their inability to achieve the specified outcomes cause or risk causing a significant impact on their wellbeing. According to the guidance:

The term 'significant' is not defined by the regulations, and must therefore be understood to have its everyday meaning. (DH, 2014, p.99)

Determining the risks posed by homelessness to health and wellbeing

While decisions about eligibility for publically funded care and support are always made on an individual 'case by case' basis via the local authority assessment process, the epidemiological evidence base on the homeless population gives a very strong indication that many 'homeless people' will meet the new national minimum eligibility thresholds outlined above. First, there is considerable evidence of the ways in which experiences of homelessness (e.g. the failure to maintain a habitable home environment and the associated difficulties of maintaining personal hygiene, nutrition and the ability to engage in work, training, etc), impact or risk impacting significantly on wellbeing (see Hewett *et al.*, 2012, for an overview of the epidemiological evidence). In summary, homeless individuals have worse physical and emotional health status than the general population, including those from deprived neighbourhoods. Homelessness is characterised by 'tri-morbidity' (linked to physical, mental ill-health and drug and alcohol problems) and other risk factors including poor nutrition, exposure to communicable diseases, harsh living environments, high rates of victimisation and unintentional injuries. Homeless people in England attend the emergency department five times more often as those people who are not homeless and are admitted to hospital 3.2 times as often. Despite high expenditure on unscheduled care for homeless people, the clinical outcomes are 'generally appalling' (Hewett *et al.*, 2012, p.1). In the language of the old FACS guidance, homeless people frequently have needs which are 'critical' (i.e. life threatening). The average age at death of a homeless person is 40.5 years. Homelessness is an independent risk factor for premature mortality. According to Hewett *et al.* (2015, p.4), this evidence should lead us to 're-examine the inverse care law and rebalance the provision of health [and social care]'.

As an indicative figure on the numbers of homeless people likely to be eligible for publically funded care and support under the new regulations, research on severe and multiple disadvantage in England, which uses data linkage to quantify the number of individuals who have overlapping experiences of homelessness, substance misuse and offending (where mental ill-health and complex trauma are common complicating factors) suggests that the 'average' local authority might expect to receive around 1,470 referrals over the course of a

year (Bramley & Fitzpatrick, 2015).

Barriers to more inclusive practices

Under the Care Act 2014, while local authorities have a statutory duty to carry out an assessment on any adult with any level of need, support remains very firmly a welfare entitlement subject to the 'gift' (or denial) of the local state. Slasberg (2013) has warned that the Care Act 2014 could potentially amount to 'no change at all' if the underpinning resource allocation system remains unchanged wherein only those needs that can be afforded by the local authority will be considered as sufficiently 'significant'.

Such a scenario is highly likely if there is to be a continuation of the underfunding of adult social care relative to need (Glendinning, 2012). Social workers are already under considerable pressure and overworked (Unison, 2014) and there are questions as to how far they will be willing to extend their case loads to reach out to homeless people and other people in formerly excluded groups.

As social workers may have limited experience of working with homeless people, achieving greater inclusion will also depend on training. In particular, local authorities will need to raise awareness among frontline staff about the need to move beyond traditional conceptualisations of homelessness. Under the community care legislation, homeless people were often denied access to assessment because it was *assumed* that their needs would not be high enough to meet the substantial and critical thresholds required (Cornes *et al.*, 2011). Homeless was often considered to be a 'housing issue' or a 'poor lifestyle choice' and something that might be best accommodated elsewhere (i.e. in the preventative/low level agenda managed by the *Supporting People Programme*). Cameron (2015) for example describes how despite the complex nature of their needs, none of the homeless women in their study were in contact with social workers from adult services.

Barriers to more inclusive practices may also emanate from inside the homelessness sector itself, pointing to the need for awareness raising and proactive implementation of the Care Act 2014 by local authorities. First, many housing and homelessness workers have little experience of working with adult social care and often the concept of 'social care' is not well understood. While the FACS guidance was clear that 'social care' should encompass needs relating to social inclusion and participation (DH, 2010, p.61), local authorities have increasingly restricted funding to personal care services (Raibee, Glendinning & Baxter, 2013). This has worked to discourage many homelessness workers from referring their clients who may have a need for support work targeted at inclusion, but not necessarily personal care.

The second factor relates to a question of readiness on the part of homelessness service providers to fully embrace the 'cash for care' agenda and to be in a position to contract directly with individual 'personal budget' holders. We now turn to consider this issue in more detail.

Readiness to contract with individual 'homeless' service users

Given the end of the *Supporting People Programme* and the reduced number of 'block contracts', the continued survival of many homeless and housing related support organisations will depend on their ability to contract directly with individual 'personal budget' holders or their proxies. A recent review of personalisation in the homelessness sector carried out by Homeless Link (2014) suggested that many organisations remain largely ill-prepared in this respect. At the regional events, there was great interest in the potential use of mechanisms such as ISFs, which were not well known about. SITRA (2014) has also found with regard to all client groups that personal budgets are still not commonly used in England to purchase housing related support services.

This lack of preparedness may in part be explained by the fact that the protected funding afforded through the *Supporting People Programme* enabled homelessness organisations to pursue their own approaches to personalisation, which are in some respects at odds with those developed in adult social care. In the homelessness and housing related support sector, personalisation is often assumed to be analogous with 'person centred care'. Therein personal budgets are 'recognised as one of the many ways of delivering personalised services, but not the central one' (SITRA, 2014, p.15). In adult social care, the Care Act 2014 affirms that everyone eligible should be offered a personal budget.

Where personal budgets exist in homelessness services these tend to be financially managed by the service provider. This means that while people who are homeless may be offered a choice of worker, or even a 'menu' of support activities from which to choose, they may not have the same choices as other adults to opt out of services altogether, or to employ their own workers or other means of having their care and support needs met. The personal budgets provided through homeless services are usually limited to either a one-off amount to enable a specific resettlement outcome, or otherwise set at the level of 'pocket money' with the workers often remaining in control of the cash without individuals necessarily knowing the amount that is available to them (Homeless Link, 2014). Discussing an evaluation of a personal budgets pilot for 'rough sleepers' in London, Hough & Rice (2010) stated that unlike the 'personalisation model' in social care, there is no specific resource allocation system and no formal assessment of individual needs. Personal budgets for the resettlement of 'rough sleepers' (currently a Pan London scheme in 2016) have been set at a one-off payment of up to £3,000 (Blackender & Prestige, 2014).

Indeed, while particular attention has been drawn to the slow uptake of personal budgets among people with mental health problems (Royal College of Psychiatrists & Association of Directors of Social Services, 2013; Larsen *et al.*, 2013), there has been very little awareness raising or campaigning about the rights of people who are homeless. In particular, this may reflect the need for staff skills development in the homelessness sector, especially as regards challenging stereotypical views about who can 'manage' personal budgets (Royal College of Psychiatrists & Association of Directors of Social Services, 2013).

However, while the possible unwillingness to put people who are homeless in control of their personal budget could be construed as evidence of paternalism, evaluations of the personalisation pilots in the homelessness sector have consistently argued that 'personalised support is just as, if not more important as the budget' (Blackender & Prestige, 2014, p.23). One advantage of the personalisation 'pilots' in the sector seems to have been that they enabled workers to spend more time with service users and to deliver the continuous, more relational and non-conditional kinds of support that are most acceptable to them, thus:

Personalised approaches seem to be most effective where workers are given time and flexibility to support clients as they require, with no time-bound targets to achieve results with small case loads. (Homeless Link, 2013, p.30)

The argument that it is 'person-centred care' and not 'personal budgets' that people want is increasingly finding expression elsewhere in adult social care where there is a growing critique of the government's highly individualist and consumerist approach. The Association of Directors of Adult Social Services (ADASS, 2012), for example, suggested that what matters most to older people is not so much who provides care and support, but what is available and when, and whether, they feel they have a rapport and a relationship with a particular care worker.

As touched upon above, while homelessness organisations have tended to view adult social care practices as an 'alternative model' of personalisation, often acknowledging the need for greater integration and more shared learning (Homeless Link, 2014; SITRA, 2014), the Care Act 2014 gives eligible people new rights to personal budgets (the adult social care model). This means that:

Everyone whose needs are met by the local authority... must receive a personal budget as part of the care and support plan, or support plan. The personal budget is an important tool that gives the person clear information regarding the money that has been allocated to meet the needs identified in the assessment and recorded in the plan. An indicative amount should be shared with the person, and anybody else involved, at the start of care and support planning, with the final amount of the personal budget confirmed through this process. (DH, 2014, p.188)

This poses a dilemma for homelessness organisations, especially those with an advocacy role. Namely, how to reconcile the need to increase the uptake of (local authority) personal budgets so that homeless people continue to receive some form of support with the belief (that is widely held across the sector) that it is actually well resourced collective services that are the way forward.

Indeed, there is already some evidence that redirecting resources to promote individualised commissioning can impact negatively on the sustainability and quality of collective services (Needham, 2013). There have been, for example, reports of home care services becoming destabilised due to the increased use of zero hour contracts since lack of certainty about business income means that companies are unwilling to offer staff guaranteed hours of work and are only able to pay staff for hours worked (Baxter *et al.*, 2011). Although probably not ideal in any sector, these isolating arrangements may pose particular challenges for the homelessness workforce where there is a recognised need for support staff to have clinical supervision and the wider collegiate infrastructure embedded as part of 'Psychologically Informed Environments' (PIEs) (DCLG *et al.*, 2012). The distressing and emotionally challenging nature of this work means that a lack of support and supervision for frontline staff may foster poor practices and high levels of staff burnout and turnover (Scanlon & Adlam, 2012).

Increased individualisation also threatens the sustainability of some collective services and has already been linked to the closure of day centres and other buildings-based resources which may find it difficult to meet necessary running costs. Touching on a report by the charity Mencap (itself a day centre provider) which claimed that the closure of day centres was leading to many personal budget holders 'being stuck at home', Needham concluded:

Certainly the roll out of personalisation in a context of fiscal austerity... ensures that as local authority services are withdrawn, it can be difficult for people to access or even know what about is replacing them. (Needham, 2014, p.4)

Conclusion

In summary, forging new gateways and pathways of support for adults who have care and support needs entwined with experiences of homelessness, is necessary given the end of the *Supporting People Programme* and the advent of the Care Act 2014. In the current climate of austerity, it may be helpful to view the Care Act 2014 as a potential window of opportunity through which it may be possible to renegotiate how professional social work discretion is applied when it comes to understandings of homelessness, thereby potentially rebalancing the provision of health and social care and addressing the inverse care law. How to manage the 'moral imperative' to practice more equitably with high case loads and already overstretched social work teams will be a key challenge for those with leadership responsibilities.

Homeless organisations and their workers will also have a key role to place in this transformation. They will need to forge more collegiate working relationships with social workers and to become more actively engaged in the implementation phases of the Care Act to ensure that their expertise around working with homeless people is shared. There is a need for example to raise awareness in adult social care about concepts such as 'multiple exclusion

homelessness', which have broadened understandings of homelessness beyond issues of prevention, housing accessibility and poor lifestyle choices.

For frontline workers in homelessness organisations, it will also be important that they receive training and become well-versed and confident in the application of the new eligibility regulations and have the skills and knowledge to undertake advocacy in this area, so as to be able to actively promote personal budgets. There is also a need for closer integration with colleagues in 'homeless health' services to ensure that the impact of homelessness on health and wellbeing is managed beyond the confines of social care and housing related support. Finally, changes will need to be closely monitored as regards the uptake of personal budgets among those adults previously considered unpopular and undeserving.

Disclaimer

The Social Care Workforce Research Unit receives funding from the *Policy Research Programme* of the Department of Health. The views expressed are those of the authors and should not be interpreted as those of the funders. The authors report no conflict of interest. The authors are responsible for the writing and content of this paper.

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Notes on Contributors

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Reviews

Critical and Radical Debates in Social Work, Ferguson, I. & Lavalette, M. (series eds.)

Bristol: Policy Press, 2014

Poverty and Inequality, Jones, C. & Novak, T.

ISBN: 978-1447316152, £8.99 (pbk.), pp.74

Children and Families, Garrett, P.M.

ISBN: 978-1447316190, £8.99 (pbk.), pp.76

These two books are part of the series *Critical and Radical Debates in Social Work*, edited by Iain Ferguson and Michael Lavalette. They are strong and deeply felt books that describe the current overwhelming sense of betrayal felt by so many citizens in this age of austerity and increasing poverty. Both texts claim as inadequate the response of the social work profession. The impact of the global economic crisis, the overwhelming sense of despair and anger for so many because of the 'extraordinary disparities in wealth and income' as compared to the 'conspicuous greed and consumption of the rich as their own living standards and wellbeing decline' is well captured by Jones and Novak.

They are right to compare this position with the challenge that social work faced in the sixties, when poverty was, as it were, 're-discovered'; and there was a sense of enterprise and even radical intervention that motivated many to become social workers. The Kilbrandon and Seebohm Reports laid the foundation of major institutional change in favour of social work in Scotland and England and Wales respectively. Local authorities, such as Strathclyde and Coventry, became great exponents of reaching out to those in need through extraordinary investment in people and resources and seemed to achieve much. Ultimately, over time, they only served to become institutions of the state, reduced through cuts and austerity, and became a part of the problem, according to the authors. However, in the opinion of this reviewer, Community Social Work achieved much in the eighties in terms of developing user-led services in localities, achievements which the authors ignore.

The popular perception and political expectation of the role of social work, as described by the authors, was seen to be to deal with the inadequate behaviour of people in poverty; and this was solely an issue of personality and deficiencies in personal behaviour. Perhaps the authors miss the fact that so many direct services for adults, particularly the vulnerable, have become in demand across all sectors of society, not just those in poverty. The continuing constriction of adult care services and the impact of inadequate community care now affects most families in Europe at some time or other, whatever their socio-economic background.

Part Two is a series of responses where broad comparisons are drawn by contributors between the perceived inadequacy of the response to poverty and inequality in the UK by social workers and social work responses to what is happening elsewhere, for example in Greece, Latin America, and North America. The shift from Welfare Capitalism to the Neo-Liberal agenda, through reductions in expenditure, and the attempt to dismantle the welfare state in the USA and Canada, are well described by Mimi Abramovitz in her paper 'Which side are we on?' The attack on public sector jobs and unions, with implications especially for women and people from ethnic minorities, is also well described.

The principal authors offer a Marxist-Leninist analysis and a view that social work, in the main, has been conspicuous by its cowardice in the face of these changes: but this is nevertheless quite narrowly argued. The example cited of the resistance of Greek power workers, refusing to cut off electricity supplies to the poor, is all well and good; but social work does not quite aspire to, never mind achieve that potential! I wish that Ferguson and Lavalette had given more concrete examples to their other contributors, perhaps updated from their own sources, especially '*International Social Work and the Radical Tradition*', published by Venture Press (2007). Venture Press is a BASW imprint, which is ironic, in view of the criticism made here of

the lack of action by the profession as a whole in the UK. BASW is growing in membership and clearly has a better possibility of campaigning than before. Alongside this, the sense of vulnerability that social workers feel, particularly in work with children and families, is a clear motivation for belonging to a strong protective body.

Social work with children has long been castigated in the public imagination, and seriously challenged in the age of neo-liberalism, which is the basis of Garrett's book. There have been 'significant and transformative changes to the welfare systems and to child protection regimes' in both England and the Republic of Ireland. Garrett's lead essay offers a critique broadly influenced by Antonio Gramsci. The argument is that political society (the state, various institutional organs, the legal system, etc.) adapts its hegemony by appearing to absorb the concern for vulnerable and abused children, whilst civil society (the family, service users, social workers and their representatives, whether trade unions or professional groups) attempts to represent their needs and concerns, but is continuously compromised by the former. The argument is that the latter, effectively, should empower themselves and organise their own services – or at least that is how this reviewer interprets the approach. Garrett goes on to analyse the service changes taking place and their impact on social workers and service users.

The commentaries, as before, offer a view of Garrett's essay from a range of perspectives across Europe and North America. The discourse is fascinating and offers a more direct analysis of what the impact of welfare changes and child protection transformations has been across nation states.

The additional argument, on the influence of key personalities, in both England and Ireland, on the so-called modernisation agenda, is well detailed. Also the review of legislation undertaken in the New Labour era is strongly argued here as an attempt not only to rebrand children's services but to give them a more corporate business appearance. Using terms such as 'Every Child Matters' and 'Quality Protects' did nothing to reassure the social work profession and people left in droves.

The delineation by Garrett of the characteristics of neo-liberalism serves to reinforce the sense of depression and strengthen the description of a profession fighting on all fronts to protect children and save their services in the face of both governmental dictats and public scepticism. This was illustrated by the failure of the Blair and Brown administrations to defend social work faced with the outcry following the deaths of Victoria Climbié and, then, Peter Connelly. The outcry often ignored the fact that child murders had fallen substantially; and England and Wales had one of the lowest rates in the Western world.

The whole 'anti-social behaviour' attitude (neighbours from hell, etc.) was easily absorbed by the subsequent coalition government. Notions of the 'big society', of volunteers helping troublesome families, and the Troubled Families Project, were simply rationalisations to force the dismantling of the state. The 'long march through the institutions', to borrow Rudi Dutschke's phrase, has continued – fast track entry into social work of unemployed Oxbridge graduates, more and more reductions in benefits, lower wages for those who can get into the job market, increased child poverty, a housing crisis, and cuts to social work services. The perspective offered is certainly not out of date!

The analysis of the situation in Ireland is equally apt, giving a historical background which will be new to many readers. The impact of the economic crisis and the reduction in services has been formidable. The relationship of public services to the historic role of the (Catholic) Church means that there have been additional power and public confidence struggles. The impact of the child sexual abuse scandals concerning the Church and other institutions has an obvious resonance in the UK. Perhaps one major distortion in the paper, and in the book overall, is the perception that the child protection agenda is solely about the poor. The examples of the recently publicised child sexual abuse scandals in institutions and by organised groups of adults show that the oppressors are not just the poor. Most social workers have experience of

dealing with abuse within middle class families and the issue of sexual politics in all this is not addressed.

Rona Woodward, in her response, agrees with much of Garrett's description of the 'relentless nature of the neo-liberal advance' and perceives social work to be both 'oppressive and conservative' at the same time. She acknowledges that many families see social work as little more than surveillance and control. This is not a revelation and sometimes one wishes that the papers at least acknowledged the good work that goes on, with much success for the children and families concerned. Woodward cites what has seemingly been achieved by the SNP Government in Scotland; but the cost has been to see heavy cuts in local authority expenditure and a social work profession equally under pressure in tackling child abuse as anywhere else in the UK. Arguably, the SNP has simply pursued a softer form of neo-liberalism under the guise of nationalism.

The remaining responses in Part Two give views from other national experiences, especially in terms of the failure of social work to ally itself with its clients in the face of austerity and the demise of welfare. We are offered a UK and Ireland solution, based on the Social Work Action Network (SWAN) and its radical campaigning. There is a lot to take in, and argue with, which is fascinating and absorbing in fewer than 80 pages.

Social work has always stood in the divide between the body politic and the worst of our feelings. It runs the paradox of defending us from popular instinct, whilst highlighting what must be done to address the issues at hand, both for the individual service user and the community as a whole. It is the true existentialist profession; and it is best when it occupies the territory of its own contradictions through its values and understanding. It can truly live the Gramscian concept of the pessimism of the intellect and the optimism of the will. Both the above books stimulate a debate for social workers on how to position themselves in the contemporary world; but perhaps they miss the point that social work is not only about the structural impact of the socio-economic landscape but also about its interaction with the human personality.

Serge Paul – Consultant and past Chair of BASW

Social Work with Troubled Families: A Critical Introduction, Davies, K. (ed.)

London: Jessica Kingsley Publishers, 2015

ISBN: 978-1849055499, £22.99 (pbk.), pp. 192

Keith Davies, at Kingston University, has marshalled a range of practice, policy and research insights into England's Troubled Families Programme (TFP), which particularly focuses on a social work approach to intensive 'whole family' work. We learn early on that the original target population of 120,000 troubled families (a contestable figure and indeed concept, as we learn later), is to be expanded to 400,000 families after a favourable National Audit Office report about the programme's impact. Given this commitment, the book is timely in examining some core elements of TFP such as the role of the dedicated worker, the ethics of a challenging intervention and the virtues of a whole family approach.

The introduction by Davies locates the essence of TFP around hands-on outreach work that draws on motivational and problem solving theory and in which the worker is supported by a network of professionals and projects. We glean quickly that the criteria for inclusion within and exclusion from TFP raise questions about equity, whilst at the same time those people selected may risk being simplistically labelled as 'problem families'. Davies and his contributors recognise that quite what or who is 'family' resists straightforward definition. Hence the re-moralising ambitions of TFP, to engender responsible citizenship amongst those deemed anti-social but also marginalised by poverty or poor opportunities, constitutes a complicated if not inchoate agenda. Also the TFP sub-text of 'tough love', of 'turning families around' via a more assertive and controlling engagement, does not sit easily with traditional social work: yet there

are affinities, in relation to the key worker role, intensive enduring engagement, systems thinking and crisis work. And it is social work's relevance to TFP that features throughout the book.

First, in Chapter Two, we get a view from David Holmes, Chief Executive of Family Action – a family support provider delivering TFP for seven local authorities. Holmes is enthusiastic about the expansion of TFP and its payment by results (PBR) approach; but he is clear that PBR, as crafted towards outcomes such as employment, school attendance, and improved behaviour, may unduly restrict the focus of intervention and insufficiently reward work in critical areas such as drug misuse, mental health, and parenting capacity. He urges a more thoughtful and social work oriented outcomes regimen that recognises process too and, not inconveniently, offers his agency's own multi-dimensional tool (Family Star Plus) as a model, using which providers and government can capture a more rounded preventive encounter as well as deal with crises.

Dr Sadie Parr, from Sheffield Hallam University, delves into the emergence of family intervention projects and particularly the nature and role of the key worker. She considers the emotional and cultural world of practice in tackling problems that TFP seeks to remedy, and compares a social work family project (supportive, non-confrontational, befriending), with a housing project engaged with similar issues but where tenancy sanctions and assertiveness are part of the service. The different roles and identities in the projects are explored and make for fascinating reading especially on the varied occupational personae that might bear upon effective engagement (or not) with families.

Chapter Four, by Professor June Thoburn at UEA, provides a compelling and persuasive process evaluation of a Family Recovery Project (FRP) run by Westminster's Children's Social Services Department. The FRP is located unambiguously in a social work model with links to specialist services and positioned alongside child protection and locality teams. What is distinctive here is how family work is shared between an outreach worker and a lead worker for the child(ren), usually from one of the children's teams. Thoburn's mixed method analysis of 100 completed cases and an intensive examination of 33 families generates a rich description of key activities (referrals, visits, types of intervention, meetings, participants, case duration and closure). Two family case studies are offered to illuminate the flexibility and responsiveness of FRP, which utilises psychosocial casework, mediation, and advocacy. The key features likely to help families are documented. As for effectiveness, Professor Thoburn makes it clear that while a majority of families improved on some measure, 12% demonstrated no positive change; and only a third could be said to have had a successful overall outcome. It is clear that the deep and enduring complexities of some family problems resist resolution; nonetheless the chapter argues cogently that schemes such as this FRP can make a real contribution to TFP and should be integrated to provide the additional benefits of a distinct social work orientation.

Carol Hayden and Craig Jenkins, at the Institute of Criminology at Southampton, return the reader directly to TFP and a large sample of 196 children living in a city of 200,000, and deemed troubled or troublesome and who entered care or custody. Most (81%) were in care. The key features of the cohort and their parents are analysed in respect of demographics, home locality, social need, and service involvement. The multiple adversities that sit beneath the stigmatising terminology of being troubled or troublesome are excavated; and the disobliging facts of poverty, entrenched inequalities, mental health difficulties, service deficiencies, and environmental decline, are seen to amplify or complicate the problems that families have and raise awkward questions for those less sociologically aware adherents of TFP.

The penultimate chapter, by Ray Jones, Anna Matczak, Keith Davies and Ian Byford from Kingston University and St George's, University of London, outlines key findings from a qualitative study of a Family Recovery Project – with location and participants anonymised. Their small scale study is based on audio interviews with 20 referred families (mainly mothers) and 20+ practitioners from various relevant occupations. This very welcome view from service

users is presented in rich detail. In talking about their difficulties, the prominence of the mothers' mental health (often single parents) was notable, as was the behaviour of a child. Children often failed to attend school because of concerns for their mother; poverty, debt and housing also featured. The clustering of acute and chronic problems that simply wore down families was evident; and what they liked about the service was the emotional and practical support and the structure and friendship it provided. The intensity of the service was also viewed positively: but as professionals noted, their 'Team around the Family' approach, while popular with families and other service providers, was a specialist and separate scheme; and unless it became part of the mainstream was unlikely to reach the multiple families where upset, depression and disadvantage takes its inevitable toll. The chapter relies on the data alone to convey the story; and while many insights are offered, the absence of any clear conceptual or theoretical development of the model seems to be a missed opportunity.

The final chapter, by Nigel Hall at Kingston University, offers a valuable summary of a global view on family support schemes. A reflective treatment of concepts and evidence across cultures provides us with a range of family strengthening models and objectives. Differences and commonalities make for interesting reading; but at root there are some obvious shared features in relation to common difficulties: economic disparities; loss of extended family and neighbourhood support; intra-family and community violence; working with men in families. The list can be extended, but at root is the family and thus family based practice as the basic building block of change. The chapter considers learning issues for social work practice and the need to embed more deeply family and community strengthening in professional training. Overall, the book succeeds in delivering what it says on the cover: it is an introduction to the matter of TFP and social work and it is not uncritical of their uneasy relationship. It is revealing and accessible, deserves reading closely, and clearly intends to be the start of a research-informed discussion and definitely not the last word.

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Vulnerability and Young People: Care and Social Control in Policy and Practice, Brown, K.
Bristol: Policy Press, 2015

ISBN: 978-1447318170, £70.00 (hbk.), pp.252

Kate Brown has crafted a stimulating and accessible multi-disciplinary and research-informed exploration of 'vulnerability' that draws on the life experiences of a small sample of young people. The concept is exposed in Chapter One to some testing examination to reveal its multiple meanings and relevance to human services, particularly those for young people. While for most of us the term denotes at a common-sense level some impulse of care and empathy for those not well placed to handle adversity, there is a veritable mosaic of alternative meanings that signify a more contested set of understandings – practical, moral and political. Drawing on sociology and social policy the author introduces some of the possible identities and ontologies of 'being vulnerable' in the contemporary UK, (England mainly). The chapter also introduces her case study of 25 young people living in a large northern city, deemed vulnerable (*viz.* – as young carers, or as involved with drug misuse, sexual exploitation, or anti-social behaviour, or with significant school problems, or being homeless/refugees/runaways) and receiving various services. Drawing on techniques of immersive ethnography, the author engages the young people in interviews, life mapping and vignettes about the way they see their lives as vulnerable (or not); interviews and vignettes are also used to engage key professionals about how they too understand vulnerability.

Chapters Two and Three take us efficiently across major conceptual and policy domains to demonstrate how vulnerability is used differentially as the rationale for intervention. A 'politics of vulnerability' is drawn out in relation to bio-ethics, feminism, behaviourism, and economic liberalism. These large discursive fields are examined and re-ordered to show how vulnerability can be linked to more negative states of disempowerment, difference, weakness, being deserving (or not), and ultimately to wider notions of governmentality and social control. The

connections between 'vulnerability', 'need' and 'risk' are critically treated in Chapter Two where there is a helpful table of key definitional sources of vulnerability. Chapter Three links, with a policy review that delineates the rise of vulnerability in many statutes promulgated by New Labour and the coalition government, in regard to, for example, housing, mental health, offenders, older people, disability, victims of crime, and children and young people. A tour across these statutes reveals subtle differences between groups and their identities that generate varied notions of vulnerability. In some cases these may convey clear sympathy and just desert; in others conditionality and expectations about behavioural change, justifying stronger controls. Accordingly, the author argues that vulnerability has consequences for the relationship between the citizen and the state, particularly in conditions of economic liberalism and public service retrenchment – in that vulnerability tends to individualise and group people and to prioritise their particular circumstances, and in doing so may obfuscate rather than challenge the questionable general adequacy of resources.

Chapter Four takes us into the world view of professionals (frontline and commissioners) and we quickly comprehend the 'real world' as more messy than policy and theory and the depictions these give about who or what stands as 'vulnerable'. Kate Brown uses interview excerpts to show how vulnerability and risk often intertwine and how behavioural and psycho-emotional aspects are often invoked to account for interventions; but that professional discretion and gendered common-sense constructions also demarcate those who can be included as vulnerable and those to be excluded. For example, sexual exploitation of young women is likely to be designated a matter of vulnerability, whereas troublesome offending young males are more likely to be excluded.

Chapters Five, Six, and Seven provide intimate and harrowing accounts of family breakdown, and abuse, and their consequences, from the perspectives of the 25 young people. Their dislocated lives, often spiralling into further abusive contexts and crime, contrasted markedly with the aspirations of many of them, one day, to go to college and get a good job. The normative and positive nature of their imagined futures whilst leading such vulnerable lives is explored in Chapters Six and Seven. Here the young participants are reported to discuss ideas about being vulnerable; and most grasped its meaning in relation to some personal weakness or deficit. In so doing they discussed vignettes about others' vulnerable lives in sometimes judgemental and moralising tones, suggesting people should take responsibility for poor choices and the consequences that flowed from them. In short, they tended to think being vulnerable was something that could be stigmatising and happened to others, not them. Their resistance to being defined as vulnerable indicates something of a battle over identity between young people and professionals; evidently the 'top down' labelling that is (official) vulnerability had no clear legitimacy for these young people. In Chapter Seven a wide range of official interventions are identified as being experienced by the young people as well as their views being given on what aspects worked best for them, or not. The lessons to be learned here for professionals are outlined regarding relationships, the timespan and timeliness of interventions, and the suitability of action taken.

Chapter Eight concludes a rewarding journey through policy, theory, practice and young people's perceptions. This final chapter is more geared to critical policy discourse than operational practice; which is fair enough, given the disciplinary focus of the book. Thus for the reader as frontline worker, or manager, or commissioner, the many nuggets of practice wisdom throughout the book need to be plucked out from a familiar and sometimes repetitive sociological chant about economic individualism and the divisive instincts of the neo-liberal state as the sources of all our unhappiness – itself an enveloping abstract concept which fails to grasp the complexity of some enduring social ills. With that reservation, this is nonetheless a really illuminating book on the contentious notion of vulnerability, and it should be read, debated and brought to bear on service design and development.

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What are SSRG's objectives?

- to provide a network of mutual support and a forum for the exchange of ideas and information on social and health care services;
- to promote high standards in social and health care services research, information, planning and evaluation;
- encourage collaboration in social, housing and health services activities;
- to develop an informed body of opinion on social and health care services activities;
- to provide a channel of communication for the collective views of the Group to central and local government, other professional bodies and the public;
- to sponsor relevant research and identify neglected areas of research;
- to encourage and, where appropriate, sponsor high quality training in research techniques.

Who belongs?

SSRG is open to anyone who subscribes to the objectives of the Group. Members are drawn from a wide range of professional groups and organisations sharing a common interest in the work of the caring services.

How is it organised?

SSRG is run by an 'Executive Committee' (EC) which comprises elected and selected officers, elected members, co-opted members and representatives from SSRG Scotland, whose principal tasks are to promote the objectives of the group and to co-ordinate its activities.

What does it do?

SSRG publishes a Journal and a Newsletter which are distributed free to all members. It maintains working links with central government departments, the Association of Directors of Adult Social Services (ADASS) and the Association of Directors of Children's Services (ADCS) and other professional bodies and organises an annual workshop on a topical theme in social and health care services research, and occasional day conferences, for which members receive generous discounts on fees. It also co-ordinates the work of Special Interest Groups which provide members with an opportunity to contribute to the formulation of SSRG responses to national policy initiatives and current issues in the social and health care services.

Equal Opportunities Policy Aims

- To ensure that every SSRG member, user, job applicant, employee or any person working with, or in contact with, the organisation receives fair treatment irrespective of their age, colour, disability, gender, ethnic origin, marital status, nationality, race, religion, sexual orientation, responsibility for dependents, political affiliation or membership of a trade union.
- To ensure that the contribution of research, information, planning and evaluation work in social care and health is sensitive to this issue.
- To ensure that SSRG promotes the equalities agenda in all its activities.

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