

volume 31: number 1: 2014/15

# Research, Policy and Planning The Journal of the Social Services Research Group

# **Editorial Team**

Joint Editors: Guy Daly and John Woolham, Coventry University. Reviews Editor: Paul Dolan. Publishing Editor: Shelley Nix.

#### **Editorial Board Members**

Mike Clark, School for Social Care Research
Colin Kelsey, Independent Consultant
Jo Moriarty, King's College London
Andy Pithouse, Cardiff University
Chris Rainey, Public Health Research Unit, West Sussex County Council
Alan Rosenbach, Care Quality Commission
Martin Stevens, King's College London
Tania Townsend, Islington Council

#### **Editorial Policy**

The Journal is devoted to publishing work by researchers and practitioners in local and central government, other statutory authorities and voluntary agencies and academic institutions which bears on the interests and concerns of SSRG members. For editorial purposes, research is taken to include empirical studies, policy analyses, planning reports, literature surveys and review articles. All papers are peer reviewed by external assessors from academic and policy communities.

#### **Notes for Contributors**

Full submission guidelines are available at: www.ssrg.org.uk/publications/rpp/index.asp.

Where possible, manuscripts for consideration should be submitted in electronic form, double spaced with wide margins. Although there is no strict limit on length, articles of more than 5,000 words will not normally be accepted. Papers should be accompanied by an abstract of not more than 200 words and a short biographical note on the author(s). Authors should also refer to the SSRG Equal Opportunities Policy which is reproduced on the inside back cover of this edition. To disseminate information about current or recently completed research, without writing a full paper, contributors can submit brief details (1,000 - 2,500 words) of the aims, methods, findings and availability of the study for inclusion in the Short Report section of the Journal. These should be sent to Shelley Nix at the editorial address.

# Disclaimer

Although attempts may be made by the editors to check the accuracy of information, the rigour of research undertaken and authors' rights to publish material, neither they nor SSRG accept any legal responsibility for statements of opinion or fact presented in articles and reviews.

#### **Publication**

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

#### Reviews

Books etc, for review should be sent to: Paul Dolan, 15 Amherst Avenue, Handsworth Wood, Birmingham, B20 2LH Email: pfdolan@hotmail.com Tel: 0121 554 1220 / 07553 788 456

#### **Back copies**

Copies of most back issues are available from the publisher at the editorial address.

#### Advertising

Full details of advertisement rates are available from the publisher at the editorial address.

#### **Editorial Address**

Shelley Nix College of Health and Social Care University of Derby Britannia Mill Mackworth Road Derby DE22 3BL

Email: s.nix@derby.ac.uk

ISSN: 0264-519X

# **CONTENTS**

Editorial	1
Articles	
Wesam Darawsheh and Gill Chard	3
John McLean  'What counts is what works': NICE's new role and approach in developing evidence-based guidelines for social care	19
Derek King, Linda Pickard, Nicola Brimblecombe and Martin Knapp	29
Numbers of working carers whose employment is 'at risk' in England	
Colin Slasberg, Peter Beresford and Peter Schofield	43
Reviews	55

Welcome to Volume 31 edition 1 of Research, Policy and Planning.

The first paper in edition 1 comes from **Wesam Darawsheh and Gill Chard**. Their paper is based on qualitative research interviews with occupational therapists working in culturally diverse areas of London. It challenges widely held views of social work and allied health professionals that independence is always an appropriate goal for practitioners to aim for when working with service users, arguing instead that interdependence – with family members or the wider local community – may offer a valuable alternative goal in culturally diverse practice, where cultural competence may require practitioners to work within wider family and social networks and to acknowledge the reality of interdependence in the lives of clients. Though drawing on experiences derived from multi-cultural practice, the issues raised resonate with contemporary debates in social work and social policy.

The second paper is from **John McLean**, who considers the new role of the National Institute for Health and Care Excellence (NICE) in social care. NICE has for a number of years played a leading role in promoting evidence based medicine – reviewing and synthesising research on the impact and effectiveness of medical interventions to ensure that clinical practice is based on robust evidence of 'what works' – and that ineffective interventions and practices are discarded. Readers may also know that since 2012, this role has extended to social care. McLean's paper describes the process NICE has adopted in developing evidence based guidelines to inform social care practice. Though drawing attention to shortcomings in the quality and range of research findings available to social care practitioners, the paper is not, as readers might assume, driven exclusively by the epistemologies of the natural sciences used in medicine, but acknowledges the relevance of different kinds of knowledge generated from research in social care.

Paper three, from **Derek King, Linda Pickard, Nicola Brimblecombe and Martin Knapp**, examines evidence relating to the number of carers whose employment may be at risk because of their caring responsibilities. This is an important topic. Unpaid carers provide the vast majority of 'hands on' care in the UK and it is difficult for many carers of working age and in employment to juggle their twin responsibilities as carers and workers. Carers who resign or prematurely retire to care for someone frequently experience poverty and social isolation, and their skills and productivity are lost to the workforce. King *et al.* re-analyse data from the 2011 Census and the ONS Survey of Carers in Households (2009-10) to overturn a widely held view that only those providing care for 20 or more hours a week experienced problems in maintaining full employment. Their evidence suggests the threshold for risks to employment is much lower, and that carers providing as little as 10 or more hours a week may be at risk of loss of employment. Evidence from this paper could be used by Adult Social Care departments to offer more targeted support to carers to enable them to continue working.

The fourth and final paper is from **Colin Slasberg, Peter Beresford and Peter Schofield** and examines the relationship between new legislation (in the form of the 2014 Care Act) and pre-existing policies relating to self-directed support and personal budgets. There remains a far-from-settled consensus as to the value of personal budgets and direct payments (at least within academic and policy communities) and Slasberg *et al.* have been at the forefront of debates, both here in this journal and elsewhere. (See the reviews section in this edition for more about this). Their paper begins with a lively critique of the third national POET survey to argue for an alternative to the current model of self-directed support enshrined in policy, drawing attention to opportunities afforded by the Care Act to achieve this. (This approach is described more fully elsewhere in another paper by the authors published earlier this year in *Disability and Society*.)

Last but far from least, Reviews Editor, Paul Dolan, offers, as usual, a series of entertaining and informative reviews of recently published books on topics ranging from critical debates in social work, ethics, the Munro Report and its aftermath, Baby P, and personalisation.

Finally, we hope you will be interested in the forthcoming second edition of this volume of the journal. This next edition, which we hope to publish very shortly, will be sponsored by the Social Care Evidence in Practice project led by the Personal Social Services Research Unit at the London School of Economics and Political Science, with support from the NIHR School for Social Care Research and funding from LSE's Higher Educational Innovation Fund. The Guest Editor for this edition will be Dr Michael Hill, who is a Visiting Professor of Social Policy at the Personal Social Services Research Unit.

#### John Woolham

Senior Research Fellow
Faculty of Health and Life Sciences
Coventry University

# **Guy Daly**

Executive Dean
Faculty of Health and Life Sciences
Coventry University

# Towards culturally competent professional practice: exploring the concepts of independence and interdependence

Wesam Darawsheh<sup>1</sup> and Gill Chard<sup>2</sup>

<sup>1</sup> University of Jordan, Faculty of Rehabilitation Sciences

\_\_\_\_\_

#### Abstract

Health and social care practitioners increasingly work with clients from diverse cultural backgrounds. While health and social care systems have emphasized the importance of culturally competent practice, professional practice has been influenced by values such as independence, a western notion that places value on the individual. It has been suggested that interdependence, a notion that places value on the family and/or community, can serve as an alternative to independence in culturally diverse practice. Using interviews with thirteen occupational therapists working in culturally diverse social care teams in London, this study aimed to explore whether the concept of interdependence could serve as an outcome and, whether it is more likely to result in actualizing culturally competent practice. The findings of this study add to the discourse in social care concerning the sources of associations made between the concepts of care and dependence, the positive meaning associated with independence and whether independence does support personal empowerment of service users. We suggest that interdependence better reflects the essence of social care delivery as a collaborative and respectful process between clients, care-givers and professional practitioners regardless of background, culture and societal expectations.

**Keywords:** qualitative research, occupational therapy, interdependence, independence

#### Introduction

There is a growing demand for cultural competency as health and social care practitioners increasingly encounter clients from different cultural backgrounds. The significant influence of culture on professional practice has been identified by others (Betancourt *et al.*, 2003; Bourke-Taylor & Hudson, 2005; Hopton & Stoneley, 2006; Capell *et al.*, 2008). Betancourt *et al.* (2003) also highlighted significant social and cultural influences at organisational and structural levels; these are also important as they influence overarching ways of delivering health and social care services. Cultural competency, therefore, should be an integral part of all practice if clients are to receive equal access to health and social care regardless of their cultural background (Betancourt *et al.*, 2003; Capell *et al.*, 2008). Moreover, Suarez-Balcazar *et al.* (2009) state that cultural competency and client-centred practice should be inseparable if practice is to be delivered in a way which is fair for all.

Cultural competence refers to a process by which health and social care practitioners respond to people from different cultures, who may speak different languages, come from different social classes, religions or ethnic backgrounds in a respectful way that affirms and values the individual and their family (NASW, 2001). Dillard *et al.* (1992) further defined cultural competence as *an 'awareness of, sensitivity to, and knowledge of the meaning of culture'* (p.722). If professionals are to deliver appropriate client-centred interventions they need to be both culturally aware of and sensitive to their own cultural values and beliefs, values and beliefs as well those of the clients with whom they work (Awaad, 2003; Betancourt *et al.*, 2003). Suarez-Balcazar *et al.* (2009) describe cultural competence as a skill that can be acquired through practice, while others describe cultural competence as an ongoing, complex process that encompasses understanding the influence of several skills and characteristics (Muñoz, 2007; Capell *et al.*, 2008). Cultural competency requires effort and commitment on the part of

<sup>&</sup>lt;sup>2</sup> AMPS UK and Ireland

individual practitioners to frequently relearn and unlearn about diversity (Dillard *et al.*, 1992; NASW, 2001), while a lack of understanding of the process, its meaning and dynamics contributes to a lack of consistency and clarity generally about the meaning and delivery of culturally competent practice (Betancourt *et al.*, 2003; Muñoz, 2007).

Cultural competency is often poorly defined in the literature. While some studies do address the process of cultural competency it is rarely discussed in depth and often identified as an issue peripheral to the research, or only understood in a partial way (Iwama, 2003; Hopton & Stoneley, 2006). In this study it was understood to mean a process that comprised a set of skills needed by occupational therapists so that they were able to respond to the specific cultural needs and idiosyncrasies of the people with whom they worked (otherwise referred to as *clients*), and that the therapists could deliver culturally competent practice within the context of the health or social care team in which they worked.

#### Independence in occupational therapy

Independence is a relative concept with multiple inferences and meanings (Bowers, 2001; Tamaru *et al.*, 2007; Fox, 2010). For example, a wheelchair user can be independent from others in performing activities of daily living but dependent on the wheelchair for support and mobility. A person with dementia may be able to make a hot drink independently but dependent on others because of risk factors such as using matches or gas appliances to heat the water on a stove. In this study, independence is defined as a state of being self-sufficient, not requiring the help or assistance of others to perform necessary daily tasks and occupations.

Traditionally, the achievement or restoration of independence has been an important aim of occupational therapy and the focus of health and social care practitioners in general (Yang *et al.*, 2006; Whiting & Whiting, 2003). Independence has long been viewed as a healthy condition while dependence has been viewed as a deficiency (Whiting & Whiting, 2003). However, as the term independence is informed by western Anglo-American models of practice its place, cross-culturally, has been questioned. For example, Yang *et al.* (2006) investigated the applicability of occupational therapy models in Singapore, and found that occupational therapists had difficulty delivering their services to clients because of the focus on independence. They concluded that independence was a western cultural artifact neither appropriate nor relevant to Singaporean cultural values. Further studies that have a clear focus, and that are aimed specifically at investigating the value and influence of independence on occupational therapy practice in specific cultures, are important if we are to measure the impact on actualizing culturally competent practice (Whiteford & Wilcock, 2000).

# Interdependence in occupational therapy

Interdependence refers to the social relations between clients and the important others, which are conducive to health and social care provision and reception (Bowers, 2001; Hansebo & Kihlgren, 2001; Sharma & Kerl, 2002; Stanhope, 2002; McWilliam, 2009; Fox, 2010; White et al., 2010). In the literature, the term interdependence is associated with the give-take relationships where help and support is offered and received to enable any individual living in the community, whether disabled or non-disabled, to function and be integrated into society (Adams, 2009; Hammell, 2009; Fox, 2010). Humans are social beings who relate to each other through spoken words as well as body language and by seeking and offering help, for example through teaching and learning, bringing up children, taking care of older people, or buying something in a shop. Researchers have demonstrated a significant and undeniable need for interdependence in promoting health and quality of life (Beeber, 2008; Fox, 2010). Interdependence is an inevitable part of the intervention process as therapeutic outcomes would not be elicited without relationships between carers, clients and professionals (Hansebo & Kihlgren, 2001). Yet the health and social care literature rarely acknowledges or employs interdependence either as a notion or as a term, making its use vague and unclear (Whiting & Whiting, 2003). There is a need to explore the meaning and use of interdependence within

occupational therapy and in health and social care generally. In this study interdependence is used to refer to the state of being interrelated within an array of social relations and to be a realistic and natural representation of the state of humans as social beings, including within health or social care settings.

# Interdependence versus independence

Interdependence is viewed as much more naturalistic, realistic and reflective of the reality of humans as social beings than independence (Hopton & Stoneley, 2006; White et al., 2010). White and colleagues argue that the notion of interdependence preserves communities and societies, whereas a focus on individualism and individual freedom undermines social interaction and the role of others. There are increasing calls for interdependence to act as an alternative aim to that of independence for individuals and their families, as it is associated with positive therapeutic effects on health and quality of life (Fox. 2010). Stanhope (2002) and McWilliam (2009) assert that the notion of interdependence empowers clients to adapt and manage their health condition in the context of their physical and social environment. Whereas the notion of independence has the effect of segregating clients from their social relations in order to actualize self-care management, Nolan (2001) and Beeber (2008) recommend interdependence (rather than independence) as the aim or outcome of healthcare as it is more likely to result in the promotion of health, quality of life and client-centred practice, especially for older people. Moreover, Fox (2010) posits interdependence as a more realistic goal to underlie practice within health and social care generally; and Stanhope (2002) states that the adoption of interdependence is associated with a better prognosis for clients with mental health conditions. The impact of adopting values of both independence or interdependence within the practice of occupational therapy generally and cultural competency specifically, have been only rarely researched. Therefore this study aimed to explore firstly, whether the concept of interdependence can serve equally well as an alternative aim of occupational therapy and, secondly, whether interdependence is a more appropriate notion for actualizing culturally competent practice, as perceived and experienced by occupational therapists.

#### Method

A qualitative, descriptive approach was used as the purpose of the study was to explore occupational therapists' views and experiences of interdependence and cultural competency (Hammell et al., 2005; Finlay & Ballinger, 2006). The study was designed in two stages. The first stage comprised individual interviews with occupational therapists currently working in community-based teams with clients from diverse cultural backgrounds. The second stage comprised individual interviews with two independent experts in the field of occupational therapy theory and practice in order to extend the findings of the first stage interviews and confirm (or refute) data already generated (Sim & Wright, 2002).

#### Sample and recruitment

London has the highest proportion of multi-ethnic communities in England (ONS, 2009). A Primary Care Trust (PCT) in one of the most culturally diverse boroughs in London (DMAG, 2007) was selected for the first stage of the study. The setting ensured participants would routinely encounter clients from a range of diverse cultural backgrounds which would enable them to provide rich data needed to address the research aim. A sample size of twelve to fifteen participants was deemed appropriate to allow sufficient rich, in-depth data to be gathered for the first stage of the study (Finlay & Ballinger, 2006). In the first instance, the Team Manager responsible for occupational therapy services was contacted and was asked to support the study, and sent copies of the invitation letters and information about the proposed research. Following discussion, the manager sent the invitation letters and information by email to fifty-five occupational therapists working within the PCT. Criteria for selecting participants were that they had to have been working as an occupational therapist for at least three years either at the research site or other similar site in the UK or other country, in order to meet the requirement of a certain level of proficiency or expertise in multicultural practice. Each was contacted by the first author (WD) and, following a meeting to further explain the research, the eligibility requirements and to answer any questions, thirteen occupational therapists agreed to participate and gave their written consent. Participants worked in a range of teams including older adults, intermediate care, mental health, children, physical health including medical, surgical, orthopaedics and neurological services.

For the second stage of the study, prominent occupational therapy theorists were identified by their contribution to the field of occupational therapy theory in the UK, as identified by a search of the literature and publications in the field of occupational therapy theory and philosophy. Participants were identified through the Head of Education and Learning and the Research Development Officer at the College of Occupational Therapy, the professional body for occupational therapists practicing in the UK. Eighteen potential experts were identified and each was contacted by email with information about the study and an invitation to participate in the second stage of the study. Two of these responded. Each was contacted (by WD), and following further discussion about the research, each consented to take part in the study. Ethical approval was sought and obtained from the Research and Development Office at the research site, and from an NHS Research Ethics Committee, reference 08/H0701/88.

# Data collection and procedures

Data collection was based on one semi-structured, in-depth interview with each occupational therapist. The interview explored each participant's knowledge and experience of the topic of study: namely their understanding of the terms independence and interdependence and whether interdependence is a more appropriate notion for actualizing culturally competent occupational therapy practice. All interviews were tape recorded and transcribed verbatim and the interview narratives used as data for analysis. The researcher who conducted the interviews (WD) also kept a field journal. This was used to records events, thoughts and insights that occurred during the whole of the data collection period and used to supplement and support the data analysis process.

The semi-structured interview was selected as the method of data collection for both stages of the study. The use of a topic guide in the interview ensured that interviews remained focused and that the data generated was relevant to the research question. Questions included:

- 1. Can you describe the ultimate aim of your work with your clients?
- 2. In your mind, what is the position of independence in occupational therapy?
- 3. According to your experience, what is your understanding of interdependence?
- 4. What should be done and where to start if occupational therapists are to achieve cultural competency?

These questions were a guide only and were typically followed by prompts, such as *Could you explain that further? Can you give an example?* 

Following completion of these interviews, data were analysed using content analysis (see next section). Next, two further interviews were conducted, one each with the two occupational therapy theorists who formed an 'expert panel'. The questions asked were developed from initial findings arising from the first level of analysis of the interviews with the thirteen practicing therapists. From these initial findings some therapists placed a high emphasis on independence and some saw independence as the main aim of occupational therapy, thus questions included:

- 1. Do you agree that independence is the ultimate aim of occupational therapy?
- 2. Do you think that emphasizing the notion of independence in occupational therapy would enable the delivery of a culturally competent practice?
- 3. Do you think that there is enough attention and recognition to the concept of interdependence in occupational therapy?

- 4. Where do you think occupational therapy is placed in relation to the achievement of cultural competency? Why?
- 5. What should be done and where to start in order to achieve cultural competency in occupational therapy?

One individual interview was conducted with each of the thirteen occupational therapists. Each interview lasted between 60-90 minutes. Two further interviews were conducted, one each with the two occupational therapy theorists, each of which lasted for about 90 minutes.

# Data analysis

Following a period of familiarisation with the data, the transcripts from the first round of interviews were read and re-read. Data generated were in narrative form in an attempt to keep the data whole. Next, thematic content analysis was used to analyse all interview data from the first round. MAXQDA2 was used for coding and retrieving data segments. It also facilitated the tabulation of coded data against the initial list of themes and sub-themes, as well as sorting it into organized thematic charts. The analysis process was adapted to suit the idiosyncrasies of the study in such a way that the focus of the analysis did not only target the data content but also the way and the context in which data were generated through notes from the researcher's field journal (Finlay & Ballinger, 2006).

Although the main approach adopted for data analysis was thematic content analysis, the principles of narrative analysis were also incorporated in the process. This allowed for reflection on the way the data were treated. For example, data were not treated as separate chunks but rather as accounts that were part of an interrelated whole, linking with each other allowing for associations to be made and interpretations to be built. Analysis focused on the purpose behind the data as well as the key messages of the text. This was clearly evident in the coding, where the aim was not to reduce the data into manageable chunks using a pre-established code system, but rather to carry out the process of coding/indexing alongside the construction of the coding system.

The initial themes and questions generated, following analysis of the first stage interviews formed the questions for the second round of interviews. Following these, the next iteration of analysis was carried out and data again collated by themes. The initial versions of the coding comprised three main themes that included: cultural competency and occupational therapy, independence and cultural competency, interdependence and cultural competency. A further round of analysis took place to ensure that interpretations were reflective of the content and key messages of original data. Next, interpretations from the second round interviews were generated in the same way referring back to initial interpretations from the first round interviews. Finally, the overall themes were drawn out of the whole analysis process for first and second rounds of interviews.

# **Findings**

Following data analysis, three overarching themes were identified each with sub-themes. These can be found in **Table 1** and will be discussed separately.

# Theme 1. Independence as an outcome

1.i Independence: an overarching aim of healthcare

Participants stated that independence constituted the identity and the ultimate aim of occupational therapy:

... from an OT point of view, you always will try and work towards getting as independent as possible. I think that's kind of like brained... you know kind of washed into our brains to what can we do, how can we support the patient to get more independent, what can we provide to

**Table 1.** Themes and sub-themes

Major Theme	Sub-theme	
1. Independence as an outcome	1.i) An overarching aim of healthcare	
	1.ii) An overarching aim of occupational therapy	
	1.iii) Independence and cultural competency	
2. Interdependence as an outcome	2.i) Interdependence and occupational therapy  2.ii) Interdependence as an outcome of occupational	
	2.iii) Interdependence and cultural competency	
3. Culturally competent practice		

get them more independent, what can we remove around in their home to make them more independent. [P2]

Moreover, participants perceived independence to be the ultimate aim of healthcare generally and other professionals did not see it as exclusive to occupational therapy:

I mean pretty much in healthcare, pretty much what everybody does is linked to independence, it's not exclusively OT... [P5]

There was a lack of consensus concerning the meaning of independence and some participants used the concept of independence (the doing of occupational tasks or roles without help) interchangeably with the performance of meaningful occupations on one's own. For example:

The word independence is to be able to do it yourself without support but I think as an occupational therapist and having to be creative in ways that people can achieve what they need to do, I think the meaning of independence has maybe changed a little bit in that, mmm, I've seen people achieving tasks but with support or with equipment or you know in a very different way to traditionally independent... [P11]

Although you say that you are kind of independent in everything, in some areas you are interdependent... like [having] a milkman who is delivering milk at your doorstep. [P10]

When exploring these definitions in more depth, independence seemed to reflect the essence of occupational therapy which was to enable participation in meaningful occupation:

I think that is what occupational therapy is, it's about engaging and participating... [P8]

1.ii Independence: an overarching aim of occupational therapy

Independence as an outcome of occupational therapy seemed to be a concept that was implicit in the healthcare system:

Generally here the services are aimed at people being as independent as possible, aimed at people being able to look after themselves and stay in their own homes for as long as possible... [P1]

This may be as a response to increased pressure from healthcare providers to facilitate early discharges which, in turn, can reduce costs and pressures on services by freeing up more beds and reducing staffing:

I quess probably part is quite financial as well in that you can get people to monitor their own conditions, it's easy you can have... you don't need so many health professionals involved ... but people are managing alternative conditions themselves so they only need their input from professionals at certain points along the way... [P8]

Some participants attributed the focus on independence to the western (Anglo-American) orientation of occupational therapy. This philosophy was constructed and developed within the western world and for their indigenous societies, which emphasized values such as independence:

A western society is so much on independence... [P6]

A lot of the thinking and writing has come from people who are embedded in western culture thinking. So they're embedded in the 'self as central' thinking rather than a collectivist type of thinking and, from that, then the whole thing... if you look to some of the professional models of occupational therapy, in the middle of it, it's me, me, me, you know it's the individual at the centre, which is a very western cultural way of looking at life. [P13]

While the study did take place in the UK, historically a country that would embrace western notions such as independence, the applicability and relevance of independence to people living in the UK but from a different, non-western, cultural background can be questioned:

... if you see occupational therapy as people maintaining their own health through doing, then that is not going to be acceptable to a lot of people... is not appropriate, not in some cultures, and not at a certain time and not even within subcultures in the UK... [P14]

1.iii Independence and cultural competency

Focusing on actualizing a state of independence sometimes resulted in participants neglecting the needs of, or even marginalizing clients from non-western cultural backgrounds. When there was a focus exclusively on independence some participants observed that this could risk imposing service-focused outcomes on clients instead of responding to their specific cultural (client-focused) needs:

If you use the concrete term of independence the whole time, then you're not gonna achieve cultural competence. You might get it right for a lot of the times but for the people that don't see independence as a high priority, you're really gonna let them down... [P1]

This, it was claimed, could result in clients' needs not being met or at best a service that was unresponsive to specific goals and cultural needs of individuals:

We work in a goal orientated service so if people don't want to improve, we tend not to be working with them. [P7]

Some participants stated that the focus on independence clashed with the delivery of culturally competent practice:

... culturally competent, no I don't think to do with independence really... [P12]

# Theme 2. Interdependence as an outcome

2.i Interdependence and occupational therapy

Most participants stated that the term interdependence was rarely used:

I haven't really used that term myself within my career, I haven't come across it... [P11]

Although the term interdependence was not used, participants had witnessed and experienced the intertwined, joint and reciprocal relationship between themselves, their clients and clients and their carers.

... it was very much a joined thing, so it's almost like looking at the two of them as one... because she relies so heavily on him and what they do is so intertwined... [P5]

They had also observed or experienced *interdependence* in different contexts for example in work, social and personal contexts. Thus the connotations associated with interdependence were understood and the implications obvious even though the term interdependence was not use in the workplace.

Sometimes you're doing it [occupation] for itself, sometimes you're doing it for somebody else and sometimes somebody else is doing it for you and to me that's the rich life... [P9]

2.ii Interdependence as an outcome of occupational therapy

Interdependence was perceived as essential in enabling the intervention *process* of achieving outcomes. Through interdependence, the important others in the client's life, such as those of carers, supporters and supervisors, could play several significant roles in facilitating the delivery of occupational therapy:

... a facilitatory role... to help them get dressed and manage their money, to provide for their basic needs in terms of feeding, hygiene, to decide for them what they need to be doing, to support them with the roles such as their parenting roles, to advocate for them in that's... particularly when there is a language barrier... [P7]

Interdependence was noted as an important factor when working as an occupational therapist with clients and their families, as the development of a collaborative and therapeutic relationship (a form of interdependence) would encourage trust and therefore more likely active involvement with the therapy:

The family members can act as... like advocate or intermediary person that actually can help the therapist with providing that treatment because ...especially if the patient is quite scared and doesn't trust the therapist, it could be really useful in gaining trust... [P3]

In addition, when working closely together (interdependently) with the client and their important others, these family members can act as a constant source of supervision and care for clients who have impaired mental capacity such as older people with dementia, or clients with other conditions affecting insight or cognition. Thus, if the important others were included as part of the process of treatment and taught to deliver services at the clients' home environment, this would help to ensure greater continuity in the type of care or treatment and any therapeutic benefits for the recipient. This might help reduce risks and enable clients to also work collaboratively with therapists to achieve outcomes. For example, the provision of care for clients who require constant supervision or to be mobilized to prevent pressure ulcers. Thus important others become an essential part of the team as they assume the role of a healthcare assistant by supervising or carrying out interventions when the therapist is absent, especially within the client's home environment:

I'm thinking about falls again... they've got a lot of these rugs lying around and you think about the word if they picked them up and then you involve the other family members with that and making to do that as well. [P8]

The family have basically gone in there and taken on the role of almost like therapy assistants, kind of like what home rehab would do but they've been getting him up and moving... [P5]

2.iii Interdependence and cultural competency

Participants acknowledged that interdependence is a concept that reflects the reality of being human, regardless of cultural background:

We're all kind of interdependent and interconnected mmm I think that's there in all the culture, maybe the... kind of the intensity varies... [P10]

There is a strong emphasis on the value of interdependence and social relations in some communities more than others. In these communities interdependence is perpetuated and synthesized within the sociocultural fabric of their life. This kind of cultural emphasis on the value of interdependence is apparent in the customs and traditions in these communities: for example where there is an emphasis on living in extended families. Here it is normal for others in the family to provide care in cases of illness or disability and a stress on making decisions collectively with other members of the social unit:

The elder son or daughter from these bigger families will often want to be like, well no, come through me, and their actual... the elderly person will be quite happy to allow their son or daughter to make those decisions on behalf of them... [P3]

Participants acknowledged the influence of interdependence on their practice and the need to adapt their approach to correspond appropriately to the cultural context in which they were working:

For example an Asian lady I've got now, I'd definitely go through all... maybe one or two of the sons or daughters to talk about it, make sure they're happy with it and as well as the person involved, so they're going to be using it and all gonna be involved... [P3]

#### Theme 3. Culturally competent practice

With regards to cultural competency, participants did not report any link with independence or interdependence as a way of actualizing cultural competence. Participants acknowledged that an understanding of the client and their culture and background was very important as cultural influences, as well as what the client does and the particular way it is done. Cultural competence appeared to be understood as a function of individual therapists rather than being influenced by notions of independence or interdependence:

You being culturally competent is you have an understanding of how your clients' culture impacts on their daily living tasks and you then use that information to help make realistic goals with your patient about what you want to work towards... [P13]

#### **Discussion**

A significant finding of this study was that occupational therapy practice had shifted from a client-centred approach of enabling participation in meaningful occupation towards a servicefocus where notions of independence predominate over client preferences. With such a focus, client-centred care that focuses on personal choice, autonomy and empowerment of individuals can be undermined. The study set out to explore the concepts of independence and interdependence, and whether using interdependence as an outcome is more likely to result in

actualizing culturally competent practice. None of the participants in this study used interdependence as an outcome, so discussion focuses on current practice as experienced by these thirteen occupational therapists and the independence – interdependence continuum.

UK social care policies are strongly rooted in principles of supporting independence, autonomy, and personal empowerment, and little attention is paid to other concepts such as dependence and interdependence (Nolan, 2013; Fine & Glendinning, 2005). This places an unrealistic demand on frail clients who require constant care because of age or condition (Nolan, 2013). Independence is associated with positive outcomes though the sources of that is not rationalized nor researched (Nolan, 2013; Fine & Glendinning, 2005). On the other hand, dependence is associated with negative outcomes and is used to measure the degree of assistance needed or level of care (Nolan, 2013; Fine & Glendinning, 2005). The source of these value-laden terms has been poorly researched and are poorly understood, and there is a need to construct a new conceptualization of care that encompasses dependence, interdependence and independence (Nolan, 2013; Fine & Glendinning, 2005).

#### Independence versus interdependence

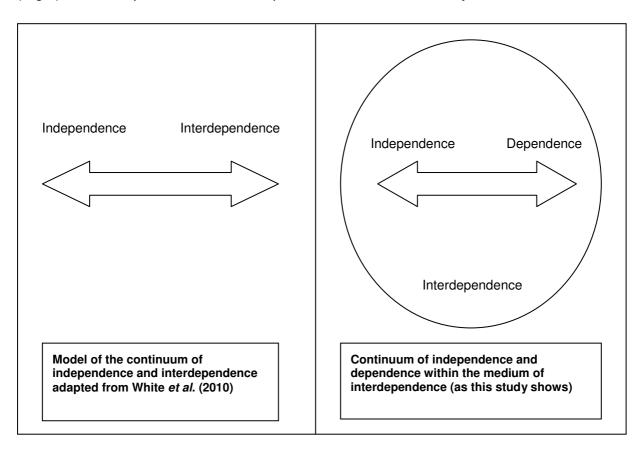
It has been suggested that interdependence and independence sit at either end of a continuum implying that they are at odds with each other (Beeber, 2008; White *et al.*, 2010). In this study we suggest that interdependence is the original state of being and independence is an emergent state, accomplished by choice within an overall network of social relationships (**Figure 1**). We assert that total and complete independence is not possible in all aspects of living and consequently cannot be used to describe an overall (or ideal) state of being. By living in communities, shopping at the store or purchasing manufactured goods and services from others, there will always be aspects of our lives for which we are dependent. Thus it could be said that human beings move between a state of independence and dependence within the overarching context of interdependence and social relationships (Hopton & Stoneley, 2006; White *et al.*, 2010):

Most care in the UK is provided by important others (Beeber, 2008; Fox, 2010). Despite this, the notion of interdependence is poorly acknowledged or researched in health or social care contexts. Yet, as identified in this study, interdependence is essential for facilitating health and social care delivery and accomplishing client-centred outcomes that support client choice. Further, in certain situations the involvement of others becomes indispensable in substituting for lost ability, reducing risks and promoting clients' safety (Beeber, 2008). For example, for clients with dementia, interdependence between client, family, carers and professionals is essential if realistic support and supervision are to maintain safe individual, family and community outcomes. A state of independence would be unrealistic because of a deteriorating health condition (Hansebo & Kihlgren, 2001). Moreover, interdependence corresponds with the aspirations of many clients for good quality of life, with strong social ties between people and communities and thus integral to the delivery of client-centred care (Bowers, 2001; Stanhope, 2002; McWilliam, 2009). Through interdependence, quality of life, healing and adaptation can be promoted by preventing the negative effects of social isolation (Sharma & Kerl, 2002).

#### Interdependence and the delivery of health and social care

The involvement of carers/important others through the support they provide represents a form of interdependence and a valuable source of unpaid work. This in turn has positive effects on reducing the costs of, and pressures on, healthcare services. Fox (2010) argues that the principle of delivering 'care' encapsulated in health and social care systems contradict the overarching aim to actualize a state of independence. Moreover, many health and social care professionals regularly use other forms of interdependence as a source of support and assistance to facilitate recovery, adaptation and re-establishment in the community (Adams, 2009; McWilliam, 2009). This can be formal sources of care such as care agencies or other forms of social relations such as the involvement of family members. The findings of this study

Figure 1. (Left) The conceptual model of interdependence adapted (White et al., 2010) (Right) The conceptualization of interdependence offered in this study



suggest that while the overall aim of occupational therapy is often independence, the delivery of occupational therapy is in itself a form of interdependence and should be overtly acknowledged as such in education and practice. Further research would establish if this is also true for other professional groups.

#### Paving the way for a culturally competent profession

The values of individualism and standing out from the crowd may be prevalent in some cultures but collectivism and conforming to the societal structure are dominant in others (Iwama, 2003; Kondo, 2004). Independence and interdependence are both cultural-specific values. Independence is entrenched in western societies as a healthy state and as a way of promoting autonomy, while dependence is regarded as an unhealthy, unacceptable and unsatisfying way of living (Hammell, 2009). In other cultures, the notion of interdependence constitutes a source of wellbeing and satisfaction while independence impedes the assumption of interdependent roles (Hammell, 2009). In such cultures, dependence could even be viewed as an acceptable way of living in cases of illness and disability (Iwama, 2006; Hammell, 2009). Therefore, while independence is a value that is emphasized in some cultures, interdependence is perpetuated and favoured in others (Sharma & Kerl, 2002; Bourke-Taylor & Hudson, 2005; Hopton & Stoneley, 2006; Yang et al., 2006). This renders both independence and interdependence as specific sociocultural values and, therefore each on its own could not result in the actualizing of cultural competency if either were adopted solely as outcomes.

Cultural competency is a complex process (Betancourt et al., 2003; Muñoz, 2007; Suarez-Balcazar et al., 2009) that relates to core concepts of and principles of health and social care practice and therefore, should be actualized in practice (NASW, 2001; Iwama, 2003; Kondo, 2004; Yang *et al.*, 2006). Despite this, research is neither directed at illuminating the process of cultural competency, how it occurs and its dynamics, nor at questioning the underlying core concepts of professional values and their potential to actualize a culturally competent practice.

In occupational therapy, many scholars have noted that current theory and practice is based on western values, designed for those who understand and live by western values and perspectives (Awaad, 2003; Bourke-Taylor & Hudson, 2005; Iwama, 2006; Yang *et al.*, 2006). Such a philosophy emphasizes the values of individualism, independence and doing implicit in western cultures but not client values of choice and collectivism. Such values are often associated with eastern cultures (Kondo, 2004; Hopton & Stoneley, 2006) or other ethnic communities and this raises ethical issues concerning the delivery of client centred, equal and holistic health and social care for all, especially multicultural societies such as those seen in the UK (Awaad, 2003).

#### Conclusion

This study found that, while the notion of interdependence is not used overtly in occupational therapy theory and practice it is described and understood by those delivering health and social care services. We suggest that the term interdependence should be introduced into the theory, practice and professional terminology of health and social care professionals including occupational therapists. Integrating interdependence into everyday practice would reflect the reality of clients as social and occupational beings living as part of a family and social group. Additionally it would reflect the essence of health and social care delivery as a collaborative and empowering process between clients, family members, carers and professionals regardless of culture, background or ethnic group. We suggest that interdependence as a concept has been neglected in health and social care practice despite it often being reflective of the true nature of humans as social beings. Further research is needed to consider the place of interdependence in the delivery of health and social care by other professional practitioners.

# **Acknowledgements**

Grateful thanks are extended to the occupational therapists who participated in this study and to their manager for allowing the study to take place. Thanks are also extended to Jennifer Creek and Professor Annie Turner who also generously gave of their time.

#### Key findings

- 1. Interdependence reflects the essence of health and social care practice as a collaborative and empowering relationship between clients, carers and professionals regardless of culture.
- 2. Cultural competence is understood as a dynamic state of individual practitioners rather than outcomes of interventions.

# What the study has added

Interdependence is highly relevant to practice outcomes and should be added to the professional terminology of health and social care practitioners.

#### References

Adams, F. (2009) 'The culture of soup', South African Journal of Occupational Therapy, 39(1), pp. 8-10.

Awaad, T. (2003) 'Culture, cultural competency and occupational therapy: a review of the literature', British Journal of Occupational Therapy, 66(8), pp. 356-362.

Beeber, A. (2008) 'Interdependence: building partnerships to continue older adults' residence in the community', Journal of Gerontological Nursing, 34(1), pp.19-27.

Betancourt, J.R., Green, A.R., Carrillo, J.E., & Ananeh-Firempong, O. (2003) 'Defining cultural competence: a practical framework for addressing racial/ethnic disparities in health and healthcare', *Health Policy Reports*, **118**, pp. 293-302.

Bourke-Taylor, H. & Hudson, D. (2005) 'Cultural differences: the experience of establishing an occupational therapy service in a developing community', Australian Occupational Therapy Journal, 52(3), pp. 188-198.

Bowers, H. (2001) 'Promoting interdependence: a new challenge in developing services for older people?', Managing Community Care, 9(6), pp. 34-39.

Capell, J., Dean, E. & Veenstra, G. (2008) 'The relationship between cultural competence and ethnocentrism of healthcare professionals', Journal of Transcultural Nursing, 19(2), pp. 121-125.

Data Management and Analysis Group [DMAG] (2007) Demography Update October 2007, http://legacy.london.gov.uk/gla/publications/factsandfigures/dmag-update-20-2007-ons-ethnicgroup-estimates.pdf (accessed 9 March 2011).

Dillard, M., Andonian, L., Flores, O., Lai, L., MacRae, A. & Shakir, M. (1992) 'Culturally competent occupational therapy in a diversely populated mental health setting', American Journal of Occupational Therapy, 46(8), pp. 721-726.

Fine, M., & Glendinning, C. (2005) Dependence, independence or interdependence? Revisiting the concepts of 'care' and 'dependency', Ageing & Society, 25(4), pp. 601-621.

Finlay, L. & Ballinger, C. (2006) Qualitative Research for Allied Health Professionals: Challenging Choices, Chichester: J. Wiley & Sons.

Fox, A. (2010) 'From independence to interdependence: integration means 'think family', Journal of Integrated Care, 18(2), pp. 41-48.

Hammell, K. (2009) 'Sacred texts: a sceptical exploration of the assumptions underpinning theories of occupation', Canadian Journal of Occupational Therapy, 76(1), pp. 6-22.

Hammell, K., Carpenter, C. & Dyck, I. (2005) Using Qualitative Research: A Practical Introduction for Occupational and Physical Therapists, London: Churchill Livingstone.

Hansebo, G. & Kihlgren, M. (2001) 'Carers' reflections about their video-recorded interactions with patients suffering from severe dementia', Journal of Clinical Nursing, 10(6), pp.737-747.

Hopton, K. & Stoneley, H. (2006) 'Cultural awareness in occupational therapy: the Chinese example', British Journal of Occupational Therapy, 69(8), pp. 386-389.

Iwama, M. (2003) 'The issue is. Toward culturally relevant epistemologies in occupational therapy', American Journal of Occupational Therapy, **57**(5), pp. 582-588.

Iwama, M. (2006) Kawa Model: Culturally Relevant Occupational Therapy, London: Churchill Livingstone.

Kondo, T. (2004) 'Cultural tensions in occupational therapy practice: considerations from a Japanese vantage point', *American Journal of Occupational Therapy*, **58**(2), pp.174-184.

McWilliam, C. (2009) 'Patients, persons or partners? Involving those with chronic disease in their care', *Chronic Illness*, **5**(4), pp. 277-92.

Muñoz, J. (2007) 'Culturally responsive caring in occupational therapy', *Occupational Therapy International*, **14**(4), pp. 256-280.

NASW (2001) *NASW Standards for Cultural Competence in Social Work Practice*, Washington DC: National Association of Social Workers.

Nolan, M. (2001) 'Adult/elderly care nursing. Successful ageing: keeping the 'person' in person-centred care', *British Journal of Nursing*, **10**(7), pp. 450-454.

Nolan, M. (2013) 'Successful ageing: keeping the 'person' in person-centred care', British Journal of Nursing, published 27/09/13, doi: http://dx.doi.org/10.12968/bjon.2001.10.7.5330.

Office of National Statistics (2009) *London: Resident population estimates by ethnic group*, http://neighbourhood.statistics.gov.uk/dissemination/LeadTableView.do?a=3&b=276743&c=London&d=13&e=13&g=325264&i=1001x1003x1004&m=0&r=1&s=1396110839893&enc=1&dsFamilyId=1812&nsjs=true&nsck=false&nssvq=false&nswid=1222

Sharma, P. & Kerl, S. (2002) 'Suggestions for psychologists working with Mexican American individuals and families in healthcare settings', *Rehabilitation Psychology*, **47**(2), pp. 230-239.

Sim, J. & Wright, C. (2002) Research in Healthcare: Concepts, Designs and Methods, Cheltenham: Nelson Thornes.

Stanhope, V. (2002) 'Culture, control, and family involvement: a comparison of psychosocial rehabilitation in India and the United States', *Psychiatric Rehabilitation Journal*, **25**(3), pp. 273-280.

Suarez-Balcazar, Y., Rodawoski, J., Balcazar, F., Taylor-Ritzler, T., Portillo, N., Barwacz, D. & Willis, C. (2009) 'Perceived levels of cultural competence among occupational therapists', *American Journal of Occupational Therapy*, **63**(4), pp. 498-505.

Tamaru, A., McColl, M. & Yamasaki, S. (2007) 'Understanding 'independence': perspectives of occupational therapists', *Disability and Rehabilitation*, **29**(13), pp. 1021-33.

White, G., Simpson, J., Gonda, C., Ravesloot, C. & Coble, Z. (2010) 'Moving from independence to interdependence: a conceptual model for better understanding community participation of centers for independent living consumers', *Journal of Disability Policy Studies*, **20**(4), pp. 233-240.

Whiteford, G. & Wilcock, A. (2000) 'Cultural relativism: occupation and independence reconsidered', *Canadian Journal of Occupational Therapy*, **67**(5), pp. 3243-36.

Whiting, S. & Whiting, J. (2003) 'The conceptual development of dependence, independence, and interdependence as potential nursing diagnoses', *International Journal of Nursing Terminologies & Classifications*, **14**(4), Supplement:10.

Yang, S., Shek, M., Tsunaka, M. & Lim, H. (2006) 'Cultural influences on occupational therapy practice in Singapore: a pilot study', *Occupational Therapy International*, **13**(3), pp.176-192.

# **Notes on Contributors**

Wesam Darawsheh is a qualified occupational therapist with experience of working in the UK and Jordan. She has a particular interest in contemporary issues in occupational therapy such as technology, culture and medical advancements. She is an advocate of occupational science and views occupation as the essence of occupational therapy, using qualitative research methodologies to explore this, as well as the delivery of client-centred practice in health and social care. This is the current focus of her teaching and research at the University of Jordan.

Gill Chard is a qualified occupational therapist who worked in health and social care practice in hospital and social care for 20 years. These included inner city, urban and rural areas as well as health and social work teams. For the past 20 years she has worked as Lecturer, Associate Professor and Professor of Occupational Therapy in the UK, Republic of Ireland and Canada. She has a long standing interest in occupational therapy and qualitative research in community practice with older people and is an educator, researcher and writer.

# Correspondence

Wesam B. Darawsheh, PhD, MScOT, BScOT Assistant Professor Occupational Therapy Department Faculty of Rehabilitation Sciences University of Jordan Queen Rania Al Abdallah St Amman 11942 Jordan

Email: w.darawsheh@gmail.com

Telephone: +962-798789290

# 'What counts is what works': NICE's new role and approach in developing evidence-based guidelines for social care

John McLean

#### **Abstract**

The past 15 years have seen what has been described as a 'post-ideological approach to public service reform' where evidence takes centre-stage and where 'what counts is what works'. The National Institute for Health and Care Excellence (NICE) embodies this ethos, using a robust methodology where evidence is systematically reviewed and guidelines with clear recommendations are developed for clinicians and public health professionals. The Health and Social Care Act 2012 extended the remit of NICE to develop guidelines for social care from April 2013, and in doing so has provoked debate within the sector on the available evidencebase for social care, the quality and applicability of research and evidence, the dangers of imposing a 'medical model' onto social care, and the challenges of implementing guidelines. This paper will outline the approach NICE has taken to address these valid concerns to develop and refine an effective and tailored methodology in order to generate guidelines and recommendations that are suitable for social care. This includes what NICE considers to be 'evidence' in social care, and the options and role of the Guideline Development Group when there is little or no evidence and consensus, or further expertise is required. It will also explore how recommendations are developed, the link between guidelines and professional opinion and the implementation of the guidelines on publication.

**Keywords:** NICE, evidence, social care, research, guidelines, implementation, methodology, recommendations

#### Introduction

The use of evidence to inform policy and practice is not a new phenomenon in the United Kingdom. The relationship between social research and social policy was shaped over the 19<sup>th</sup> and 20<sup>th</sup> centuries, evidenced strongly in the 1960s, but giving way to the doctrine of conviction politics in the 1980s and 1990s which arguably marginalised the use of research in policy making (Nutley, Davies & Walter, 2002). The election of the New Labour Government in 1997 revived the focus on evidence, research and policy, with the promise of a modernising agenda based on a third-way ideology and the mantra that 'what counts is what works'. The paper Modernising Government (Cabinet Office, 1999) affirmed that policy development as a process should encompass the key feature of being evidence-based. Since the mid-nineties, the UK has seen a range of think-tanks and organisations exert influence over policy development with the purpose of getting research and evidence into practice in a range of areas including justice. education, health and social care. Examples of the latter include the Centre for Evidence-based Social Services at the University of Exeter, and the 'Research on the Outcomes of Social Care for Adults' initiative at the University of Salford, and in 1999 the Government emphasised that rather than just 'using research evidence', there was a desire for social work practice to be 'grounded in evidence-based knowledge' (Department of Health, 1999).

In 2012, the Health and Social Care Act extended the remit of the National Institute for Health and Clinical Excellence (NICE) to publish quality standards for social care, to be developed using evidence-based guidance. Earl Howe stated that 'the *Care and Support White Paper* set out our plans to drive up the quality of care. NICE's new quality standards on social care will be a key driver of this. They will help define what good care and support looks like for commissioners and care providers as well as people using services' (Howe, 2012). Following this, NICE's name was changed to the National Institute for Health and Care Excellence to reflect this new remit.

This new remit has provoked debate within the social care sector. Since its creation in 1999, NICE has been a predominately health-focused organisation producing 'technology appraisals' assessing pharmaceuticals, surgical procedures, medical devices and screening technologies, as well as clinical guidelines and public health guidelines. The applicability of the evidence and methodologies developed for use in health care to the social sciences has been met with some scepticism and concern by early stakeholders of the NICE social care programme; the main concern being that a restrictive medical model as perceived, in use for clinical guidelines, would be applied unthinkingly. In practice, NICE also has considerable experience in public health where similar issues exist as for social care with regards to the evidence. This learning was considered in the development of the social care methods manual which is used to develop social care guidelines; however, this paper contrasts the perceived 'medical model' alone with the methods for social care.

This paper will consider the challenges for evidence-based social care, outlining the steps that NICE has taken to not only ensure that the process and methodology employed in developing social care guidelines has taken into account the differences between social care and clinical care, but also learns from the experience of guidance development in a diverse range of health topics, including that of public health. The paper will particularly focus on the range and quality of evidence available, the ongoing debate on the 'hierarchy of evidence' and the process by which the Guideline Development Groups assess the evidence and make recommendations. Finally the paper will briefly consider the challenges for effective implementation of social care guidelines.

#### Evidence-based social care

The term 'evidence-based' has become something of a buzzword in light of the reliance placed on research and evidence in the last 15 years. Indeed, some have sought to re-invent the term as 'evidence-informed', 'evidence-led' and even 'evidence-searched' (Knaapen, 2013) in recognition of the breadth and possibly misleading nature of the term 'evidence-based'. However, for the purposes of this paper evidence-based social care is described as the 'conscientious, explicit and judicious use of current best evidence in making decisions regarding the welfare of service-users and carers' (Sackett *et al.*, 1996). The principle underpinning this is that decisions are made based on the best available evidence and consider what interventions are likely to work in different circumstances, and organisations including the Social Care Institute for Excellence (SCIE) and the College of Occupational Therapists (COT) currently develop such guidelines using NICE-accredited methodologies.

Practitioners such as Geraldine MacDonald and Brian Sheldon have long been proponents of the evidence-based approach to deal with issues and variations in practice. MacDonald observes that the value in an evidence-based approach is that it is not reliant 'purely on ideological assumptions and subjective views about the basis of decision making' (MacDonald, 1999).

However, it is fair to say that in both social care and medicine, decisions may be taken with consideration given to subjective values and knowledge of external factors such as the financial and political landscape, as well as being inherently affected by the limitations of practitioner knowledge, or as Daniel Kahneman would describe it, the belief that 'what you see is all there is' (Kahneman, 2011). Whilst this paper does not intend to explore the behavioural science concept of system one/system two thinking in relation to the processes behind social care decision making, it will explore a little later the necessary part that practitioner opinion and judgment has to play when developing social care guidelines as well as the relationship between professional judgement and guideline implementation.

Perhaps one of the most convincing arguments for evidence-based guidelines is that there has been a fiscal squeeze in recent years on public services resulting in the reduction and even termination of social care services and provision. Falling staff numbers, departmental

restructures and a desire to ensure that quality is not compromised means that the promise of evidence-based approaches are even more salient than ever before (Webb, 2001). Whilst NICE has been clear that social care guidelines are not being developed with the primary purpose of cost-savings, the review questions that will be considered on the referred topics will look at what is effective and what is cost-effective; and also bear cost-saving in mind as guidelines are developed.

# Developing evidence-based guidelines: what counts as evidence?

One of the concerns expressed regarding NICE's new role was that the approach to evidence would have a significantly clinical bias, and not without cause. NICE's experience in the development of technology appraisals and clinical guidelines has been perceived as being over-reliant on experimental research such as Randomised Controlled Trials (RCTs). This is a valid concern as NICE has historically referenced a 'hierarchy of evidence' which puts systematic reviews, randomised controlled trials and double blind clinical trials, which are traditionally scientific forms of evidence, at the top of the hierarchy. This hierarchy which puts these types of evidence at the top is based on the methodological design and its internal validity, that is to say whether it is replicable, rather than its external validity, which is to say whether it is ultimately valid and useful (Cartwright, 2007). The social work sector is therefore rightly concerned at the applicability of a model where this type of evidence would be demanded to develop social care guidelines; particularly since there is little confidence that large amounts of this kind of research exists, or would even work, for many areas of social care. However, it is worth noting that even in clinical guideline development at NICE, this simplistic hierarchical model has been superseded by a more considered and sophisticated approach to assessing the quality of the evidence.

It is notable that this concern regarding the availability of this type of evidence, i.e. 'scientific', is not unique to social care but also extends to medicine. In 2007, the 'Program in Evidence-Based Care' in Canada, which produces clinical guidelines for cancer, held a symposium focusing on the challenges of providing evidence-based advice where the evidence is lacking, of poor quality, immature or incomplete (Knaapen, 2013). Therefore it is not just in the social care sector where there is concern over the definition of 'evidence', as the hierarchy has generated criticism from clinicians for undervaluing many different kinds of knowledge and has been described as the source of evidence-based medicine's 'questionable epistemic practices' (Goldenberg, 2009, p.171).

Aside from the concern that there would be a paucity of 'gold standard' evidence if such a simplistic hierarchy were to be used, there was also the valid concern that outcomes in social care are more likely to be found in pre-test/post-test designs, ideas and opinion based studies which are usually associated with social sciences and can be found at the bottom of this hierarchy. An additional criticism of some clinical guidelines is that patient perspectives may not always be considered. NICE has always included consideration of the patient experience when drafting clinical guidelines (sometimes through a review of evidence on patient perspectives or experience, but always through involving patient and carer input at several stages). However, this may be even more important to consider in social care guidelines where service user experience may be the primary outcome.

Rigid adherence to a simple hierarchy of evidence without due consideration of service user experience could therefore limit and exclude valuable evidence, and would result in a clinical model being imposed on social care (Gould & Kendall, 2007). Reputationally and methodologically, this was exactly what NICE was determined to avoid. It was essential that published guidelines would not only be based on the best available evidence, but that they would continue to ensure public involvement, reflect service user and carer opinion and input, and that they are something that is ultimately useful and adds value for the sector. Therefore, in preparation for taking on the new social care remit, NICE acknowledged that the disciplines of social work and medicine are very different, and that a broader consideration of a wider range of evidence and inputs to guideline development were essential.

Previous experience in the development of a joint health and social care dementia guideline with the Social Care Institute for Excellence (SCIE), had allowed NICE to enable 'practitioner, service user and carer involvement and consultation at the stages of defining topics, research questions, deciding on appropriateness of types of evidence and producing the summary review of evidence' (Gould & Kendall, 2007, p.486). It was acknowledged that in comparison with clinical topics, there was a notable absence of the more scientific studies that NICE have been traditionally familiar with and that the production of this guideline relied on systematic review and meta-analysis of qualitative data and a more pragmatic approach to the evidence. However, it remained faithful to the fundamental principles of systematic reviewing and resulted in the production of a guideline which was therefore transparent and replicable (Gould & Kendall, 2007).

Building on the learning from the publication of this guideline, NICE was clear when developing the new methods and processes manual for social care guideline development that in social care a greater variety of evidence may need to be considered. The Social Care Manual states specifically that NICE supports 'innovative and flexible approaches to searching. The use of iterative searching (sometimes referred to as emergent searching) in which the evidence base is not pre-defined is welcomed, as is the use of grey literature sources, such as charity and government department websites' (NICE, 2013). NICE has emphasised to all Guideline Development Groups (GDGs), and at every stakeholder workshop and public event relating to social care, that a robust search strategy would be devised and agreed with the GDG, and a wide range of evidence would be considered and systematically reviewed with recommendations being developed that reflect the strength and validity of the evidence used. Therefore concerns about a restrictive approach in terms of searching for evidence in the social care programme are largely unfounded. The types of evidence may be categorised in terms of their quality based on the methodology used, but searches for evidence are not limited to the perceived 'gold standard' in recognition of its limitations to social care practice and interventions.

# Absence of evidence

There remains, however, the question of what if there is no research evidence, gold standard or otherwise, at all. Interventions that are easier to measure and are more replicable tend to receive the most attention, meaning that some types of practice will not be well represented in the research literature (Adams *et al.*, 2009, p.170). The absence of evidence has in fact been considered an achievement in itself by NICE, and as a guideline developer they have focused on the positives of establishing knowledge of the unknown. As part of NICE's work on cancer guidelines, they have helped set up a 'database of cancer uncertainties' (DoCU) which collects and advertises where there is an absence of evidence during guideline development as a prompt for further research. For NICE's social care guidelines where there may be many gaps in the evidence, the Guideline Development Group will be encouraged to select key research recommendations to include in the final guideline, and similarly encourage further research in these areas.

However, the gaps in evidence may not be because the evidence does not exist, but because it has not been found using standard information retrieval methods. For some review questions, other types of information are required such as ongoing research in a field, new services or interventions, abstracts of studies, data on adverse effects, economic models and reports of the experiences of service users, carers or social care practitioners or other professionals. Similarly, where service guidance is being developed, this may rely on statistics which vary between localities and regions, as well as evidence on service configurations and models to generate a baseline assessment (NICE, 2013).

In these situations, a 'call for evidence' may be made to all registered stakeholders specifying the question being addressed and detailing the type of evidence being sought. For example, the structured framework being used and study design for questions of effectiveness. For service guidance, reports, datasets and survey data may also be requested from a variety of organisations to clarify the baseline position. Furthermore, 'expert witnesses' can be requested to attend and give testimony to the GDG on specific review questions where there are gaps in the evidence.

In order to produce the best guideline and recommendations possible, it is important to look to as many available sources as possible for the information to answer the review questions for the guideline. An absence of strong evidence, or any evidence, presents a significant challenge. There has been criticism that a 'weak' recommendation is oxymoronic by nature, and that an absence of certainty and confidence in the evidence should preclude any kind of recommendation being made at all (Knaapen, 2013, p.686). However, a guideline developer in the Netherlands has pre-empted this in their process manual by stating:

Evidence-based means that a systematic search of evidence from literature has taken place and was reported on transparently... if there was insufficient evidence - and this happens frequently - an answer still needs to be provided for the key question. Then the opinion of and consensus between - the various experts will be decisive. We still call the method 'evidence-based': where possible, we have based our recommendations on evidence and made it explicit that the selected search methods did not provide any evidence. (EBRO, 2007, p.4)

NICE takes a similar approach and includes an 'evidence to recommendations' section in its guidelines demonstrating how the final recommendations track back to the available evidence and how they were formed. However, the evidence first requires review and discussion by the Guideline Development Group.

# The Guideline Development Group (GDG)

One of the strengths of the NICE methodology is the way evidence is systematically reviewed. synthesised, presented, discussed and formed into action-oriented recommendations by the Guideline Development Group (GDG).

The GDG are an advisory committee to the NICE Board and are made up of a constituency of approximately 15 individuals from different disciplines relevant to the topic. These can include professionals and practitioners across health and social care, commissioners, academics and for social care topics a minimum of 4 service user and carer members. The group is chaired by either an experienced chairperson with support from a topic expert, or an expert chair with prior experience of the subject.

The primary role of the GDG is to agree what the topic specific review questions should be which will generate the evidence searches to answer those questions. The evidence searches are then carried out by the information specialists at the NICE Collaborating Centre for Social Care and the relevant studies are then assessed against pre-defined criteria. Each included study is then assessed for quality and validity, summarised in the form of evidence tables and presented to the GDG with a narrative summary of what has been found and concluding with an evidence statement. This evidence statement briefly summarises for the GDG the number of studies and participants, the quality of the evidence overall and any significance in the findings. An absence of evidence, or lack of sufficient evidence, can still generate an evidence statement which can then guide the GDG to consider other means of making a recommendation (NICE, 2013).

An important aspect of the role of the practitioner members on the GDG is that they do not represent the views of their professional organisations, but rather are appointed to the group by virtue of their expertise, skills and knowledge. Earlier in this paper, it was noted that subjective views of decision making, individual expertise and the reliance on limited practitioner knowledge are seen as running contrary to the evidence-based movement. However, what counts as evidence does not depend solely on published research, but also on how that evidence is then interpreted and the subsequent agreement of recommendations. This is done by the members of the GDG who mobilize a range of other knowledge, including their qualified opinions, experience and understanding of the context. This is applicable across all NICE guidelines in social care, public health and clinical practice.

Indeed much of the criticism of evidence-based guidelines in general has been amongst clinicians who claim that guidelines based predominately on evidence such as Randomised Controlled Trials were reducing their profession to 'cookbook medicine' (Sackett et al., 1996, p.71). Before NICE was established, one of the most quoted paragraphs ever published in the British Medical Journal acknowledged the increasing development of clinical guidelines, stating that 'the practice of evidence-based medicine means integrating individual clinical expertise with the best available external clinical evidence... by individual clinical expertise, we mean the proficiency and judgement that individual clinicians acquire through clinical experience and clinical practice' (Sackett et al., 1996, p.71). This statement is indicative that the authors believed that any separation of the science of medicine and the practice of it is in fact a false dichotomy, and that a combined approach is preferential. The appointment of a GDG with a range of perspectives, proficiencies and knowledge aims to do exactly the same in the production of guidelines aimed at social care; to bring together those with knowledge of the practice of social care to discuss and interpret the best available evidence on interventions and processes. In the absence of evidence, or where the quality of evidence is questionable; this is where the GDG and their interpretation of the evidence, or collective consensus on what should form the basis of a recommendation is invaluable by virtue of that very expertise.

# **Developing recommendations**

The predominant feature of the NICE guidelines is the recommendations which are made based on the available evidence. The recommendations are developed by the GDG and describe the relative value placed on outcomes, benefits and harms, net benefits and resource use, and the overall quality of the evidence; as well as any other influences on the group in reaching their decision. The wording of these recommendations is crucial and the below table illustrates how the strength of the evidence translates to how recommendations are worded in the guidelines.

Strength of Evidence	Wording to Use
Where the recommendation expands upon something where there is a legal duty, or where the consequences of not following the recommendation would be significant.	Must or Must not
Where the GDG is confident that the action will do more good than harm and be cost-effective.	Should + verb (strong) 'offer', 'refer', 'advise', and 'discuss' are also used for strong recommendations
Where the GDG is confident that the action will do more good than harm for most people and will be cost-effective, but that other options may be similarly effective or that there are cheaper alternatives which may be slightly less effective.	Could + consider (weak)
Where there is no evidence or a significant lack of evidence – recommendations may focus only on the research value of particular interventions where this is feasible and where they have a likely prospect of being beneficial to service users.	Research recommendations in the form of a question.

Agreeing recommendations across a large group of people is challenging as there are many different approaches to making group decisions and a lot depends on the individual members of the group and the dynamic cultivated throughout development. In the majority of cases, the GDG reaches decisions through a process of informal consensus, although formal consensus methods such as the Delphi Technique (Linstone & Turoff, 2002) and formal voting methods may also be used. It is also important to note that recommendations can be based on the GDG's view of current cost-effective practice where no other evidence has been identified, and consensus techniques can be used to capture those opinions and record any areas of disagreement. The 'evidence to recommendations' section of the guideline is clear on how decisions have been made.

It is worth noting that not only do all NICE guidelines have the benefit of having been developed using the best available evidence by practitioners and experts in the field, but that both the scope and the draft guideline are also subject to stakeholder consultation. Therefore, the recommendations will have been refined based on stakeholder feedback. On publication the recommendations will clearly identify the audience, the population covered, the setting, what specifically should be done and, if relevant, a timeframe for doing so. Having gone through this full process the guideline is then ready for publication and implementation.

# Implementation and professional judgement

The implementation of NICE guidelines for social care is a further challenge as the programme is still in its infancy, and the intended audience comes from a variety of backgrounds. Also, there is a need for NICE to tailor its messages and products to the social care sector as it is a new audience for NICE with a different language and a varied audience of practitioners, local authorities, commissioners and providers. Part of this implementation will be awareness raising, and emphasising the value of the guideline, assuring the sector that it has been produced in a robust and methodologically sound way. However, it will also rely on encouraging practitioners and professionals to use the guideline as a tool to enable effective decision making in conjunction with service users and to explore the options set out in the recommendations.

As regards the 'enforceability' of NICE guidelines, NICE guidelines for social care and clinical care are not legally binding, although strong links with social care regulators (CQC and Ofsted) will doubtless see recommendations strongly linked to inspection and regulation handbooks. Guidelines try and create consistency, to evidence best practice and to guide practitioners in their decisions. The development and use of guidelines provides an approach to social care based more on evidence and objective demonstration of 'what works' as opposed to an intuitive or subjective method. However as Woolf et al. (1999) highlight, guidelines need to be interpreted and applied in an appropriate manner and are just one option for improving the quality of care, that is, the guidelines cannot be applied in a vacuum with little regard to the service user narrative. The nature of guidelines is that they are formulated based on evidence derived from a sample population and therefore the recommendations or conclusions are not magic bullets. As the amusing analogy goes, 'just because the average UK dress size is 16, it does not mean all women should wear that size clothes' (Goodman, 1999, p.250); in other words, one size really doesn't fit all.

This interpretation could dispel any idea that NICE guideline recommendations are binding or could railroad social workers into using them against their professional judgement, much like the 'cookbook medicine' argument. There are many academic studies which argue that the use of judgement, intuition and lay knowledge is less preferable due to the limits of bounded rationality or the potential use of the representative heuristic which may result in bias and error (Rosen, 2003, p.199). However, in line with the commitment to person-centred care, NICE states in the introduction to all of its guidelines that whilst the primary audience (social care practitioners) are expected to take the guideline into account, this is not a substitute for professional judgement, as decisions are taken in conjunction with service users or carer(s) having discussed the risks, benefits, values and preferences enabling them to make a fully informed decision.

Therefore the status of 'quideline' as well as this introduction section should assure social care practitioners that professional judgement remains a prevalent feature in decisions about social care. Bearing this in mind, the challenge for NICE going forward will be to engage effectively with the social care sector to demonstrate the strength of the evidence used and encourage practitioners to exercise their judgement in conjunction with the recommendations set out in the quidelines and have regard for them. This is particularly relevant as a recent judgement in R (Elizabeth Rose) v Thanet Clinical Commissioning Group (CCG) held that Thanet CCG had acted unlawfully by having a policy on fertility which contradicted a NICE guideline, because the CCG did not have confidence in the strength of the evidence. NICE guidelines are not legally binding, but the court ruled that Thanet CCG was still under an obligation in public law to have regard for the guideline. The fact that the CCG simply disagreed with it and created a policy which was contrary to the guideline was unlawful (Laird, 2014). Therefore, part of the argument that NICE will have to make is that guidelines are a useful tool to deliver fundamental standards of care by demonstrating the robust process by which they have been developed and by highlighting the range of evidence from which the recommendations have been formulated. In addition, implementation tools and tailored versions of the guidelines may be produced for different audiences, to better help the sector understand the key messages, as well as signposting them to resources which can help them get the research into practice, and potentially demonstrate this as an example of shared learning to the rest of the sector.

#### Conclusion

Evidence-based social care is a contentious issue, particularly when considering the quality and range of evidence that is available. This paper has discussed the challenges facing NICE in the development of guidelines for the social care sector, and has explored how NICE has responded to these challenges.

Firstly, the challenge of overcoming the assumption that NICE's experience in developing clinical guidelines will result in the rigid application of a 'medical model' on social care guidelines, whereby only 'gold standard' evidence such as Randomised Controlled Trials should be used and considered to be 'evidence'. It has been shown that this type of evidence is not always available even for clinical conditions, and experience from the development of early social care guidelines and public health guidelines is that a traditional medical hierarchy of research evidence would not be applicable to social care. To develop recommendations based only on available evidence in the form of systematic reviews and RCTs would be a significant challenge; and therefore a more inclusive methodology is required.

NICE has addressed this in the development of the social care guideline development manual, which includes more robust methodologies allowing the reviewers to take a broader view of evidence, using a range of search methods and putting out calls for evidence where this is required. The involvement of practitioners, professionals and service users and carers in the development of the guidelines also adds the dimension of expertise from those immersed in the sector. These methodologies are included in the new NICE Process and Methods Manual which came into effect on 1<sup>st</sup> January 2015 and harmonises guideline development across various guideline development centres within NICE and ensures that all guidelines are developed using substantially similar processes and methods.

By addressing these challenges of development, NICE is now well underway in the delivery of social care guidelines, with the first publications due in summer 2015. The next challenge is of implementing and disseminating the guidelines to the social care sector and encouraging their use in order to improve care and support and limit variation in practice where possible. In conjunction with practitioner-friendly tools and resources targeted at different audiences, and the capturing of shared learning; this will be how NICE's foray into social care will ensure that evidence truly gets into practice and that 'what counts is what works'.

#### References

Adams, K.B., Matto, H.C. & LeCroy, C.W. (2009) 'Limitations of evidence-based practice for social work education: unpacking the complexity', Journal of Social Work Education, 45(2), pp. 165-186.

Cabinet Office, White Paper (1999) Modernising Government, London: HMSO.

Cartwright (2007) 'Are RCTs the gold standard?', BioSocieties, 2(1), pp. 11-20.

Department of Health (1999) Framework for the Assessment of Children in Need and their Families, Consultation document, September, London: HMSO.

EBRO (2007) Handleiding voor werkgroepleden [Manual for working group members], Utrecht: Kwaliteitsinstituut voor de Gezondheidszorg CBO, accessed 17 September 2014 at: http://www.ha-ring.nl/download/literatuur/EBRO handl totaal.pdf (from Knaapen, 2013).

Goldenberg, M.J. (2009) 'Iconoclast or creed? Objectivism, pragmatism and the hierarchy of evidence', Perspectives in Biology and Medicine, 52(2), pp. 168-187.

Goodman, N.W. (1999) 'Who will challenge evidence-based medicine?', Journal of the Royal College of Physicians of London, 33(3), pp. 249-251.

Gould, N. & Kendall, T. (2007) 'Developing the NICE/SCIE guidelines for dementia care: the challenges of enhancing the evidence base for social and health care', British Journal of Social Work, **37**(3), pp. 475-490.

Howe, E. (2012) NICE to help drive standards in social care, accessed at: https://www.gov.uk/government/news/nice-to-help-drive-standards-in-social-care.

Kahneman, D. (2011) Thinking Fast and Slow, New York: Farrar, Straus & Giroux.

Knaapen, L. (2013) 'Being evidence-based in the absence of evidence: the management of non-evidence in guideline development', Social Studies of Science, 43(5), pp. 681-707.

Laird, K. (2014) When NICE guidance is more than just guidance – the duty on CCGs following R (Elizabeth Rose) v Thanet Clinical Commissioning Group, Wragge & Co, accessed at: http://www.wragge-law.com/insights/when-nice-guidance-is-more-than-just-guidance-the/

Linstone, H.A. & Turoff, M. (eds) (2002) The Delphi Method: Techniques and Applications, accessed at: http://is.njit.edu/pubs/delphibook/

MacDonald, G. (1999) 'Evidence-based social care: wheels off the runway?', Public Money and Management, **19**(1), pp. 25-32.

NICE (2013)The Social Care Guidance Manual. accessed at: http://www.nice.org.uk/article/PMG10/chapter/1%20Introduction

Nutley, S., Davies, H. & Walter, I. (2002) Evidence Based Policy and Practice: Cross Sector Lessons From the UK, Working Paper 9, London: ESRC UK Centre for Evidence Based Policy and Practice.

Rosen, A. (2003) 'Evidence-based social work practice: challenges and promise', Social Work Research, **27**(4), pp. 197-208.

Sackett, D.L., Rosenberg, W.M., Gray, J.A., Haynes, R.B. & Richardson, W.S. (1996) 'Evidence-based medicine: what it is and what it isn't', British Medical Journal, 312, pp. 71-72.

#### 28 John McLean

Webb, S. (2001) 'Some considerations on the validity of evidence-based practice in social work', *British Journal of Social Work*, **31**(1), pp. 51-79.

Woolf, S.H., Groll, R., Hutchinson, A., Eccles, M. & Grimshaw, J. (1999) 'Clinical guidelines: potential benefits, limitations and harms of clinical guidelines', *British Medical Journal*, **318**, pp. 527-539.

#### **Notes on Contributor**

**John McLean** is a Law graduate with a Postgraduate Diploma in Local Government Management. He has worked for various local authorities and public sector bodies, predominately in the field of social care policy and performance and is in the final stages of an MSc in Leadership and Management.

# Correspondence

Email: john.h.mclean7@gmail.com

# Numbers of working carers whose employment is 'at risk' in England

Derek King<sup>1</sup>, Linda Pickard<sup>1</sup>, Nicola Brimblecombe<sup>1</sup> and Martin Knapp<sup>1</sup>

<sup>1</sup> PSSRU, London School of Economics and Political Science

#### Abstract

Recent evidence suggests that a key threshold at which carers in England are at risk of leaving employment occurs when unpaid care is provided for 10 or more hours a week, a lower threshold than previously thought. Previous studies had shown that providing care for 20 or more hours a week had a negative effect on employment. One implication is that there are more working carers whose employment is at risk than previously thought. This paper aims to estimate the numbers of working carers whose employment is at risk because they provide care for 10 or more hours a week. A subsidiary aim is to estimate the numbers of working carers providing care for 10 or more hours a week to someone in a private household. Using the 2011 Population Census, Understanding Society (2010/11) and the Survey of Carers in Households (2009/10), we find that there are approximately 790,000 working carers aged 16-64 whose employment is at risk because they provide care for 10 or more hours a week. Of these, approximately 735,000 provide care to someone in a private household. There are nearly a quarter of a million more carers whose employment is at risk than previously thought.

Keywords: unpaid carers, employment, hours of caring, England

# Background

In the context of population ageing, there is increasing emphasis in government policy in England on enabling people to combine unpaid care and employment (Her Majesty's Government (HMG), 1999, 2008, 2010, 2014; HMG & Employers for Carers, 2013). Need for care is rising and the government is keen to support the provision of unpaid care to meet this need. Yet, at the same time, the government is extending working lives and encouraging older workers, who are particularly likely to provide unpaid care, to continue in employment. Therefore, one of the priorities of the Coalition Government's *Carers Strategy* is to enable 'those with caring responsibilities to fulfil their education and employment potential' (HMG, 2010, p.6), an objective restated in the *Carers Strategy: Second National Action Plan 2014-2016* (HMG, 2014). The *2014 Care Act* broadens eligibility for local authority assessments of carers, and states that assessments must consider whether the carer wants to work, as well as introducing a new duty on local authorities to provide support to meet carers' needs.

If local authorities are to meet carers' needs in relation to their employment, it would be helpful if they had a clear understanding of when a carer's employment is likely to be at risk. Recent evidence suggests that the threshold at which carers leave the labour market in England is lower than previously thought (King & Pickard, 2013). Previous studies had shown that care provided for 20 or more hours a week had a significant impact on employment (Heitmueller, 2007; Carmichael *et al.*, 2010). However, King and Pickard's research found that a key threshold at which carers are at risk of losing their employment in England can occur when care is provided for only 10 hours a week (King & Pickard, 2013).

If carers' employment is at risk at a lower threshold than previously thought, the implication is that there are more working carers whose employment is at risk. Assuming that the threshold at which carers' employment is at risk is 20 or more hours a week, then Census information can be used directly to estimate the numbers of carers whose employment is at risk, because the Census includes the relevant information. The 2011 Census shows that there are over half a million working carers in England who care for 20 or more hours a week (Nomis, 2013). However, in order to estimate the numbers of working carers providing care for 10 or more

hours a week, there is a need for large-scale survey information that includes data on care provided at this lower threshold.

The main purpose of this paper is to estimate the numbers of working carers in England whose employment is at risk because they provide unpaid care for 10 or more hours a week. The estimate is based on numbers derived from the 2011 Census, where relevant published information is available. In addition, the estimate uses the *UK Household Longitudinal Study (Understanding Society)* (2010/11) to identify working carers who provide care for 10 or more hours a week, since relevant information is included in the survey (University of Essex, 2012).

A further aim of the paper is to estimate the numbers of working carers providing care for 10 or more hours a week to someone living in a *private household*, rather than to someone living in residential care (hospital, residential care home or nursing home). Not all definitions of unpaid care include people caring for someone in residential care and, in particular, the *General Household Survey* (GHS) definition of unpaid care excludes 'those caring for someone receiving care in an institution' (Maher & Green, 2002, p.3). The identification of those caring for someone living in a private household is achieved in the present study using the 2009/10 *Survey of Carers in Households* in England, which was largely based on the GHS (Health and Social Care Information Centre (HSCIC), 2010).

This paper has sections on data and methods; findings; and discussion and conclusions. There are three stages in the analysis, and the methods and findings sections are both structured around these stages. The first stage is concerned with the *factors* affecting provision of care for 10 or more hours a week and provision of care to someone in a private household. The second stage is concerned with dividing the numbers of working carers in the Census by the factors affecting provision of different types of care. This stage is needed because the published Census information does not provide information on working carers by all the relevant variables. The third stage is concerned with estimating the numbers of working carers providing care for 10 or more hours a week, as well as the numbers of working carers providing care for 10 or more hours a week to someone in a private household.

#### **Data and methods**

# Data

In making estimates of the numbers of working carers in England whose employment is at risk, the paper draws on three sources of information: the 2011 Census, *Understanding Society* (2010/11) and the *Survey of Carers in Households* (2009/10).

The UK Census included a question on unpaid care for the first time in 2001, and the question was repeated in 2011. Published information from the 2011 Census includes numbers of employees in England who provide unpaid care, by gender, employment status (part-time/full-time work) and hours of care provided. The Census defines unpaid care as looking after 'family members, friends, neighbours or others because of long-term physical or mental ill health or disability, or problems related to old age' (Office for National Statistics (ONS), 2014, p.43). Information is available on care provided for 1-19 hours, 20-49 hours and 50 or more hours a week.

*Understanding Society* is a longitudinal survey of people living in UK households, which includes questions about unpaid care provision (University of Essex, 2012). The present paper uses weighted cross-sectional individual level data for England from the 2010/11 survey (wave 2), using weights supplied by the *Understanding Society* study team. The number of people in the weighted sample is 32,486 individuals aged 16 years and over, of whom 5,691 provide unpaid care and 2,450 are working carers. The survey allows for most carers to be classified according to provision of care for 10 or more hours a week.<sup>2</sup>

The Survey of Carers in Households is a survey of adult carers in the general population, carried out in 2009/10 (HSCIC, 2010). The survey captures information about people aged 16

years and over providing unpaid care in a nationally representative sample of households in England. The weighted sample size of working carers in the Survey of Carers in Households is 1,169 individuals. In the survey, people who care exclusively for someone in residential care are not defined as 'carers' and, in order to establish this, the survey asks the carer whether the cared-for person usually lives in a hospital, residential or nursing home, thereby allowing for the identification of carers who look after people in private households. In the survey, carers who care exclusively for someone in residential care are not asked further questions, so there is no information on the hours of care they provide. The data on provision of care to someone living in a private household, rather than in residential care, therefore relates to all carers, and this needs to be borne in mind in the analysis that follows.

Where possible, the analysis here used *Understanding Society* because the survey has a larger sample size of working carers and a more robust methodology than the Survey of Carers in Households.3

#### Methods: factors affecting provision of different types of care

Two different types of care were analysed here: care for 10 or more hours a week, using Understanding Society, and care for someone in a private household, using the Survey of Carers in Households. Multivariate logistic regression analysis of data from each survey was used to determine the factors to be taken into account in dividing the population of working carers by the type of care provided.4

The covariates in the logistic regression analyses were age, gender and ethnicity, all of which are likely to affect the type of care provided (Parker & Lawton, 1994; Young et al., 2005; Dahlberg et al., 2007). Only a small number of variables were considered because care provision is likely to be endogenously associated with many factors. This means that, beyond age, gender and ethnicity, which are largely unchangeable, we cannot be absolutely sure about the direction of the relationship between caring and other variables, and other variables are therefore not usually included in explanatory models of care provision (Parker & Lawton, 1994; Richards et al., 1996). The division by employment status, which is available in the Census figures for working carers, was retained in the present analysis, so that all analyses controlled for whether the carer worked part- or full-time. Following the definition used in the Census, fulltime employment was defined as working for over 30 hours a week.<sup>5</sup> The analysis was concerned with working carers under the age of 65 years, 6 and age was divided into three broad age-groups: 16-44 years; 45-54 years and 55-64 years. Ethnicity was divided into two categories: people from Black and Minority Ethnic (BME) backgrounds and those not from BME backgrounds. In the logistic regression analysis, the odds ratio for each variable was estimated, along with the significance level. A level of 0.05 was used as the criterion to determine significance. For each model we compared the fit (based on likelihood ratio Chi-squared statistics) of the full model, with all covariates included, and the final model, including only significant covariates. In each case, the final model had a better fit than the full model, and is reported here.

The logistic regression analysis initially considered provision of care for 10 or more hours a week using *Understanding Society*. Numbers of carers providing care for 20 or more hours a week were derived from the 2011 Census (as explained below), so the analysis was concerned with dividing working carers who provide care for less than 20 hours a week into those caring for under 10 hours a week and those caring for 10-19 hours a week.

The logistic regression analysis then considered provision of care to someone living in a private household using the Survey of Carers in Households. As already noted, there was no information on the hours of care provided by those caring exclusively for someone in residential care in the Survey of Carers in Households, so the analysis relates to all carers, whether or not they care for 10 or more hours a week.

The results of the logistic regression analysis were used to derive percentages of working carers providing different types of care, by age, gender, ethnicity and employment status. These percentages were subsequently used to estimate the numbers of working carers providing different types of care by relevant characteristics.

#### Methods: estimation of numbers of working carers by key characteristics

The multivariate analysis took into account gender, age, ethnicity, employment status and provision of care above and below 20 hours a week. However, of these variables, the published Census information only includes numbers of working carers by gender, employment status and hours of care provided, and does not include numbers of working carers by age and ethnicity. Therefore, the Census numbers potentially needed to be broken down further by age and ethnicity, and this was achieved using *Understanding Society*. This breakdown allowed for the factors affecting provision of different types of care to be taken into account in the estimation of numbers of working carers by type of care provided.

The further breakdown of the Census numbers by relevant characteristics was preceded by bivariate analysis of the distributions of working carers by age and ethnicity, using sample data from *Understanding Society*. Previous studies suggest that the age and ethnicity of carers may vary by the hours of care provided (Young *et al.*, 2005; Pickard, 2007). In order to take this into account, the distributions by age and ethnicity in the sample data were examined using bivariate analysis to identify variations according to provision of care for under 20 hours a week and for 20 or more hours a week, controlling for gender and employment status. Significant differences in distributions by age and ethnicity were identified using a Chi-squared test of the associations.

The results of the bivariate analysis were used to derive distributions of working carers by age and ethnicity, controlling for gender, employment status and hours of care provided. These distributions were then used in the estimation of numbers of working carers by key characteristics.

# Methods: estimation of numbers of working carers providing care for 10 or more hours a week

Working carers providing care for 10 or more hours a week were identified in the following way. Numbers caring for 20 or more hours a week, derived from the Census, were included in the estimate of numbers at or above the 10 hours a week threshold. As indicated above, those caring for under 20 hours a week were divided into those caring above and below 10 hours a week, using data from *Understanding Society* (2010/11). The percentages providing care for 10-19 hours a week were applied to the numbers of full-time and part-time working carers providing care for under 20 hours a week, by age, gender and ethnicity. The numbers caring for 10-19 hours a week were then added to the numbers caring for 20 or more hours a week, in order to estimate the total numbers of working carers providing care for 10 or more hours a week.

Working carers providing care for 10 or more hours a week were then divided into those caring for someone in a private household and those caring exclusively for someone in residential care, using data from the *Survey of Carers in Households*. The percentages of working carers providing care to someone in a private household were applied to the numbers of full-time and part-time working carers caring for 10 or more hours a week, by relevant characteristics. As indicated earlier, the information on provision of care to someone usually living in residential care in the *Survey of Carers in Households* was not available by the number of hours of care provided, and so the assumption was made that the probability of providing care to someone in a private household is the same for all working carers, irrespective of the amount of care provided.

# **Findings**

#### Factors affecting provision of different types of care

Logistic regression analysis was used to examine the factors affecting, first, provision of care for 10-19 hours a week, rather than care for less than 10 hours a week and, second, provision of care to someone living in a private household, rather than in residential care. In both analyses, the covariates were age, gender, ethnicity and employment status.

The results of the first logistic regression analysis, using *Understanding Society*, are shown in **Table 1**. The table relates to working carers providing care for under 20 hours a week and shows the factors affecting provision of care for 10-19 hours a week, compared to less than 10 hours a week. The final model, including only significant covariates, is shown in the table. The results show that gender and ethnicity significantly affect working carers' provision of care for 10-19 hours a week, compared to less than 10 hours a week. Women carers have significantly higher odds of providing care for 10-19 hours a week than men, controlling for ethnicity. Working carers from BME backgrounds have significantly higher odds of providing unpaid care for 10-19 hours a week than those who are not from BME backgrounds, controlling for gender.

**Table 2** shows the proportions of working carers, caring for under 20 hours a week, who provide care for under 10 hours a week and for 10-19 hours a week, by gender and ethnicity. The table shows that, of the working carers providing care for less than 20 hours a week, 86 per cent provide care for under 10 hours a week and 14 per cent provide care for 10-19 hours a week. Only nine per cent of male working carers, who are not from BME backgrounds, provide care for 10-19 hours a week, compared to 16 per cent of women carers from similar backgrounds. The percentages of working carers from BME backgrounds who care for long hours are even higher. It is the percentages shown in **Table 2** that are later used to estimate the numbers of working carers providing care for 10 or more hours a week.

The results of the second logistic regression analysis, using the *Survey of Carers in Households*, are shown in **Table 3**. The table shows the factors affecting provision of care to someone living in a private household, compared to those caring exclusively for someone living in residential care. The final model, including only significant covariates, is shown in the table. The results show that age and employment status significantly affect provision of care to someone living in a private household. Working carers aged 55-64 years have significantly lower odds than younger carers of looking after someone living in a private household, and are more likely to care for someone living in residential care, controlling for employment status. Carers who work full-time have significantly lower odds than those who work part-time of caring for someone living in a private household, and are more likely to care for someone living in residential care, controlling for age.

**Table 1**. Working carers aged 16-64 years who provide care for less than 20 hours a week: regression results for factors associated with provision of care for 10-19 hours a week, England 2010/11.

		Odds ratio, p value and significance level		
		Odds ratios	p value & significance level	
Gender	Men	1.0		
	Women	1.9	p = <0.001**	
Ethnicity	Non-BME background	1.0	·	
•	BME background	1.7	p = 0.018*	
Constant	· ·	0.1	p = <0.001**	
N		1,935	•	

Source: Understanding Society, 2010/11

Notes: Significance levels, \* p < 5%; \*\* p < 1%. BME refers to Black and Minority Ethnic. The full model also included age and employment status but these covariates were not significant and are not reported in the final model, shown in the table.

Table 2. Working carers aged 16-64 years who provide care for less than 20 hours a week: percentages providing care for under 10 hours a week and 10-19 hours a week, England 2010/11.

Sample numbers and percentages Ethnicity Gender Hours a week of care provided 10-19 hours a week Under 10 hours a week Sample base Number % Number 632 91.1% 8.9% Non-BME background Men 62 694 Women 967 83.8% 187 16.2% 1,154 BME background Men 59 81.9% 13 18.1% 72 83 Women 65 78.3% 18 21.7% All caring under 20 hours a week 1,723 86.0% 280 14.0% 2003

Source: Understanding Society, 2010/11 Note: BME refers to Black and Minority Ethnic.

**Table 3.** Regression results for factors associated with provision of unpaid care to someone living in a private household by working carers aged 16-64 years, England 2009/10.

Odds ratio, p value and significance level p value and significance level Odds ratios Age 16-44 years 1.0 45-54 years 8.0  $p = 0.486 \, ns$ 55-64 years 0.3 p = <0.001\*\*Employment status Part-time 1.0 Full-time 0.6 p = 0.028\*Constant 35.6 p = <0.001\*\*Ν 961

Source: Survey of Carers in Households, 2009/10

Notes: Significance levels, \* p <5%; \*\* p <1%; ns = not significant. The analysis relates to all working carers irrespective of hours of care provided. The full model also included gender and ethnicity but these covariates were not significant and are not reported in the final model, shown in the table.

Table 4 shows the proportions of working carers providing care to people in residential care and to people in private households, by age and employment status. The table shows that, overall, 93 per cent of all working carers look after someone living in a private household and seven per cent care exclusively for someone living in residential care. At ages 16-44 years, only two per cent of carers working part-time care for someone living in residential care, whereas at ages 55-64 years, 10 per cent of carers working part-time, and 15 per cent of carers working full-time, look after someone in residential care. The percentages shown in Table 4 are later used to estimate the numbers of working carers providing care for someone living in a private household.

#### Numbers of working carers by key characteristics

The analysis so far suggests that the carer's gender, age, ethnicity and employment status, as well as hours of care provided, are all relevant to the estimation of the numbers of working carers providing care for 10 hours a week or more to someone in a private household. Of these characteristics, the published 2011 Census information includes information on the numbers of working carers by gender, employment status and hours of care provided. The estimation of numbers of working carers by key characteristics therefore begins with these numbers in the 2011 Census. **Table 5** shows that, according to the 2011 Census, there are approximately 2.3 million employees who provide unpaid care in England. Of these, over half a million (575,000) provide care for 20 or more hours a week.

**Table 4**. Percentages of working carers aged 16-64 years providing unpaid care to someone living in a private household, England 2009/10.

Sample numbers and percentages **Employment** Whether provides care to someone living in a Age groups private household status Cares exclusively for Cares for someone in Sample base someone in residential private household care Number Number Part-time 16-44 years 1.7% 172 98.3% 175 3 4.1% 45-54 years 6 141 95.9% 147 55-64 years 10.0% 90.0% 130 13 117 Full-time 16-44 years 15 5.6% 254 94.4% 269 45-54 years 12 5.7% 199 94.3% 211 55-64 years 23 15.0% 130 85.0% 153 All working carers aged 16-64 years 72 6.6% 1,013 93.4% 1,085

Source: Understanding Society, 2010/11

Notes: For reasons given in the text, the analysis relates to all working carers irrespective of hours of care provided. Residential care refers to a hospital, residential care home or nursing home.

**Table 5**. Numbers of employees providing unpaid care, by gender, employment status and hours of care provided, England, 2011 Census.

Numbers in thousands (to nearest 5,000) Gender Employment status Hours of care provided Part-time Full-time Total Men Under 20 hours a week 100 620 720 20 or more hours a week 40 195 235 All men 140 815 955 Women Under 20 hours a week 480 1,045 560 20 or more hours a week 190 150 340 710 All women 1,380 670 Under 20 hours a week 580 1,765 Men and women 1,185 20 or more hours a week 230 345 575 All working carers 810 1,530 2,340

Source: 2011 Census (Nomis, 2013)

Note: Figures may not add exactly due to rounding.

The numbers of working carers by gender, employment status and hours of care provided are further broken down by age and ethnicity, using sample data from *Understanding Society*. Using bivariate analysis, the age and ethnicity distributions for men and women carers, employed part-time and full-time, are compared in terms of the hours of care provided, that is, whether or not care is provided for 20 or more hours a week (**Table 6**). The results show that there is no significant difference in the age and ethnicity distributions of working carers by the hours of care provided, with one exception. The age and ethnicity distribution of male carers working full-time varies significantly by hours of care provided. Male carers working full-time and not from BME backgrounds, who care for under 20 hours a week, have a younger age-profile than similar men caring for 20 or more hours a week.

The relationships identified in the bivariate analysis inform the distributions used in the estimation of numbers of working carers, by age and ethnicity (**Table 7**). Different age and ethnicity distributions apply to male carers working full-time who care for under 20 hours a week than male carers working full-time who care for 20 hours a week or more. However, the same age and ethnicity distributions apply to male carers working part-time and women carers working part-time and full-time, irrespective of the hours of care they provide. In **Table 7**, the percentages are expressed in terms of the total numbers of working carers from both types of ethnic background together, because (as **Table 6** indicates) sample sizes of working carers from BME backgrounds are small.

**Table 6**. Bivariate analysis: age and ethnicity distributions of men and women working carers, employed part-time and full-time, by hours of care provided, England 2010/11.

Column percentages and Chi-square association Men Age groups Women and Works part-time Works full-time Works full-time Works part-time ethnicity Cares for < 20 hrs 20+ hrs < 20 hrs 20+ hrs < 20hrs 20+ hrs < 20 hrs 20+ hrs Non-BME 41.7% 16-44 years 31.1% 34.8% 38.5% 36.7% 40.0% 39.0% 36.6% 45-54 years 19.8% 13.0% 35.8% 37.2% 32.0% 36.3% 43.8% 45.1% 55-64 years 43.5% 19.2% 25.7% 16.9% 29.2% 21.9% 20.7% 16.9% 1.4% 65 years 19.8% 8.7% 0.5% 5.1% 5.7% 3.0% 0.4% 106 23 78 635 135 71 Ν 611 557 Chi-square p = 0.002 (\*\*)p = 0.4 (ns)p = 0.3 (ns)p = 0.7 (ns)**BME** 16-44 years 70.2% 72.7% 68.4% 64.4% 40.0% 84.6% 66.7% 65.0% 45-54 years 7.7% 16.7% 21.3% 0.0% 23.7% 30.0% 24.4% 30.0% 16.7% 55-64 years 8.5% 5.3% 11.1% 30.0% 3.8% 27.3% 5.0% 65 years 3.8% 0.0% 0.0% 0.0% 2.6% 0.0% 0.0% 0.0% Ν 26 6 47 11 38 20 45 10 Chi-square p = 0.6 (ns)p = 0.08 (ns)p = 0.9 (ns)p = 0.2 (ns)

Source: Understanding Society, 2010/11

Notes: Significance levels, \*\* p < 1%; ns = not significant. Column percentages may not add to 100% because of rounding. BME refers to Black and Minority Ethnic. 'Hrs' refers to 'hours per week'.

**Table 7**. Age and ethnicity distributions of men and women working carers, employed part-time and full-time, by hours of care provided, England 2010/11.

					Per	centages
Ethnicity	Age groups	Men			Women	
	(in years)	Working part-time	Working full-time, cares < 20 hrs pw	Working full-time, cares 20+ hrs pw	Working part-time	Working full-time
Non-BME	16-44	25.5%	38.8%	33.7%	34.4%	35.4%
	45-54	14.9%	33.3%	32.6%	30.0%	40.5%
	55-64	25.5%	20.4%	16.9%	23.5%	15.6%
	65 and over	14.3%	0.5%	4.5%	5.0%	0.4%
BME	16-44	16.1%	5.0%	9.0%	4.8%	4.8%
	45-64	3.1%	2.1%	3.4%	2.3%	3.3%
	65 and over	0.6%	0.0%	0.0%	0.1%	0.0%
	All	100%	100%	100%	100%	100%
N		161	658	89	841	693

Source: Understanding Society, 2010/11

Notes: Percentages may not add to 100% because of rounding. The words 'hours per week' are abbreviated to 'hrs pw'. BME refers to Black and Minority Ethnic. In this and subsequent tables, the age groups of carers from BME backgrounds, aged 45-64 years, are reduced from two groups (45-54, 55-64 years) to one (45-64 years) because of small sample sizes.

**Table 8**. Estimated numbers of working carers providing unpaid care *for under 20 hours a week and for 20 or more hours a week*, by gender, employment status, age and ethnicity, England 2011.

Estimated numbers in thousands (to nearest 5,000) Ethnicity Men Women Men and women and age Cares for Cares for Cares for Cares for Cares for groups < 20 hrs pw 20+ hrs pw < 20 hrs pw 20+ hrs pw . Works Works Works 20+ ΑII (in years) Works Works Works Works Works < 20 fullfullfullpartfullhrs hrs partpartparttime time time time time time time time pw pw Non-BME 16-44 25 240 10 65 200 55 630 195 825 165 65 45-54 15 205 5 65 145 230 55 60 595 780 185 55-64 25 35 25 125 10 115 85 45 355 110 465 65 +15 <5 5 10 25 <5 10 <5 45 25 70 **BME** 15 30 5 15 25 25 10 5 95 40 135 16-44 5 5 5 45 45-64 15 10 20 5 15 65 <5 <5 <5 <5 <5 65+ <5 <5 <5 100 620 40 195 480 560 150 1,765 575 Total 16+ 190 2,340 85 35 185 460 560 150 Total 16-64 620 180 1,720 550 2,270

Sources: 2011 Census (Nomis, 2013); Understanding Society (2010/11)

Notes: Figures may not add exactly due to rounding. The words 'hours per week' are abbreviated to 'hrs pw'. BME refers to Black and Minority Ethnic.

The distributions by age and ethnicity (**Table 7**) are now applied to the numbers of working carers in the Census by gender, employment status and hours of care provided (**Table 5**) to produce an estimate of the numbers of working carers, by key characteristics. The results are shown in **Table 8**. As indicated earlier, the estimate of the numbers of working carers whose employment is at risk relates to those aged under 65 years. Of the 2,340,000 working carers in the 2011 Census, an estimated 2,270,000 are estimated to be 16-64 years old and, of these, approximately 550,000 provide unpaid care for 20 or more hours a week.

## Numbers of working carers providing care for 10 or more hours a week

The numbers of working carers aged 16-64 years who provide unpaid care for 10 or more hours a week are now estimated, and the results are shown in **Table 9**. Those caring for 20 or more hours a week are reproduced from **Table 8**. Those caring for less than 20 hours a week are divided into those caring for under 10 hours a week and for 10-19 hours a week, by applying the percentages shown in **Table 2** to the numbers caring for under 20 hours a week shown in **Table 8**. The numbers caring for 10 or more hours a week consist of those caring for 10-19 hours a week, plus those caring for 20 or more hours a week (**Table 9**). The results show that there are approximately 790,000 working carers aged 16-64 years in England whose employment is at risk because they provide unpaid care for 10 or more hours a week. Of these, approximately 240,000 care for 10-19 hours a week and approximately 550,000 care for 20 or more hours a week.

The numbers of working carers providing care for 10 or more hours a week to someone living in a private household are shown in **Table 10**. These results are obtained by multiplying the percentages of working carers providing care to someone in a private household (**Table 4**) by the numbers of working carers caring for 10 or more hours a week (**Table 9**), by relevant characteristics. The results show that, of the 790,000 working carers in England who provide care for 10 or more hours a week, approximately 735,000 look after someone in a private household (**Table 10**). This implies that approximately 55,000 working carers, who provide care for 10 or more hours a week, care exclusively for someone in residential care.

**Table 9**. Estimated numbers of working carers aged 16-64 years providing unpaid care *for 10 or more hours a week*, by gender, employment status, hours of care, age and ethnicity, England 2011.

Estimated numbers in thousands (to nearest 5,000) Working full-time, cares for Gender, Working part-time, cares for Total ethnicity and 20+ 10-19 20+ 10 +10-19 20+ 10+ 10-19 10+ age groups hrs pw (in years) Men Non-BME 16-44 <5 45-54 <5 55-64 <5 **BME** 16-44 <5 45-64 <5 <5 <5 <5 <5 All men Women Non-BME 16-44 45-54 55-64 **BME** 16-44 45-64 <5 <5 All women All men & women 

Sources: 2011 Census (Nomis, 2013); Understanding Society (2010/11)

Notes: Figures may not add exactly due to rounding. The words 'hours per week' are abbreviated to 'hrs pw'. BME refers to Black and Minority Ethnic.

**Table 10**. Estimated numbers of working carers aged 16-64 years providing unpaid care for 10 or more hours a week *to someone living in a private household*, by gender, employment status, hours of care, age and ethnicity, England 2011.

				Estim	ated num	bers in the	ousands (i	to nearest	t 5,000)
Gender,	Working	part-time, o	ares for	Working	full-time, c	ares for	•	Total	•
ethnicity and	10-19	20+	10+	10-19	20+	10+	10-19	20+	10+
age groups	hrs pw	hrs pw	hrs pw	hrs pw	hrs pw	hrs pw	hrs pw	hrs pw	hrs pw
(in years)	•	•	•	•		•	•		
Men									
Non-BME									
16-44	<5	10	15	20	60	80	25	70	95
45-54	<5	5	5	15	60	75	20	65	85
55-64	<5	10	10	10	30	35	10	40	50
BME									
16-44	<5	5	10	5	15	20	10	25	30
45-64	<5	<5	<5	<5	5	10	<5	5	10
All men	10	35	45	55	170	225	65	205	270
Women									
Non-BME									
16-44	25	65	90	30	50	80	55	115	170
45-54	20	55	75	35	60	95	55	110	170
55-64	15	40	55	10	20	30	30	60	85
BME									
16-44	5	10	15	5	5	10	10	15	25
45-64	<5	<5	5	5	5	10	5	10	15
All women	70	170	240	85	140	225	160	310	470
All men & women	80	205	285	140	310	450	220	515	735

Sources: 2011 Census (Nomis, 2013); Understanding Society (2010/11); Survey of Carers in Households (2009/10) Notes: Figures may not add exactly due to rounding. The words 'hours per week' are abbreviated to 'hrs pw'. BME refers to Black and Minority Ethnic.

## Discussion and conclusions

Recent evidence suggests that the threshold at which carers leave the labour market is lower than previously thought. Earlier studies showed that care provided for 20 or more hours a week had a significant impact on employment (Heitmueller, 2007; Carmichael et al., 2010). However, a more recent study shows that carers are at risk of losing their employment when care is provided for only 10 or more hours a week (King & Pickard, 2013). The implication is that there are more working carers whose employment is at risk than previously thought.

The present paper shows that there are approximately 790,000 working carers aged 16-64 years in England whose employment is at risk because they provide unpaid care for 10 or more hours a week. At a threshold of 20 or more hours a week, the employment of approximately 550,000 working carers is at risk. Therefore, there are approximately 235,000 more carers whose employment is at risk in England than previously thought.

The validity of our estimate of the numbers of working carers providing unpaid care for 10 or more hours a week derives from the fact that the figures come primarily from the 2011 Census and therefore derive mainly from numbers in the population rather than sample data. The Census identifies over half a million working carers providing care for 20 or more hours a week in England. Of the 790,000 working carers estimated in this paper to be providing care for 10 or more hours a week, the majority care for 20 or more hours a week and information on them is derived from numbers in the 2011 Census. Therefore, although secondary analysis of sample data has been used in our estimate of the numbers of carers whose employment is at risk, a key strength of our estimate is that it primarily draws on numbers from the Census.

In addition, the present study has estimated the number of working carers who provide care for 10 or more hours a week to someone living in a private household. This figure has been estimated because not all definitions of unpaid care include people caring for someone in residential care. The present study finds that 93 per cent of working carers caring for 10 more hours a week look after someone living in a private household. Of the 790,000 working carers whose employment is at risk, approximately 735,000 care for someone living in a private household.

The estimate of the numbers of working carers who provide care for 10 or more hours a week rests partly on an analysis of the factors affecting provision of care using cross-sectional data from *Understanding Society (2010/11)*. The study shows that, among working carers who care for under 20 hours week, gender and ethnicity affect provision of care at or above the 10 hours a week threshold. Working carers who are women or from BME backgrounds are significantly more likely to care for longer hours than men or carers not from BME backgrounds. These results are consistent with previous research on working carers, which shows that women and those from BME backgrounds are more likely than others to care for 10 or more hours a week (Corti et al., 1994; Buckner & Yeandle, 2006).

The estimate of numbers of working carers who provide care for 10 or more hours a week to someone living in a private household rests partly on an analysis of the factors affecting provision of care using data from the Survey of Carers in Households (2009/10). The study shows that the overwhelming majority of working carers look after people in private households, but that those aged 55-64 years and those working full-time are more likely than others to care for someone in residential care. Although more recent evidence does not seem to be available, our findings are consistent with earlier literature, which shows that carers of older people in care homes in England are more likely to be the children of the cared-for person than carers of older people in private households (Bond et al., 1999) and that most carers looking after their parents are in mid-life or older (HSCIC, 2010).

The number of working carers whose employment is at risk is likely to increase in the coming years in response to population ageing and, in this context, it is important that policy and practice provide greater support for working carers. The present analysis is part of a wider study looking at the costs of meeting the unmet needs for services of working carers whose employment is at risk (Pickard *et al.*, 2013). The very large numbers of carers whose employment is at risk, which has been identified in the present paper, suggests that the costs of meeting their needs for services may be high. The key question is whether the public expenditure costs of meeting working carers' needs for services are likely to exceed the public expenditure costs of carers leaving employment, which have been estimated at more than a billion pounds a year (Pickard *et al.*, 2012). This question is now being addressed by the present authors.

## **Notes**

- <sup>1</sup> The studies identifying a threshold effect of 20 or more hours a week did not explore a threshold of 10 or more hours a week.
- <sup>2</sup> Understanding Society asks about care provided in the following time-bands (hours per week): 0-4; 5-9; 10-19; 20-34; 35-49; 50-99; 100 or more; varies under 20 hours; varies 20 hours or more; and other.
- <sup>3</sup> Due to the methodology used, the *Survey of Carers in Households* underestimates the prevalence of caring (HSCIC, 2010, p.155).
- <sup>4</sup> Multivariate logistic regression assesses the association between a binary (or two-level) outcome, or dependent variable, and a set of independent variables, or covariates, that are indices of factors potentially associated with the outcome variable. By including all the relevant covariates in a single regression, we estimate the association between each covariate and the outcome variable, after adjusting for other covariates in the model.
- <sup>5</sup> In the dataset for the *Survey of Carers in Households*, part-time and full-time working are not defined (HSCIC, 2010). It is therefore assumed that the definition is the same as in the Census, since it is common to define full-time work as working for over 30 hours a week (*cf.* Evandrou & Glaser, 2002).
- <sup>6</sup> The analysis is concerned with carers of 'working age', defined as those below State Pension Age, which is 65 years for men and (currently rising to) 65 years for women.
- <sup>7</sup> **Table 1** can be approximately interpreted to mean that working carers who are women have 90 per cent higher odds than those who are men of providing care for 10-19 hours a week; and that working carers from BME backgrounds have 70 per cent higher odds than those not from BME backgrounds of providing care for 10-19 hours a week.

## **Acknowledgements**

The research on which this paper was based was funded by the National Institute for Health Research (NIHR) School for Social Care Research. Material from the *UK Household Longitudinal Study* (*Understanding Society*) and the *Survey of Carers in Households* is crown copyright and has been made available via the UK Data Archive. The views expressed are those of the authors and are not necessarily those of the NIHR School for Social Care Research or the Department of Health, NIHR or NHS. Responsibility for any errors lies with the authors.

## References

Bond, J., Farrow, G., Gregson, B.A., Bamford, C., Buck, D., McNamee, P. & Wright, K. (1999) 'Informal caregiving for frail older people at home and in long-stay care institutions: who are the key supporters?', Health and Social Care in the Community, 7(6), pp. 434-444.

Buckner, L. & Yeandle, S. (2006) Working Carers: Evidence from the 2001 Census, London: Carers UK.

Care Act 2014 (c.23), London: The Stationery Office (TSO), accessed 11 February 2015 at: http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted/data.htm

Carmichael, F., Charles, S. & Hulme, C. (2010) 'Who will care? Employment participation and willingness to supply informal care', Journal of Health Economics, 29(1), pp. 182-190.

Corti, L, Laurie, H. & Dex, S. (1994) Caring and Employment, Colchester: University of Essex.

Dahlberg, L., Demack, S. & Bambra, C. (2007) 'Age and gender of informal carers: a population-based study in the UK', Health and Social Care in the Community, 15(5), pp. 439-445.

Evandrou, M. & Glaser, K. (2002) 'Changing economic and social roles: the experience of four cohorts of mid-life individuals in Britain, 1985-2000', *Population Trends*, **110**, pp. 19-30.

Health and Social Care Information Centre (HSCIC) (2010) Survey of Carers in Households 2009-10, Leeds: HSCIC.

Heitmueller, A. (2007) 'The chicken or the egg? Endogeneity in labour market participation of informal carers in England', Journal of Health Economics, 26(3), pp. 536-559.

Her Majesty's Government (1999) Caring About Carers. A National Strategy for Carers. London: TSO.

Her Majesty's Government (2008) Carers at the Heart of 21st-Century Families and Communities. 'A Caring System on your Side. A Life of your Own', London: TSO.

Her Majesty's Government (2010) Recognised, Valued and Supported: Next Steps for the Carers Strategy, London: TSO.

Her Majesty's Government (2014) Carers Strategy: Second National Action Plan 2014-2016, London: TSO.

Her Majesty's Government & Employers for Carers (2013) Supporting Working Carers: The Benefits to Families, Business and the Economy, London: Carers UK.

King, D. & Pickard, L. (2013) 'When is a carer's employment at risk? Longitudinal analysis of unpaid care and employment in midlife in England', Health and Social Care in the Community, **21**(3), pp. 303-314.

Maher, J. & Green, H. (2002) Carers 2000, London: TSO.

Nomis (2013) Official Labour Market Statistics, Table DC6301EWLA, accessed 11 February 2015 at: https://www.nomisweb.co.uk/census/2011/dc6301ewla

Office for National Statistics (ONS) (2014) 2011 Census Glossary of Terms. May 2014. London: ONS, accessed 11 February 2015 at: http://www.ons.gov.uk/ons/guidemethod/census/2011/census-data/2011-census-user-guide/glossary/index.html

Parker, G. & Lawton, D. (1994) Different Types of Care, Different Types of Carer. Evidence From The General Household Survey, London: HMSO.

Pickard, L. (2007) 'Unpaid care and the family', in Smallwood, S. & Wilson, B. (eds.), *Focus on Families*, Basingstoke: Palgrave Macmillan, pp. 19-34.

Pickard, L., King, D., Knapp, M. & Perkins, M. (2012) *Overcoming Barriers: Unpaid Care and Employment. Findings from the Scoping Study*, London: National Institute for Health Research (NIHR) School for Social Care Research (SSCR).

Pickard, L., King, D., Knapp, M. & Brimblecombe, N. (2013) Can we save the Government £1.3 billion in benefits and lost taxes annually by supporting carers to stay in work?, London: NIHR SSCR, accessed 11 February 2015 at: http://www.sscr.nihr.ac.uk/PDF/Insights/IN35.pdf

Richards, E., Wilsdon, T. & Lyons, S. (1996) *Paying for Long-term Care*, London: Institute for Public Policy Research.

University of Essex, Institute for Social and Economic Research and National Centre for Social Research, *Understanding Society: Waves 1-2, 2009-2011 [computer file]*, 4<sup>th</sup> Edition, Colchester, Essex: UK Data Archive [distributor], December 2012, SN: 6614.

Young, H., Grundy, E. & Kalogirou, S. (2005) 'Who cares? Geographic variation in unpaid caregiving in England and Wales: Evidence from the 2001 Census', *Population Trends*, **120**, pp. 23-34.

#### **Notes on Contributors**

**Derek King** is a Research Fellow in the Personal Social Services Research Unit (PSSRU) at the London School of Economics and Political Science (LSE). Derek works across a number of areas, including some focusing on carers, people with dementia, question wording for surveys, adherence to medications, and data availability and utilisation in social care.

**Linda Pickard** is a Senior Research Fellow in the PSSRU at LSE. Linda's research is primarily concerned with unpaid care both in the UK and internationally. Linda is currently leading a major project on unpaid care and employment in England.

**Nicola Brimblecombe** is a Research Officer in PSSRU at LSE. Nicola's research interests include the analysis of unpaid care and employment and work on children and young people, with recent research on youth mental health services and early intervention programmes.

**Martin Knapp** is Director of PSSRU and Professor of Social Policy at LSE, and Director of the NIHR School for Social Care Research. His research interests are primarily in evidence generation and utilisation in social and health care.

## Correspondence

Dr Derek King Personal Social Services Research Unit London School of Economics and Political Science Houghton Street London WC2A 2AE

Email: D.King@lse.ac.uk Telephone: 020 7955 7863

# Further lessons from the continuing failure of the national strategy to deliver personal budgets and personalisation

Colin Slasberg<sup>1</sup>, Peter Beresford<sup>2</sup> and Peter Schofield<sup>3</sup>

\_\_\_\_\_\_

#### Abstract

The Government continues to act on the basis that the model of 'self-directed support' as devised by In Control is working and should be the basis of current and future social care and health strategy. They are sustained in this belief by national surveys of 'personal budget' holders which claim that personal budgets are improving outcomes for people. However, examination of the survey results shows this to be a potentially misleading assertion. It actually suggests that the opposite is more likely to be the case.

Whilst political and sector leaders continue to declare their commitment to the model, the legislation has not actually supported it given the way the Care Act has been formulated. This offers the possibility of an alternative future for social work and social care services. However, it will require a refreshed understanding of the widely acknowledged shortcomings of the system that the In Control model had itself been created to overcome, but which has failed to do.

Keywords: personal budgets, personalisation, POET, direct payments, evidence base

## Context

In 2012, we published a paper in this journal (Slasberg *et al.*, 2012a) which presented evidence that showed how *In Control's* model of self-directed support – based on an up-front allocation of money to allow the person to choose their own supports – was failing to deliver either personal budgets or personalisation. We further concluded that the fundamental flaws in the model meant there was little if any prospect that it could succeed. The following year showed a growing body of evidence that strengthened these conclusions (Series & Clements, 2013; West, 2013; Slasberg *et al.*, 2013a).

The 2012 paper urged that the legislation being planned at that time 'takes on board what the evidence says about this model' (Slasberg et al., 2012a). The subsequent Care Act 2014, whilst introducing the concept of a personal budget, does not, crucially, support the notion of up-front allocations. A personal budget is simply defined as:

... the cost to the local authority of meeting those of the adult's needs which it is required or decides to meet (HM Government, 2014, paragraph 26).

This cannot be known until needs have been assessed on an individual basis and resources identified to meet them.

We also urged sector and political leaders 'to recognise what is happening and bring about a change in direction' (Slasberg et al., 2013a, p.103). Whilst the legislation appears to have heeded the evidence in that the Care Act 2014 does not give up-front allocations a legal basis, the same cannot be said for policy as expressed through the Guidance to the Care Act (Department of Health, 2014). The Guidance, which is not primary legislation, states:

It is important to have a consistent method for calculating personal budgets that provides an early indication of the appropriate amount to meet the identified needs to be used at the beginning of the planning process (Department of Health, 2014, paragraph 11.22).

<sup>&</sup>lt;sup>1</sup> Independent Consultant

<sup>&</sup>lt;sup>2</sup> Brunel University, London

<sup>&</sup>lt;sup>3</sup> Department of Primary Care and Public Health Sciences, King's College London

## 44 Colin Slasberg et al.

Thus the *In Control* concept of personal budgets through up-front allocations continues to be the strategy the Government believes will deliver personalisation. We shall explore how this gap between policy and legislation creates a window of opportunity to create an alternative future.

Policy makers are being sustained in their support for the policy by analysis from *In Control* in collaboration with Lancaster University and published by *Think Local Act Personal* (TLAP) the body funded by Government to progress the strategy. Its third national survey of personal budget holders (Waters & Hatton, 2014), known as POET, involved 'record numbers' of respondents said to have very high levels of satisfaction.

This paper sets out why a careful examination of the POET data shows this conclusion to be misleading. It also suggests an alternative direction for social care.

# The third national personal budget survey

Norman Lamb, Minister for Care Service and Support, introduces the survey by noting 4,000 people participated – the 'largest ever' – and that 'they experience positive effects of using personal budgets and improvements to feelings of dignity, independence and quality of life' (Waters & Hatton, 2014, p.4). This has provided the headline message, reflected by the Guardian's reporting that amongst these 4,000 people, '82% considered that having a personal budget had enhanced their dignity, 81% their quality of life and 79% their independence' (Guardian, 2014).

However, examination of the data behind these headlines challenges their reliability.

## Size and nature of the sample

4,000 respondents represents about 0.4% of the 1,048,660 people who used community support services in 2013/14 (NASCIS). The POET authors acknowledge that the survey 'does not represent a nationally representative sample' (Waters & Hatton, 2014, p.10). Only volunteer councils participated, 26 from 152. The report does not say how the councils set about choosing the people to participate.

## The positive impacts ascribed to personal budgets

Respondents reported high levels of positive outcome which they ascribed to what they called their 'personal budget'. For example, 81.4% said their quality of life was better and 78.9% more independent (Waters & Hatton, 2014, p.6). However, there is a question about what respondents actually understood by the term 'personal budget'. The headline message conveys the impression that it is the reformed process of assessment and support planning, marking a clear distinction with the previous system whereby a professional decided what needs would be met and how. However, this would require respondents to separate out the *process* of securing their services from the actual service received. The outcome measures used, such as the two above, clearly relate to the impact of the *services received* and not the *process* by which they were arrived at. This makes it likely that respondents are bundling up the *process* with *actual services* received. Their 'personal budget' is synonymous with their support services. This is not a measure; therefore, that compares the personal budget process with any other process. Indeed, only 43% of respondents (p.22) had any service before their personal budget by which to compare any other process.

What is actually measured is *the impact of having a service with having no service at all.* Even with all the concerns about the state of social care, most people are likely to report it is better to have something than nothing at all.

The POET authors do not acknowledge this issue.

# The conditions under which the most positive outcomes occur

The headline messages of the POET survey conceal some important findings that pose a further challenge to the validity of these headlines.

POET shows the relationship between outcomes and a range of factors. It groups the factors into four categories (p.36):

- 1. Personal characteristics, such as ethnicity, gender and impairment.
- 2. Administrative issues, such as whether the person had a direct payment, and how long the 'personal budget' had been held.
- 3. Perceptions of the process, including whether their views were included.
- 4. The services purchased.

Each factor is then mapped to each of the 15 outcomes, which included outcomes such as quality of life, independence, control and self-esteem. They used what are called odds ratios to measure the degree of influence. An odds ratio (OR) is a measure of association between an outcome and an exposure, i.e. some factor we are interested in. The OR represents the odds that an outcome will occur given a particular exposure, compared to the odds of the outcome occurring in the absence of that exposure. So, for example, where the outcome is 'services having a positive impact' and the exposure is 'whether service users are helped to plan or not' then an odds ratio of 1 would mean that the odds of a positive impact were no more or less if people had been helped to plan. An odds ratio less than 1 would mean that the odds of a positive impact were less if people had been helped to plan. An odds ratio more than 1 would mean that the odds of a positive impact were greater if people had been helped to plan.

A word of caution is needed as the POET survey claims the use of odds ratios 'make interpretation easier' (p.37). Odds ratios are notoriously easy to misinterpret and there is a large body of literature warning against their use in situations where the reader could be misled (see, for example, Davies et al., 1998; Knol et al., 2012). The problem occurs when we try to interpret an odds ratio as we would normally understand a ratio of probabilities (as opposed to odds). For example, say we were interested in factor x predicting user satisfaction. If average satisfaction for those without x was, say, 65% then an odds ratio of 2 associated with x would mean x actually increases satisfaction by a factor of just 1.2 or 20%. This can be checked at the following link: http://clincalc.com/Stats/ConvertOR.aspx

The POET survey authors make the mistake of presenting an odds ratio of two as if it meant 'twice as likely'. We are left with a series of tables that potentially overestimate the effects they are examining.

Despite this 'health warning' the authors do report findings which suggest some important conclusions. The survey found there were no statistically significant patterns in relation to personal characteristics or the way the budget was administered. This includes the important finding that having a direct payment was not consistently positively associated with better outcomes. However, there were statistically significant relationships in respect of services purchased and perceptions of the personal budget process.

## Services purchased

POET divides purchased services into four groups:

- Care and support services
- Personal assistants
- Community and leisure activities
- Equipment

Equipment was not a significant factor. By far the most positive relationship was when a personal assistant was used. This was positively associated with all fifteen outcomes, to a level POET describes as 'significant' in thirteen of them. (The report states 'where we refer to a difference between groups or a significant association between factors, this is underpinned by a non-parametric statistical test with p<0.05, p.9). The average odds ratio was 1.8.

In direct contrast, 'care and support' services were negatively associated with all fifteen outcomes, and to a level described by POET as significant in 6 of those. The average odds ratio was 0.8.

Spending on community and leisure activities was also positively associated with outcomes. The average odds ratio was 1.21.

These findings are inconsistent with the findings of POET that direct payments were not consistently associated with better outcomes. Employing a personal assistant can only ever happen through a direct payment. Meeting community and leisure activities is likely to require the person to have a level of resource beyond that required to meet the higher priority needs for survival and safety. We have pointed out previously (Slasberg *et al.*, 2012b, p.1031) that there is a prima facie case that people with a direct payment have traditionally enjoyed significantly greater resource than others. In 2009/10, people on direct payments accounted for 7.7% of service users but spent nearly 13.7% of the budget. Woolham and Benton (2012) in a study within a large council found that the average value of direct payment was 44% greater than the value of other support packages. Differences in dependency levels are unlikely to account for such large differences given that direct payments can be used for small and large packages.

How can this apparent contradiction be explained? The following section seeks to shed light on this key issue.

## The changing nature of direct payments

It has been a part of the personalisation strategy to maximise the numbers of people with a direct payment. Government called for direct payments to be the default option for a personal budget as research had shown direct payments resulted in the best outcomes. The results have been palpable. In 2008/9, the percentage of service users with a direct payment was 5.6% and in 2013/14 14.8% (NASCIS, 2014). It was initially assumed that all new recipients were behaving in the way the research had shown worked best, which was through the employment of personal assistants to replace regulated care services. Thus Community Care (2011) reported a 'boom' in the number of personal assistants between 2009 and 2010 of 35% to 92,000.

The Community Care report was based on work by Skills for Care. They made the assumption that all new direct payment recipients were employing personal assistants. Their 2013 workforce survey (Skills for Care, 2013) noted 'In previous versions of this report, due to a lack of information, all direct payments recipients were treated as employers'. In 2012 their workforce report stated that personal assistants, numbering 420,000 made up the single largest section of the domiciliary workforce of 831,000 (Buchanan et al., 2012, p.12). However, they acknowledged this assumption may have led to an over-estimation. This caused Skills for Care to test the assumption by use of surveys. This showed that it was indeed a major overestimation. For the 2013 report, they estimated that only 52% of direct payment recipients employed a personal assistant. By 2014 this had fallen to a mere 33% of direct payment recipients employ a personal assistant (Fenton, 2014, p.20).

This may well reflect the impact of the 2010 policy directive that all service users should have a personal budget, and 'preferably as a direct payment' (Department of Health, 2010, p.8). Councils have perhaps found it easy to increase numbers of people with a direct payment by

simply encouraging people with regulated services who either themselves, or through a third party, are able to use a bank account to pay the provider's invoices.

This suggests there are perhaps now two cohorts of direct payment recipients: an original cohort who use it to create and manage their own support system, and a second, more recent cohort who simply act as purchaser of regulated services.

There is no evidence to believe that using direct payments simply to purchase regulated services improves outcomes. On the contrary, we have noted previously (Slasberg et al., 2012a) evidence from the Office of Fair Trading that people who fund their own care ('selffunders') not only receive the same level of service from regulated services as people publicly funded, but pay more for it.

Helga Pile (2013) reports on UNISON members' experience of the policy of increasing the numbers of people with a direct payment in the following ways:

Practitioners responding to a UNISON survey felt that they were implementing a 'one-sizefits-all' approach to personalisation, driven by sign-up targets. This has been exacerbated by the 2010 announcement by government ministers in England that 'direct payments should be the preferred option' for receiving a personal budget. Respondents do not feel that this is real personalisation because the focus is on process not outcomes (Pile, 2013, p.56).

POET's finding that regulated services are not associated with better outcomes, regardless of whether they are council purchased or through a direct payment, is perhaps the first empirical evidence that direct payments are not, per se., a guarantee of better outcomes. Better outcomes continue to be associated with the type and nature of support purchased, with a focus on the use of personal assistants and being able to meet social and leisure needs.

The implications of this finding for national policy, with its emphasis on direct payments as the preferred approach to 'personal budgets', is highly significant. In 2013/14 just short of 15% of all who used community services had a direct payment. However, if only 33% of those purchased a personal assistant, that means that 95% of people used regulated care and support. If it is the case that the use of regulated services is not associated positively with better outcomes, regardless of whether delivered through a direct payment or 'council managed' budget, this points to the personal budget strategy having no benefit for a 95% majority.

## Importance of the person's views

POET showed a very strong association between the extent to which the person felt their views were influential and how easy they perceived the personal budget process to be. This led the authors to believe council practice was the deciding factor and recommend:

Given the very strong association between these process conditions and outcomes, councils can prioritise good practice in these areas to achieve good results (p.16).

However, this is an assumption that can be challenged. An alternative explanation lies in the characteristics of the person, and that people with the requisite experience and social skills are able to be more influential in the process. There is evidence that people who use a direct payment to manage their own support systems have high levels of assertiveness and social skills. For example, a study of direct payments in Essex published by the Office of Public Management noted:

For the majority of the people interviewed (both service users and relatives) the most important skills needed to make cash payments work were confidence, assertiveness, and an ability to articulate needs (Holloway et al., 2011, p.42).

In addition, an earlier study also found:

Most older people used their direct payments to employ personal assistants. Those with transferable skills from past career and life experiences often successfully adapted them to help manage them (Clark et al., 2004, p.7).

People with these levels of skill and assertiveness are more likely to ensure their views are influential, and thus more likely to report the process as easy, no matter which council they find themselves working with. They are perhaps also more likely to look favourably on a process that results in them getting the level of resource they require.

The importance of the POET assumption is that it supports the message that some councils are delivering the strategy well and, therefore, if all councils did likewise the strategy would be even more of a success. Indeed, the view that some councils are delivering the strategy well is presented as vindication in itself that the strategy is the right one to pursue.

This is a theme in the second POET survey (Hatton & Waters, 2013) which identified large variations in better outcomes between councils. We pointed out the following:

Whilst the report identifies a 30% variation in the best and worst performing councils it is also the case that there is a similar spread between councils in terms of the proportion of their samples with a direct payment (Slasberg et al., 2013a, p.101).

The POET authors failed to notice a potential link between the spread of differences between councils in terms of better outcomes, and a similar spread of differences in the percentage of service users with a direct payment. At the time of the second survey, given the rapid expansion of those with a direct payment being in the second cohort as identified previously, the percentage of people with a direct payment who used it to create and manage their own support system, as opposed to simply purchasing regulated services, would have been much higher than at the time of the third survey. Therefore, there was a greater likelihood at the time of the second survey that a council with a higher number of direct payment recipients in their sample would find more of their sample reporting a better outcome.

The failure to acknowledge this link allowed the POET authors to claim that some councils were delivering the personal budget process well and others were not. In reality all they were seeing were that some councils had more people with a direct payment and using it to purchase and manage their own support system in their sample than others.

## Other sources of evidence for government commitment to the strategy

Not only is the Minister for Care pleased to be closely associated with the POET surveys, the recently published guidance to the Care Act (Department of Health, 2014) also makes the following claim (p.151):

Independent research shows that where implemented well, personal budgets can improve outcomes and deliver better value for money.

Once again, closer examination of the sources they cite challenge this assertion:

• The national evaluation of the individual budget pilots (Glendinning et al., 2008). The evaluation was far from unequivocal in its findings. It found that some people amongst the group of service users with a personal budget had better outcomes than those in the control group who did not. However, it also found that many did not. This was noted most commonly amongst older people. We have pointed out previously (Slasberg et al., 2012a) that while the sample was meant to be representative of the population of service users, that appears unlikely to have been the case. 26% of the sample were existing users of

direct payments whilst at that time, only about 4% had a direct payment nationally. In terms of value for money, the study also found an 11% increase in infrastructure costs. thus contradicting the claim that the process would increase value for money.

- Improving Value for Money in Adult Social Care (Audit Commission, 2011). The guidance (Department of Health, 2014, p.151) states that 'this study pointed out that 36 per cent of councils cited personalisation as a driver of better value for money in 2009/10. This rises to 45 per cent for 2010/11. Better value came mostly from improved outcomes, not savings'. However, this reflects direct statements made by the councils. No evidence was presented in this report to substantiate their claims. Whilst the Audit Commission may have been independent, it could not be said that their information sources, as deliverers of the government strategy, were.
- The Financial Management of Personal Budgets (Audit Commission, 2010). This study was based on interviews with selected senior managers and project officers at eight sites selected in collaboration with In Control. Both the councils and the officers are therefore likely to have been sympathetic to the strategy. As above, relying on the views of staff engaged in delivery of the strategy could not be said to be an independent source.
- Users of Social Care Personal Budgets (Ipsos MORI, 2011). This study interviewed 48 'personal budget' holders. They found that 'On balance, it appeared that only direct payments offered a genuine choice to budget holders', and that 'direct payments were chosen by people who wanted to have more choice and control over the care they received, and wanted to benefit from the added flexibility a direct payment offered'. This appears to describe people in the first cohort of direct payment recipients as described above. Their finding reaffirms the messages from research that people in this group achieve better outcomes, as they have since their introduction in 1996, whilst 'personal budgets' per se. - based on the provision of an up-front allocation of money - had no impact.

Thus the 'independent research' the guidance cites is either not truly independent, or when it can claim to be independent, does not support the claim that personal budgets deliver better outcomes and better value for money.

#### Conclusion

Ironically, a careful examination of the evidence the Government uses to support its view that the national strategy of personal budgets through up-front allocations to enable people to exercise choice - the POET surveys - is working, actually does the exact opposite. The surveys also support the view that the only service users experiencing better outcomes are those using a direct payment to employ personal assistants and have enough resource to meet social and leisure needs. This has been the case since the mid 1990s:

The benefits of direct payments for users and local authorities are undisputed and widely researched (Hasler & Stewart, 2004, online).

The Government's Guidance to the Care Act 2014 confirms its view:

The allocation of a clear up-front indicative (or 'ballpark') allocation at the start of the planning process will help people to develop the plan and make appropriate choices over how their needs are met (Department of Health, 2014, p.188).

However, the Care Act itself defines a personal budget in a quite different way, making no reference to an up-front allocation. Section 26 of the Act defines a personal budget as simply the financial value of the services required to meet the needs the council has decided to meet. This is an amount that can only be known following the support planning process. The Act also confirms that the decisions about what a person's needs are, which of them will be met and with what resource will continue to be ones for the council to make. It would appear that if the policy makers advising Government are maintaining faith in the current strategy, the legislators advising Government have a quite different view.

This places the service at considerable risk. An ineffectual strategy – personal budgets through up-front allocations of resource – is serving only to disguise the perpetuation of a system that works in ways that are dysfunctional and depersonalising for all but a small minority. A system that is personalised for all can only happen with fundamental reform of that system.

We have set out how we believe this can be made possible (Slasberg & Beresford, 2015). In broad terms, we argue that the present national strategy has been built from the wrong lessons about the early success of direct payments. *In Control* believed it resulted from the exercise of *consumer choice* and that extending choice to all through an up-front allocation would lead to better outcomes for all. However, an alternative reading is that the success of direct payments did not derive from consumerist notions of choice, but from an accurate and holistic assessment of individual needs allied to sufficient resource to meet them. Unlike the *resource led* council based assessments of need, the assessments by this group of people have been authentically *person-centred*.

If this view is correct, the implications are that what is required is:

- for all assessments of need to be holistic and person-centred
- for as much need as current resources permit to be met
- open acknowledgement of the funding gap in terms of needs not met
- a commitment to close the gap over time as the democratic will permits.

This needs to replace the prevailing system whereby perception of 'need' is restricted to that which is affordable, thus depersonalising the process for the service user whilst also denying the existence of a funding gap.

While we believe such an agenda is legally and professionally possible, we acknowledge it will require a level of political openness and commitment to social care that will pose a challenge to political leaders.

#### References

Abrahams (2014) The NHS's Fight to Survive Will be Won with Equality, Efficiency and Quality, accessed November 2014 at: http://www.hsj.co.uk/5075789.article#.VHMZL9JyZMs

Audit Commission (2010) Financial Management of Personal Budgets, London: Audit Commission.

Audit Commission (2011) *Improving Value for Money in Adult Social Care*, London: Audit Commission.

Beresford, P. & Stansfield, J. (2013) *Are Social Care Personal Budgets Working*?, Society Guardian, accessed at: http://www.theguardian.com/society/2013/feb/12/are-social-care-personal-budgets-working

Buchanan, P., Fenton, W. & Woodrow, S. (2012) *The State of the Adult Social Care Sector and Workforce in England*, Leeds: Skills for Care.

Clark, H., Gough, H. & Macfarlane, A. (2004) 'It Pays Dividends'. Direct Payments and Older People, Joseph Rowntree Foundation, Bristol: The Policy Press.

Community Care (2011), Boom in Personal Assistants Drives Adult Sector Growth, accessed November 2014 at: http://www.communitycare.co.uk/2011/09/01/boom-in-personal-assistantsdrives-adult-sector-growth/

Davies, H.T.O., Crombie, I.K. & Tavakoli, M. (1998) 'When can odds ratios mislead?', British Medical Journal, 316, pp. 989-991.

Department of Health (2010) A Vision for Social Care, London: The Stationery Office.

Department of Health (2014) Care and Support Statutory Guidance, London: The Stationery Office.

Duffy, S. (1996) Unlocking the Imagination (re-published by The Centre for Welfare Reform, 2014), accessed at: http://www.centreforwelfarereform.org/uploads/attachment/420/unlockingthe-imagination.pdf

Fenton, W. (2014) The Size and Structure of the Adult Social Care Sector and Workforce in England 2014, Leeds: Skills for Care.

Glendinning, C., Challis, D., Fernandez, J-L., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, M. & Wilberforce, M. (2008) Evaluation of the Individual Budgets Pilot Programme, York: Social Policy Research Unit, University of York.

Goldacre, B. (2014) Why Won't NHS England do an RCT on this £5bn/yr Intervention?, accessed November 2014 at: https://storify.com/bengoldacre/why-won-t-nhs-england-do-an-rcton-this-5bn-yr-int

Guardian (2014) Speeches by Eric Pickles, Jeremy Hunt and Andy Burnham at the National Children and Adult Services Conference, accessed November 2014 http://www.thequardian.com/social-care-network/2014/nov/03/ncas-hunt-pickles-burnhamspeeches?CMP=new\_1194

Hasler, F. & Stewart, A. (2004) Developing Direct Payments in the North East of England. Joseph Rowntree Foundation, accessed at: http://www.jrf.org.uk/publications/developing-directpayments-north-east-england

Hatton, C. & Waters, J. (2013) Second National Personal Budget Survey (POET). Think Local Act Personal, London: In Control Publications.

Health Select Committee (2012) The Health Committee Questions Department of Health Officials and Paul Burstow MP about Social Care Provision in England, accessed August 2013 http://www.parliament.uk/business/committees/committees-a-z/commons-select/healthcommittee/news/12-01-12-socialcare-ev6/

Henwood, M. & Hudson, B. (2008) Lost to the System? The Impact of Fair Access to Care: A Report Commissioned by Commission for Social Care Inspection, London: CSCI.

HM Government (2014) *The Care Act*, London: The Stationery Office.

Holloway, S., Neville, S. & Watts, R. (2011) Longitudinal Study of Cash Payments for Adult Social Care in Essex, London: Office of Public Management.

Ipsos MORI (2011) Users of Social Care Personal Budgets, London: Ipsos MORI Social Research Institute.

Knol, M., Le Cessie, S., Algra, A., Vandenbroucke, J. & Groenwold, R. (2012) 'Overestimation of risk ratios by odds ratios in trials and cohort studies: alternatives to logistic', Canadian Medical Association Journal, 184(8), pp. 895-899.

Labour Party (2014) National Policy Forum Report, London.

NASCIS, National Adult Social Care Intelligence System, *P2f, Number of Service Users in the Community in the Year*, accessed November 2014 at: https://nascis.hscic.gov.uk/

Needham, C. & Glasby, J. (2014) Debates in Personalisation, Bristol: Policy Press.

Pile, H. (2013) All in the Name of Personalisation. Critical and Radical Debates in Social Work, edited by Ferguson, I. & Lavalette, M., Bristol: Policy Press.

Series, L. & Clements, L. (2013) 'Putting the cart before the horse: resource allocation systems and community care', Journal of Social Welfare and Family Law, **35**(2), pp. 207-226.

Skills for Care (2013) *The Size and Structure of the Adult Social Care Sector and Workforce in England, 2013*, Leeds: Skills for Care.

Slasberg, C., Beresford, P. & Schofield, P. (2012a) 'How self-directed support is failing to deliver personal budgets and personalisation', *Research, Policy and Planning*, **29**(3), pp. 161-177.

Slasberg, C., Beresford, P. & Schofield, P. (2012b) 'Can personal budgets really deliver better outcome for all at no cost? Reviewing the evidence, costs and quality', *Disability and Society*, **27**(7), pp 1029-1034.

Slasberg, C., Beresford, P. & Schofield, P. (2013a) 'The increasing evidence of how self-directed support is failing to deliver personal budgets and personalisation', *Research, Policy and Planning*, **30**(2), pp. 91-105.

Slasberg, C. (2013b) 'A proposed eligibility and assessment framework to support delivery of the government's vision for a new care and support system', *Journal of Care Services Management*, **7**(1), pp. 26-37, accessed November 2014 at: http://www.maneyonline.com/doi/abs/10.1179/1750168713Y.0000000024

Slasberg, C., Watson, N., Beresford, P. & Schofield, P. (2014a) 'Personalisation of health care in England: have the wrong lessons been drawn from the personal health budget pilots?', *Journal of Health Services Research and Policy*, **19**(3), pp. 183-188, accessed 2014 at: http://hsr.sagepub.com/content/19/3/183

Slasberg, C. & Beresford, P. (2014b) 'Government guidance for the Care Act: undermining ambitions for change?', Disability & Society, **29**(10), pp.1677-1682, accessed 2014 at: http://dx.doi.org/10.1080/09687599.2014.954785

Slasberg, C. & Beresford, P. (2015) 'Building on the original strengths of direct payments to create a better future for social care', *Disability and Society*, accessed at: http://dx.doi.org/10.1080/09687599.2015.1007672

Waters, J. & Hatton, C. (2014) *Third National Personal Budget Survey. Think Local Act Personal*, London: In Control Publications.

West, K. (2013) 'The grip of personalisation in adult social care: between managerial domination and fantasy', *Critical Social Policy*, **33**(4), pp. 638-657.

Woolham, J. & Benton, C. (2012) 'The costs and benefits of personal budgets for older people: evidence from a single local authority', *British Journal of Social Work*, Advance Access published July 20, 2012, doi: 10.1093/bjsw/bcs086.

## **Notes on Contributors**

Colin Slasberg qualified as a Social Worker in the 1970s. He has worked in shire and unitary councils as a practitioner, operational and strategic manager in both children's and adults' services. He currently works as an independent consultant with a focus on the challenges of bringing about personalised care and support for all service users. He has published a number of papers both singly and with others that have critiqued national policy in relation to personalisation and offered alternative options. He works with organisations who wish to explore these themes.

Peter Beresford, OBE, is Professor of Social Policy at Brunel University, London. He is Co-Chair of Shaping Our Lives, the national user controlled organisation and network of service users and disabled people. He has a background as a long-term user of mental health services and has had a longstanding involvement in issues of participation as activist, writer, researcher and educator.

Peter Schofield is a Research Associate with interests in mixed method approaches. He has worked on a wide range of primary care related projects applying advanced statistical techniques. He is a statistical advisor on the board of the British Journal of General Practice.

# Correspondence

Colin Slasberg Independent Consultant

Email: colin.slasberg@gmail.com

#### Reviews

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

Bristol: Policy Press, 2014

Adult social care, Ferguson, I. & Lavalette, M. (eds.)

ISBN: 978-1447316169, £7.99 (pbk.), pp.76

Mental health, Weinstein, J. (ed.)

ISBN: 978-1447316176, £7.99 (pbk.), pp.76

Personalisation, Beresford, P. (ed.)

ISBN: 978-1447316145, £7.99 (pbk.), pp.76

From the 1970s Macmillan published an influential series of textbooks that presented an alternative view to mainstream thinking on the causes of social deprivation and exclusion. Edited by Peter Leonard. Critical Texts in Social Work and the Welfare State were written from the perspective of critical social work, which has been described later by Healy (2005) as 'concerned with the analysis and transformation of power relations at every level of social work practice' (p.172). Critical social work is built upon the traditions of radicalism (which in turn draw heavily on Marxism), but can now be differentiated from earlier approaches through the 'incorporation of themes and concepts drawn from post-modernism and post-structuralism' (Ferguson, 2007, p.104). Critical social work thinkers are concerned about the role of the profession and wider social care service in implementing top-down policies that are based on assumptions that it is the deficits of individuals and their communities that are to blame for their difficulties. Such practices are seen to mask the influence of underpinning structural injustices, and result in social workers acting as conduits of oppression. Topics of the original book series included 'Social work practice under capitalism: a Marxist approach', 'Feminist social work', 'The politics of mental health', 'Striking out: social work and trade unionism', and 'The politics of disablement', with authors such as Lena Dominelli, Paul Corrigan, Peter Leonard and Michael Oliver.

The current series similarly seeks to provide a critical and radical social work perspective on current social work policies and their implications for the profession. The series editors are clear that whilst not all of the contributors would align themselves within these traditions *per se.*, they do share a view that social work is 'much wider than the currently dominant neo-liberal models' and that 'human rights and social justice should be central to its mission' (Ferguson & Lavalette, 2014, p.ix). There are five books in the series so far, with this review covering three – *Personalisation* (edited by Peter Beresford), *Mental Health* (edited by Jeremy Weinstein) and *Adult Social Care* (edited by Iain Ferguson and Michael Lavalette). All of them have a similar format, with the editor(s) providing a lead essay to which multiple contributors provide brief responses. They end with final concluding remarks by the editor. They are all under 80 pages and are therefore a brief (although intense) read.

The lead essays consistently provide thoughtful and passionate critiques of current social work and its policy environment. Ferguson and Lavalette seek to demonstrate that crises such as care provided by Southern Cross and Winterbourne View are but the tip of the iceberg of the problems in adult social care policy. They present a picture of a system that has been built on discrimination, undermined by marketisation and ravaged by austerity cuts. Its salvation, they argue, will require new alliances between those supported and those providing support, social care contributing to campaigns against injustices, and learning from global best practices.

Weinstein sets a context in which 'madness' is still connected with 'badness', compulsory treatment orders promote stigmatisation, and general welfare policies conflict with official government recognition that poverty negatively affects mental wellbeing. He paints a grim picture in which health-led integrated teams and fears over public safety have led to social work losing its creativity and becoming over-shadowed by psychiatry, and with connected falls in

morale, confidence and social workers' wellbeing. He suggests an alternative future in which social work champions a more 'humanistic' response around which other disciplines can rally.

Beresford identifies commonalities between personalisation implementation and the interest in patch-based and community social work in the 1980s. These included unrealistic expectations of the opportunity for individuals and communities to be self-reliant, a transfer of responsibility but not power, and a limited evidence base for a national policy. This comparison builds into a wide-ranging critique of both the development process and current realities of personalisation, with unfavourable comparisons made to the user-led direct payment movement. He advocates broader changes in the overall system, better implementation, and more objective use of evidence if personalisation is to be part of the solution rather than part of the problem.

Lead essays in this range of texts are delivering part of what they promised – analyses of social work and social policy based on critical and radical perspectives. One may not agree with all of the conclusions, and could criticise their selection and interpretation of the evidence; but the arguments are well made and coherent. In many ways they read like the speeches of the proposer at a debate, and following this metaphor, they make eloquent cases for their stances. Beyond this point, however, the limitation of the overall format becomes evident. The other respondents have little space to present their arguments and therefore largely struggle to address other aspects of the topic in any depth. Some new considerations are introduced, for example the perpetuation of colonisation in mental health services (Sadd, in Weinstein) and the potential of a socialist model of social care (Whitfield, in Ferguson & Lavalette), and there are occasional words of minor dissent and variation. On the whole, though, the responses (which number between 6 or 7 per book) essentially reiterate what has already been eloquently presented in the lead essays. This is true within and between the texts, with numerous contributors across all three expressing similar concerns regarding personalisation. For the reader this reduces the interest and also leaves one (or at least this reader) wanting to hear more alternative views: or indeed have greater depth provided by fewer authors. In the conclusion to the Personalisation text Beresford states that 'there is a remarkable unanimity of view among the contributors within these covers (p.79)' - true, but this need not have been the case. At its worst this 'unanimity of view' leads to social work presenting itself as an embittered profession which assigns responsibility to everyone but itself for the woes of its own practice and the broader society. Psychiatrists are, in effect, portrayed as being part of a neo-liberal conspiracy with pharmaceutical companies, managers as exploitative dictators obsessed with timescales and targets, and the views or actions of named individuals and organisations scapegoated with no 'right to reply'. This is despite the reality that many of those individuals, professions and organisations could well agree with much of the analysis presented, and some have indeed been instrumental in trying to change practice and policy as a consequence.

In conclusion, these texts, and the lead essays in particular, are to be commended to anyone looking for a different narrative to that presented by mainstream social care policy narratives. At their best they provide an urgent and energetic call to arms for the social work profession, and underline why it still has a vital and unique role in tackling structural discriminations. They would be excellent preparation for debates in classrooms and professional development sessions, with such arenas also providing opportunity for other perspectives to be heard and for healthy challenges on both sides.

#### References

Ferguson, I. (2007) Reclaiming Social Work: Challenging Neo-liberalism and Promoting Social Justice, London: Sage.

Healy, K. (2005) *Social Work Theories in Contest: Creating Frameworks for Practice*, Basingstoke: Macmillan.

## **Robin Miller**

Senior Fellow, School of Social Policy, University of Birmingham

## Critical and Radical Debates in Social Work: Ethics, Banks, S. (ed.)

Ferguson, I. & Lavalette, M. (series eds.)

Bristol: Policy Press, 2014

ISBN: 978-1447316183, £7.99 (pbk.), pp.76

This book is a brief debate about social work ethics; it is politically committed, noting that codes of ethics are used to direct and discipline social workers, part of the controlling element of the New Public Management. Banks proposes instead that social workers have to reclaim a focus on social justice, act responsibly to confront oppressions, show moral courage and collectively resist unjust practice and policies. In pursuit of this she proposes that social workers should develop a 'situated ethics', responding to the circumstances, pressures and individuality of the people they are working with. This argument is introduced in an initial piece by Banks herself. Eight responses to her article follow, from social work academics in Japan, the USA, South Africa, Canada and the UK. Finally Banks responds to the responses. All of this in fewer than 80 pages makes it accessible to a wide audience and gives a satisfying contribution to this debate.

Or it should do. There are two significant problems with this structure. First, it is too brief and Banks doesn't have the space in particular to adequately elaborate some of her arguments. Second, of the eight responses, six do not take up the opportunity to properly debate Banks' ideas, most repeating her points and largely agreeing with her thinking. In this group I thought Cowden's assertion, based it seems on the evidence provided by a single TV programme, that CQC inspectors collude with bad practice in private care, was outrageous. Only two responses disagree with Banks to any significant extent. Paul Blackledge does so from a Marxist perspective, using arguments I cannot claim to fully understand. But like Marxians over time, he ably demonstrates how Marx's scholarship implicitly covered areas of human activity that he did not explicitly write about – social work ethics being one of them.

Chris Beckett's response is more interesting, and probably runs along the lines that social work's leaders - those who commission codes of ethics for instance - might pursue. Beckett, while accepting the nub of Banks' argument that social work ethics cannot be reduced to sets of universal rules, says 'we should stop constructing a composite straw man... (managerialism), made up of all the things we dislike and disapprove of'. Banks' straw man is the New Public Management (NPM); targets, contract culture, oppressive recording requirements and so on. In addition to Beckett's comment, this focus, on how neo-liberalism and NPM have comprehensively undermined good social work practice, smacks of 'Golden Age' thinking i.e. that before NPM came along everything was just fine. The New Public Management however, is much like the 'Old' Public Management, but with electronic teeth. Central governments want to control local activity, always have, but until IT allowed ministers to think they knew what was happening everywhere, their ability to direct local activity was limited to the crude cudgel of legislation. In the 1930s when many local authorities defied the Government by paying unemployed workers too 'generously', a nationally run Unemployment Assistance Board was created to manage that responsibility. Similarly in 1946 Bevan was unsure he could rely on local authorities if they kept responsibility for health, so he established the centrally run NHS. The difference now, the 'new' in NPM, is the minister's panopticon of close to real time access to local activity and performance data. In this sense I think Banks' focus on NPM threatening social work is very old news, emphasised perhaps because this book appears in the Radical Social Work (RSW) - inspired Critical and Radical Debates in Social Work series.

Banks may or may not be a natural supporter of RSW ideas, but the juxtaposition here of the proposed 'situated ethics' of care – a subtle, constantly negotiated understanding – with RSW thinking, based on solidarity between workers, service users and community representatives, is in places uneasy. For instance, Banks claims that NPM, with its emphasis on contracts, assumes and fosters 'low trust' relationships, which undermine constructive, caring relationships. Yet trades unionism, a central plank of RSW thinking, is traditionally based on tight contracts of employment with employers because 'low trust' relationships prevail.

And Banks does not square her criticism of universalist codes of ethics with the need in her 'situated ethics' for a starting point – a view of what a good society or good social work looks like. Without that her prescriptions surely lead to ethical relativism and nothing more. But this gap may be to do with the constraints of the book's format. I was also confused by Banks' requirement on the one hand for 'bringing the personal back into social work ethics' and her criticism of 'individualising social problems through a focus on individual dilemmas'. The conundrum here - about where the focus of activity should lie, on the individual or society, is age old. What is not mentioned in this book is that state-sponsored social workers (and this book considers no other) are employed, by and large, to work with individuals and families, while RSW demands that social workers engage in political activity in order to change society. Two masters then – the ideal v. the contract of employment. How can this conflict be resolved?

Banks avoids tick box answers to anything, and advises social workers to do the same, pointing out that 'ethical judgements... based on rational deduction from abstract principles are tools of the powerful'. Her necessarily brief exposition of a 'situated ethics' is authoritative, and her prescriptions make great sense - demanding as they do an emphasis on empathic solidarity, social justice, asserting the rights of service users and moral courage. Read at face value, such proposals may seem commonplace, but in the light of tight procedural requirements, even if only at slight variance with the workers' perceptions, these ideas can be a lifeline. Older people may not want to exercise their right to officially sanctioned 'choice', but may want to be 'looked after'. Which prescription does the worker follow? It is the last of Banks' proposals, to be ethically courageous, which is the strongest card in the worker's hand and has to be at the heart of any worker's deliberations about their own ethical stance.

#### **David Burnham**

Analyst in Adult Social Care

Moving on from Munro, Blyth, M. (ed.)

Bristol: Policy Press, 2014

ISBN: 978-1447315667, £16.99 (pbk.), pp.199

This edited text pulls together a range of viewpoints from providers, managers, practitioners and policy leads who reflect on 'whither child protection' in the three or four years since the 2011 final Munro Report 'A Child Centred System'. The contributors are very much leaders in their field, which lends the text a sometimes 'top down' and aspirational resonance in places, but is balanced by sufficient roughage from those contributors more routinely exposed through practice or research to the operational world. That said, there is no distinct voice from families, nor from those entrenched in the workplace and about whom there is much comment upon their virtues and vices. The text addresses key domains around regulation, multi-agency working, sector led improvement strategies, back to basics relationships, early intervention, adolescent neglect and Child Sexual Exploitation (CSE) information sharing, Local Safeguarding Children's Boards (LSCBs) and learning from Serious Case Reviews (SCRs), the delights of OFSTED visits, and many other topics that should appeal to an informed readership who have had to grapple with making child protection policy a safe reality.

Mark Gurrey and Eleanor Brazil are first with a distillation of their hard-won leadership spurs about key attributes of what a 'good' child protection organisation looks like. Despite the somewhat folksy style (where we learn to 'walk the talk' of change management, while doing so with 'confident humility') we garner their insights into what makes for thoughtful leadership and successful protection systems. Based upon their experience and uncluttered by references to evidence the chapter bristles with a kind of exhortatory 'we've done it, why can't you?' optimism, and gets the book off to a brisk start. However, few silver linings follow in the chapter

by Ray Jones, who begins with a brief history of the catalytic effects of public enquiries into child deaths that have powered so much occupational change and reputational damage. This is followed by Jones' trenchant critique of SCRs as a mechanism for assigning accountabilities and thereby a new elaboration of the blame instinct from government and media. The current phase of privatisation in England's child protection also comes in for some firm handling, and a re-assertion that good child protection needs to emanate from public enterprise, cooperation and decision visibility. The whole chapter is a cautionary tale from a much experienced professional voice: but this is not the only chapter to look long at England and little beyond in searching for ideas and solutions.

The anxieties shared by Jones find no obvious place in the upbeat chapter by Chris Wright, Chief Executive of Catch 22, an agency that works with families near or on the edge of care proceedings. Here, the sunlit uplands of voluntary sector verve are sharply on display. Citing its success in working with troubled families in the Wirral we learn of a 91% reduction in domestic violence, 83% reduction in anti-social behaviour, 67% reduction in drug and alcohol problems and 83% improvement in children's behaviour and attendance at school. These numbers are baldly stated with no accompanying evidence of attribution. While it would be unwarranted to impute more 'puff' than proof to the extraordinary successes claimed (what the interventions were, the criteria for success, how measured, whether change was sustained etc., etc., we don't know), we nonetheless get a sense of energy and innovation by an ambitious and challenging third sector body. We also get a sort of sub-text that such innovators are often hobbled by an unappreciative local authority lumpen salariat, in the shape of commissioners who know not whereof they commission, and resort to restrictive rules and penny pinching to frustrate the visionaries in the voluntaries. No doubt there could be some truth in this reviewer's caricature, but this remains a very useful chapter that reminds us that no one has a monopoly on what 'good' family support services look like.

Chapter four, by leading social work research academics (Sue White, Kate Morris, Brid Featherstone, Marian Brandon and June Thoburn) rehearses the twin dangers of thoughtless obeisance towards defensive proceduralism and the grail of the RCT as the panaceas for risk and uncertainty in child protection. Instead the plea is for a return to relational work and to supportive early intervention. While a now familiar refrain it nonetheless provides a salutary reminder of how much social work has departed from the optimistic ambitions of the Seebohm era for a family-oriented community based service; and the argument is well made about how much it needs to change back again.

Jenny Clifton's chapter provides a cogent and research-driven argument on listening to children. It offers valuable insights into the emotionally complex nature of harmful relationships between the abused and abuser(s) (parents, peers, friends, and strangers). The conflicted feelings involved and ways of getting children talking about these are charted through the voices of young people who describe critical moments that assisted disclosure. Key features of a child-centred approach are outlined and conclude a valuable synthesis of data, concepts and practice.

The neglect of adolescent neglect comes to the fore in Leslie Hicks' Chapter six. It offers an illuminating overview of organisational, conceptual, cultural and policy challenges in identifying and ameliorating this complex phenomenon. While an intervention framework is usefully outlined at a general level, the chapter tends to focus on obstacles and the need for more research. There seems to be little if any casting about in other jurisdictions for examples of what might have been tried and found to work. Similarly, Chapter seven, by Jenny Pearce, on child sexual exploitation, does a good job on setting out the complexity of the problem and explores the subjectivities of the abused young person, notably the confounding issues of apparent complicity or consent. In exploring such themes with older young people the author suggests we consider using the LAP (Learning Action Partnership). The LAP is based upon trust-building exchanges over time where respect for one another's identity and agency are the foundation for identifying ways out of an abusive experience. This method may be valuable but clearly it is not intended to tackle the scale and recalcitrant nature of CSE; and we get no sense of a bigger system approach (e.g. involving: the *Child Exploitation and Online Protection* Centre (CEOP), cross-jurisdiction arrests, the police, courts, schools, street-based workers, drug and mental health services, community leaders, training, attitude-changing and so forth) that needs to be jointly promoted. Again, if this pernicious problem has been tackled with any success beyond the UK we get no glimpse of this. This comment may be unfair given the limited space allowed for an average chapter in an average length edited text: but who knows what exciting work may be underway elsewhere, and some glance abroad would have been welcome.

The next chapter, by former policeman Charlie Hedges at CEOP, provides a wide-ranging account of organisational and policy developments regarding missing and runaway children. There is no dutiful plodding here, but a well paced and plain speaking overview of the complex architecture of agencies and professionals and the progress they've made, as well as pointing to gaps in knowledge and interventions. Important reading for anyone unfamiliar with this field. The final contributors – Michael Preston-Shoot and Martin Pratt – provide an extensive reprise of what is known about LSCB effectiveness, particularly in regard to leadership, governance, learning and prevention. This is not particularly comforting, given the many defects detected in a forensic search of recent research and inspections, coupled with the authors' direct experience. We get a thorough treatment that perhaps dwells overly on the DNA of problems rather than what works well, but the expert analysis exudes insight and it is required reading.

The concluding piece, by the editor Maggie Blyth, rightly notes the improvements that have been made as well as challenges ahead to secure the Munro legacy. Edited texts are often an uneven feast and this is no different; but there is enough fresh protein overall to make it a nourishing and recommended read for busy people.

## **Andy Pithouse**

School of Social Sciences, Cardiff University

Changing Children's Services: Working and Learning Together, Foley, P. & Rixon, A.

(eds.), 2<sup>nd</sup> edition

Bristol: Policy Press, 2014

ISBN: 978-1447313793, £21.99 (pbk.), pp.288

Social work trainees are busy people and they need to get to grips quickly with key issues and critical thinking – this they can do through this updated edited text on children's services that is aimed largely at new entrants and their trainers. Six extended chapters focus on the world of work and the text is broken up frequently by 'Practice Boxes' and 'Thinking Points' – and commendably, evidence is drawn from across the UK and beyond. We get off smartly with an overview of the many tributaries of organisational and policy change that have shaped contemporary UK children's services. This chapter sets out the virtues of an interdisciplinary approach and captures much of the complexity of multi-agency practice. The next chapter, by Bill Stone and Pam Foley, pursues related themes around integrated working and the key drivers, issues and skills needed. An ecological approach illustrates well the different levels and concepts of working across boundaries. This is a chapter rich in examples of what seems to make for success – students reading this might well be forgiven for thinking they are entering a career where they can actually do some real good, via social work values, and commitment to a child-centred practice where inter-professional differences must not impede winning the bigger prize – how refreshing!

Stephen Leverett's chapter on parenting addresses that most contested of realms: who or what is a parent, and what does 'good' look like. The parenting roles of state, families, mothers, fathers and kin come up for scrutiny here, as do intervening factors such as gender, environment and poverty. The chapter then takes a more sociological gaze towards aspects of

capital (social, economic, cultural) that bear upon a child's upbringing. This is a reflective and demanding chapter that returns often to everyday dilemmas around problem definition and intervention in parenting, and should prove stimulating and accessible to early career readers.

Chapter four, by Nick Frost, engages with the disarmingly simple theme of what makes a difference in inter-agency working. Examples of the Common Assessment Framework (CAF) are offered to argue the case that effective joint working is feasible and when linked to supportive early intervention can be a powerful force for prevention. The chapter focuses in detail on what helps to dissolve unhelpful boundaries and status issues, and seems for the most part unblushingly upbeat about the joys of joint working. The topic is not much 'troubled' by a more sceptical and critical theory about what works or not – perhaps that is best left to a later time when the reader as occupational neophyte has been round the block a few times, and is ready to understand better the doubts and disputes over the claimed virtues of working together.

Working together requires learning together, and Andy Rixon in Chapter five starts with a reprise of landmark reports and inquiries from across the UK that implicate insufficient training as part of some failures and good inter-professional training as the remedy and a prerequisite of quality services. But what is to be learnt and how? The chapter quickly gets to grips with the contested matter of what counts as appropriate knowledge. Similarly, we get a useful tour of proven technologies of transmission that include engaging with service users, particularly children. An outline of reflective practice and the learning organisation completes an extended and easily digested introduction to matters of shared learning.

The final Chapter six, by Nick Frost, looks at key characteristics and causes of change in the workplace. The external challenges of audit and inspection are explored as is the impact of the voice of service users, particularly the expectations surrounding participation by children and young people in the way children's services operate. The importance of clear governance and an open culture able to accept criticism is much affirmed in a post-Savile risk-averse climate. Overall, the chapter offers useful descriptions of what a good inter-agency setting looks like in the context of frequent change. Finally, there is some brief comment on the general nature of change in modern workplaces. Overall the book is a worthy successor to the 2008 edition, perhaps overly loyal in places where the literature has a dated feel and reads more 'then' than now. If, like me, you are not a fan of 'boxes' which tell you what you have just read, or must learn, or must think further about - the implication being of reader as doofus - then you will have to get over that to enjoy what is, in essence, a valuable introduction to organisational complexity in the workplace that moreover doesn't lose sight of children, childhood and parenting. It is essential reading for social work trainees and others new to the changing world of children's services. It even dwells in some detail on what can be learned from far-flung places like Scotland, Wales and Northern Ireland - a welcome and prominent feature, and all too rare in much literature in this field, which narrows its ambit to the policy borders set by DfE or DH. Much recommended.

## **Andy Pithouse**

School of Social Sciences, Cardiff University

## The Story of Baby P: Setting the Record Straight, Jones, R.

Bristol: Policy Press, 2014

ISBN: 978-1447316220, £12.99 (pbk.), pp.339

It would be remarkable if any adult living in Britain in November 2008 and subsequently did not know the story of Baby P and the circumstances of his tragic death. Such was the saturation of his sad story in all forms of the nation's media, and most particularly in the tabloid press, that his blond curls and blue eyes staring up at the camera became instantly recognisable and remain an enduring image. However, because of the approach taken by the media, most British adults would also describe how Baby Peter (as he later became known, once Peter's full name was revealed) was let down by the social workers who were intended to protect him. Ray Jones' assertive text seeks to redress the balance: to acknowledge the problems experienced within Haringey, the local authority with responsibility for Peter's protection, but also in an impassioned way to recognise the multi-agency responsibilities and accountabilities, which appear to have been lost sight of in the fierce scapegoating by the media and others of the social work staff, their managers and director.

Peter Connelly died of multiple injuries, neglect and malnutrition; and three people, his mother Tracey Connelly, her partner Steven Barker and his brother Jason Owen, were convicted of causing or allowing his death. Ray Jones examines in detail the information known about Peter's short life, deliberately drawing only on published texts to inform his analysis. From the perspective of appraising policy, this is a useful strategy as it calls on the same evidence (albeit in some instances heavily redacted) which would be available to policy makers and analysts in considering whether any individual malpractice or systemic failure (or perhaps a combination of the two) contributed to Peter's death. A later documentary, the powerful BBC programme screened on 27<sup>th</sup> October 2014 'Baby P: The Untold Story' drew also on personal testimony of many key individuals involved, such as the former Haringey Director of Children's Services Sharon Shoesmith and Peter's social worker Maria Ward, whose primary evidence gives another compelling element to Peter's story and the aftermath of his death. Ray Jones was also a consultant for this documentary, and in combination with his book it prompts deep thought about the positioning of blame.

'The Story of Baby P: Setting the Record Straight' is structured to guide the reader through the narrative of Peter Connelly's life, and his death; and then, in a similar manner, to the media frenzy itself, through a whirlwind of whipped-up public opinion, political intervention and press persecution. It carefully examines the information and evidence used by the independent authorities involved in assessing what had happened to Peter, but also in considering the efficacy of the local authority and partner agencies. Jones raises questions about the multiple revisions of OFSTED reports, and questions the process of serious case reviews as an effective learning tool and agent for improved practice.

National policy, legislation and social work practice have always been inextricably interlinked, but the influence of the media in orchestrating political knee-jerk reactions and subsequent direct interference with local government decisions has probably never been more animated or forceful than with the Baby P coverage. Jones describes the direct intervention by Ed Balls (then Secretary of State for Children) leading to the immediate dismissal of the Director of Haringey's Children's Services, Sharon Shoesmith, which was unprecedented. He comments on the campaign led by 'The Sun' newspaper being a graphic illustration of the emerging powerful combination of published and social media. The book highlights the immediate personal impact of the death of this young child, but also the impact of press hounding – effectively ending some professional careers. It also illustrates how, at the time of the huge press interest, Jones found himself a lonely voice as he commented in the media contemporaneously on the unfolding events. However, his first-hand experience of having been asked to share his views publicly amid the general tone of persecution lends gravitas to this book. Ray Jones was one of the few prepared to risk the wrath of the press, and to seek to inject balance into appraising the situation.

The involvement of politicians in condemning the work of social workers is not new; reviews and radical reform of social care policy and legislation is unfortunately prompted too frequently by the death of a child. Victoria Climbié was an obvious example, a child whose tragic death, like Peter's, occurred earlier, also within the boundaries of Haringey local authority. Ray Jones steers his readers to understand how, in Peter Connelly's case, the broader political involvement was different, with rapid political reaction rather than considered policy change. He explores the issue that in this case, many senior national politicians appeared to act (and to speak publicly) on the basis of inaccurate and inadequate information. For example, in opposition David Cameron referred to Tracey Connelly as being seventeen years old (when she was twenty eight at the time) and questioned rhetorically "Where were the professionals?" This was in contrast to the comments of the co-author of a serious case review into Peter's death who noted that the serious case review prompted 'nothing in particular to give pause for thought' amongst other serious case reviews.

Ray Jones also questions whether Ed Balls (then Minister for Children) as an individual was unduly influenced by the media clamour following Peter's case reaching the press; an influence which in turn rippled through Parliament and local government, seemingly prompting extreme knee-jerk reactions such as his dismissal of Director Sharon Shoesmith. Whilst questioning the roles of professionals is a valid exercise (and is indeed a component of any serious case review enquiry) Jones highlights the damaging systemic effect of the media and political storm along with the intensely personal impact on professionals involved. Jones reminds us that 'Good child protection services require competence, care and commitment. They also require confidence, continuity and stability' (p.110). In my view, Jones deals well with the ripple effect of the damage created by the media frenzy following Peter's death, damage which is still being felt today, with local authorities working to stabilise and create continuity for and in their workforces.

Largely the book is well written, with arguments flowing logically and the questions posed receiving thorough and robust examination. Ray Jones' professional social care background is readily apparent throughout this text, not only by demonstrating knowledge and expertise as he evaluates the actions of the social work team, but also, at times somewhat testily, in his defence of the local authority and his criticism of the passive absolving of responsibility he observes by the other leading agencies including health and the Metropolitan Police.

Within this context then, it is difficult to understand why Jones repeatedly refers to Jason Owen (older brother of Steven Barker, Tracey Connelly's partner) as having a young girlfriend (with whom it appears he lived in Tracey Connelly's house). The 'girlfriend' was fifteen at the time (a child) and Jason Owen was approximately 36 (an adult), with three of his own children living with him. The exploitative nature of this child/adult relationship is not considered in Jones' book. It is not clear from the evidence supplied in the book whether the local authority knew at the time about Steven Barker and Jason Owen being part of the household, but in my view it is regrettable that Ray Jones does not, with hindsight, highlight the arrival of Owen's fifteen year old 'girlfriend' as yet another vulnerable child in the household, alongside Peter, his siblings and Owen's own three children.

Overall the book is thoughtful and thought provoking (although possibly rather hurried in the final chapters and, by comparison to the early chapters, perhaps scaled back in analysis). It prompts social work professionals to re-validate the principles upon which their profession is based and will help to counterbalance the current bombardment of advice aimed at social workers regarding 'how to stay out of the press'.

Despite these specific reservations, this book is a riveting 'must read' for any professional working in Children's Services, and also for those working in partner agencies (who, on this occasion, managed to escape the limelight). However, perhaps the groups who most need to reflect on Jones' analysis and findings are the press and politicians.

From the world of policy and guidance 'Working Together 2013' describes how agencies must

work together to protect children. Jones' work serves as a reminder to workers in all those agencies that increased progress could be made in better protecting children if agencies not only work together but also stand together when things go wrong. His final comment is for politicians, challenging them to stand up to bullying from the press and not to be sucked into bullying: but rather to recognise the courageous and difficult work undertaken every day by children's social workers.

#### **Andrea Morris**

Principal Social Worker, Devon County Council

**Debates in Personalisation**, Needham, C. & Glasby, J.

Bristol: Policy Press, 2014

ISBN: 978-1447313427, £21.99 (pbk.), pp.219

Self-directed Support - Personalisation, Choice and Control, Pearson, C., Ridley, J. &

Hunter, S.

Edinburgh: Dunedin Academic Press, 2014 ISBN: 978-1780460246, £18.95 (pbk.), pp.110

As we all know, personal budgets, given as direct payments, are the preferred means by which the Government would like local authority adult social care departments to deliver social care. Putting financial control in the hands of people with social care needs is the best way of empowering them, enabling them to participate in wider society as independent, self-directing citizens. And so successful has the introduction of personal budgets and direct payments been in social care in England that the Government is introducing personal budgets in the NHS.

There's evidence to support all this, of course. In social care there has been consistently positive support reported from surveys conducted by In Control (Poll *et al.*, 2006; Hatton *et al.*, 2008; Hatton & Waters, 2011), the not-for-profit organisation that probably did more than any other to promote the cause of self-directed support and to ensure the Government paid attention. The IBSEN evaluation (Glendinning *et al.*, 2008) found that apart from older people, budget users achieved good outcomes. And another DH funded study of a pilot of personal budgets in the NHS amongst people with long-term health conditions found that people with a budget did better than those without (Forder *et al.*, 2012).

And yet, and yet. We also know that older people are by far the largest group of users of adult social care, and despite a lot of exhortation, guidance and support from the Department of Health and others, the evidence continues to suggest personal budgets don't work as well for many older people as for members of other groups. (Lloyd, 2010; Woolham & Benton, 2012; Woolham et al., 2015). Then there have also been some vituperative but amusing comments from Ben Goldacre, and others on the quality of the personal health budgets evaluation (https://storify.com/bengoldacre/why-won-t-nhs-england-do-an-rct-on-this-5bn-yr-int). weren't enough, respected figures such as Peter Beresford, a long-term and very effective advocate of direct payments, and Simon Duffy, arguably the intellectual driving force behind self-directed support, have distanced themselves from the Government's policies - the former by a country mile or two, the latter perhaps by more of a short walk. In local authority adult social care departments, criticism of government policies has been muted, as there is, at senior levels at least, widespread support, but controversy still exists in academic and policy communities, with advocates and opponents of personal budgets and direct payments queuing up from time to time (sometimes even in this journal) to give one another a bit of a going over. This debate has been respectful, but it is also clear that seven years after the DH Transformation Grant, there is far from a settled consensus about the value and significance of personal budgets and direct payments.

Into this arena of controversy two more books have recently been published: Debates in Personalisation, edited by Catherine Needham and Jon Glasby, and Self-directed Support -Personalisation, Choice and Control by Charlotte Pearson, Julie Ridley and Susan Hunter. That neither book offers remarkable new insights should not really be a surprise, as the topic has preoccupied many researchers, policy analysts and others over the last few years. However, each, in rather different ways, has some interesting things to say.

Debates in Personalisation is a remarkably generous and even-handed book. The editors acknowledge their own differences of opinion. Jon Glasby has been a not uncritical supporter of personal budgets and direct payments, whilst Catherine Needham has in more recent writing been more sceptical. However, they are scrupulously fair to their contributors - and with arguably one or two exceptions, the book represents quite well the wide spectrum of opinion in research and policy communities about personalisation and personal budgets. It's logically structured into five parts - beginning with an overview and introduction. In this section, largely written by the editors, there's a good description of the main issues; and though I might disagree with some of their claims (for example, though it may be true that (p.18) 'almost all formal evaluation data has indicated that people who receive direct payments receive better outcomes', this glosses over the - to say the least - very variable quality of a lot of these studies and data sources) it is a useful introduction to important issues and controversies.

The main sections of the book - parts two to four - deal respectively with personalisation challenges, frontline perspectives, and personal health budgets. Contributors include Lucy Series on the obscurities of Resource Allocation Systems, Jill Manthorpe on Safeguarding and Risk (referring to a current major research project), and Liz Lloyd, who describes how personalisation policies are written predominantly with younger adults in mind, reflecting an impoverished perception of need in old age at odds with the ideals of personalisation. Further tensions are reported by Wendy Mitchell and Jenni Brooks in relation to carers; and a major challenge for authorities in relation to self-funders is described by Melanie Henwood. The three contributions on the workforce and employment issues reflect what is described as a two-tier system - for those able to manage, or have gold standard support; and a second rate service for others. Another group of contributions is on the incipient Personal Health Budget programme and its ongoing evaluation.

The final section, of responses and conclusions, offers, amongst other things, interesting and personal accounts, by Simon Duffy and Peter Beresford, of the evolution of their thinking. (A few years ago I attended a conference at which Simon Duffy spoke. It was an engaging and thoughtful presentation and I thought at the time that the Government would probably steal his clothes. And so it seems to have proved - as readers will find if they read his chapter 'After Personalisation'). Though differences in opinion between Duffy and Beresford remain, both have a shared experience of being feted then frozen out by the Department of Health. Duffy suggests it was probably inevitable that 'we would end up with the expensive mess that personalisation has become' (p.178). In their own conclusion Glasby and Needham remind us of another thing we all know: that the resource glass might not only be judged half-full or halfempty, but that it might be judged twice as big as it needs to be.

Many of the contributions are essentially based on arguments expressed by the authors in other publications. However, these are not always readily accessible to busy, but interested social work students, practitioners and managers with restricted time and library facilities. These are the groups likely to find this book of most interest - so it offers a very valuable contribution by bringing together these very different perspectives in a single, readable volume.

Self-directed Support - Personalisation, Choice and Control also offers a summary of the history of self-directed support (SDS) and the policy directives that have shaped its development. It also draws on findings from an evaluation of three SDS sites in Scotland. Although the book has relevance to a wider constituency, parts of it are likely to be of particular interest to practitioners, managers and policy makers in that country. Demographic and cultural differences mean that those responsible for implementing SDS and personal budgets will need to address some very specific challenges which are less apparent in England. For example, low population densities may make it even harder for local, responsive, sustainable social care markets to develop. There is also a rather stronger tradition of collectivism – at least in central Scotland – which sits uneasily alongside the privatised, choice-based, individualised forms of service provision that are becoming the norm in England. All of this suggests a stronger role for the public sector in relation to personalisation and personal budgets than in England. Importantly, too, Scotland is a few years behind in developing personal budgets. There are therefore opportunities to learn from mistakes made in England. Many of these are identified and described in this book.

A notable strength of this fairly slender volume is the care with which the authors summarise the key issues. This also means, however, that the prose could be a bit livelier in places, and though Pearson *et al.* summarise some of the key literature thoroughly, in places they seem reluctant to pass their own judgement on it – leaving the text a bit too descriptive in places. And though they draw on empirical data collected from three sites, this evidence – some of which might be of particular interest to readers south of the border – seems rather overwhelmed by summaries of the work of others presented alongside these findings.

An interesting difference from Needham and Glasby's book is reflections by Pearson and colleagues on personalisation strategies in Europe, where personal budgets and direct payment policies have been curtailed, postponed or cancelled post-austerity. By contrast, in England, the roll-out of personal budgets has continued. The authors also draw attention to an interesting paper by West (2013), describing how, in the face of swingeing budget cuts, a large English City Council continued to implement its personalisation scheme, arguing both for its transformational character (and described as being between 'managerial domination and fantasy'); and they refer to Ferguson's critique of the ideology of personalisation (2007). Both papers are highly critical of personalisation, and though Ferguson's work is mentioned in passing in Needham and Glasby's book, West's paper is apparently overlooked (possibly because it was published fairly recently).

Neither book – probably wisely – tries too hard to synthesise contrasting perspectives or formulate advice or guidance for policy makers or practitioners. However, whereas Needham and Glasby offer a fair and balanced summary of their contributors' work, Pearson *et al.* sometimes fail to rise above the general and the ordinary. For example, statements such as 'Recognition of the uncertainty in new roles for social work and other frontline staff... must be reflected in substantive training and development programmes...' and 'Experience to date suggests that the 'transformational' shift in power relationships is proving to be a challenge' (p.80) seem rather underwhelming and disappointing given the thoughtful and useful scholarship evident in earlier chapters.

None of the criticisms in this review, though, should deter the interested reader from getting hold of these two books. In different ways, both make valuable contributions to what are arguably the most important debates happening in UK adult social care at the present time. Go on, buy or borrow them, and see what you think.

#### References

Ferguson, I. (2007) 'Increasing user choice or privatizing risk? The antinomies of personalization', *British Journal of Social Work*, **37**(3), pp.387-403.

Forder, J., Jones, K., Glendinning, C., Caiels, J., Welch, E., Baxter, K., Davidson, J., Windle, K., Irvine, A., King, D., & Dolan, P. (2012) *Evaluation of the Personal Health Budget Pilot Programme*, PSSRU Discussion Paper 2840\_2, accessed at:

http://www.personalhealthbudgets.england.nhs.uk/\_library/Resources/Personalhealthbudgets/2012/PHB E personal health budgets final report Nov 2012.pdf

Glendinning, C., Challis, D., Fernández, J-L., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, M. & Wilberforce, M. (2008) IBSEN: Evaluation of the Individual Budgets Pilot Programme: Final Report, York: Social Policy Research Unit, University of York, accessed at: http://www.york.ac.uk/inst/spru/pubs/pdf/IBSEN.pdf

Hatton, C. & Waters, J. (2011) The National Personal Budget Survey - June 2011, In Control and Lancaster University, London: Think Local, Act Personal.

Hatton, C., Waters, J., Duffy, S., Senker, J., Crosby, N., Poll, C., Tyson, A., O'Brien, J. & Towell, D. (2008) A Report on In Control's Second Phase: Evaluation and Learning 2005-2007, London: In Control Publications.

Lloyd, L. (2010) 'The individual in social care: the ethics of care and the 'Personalisation Agenda' in services for older people in England', Ethics and Social Welfare, 4(2), pp.188-200, accessed at: http://www.tandfonline.com/doi/abs/10.1080/17496535.2010.484262#.VMdaMSz2QmU

Poll, C., Duffy, S., Hatton, C., Sanderson, H. & Routledge, M. (2006) A Report on In Control's First Phase 2003-2005, London: In Control Publications.

West, K. (2013) 'The grip of personalisation in adult social care: between managerial domination and fantasy', Critical Social Policy, 33(4), pp.638-657.

Woolham, J. & Benton, C. (2012) 'The costs and benefits of personal budgets for older people: evidence from a single local authority', British Journal of Social Work, 43(8), pp.1472-1491, accessed at: http://bjsw.oxfordjournals.org/content/early/2012/07/19/bjsw.bcs086

Woolham, J., Steils, N., Daly, G. & Ritters, K. (2015) Are personal budgets always the best way of delivering personalised social care to older people?, Research findings (NIHR School for Social Care Research), accessed 19 February 2015 at: http://www.sscr.nihr.ac.uk/PDF/Findings/RF19.pdf

#### John Woolham

Senior Research Fellow, Coventry University

# 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 coordinates 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.