Good Practice in Social Care for Disabled Adults and Older People

with Severe and Complex Needs: Evidence from a Scoping Review

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Abstract

This paper reports findings from a scoping review of the literature on good practice in social care for disabled adults and older people with severe and complex needs. Scoping reviews differ from systematic reviews in that they aim to rapidly map relevant literature across an area of interest. This review formed part of a larger study to identify social care service models with characteristics desired by people with severe and complex needs and scope the evidence of effectiveness. Systematic database searches were conducted for literature published between January 1997 and February 2011 on good practice in UK social care services for three exemplar groups: young adults with life-limiting conditions; adults who had suffered a brain injury or spinal injury and had severe or complex needs; and older people with dementia and complex needs. Five thousand and ninety-eight potentially relevant records were identified through electronic searching and 51 by hand. Eighty-six papers were selected for inclusion, from which 29 studies of specific services were identified. However, only four of these evaluated a service model against a comparison group and only six reported any evidence of costs. Thirty-five papers advocated person-centred support for people with complex needs, but no well-supported evaluation evidence was found in favour of any particular approach to delivering this. The strongest evaluation evidence indicated the effectiveness of: a multi-disciplinary transitions team for young adults; intensive case management for older people with advanced dementia; a specialist social worker with a budget for domiciliary care working with psycho-geriatric inpatients; and inter-

professional training for community mental health professionals. The dearth of robust evaluation evidence identified through this review points to an urgent need for more rigorous evaluation of models of social care for disabled adults and older people with severe and complex needs.

What is known about the topic

- The population of people with severe and complex needs is growing.
- Support for these groups comes from a wide range of organisations and is often criticised for being poorly uncoordinated.
- The preferred policy in the UK is to issue personal budgets to enable services user to purchase their own support.

What this paper adds

- There is little evaluation evidence about the costs or outcomes of 'good practice' approaches to UK social care for people with severe and complex needs.
- Some promising evidence was identified indicating the effectiveness of: a young adults' multi-disciplinary transitions team; intensive case management for people with severe dementia; specialist (psycho-geriatric inpatient) social work; and multi-disciplinary training for mental health professionals.

Introduction

The population of older and disabled users of adult social care services in England is changing. Advances in medicine and surgery are enabling more young people born with complex conditions to survive into adulthood and more adults who have suffered major trauma or life-threatening illnesses to live on with multiple and severe impairments. With population ageing, numbers of people with dementia and additional health problems will also increase; the numbers of older people with complex needs in England are already estimated to have grown from 551,000 to 631,000 from 2002 to 2012 (CSCI, 2009). Meanwhile, technological advances enable those with very complex or severe health problems to be supported at home rather than in hospital. These developments present major new challenges for adult social care services and require new service responses and skills.

Support for people with severe and complex needs in England can come from local authority social care services, specialist and community-based National Health Services (NHS), and a wide range of specialist third sector, private and user-led organisations. Not surprisingly it has often been criticised for being fragmented and uncoordinated (Morris 2004, Rosengard *et al*. 2007, Beresford & Cavet 2008). Current health and social care policies strongly advocate personalised approaches, particularly the use of personal budgets to enable service users to arrange and purchase support to meet their own individual needs and preferences (DH 2010b). However, we do not yet know how effectively these approaches are working for people with severe and complex needs (Henwood & Hudson 2008).

This paper reports a scoping review of evidence of 'good practice' in social care for disabled and older people with severe and complex needs, conducted during 2011. It formed part of a larger study that aimed to identify social care and related services with characteristics that were desired by these groups and had evidence of effectiveness. The aims of the wider study were to:

- Identify the features of service and support arrangements desired by adults and older people with severe and complex needs, and their carers.

- Identify services with the desired features and potential to constitute examples of 'good practice', subject, where necessary, to further evaluation.

- Make recommendations about service developments and future research in adult social care, based on the above evidence.

The scoping review element of this study aimed to ascertain and evaluate the size and robustness of the evidence base about UK adult social care services and support arrangements for disabled and older people with severe and complex needs. Evidence on the costs and outcomes of services was of particular interest, not only because of its centrality to robust and comprehensive evaluation, but because of its importance to service commissioners and providers, given the high levels of support required by this group.

Definitions

No single definition of 'people with complex needs' exists (Henwood & Hudson 2008, Rosengard *et al.* 2007) but Rankin & Regan (2004) argue that broadly speaking this group can be distinguished by the breadth and depth of their support needs, requiring intensive help from multiple services. In this study the focus was disabled adults and older people with intensive and multiple needs.

Hereafter this group will be referred to as 'people with complex needs'. To give the literature review manageable boundaries the searches were restricted further to evidence about services for three 'exemplar' groups of people with complex needs:

- Young adults with complex or life-limiting conditions;

- Adults with brain or spinal injury and complex needs;

- People with dementia and additional physical or sensory impairments.

Young people with learning disabilities and complex needs were not selected as an exemplar group because a review of services for this group had recently been published (Mansell 2007). However, where evidence relating to this, or other non-exemplar groups, was identified, it was not discarded.

A broad definition of 'social care' was employed, including services from local authority, charitable and private sector providers, those purchased using personal budgets and NHS-funded support meeting social care needs. As social care systems around the world differ widely the focus here was on evidence from UK services only.

Aims

The scoping review aimed to identify:

- Evidence about arrangements for delivering, organising and commissioning services for people with complex needs, particularly (but not exclusively) the three exemplar groups listed above.

- Evidence of the effectiveness and cost-effectiveness of these arrangements.

- Gaps in the evidence base.

Methods

The review followed Arksey & O'Malley's methodological framework for scoping reviews (2005). Scoping reviews differ from systematic reviews in their intention to rapidly map relevant literature across an area of interest. As such they are characterised by breadth, including a wide range of publications and study designs, but tend not to apply the rigorous quality criteria of a systematic review. However, this scoping review did include a broad assessment of study quality by applying a schema adapted from Eager *et al.* (2007).

Electronic searches

Electronic searches were carried out in February 2011. Three searches looked for UK literature published in or after 1997 about:

- Social care AND young people AND complex health problems or life-limiting conditions including chronic OR rare diseases

- Social care AND brain injured OR physically impaired people

- Social care AND people suffering from dementia AND physical disabilities OR chronic disabling conditions.

Twenty-five databases were searched (Box 1 below):

Box 1: Databases searched

- MEDLINE and MEDLINE In-process

- EMBASE

- Cumulative Index to Nursing & Allied Health (CINAHL)

- Health Management Information Consortium (HMIC)

- Science Citation Index (SCI)

- Social Science Citation Index (SCI)

- Conference Proceedings Citation Index-Science (CPCI-S)

- Conference Proceedings Citation Index-Social Science & Humanities (CPCI-SSH)

- Social Policy and Practice

- Applied Social Science Index and Abstracts (ASSIA)

- Social Services Abstracts

- Social Care Online

- PAIS International

- PsycINFO

- Cochrane Database of Systematic Reviews (CDSR)

- Database of Abstracts of Reviews of Effects (DARE)

- Cochrane Central Register of Controlled Trials (CENTRAL)

- Health Technology Assessment database (HTA)

- NHS Economic Evaluation Database (NHS EED)

- ScienceDirect

- JSTOR

- Ingentaconnect

- zetoc

- OAIster

- Economic and Social Research Council (ESRC)

Inclusion and exclusion criteria

Provisional criteria based on the review aims were devised and refined during the first stage of selection for retrieval (Parker *et al.* 2000). The following refined inclusion criteria were then applied:

- Papers about, or relevant to, one of the three exemplar groups OR another group of people with severe and complex needs where learning could be transferable.

  AND

- Containing evidence about adult social care commissioning, organisation, delivery or costs (including non-statutory services funded from statutory sources).

  AND

- Based on research OR review of evidence OR an account of perceived good practice in adult social care commissioning, organisation, or delivery.

  AND

- Containing evidence of good practice OR an account of perceived good practice in adult social care commissioning, organisation, or delivery.

Papers were excluded that were:

- About services for people whose needs were not complex or severe;

- About children's services;

- Not about evidence of good practice in adult social care;

- Discussion pieces, text books, policy or guidance documents.

Where there was insufficient information to make a decision, the document was not retrieved.

Applying the criteria

Two researchers simultaneously read the first 30% of abstracts and decided independently whether the inclusion criteria applied. Their decisions were compared; disagreements put to the principal investigator and differences in interpretation clarified. All records meeting the inclusion criteria at this stage were selected for retrieval. The two researchers then decided independently about inclusion and retrieval of the remaining 70%. All retrieved papers were read in full and the inclusion criteria re-applied. Decisions at this stage were only checked if there was uncertainty.

Hand searching

The team also collected potentially relevant citations from websites and reference lists and applied the refined inclusion criteria. As the electronic searches identified far more records than originally anticipated (see below), time did not permit reference list searching.

Data extraction

The following information was extracted from each paper:

- Full reference;

- User group;

- Type of research or expert account;

- Description of potential good practice;

- What elements contribute to it being considered 'good practice' for people with complex needs, either as identified by evaluation or in the authors' opinion;

- Summary of any evaluation, including design, outcome measurements, main findings, and any limitations;

- Robustness of evaluation (see below);

- Implications for social care.

Quality assessment

For each evaluation identified, the following schema was applied to indicate the robustness of the evidence produced (adapted from Eager *et al.* 2007):

Hierarchy of evaluations:

1. **Well-supported practice** – prospective randomised controlled trial;

2. **Supported practice** – evaluated with a control group and reported in a peer-reviewed publication;

3. **Promising practice** – evaluated with a comparison group;

4. **Acceptable practice** – evaluated with an independent assessment of outcomes but no comparison group (e.g. pre- and post-testing or qualitative methods) or historical comparison group (e.g. normative data);

5. **Emerging practice** – no independent assessment of outcomes (e.g. formative evaluation, evaluation conducted by host organisation).

It should be noted that, while qualitative methods came under 'acceptable practice' in this schema, the authors recognise that qualitative studies can (and often do) present knowledge of equal quality to the highest quality quantitative evaluations. However, qualitative evaluation tends to focus on the experience of participants - what happened, how and with what consequences, from various perspectives – (Patton 2002), whereas quantitative evaluations focus on

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effectiveness and cost-effectiveness. This review aimed specifically to identify this latter type of evidence, and, while it is recognised that randomised controlled trials are not infallible (Slade & Priebe 2001) these are still considered to be the 'gold standard' in producing evidence of 'what works' (Coates 2009).

An additional aim of the review was to identify approaches to supporting people with complex needs that are yet to be evaluated and in doing so highlight gaps in the evidence. As such, a range of non-evaluative material was included in the review, which did not fit the above scheme and was instead categorised (without hierarchy) as follows:

- **Service users' views** (e.g. general surveys or interviews about good practice in social care for people with complex needs - not evaluating a particular service or approach);
- **Review paper** (not necessarily systematic, but excluding discussion papers with no systematic presentation of evidence);
- **Expert opinion**
- **Description**

Findings

Included papers

Five thousand and ninety-eight potentially relevant publications were identified through the systematic searches; 296 of these were selected for retrieval; and 66 were included (see Table 1). A further 51 papers were identified by hand, of which 20 were selected for inclusion (see Table 2).

Table 1: Electronic search results by exemplar group

(% of total records identified)

	Brain or spinal injury	Dementia and additional complications	Young people with life-limiting conditions	Totals
Records identified through electronic searching	2724	888	1486	**5098**
Selected for retrieval and full reading	175 (6.4%)	77 (8.7%)	44 (3.0%)	**296** (5.8%)
Selected for inclusion	**39** (1.4%)	**13** (1.5%)	**14** (0.9%)	**66** (1.3%)

Table 2: Total included papers

Electronic searching	66
Hand searching	20
Total included papers	**86**

In some instances, more than one paper about the same study was identified: 29 evaluations of particular service models or approaches were reported in 34 papers; 10 studies of service user views on good practice were reported in 11

papers; and seven reviews were reported in eight papers. The remaining 33 papers described services or presented expert accounts of models and approaches considered by their authors to be good practice, but without any supporting evaluation evidence. Table 3 summarises all the included studies, reviews, accounts and descriptions by exemplar group and study quality. Where a paper reports evidence of costs this is also noted.

Table 3: Studies, reviews, expert accounts and descriptions by exemplar group and study quality

	Young people with complex needs	Adults with brain or spinal injury	Older people with complex needs	Other groups/ complex needs in general	Total
1. **Well-supported practice**	0	0	0	0	**0**
2. **Supported practice**	0	0	0	0	**0**
3. **Promising practice**	1 Bent *et al.* (2002) AND Chamberlain & Kent (2005) – **reports costs**	0	2 Challis *et al.* (2002) – **reports costs** Shah *et al.* (2001) – **reports costs**	1 Carpenter *et al.* (2006)	**4**
4. **Acceptable practice**	0	2 Cunningham *et al.* (1998) Easton *et al.* (2007)	4 Bond & Syson (2010) Brooker *et al.* (2007a) AND (2007b) McKeown *et al.* (2010) Ryan *et al.* (2009)	6 Beresford *et al.* (2008) Carnaby *et al.* (2003) Felce *et al.* (1998) – **reports costs** Jones *et al.* (1999) – **reports costs** Kennett & Payne (2005) Spandler & Vick (2006)	**12**
5. **Emerging practice**	2 Adams & Shaw (2008)	5 Baker & Shears (2010) Coetzer *et al.*	2 Ackermann *et al.* (2003) – **reports costs**	4 Bright (2009) Foundation For People With	**13**

	Cowen (2010) AND Cowen (2011)	(2003) Glover (2003) Gurr (2006) Stewart (2009)	Das & Bouman (2008)	Learning Disabilities (2009) Lacey (1998) Morgan (2000) AND (2002) AND Foundation for People with Learning Disabilities (2000)	
Studies of service users' views on good practice (i.e. no particular model)	2 Abbott *et al.* (2009) Clarke *et al.* (2011)	1 Mental Welfare Commission for Scotland (2010)	2 Foundation For People With Learning Disabilities (2002) Lawrence & Murray (2009a) AND Lawrence & Murray (2009b)	5 Bernard *et al.* (2010) Glendinning *et al.* (2000) Hardy (2004) Henwood & Hudson (2009) Rankin & Regan (2004)	**10**
Reviews	1 Social Care Institute For Excellence (2005)	1 Research In Practice For Adults (2007)	1 Challis (2010) – **reports costs**	4 National Centre for Independent Living (2008) Rosengard *et al.* (2007) Social Care Institute For Excellence (2009a AND 2009b) Weston (2002) – **reports costs**	**7**
Papers giving expert accounts	2 Children's Services Development Group and Local Government Association (2009) Hopkins (2007)	0	6 Bowers *et al.* (2007) Jacobs (2007) Janicki *et al.* (2002) Lawrence & Murray (2010) Wilkinson & Janicki (2002) Wilkinson *et al.* (2004)	6 Department of Health (2010a) Fiedler & Ellis (1997) Garboden (2007) Leslie *et al.* (1999) Moulster (2007) Ogilvie (1997)	**14**
Descriptions of services or approaches to good practice	3 Hamnet (2009) James *et al.* (2010) McFarlane (2009)	5 Boughey (2005) Carey *et al.* (2001) Hayes *et al.* (2003) Redhead (2010) Social Care Institute For Excellence (2010)	3 Burgess (2007a AND 2007b AND 2007c AND 2009) AND Shoard (2007) Chalfont (2011) Pitt (2009)	4 Jay (2003) Skirton & Glendinning (1997) Valios (2010) Watts (2008)	**15**
Totals	**13**	**15**	**26**	**25**	**75**

It is notable that no 'well-supported' or 'supported' practice was identified and only six studies and two reviews made reference to the costs or cost-effectiveness of services. The strongest evaluation evidence, assessed as 'promising practice', supported the effectiveness of:

- A multidisciplinary young adults' transitions team (Bent & Chamberlain 2002, Chamberlain & Kent 2005).

- Intensive case management for people with severe dementia (Challis *et al.* 2002).

- Specialist (inpatient, psycho-geriatric) social work (Shah *et al.* 2001).

- Inter-professional training for community mental health professionals (Carpenter *et al.* 2006).

The evidence from these four 'promising' studies is summarised below, together with evidence from other papers relating to similar models. A fifth section describes the largest body of literature identified – person-centred support. Thirty-five papers on this topic were identified, but none contained strong evaluation evidence.

1. Multidisciplinary specialist teams

Bent *et al.* (2002, 'promising practice') reported a retrospective cohort study comparing support from a multidisciplinary Young Adults Team (YAT) with the same support from ad hoc uncoordinated services. Two hundred and fifty-four disabled young people were interviewed using standardised measures, 'similar numbers' [sic] of whom used YAT and uncoordinated services; logistic regression analyses tested for effects. The primary outcome measure was participation in society, assessed using the London handicap scale (Harwood *et al.* 1994). After

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adjustment for pain, fatigue, and stress, young people using YAT services were 2.54 times (95% CI 1.30–4.98) more likely than those using uncoordinated services to participate in society. There were no significant differences in the volume or costs of the resources used by clients using the YAT or uncoordinated services.

Three other evaluations of specialist multidisciplinary teams were identified: Bond & Syson (2010) and Cunningham *et al.* (1998) (both 'acceptable practice'); and Coetzer *et al.* (2003) ('emerging practice'). A further study based on service users' views identified inter-disciplinary community neurological rehabilitation teams as promoting continuity of care for people with long-term neurological conditions (Bernard *et al.* 2010).

Cunningham *et al.* and Bond & Syson both employed qualitative and quantitative methods. The former looked at the Connections service supporting people with brain injury to live in mainstream housing. The latter was a pilot study of an integrated health and social care team working with older and vulnerable adults. Both studies concluded that multi-disciplinary approaches improved coordination and access to support. Coetzer *et al.* reviewed the clinical records of 24 people with brain injury using the North Wales Brain Injury Service. A Wilcoxon comparison of European Brain Injury Questionnaire scores (on average 10.1 months apart) showed significant improvements in self-reported symptoms (T=53; p=.0056). As the average time since injury was over five years, this was unlikely to reflect spontaneous recovery.

2. Key workers and case management

Key workers and case managers in the UK are usually named workers with a care-coordination role, who often also provide some direct support and advocacy. Key worker and case management models featured heavily in accounts of service users' views about good practice. However, only two evaluations of such models were identified: a quasi-experimental study of intensive case management for older people with dementia (Challis *et al.* 2002 - 'promising practice'); and a survey of key workers and patients in a brain injury rehabilitation service (Gurr 2006 - 'emerging practice').

In the Challis study, outcomes for 45 older people with dementia receiving intensive case management in one community mental health team were compared with 50 from a similar team without such a service. From these, 43 pairs were matched on a number of indicators. Participants and carers were interviewed at uptake, six and 12 months. Findings included a significantly greater reduction in needs associated with activities of daily living in the case management group than in the comparison group at six months (as judged by both research assessors and carers), and these gains were largely maintained at 12 months. There were also significant gains for the case management group at six and 12 months on assessors' ratings of overall need and levels of risk. Carers of older people in the case management group also reported significantly greater reductions in carer burden and total caring input at 12 months. At follow-up, all the case management carers also stated that they had someone they could turn to, compared with only two-thirds of the comparison group. However, it was not possible to blind assessors to the treatment group and this may have skewed results.

The Challis study was one of the few that measured service costs. In the first year, social care and health costs were significantly higher for the case management than the comparison group. However, the authors estimated that in year two overall costs would have reduced for the case management group due to reduced admission to residential care (at the end of two years 51% of the case management group remained at home compared with 33% of the comparison group).

The only other study of a particular key worker or case management service was a small survey by Gurr (2006) of the 25 patients (and their relatives) who had used a hospital rehabilitation key worker service, together with a survey of the seven key workers involved. Twelve relatives and two patients responded to the survey, reporting mixed views of the service. Nevertheless, the key workers themselves were generally positive and the authors concluded that a key worker model could enhance information-sharing between patients, relatives and rehabilitation team members.

Seven further papers argued the benefits of key workers and/or case management after canvassing the views of people with complex needs or professionals about good practice. A survey and focus groups of people with long-term conditions, carers and specialist support organisations by Hardy (2004), for example, found key workers were highly valued, particularly by people who had difficulty making decisions. More specifically, interviews with staff (n=130) and a survey of parents (n=143) and young people (n=97) receiving transition services by Clarke *et al.* (2011) found direct support from a transitions

worker was highly valued, and a Children's Services Development Group and Local Government Association report (2009) presented examples of successful transitions for young people, including a dedicated key worker. Abbott *et al.* (2009) found that young men with Duchenne Muscular Dystrophy (n=40) and their families particularly valued Family Care Officers/Neuromuscular Care Advisors with a co-ordinating role, similar to that of case managers and key workers, spanning health, social care and the voluntary sector. Skirton & Glendinning (1997) also recommended key workers to improve Huntington's disease care pathways; this recommendation was informed by an earlier survey but the key worker role itself was not evaluated. Finally, based on interviews and discussions with staff and service users at Turning Point projects, Rankin & Regan (2004) recommended a new professional role of 'service navigator' for people with complex needs to provide case management, advocacy and support. A Department of Health (2010a) report also advocated care navigators for people with long-term conditions, but gave no evidence in support of their effectiveness.

Judging from the volume of arguments in support of key worker and case management models, and the relative lack of evidence about outcomes or cost-effectiveness, it is clear that more robust evaluation research is required.

3. Specialist social work

A model much less frequently discussed in the literature was specialist social work, which featured only twice as potential good practice. However, both papers advocating this model presented the findings of evaluation research to support their case (one from a study assessed as 'promising practice', the other 'acceptable practice').

In the UK, social work practitioners tend to be referred to as 'specialist' when they have a dedicated role with a specific user group, allowing them to bring to bear and/or build expertise in meeting the needs of that particular group. Shah *et al.* (2001 - 'promising practice') reported a retrospective cohort study of the impact of a specialist social worker with a budget for purchasing domiciliary care services for psycho-geriatric patients discharged from hospital. This was a short-term project designed to expedite hospital discharge following increased winter admissions. Length of stay and bed usage for 210 discharges during this period were compared with an identical period the year before, as were the costs of admissions to other hospitals as a result of extra-contractual referrals (ECRs) made when there were no available beds in the study hospital. No statistically significant reduction in length of stay was found, but bed usage was reduced in the study hospital and the costs of ECRs also decreased. The measured cost savings were similar to the costs of employing the specialist social worker for the seven month period coupled with the £10,000 domiciliary care budget. Shah *et al.* noted that other costs associated with ECR (such as transport) were not included in cost saving calculations, meaning the total savings were probably greater than the cost of the social worker and budget, and concluded that the service was therefore cost effective. It is notable, however, that no outcomes for service users or their families were reported.

The other study of specialist social work (Beresford *et al.* 2008 – 'acceptable practice') drew on 111 interviews with people with life-limiting conditions who had specialist palliative care social workers. This study highlighted the importance of the continuity, specialist knowledge and expertise offered by specialist social

workers and how their empathy, respect, listening, and the time they could dedicate were valued by service users and families. Beresford *et al.* concluded that social workers not only have a navigating role, but should offer hands-on support, friendship and partnership to people at the end-of-life.

4. Interdisciplinary training, and training about complex needs

The final study of 'promising practice' evaluated a programme of inter-professional postgraduate education for community mental health professionals (Carpenter *et al.* 2006). This five-year, mixed methods study measured outcomes for the clients of students undertaking the training as well as for students themselves. Three cohorts of students (n=111) were tracked through the course and compared with colleagues who did not take part in the programme (n=62), using data collected through structured interviews and participant observation. Client outcomes were assessed using standardised measures and compared to outcomes for users of a similar service where staff had not received inter-professional education. While there were no significant impacts on clients' psychiatric symptoms, life satisfaction or mental health, the life skills (Rosen 1989) of clients in the intervention group improved significantly more than those in the comparison group, and more intervention group than comparison group clients felt that professionals involved them in care planning as much as they wished.

Two further 'emerging practice' studies of inter-professional training courses were identified. One evaluated a one-day workshop for health and social care professionals on acquired brain injury and sexuality (Baker & Shears 2010); 24 participants completed a post-course evaluation form, generally rating it

positively. The other was a one year part-time inter-disciplinary course for staff working with people with profound and multiple learning disabilities (Lacey 1998). This was evaluated over four years using questionnaires, interviews and personal diaries; the training was found to facilitate multidisciplinary team-working between people with different professional backgrounds.

Interdisciplinary training and/or a common professional understanding of how to meet complex needs was also advocated in four more papers reporting service users' views, three expert opinion papers and one descriptive paper. From interviews with older people with sight loss and dementia (n=17), family carers (n=17) and care professionals working with them (n=18), Lawrence & Murray (2009a, 2009b; Lawrence & Murray 2010) argued that joint training for mental health and sight loss professionals was needed to encourage exchanges of expertise. Wilkinson & Janicki (2002) recommended that residential homes for people with Down's syndrome recruit and train staff who are also familiar with dementia care. The Foundation for People with Learning Disabilities (2002) also called for professionals to pool expertise and Fiedler & Ellis (1997) argued for better staff training, especially amongst service commissioners. From interviews and group discussions with people with learning disabilities, mental health and substance misuse problems, service managers and other stakeholders, Rankin & Regan (2004) argued for Connected Care Centres staffed by professionals with training across health, social care, housing and employment. Finally, Redhead (2010) argued for specialist brain injury training for support workers working with this group.

5. Approaches to personalising care and support

This was by far the largest group of included literature (35 papers, over 40%); however, within this no evidence from high quality evaluation studies (i.e. 'promising practice' or above) was identified. Thirteen papers reported nine studies of particular approaches or initiatives, five of which were 'acceptable practice' and four 'emerging practice'; six papers reported service users' preferences for person-centred ways of working; and six were expert accounts. The remaining 10 papers were descriptive.

One of the higher quality studies (Brooker *et al.* 2007a, 2007b) was of the Enriched Opportunities Programme for care home residents with dementia. The programme incorporated specialist expertise; individualised assessment and case work; management and leadership; an activity programme; and staff training in person-centred working, mental health awareness and communication. Data were collected from three nursing homes at four points in time: baseline (just before the appointment of staff); three months after the appointment of an additional senior staff member but before new practices were introduced; final measures (seven months later) from 99 residents with dementia; and follow-up 7-14 months later from 76 residents. Significant improvements in residents' average well-being were found in final measures from two homes and in the third home on follow-up, regardless of residents' dependency levels, diagnosis or cognitive impairment. However, it should be noted that the study was conducted in care homes that were already enthusiastic about the programme and it is not known whether a similar approach would be as successful in establishments with less motivated staff.

Four more papers on personalising support in residential or day settings for people with advanced dementia were identified: Practicalities and Possibilities (tools to facilitate communication and personal histories, Bowers *et al.* 2007); the Eden Alternative (based on the benefits of giving and receiving care and contact with plants, animals and children, Burgess 2007a, 2007b, 2007c; Shoard 2007, Burgess 2009); 'Personal Best' (a programme to help staff understand residents' needs, Jacobs 2007); and a model of enhanced day care (also applicable to residential care) using nature as a therapeutic tool and resource (Chalfont 2011). A fifth paper described a family-run care home for people with a range of conditions which tailored support to individual resident's needs (Boughey 2005). No evaluations of these models were reported, but a qualitative study of life story work, similar to the life histories approach advocated in the Practicalities and Possibilities toolkit, was identified (McKeown *et al.* 2010). McKeown explored the experience and outcomes of life story work through case studies of four people with dementia, conducting observation and interviews over 10-23 months. She concluded that this approach could enhance person-centred care; however her sample was very small.

Another study (Jones *et al.* 1999) evaluated Active Support - activity planning, support planning and practical staff training - for residents (n=19) with severe intellectual disability and complex needs in five community houses. Analyses showed significant differences between baseline and initial follow-up in residents' overall engagement and domestic engagement, staff attention and assistance to residents, but no effect on residents' social engagement. These gains were fully maintained at follow-up in three of the five houses, partially in one house and

variably in one house. Results were achieved without increasing the level of staffing in any of the houses, and with only minor costs for training.

Three studies looked at personalised transition planning for young people with complex needs. Adams & Shaw (2008) reported the use of short films made by young people and artists to inform professionals, families and others and concluded that these provided a more rounded introduction to the young person than standard assessment. Carnaby *et al.* (2003) studied enhanced participation by 12 severely disabled young people in transition review meetings and identified a number of factors contributing to improved transition experiences. Cowen *et al.* (2010, 2011) evaluated another approach characterised by family leadership, citizenship curriculum, individual budgets and coordinated expert support. Interviews with parents and professionals and workshops with disabled young people indicated that an important success factor was the willingness of adult social care staff to innovate using individual budgets.

Individualised funding was a notable sub-theme in the literature on personalising support. Hamnet (2009) described the positive impact of individual budgets on a young man with complex needs and Glendinning *et al.* (2000) conducted interviews with direct payments users with complex needs, health professionals, local authority managers and personal assistants, concluding that direct payments had the potential to enhance users' control over their support, including in the 'grey areas' between health and social care. Henwood & Hudson (2009) proposed direct payments as one approach to good practice for people with complex, unstable, needs; other examples included dedicated transitions teams; communication passports; day services (valued by family carers); and advocacy.

This report drew on 76 interviews with policy, operational and frontline staff, and 35 service users and carers. While some problems with self-assessments and direct payments were noted, successes included new alternatives to residential care, traditional day services and out-of-area placements. Finally, Spandler & Vick (2006) reported increased choice and control, independence, autonomy and access to social, cultural and physical activities from a study of direct payment users (n=27) with severe mental health problems. However, only short-term outcomes were assessed.

Common to all these papers was the recognition of the importance of intensive support to manage individualised funding allocations. Morgan (2000, 2002) concluded that people with complex needs accessing direct payments may have more choices but also require more time and support from trained staff to make them work. Similarly, the Foundation for People with Learning Disabilities (2009) suggested that, while people with complex needs (and their supporters) do want individualised funding, this requires enthusiastic and knowledgeable care management, which is often unavailable.

The need for adequate support to set up and manage care packages was, in fact, a common conclusion in all the studies about personalising support. Jay (2003) and Moulster (2007) both described Circles of Support – whereby volunteers committed to an individual's well-being provide support, initially with an independent facilitator and later independently. Both papers argued that Circles of Support are powerful tools for person-centred support, but neither included evidence on outcomes or costs. Rankin & Regan (2004) advocated 'navigators' for people with complex needs, to coordinate support across health and social

care. Some papers focussed on specific aspects of personalised support, such as individualised housing-based support (Fiedler & Ellis 1997); help to access and maintain employment (Ogilvie 1997); and key workers for people who find it hard to make decisions (Hardy 2004). All emphasised the time and commitment necessary to make personalised support work for these groups. Hopkins (2007) illustrated that it is possible to design good support for people with very complex needs if enough time and effort is put into assessment and the resultant services are tailored to fit the person's individual needs, but warned that such a bespoke service would inevitably be expensive. Lawrence & Murray (2009a, 2009b), reported interviews with older people with sight loss and dementia, as well as carers and care professionals, highlighting the extra staff time needed to ensure support arrangements promote, rather than undermine, autonomy.

Finally, one paper described a model of person-centred agency provision for people with a range of complex needs that was jointly commissioned and funded by health and social care (Valios 2010). Care packages were developed to address both clinical need and the individual's aspirations, and support workers were recruited and trained specifically for each package. However, no evaluation evidence was presented to support this approach.

6. Information, advocacy, peer support and other models

Ten papers stressed the importance of information, advocacy and peer support for people with complex needs (Bright 2009, Carey *et al.* 2001, Easton *et al.* 2007, Glover 2003, Hardy 2004, Hayes *et al.* 2003, James *et al.* 2010, NCIL 2008, SCIE 2009a, 2009b). However, none included robust evaluations of specific approaches to providing this. The highest quality study was Easton *et*

al.'s (2007) survey of Encephalitis Society service users (n=130), rated as 'acceptable practice'. Eight papers (Das & Bouman 2008, Fiedler & Ellis 1997, Foundation For People With Learning Disabilities 2009, Henwood & Hudson 2009, Janicki *et al.* 2002, Mental Welfare Commission for Scotland 2010, Rankin & Regan 2004, and Skirton & Glendinning 1997) described ways of organising or commissioning good support for people with complex needs, but all lacked robust supporting evidence.

Three 'acceptable practice' papers were identified which did not fit any specific theme. Kennett & Payne (2005) investigated users' (n=34) views of palliative day care at a Creative Living Centre; this was reported to have improved mood, sense of achievement, community and mutual support, and relationships. Felce *et al.* (1998) concluded from a survey of service input, outcomes and costs across three different residential settings for people with severe learning disability (n=41) that specialist community group homes were twice as costly as traditional services, but these costs should be set against gains in residents' quality of life, compared with 'traditional' (hospital based) services. Finally, Ryan *et al.* (2009) interviewed 17 older people and 14 carers to explore the impact of community care in enabling older people with complex needs in Northern Ireland to remain at home. They concluded that community care was preferable to institutionalised care and that, other than family carers, home care assistants who were experienced, reliable, friendly and had time, were the most important resource for this group.

The final two studies were by Stewart (2009) of a brain injury identity card; and Ackermann *et al.* (2003) of an integrated intermediate care service (both

assessed as 'emerging practice'). Five additional reviews were identified: Challis's (2010) expert briefing paper on generic and specialist domiciliary support; a report by Research in Practice for Adults (2007) on social care interventions for acquired brain injury; Rosengard et al.'s (2007) review of service provision for people with multiple and complex needs; a research briefing paper (SCIE 2005) on transition from children's to adults' services; and Weston's (2002) review of supported employment. The remaining papers reported: expert opinion on supporting people with learning difficulties and dementia (Pitt 2009, Wilkinson & Janicki 2002, Wilkinson et al. 2004); specialist changing facilities (Garboden 2007); and services to help people with complex needs back into work (Leslie et al. 1999). McFarlane (2009) described the use of attachment theory to support a young woman with multiple issues; Watts (2008) described a benefits advice service for people with complex needs; and a video about Headway described support for people with brain injury to find employment (SCIE 2010).

Limitations

None-UK publications were excluded from this review, so it is possible that some transferable evidence from other countries has been overlooked. However, given the significant numbers of records identified through initial searching (5,098) and subsequently selected as potentially relevant (296), a broader search would have been unfeasible.

A further limitation stemmed from the broad reach of the term 'severe and complex needs'. The searches were designed to identify evidence about services for the three exemplar groups primarily, but they nevertheless pulled in additional literature about other groups. All papers about services for people with severe

and complex needs that fitted the inclusion criteria were retrieved and considered, including those about services for people not from one of the three exemplar groups (such as the Carpenter *et al.* study of interdisciplinary training for professionals whose clients had severe mental health problems). This broadened the scope of the review but, as the inclusion of non-exemplar groups was not exhaustive, firm conclusions about the evidence relating to these could not be drawn.

Almost one-quarter (20/86) of the papers included in the review were identified through hand searching. This suggests that, even with extensive electronic searching, other relevant papers may have been missed.

A final limitation came from the difficulty of separating evidence about people with severe and complex needs from the general findings of research about services for disabled and older people. The review excluded papers that did not make *specific* reference to meeting the needs of people with severe and complex needs. As such, studies such as the national evaluation of the individual budgets pilot programme (Glendinning *et al*. 2008) were excluded.

Discussion

There is currently little robust evaluation evidence about social care service models considered to be good practice for people with complex needs in the UK. While 86 relevant publications were identified, these only reported 29 evaluations of specific models or approaches, only six of these made any reference to costs, and none was robust enough to constitute 'supported' or 'well-supported' practice. Four studies classified as 'promising practice' offered some evidence on

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the effectiveness of multidisciplinary specialist teams; intensive case management; specialist social work; and inter-professional training. Conversely, 35 papers advocated person-centred support for people with severe and complex needs through a variety of approaches including, but not restricted to, personal budgets. However, the approaches to delivering this varied widely and no 'supported' or even 'promising' evidence was found in support of any particular model. Thus, while both expert and service user opinions advocate person-centred support, there is a need for more well-designed evaluation research to ascertain the costs and outcomes of the various approaches to delivering this for people with complex needs.

A common theme running through the literature on person-centred support was that personalised services for people with severe and complex needs require intensive support to set up and maintain. This requirement for dedicated time and on-going support appears to run contrary to the current emphasis in English adult social care on greater self-management. It is notable, however, that three of the four initiatives supported by the most robust evaluation evidence (a young adults' multi-disciplinary team, specialist social work and intensive case management) are the types of services that do deliver intensive, on-going support. With relatively strong evidence behind these approaches, including evidence of cost-effectiveness, it is surprising that they are not currently practiced more widely.

Conclusions

There is an urgent need for more rigorous evaluation of models and approaches to support for people with severe and complex needs. While practical and ethical considerations involved in controlling real world environments make conducting

randomised controlled trials and other quasi-experimental research in social care difficult, there is no reason why services could not be more rigorously evaluated, with comparison groups and clear reporting of costs and outcomes. Moreover, where evidence does exist of positive outcomes or the cost-effectiveness of particular services or approaches, as is the case for the four examples of 'promising practice' identified through this review, more should be done to ensure that such evidence influences practice and commissioning decisions.

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