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GRIDLEY, Kate, BROOKS, Jennifer and GLENDINNING, Caroline

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Published version

GRIDLEY, Kate, BROOKS, Jennifer and GLENDINNING, Caroline (2012). Good support for people with complex needs: What does it look like and where is the evidence? Project Report. NIHR School for Social Care Research.

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Good support for people with complex needs: What does it look like and where is the evidence?

KEY POINTS FROM THE RESEARCH

- People with complex needs (and those close to them) emphasise the importance of individually tailored support and value a range of person-centred approaches to social care. Good support requires staff to have the time, and services the flexibility, to respond to each individual's unique needs and preferences. Support should be holistic, addressing social and emotional, not just personal care, needs.
- People with complex needs value support through the way services are organised as well as at an individual level. There were strong arguments, for example, in favour of dedicated key workers and case managers to facilitate access to disparate services and coordinate support across sectors and boundaries. Participants wanted key workers to have expert knowledge and the skills to navigate complex service and funding systems.
- A scoping review of UK literature found many publications advocating person-centred support, covering a wide range of approaches, but no robust evidence to support any specific model.
- Some promising evidence was found on the effectiveness of four ways of organizing services for people with complex needs: multidisciplinary specialist teams; intensive case management; specialist social work; and inter-professional training.

This study aimed to scope the evidence on good practice in social care for disabled and older people with severe and complex needs, and to find out what this group consider to be key features of good support. The study also aimed to identify examples of potential good practice and make recommendations for future evaluation.

The research was carried out by Kate Gridley, Jenni Brooks and Caroline Glendinning, Social Policy Research Unit, University of York.

Further information is available from:

kate.gridley@york.ac.uk
(01904) 321 988



- Overall, the review found a dearth of evidence about the outcomes and costs of models of social care considered to be good practice for people with complex needs.
- Several examples of services and support arrangements were identified that appeared to illustrate key features of good practice, but none of these had been formally evaluated.
- There is an urgent need for rigorous evaluation of models of support for people with severe and complex needs.

Box 1: Definitions

'Complex needs' is a broad term, so the study focussed on three 'exemplar' groups:

1. Young adults with complex or life-limiting conditions
2. Adults with brain or spinal injuries and complex needs
3. Older people with dementia and complex needs.

'Social care' covered statutory, voluntary and private sector services, including those purchased using personal budgets.

The study represents independent research funded by the National Institute for Health Research (NIHR) School for Social Care Research (SSCR). The views expressed are those of the authors and not necessarily those of the NIHR, SSCR, Department of Health, or NHS.



BACKGROUND

The population of adult social care users is changing. Advances in medicine are enabling more children with life-threatening conditions to live into adulthood, more adults to survive major injuries or illnesses with on-going needs, and growing numbers of older people to live longer, often with long-term conditions. These developments present new challenges for adult social care and require new responses.

WHAT PEOPLE WITH COMPLEX NEEDS WANT FROM SOCIAL CARE

Sixty-seven people were consulted about good support for people with complex needs, including 22 people with complex needs, 23 carers and 22 members of specialist organisations. Table 1 summarises the features of good support identified by participants

Individual level support

Participants felt strongly that social care should meet the full range of people's practical, social and emotional needs, including maintaining friendships, socialising and pursuing interests.

Support should be reliable, well-coordinated and individually-tailored to fit unique situations. Considerable time and flexibility is needed to achieve this.

Personal characteristics of paid carers, such as good communication skills and a desire to spend time with the individual, were vitally important. Consultees also valued continuity in staffing.

Achieving good support is, however, dependent on sufficient funding being available to resource person-centred packages and approaches. People with complex needs often require intensive, specialist support for long periods of time, costing considerably more than standard care.

Service organisation

Organising services to be person-centred requires imaginative approaches to assessment, flexible processes and freedom to make changes to support arrangements. Prompt responses to requests for help are essential to prevent crises. It was strongly felt that on-

Table 1: Summary features of good social care

| Level | Key features of good practice |
|--------------------------|---|
| Individual level support | <ul style="list-style-type: none"> Person-centred ways of working Meeting practical, emotional and social needs Reliable, well coordinated delivery Staff attitudes and approach Continuity in support Sufficient resources |
| Service organisation | <ul style="list-style-type: none"> Flexibility Specialist expertise Support to access and use information Key workers and coordination Timely, proactive approach |
| Commissioning | <ul style="list-style-type: none"> Specialist expertise Crossing boundaries Two-way communication |

going access to a designated key worker or case manager with specialist knowledge could improve access to, and continuity of, support. Input at this level can be critical to the success of individual care packages, particularly where people are not in a position to organise and manage their own support.

Commissioning

Participants felt that commissioners needed better understanding of the requirements of people with complex needs. Good commissioning entails working across boundaries, effective user and carer involvement and two-way communication between commissioners and organisations with experience of working with people with complex needs.

Case examples

Participants were asked to suggest examples of particularly good services or support (see Box 2). Full details of these services, including how they appear to demonstrate the identified features of good support, can be found at: <http://php.york.ac.uk/inst/spru/research/summs/complex.php>. None of these services has been formally evaluated.

SCOPING THE EVIDENCE

A review of UK literature was conducted to establish the size and robustness of the evidence base on good social care support for people with complex needs: 5,098 potentially relevant papers were identified through electronic searching and 51 by hand, 86 papers were finally selected for inclusion (see Table 2).

Only six studies and two review papers reported any evidence of the costs of services, Thirty-five papers advocated person-centred support for people with complex needs, covering a diverse range of approaches. However, no robust evidence was found to support any of these approaches.

Twenty-nine studies of particular services were identified. While none were considered supported or well-supported practice, four were classified as promising practice. This was the most robust evidence identified through

Box 2: Models of potential good practice identified through consultation

1. Integrated brain injury social work
2. Integrated transitions for young people
3. Personalised social care for people with complex needs
4. Integrated commissioning for older people
5. Case management for people with brain injury
6. Support for young people in residential college to 'move on'
7. Independent living training for inpatients with spinal injury
8. Specialist provision to meet social and leisure needs for people with dementia
9. Live in support from specialist provider for people with dementia
10. Live in support from specialist spinal injuries agency.

Table 2: Papers and studies included

| | Papers ¹ | Studies | Study quality ² |
|--|---------------------|---------|----------------------------|
| Evaluations of a particular service or model | 34 | 29 | Well supported: 0 |
| | | | Supported: 0 |
| | | | Promising practice: 4 |
| | | | Acceptable practice: 12 |
| | | | Emerging practice: 13 |
| Service users' views on good practice | 11 | 10 | n/a |
| Review papers | 8 | n/a | n/a |
| Expert accounts | 14 | n/a | n/a |
| Description only | 19 | n/a | n/a |
| Totals | 86 | 39 | 29 |

1. Some studies were reported in more than one paper, some papers described services without presenting any evaluation findings.

2. Where a service model or approach had been evaluated, a schema was applied to indicate the study quality as follows:

Well-supported practice = evaluated with a prospective randomised controlled trial

Supported practice = evaluated with a control group and reported in a peer-reviewed publication

Promising practice = evaluated with a comparison group

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

Emerging practice = evaluated without an independent assessment of outcomes (e.g., formative evaluation, service evaluation conducted by host organisation).

Adapted from Eager K at al. (2007) *Effective Caring: A Synthesis of International Evidence on Carer Needs and Interventions*, Centre for Health Service Development, University of Wollongong, Wollongong, Australia.

the review and all four studies related to service organisation level models. These were:

1. A multi-disciplinary transition team for young people¹
2. Inter-professional training for community mental health professionals²
3. Intensive case management for older people with advanced dementia³
4. A dedicated social worker with a budget for domiciliary care services working with psychogeriatric inpatients⁴

Each of these service models was evaluated against a comparison group and demonstrated positive outcomes for people with complex needs. The multi-disciplinary team, case management and specialist social worker models also provided some evidence of cost effectiveness.

CONCLUSIONS

People with complex needs value person-centred support, typified by the availability of time to get to know a person and flexibility to manage changes in circumstance. There is a large body of literature advocating person-centred support for people with complex needs but no robust evidence was found in support of any particular approach.

In general there is a dearth of evidence about the outcomes and costs of models of social care considered good practice for people with complex needs. The most robust evidence of effectiveness related to four different models of organising services: a multidisciplinary specialist team; intensive case management; specialist social work; and inter-professional training. This fits with the findings of the consultation, where participants argued strongly for on-going contact with a key worker or case manager with specialist knowledge.

ABOUT THE STUDY

The study was conducted between June 2010 and February 2012 and had three stages:

1. Consultation with people with severe and complex needs, their carers and members of specialist organisations.
2. Identification of service examples that demonstrate key features of good practice.
3. A scoping review of the UK literature (published and 'grey') available since 1997 on good practice in social care for people with severe and complex needs. Studies were grouped by quality.

Ethical approval for the study was granted by the Social Care Research Ethics Committee (SCREC).

RECOMMENDATIONS

There is an urgent need for rigorous evaluation of models of 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 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.

While the consultation highlighted a very real need to personalise individual level support for people with complex needs, the review found no robust evidence of how best to achieve this. It is only at the service organisation level that robust evidence of effective services was identified. Support at this level may be less important for disabled and older people with less complex needs if they are in a position to manage packages of care themselves (or with support from family), but for people with more complex needs the service organisation level is vital.

1. Bent N et al. (2002) Team approach versus ad hoc health services for young people with physical disabilities: a retrospective cohort study, *Lancet*, 360, 9342, 1280–1286.

2. Carpenter J et al. (2006) Outcomes of interprofessional education for Community Mental Health Services in England: the longitudinal evaluation of a postgraduate programme, *Journal of Interprofessional Care*, 20, 2, 145–161.

3. Challis D et al. (2002) Care management, dementia care and specialist mental health services: an evaluation, *International Journal of Geriatric Psychiatry*, 17, 4, 315–325.

4. Shah A et al. (2001) Is a dedicated specialist social worker working exclusively with psychogeriatric inpatients and an associated dedicated domiciliary care package cost-effective? *International Psychogeriatrics*, 337–346.