Service user and carers perspectives of joint and integrated working between health and social care

Abstract

Purpose

This article provides an update to a review of the joint working literature in the field of health and social care for adults, with particular emphasis given to the experiences of users and carers.

Approach

The aims of the literature review remained largely the same as those of the original, they were to identify: models of joint working, evidence of effectiveness and cost effectiveness and the factors promoting or hindering the models. However, to reflect the growing interest in the experiences of users and carers a fourth aim was added to map these experiences. Given their prominence in terms of policy debates about integration, the review focused on jointly-organised services for older people and people with mental health problems in the UK only.

In line with the original review, peer-reviewed papers were only included if:

- they referred to an actual, rather than proposed, model of joint working
- they included primary data
- an evaluation of the model had been carried out
- were published since 2000.

Findings

The review demonstrates tentative signs that some initiatives designed to join-up or integrate services can deliver outcomes desired by government. Importantly some studies that report the experiences of users of services and carers suggest that they perceive benefits from efforts to join-up or integrate services.   However it is our contention that the

evidence is less than compelling and does not justify the faith invested in the strategy by current or previous governments.

Originality

The study updates our knowledge of the impact of joint working in the field of health and social care for adults. Importantly the article highlights what is known about the experiences of users and carers of joint/ integrated services.

Key words: Joint Working; Integration; User and Carer experiences; Outcomes; Literature Review

Introduction

Government interest in joint working between health and social care agencies continues unabashed. The Health and Social Care Act 2012 and the White Paper, Caring for our future: reforming care and support (DH 2012), made clear that the draft Care and Support Bill in England would set out a duty on Local Authorities to promote further integration of services in much the same way as that already mandated for the NHS. The policy direction in Scotland and Wales similarly emphasizes the need for greater integration (SG 2013, WG 2013) The reasons for this continued interest are palpable: increasing numbers of older people; more people living with multiple complex needs in the community and a government agenda prescribing fiscal restraint. However, policy maker's faith in joint working as a strategy to improve the effectiveness of health and social care services is at odds with the limited evidence available. Our systematic review, published in 2003, concluded that there was little evidence to support the notion that joint working was a 'good thing' (Cameron & Lart 2003). Similar disquiet about the lack of evidence of impact has been reported more recently (Rummery 2009).

Concern about the lack of evidence has largely focused on the impact of joint working in relation to outcomes influenced by the priorities of government. In other words outcome measures commonly relate to the effective use of resources, for example whether the

introduction of joint and integrated services leads to reductions in inappropriate admissions to hospital or residential care, or to improvements in clinical outcomes, such as ratings of activities of daily living. Whilst these outcomes are important they tell us little about the experiences of those using services. Indeed very little attention has focused on the experiences of those using joined-up services (Future Forum 2012). This lack of attention is surprising given governments insistence that the participation of services users and carers should have an important role to play in improving the quality of services as well as informing how resources are used by commissioners (DH 2005). This paper reports findings of an update of our original review, with a specific emphasis given to the experiences of those using services. The term 'joint working' is used as an umbrella term to describe all models of working together, with 'integrated services' used only to refer to health and social care services that have been structurally merged.

Methods

Our previous review of the literature (Cameron and Lart 2003) concluded that whilst the literature had a lot to say about the process of joint working, little attention had been paid to exploring the effectiveness of this approach either for users and carers of services or the organisations providing services. In 2011 the Social Care Institute for Excellence (SCIE) commissioned an update of the review (Cameron et al 2012). The aims remained largely the same as those of the original, they were to identify: models of joint working, evidence of effectiveness and cost effectiveness and the factors promoting or hindering the models. However, to reflect the growing interest in the experiences of users and carers a fourth aim was added to map these experiences. Given their prominence in terms of policy debates about integration, the review focused on jointly-organised services for older people and people with mental health problems in the UK only.

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The search strategies and inclusion criteria were developed by the authors in accordance with a methodology established by SCIE (Rutter et al. 2010). The decision to limit inclusion to papers published in peer-review journals meant that some evaluations, particularly those led by organisations themselves, were not included and may dilute the findings of the review. Forty-six papers were identified, reporting 30 separate studies. The majority of studies (22) evaluated services for older people while six looked at mental health services, two papers looked at services to both older people and people with mental health problems. The final list of papers for inclusion was independently reviewed.

Findings

Before focusing on the experiences of users and carers we briefly consider what the review revealed in relation to models of joint working and the effectiveness of joined-up and integrated services.

Models of joint working

Within this area, research is overwhelmingly focused on frontline services and service delivery. Studies fall into the following categories: multi-agency teams; placements of individual staff across agency boundaries; co-locations of staff that were not formal teams; single assessment process (SAP); the provision of intermediate care; structurally integrated services (e.g. some Community Mental Health Teams (CMHTs) and use of pooled budgets.

Evidence of effectiveness

In contrast to the original review more studies published in the ensuing years had attempted to evaluate what impact services had, for whom, how and why (HM Treasury, 2011). However, many of these evaluations were descriptive, providing no clear data on effectiveness; while others did not define outcome measures or reported outcomes that were unrelated to the evaluation. Few studies were comparative in design or offered a before and after analysis, making it difficult to assess if an intervention has been a success.

Additionally the myriad models of joint working evaluated and the range of working arrangements identified made it difficult to compare services.

Despite these limitations trends in the data were evident. For example improvements in quality of life, health, well-being and coping with everyday living were reported for users of services in a number of studies (Banerjee et al 2007, Clarkson et al 2011). However in studies using a comparative design, assessing different types of integrated and non-integrated care, no significant differences or only marginal differences were reported (Davey et al 2005, Trappes-Lomax et al 2006). Studies evaluating initiatives designed to avoid inappropriate admission to acute / residential care found that they did reduce inappropriate admissions (Beech et al 2004) while a study of rapid response teams suggested that such services can have an important role in supporting people to remain in their own home (Brooks 2002). Despite these positive findings the evidence suggests that the organisation of services does not appear to improve the likelihood of living in the community. Rather need and access to support at home are key factors (Clarkson et al 2011).

Evidence of cost effectiveness

Those studies assessing costs and cost-effectiveness revealed similar methodological problems, demonstrating that evaluations of these kind are hampered by a lack of economic evaluation evidence, including incomplete and old data and the diversity in approaches to integrating services (Rutter et al 2004, Schneider et al 2002, McCrone et al 2005). As a result it was difficult to draw firm conclusions about the impact on costs of different types of provision. However there was some evidence that intermediate care can save costs (Asthana and Halliday 2003).   Kaambwa et al (2008) found that patients who were admitted as part of hospital avoidance schemes as opposed to those admitted as part of a supported discharge scheme, experienced greater health and functional gains. Importantly, hospital avoidance services cost less compared to supported discharge cases (Kaambwa et al 2008). One study that undertook a sophisticated analysis of costs across four districts providing community mental health services, either in an integrated or traditional manner, illuminated the impact of service need rather than service organisation on costs. However,

there were indications that when taking health and social care costs together, fully structured integrated districts may be less costly (Schneider et al 2002).

While these findings do not provide a compelling case that joint working can achieve all of the positive outcomes imagined by government they do suggest that some benefits are being realised. Although the case for more high quality research studies to test out these benefits on a larger scale remains salient.

Service user and carer views on joint and integrated services

As previously mentioned an important aim of the updated review was to consider the views of service users and carers about their experiences and what outcomes matter to them. Disappointingly the review revealed that such perceptions are rarely included in evaluations of joint working. When they are included, often surprisingly limited details are reported. This in part, reflects an evidence base characterised by small or unspecified samples sizes (Brooks 2002, McLeod et al 2003) and partly because the views of service users and carers are rarely disaggregated in a way that promotes understanding of their differing and potentially competing needs (Asthana and Halliday 2003, Beech et al 2004). In some cases, it reflects the fact that the views of service users and carers were reported separately in research reports that the reviewers were unable to access. Where service users and carers were included, samples were largely drawn from White groups, meaning that minority ethnic groups are under-represented. Only one evaluation directly addressed the importance of improving referral rates from minority ethnic groups, although views are not reported in any detail (Banerjee et al 2007). Diversity in terms of sexual orientation is never specified, meaning implications for lesbian, gay, bisexual and transgendered (LGBT) people is missing from evaluations of different types of service delivery. These limitations make it difficult to assess the impact of joint and integrated services on the experiences of service users and carers. However there are some interesting findings reported that begin to shed light on the experiences of service users and carers.

Experiences

Many service users report high levels of satisfaction with joint working arrangements particularly where services had been structurally integrated (Rothera et al 2008, Carpenter et al 2004, McLeod et al 2003). The elements that service users valued included: responsiveness to their needs through more timely initial assessment and subsequent interventions (Brooks 2002, McLeod et al 2003), partnership working and the development of trusting relationships with named key workers (Taylor 2001, Brooks 2002); improved communication between the agencies (Freeman and Peck 2005)   help to interpret information and navigate unfamiliar and complex systems (McLeod et al 2003), and support to maintain independence in the community (Drennan et al 2005, McCormack et al 2008). Drennan et al 2005 illustrate their findings through the comments of a service user who reported,

> I think it's [the team service] is excellent; it's been a lifesaver for me. It's opened up so many vistas for me. They've helped enormously, they're both so kind. I'm most grateful to them both (Older person who had been referred to five different health and social care services following assessment by a multi-disciplinary team targeting older people at risk).

Like service users, carers also welcomed the responsive nature of the service, highlighting timely assessments and interventions that were tailored to their individual needs as well as that of the service user (Rothera et al 2008). They valued the additional support, feeling relieved of some of their responsibilities, leading to reduced stress and fewer crisis situations (Mcleod et al 2003). This was particularly welcome where carers were combining caring with other responsibilities, such as parenting or crucially, where service users were carers themselves, Brooks (2002) reports a carer and service user reflecting on their experiences

> I don't want to go into hospital, you know. I look after my wife … I think that the idea that the scheme prevents this is very good (Carer and service user, describing new intermediate care rapid assessment service).

Comparative studies suggest such support was not necessarily available in standard, non-integrated services (Rothera et al 2008). Based on a study of 64 carers of people with severe

mental health problems served by four different mental health care services, Schneider et al. conclude that that carers in integrated districts were 'on the whole less adversely affected by their role' (Schneider et al, 2001).

Links between service organisation and service user satisfaction
Not surprisingly unravelling the impact of service organisation on service user and carer satisfaction is difficult. Where studies attempted to identify a direct relationship between their experience of a service and changes in organisation arrangements, people made little distinction about who organised or delivered the service, only that it was appropriate (Scragg 2006, Brown et al 2003, Taylor 2001, Peck et al 2001). In other words, people did not reflect on the organisational structure of the services they received; they merely commented on whether they had access to support and services of their choice.

> I think the clinical care is fine, it's the social support that is lacking, its more difficult now and the Trust seems to run less and less [local drop-in facilities] (Evaluation of new integrated team structure (Scragg 2006: 45).

As part of the suite of papers on how different models of community care impact on the experiences of 260 mental health service users, Carpenter *et al*. found 'a statistically significant advantage in terms of users' satisfaction with integration as an approach.' (Carpenter et al 2004:329). Users in integrated districts felt more able to state aims for care and treatment, less limited in choice of care, better informed about medication, less negative about their family's involvement and more positive about being helped to be independent. The authors suggest that their satisfaction might reflect the following features of the integrated services: 'holistic' common assessment protocol that included social care as well as psychiatric needs; single key worker/care manager based in the community; a system that both service users and carers welcomed as promoting more choice than hospital based discharge planning; key workers having authority to use resources of both agencies, without having to refer users to an assessor in another agency. The authors conclude that 'user involvement and choice is facilitated by policies and procedures in integrated service districts (Carpenter, 2004: 329). This finding is clearly important as a means to demonstrate why integrated services can be beneficial beyond an organizational

agenda that demands a greater emphasis on cost containment, in this case the study reports how integrated services can support the development of user centered services.

Dissatisfaction and difficulties

Not all service user and carers experiences were positive, significant problems were reported in several studies. Areas of dissatisfaction included continuing communication difficulties between agencies, particularly when a service user is to be admitted to respite or hospital and continuity of care is broken (Brooks 2002). Service users also identified difficulties with their involvement in care planning and ability to influence the choice of care options (McCleod et al 2003, Peck et al 2001, McCormack et al 2008, Asthana & Halliday 2003, Beech et al 2004). Even in the best services, there is room for improvement. Carpenter *et al*.2004 highlights that only one-half of service users reported that they had a written care programme. Feedback from professionals acknowledged that the discrepancy could not be accounted for by users having lost or forgotten their care plan alone. Given that users were generally positive about their care plan, the authors report that this is an area of serious concern and that practitioners must 'redouble their efforts to ensure users receive their entitlement to a care programme'. (Carpenter et al 2004: 330).

Discussion

Although the evidence reported in relation to the experiences of users of services and their carers is not a wholesale endorsement of joined-up services and integrated services per se, it does suggest that some of the problems of poorly co-ordinated services that this strategy is thought to resolve may be amenable to improvement. Better communication between agencies, more timely initial assessments, increased responsiveness to individual needs and an ability to support people to live in the community are reported by people using services and carers in some of the studies described in the review.

However, to be more persuasive these tentative findings should be confirmed by large scale studies that incorporate a comparative design allowing researchers to test out, in a more robust fashion, whether improvements are due to changes in organisational structure and service delivery rather than to unrelated local factors. Such larger scale studies would also

provide an opportunity for researchers to ensure that user and carer samples are as representative as possible of the total population intended to use the service, thereby providing a more sophisticated and finely grained understanding of the user experience, rather than assuming that all services users have the same expectations and experiences of the services they use.   In particular it is important to explore whether these positive evaluations of services are not just facsimiles of responses given by service users concerned that services might be withdrawn if they do not give a positive evaluation as previous research has suggested (Bauld et al 2000).

A significant finding of the review that concurs with previous work (Ovretveit et al 2010) was the degree of scepticism and protectionism amongst professionals working in integrated services. Several studies reported that professionals were unclear about the aims and objectives of joint working as well as being concerned that the priorities of community health and social care services might be marginalised in favour of those of the acute sector (Clarkson et al 2011, Asthana and Halliday 2003, Glasby et al 2008). In some studies authors note the efforts to pre-empt some of these difficulties, for example ensuring the aims and objectives of the new service were known and understood and providing training to support staff thereby creating a more conducive context (Brown et al 2003). The recent initiative, 'Integrated Care and Support: Our Shared Commitment' (DH 2013) recognised the need to establish a shared understanding of integrated care and support across health and social care and plans to ensure that this is adpopted at the local level.   However, while such developments are to be welcomed they don't resolve the cynicism these studies report. Perhaps such scepticism could be overcome if managers were able to draw on a more extensive evidence base that included data gathered about the experiences of users of services and carers. Such an evidence base might, if positive, help managers articulate a stronger and possibly more persuasive argument of the benefits of joined-up and integrated working, rather than relying on exhortations about the need to save public money. Additionally, as Malley and Fernandez (2010) argue it is important, particularly in times of austerity, to monitor services as a means to ensure that quality is not undermined by initiatives designed to reduce costs. This argument seems to be particularly pertinent to integrated services. We would argue that evaluations of joined-up and integrated services

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should include examination of the experiences of service users and carers as a means of monitoring whether or not improvements in effectiveness cost effectiveness are achieved at the expense of the satisfaction of those intended to use them.

Perhaps government has recognized this need. The 2012 White Paper states that the government will set out a framework "that will support the removal of barriers to making evidence-based integrated care and support the norm over the next five years (2012: 59)." Significantly this framework will include "*Measuring people's experience of integrated care. As recommended by the NHS Future Forum, we will put in place better ways to measure and to understand people's experience of integrated care. We will use that information to set a clear, ambitious and measurable goal which will drive further improvements to people's experience*" (Op cit). Significantly the White Paper does not make clear what government would do if the evidence indicated that people's experiences of integrated care services suggested a diminution of quality. In other words there appears to be no alternative strategy to that of integration, an important observation in and of itself.

Conclusion

The updated review reported in this article indicates that some initiatives designed to join-up or integrate services show tentative signs that they can deliver some of the outcomes desired by government. Additionally some of the studies that consider the experiences of users of services and carers report that they do perceive benefits from this strategy. However the limitations of the evidence based discussed in this article suggest the need for more robust evaluations that consider both questions of effectiveness as well as acceptability amongst service users and their carers. Until such a time it is our view that there remains a need for caution, the existing evidence remains underwhelming and does not justify the faith invested in the strategy by current or previous governments.

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