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Don Redding,

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The narrative for person-centred coordinated care

Person-centred
coordinated care

Don Redding
National Voices, London, UK

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Abstract

Purpose – The purpose of this paper is to describe the development of a narrative to redefine integrated care from the user’s perspective, which is being promoted across England.

Design/methodology/approach – The content of the narrative for person-centred coordinated care, recently launched in England, is described. The need for the narrative is explained in the context of the failure of previous integrated care programmes to identify and deliver clear benefits to service users. The sources and stages of development of the narrative are described. The author considers its place in national policy, further content development and its potential to help those planning programmes of integration.

Findings – A clear consensus on the need to define integrated care from the service user perspective now exists in England, and a narrative now exists to fulfil this purpose which has been developed by service users, patient groups, care professionals and system leaders. It has radical potential to change service delivery but this will be subject to the degree of local adoption.

Originality/value – The paper is the first journal publication describing the narrative for person-centred coordinated care and creates a record of its developmental stages which will be of interest to system leaders, professionals and researchers in England and internationally.

Keywords Integrated care, Integrated provision of care, Voluntary and community sector, Integrated health and social care, Long-term conditions, Self-directed care

Paper type Case study

Introduction

Although it is widely agreed that integration is a crucial component of a high-quality health and social care system there is somewhat of a lack of evidence clearly demonstrating a link between integration and service user outcomes. Although there are many examples of good practice in this journal and other publications, there is a distinct lack of high-quality evidence in the research literature (e.g. Cameron *et al.*, 2012). It has been noted that it is very difficult to evaluate joint working (Sullivan, 2011). Powell and Dowling (2006, p. 305) describe attempts at joint working in health and social care as “the indefinable in pursuit of the unachievable” as integration is rarely defined in terms of what it means precisely and it is often unclear just what kinds of outcomes they are aiming to achieve for service users (Dickinson, 2008). Against this background a new experiment in policy and practice is taking place in England, where service users and third-sector organisations (TSOs) have worked with system leaders to create a common definition of “integrated care”, which is intended to drive a new wave of integrated care programmes in every locality over the five years to 2018.

The distinctive aspect of this definition is that it is written from the point of view of patients, service users and carers. It sets out what will happen in their experience of care and support when a high standard of coordinated care is achieved. The definition



The production of the narrative was funded by NHS England through a contract with National Voices.

sits within a “narrative” which was part of a package of commitments launched in London by a minister of state on 14 May 2013 (Department of Health, 2013). It should be carefully watched to see whether it has any greater impact and significance than previous, piecemeal attempts to bring health services and social care services closer together.

This paper, written by the principal author of the “narrative”, describes its content and explains the background to the initiative, the sources used and the method of its development. It also considers what factors may influence success, and offers some thoughts about the implications of this approach for other areas of health and social care policy and practice.

Background: the need for a narrative

Between the summer of 2011, when amendments were made to the government’s health bill, and June 2012 there emerged in English health policy circles what a report commissioned by Monitor (Frontier Economics, 2012, p. 15) described as “a clear consensus that successful integrated care is primarily about patient experience”. This consensus cohered around the realisation that the lack of a common definition was one of the principal barriers preventing organisations from working together to integrate care. Both the research literature and the stakeholder workshops revealed this problem. A review by Armitage *et al.* (2009) that found 175 definitions was frequently quoted. Another (Kodner, 2009) concluded that “Integrated care as a concept is an imprecise hodgepodge”.

The King’s Fund and Nuffield Trust report to the government and the NHS Future Forum in January 2012 (Goodwin *et al.*, 2012, p. 3) highlighted this problem:

It is important to define the ambitions and the goals of integrated care and to translate these into specific and measurable objectives. Making a compelling case for integrated care, both as a national policy and in terms of local care redesign and delivery, is essential if people are to understand why it is being promoted as a priority.

Paramount among its recommendations for overcoming barriers was, therefore, to find a common definition:

The most fundamental prerequisite to the development of integrated care at scale is the crafting of a powerful narrative at both a national and local level about how services could and should be delivered for people with complex conditions.

The paper now moves on to consider why it is that a service user perspective is important.

Why a service user perspective?

What should be the orientation of such a “narrative”? It appeared that previous programmes of integrated care had often failed to demonstrate benefits to patients and service users. This may be because of badly designed evaluations and research studies. However, it might also be because service providers and their managers tend to adopt organisational perspectives that emphasise organisational processes (integration) rather than outcomes (integrated care). Their emphasis has been on “joint working” between systems, so that “success” has been thought of in relation to better organisational coordination, or numbers of care plans executed, rather than better care coordination.

For example, evidence from around the UK showed that where there was formal organisational integration of acute and community care trusts during the 1990s, this

did not necessarily result in the delivery of more integrated care (King *et al.*, 2001). From 2000 onwards the establishment of a new wave of Care Trusts was encouraged. These aimed to secure closer working between NHS and local councils to support better coordinated health and social care, based on the principles of pooled budgets, lead commissioning (where one partner organisation commissions integrated services provided by both partners), and integrated provision. By 2005 a review of these trusts found that, while staff believed they were worthwhile, and that services were more accessible and flexible, clear measures of effectiveness in terms of cost and impact on health outcomes had not been reported (Glasby and Peck, 2005). Further research reported in this journal has found that care trusts have not necessarily delivered all that was originally intended of them (Miller *et al.*, 2011).

In the mid-2000s, in another attempt to bring statutory organisations closer together, Local Strategic Partnerships (LSPs) were established. These were hosted by local authorities and aimed to gather all relevant local agencies under common strategies, including for health and social care. A review of their impact after three years concluded that: “Many of the spheres in which survey respondents reported progress are process ones, ranging from developing a collective vision and coordinated strategy and understanding partners’ priorities to widening the range of interests involved in local decision making”, while much less progress was reported on bringing budgets and commissioning together (Russell and Jones, 2009, p. 13).

In the same year an authoritative review of joint working between health and social care agencies through joint financing arrangements (Audit Commission, 2009, p. 1) concluded that:

Organisations can usually describe how they now work better together but often not how they have jointly improved user experience. Partnership agreements often fail to include quantifiable outcome measures, and partners rarely monitor them when they do.

Most recently, the evaluation of 16 local integrated care pilots sponsored by the Department of Health also had difficulty in identifying gains in relation to patient experience and outcomes (RAND Europe and Ernst & Young, 2012). Staff reported “process improvements such as an increase in the use of care plans and the development of new roles for care staff”, but “patients did not appear to share the sense of improvement” (p. i). This was partly the result of “professional rather than user-driven change”.

Even before 2011, therefore, there were influential voices suggesting that a different approach to goal setting was required. Professor Chris Ham, then of the University of Birmingham, argued that: “The journey towards integration needs to start from a focus on service users and from different agencies agreeing what they are trying to achieve, rather than from structures and organisational solutions” (Ham, 2009, p. 1). Likewise, the NHS Integrated Care Network made up of enthusiastic adopters and sponsored by the Department of Health, produced resources advising that: “For a successfully integrated care service, the outcomes must shape the form that enables them to happen [...] Keep the service user at the heart of the process of change with a strong focus on achieving better outcomes” (Community Health Partnerships and The Integrated Care Network, 2010, p. 37). These realisations also began to spread through the managerial class. A set of interviews with leaders of integrated care reported that: “One trait considered vital to successful leadership of joint services is a constant focus, instilled throughout their organisation(s), on improving outcomes.

Our interviewees observe that too often the process of integrating services and systems together is confused as an end in itself" (NHS Confederation, 2010, p. 2)

Thus in 2011-2012 the new policy consensus began to cohere around a quote from an international symposium which declared that integration "imposes the patient's perspective as the organising principle of service delivery" (Lloyd and Wait, 2005, p. 7). Any new narrative for integration would need to avoid the trap of describing processes, and focus resolutely on the benefits and outcomes for those who use the service.

Developing the narrative

In the English context National Voices had attempted to articulate this service user perspective in a paper for the NHS Future Forum (National Voices, 2012, pp. 1-2):

People want co-ordination. Not necessarily (organisational) integration. People want care. Where it comes from is secondary [...].

Patients have little interest in organisational/institutional priorities or mergers. They want organisations not to argue between themselves or send conflicting messages. They expect professionals to work together as a "team around the patient", and they want services to work together likewise: that is, to come together at the point they are needed, and to meet people's needs in the round.

The people for whom integration is most relevant, especially those with long term conditions, consistently say that they are looking for the 'system' to combine two things in one place:

- knowledge of the patient/service user/carer as a person, including their home circumstances, lifestyle, views and preferences, confidence to care for themselves and manage their condition(s), as well as their health status and symptoms; and
- knowledge of the relevant condition(s) and all options to treat, manage and minimise them, including knowledge of all available support services.

People know they may need a variety of professionals and support services, but within this they want a single trusted point of liaison, to which they can have recourse as necessary, where the above knowledge is held. They expect this person/service to advise them on how to take next steps and, ideally, to co-ordinate their care or to help the patient/carer to co-ordinate it.

The "I" statements

To illustrate what good coordinated care might look like from this perspective, the Future Forum paper included a series of statements to which patients could agree if their care was well coordinated, such as "I was always kept informed about what the next steps would be". These became known as the "I" statements and would be the first building block for the full narrative.

The "I" statements were based on three main sources. The first was patient experience research. In particular the testing and evaluation of questions about what matters to patients, for the purpose of inclusion in national surveys commissioned by the quality regulator, the Care Quality Commission, such as "I was as involved as much as I wanted to be in decisions about my care and treatment".

The second was extensive policy formation with National Voices members – health and social care charities – over the preceding two years. In a submission to an earlier round of the Future Forum (National Voices, 2011) the following demands relevant to integration were stated:

- Services organised around, and responsive to, our human needs.
- No more gaps. Reduce organisational barriers and boundaries.
- Services to be seamless and care continuous.
- Information about services should come to us.
- Information about us should follow us.

In relation to person-centred care the document also called for support to people with long-term conditions to:

- understand our conditions and medications;
- learn how to use health information;
- take achievable steps to improve our health;
- prevent emergencies developing;
- navigate services and support;
- manage our own care and treatment; and
- take part in deciding our care plans and our treatment options.

This document was a summary. To produce the initial draft, National Voices reviewed all the policy positions taken by its members since 2009, including responses to the coalition government's White Paper and associated consultations; and all written evidence supplied by TSOs (whether or not they were National Voices members) to the Commons committee on the Bill. There were then three rounds of consultation on successive drafts with the members. Thus there was a considerable hinterland of "processed" and refined policy work behind the "I" statements.

The third source was the evidence base (e.g. Coulter and Ellins, 2006; Invest in Engagement, 2010), comprising research on: the effectiveness of patient-focused interventions such as tailored patient information, support for self management, shared treatment decisions and care planning; and research on what elements of service organisation are most likely to favour the success of integrated care (such as integrated information systems).

Narrative production, September 2012-March 2013

In September 2012 the first staff were employed by the NHS Commissioning Board and an "integration" workstream was immediately established. Later renamed NHS England, this was the new statutory body, independent of government, responsible for the majority of the NHS budget and for using it to commission health services in England either directly (primary care and specialised services) or indirectly, through local clinical commissioning groups. It formally assumed responsibilities on 1 April 2013 but operated as a shadow body from September to November 2012 and then as an "authority" until establishment. The Board would have primary responsibility for driving integration of health services and knew that it would therefore need to act early to pick up from the recommendations of the King's Fund and Nuffield Trust.

Creating a partnership with the Local Government Association, representing local councils that run social care, the Board commissioned National Voices to work with it to co-produce a new definition of integration in the form of a narrative, taking the user perspective as the organising principle. This section describes the methods used to develop the narrative.

First, National Voices drew up a shortened set of “I” statements, including removing those which were service-specific in order to produce a generic set, and proposed a first version of the overall summary statement and definition. Second, a workshop was organised at which these were debated and tested. Participants included, on the one hand, leaders of health and social care services and key civil servants and, on the other, a high ratio of individual service users and representatives from service user organisations. Care was taken to ensure that the key patient groups who need coordinated care were present: older people, children with complex needs, people with long-term conditions and with continuing mental health problems. From this feedback a second version was produced and circulated for amendment and agreement by the workshop participants. This was made public for testing and further refinement between December 2012 and February 2013. The key revisions focused on ensuring the “I” statements were giving more emphasis to the need for service users to control their care, and ensuring the “I” statements were equally applicable to health and social care recipients.

For the latter purpose the statements were cross-referenced to an existing initiative called “Making it Real”, developed by the Think Local Act Personal Coalition (TLAP, 2012), whose aim was to promote more personalised social care by encouraging local authorities to adopt and implement a set of first person statements that had been coproduced with service users. Where these covered aspects of service user experience that were not already covered by the National Voices set, they were either imported or amended for inclusion in the narrative.

In March 2013 a second workshop, with similar composition to the first, gathered to review and analyse all the public feedback and make decisions on the final shaping of the narrative. The third and final version was completed by the end of March for publication in May. In this version, as mandated by the workshop, the key revisions were:

- Inclusion of further statements from “Making it Real” in relation to people controlling personal budgets. These already existed in social care, and during the development of the narrative the government published results from budget piloting in healthcare and declared its intention to roll these out from 2014.
- Again increasing the emphasis on the service user’s autonomy, control and decision power, including by putting all statements in the present tense and changing verbs to be more active.

Throughout the process there was considerable discussion about how far people in need of coordinated care were expected to be “in control” of their care, with a spectrum of views ranging from those who believed that all service users have the right to maximum autonomy, to those who believed it was the job of services to coordinate care properly without placing too great a burden of responsibility on vulnerable people in need. This split was found among service users and their organisations as well as among managers and professionals. However, the public feedback was clearly in favour of autonomy.

At the second workshop, participants debated whether the growing emphasis on active, autonomous service users being supported by holistic service approaches – an ethic at the forefront of social care – would work for healthcare, where the bio-medical model remains dominant. Their conclusion was that this should be the strong aspiration of the narrative, with an expectation that cultures would change.

The content of the narrative

The body of the narrative (National Voices, 2013) consists of a set of statements grouped into six domains:

- my goals/outcomes;
- care planning;
- communication;
- information;
- decision making, including budgets; and
- transitions.

The statements express what the service user will experience if care, treatment and support is well organised to meet their needs and preferences. Thus, under “my goals”, the statements include:

I am supported to understand my choices and to set and achieve my goals.

Taken together, my care and support help me live the life I want to the best of my ability.

“Care planning” is seen as a central element in these aspirations, and this domain includes statements such as:

I work with my team to agree a care and support plan.

My care plan is clearly entered on my record.

I have regular reviews of my care and treatment, and of my care and support plan.

I have systems in place to get help at an early stage to avoid a crisis.

Care planning will require that services and support are “joined up” around the needs of the person, and this demand is expressed in a number of statements throughout the narrative. For example, under “communication”:

I always know who is coordinating my care.

I have one first point of contact. They understand both me and my condition(s). I can go to them with questions at any time.

A key difference in the quality of overall care towards which the narrative points will be the person’s experience of “transitions”. Unlike the current experience, which is often one of risk, uncertainty and discontinuity of care, the statements posit that:

When I use a new service, my care plan is known in advance and respected.

I know in advance where I am going, what I will be provided with, and who will be my main point of professional contact.

The six domains of statements are summarised near the top of the narrative in a single paragraph descriptor of what a high quality of joined up care means to the service user:

I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me.

Above that in turn is the headline definition:

“Integration” means [...] person centred coordinated care.

The aspiration of the national system leaders for health and social care is that this definition will be understood and adopted by all local planners and commissioners.

The narrative within the national initiative

During the development phase, political momentum for the implementation of integrated care had continued to grow. The early collaboration between NHSE and the LGA evolved into a wider working partnership with other national bodies. As they joined, the draft narrative offered a common frame of reference for what they were seeking to achieve together and was adopted by each in turn.

With ministerial urging, these national bodies developed a “common purpose”, launched on 14 May 2013, to spread integrated care to all localities in England[1]. This was to include encouraging around ten areas to be identified as “pioneers” who would be encouraged and supported to develop integration at scale and pace; establishing a central support unit to help all localities make integrated care plans by 2015 and have them implemented by 2018; promising new indicators to help measure people’s experience of coordinated care; and asking every local area to adopt the narrative as its guide to achieving benefits for patients and service users.

Hence, in principle, the narrative should become the “common definition” for all parts of England, encouraging them to strive for “person-centred coordinated care” rather than organisational “integration”.

Potential for further development

The aim of the narrative is to be generic – it does not relate to any specific service user group or care setting but attempts to hold true for all groups who may need coordinated care. However, it was acknowledged from the start that this would mean leaving out some aspects of care that may be highly significant for specific sub-groups of people. For example, if children with disabilities experience delays in the supply of adaptive equipment it can quickly cause educational or developmental delays; and the transition from children’s to adult services may require special attention. The intention was to create additional “I” statements for these groups, and although this was not possible prior to publication, it was hoped progress could be made after publication. Again this somewhat mirrors the experience of “Making it Real”, where subsidiary publications explaining the meaning of the overall statements for various sub-groups of people were later published alongside.

Thoughts on the potential impact of the narrative

The coalition government’s health reforms intended to create a system which is both more devolved – with the Department of Health ceding responsibilities to various arm’s-length national bodies – and more “localised”, with decision power given to local areas through clinical commissioning groups and Health and Wellbeing Boards. There was also new emphasis on the use of competition among providers to raise quality.

In the view of many critics, this would create a more fragmented and unplanned set of services. The cry for “integration” that arose during the pause in the legislation in May 2011 can partly be seen in this light – as an attempt to create a bulwark against, or an alternative commissioning path to competitive procurement. Although the government, regulators and think tanks have insisted that integration and competition are compatible, there is no doubt that bolting a new imperative for integrated care onto the final Act risked creating significant problems for commissioners and others. To create, then, a national drive for coordinated care took considerable effort between the partners. It was aided by the new policy consensus previously described, centring around using the service user perspective as its “organising principle”, and it appears that the narrative, as an early “flagship” expression of this, also helped to create unity of intent among the national bodies.

However, in the reformed system, with its disavowals of “top-down” approaches and mandatory targets, it is no longer permissible for these national leaders to dictate actions to local areas. NHS England strives not to dominate and give orders to CCGs which are intended to make autonomous commissioning decisions. On the social care side, the Local Government Association is a group of voluntary members and does not dictate policy or practice to local authority commissioners. Therefore the extent to which a national “common purpose” initiative will have local impact remains to be seen.

The narrative will almost certainly have one set of impacts, however, which is to become the source of measurement for people’s experience of coordinated care. The Department of Health will draw on it to create new survey questions for some of the largest national surveys, and use these to generate national level indicators for inclusion in its overlapping outcomes frameworks. The national collaborative will also support local commissioners to develop measures for success based on the “I” statements; while a consortium of research bodies, including National Voices, is seeking to develop a common assessment tool for quality improvement.

The complex and difficult organisational challenges required to achieve integrated care and discussed in the pages of this journal remain to be conquered. The narrative may simply add a decorative touch to these, being used as an occasional reminder of “why we’re doing this”. But there is apparent potential for it to achieve more, where partners in local areas agree to unite around it and to use it as the basis for goal setting (the overall summary statement) and benchmarking (the “I” statements). NHS London, which supports several large scale integrated care programmes across the capital, intends to use it in this way. Anecdotal feedback from integrated care partnerships that are already running (Leeds, Liverpool and others) suggests at least some do find it useful as a story about what they are doing which can act as a guide towards future outcomes.

For some areas, it is possible that the apparent simplicity of the service user story will turn out to be something quite different, however. Where organisations adopt the narrative most fully and make it central to their plans, they are likely to find that it begins to disallow previous approaches based on organisational priorities and processes, leading to the conclusion that services need fundamental redesign rather than merger or realignment.

It is worth remembering the full original quote from Lloyd and Wait, (2005):

Integrated care [...] imposes the patient’s perspective as the organising principle of service delivery and **makes redundant** old supply-driven models of care provision (p. 7, our emphasis).

Note

1. www.england.nhs.uk/2013/05/14/c-care/

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About the author

Don Redding is the Director of Policy for National Voices, the coalition of health and social care charities working to strengthen patient and service user voice in policy in England. He co-produced the narrative with NHSE England, the Local Government Association and other partners. A former health and social care journalist, he has worked for leading UK voluntary organisations since 1991 and was previously Head of Policy and Communications for Picker Institute Europe, for whom he authored numerous articles and reports. He is a contributor to the *Health Service Journal*. Don Redding can be contacted at: don.redding@nationalvoices.org.uk

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