



6 October 2011

## **Seamless Care: Whose Job is it Anyway?**

Party Conference fringe events 2011  
by National Voices, The Royal College of GPs & the Alzheimer's Society

We all want to see more joined-up care. This is not controversial. Patients, carers, other service users, government and professionals have all signed up to it. But who is responsible for improving integration? Who is accountable? Our party conference fringe events are exploring these issues.

### **Liberal Democrat Party Conference, 19 September 2011, Birmingham**

Barbara Pointon set the scene. Barbara is a former carer to her husband, Malcolm, who lived with Alzheimer's for 16 years. She held up an illustration of Malcolm's dizzying complex '[web of care](#)' and gave a heart-rending account of the challenges they faced in navigating: 'primary care, secondary care, domiciliary social care, respite and day care, benefits, residential and nursing home care, A&E, community physical, social and mental health care, palliative care, specialist nursing care and family social care'.

While she praised individual clinicians, the lack of coordination meant Barbara's years of caring for Malcolm were spent managing battles with officialdom as well as 'glass curtains, stone walls and pitfalls under foot'. On numerous occasions, she said, they were 'batted between health and social care – each trying to protect their budgets...for example, when Malcolm lost his ability to stand, we required a standing hoist to facilitate the changing of incontinence pads and washing. It took four months for health and social care to decide how it was to be funded, during which time we came close to injuring ourselves and Malcolm.'

Barbara pointed out that it wasn't only at the interface between health and social care where they encountered barriers and also raised a series of related issues. Malcolm was pushed into doing day centre activities he didn't enjoy; staff concerns around confidentiality meant Barbara wasn't able to get important information and there were endless frustrations around information not being passed forward so Barbara had to repeat herself again and again. Meanwhile she despaired at the mountains of paperwork created by the inefficiencies and the wasted resources spent on them.

Barbara said 'practically every carer I meet wants one single point of contact, an expert in that condition, who holds all the information about the patient, gives advice when required, and only calls in higher levels of expertise when required? A person who has the power to push health and social care buttons and get things done'.

[Read Barbara's full talk here.](#)

**Chair Jeremy Taylor then posed the question Seamless Care: Whose Job is it Anyway?** to our panel: RCGP chair, Dr Clare Gerada; Liberal Democrat health spokesperson Baroness Jolly and Councillor David Rogers (East Sussex County Council & Lewes District Council), chair of a Local Government Group Community Wellbeing Board. Our panellists outlined their roles in joining up care and then responded to questions from the audience.

**Baroness Jolly** said her role as a legislator was to provide the framework to make integrated care work, spending the next six months improving the [Health & Social Care Bill](#) as it goes through the House of Lords. While she didn't believe she and her colleagues could make wholesale changes, they could improve the Bill by firming up the responsibilities of the Secretary of State; by asking [Monitor](#) - which has a new responsibility to promote integration - what the levers are for doing this; by ensuring we have good quality data on things like diagnosis of dementia, centrally collated then filtered down to Clinical Commissioning Groups; and by ensuring local HealthWatch has some teeth - with breadth and depth of membership and the ability to refer back up the line to the Care Quality Commission.

Baroness Jolly held up her own area of Torbay as a good example of integrated care, supported by a common budget for health and social care. She suggested there were other areas across the country where similar successful initiatives were in place, but the new legislation is now in danger of dismantling them.

**RCGP chair, Dr Clare Gerada** boldly stepped up to the mark, pointing at Malcolm's care web and saying 'that's my job'. As a GP it is up to Clare and her colleagues to navigate care for their patients: 'My job is the single point of contact. My job is to make your life better. I'm there for you. I'm your advocate'. However she offered a note of caution, feeling care can never be 'seamless' and is rather about 'managing the transition of patients' between care settings and 'multi-disciplinary teams, ideally led by a GP, working across boundaries but each maintaining allegiance to their own organisation'. Clare stressed the importance of pooled budgets and shared electronic records.

Clare pointed out we should celebrate the fact Barbara did receive her NHS care free at the point of need, and this is unique to the UK. She also pointed out that clinicians need to be freed up from major reorganisations by government every few years in order to focus on improving care.

**Cllr David Rogers** agreed the House of Lords stage will be key to ensuring the Bill promotes integrated care, and many organisations will have responsibility for delivering it. He said GPs are the key player in joining up care and liked the idea of a single point of contact. He felt the concept of pooled and shared budgets could be taken further. However he felt full integration may never be possible while NHS care is free at the point of need and social care is not. There will always be rubbing points. Self funders also need advice and information. In his additional role as vice-chair of an overview and scrutiny committee (OSC). David said OSCs' time is dominated by work on reconfigurations which leaves little time to explore issues of patient-centred care. He was challenged on this by a member of the audience, also

an OSC committee member, who believes local authorities can examine single issues in depth and show leadership in improving care despite all the constraints.

**Suggestions and comments** from the audience and the panel included:

- **Co-design** – we need to involve patients and carers more throughout the system
- **Local government and OSCs** should examine **single issues** in depth.
- **We need to explore new ways of pulling the care patchwork together** (following the example of innovators like Torbay). Some suggested we need top down implementation of best practice – ‘if we know something works, let’s get on and implement it now’. There was concern that some of the best innovative work of Trusts is under threat through reform and cuts.
- **Personal health budgets** should be extended. But we also need **genuine personalisation of care** which is not only about budgets.
- **We need to invest in specialist staff**. This saves money in the long run. Campaigning for these can work eg in the case of dementia advisors. We should also explore the relationship between general and specialist work and how it can work to best effect.
- **There was much support for giving GPs more responsibility as navigators of care** and Clare’s acceptance of responsibility was appreciated. However there was also audience scepticism about the capacity and willingness of GPs as a profession to do this and challenges around failures in diagnosis, notably in dementia.
- We should give real weight to the **quality of patient experience** and ensure this is acted on.
- **Trust the carer** – confidentiality concerns can cause barriers to effective care, yet professionals should always work in the best interests of the patient.
- Event organisers should have a **follow-up conversation** with Baroness Jolly to discuss details to take forward in the Lords.

### **Labour Party Conference, 26 September 2011, Liverpool**

As above, Barbara Pointon set the scene. She and Dr Clare Gerada were joined on the panel by Baroness Thornton, Opposition Spokesperson for Health & Equalities Office and Councillor Linda Thomas, Deputy Chair, Local Government Group Community Wellbeing Board. Our panellists outlined their roles in joining up care and responded to questions from the audience.

**RCGP chair, Dr Clare Gerada** repeated her statements above and added a resolution to step up integrated working, starting by ensuring people with dementia have a single, named contact to navigate their care - who may not necessarily be their GP. Her statement around the impossibility of making care completely seamless was challenged by Barbara who said, on Clare’s model, in their case the seams ‘would have burst’ and that it isn’t acceptable to allow service users to drop through the gaps.

Meanwhile Clare said she feared the Health & Social Care Bill (H&SC Bill) in its current form will lead to more fragmented care and was heading towards a market-driven system to care for ‘the fit, the well and the vocal’.

**Baroness Thornton** said central government is accountable for providing a coherent framework; legislative rights and enough funding. She criticised the H&SC Bill, showing particular concern that it will erode the accountability of Secretary of State. She also wanted to see tariffs looked at. As an opposition peer she resolved to hold the government to account on the reforms. She did however, see potential in Health and Well Being Boards to join up care, but was concerned these weren't adequately funded. She wanted to see patient and carer voices like Barbara's being more prominent and 'heard from the top' - HealthWatch being important to this.

**Cllr Linda Thomas** said she'd like to see 'strategic heads banged together' and 'now is the time to start creating a few waves'. She also saw potential in Health and Well Being Boards to join up care and said they should be the arbitrator between what the GPs deliver and what carers need. She would like to see the government giving overall responsibility for coordinating care to local authorities – with the resources to match. She flagged some good practice in her patch – Bolton – for example, a proactive carers group and an ageing-well centre which has helped integrate care and provide services such as respite care. She acknowledged this isn't a full solution, rather an example where progress has been made. She said a range of people must be involved to really tackle the problems around integrated care – local government is keen to do its bit but this also means others will also have to play their part.

**Suggestions and comments** from the audience and the panel included:

- Widespread agreement that navigating a messy maze of care **wastes resources** and **we can no longer afford to work in this way**.
- There are examples of **good practice in children's care that might be replicated** in other arenas – eg key workers who coordinate services.
- While the audience appreciated Clare Gerada's determination to take forward integrated care with GPs at the heart of this, there were **concerns as to why the GP role here doesn't always work**. One person commented that it was right that GPs should be managing the pathway but that they don't have time to do so. The Alzheimer's Society flagged **diagnosis failure** - 60% of dementia cases are left undiagnosed. Clare Gerada said the high statistic was partly due to the way diagnosis is recorded but agreed to look further into this.
- There was much support for taking forward the idea of **pooled health and social care budgets**, with Health and Wellbeing Boards either having a say in these or full responsibility for them, albeit some concern that election cycles could affect continuity here.
- Several members of the audience flagged **similar experiences to Barbara and Malcolm's**. One said that, even with deep knowledge of the NHS (with family members working within and an MP wife) he still couldn't work out how to navigate the system effectively, despite great effort in trying to do so.
- There were strong calls for a **named point of contact** – a case worker or a key worker – for every patient with a long-term condition. There were suggestions that this might be a GP or another key player eg a specialist nurse.
- There was **widespread support for specialist nurses and concern about cuts** for some conditions. Several members of the audience gave examples that have been successful eg in breast cancer and dementia care.

## **Conservative Conference, 3 October 2011, Manchester**

As above, Barbara Pointon set the scene. She and Dr Clare Gerada were joined on the panel by the Rt Hon Simon Burns MP, Minister of State for Health and Councillor Dr Gareth Barnard, Vice Chair, Local Government Group Community Wellbeing Board. Our panellists outlined their roles in joining up care and then responded to questions from the audience.

**RCGP chair, Dr Clare Gerada** repeated her points above, saying 'it's my responsibility to stop your husband falling through those gaps'. She said the role of the generalist is vital - there are 19,000 different diseases and it is impossible to have a specialist, single point of contact for each one. When challenged on whether GPs have the time or knowledge to navigate care for service users she said: 'I'm not saying GPs have all the knowledge but that we coordinate the care'.

She called for more investment in GPs and community services saying this delivers better outcomes.

She said we have to make integrated care work: 'It is time to stop talking about health, about social care' and time to talk about 'our NHS, our patients'.

**Rt Hon Simon Burns MP** said all the new bodies being set up will have a role and responsibility in delivering integration and the social care funding system will and must be reformed. His colleague, the minister Paul Burstow, is looking at fragmented care for people with long-term conditions and social care including the Dilnot review on funding. Meanwhile, the second phase of the NHS Future Forum was moving towards a more integrated system of care.

He said fragmentation had been a concern for many decades. In the Major government there were fights over responsibility and payments. He said some progress had been made, including under Labour, and there are some examples of good integration but progress has been too slow.

'Modernisation of the NHS' came from the need 'to put patients at the centre of care' rather than treating them 'as appendages'. The H&SC Bill would ensure local government and NHS work was done 'more collaboratively, as a partnership'. Health & Wellbeing Boards would give 'democratic accountability for the first time', because they include elected councillors. They have 'a role to encourage closer working between public health; the NHS and social care and also other issues that impact on health, like housing. Meanwhile PCTs are developing succession plans for pooled budgets.

When asked about 'competition versus integration' in the Bill he said that there was a 'lot of unadulterated claptrap talked about competition' and it is not about price but about quality.

**Cllr Dr Gareth Barnard** said patients must be at the heart of the reforms and this is about empowering professionals to build services around them. Carers should be able to focus on caring and not navigating a complex system. He said local authorities sometimes get wrapped in the detail of the process rather than focusing on the service users. He agreed with Barbara that 'a single point of contact is important'.

He said 'we have to have the courage in local government to disinvest in some services and reinvest in others.

He felt Health & Wellbeing Boards would have the power to break down some of the boundaries, helping give professionals the permission to exercise judgement and help 'ensure personalisation means something'. The boards would also be well placed to look at other things that affect people's quality of life like housing and leisure activities available. He saw a role for the voluntary sector, and praised Age UK who had found support for his carer father.

He was asked whether, with budget cuts, Health & Wellbeing Boards would hold enough power. He replied that they must be properly set up, with adequate resources; they need a strong performance management framework and also said Overview & Scrutiny Committees can be very effective - talking to service users and carers and dissecting what is going on. He said: 'I'm confident that the framework I've been given will empower professionals and give them teeth'.

**Suggestions and comments** from the audience and the panel included:

- A representative of the charity Contact a Family said they would love GPs to coordinate services but 76% of their families had **no connection with their GP**
- GPs often **struggle to navigate social care**
- There were several questions to Barbara on whether **someone from a charity or a non clinician could perform the role of single point of contact**. Barbara said she thought this may well be possible as long as they have a 'backpack of advice and the ability to make things happen in both health and social care'. She felt GPs often don't have the time or the knowledge to perform the role effectively.
- Barbara Pointon also raised **concerns about cuts to charities** ('the best advice I had came from the Alzheimer's Society') and said **cuts will affect carers' ability to carry on caring**.
- The Terrence Higgins Trust flagged a scheme called My HIV, **a set of tools developed with patients to help them hold effective discussions with their GP** – this could be replicated for other conditions to help all patients have a say.
- Jeremy Hughes of the Alzheimer's Society pointed out the **gulf in funding between health and social care** (it's like stitching together a jacket with one sleeve made by Jacquard and one by Primark – one sleeve will fall apart before the other). He said we can make seamless care much easier by **taking £2billion from the health budget and adding it to the social care budget**.

- Diabetes UK said people with diabetes want a coordinator ‘who knows more about the condition than they do’. They praised diabetes **specialist nurses**.
- Getting **service users involved in commissioning is key. In some areas this has been done well and in others ‘appallingly’**
- Diabetes UK also raised concerns on the role of **Monitor and how it can bring about integrated pathways of care while following competition rules**: ‘competing elements of the pathway aren’t going to work’ The Chartered Society of Physiotherapy added a related query on **how choice and commissioning would work when, for example, there is a choice of 30** physiotherapists in a given area. Simon Burns said choice of provider would help drive up quality and ‘commissioners would choose care from the people best qualified medically’. Clare Gerada said, in this context, ‘it is disingenuous to expect me as a GP to be able to choose, let alone a patient.’ Alistair McLellan from the Health Service Journal raised the possibility of competition-free zones.

We’ll give the last word to former carer, Barbara Pointon, who raised serious concerns about cuts to charities and support for carers in the reformed system: ‘Family carers need support through infrastructure and planned breaks. They are the biggest health and social care work force’.

Thank you to our panellists and to all those who came along on the day to ensure high-quality debates. Thank you also to National Voices members who provided [care webs](#) and patient quotations which were on display on the day.

*Report by Jules Acton 6 October 2011*