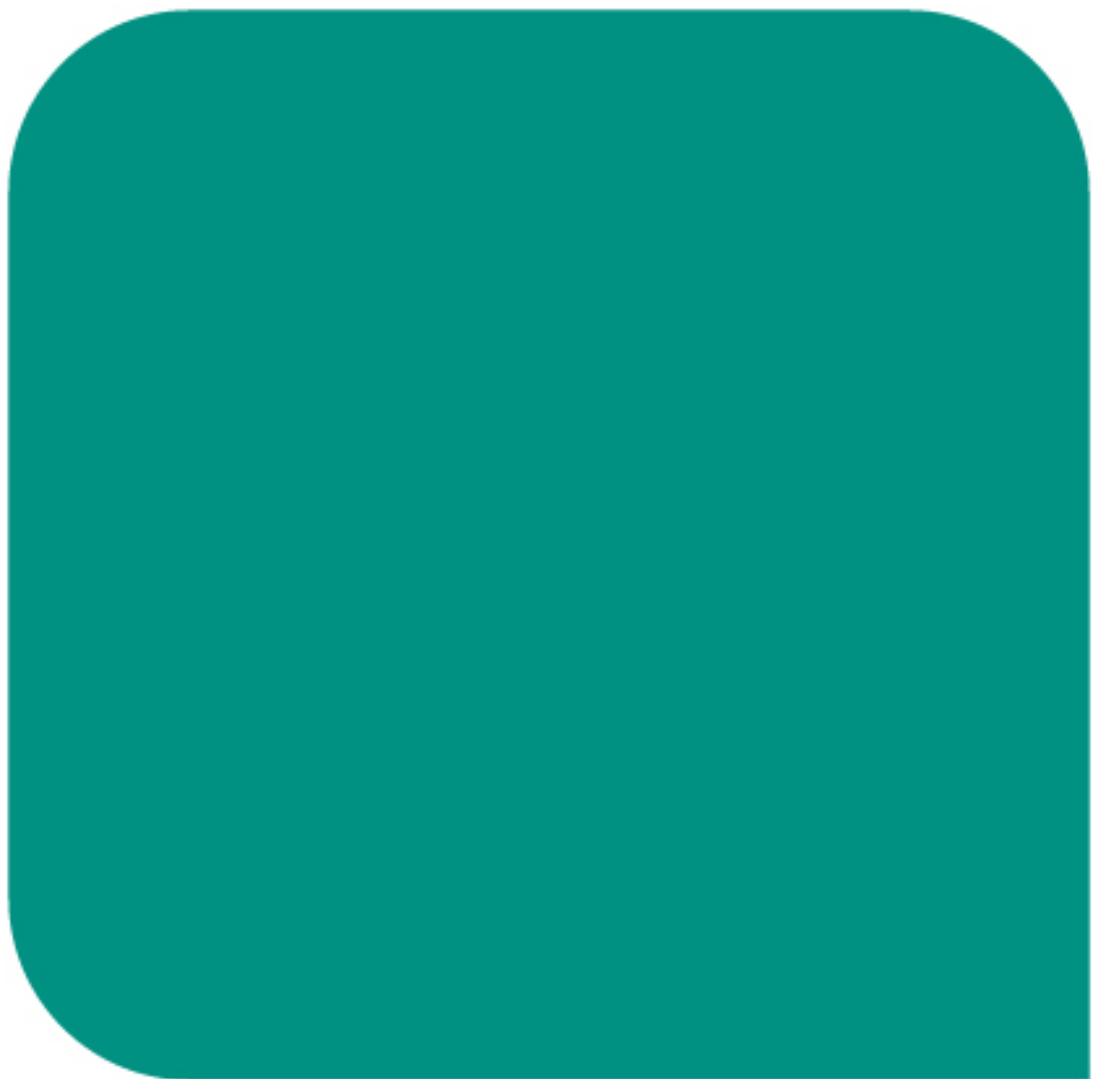




social care
institute for excellence

SCIE roundtable discussions:
New perspectives on the future of care and support

Community-led care and support: a new paradigm



The Social Care Institute for Excellence (SCIE) improves the lives of people who use care services by sharing knowledge about what works.

We are a leading improvement support agency and an independent charity working with adults', families' and children's care and support services across the UK. We also work closely with related services such as health care and housing.

We improve the quality of care and support services for adults and children by:

- identifying and sharing knowledge about what works and what's new
- supporting people who plan, commission, deliver and use services to put that knowledge into practice
- informing, influencing and inspiring the direction of future practice and policy.

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Community-led care and support: a new paradigm

Report from SCIE Roundtable held on 12 February 2015

‘Community-led services help to break down the differences between people who need, and people who provide, care and support.... It is important that community-led care and support services are supported to become sustainable. Failure damages not just the people delivering the service but the people using it.’

Sian Lockwood, Chief Executive, Community Catalysts



SCIE roundtable discussions

In early 2015, SCIE arranged a series of roundtable discussions exploring how to improve care and support at a time of growing demand, demographic change and financial constraint.

These sessions covered:

- Community-led care and support
- Leading the Care Act
- Health and wellbeing boards (jointly with The King's Fund)
- Social care and technology (jointly with the Department of Health)

This is the report from the discussion on community-led care and support.

Introduction by Lord Michael Bichard, Chair, SCIE



'The move towards genuine community-led support is about challenging the accepted wisdom of delivery of services – including statutory services. It's a huge shift.'

***Lord Michael Bichard
Chair, SCIE***

The aim of the Social Care Institute for Excellence (SCIE) roundtable discussion was to identify, celebrate, support and learn from community-led activity. We aimed to identify practical steps stakeholders can take to support community-led services and share that knowledge with the sector including policy-makers.

The challenges facing care and support cannot be met in the traditional way by traditional services. Statutory services can sometimes fail to provide what people want and need, but community-led services are often closer to the client, more trusted and can release the real potential in our communities. We need to reignite that potential.

Statutory services can sometimes be reluctant to cede power. On the other hand, as communities are expected to take on additional responsibilities – such as youth work and libraries – do they have the capacity and capability to do this? Statutory services need to rethink their role and focus on commissioning outcomes, rather than protecting the traditional system.

Key messages

Positive impact of community-led services

1. Community-led services help to break down the differences between people who need, and people who provide, care and support.

Challenges and barriers

2. Community entrepreneurs always expect to face barriers – such as the complexity of regulations and funding regimes.
3. Communities with greatest need are at the most risk of losing support.
4. We need to challenge whether or not commissioners are best placed to understand the mix of community needs. Local communities really understand the context in which care and support services work.
5. Many professionals feel restricted by current practice and would welcome the opportunity to engage more directly with people and communities.
6. While the rhetoric increasingly talks about the need for local communities to define their needs and local solutions, we still see distrusting relationships between statutory organisations and professional groups and local communities. We need to generate trust amongst commissioners and statutory services in small, local organisations.

‘There is a deficit of candour as well as a deficit of funds. How we develop relationships and trust really plays into this. If people can understand their rights and responsibilities, you can begin to build relationships, trust and a concept of what’s possible.’

Rich Watts, Programme Lead, Mental Health, National Development Team for Inclusion

Building and sustaining community-led services

7. When it comes to community-led support, it is about spreading out, not scaling up. These types of services are likely to remain small and local – but they can be numerous.
8. The move towards genuine community-led support is about challenging the accepted wisdom of delivery of services – including statutory services. It’s a huge shift.
9. We need practice-based evidence, not evidence-based practice to really understand what is going on and what works – and does not work.
10. Passion is impossible to replicate. What works is to be able to provide support to individual passionate, courageous individuals, e.g. through providing coaching, leadership development and networks.
11. It is important that local organisations measure the impact of their work, especially on wellbeing. We need to provide support to local organisations and consistent and simple to use evaluation frameworks to help them to measure impact.

‘It is important that community-led care and support services are supported to become sustainable. Failure damages not just the people delivering the service but the people using it. People with good ideas who want to provide a care service for other local people need the right kind of advice and mentoring tailored to them. Quick-fix initiatives, such as seed-fund grants and some training, don’t help to build sustainable services. Most of these little ventures will stay small and local and individual. Passion is impossible to replicate.’

Sian Lockwood, Chief Executive, Community Catalysts

Enabling community-led services to thrive

12. Local community enterprises need support to connect and share with each other. Larger voluntary sector organisations could play a role in facilitating this.
13. Most care and support is provided by family and friends – not by official services. Carers are often part of ‘virtual’ communities – not just geographical communities. Need to consider this when supporting concept of community-led care and support.
14. Commissioners do need some level of evidence of impact, but if community organisation can demonstrate that they are identifying, engaging and benefitting people at risk or in need of support, that is sufficient.

‘We need to consider what is the productive system that can develop and support local learning of what works to promote community actions that can benefit from more older people and second can help support more older people? What ingredients and recipes appear to be most effective in producing useful, innovative, risky activity that can then be tested? It is about learning models that are not just centralised national models but about getting into a locality and learning alongside that locality for a number of years. It’s about having an ongoing programme of learning that is also credible to others, and generates evidence of what works to others including commissioners.’

Lord Filkin, Chair, Centre for Better Ageing

‘As a commissioner I am satisfied if community-led groups can demonstrate that they are identifying, engaging and benefiting people at risk. That’s enough for me – that’s sufficient evidence to support a commissioning decision.’

Joe Fowler, Director of Commissioning, Sheffield City Council

Presentations

Matt Clifton, Chief Executive and Steven Chapman,
Non-Executive Director

Skillnet Group Community Interest Company, Kent



‘Skillnet helps people with learning disabilities to be seen and heard – to have work in the community and be part of the community.’

Steven Chapman

‘Skillnet believes passionately in working together equally. It is neither user, nor professional-led. It is very mutual and we support each other. We aim to co-produce from top to bottom. Our Board, policies and all work is co-produced.’

Matt Clifton

Skillnet is a small locally run service and a community interest company. It is a group of people with and without learning difficulties working together to achieve equality. It supports people with learning difficulties to speak up, make choices and become powerful and influential. It supports people to gain opportunities and become more independent in learning, housing, work, health, money, travel, leisure and relationships. It runs co-produced social businesses – such as a music studio and café – that offer paid work and work experience to people with learning difficulties.

Skillnet started as a reaction against statutory services. Young people did not want the services that were being offered such as day centres. So they started working with Job Centre Plus to look at what young people with learning disabilities really wanted to achieve and do and working around the person. This approach started to break down the initial suspicion held by statutory services, and now the working relationship with Kent County Council is very supportive. For example, Steve Chapman is co-facilitating an open space event to begin to co-produce Kent’s advocacy services.



Sian Lockwood

Chief Executive, Community Catalysts

'Community-led services help to break down the differences between people who need, and people who provide, care and support. But community entrepreneurs always expect to face barriers – such as the complexity of regulations.'

Community Catalysts is a social enterprise and community interest company. It nurtures very small community enterprises, groups and initiatives that care for or support people in their

local are. Community Catalysts works directly with people who use care and support services, councils, CCGs, charities and care providers.

Community-led services help to break down the differences between people who need, and people who provide, care and support. But community entrepreneurs always expect to face barriers – such as the complexity of regulations.

Five years ago, Debenham – a well-off village in Suffolk with a history of community action – made a commitment that no one with dementia should have to leave the village in order to get care and support. The plan was started by a local vicar who asked residents what worried them and what the church could do to help. The overwhelming worry was that there was no support for residents with dementia – the nearest specialist service being ten miles away. As a result, many people were going into residential care much earlier than they would have, if they had community-based services within the village.

One hundred and fifty people attended a village meeting – including people with dementia, the local GP and local authority staff – where they mandated a village elder and group to develop a local plan. At this stage the vicar who had initiated the meeting stepped aside to ensure that it was a community- rather than church-led initiative.

The guiding principle was simple – to encourage people who had a good idea to do them. For example, local people organised a pop-up restaurant, chair-based exercise classes, training sessions on how to navigate the internet at the library, and an out-of-hours helpline. This work would not have been possible without an individual taking the initiative. You often need a charismatic, passionate person to get this type of community-led service off the ground. The group did not receive a lot of official help from the local council, but individual council staff were very supportive. It received grants from charitable trusts, and needed technical help with regulation. For example, the village wanted to run its own care agency but it proved impossible because the regulations were too complex and expensive. Instead it found a care agency to deliver the services locally.



Heléna Herklots

Chief Executive, Carers UK

‘Don’t think just about local communities. Your community is not always about where you live. There are communities of interest and issues making connections online or through peer support arrangements.’

Carers UK is a national charity that supports carers and provides information and advice about caring. It influences policy through research based on carers’ real life experiences. It campaigns to make life better for carers.

Most care and support is provided by family and friends – not by official services. And carers are already under pressure with many people caring across the age range as sandwich carers supporting children and ageing parents or serial carers, or distance carers.

Two million people each year start caring.

One carer said: ‘You need to know another carer who’s been there and can tell you about the shortcuts.’ *A carer responding to Carers UK survey*

There are many carers out there who want to help others. Carers UK have hundreds of carer ambassadors who work in their own community to, for example work with GPs or the local press and spread the word about how to support carers. Carers provide peers support to others – acting as a listening service as many carers feel they cannot speak to their own family about the issues they have to manage as carers.

The online community offers a real 24/7 community with direct access to thousands of people to answer questions at any time. Supportive communities for carers and of carers is incredibly important. Carers need help and support to ensure that their own lives are not lost as a result of caring.

Carers Week which starts on 8 June 2015 will focus on carer-friendly communities. It is important to remember that most carers have not chosen to join that community – it has been forced upon them. Other parts of the community need to recognise this and reach out to them.

Being a carer can be extremely isolating, as one carer who had to give up work told us: ‘Nothing prepared me for the loss of identify. As soon as I start to talk, eyes glaze over when I talk – it’s as though I cease to exist.’



Joe Fowler

Director of Commissioning,
Sheffield City Council

'In order to get best value, we need to work with all local stakeholders to open up the discussion and look at how resources are invested at local level. GPs were saying 'I need a social worker' when in fact what they meant was they needed someone with social care knowledge – that didn't have to be a social worker.'

Joe Fowler manages Sheffield City Council's health and social care spending including half of the £250 million Better Care Fund. He also

manages long-term business planning for council housing.

The reality is that the current model of social care is not sustainable over the next couple of years. As a commissioner, we are looking for solutions that can help and we recognise the value of communities and informal care.

When I first started as a commissioner, there were lots of good preventative services available and we had support workers in local communities. Many voluntary sector organisations provided valuable support such as Shelter supporting families at risk of becoming homeless, Life Navigators from Age UK helping older people with complex needs, volunteer health champions working on the ground in communities. There are a lot of people willing to do a lot of useful things. And there are a lot of great case studies – but very little research on impact.

The commissioner's dilemma is: Do you continue to fund your core statutory services – or community services that you cannot 'count' or calculate the benefits of?

The real care system is not about statutory services provided by the NHS and social care. The real care system is managed and delivered by individual people, their families and carers. The statutory sector needs to find ways of better supporting the informal care system. We should be, if anything, more concerned about how we do this than how we design new services, pathways etc.

The current focus on 'integration' illustrates these tensions – is integration about reducing the gap and tensions between two monolithic structures (health and care) or is it about an individual, their family and carers feeling like they are getting joined-up support to achieve their wellbeing goals? The weight of effort should be on the latter.

Local-level community organisations, can, when at their best, have personal relationships with local people, they operate those beyond the formal care system.

We have worked with local stakeholders in Sheffield and national partners and researchers to identify some key *ingredients* that support community-level prevention. These are: risk stratification; outreach work to those beyond existing support systems; a strong focus on helping individuals define and plan for achieving their goals; community-based assets that are tuned to the needs of people at risk achieve their goals; 'sort and support' assessments to quickly connect people to local assets, good quality *local* information and advice, and help to navigate the system so that people can get what they need and then get back out again!

We need to understand that this recipe will need 'cooking' differently in different communities. And, we need to challenge whether commissioners in town halls and CCG offices are best placed to get this right. Local communities and people working on the ground better understand the context and, with the right levels of trust and support, they can get the recipe right.



Paul Streets

Chief Executive, Lloyds Bank Foundation

'We need to rethink regulation – it's the death knell for small community groups. And we need to rethink the concept of scale. Community support is not about scaling up – it's about spreading out. And my call to SCIE is you need to shift to *how* it works, not *what* works.'

The Lloyds Bank Foundation supports small and medium charities working with people to break out of disadvantage at critical points in their lives. The

funding programmes offer short- and long-term grants. Support is adapted to the needs of small- and medium-sized charities that are committed to delivering work which breaks or prevents cycles of disadvantage.

As funders, foundation trusts have traditionally been the icing on the local authority fruitcake. But the shift from grants to contracts is particularly challenging for small local organisations. The risk is that communities with greatest need are at the most risk of losing support. For example, some areas have a combination of low levels of care services, low numbers of local charities and a high level of need.

Lloyds Bank Foundation Trust funds small, local, user-driven organisations and projects that tend to be holistic in their approach. These groups have courageous leaders who inspire institutional empathy. But the reality is that they are not scaleable or standard. As a result they can be hard to contract.

As a funder we advocate the use of grants to support these types of organisations. But we can shift the paradigm around so that grants can be as selective as contracts. If you must contract, we would have four wishes: an absolute bias in favour of local organisations; acknowledgement that they know best what is needed; work on the basis of trust, not as you would with commercial sector; shift the cost that you have into partnerships, learning and joined-up commissioning.

In order to develop a new paradigm, we need to: rethink the concept of scale. It's not about scale it's about spread of community and local support; rethink our approach to evidence for community-led organisations. They will never have the scale to make randomised controlled trials work; and rethink the model of risk sharing between commissioners and services. In the grant funding world, we share risks.

SCIE should invest in how to create learning networks between those who provide, those who commission or provide grants. Work alongside the major providers like Age UK, Women's Aid to share learning.

Views from the roundtable

‘As a new small, start-up enterprise, I faced big barriers especially regarding access to funding. And I have to do everything myself. What helped was following the needs of the people who would benefit from my service, and growing organically.’

Vicki Phipps, Founder/Director, Mindful Gifts

‘In terms of the evidence base for social care – it’s a question of horses for courses. Some areas of social care can benefit from randomised control trials (RCTs) but for many – especially innovative local services – this is not appropriate. SCIE and NICE both see user views as evidence.’

Amanda Edwards, Deputy Chief Executive, SCIE

‘The word that comes to mind is ‘preciousness’ – professionals believe that they know better. But people who use services actually know what does, and doesn’t work. We need to consider the development of practice-based evidence, rather than evidence-based practice.’

Tina Coldham, SCIE trustee and co-Chair of the SCIE Co-production Network

‘Staff within the health service do not understand the concept of co-producing integrated services with people who use those services. We need to educate health professionals on the basic issues of person-centred thinking. Collaboration and co-production is going to be the way forward.’

John Evans, Disability Rights, Equalities and Diversity consultant, trainer and researcher

‘Integration is not always the answer. There is a risk that if you integrate two poor organisations, you just get one poor one.’

Michael Bichard, Chair, SCIE

‘A focus on prevention is important, but there is also a wider question about the type of care and support we want around us irrespective of the impact on acute services. Most of us probably don’t want the most intensive forms of care, but would rather like more resources to be invested on building more informal and lower level support. To achieve such support we need to consider a different scheme where funding follows people’s active engagement. For example, in Scandinavia if high numbers of people are engaged in a mutual association, the state tends to back the association – relying on their judgement that it is a worthwhile activity.’

Ben Jupp, Director, Social Finance

‘Larger voluntary sector organisations can play a role in sharing learning. Turning Point’s Community Navigator model aims to reduce the demand for funded social care by connecting people to local community services and building capacity within the community for self-help. But we faced challenges. For example, one local authority said they did not want us to refer people to a community-run Time Bank on the basis that members were not DBS (Disclosure and Barring Service) checked. There is still a concept that the local authority has the ultimate responsibility.’

Gemma Bruce, Head of Research, Community Engagement and Co-production, Turning Point

‘We need courageous leaders in the public sector too – they need to be disruptive.’

Lord Michael Bichard, Chair, SCIE

‘Many professionals feel constrained by their roles. For example, when I was at Diabetes UK, the question was ‘Why won’t people take their insulin?’ But we started a campaign about ‘Eat what you like, and like what you eat’, providing people with more practical information about diet. One practitioner told me ‘At last I am practising the diabetes care I want to’.”

Paul Streets, Chief Executive, Lloyds Foundation Trust

Roundtable – Community-led social care

Chair

Lord Michael Bichard, Chair, SCIE

Speakers

Steve Chapman, Non-executive Director, Skillnet Group Community Interest Company

Matt Clifton, Chief Executive, Skillnet Group Community Interest Company

Joe Fowler, Director of Commissioning, Sheffield City Council

Helena Herklots, Chief Executive, Carers UK

Sian Lockwood, Chief Executive, Community Catalysts

Paul Streets, Chief Executive, Lloyds Bank Foundation

Attendees

Laura, Able, SCIE Co-production Network

Sue Brown, Head of Public Policy, Sense

Gemma Bruce, Assistant Director / Head of Research, Community Engagement and Co-production, Turning Point

Tina Coldham, Trustee, SCIE

Amanda Edwards, Deputy Chief Executive, SCIE

John Evans, Disability Rights, Equalities and Diversity Consultant, Trainer and Researcher

Lord Geoffrey Filkin, Chair, Centre for Ageing Better

Jane Green, SCIE Co-production Network

Jessica Harries, Cultural Commissioning Project Manager, NCVO

Ben Jupp, Director, Social Finance

Sukhvinder Kaur-Stubbs, Trustee, SCIE

Henry Kippin, Executive Director, Collaborate

Colm Munday, Care Act Marketing Coordinator, SCIE

Patrick Murray, Policy Officer, National Housing Federation

Vicki Phipps, Director, Mindful Gifts

Iris Steen, Head of Marketing and Communications, SCIE

Rich Watts, Programme Lead, Mental Health, National Development Team for Inclusion

Caroline Weston, Policy and Public Affairs Manager, Marie Curie Cancer Care

Community-led care and support: a new paradigm

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