The ‘Building the Connections - Setting the Agenda for Joined-Up Self Directed Support’ event took place on Wednesday 5th March 2013. The ALLIANCE, in partnership with CCPS, SDSS, ILIS, LCIL, IRISS and JIT, focused the event on initiating a dialogue on the potential implementation of Self Directed Support within an integrated health and social care system. The timing of this event was particularly significant given that the Social Care (Self Directed Support) (Scotland) Act has recently been passed into law and the integration of health and social care agenda is beginning to take shape. ‘Building the Connections’ was therefore an opportunity for people working across sectors and people who employ Self Directed Support to come together to discuss the potential benefits of integrated Self Directed Support between health and social care services.

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The Cabinet Secretary for Health and Wellbeing, Alex Neil was invited to give the Keynote speech on his vision for Self Directed Support in the context of an integrated health and social care landscape. His speech is summarised below.

The Cabinet Secretary began by telling the conference that Scotland has reached a crossroads for both health and social care. This is driven by three issues that mean radical change for Scotland’s support system:

1. The financial challenges and the need to do more for less
2. The challenges that come from having an increasing and ageing population
3. The inequalities challenge – too many people do not have access to or do not use services

He continued that it is very important that people have much more choice and control over their own lives in health and social care. However, because of the specialities in health it is much more difficult to extend the principles of Self Directed Support in the same way as has been done in social care, but it is very important that things in the health service happen with the patient and not to the patient. This should involve taking the end user and those closest to them with us when we can.

As an MSP, Mr Neil explained that he had met many people who have been let down by the system, particularly those with complex needs. Very often this is because people have been put into a box or a silo and not considered as an individual. One reason is that the system itself is organised in silos.

The integration agenda is often seen as trying to change two cultures; those of healthcare and social care. But, the Minister stated that there are not just two cultures within the NHS, there are many cultures and the same with local authorities. We need to mould these into one culture – “a Team Scotland approach”. Departments or organisations should not matter – what should matter is asking “are we doing the right thing for the person at the centre of the care strategy?”

Self Directed Support cannot be seen in isolation from integration and we cannot see integration as isolated from the person-centred strategy. It is all part of the same plan to improve the quality of service delivery.
In reference to delayed discharge, Mr Neil said that we should never compromise care for bureaucratic reasons. Without the bureaucracy we would not be able to deliver services but the bureaucracy itself has to be person-centred, not dictated to people. We are there to facilitate people to make their own choices, control their own lives and as far as possible to live independently in deciding what they want to do and what services they want.

When comparing local authority services Mr Neil said that there was, in his opinion, a close relationship between those of greater quality and those already delivering a high percentage of self-directed support in their area. Mr Neil expressed his belief that the level of Self Directed Support already available is a proxy indicator for their commitment to this agenda.

The Social Care (Self-Directed Support) (Scotland) Act is needed because some authorities have not been prepared to go down this road in the past. Legislation was needed to make sure it happens everywhere but local authorities do not need to wait for the legislation to come into force to make it happen. They have the power, what we need now is the commitment to make it happen.

The emergency care package is also part of this agenda and in particular the move towards supporting people at home, rather than being admitted to hospital. The role of all of those who work in the community is crucial to the success of this agenda.

West Lothian, for example, has had an integrated system for 8 years that started with adult health and social care and has organically grown to children’s services and now includes acute services. This did not need ministerial or political direction because they could see the sense of it and experienced the satisfaction of delivering better services.

This is not just about the public sector. The heavy involvement of the third sector is vital. We get most out of public funding and cost effective delivery is from third sector providers. Mr Neil wants to see the third sector, and the independent sector, not just involved in the delivery of services and contracting but actually involved in the design of services in every locality in Scotland.

All sectors must work together as a team, as Team Scotland, to deliver the best healthcare and social care for people in the future.
Personal Experience - Robert McPherson

Building the Connections was based on practical and lived experience of people who employ Self Directed Support to live independently. Robert McPherson’s presentation demonstrated the positive opportunities that can be attained through joined-up Self Directed Support:

- Robert began by describing the positive aspects of his support that have been achieved by him receiving funding from both health and social care services
- After being diagnosed with MS, Robert described having to readjust to needing care of an intimate nature and that Self Directed Support enabled him to employ personal assistants who could meet his needs in his own way
- Robert values the support he receives from personal assistants as it is preferable to having many different people providing intimate care and therefore it enables him to retain his dignity
- Robert highlighted the benefits of being able to purchase equipment such as his adapted wheelchair as he is able to travel independently
- Robert then went on to express the value he sees in residential respite which he visits on an annual basis, where he is able to meet with other people who have had similar experiences. However, he expressed concern over the future of this support due to current proposals to reduce the number of places available.
- Robert was commended by an audience member for speaking openly about his experience.

Mapping out the journey of Self Directed Support – IRISS

Judith Midgley is the Project Manager for Pilotlight at the Institute for Research and Innovation in Social Services. Pilotlight is developing a framework for providers to better facilitate a person’s journey through Self Directed Support. At the event, Judith took an interactive session inviting participants to consider a scenario of an older woman who, after having a stroke, wished to live independently in her own home. Participants were asked to consider themselves in the year 2020, where integrated Self Directed Support had been implemented, and to discuss how the woman could be supported to achieve her desired outcomes:

The aim of the exercise was to map out a pathway home, identifying the roles and actions of everybody involved in the individual’s support. Summary feedback was then provided to the room.
Participants commented that in order to complete the mapping successfully, the individual concerned was required to be present to give a fuller understanding of her wants and needs.

- A conceptual issue was raised that it may be that predefined pathways are too restrictive within a Self Directed Support framework.
- As the individual concerned began her journey in a health care setting, discussion arose around the role of inpatient planning for the person’s support upon leaving hospital.
- This led to queries around the responsibilities of different agencies to undertake the initial assessment of the person’s need. However it was debated that the assessment should be a continuous process that followed the person throughout their journey.
- High on people’s list to support this process was the need for a ‘navigator’ – an individual who would be the point of contact throughout the individual’s journey to engage with other professionals, facilitate their assessment, advocate for their best interest depending on their instructions and supporting the establishment of their Self Directed Support and management thereof.
- This was accompanied by suggestions of better, more frequent use of supportive technology that would enable individuals to be a part of the community in a more inclusive setting such as tele-care services, online financial management options and maintaining community links through Skype etc.
- Finally, participants made reference to community cohesion through utilising asset based support and informal support mechanisms that encouraged social inclusion through benefiting from collaborative arrangements, such as micro-providers or car sharing.
Allie Cherry is the Programme Manager for NHS Lothian Self Directed Support Test Site. In phase 1 of the test site, now completed, Lothian & Fife explored the opportunities for people to use additional money from the health service to meet their rehabilitation outcomes following a stroke or acquired brain injury, or a diagnosis of Multiple Sclerosis. Allie described the creative ways that people involved in the test site used their budgets:

- 50 people across Lothian and Fife were involved in the test site from rehabilitative services
- People used funding from £250 to over £4000 on a range of support mechanisms such as: gardening equipment, gym memberships, college courses and personal assistants
- The ways that people used their budgets supported their rehabilitative process, reduced the use of health services and increased their overall physical health
- Allie highlighted one experience in particular where a person with MS used horse riding as a mode of reducing the deterioration of their MS
- The key outcomes for the participants involved in the study included:
  - Individual outcomes – these included improved health and wellbeing, greater involvement, improved independence, reduced health service usage and, unexpectedly, improved physical health
  - Carer outcomes – these included improved relationships, reduced social isolation, reduced carer burden and reduced stress
  - Staff outcomes – these included a sense of reward and improved relationships with the individual, better partnership working with social care, greater awareness of resources out there and thinking more about practice and alternatives, but at the expense of extra workload and difficulties dealing with disappointments.

Allie explained that the learning to have come from the test sites focused on the benefits Self Directed Support could have for health were most appropriate in the community setting

- The phrase “the more acute the treatment the less appropriate Self Directed Support is” was an important lesson
- The case was made for using Self Directed Support as a safety net for those with fluctuating conditions by having a base fund available for people to access when they feel they require extra support.
Developing Joined-Up Budgets – A Discussion

Margaret Gallacher (Complex Care Sister: Health Perspective) and Margaret Petherbridge (Policy and Development Officer, Social Work Perspective)

- NHS Forth Valley / Falkirk Local Authority have provided a number of joint packages incorporating health and social care components over the last decade.
- The packages are paid for by social work who then invoice health for the health share.
- In the case of the complex care team in Forth Valley, community access and prevention components are built in to the packages.
- Support tends to be for people with complex needs - progressive neurological conditions or sudden onset conditions e.g. tracheotomy patients being supported by PAs to carry out suctions / tube changes.
- Health and social care components are the norm, but it could be that a purely health component kicks in, for example when someone acquires a chest infection.
- Personal assistants need to be up to the task – GPs input into training and skill development.
- Also need someone to case manage: a central port of call.
- Anecdotal evidence of hospital admissions decreasing, but hard to evidence.

Jack Blaik (Independent Consultant)

Jack previously worked with a Direct Payments team with a number of packages (25) jointly commissioned, but they were arranged and not evidently about supporting choice. The opportunities speak for themselves. However, a bottom up initiative will at some point meet top down scrutiny (which often may kill it). Unfortunately this was where his endeavours failed. They had a fairly robust process in place to look at submissions BUT:

Issues
- Strategic sign-up was the major problem.
- Plus lack of transparent eligibility criteria.
- Reviewing personal outcomes was devolved to social care, rather than joint and robust.
- The packages tended to be in response to a crisis.
- Each package on its own was commendable, but it did not sit within an overall strategic framework.
- Insufficient liquidity in health budgets to free up resources.
- It was hard to see how to fund this on a sustainable and scalable basis.

Observations
- Process is the same whether looking at a joint package or joint funding.
- Most important thing is knowledge of the person.
• Joint packages make sense when it is clear that the support that was in place no longer works
• Continuity and familiarity of care is increasingly less achievable through in-house services
• If people want to opt out of in-house provision they should be able to

**Challenges**

• Supporting people to make use of alternative support arrangements is very tough when both professionals and individuals are used to existing ones
• Scaling up joint support packages requires structural investment
• Feasibility - can all types of support be replicated (or replaced) by alternatives?
• Trust - professionals and individuals need to trust alternatives to the current system

**Workshops**

**Workshop A – Developing a shared framework (by Eva McCracken, Chris Bruce and Debbie Bayne)**

The focus of the workshop was to facilitate a discussion on the changes in policy and practice that have to take place in order to rebalance the power and redirect the focus of health and social care to a more outcomes based approach. The facilitators began by outlining:

• the importance of making sure that common objectives for health and social care are underpinned by a rights-based approach and the vision of the Independent Living movement
• that personalisation and Self Directed Support are means to achieve this, rather than ends in themselves
• there needs to be recognition that current budget allocation systems mean individuals are not equal in the process
• that it is important to maintain awareness of, and ways of fulfilling, collective outcomes, rather than just each individual’s own outcomes

The discussions from participants turned to a culture that would empower both professionals and individuals to have confidence in adopting the new approach that Self Directed Support requires. To do this, the participants highlighted that:

• This will be a huge shift in attitude and practice for people – professionals need the opportunity to really understand what an outcomes focussed conversation means, and the time and training to learn how to use it – training will be key, both CPD for people in post and initial training to make sure this practice is embedded from the start
• Why are there hardly any health professionals at the conference? What is it about this that is failing to engage with health?
  - Self Directed Support is seen as a social care issue
  - Differing language and attitudes is a barrier (e.g. health professionals are frustrated by being told not to call people patients). Joint training and professional formation are needed to address this.
• Revolution, not increments, is needed to bring about change.

Workshop B – Open for business (by Robert Dalrymple, Dee Fraser and Catherine Garrod)

This workshop considered the role of the market in facilitating choice in social care asking do markets generally lead to choice? Participants then went on to think about how a market could work in joint health and social care support provision identifying the pros of a market as:
  • More choice for supported people
  • Shift in power to the supported person - they are the ‘consumer’
  • More flexible and responsive support
  • Better quality - poor providers will have to close.

However concerns were expressed that a market might lead to a loss of services, choice, and an observation that low price does not always mean the best deal. Participants identified low choice markets (e.g. utilities) as not always giving the customer the best deal.

Participants then went on to discuss which NHS support/services would be appropriate for Self Directed Support. They identified services where there is a supply problem (e.g. long waiting lists) such as counselling and physiotherapy as a good area to explore. Participants excluded acute services from Self Directed Support arguing that choosing between A&E departments (for example) was not a meaningful or helpful choice. A few participants noted there is a fundamental ethical conflict between Self Directed Support and markets on the one hand and ‘free at the point of delivery’ NHS services on the other. One participant remarked that we would need a set of values and ethics for a Self Directed Support market and this would be key to informing market decisions and the inclusion of NHS services within Self Directed Support.

The workshop closed with a vote – markets for the NHS? 16/20 participants said yes (with some reservations) 2 said a clear ‘no’ and 2 weren’t sure.

Workshop C – Balancing power between services, providers and people (by Nathan Gale, Lisa Pattoni, Emma Collins and Kerry Musselbrook)

The workshop focused on issues of power between services, providers and people. We shared some of the lessons that we had learnt from our projects in IRISS and what we felt had enabled power structures to be broken down. Enablers that were endorsed by the group included:
  • Not having an agenda – to be truly co-produced – need to be open
• An activity that takes everyone out of your comfort zone – essentially take away the expert
• Support for practitioners – flexibility of role important
• A network model of management which blurs boundaries
• Neutral facilitation – create enough structure but do not direct
• Peer support workers give confidence to users, but also challenge behaviour and attitudes

However the most powerful and engaging part of the workshop was the lived experience shared by Nathan Gale. He described his experience of employing PAs and how being able to do this had affected the power structures in three main ways: between himself and his PAs, between himself and the local authority gatekeepers and between himself and his family. Much of the workshop was spent in Q&A with Nathan and the participants found this really valuable and enlightening. They were particularly interested in his perception of how being able to employ PAs has enabled him to have a different kind of relationship with his family and partner. His experience of acting as an employer of PAs was another key focus - how he effectively taught himself over time (through trial and error) to interview, employ and set effective boundaries.

Workshop D – The right amount of risk (by Emma McKendrick, Colin Young and Stephen Finlayson)

Emma McKendrick gave a very topical and powerful demonstration of the balance that had to be struck between ensuring her own freedoms and the potential risk her care can have on her PAs. Specifically she referred to time she has spent in hospital when she was refused her own support staff during her stay. This represented the problem that can rise between the separation of health and social care. This was followed by a DVD “Handle with Care” which showed young people identifying the issues of moving and handling and the impact on their own rights. Participants in the workshop were keen to promote their practice of ensuring that people who require support are enabled to attain their rights but highlighted that certain procedures and protocol policies prevented them from full participation on an equal level.

Workshop E – Whose agenda is it and who has the power to influence it? (by Robert MacPherson, Heather Fisken and James Blair)

The facilitators conducted an interactive seminar on ‘Whose agenda is it and who has power to influence it?’ The presentation highlighted the responsibilities and rights of individuals, providers and statutory authorities in social care/support. The members of the workshop exchanged views and experiences of involvement methodologies, including coproduction and we discussed some of the pressures and opportunities that people face. The facilitators developed the themes around partnership working from a human rights perspective.
Plenary Session

Each member of the panel was asked to give a summary of their views on the event and the main issues arising. In brief:

Craig Flunkert – Asked who in the audience was employed by NHS to which three people indicated. This, Craig pointed out was the drawback of an event which focused on the integration of health and social care as it is crucial to have health representatives engaged in order to progress the agenda. Building on this, Craig highlighted the need for the conversation to take place at a middle management level to ensure that everyone is signed up to a shared vision.

Beth Hall – Choice and flexibility outweighs the challenges of Self Directed Support. Self Directed Support now needs to be considered in the context of the integration agenda. Beth stated that to achieve the aims we need to make sure we can exercise choice over both halves of a package. Resources are tied up in buildings and eligibility criteria are still not perfect but we can make this agenda work. The focus now needs to shift from SDS to the integration agenda.

Allie Cherry – Making reference to her experience of the NHS test sites, Allie considered trust to be an important aspect of integration as professionals have to ensure that the new system is a combined investment. This can be achieved, she continued, by abandoning silo ways of working whereby health and social care focus on the outcomes of providing support to people in a personalised setting with the default being at home.

Emma McKendrick – Identified the few opportunities there were for disabled people to actively engage in a consultative capacity and called for greater investment in the consideration of the views of disabled people.

Following this, delegates were invited to pose questions to the panel. The themes of the questions revolved around:

- Marketisation in the health system – It was identified that while England appeared to be moving towards a market place within the health service, such as the introduction of clinical commissioning and personal health budgets, the Scottish government are reluctant to take that course for fear of privatising the health service.

- Engaging with health services – Concern was raised about the difficulties in getting funding from health services for interventions that are considered less clinical and therefore engaging in joint budgets may be more difficult than integration is promising.
• Health or social care bath? – The dilemma between funding arrangements according to which service is responsible to meet which of a person’s requirements continues to be a barrier for integrated budgets.

• Universal verses individual? – With health being accepted as a universal service, the issue was raised that the charging principle would challenge the concept of free health care. Therefore questions over how integration of health and social care would manage the differing policies to the benefit of people who require use of both.

Conclusion

The significant number of attendees and the volume of conversation throughout the event demonstrate the interest in the future of Self Directed Support within a health and social care context. Given the high profile nature of the event, with the Cabinet Secretary for Health and Wellbeing and representatives from the Scottish Government’s Self Directed Support team, there is clearly a mutual investment in this agenda. Presentations given from both professionals working in the health sector, the social care sector and individuals with experience of joined-up budgets exemplified the potential opportunities that can be achieved through collaborative responsibility between health and social care in delivering joined-up budgets through Self Directed Support. Meanwhile delegates raised concerns that the lack of health engagement would undermine the aspiration to develop an integrated Self Directed Support approach. At the heart of this approach there was common consensus that culture needed to shift from one that treats a person as a recipient of support to one that places the power in the hands of people who control their own lives.

More information

To discuss any of the information enclosed in the above report or to discuss the implementation of Self Directed Support more widely please refer your enquiries to the contact below:

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