

Partners' Council

Date: Wednesday 19 November 2008

Where: Copthorne Tara Hotel, Kensington, London

Welcome & Introductions

Ann Pridmore welcomed the following people to the meeting:

New members

- Sharon Flower, Carers UK
- Jim Couchman, Local Government Association
- Karen Harvey, Action for Children
- Patrick Wallace, Care who has sent his apologies today

Board Members

- Terry Philpot
- Mike Lauerman
- Brenden Keane

Observers

- Geraldine Campbell, Northern Ireland Social Care Council participation group
- Miriam Carp, Northern Ireland Social Care Council participation group
- Robin Hanau, Survivors Speak out

New SCIE staff

- Hannah Cooper, Publishing Officer
- Annie Stevenson, Programme Director for Older People

Photographer

Bob Fallon attended to capture images of the day and take portraits for members' biographies.

Vox pops

Anthony Avery, University of Brighton attended to record members' vox pops. He also recorded a number of videos of members talking about accessibility. These will be edited into a short film which will be used to help speakers and facilitators of future SCIE events make sure their talks are in plain English and accessible to everyone.

Quilt of light

A display called the quilt of light was exhibited. Dulwich Picture Gallery worked with residents from Nightingale House a Jewish Care Home to create the piece in celebration of Hanukah.

Activity since the last meeting

Involvement to Impact Awards

SCIE has been shortlisted for an award in the 2008 Involvement to Impact Awards run by the NHS Centre for Involvement.

Update: Tina Coldham, Partners' Council co-chair and a number of Partners' Council members attended the awards dinner on the Tuesday 25 November in Birmingham. SCIE was awarded second place.

Reflection meeting

A meeting took place with SCIE staff and a number of members to consider the progress of the council so far. It was a productive meeting and a lot of useful suggestions were made such as having a slot at the end of the day for members' feedback about the day.

SCIE update and introduction to the theme of the day

SCIE update

- Allan announced that former Partners' Council member Brenden Keane has been appointed to SCIE's board. He went on to highlight the important relationship between the board and the Partners' Council.
- A Review of social care agencies including SCIE, GSCC, Skills for Care is underway and will be completed in January 2009
- SCIE coordinated the winning bid for the Skills Academy for social care.
- A rough guide to personalisation has been published.
- SCIE attended the recent Party Conferences and continues to work to raise its profile and that of social care in the political arena. Allan noted that Government seemed to have acknowledged the status of social care by raising the status of the minister from Under Secretary to Minister of State.

Future funding of social care

Allan introduced the theme of the day and suggested that the day would provide a good opportunity to try to influence the content of the Green Paper on the future funding of social care for all adults. Allan went on to make the following points:

- It is important to gain consensus around what is meant by social care in terms of what it means for the public, individuals, people who use services and carers.
- Considerations around the future funding of social care should focus on developing a system that will last for the next forty to fifty years and has consensus from all the political parties and those who currently use services and importantly from all those who will in the future.
- The 6bn funding gap in the next 20 years predicted by the government should be looked at in the context of the current financial climate. This will need us to take a radically different approach than the way funding may have been looked at traditionally. This may be to consider the opportunities for employment that may arise from the need for readily accessible support services across the community. There maybe an opportunity to begin to invest in things that create jobs in a matter of months and not years as some of the bigger investment plans would do.
- The overall aim of funding social care in the future should be to enable a system of accessible support services for the community and protect those without the necessary financial resources.

Allan referred members to the questions being asked by the DH and invited them to consider them throughout the day. He closed the session by introducing a short film about the future funding of social care.

<http://www.youtube.com/watch?v=eFk6B-knzW8&eurl=http://www.careandsupport.direct.gov.uk/category/updates/>

Future funding of social care workshop sessions

In response to members' concerns about access issues and past over reliance on plenary speakers a new format for the meeting was piloted. There were 3 workshop sessions throughout the day and 3 groups running during each session. Each group was led by Partners' Council member speakers and a SCIE facilitator. Each group identified 3 key points to feedback to the panel in the afternoon plenary session. Panel members included Alexandra Norrish, Head of Social Care Strategy, Department of Health and Ian Loynes, Chief Executive, Southampton Centre for Independent Living. A report will be produced on the discussions that took place at the meeting and published as part of an ongoing series of Partners' Council discussion papers. SCIE has also incorporated discussions which took place throughout the day into a formal response to the consultation.

A summary of the feedback is as follows:

Views from Northern Ireland and Wales

Geraldine Campbell & Andy Pithouse led this group. Andy fed back the group's key points as follows:

1. **Integration between health and social care:** There was support for the model of integration of health and social care services in both countries. There was a discussion about whether this could apply in England.
2. **Diversity** needs to be recognised in the way social care is funded and arranged. This includes considerations of funding social care in rural/urban contexts.
3. **Injustice in social care provision** needs to be addressed: Some people feel they save and work hard but are just outside the framework or line of support that is provided through social care.

Perspectives of people who use services and carers

Linda Cooper & Ian Loynes led this group. Linda fed back the group's key points:

1. **Take a rights-based approach to social care provision:** Any future social care system needs to take a rights based approach. This should move away from people having to prove how badly off they are in order to get any support. This is demoralising and degrading for people. It also stops people using services that would potentially enhance their quality of lives. The notion of social care should not focus on dependency but on an idea of support that is more ordinary and liberating.
2. **Consensus is needed around the definition of social care:** A wider debate should take place not just about what social care means, but also how it may affect people and their family and about how this should be shared between them and the state.

Views from the independent and statutory sectors

Daphne Obang & Lizzie McLennan led this group. Daphne fed back the key points from the group's discussion:

1. **Take a values-based approach to social care provision:** There is no point talking about social care reform and what you pay and what models you go for, unless it was a values- based debate. The principles behind social care should be owned by the nation as a whole therefore there needs to be a national discussion about what social care is and the principles that lead its delivery.
2. **Market considerations:** There is a need to shape the market and consider that when a market is created for social care, there can be a tension between corporate organisations and user led organisations and their desired outcomes. This needs to be balanced. Without this kind of shaping, two very important groups of people remain invisible. One is the people who use the services and the second are the carers. An immense amount of money is estimated to be saved by the Government because informal carers are not paid
3. **Wider consultation with the public is needed:** so that, when they vote for elected members and make decisions, they are making an informed decision about who pays and how.
4. **Public attitudes to social care** need to be addressed via the media so that, we talk about the contract between the state and the individual and between the state and family networks, family in its widest sense.

Funding green paper panel (response & short introduction)

Alexandra Norrish informed the council that she is Head of the Green Paper Team at the Department of Health. Her team will be writing the Green Paper, running the public engagement events and public debate. The public engagement process was launched by the Prime Minister in May 2008. The consultation ends on 28 November 2008. Public engagement has two strands: the formal arranged events and a media campaign. The events have reached 1400 people so far and have been run with the help of MORI. Alexandra reported that they were keen to get as much media coverage as possible and reach as many people as possible. She therefore encouraged any members with links to publications or networks to forward details of the consultation on to them.

Alexandra went on to outline some of the issues that came up in the consultation. These echoed those fed back from the group discussions (considerations around a rights-based social care system, consensus around language and whether the term care should be used, debates around citizenship and who should pay for social care). Alexandra went on to say that what was coming out of the consultation was that people thought that we should be in a situation where no one is being left to fight through the system by themselves. However there was also the opposite view to this voiced by people who believed that the system was not relevant to them and therefore they should not be paying for it. Alexandra went on to say that in order for there to be a system where everyone has a responsibility and where everyone is contributing and everyone

is part of it, there is going to have to be quite a seismic shift in how people view the system. And so they would be putting out a range of different funding options.

Ian Loynes responded to the feedback from the discussions and made the following points:

- Many of the aspirations about reforming social care are a dream for most disabled people. Particularly people who are the most disempowered within our community and living in residential care. This is because many people are not aware that there is a debate going on, much less having any power to have any say about that.
- It is important to realise that not everyone can be part of the debate. However systems should be designed which will allow people to have a useful and beneficial life and to be empowered.
- If we are serious about people being able to live independently, then, the only way we are going to get that is by legislating
- 15% of the UK population are quoted as being disabled people. We are doing nothing about looking at the society's benefit through actually having those people economically active and not just working, but contributing in all other sorts of ways. If we made use of that that percentage then the benefit would far exceed any cost.
- General taxation has to be the basis for this kind of system. Arguments about scarce resources are a red herring. If it's about rights then, resources are irrelevant. In certain what might be called third world countries, disabled people's inclusion in society is far higher than it is in the so called civilised world which is a cultural issue. There is a need therefore to engage with society at large about seeing social care as an important issue.
- The only way we'll have a proper engagement and a proper understanding with society about the life of being a service user is about empowering them to actually force that debate to happen and to demand change. We need to create far more opportunity for disabled people and carers to collect together to form their own agendas and demand change.
- It is fundamentally about government leadership saying, we, in a civilised society believe that these people should have a basic right to have a basic level of existence and a basic level of freedom and opportunity.

Questions and answers

Members of the Partners' Council put the following questions to Alexandra and Ian:

Member: I'd like to ask Alexandra, when is the UK going to ratify the UN convention on the rights of people with disabilities, please?

Alexandra: That would help with some of this discussion, I feel. Not my area. Really sorry.

Member: There is a big bit of DH bit in that in terms of people's right to inclusive living and independent living and so on and social care.

Member:

The provision of social care still functions under a 60 year old piece of legislation, the National Assistance Act. Can we expect that legislation in this area might actually replace the National Assistance Act?

Alexandra:

Will we be looking at the National Assistance Act? Yes, we are looking at its most fundamental tenets. Will there be legislation? In two years time, we'll be looking at what a green paper then means and we'll have a white paper and then I assume, at some point there will be a bill, but it depends very much what the provisions are.

Member:

We recognise the difficulty of getting people to understand social care and get their heads round it. But at the same time, we don't like the word, care and can we replace it. This is a question really for both Alexandra and Ian about whether, at the same time we are going to sort of make the language more acceptable but make the branding and getting people to cotton onto what social care is about, more difficult?

Ian:

It's impossible to know what rights you have and haven't got. We've to be clear to people, about rights, even if they have no rights, let's just be honest about that. If they do have rights, let's make that clear and provide some kind of access to the legal system to allow that to take place.

Alexandra:

On trying to raise the profile of a term which actually people don't like and don't accept: This is why we've used care and support rather than social care, because, quite apart from the views that people have expressed to us from within, actually within the world of social care saying, they don't like the word, care. When you go out to members of the general public who have never had any contact with the system, they say, they can't stand the word, social, because to them it means, Social Security and it means having your children taken away from you. So, we put in. Care is seen as having all sorts of positive associations. We tried to find a middle way that would actually have something which was acceptable to both sides and which we can actually try and raise the profile of.

Ian:

I think there is an issue about language, but what I think people want is just something to happen, rather than just keep changing the terminology to fit. We used to call it consultation and we now call it coproduction. It may well be that things are improving in that respect. We just need to get on and make something happen and make something change, rather than debating about whether independence is a good word or a bad word.

Member:

You should have set more perimeters. Everyone knows that, it is going to be resources, resources, resources. Whatever happens to the National Assistance Act, there will be still be means testing in some form or another. We were assured of that before this exercise began by the Secretary of State. Can you assure me however that the green paper will be green and not green with white edges?

Alexandra:

On your point about setting more perimeters. I sometimes, in my moments when I'm sitting there facing a mass of documents would absolutely agree with you. But then, I think it was Daphne who made the point, please don't rule anything out. You can't please all of the people all of the time. We wanted to have a debate which would actually look at the key underlying principles of care and support, whether or not it is possible, in the end to follow whatever comes out of that. Whatever the changing economic situation is. We are in a completely different world now to what we were in May, to be honest. If, in May, we had set out, this is the exact perimeters of what we can and can't talk about then, the perimeters what we then set up in November would be different and the perimeters which we might set up next February might be different. So, if you are going to have a principle discussion, the judgement call we took on that was that we needed for there to be space to actually have that discussion. Whether it will be a green paper with white edges, blue edges, purple edges or pink edges, it's got to be green. It's absolutely got to be green, because the whole point of having the engagement process was that we look at the principles and we come up with a range of options and then there will be the more traditional process of a consultation on those options, following on from the green paper. Yes, absolutely, what we are in now is not the consultation process, which can then result in one option. It's very much about clearing the ground and trying to get a basic framework into place.

Member:

Are there any current proposals to change the charging systems for people in residential care such that they will be able to earn and keep some of their earnings and the underlying assumptions that are in there about people's abilities or otherwise to contribute to society whilst they are living in residential care?

Alexandra:

on the change of the charging system: really important issue. It's not one that I'm looking at. It's much more of an immediate issue. And so it's one of the ones which is on the side of the putting people first work. Essentially, the way we've divided the work on all of this up is that there is a team in DH which is doing the next few years, the next five years or so. And that's one of the issues that falls in that bracket. And then, the green paper is for the next decades. So, I don't know the detail, I'm afraid, although if we have a quick word afterwards, I can ask one of my colleagues to come back to you on that.

Member:

Given the emphasis on choice, why is it that direct payments cannot be used to purchase residential care

Alexandra:

Direct payments would fall in the short term what's happening over the next three to five years box, rather than in my box. So again, I can ask one of my colleagues to get back to you on that one.

Ian:

I think the concept of direct payments for residential care seems to me to be a contradiction in terms, direct payments are about independence and residential care at any level is not about independence. Everything has to start from a principle and that's my principled position on that, without going back on the resources thing a bit. I think the main issues on resources are about any time at the whim of the local authority, I could be chucked into residential care if they decided in their wisdom that my care package was too expensive, which as, Doug said, deprive me of the option of working with the realistic option of working would deprive me of everything that I've got that's important in my life and that's just basically wrong and we need to do something about that. We also need disabled people to either travel and move wherever they want to in the country and the fact that, I can't do that at the moment, without fearing of losing my care package is wrong and we need urgently to address that and then we can have a wider debate about whether resources are relevant or not.

Member:

It says in here, the document Care Support and Independence, May/November 2008 there was a series of events where the key issues will be discussed in further detail. These include a stakeholder event in every government region and the number of citizen events. And then it goes on to refer to spectrum of reviews from citizens, etc, etc. I'd like to know exactly how extensive it was in asking citizens?

Alexandra:

We had four citizen events. We had one in the north and south, east and west. I would love to have had dozens of these things. They cost about a £100,000. So, there is a limit to how many these events you can actually have. And that's because you have to pay for people's time and you have to pay for people to be able to access them. They are mightily expensive. So that's why we had four. A hundred people at each one, actually it turned out more about 110, 120 at each one. We gave Mori very careful, detailed scope of the groups that we wanted to be represented, so we broke it down by age and by gender and by ethnic group and by about a dozen other specifications. We actually mirrored the structure of the UK population to try and get a really representative group. The only specification we made was that the people who we invited must not have had any formal contact with the world of social care. The people who were on the stakeholder's side had already had the opportunity to come in through a thousand other different stakeholder events. That's why you wouldn't have got an invitation. But actually it turned out to be mightily difficult to find people who have had no formal contact with the services, because you find out that even if people aren't working in the area, everyone has had informal contact. But that's the methodology and that's how we did it and we made it as rigorous as we could.

Member:

The other thing is that, one thing that is of benefit tax on disabled people getting into work, which nobody has over many years been able to work out is, housing benefit. For example, I know people who have got part time jobs and earning the national minimum wage, in London and then, by the time their housing benefit has been adjusted by the income they get, they get £20 a week to spend after they've worked a ten hour week. I'm not saying people should keep all their housing benefit if they've got a full time job. But they should have a tiered system where people who do a part time job can keep some of their income, because I know people who work ten hours a week and they walk home with £20 a week by the time the housing benefit has been adjusted.

Alexandra:

That sounds like one for your five year team, again. DWP as well. I know that colleagues in DWP are working on the benefits issues. That's not the only example. There is so many places where one benefit works against another benefit or people starting to work on otherwise what they can claim and it's not just a problem in that particular area. It's not a tangle that I know how to find my way through, but I know it's one that's being looked at.

Chair's closing remarks

Allan said that SCIE's feedback to the Department of Health will be that one of the areas for consideration is the impact on working age adults. He went on to say that there is going to be a very robust and probably extensive response around the issue of older people and SCIE is particularly keen to pick up some of the things that have come out in today's discussions about that.

Allan responded to concern expressed about the salary for the Chief Executive of the Skills Academy by saying that SCIE wants the best possible person it can get for the job and has put the salary at £100K to reflect this. He encouraged members to apply and said that perhaps people with disabilities in positions like that might help to make positive changes in social care. This was exemplified in the work of Jane Campbell He also said that this is an opportunity to exercise leadership and leadership over the leaders in social care

Next meetings

20 March 2009, Copthorne Tara Hotel, Kensington, London (a joint meeting with SCIE's board)

Thursday 11 June 2009, Copthorne Tara Hotel, Kensington, London

Thursday 26 November 2009, Copthorne Tara Hotel, Kensington, London