

EAST SUSSEX LINK

The County's Local Involvement Network in Health and Social Care

**REPORT OF MEETINGS HELD ON
TUESDAY 3RD NOVEMBER
Council Chamber, Town Hall, Lewes
10.00am – 12.30pm Mental Health
2.00pm – 4.30pm Putting People First**

In attendance:

Maureen Lawrence (LINK Vice-Chair), Elizabeth Mackie (LINK Manager), Jan Cutting (LINK Development Worker), Val Young (LINK Development Worker), Claire Wright – notes (LINK Administrator).

Speakers:

Morning session– Mental Health: **Andy Porter**, Deputy Director for Social Inclusion, Sussex Partnership NHS Trust

Afternoon session – Putting People First: **Vicki Smith**, Work-stream Manager – Choice, Market Development and Engagement, Adult Social Care, East Sussex County Council

MORNING SESSION – MENTAL HEALTH

Welcome and Introductions

Elizabeth welcomed everyone to the meeting, made brief introductions and ran through the housekeeping rules. It was also noted that there would be a slight change to the morning's agenda.

Maternity Service Update

There then followed a power point presentation from Alison Newby and Jenny Phaire of the Maternity Services Development Group (MSDG). Copies of the notes of this presentation are available from the LINK office if required.

An opportunity was then given for anyone to ask questions.

Q - Is there a target with regards to the number of children's centres being set up and the facilities being provided in them?

A - The lack of Children's Centres is more of a problem in Eastbourne rather than Hastings which is an area of such deprivation more money and resources were put in earlier. Children's centres are a national project which is being rolled out over a three year programme, the centre in Hampden Park is to open shortly. It is planned that wherever there is a Children's centre we will aim to provide services from that centre.

Maureen Lawrence then indicated that there is booklet 'Maternity Services in East Sussex' which will be available from the LINK after the weekend which lays out what Jenny and Alison have been talking about. Elizabeth then introduced Maureen as the Vice-Chair of the LINK and as someone who is working closely with the Maternity Services Development Group. Details of how this fits in with the LINK are included on the LINK work programme copies of which are available on request.

Elizabeth explained that the next item on the agenda had been changed and introduced Andy Porter, Deputy Director for Social Inclusion of Sussex Partnership NHS Trust.

Andy explained that the Trust provides services for mental health, substance abuse suffers and those with learning disabilities across Sussex, which means we cover three Local Authority areas and three LINKs, he explained that the Trust is now a Foundation Trust and described the process that entails, followed by a brief outline of his responsibilities and a brief overview of the services that the Trust provides.

- Patient Advice and Liaison Service (PALS), there is a PALS officer in each of the three geographical areas, their role is to provide advice, information and support, and also acts as a trouble shooter for individuals to help them cut through the red tape.
- Patient Public Involvement – engaging with the public as well as with the three LINKs which the Trust boundaries cover (East and West Sussex and Brighton and Hove). This includes quarterly review meetings with LINKs and other key operational bodies, including our director of social care and partnership. This has proved to be very useful and has helped the Trust to develop strong user and carer involvement strategies.
- The Trust has introduced a postcard system with five questions, the outcomes of which will be published quarterly on the Trust's website. The Trust can come up with strategies on how to deal with any areas of concern raised.
- Equality and Diversity - the Trust believes that this is an important area and the Equality and Diversity Team has developed a large number of actions around both for the role of the employer as well as a service provider. These actions need to be taken around all six equalities which are: race, disability, faith, gender, sexual orientation and age. The Trust needs to meet legal requirements and to work towards eliminating discrimination. All Trust staff are given a one day induction. When services are changed they provide a detailed report on the Trust's website.
- Recovery is a way of working within mental health that puts service users at the centre of the services requirements. It is about living well with a mental illness and helping to develop training programmes for peer support workers, this is not new within mental health but it is new within the NHS. The Trust has a large volunteer support network of approx 350 volunteers.

The Trust is a big organisation which covers a large area that includes different clients and different age groups. Andy said that he would provide an update on various initiatives the Trust was involved with and then would open the floor to any questions. Any questions he could not answer would be taken away and updates would be provided in the report.

- Time to Change Campaign – This is a national campaign; its aim is to challenge the stigma and discrimination which mental health sufferers can face from family, friends and neighbours.
- Sussex Partnership NHS Trust has also been chosen by Primary Care Trusts in Sussex to receive funding to enable them to create a stronger presence at the primary care level, involving GP's, wellbeing and prevention. Also to include improved access to psychological services.
- Significant changes in the way the Trust works with Social Services from April 2010. East Sussex County Council will be directly managing social workers working with all age groups from 16 and including older people. This means that there will no longer be integrated teams within psychiatric units as at present. This has come about because it is envisaged that social work intervention will change when social care becomes person centred under the Putting People First agenda.
- The decision was made last week to close Woodlands, an inpatient unit in Hastings; this followed two suicides within three months. The ward has temporarily been closed and patients have been transferred to other units within the Trust. An investigation will now be carried out into what happened and how it can be prevented in the future.
- Better by Design, mental health and provisioning is a consultation process looking at health services within the community and how these services can be improved and become more accessible.

There then followed a question and answer session.

Q – Please explain the change of social work management as mentioned.

A – Community mental health teams were created about 10 years ago as a national initiative and generally social workers were seconded into these teams. However, this did not happen in East Sussex where they remained employed by East Sussex County Council but managed by Sussex Partnership Foundation NHS Trust. Now the management of social workers will go back to ESCC and their roles will change with the implementation of the Putting People First and the targets in relation to self directed support and direct payments.

It was commented - Putting People First (PPF) gives people the option to have an individual and personalised budget. I find in adult social care that some of the provisioning is not working as well as it should. Personalised budget within health, supported housing with support, therefore lots of changes affects housing, individuals and budgets.

Q – How are the initiatives developed by the Trust ‘equitable’ across the Trust?

Andy explained that the postcard scheme was hoping to be able to track this and so far they have received a very large response and it is only in its first month.

A myth busting session then took place and the meeting heard some of the top ten mental health myths.

- No. 3 – Mental health is a result of bad parenting.
- No. 6 – Depression is a normal part of the ageing process.
- No. 9 - Addiction is a life style choice and a result of poor willpower.
- Depression results from character weaknesses or flaws, you can just ‘snap out of it’ if you’re strong enough.

Rachel Kenny PALS and PPI Manager, SPNFT - people believe that they do not know anyone who suffers from a mental illness. However, the statistics point out that this affects 1 in 4 people, of these 90% will be able to manage their illness with the help of GPs and peer support. Of the 10% who do require some kind of overnight stay the vast majority are not labelled as ‘nutters’, this applies to only a very small percentage of people who suffer from mental health problems.

- The statistics show that 1 in 10 children aged between 5 and 15 will need support for mental health problems, and that 4000 people a year take their own life.
- A common misconception is that if you take medication you will be on medication for the rest of your life – this is not always the case.
- One of the myths that Time to Change is looking to address is that once you’ve had a mental health problem you won’t be able to go back to your regular employment but may possibly be able to get a job in Tesco’s.
- Another myth is that people with mental health problems carry out unprovoked attacks on strangers. It was commented that you are more likely to be attacked by someone you know or a stranger than a mental health sufferer and the statistics for such attacks over the last fifty years have not changed.
- We suffer from a press that does not use statistics and blow up any incidents out of proportion. The public’s inability to think for itself about risks provides very false perspectives.
- The reality is that a mental health sufferer is more likely to be the victim.
- Reference was then made to Post War Traumatic Stress Syndrome following the two world wars with the assumption that “we didn’t need it then so why now”

Jan Cutting, East Sussex LINK Development Worker for Hastings and Rother and lead on the Mental Health Focus Group, then gave a presentation on the following key areas.

Psychological Therapies

- Improving Access to Psychological Therapies, (IAPT) - have proposed changes been implemented and published? (as stated at Hastings meeting as a priority)
- NHS ignoring Voluntary Sector Psychotherapy services already in place

Counselling Services

- Availability of Counselling services in 'crisis' - some people experiencing up to three months' delay
- Lack of information to the patient about waiting times – is this because GPs are unaware of the waiting list?
- Period between diagnosis and treatment – some form of intermediate help

General ongoing concerns:

Prison Services

- Substance abuse and testing
- Help and support within the criminal justice system
- Misdiagnosis

Transport

- Availability of patient transport services
- Community transport
- Reliability of services

Diverse communities

- An understanding of cultural differences
- Community needs of LGBT (Lesbian Gay Bisexual Transgender)

Other comments received:

Childhood bullying

- Leading to mental health problems in the future

Accessing Adult Social Care Services

- Inability to access physical adult social care services, when you have both mental health and physical disabilities
- More specialised training for Community Psychiatric Nurses (CPNs) in physical disabilities

Unannounced inspections

- The need for truly unannounced inspections in order to reflect a true picture

The floor was then opened to any other concerns or issues.

Q - As a volunteer for over ten years it is astounding that the same concerns and issues that were being raised then are still being raised now. These are the same complaints and nothing seems to have changed.

Q – Part of the problem is down to a lack of communication.

A - Rachel Kenny responded - I share the same frustrations, things that are important, any restructuring that occurs; the bottom line is how we support these people. Transport is key and it is about thinking about issues from the point of view of the people who use the service. I will get some specific answers to the questions that have been raised today.

The floor then heard responses and positive suggestions on the following:

- Greater clarity is required around each issue and who it affects.
- Counselling – a review is required to allow better integration of services both new and existing.
- Prisons – At Lewes prison we have a governor who has worked within the health service and therefore has a greater understanding of the issues involved and has allowed greater liaison between services when leaving the prison system.
- Transport – Need to look at developing further community transport systems through the Parish Councils; several local initiatives have proven to be a success across the county and this is something that we need to look at developing further. There is also an issue for people in crisis as public transport is not always possible and for those that it is, it can be a nightmare.
- An open invite was then given to work with the LINKs to allow further review of these issues.

Presentation by Jackie Nicolson-Hook of WELMind

Jackie introduced herself as the Chair of Wealden, Eastbourne and Lewes Mind. Formally based in Lewes, last year it relocated to Eastbourne due to funding issues and is currently looking into relocating and downsizing again, also due to funding problems. As well as attending meetings trustees also have a proactive role in helping with office management and fundraising.

- Time to Change – its aim is to reduce the stigma around mental health. WELMind run two-day courses of workshops and exercises, based on the Mental Health First Aid (MHFA), originated in Australia, for people who have no previous knowledge of mental health issues.
- Reference was made to the way that the media cover mental health issues compared to physical health issues. An example of this was the difference between how Kylie Minogue coped with cancer compared to Frank Bruno coping with depression. We need to help people to recognise and identify the support that people need and encourage them to get the right help. The earlier the intervention, the speedier the recovery and the better the recovery.
- Applied Suicide Intervention Skills Training (ASIST), this is an internationally recognised programme we offer our services within and outside of our area and are often commissioned by other PCTs, most recently the MOD and the RAF.
- 'Bridges' is a ten week education course, after which people are able to set up new groups and become trainers; as a follow on they may also be able to seek paid employment. This is a peer led recovery programme designed developed and delivered by service users.

Jackie's closing comment was "WELMind is often contacted by carers with family problems, we endeavour to sign-post and support as much as we can. Many of our members have come to us from that personal background. It can be difficult to keep up with changes in trusts and hospitals; we are only experts by experience."

What are the key concerns that the LINK needs to take forward?

- Equality and diversity for diverse communities - does advocacy feature in this?
- Language support - accessibility not always about language but also about communication and understanding of cultural communities, reflective of training for all staff. Need more involvement from these communities.
- Accessing Adult Social Care services – primary and tier 2 – Are these difficulties in accessing at first point of contact or further along the line? People may be using some services successfully but still have other issues.
- There is a growing interest in advocacy from the LINK, in particular West Sussex are focusing on it as one of their priorities in the same way that

Brighton and Hove are focusing on mental health. Advocacy maintains a big issue.

- There is a new paper due to be published by the Mental Health Partnership Board about cultural differences and how mental health is perceived. Many practitioners are less aware of these issues than they should be.

A closing statement was then made by Maureen Lawrence thanking everyone for their input and tendering apologies from Janet Colvert, the LINK Chair, who unfortunately had another meeting to attend. She also stated that there would shortly be a new campaign by the Department of Health about LINKs, details of which will be on the website.

AFTERNOON SESSION – PUTTING PEOPLE FIRST

Elizabeth welcomed everyone to the meeting, made brief introductions and ran through the housekeeping rules.

LINK update from Maureen Lawrence, Vice-Chair

The LINK has an overview and an undertaking to be involved in the planning and development of health and social services. Networking is vital to be effective and make a difference and that is what the LINK is here for. The work of the LINK is available through the work plan, copies are available at this meeting, from the LINK office and online. The Health Overview Scrutiny Committee (HOSC) has commissioned the LINK to work together in partnership as part of their review of nutrition and feeding in hospitals. The LINK now have authorised representatives to be able to enter and view premises.

Maureen stated that she acts as the LINK representative on the Maternity Services Development Panel which is looking at the model of care. A booklet has been produced by Maternity Services in East Sussex and this will also be available from the LINK office in due course.

We have representation on various health and social care boards and our representatives report back on anything that needs to be noted, followed up or consulted upon.

Focus groups are led by members working on dentistry, older people matters and out of hour's services. We have recently set up a group of participant members to catalogue the information we hold into a library.

As the LINK develops it needs to become a more effective communicator; the LINK is about working in partnership with others, PCTs, Hospital Trusts, Care Quality Commission and various bodies in social care to work together to look at services, not about doing everything on your own because there is not the capacity to be able to do that.

To ensure that the LINK reaches all members of the community and all age groups, a youth event is currently being planned for next year.

Maureen also stated that she would like to thank the LINK host group for all the support and encouragement that the core group has received.

A myth busting session then took place and the meeting heard some of the top Putting People First myths.

- People feel they don't have a choice.
- There are plans to create a new national care system, the myth is that this will pay for care services the same way that the NHS pays for healthcare, therefore PPF is not needed.
- PPF agenda wants to get rid of residential care.
- PPF only works for people who manage their own money and support.
- People will be more isolated and more at risk.

Comment - These are not so much myths as fears that people have. From the feedback received where people feel they currently have a place of safety and do not face discrimination, they have a fear of becoming isolated. There is an increased risk of abuse, with no support to enable people to access these places. Myths with regards to 'isolation' - from the feedback from our client base, they have a fear of being isolated because their access to present services is a place of safety where they are not judged and do not feel discriminated. They will end up staying at home and withdrawing.

Elizabeth then asked whether people thought that this session should be called 'myths and fears'.

Comment - People fear that residential homes are becoming more like workhouses, or is this just another misconception perpetuated by the media?

Comment – With regards to Day Care Services people think that these will not exist anymore. If people are given more control, people get more choice then they will not need to access day care services any more; there is a fear from both clients and service providers that this service may disappear.

Presentation from Theresa Hodges of the Disabled Peoples Participation Group (DPPG)

Theresa explained that DPPG was set up in partnership with East Sussex County Council, Adult Social Care, the Children's Services Department and the Primary Care Trust in East Sussex, as a way of getting the views of disabled people on the services they use so as to know how to develop services in the future.

PPF have big concerns from disabled people; to begin with the advantages of PPF is that people can receive more self directed support and more control over how their social care needs are met (have a choice as to whether they stay the same or if support needs to be provided in a different way). People looking at receiving social care services will have a self directed assessment which can be completed on your own or with help. A budget is then given based upon this assessment. The idea is that the support given will be tailored to the individual's life rather than the system saying this is what we can offer you and this is what you will have.

Theresa stated that she was currently going through the pilot for this scheme, this is the beginning of PPF and her understanding as a disabled person is that she can spend on employing personal assistance, equipment and access to local facilities. One of the key things and concerns about PPF is that there will be the resource allocation system – money is allocated according to the answers in that assessment. This is about to be applied to Theresa from her assessment, when the pilot ends at the end of March. This makes her nervous as it means that the support she is currently receiving may go down as well as up and also means that she may not get more support but may end up receiving less. This is a general concern. Even though this process is about being more in control there is still an element of someone else making that decision about you. Planning the support that disabled people need in their lives can be very daunting. All your needs need to be reported in the assessment to make sure that they are catered for in your personal budget, so if the budget is allocated on the basis of someone's self assessment, what happens if you get it wrong, or leave things out? Many people will be unable to translate their needs adequately. There is a fear that self directed support means you have to do it all on your own. It is not clear who else can be involved, or is it a family member, is it Adult Social Services, is it someone from an organisation like ESDA? Will there be enough independent support out there to help with the assessment process? She agrees that services do need to be reviewed but there are two sides to this– are the individual's support needs the same? There is a feeling that you still need to prove your need of these services to meet the eligibility criteria, although there is a limit to what can and can't be funded. Resources are limited and the eligibility criteria may be tightened.

There are concerns around managing of the budget as you would have to contact social services if you wanted to spend your budget on something that was not pre-agreed, but who do you call? - someone who knows your situation or someone who works in the finance department with no knowledge of disabled people? Theresa considers herself secure in how to write about herself and her needs but no everyone is the same, many people will require more help. This pilot is still in the early stages, there are few concerns at the moment but there will be many more. If you are currently in receipt of agency services and move to a personalised budget you may not be able to receive the same level of care. DPPG

is here to make sure that these views are fed into other groups and networks which is why its involvement with the LINK is so important.

Val Young, East Sussex LINK Development Worker for Lewes and Wealden and lead on the Putting People First Focus Group, then gave a presentation on the following issues.

Personal Budgets

- People using personal budgets for other things
- Is part of personalisation to work with an individual to assess their needs and then see how their needs can be met?
- How will some service users deal with their own finances?
- Personal budgets are not suitable for everyone
- Are people aware they do have a choice?
- Enabling service users to have a choice and control is not all about personal budgets
- What is the difference between a direct payment and an Individual Service Fund (ISF)?

Implementation of Putting People First

- Guidance and advice is available to professionals with regard to national milestones, but how does the 'community' find out about them?
- How does East Sussex County Council compare to the rest of the country with regard to the national milestones set?
- Has the 'Pilot' scheme in Lewes started?
- At the Hastings meeting it was suggested that there should be a pilot scheme in Hastings – is there any progress?

General On-Going Concerns:

Safeguarding vulnerable adults

- Overall impact of vetting and barring scheme on individuals
- People having the right to 'manage' their own risk

At the Hastings Meeting in Public the following question was asked, response has now been received.

'Why don't you pilot personal budgets in Hastings issue.'

Comment: The Putting People First pilot scheme ought to be in Hastings rather than Lewes and Wealden - the population of Hastings is 86,120 which is one sixth of the population of East Sussex. There is a large elderly population, poverty is prominent and it is one of the most deprived areas in the country. If the pilot can work in Hastings, it can work anywhere.

The demonstrator site had already been selected by September and is now operating the new process with new service users. The decision to go with Lewes

was based on the enthusiastic staff team based there, stable management and that the area was performing well in respect of waiting times. Additionally they had recruited a social worker to the duty team and were well placed to "manage" more cases through the Duty and Assessment Team (DAT). Finally the locality directly provided home care service is managed from the same office and that will help to establish what communication is needed internally. So the decision was more to do with staff readiness to test out a new way of working, rather than the demography of the area. It is anticipated that the personal budget approach will be rolled out in all areas in April 2010. So Hastings will be involved from then.

Update from the Putting People First Team, speaker Vicky Smith, Workstream Manager – Choice, Market Development and Engagement, Adult Social Care, East Sussex County Council.

Putting People First and transforming social care for adults – meeting needs by enabling choice

East Sussex Adult Social Care is transforming the way its services will be delivered. Under the government's policy Putting People First, the Council is starting to implement a new way of working called Self-Directed Support. Self-Directed Support seeks to change the way the Council provides social-care to people who the Council assess as needing a service. It is designed to help people take control of their own social care budgets. These budgets will be known as personal budgets in the future - people will be able to use their personal budget to manage their own support and choose the services that suit them best using the money more flexibly.

The person will be at the centre of the planning process as they are best placed to understand their own needs. If people do not want to manage their personal budget directly, there will be a range of help and options that people can access to assist them in planning and arranging their care and support to suit them.

Whatever option they choose people will still have control over the services and support they need.

The Government expects to see significant progress towards implementation of Self-Directed Support in all councils by March 2011. The Council's success will need involvement from everyone in Social Care, including operational staff, service users, commissioners and service providers. More information will be available in the future regarding the changes.

More information on Self-Directed Support and what is happening in East Sussex can be found at www.eastsussex.gov.uk/puttingpeoplefirst

Alternatively people can contact the Putting People First Programme Team on 01273 335670 or peoplefirst@eastsussex.gov.uk.

“People want, and have a right to expect, services with dignity and respect at their heart. Older people, disabled people and people with mental health problems demand equality of citizenship in every aspect of their lives, from housing to employment to leisure”

Vicky then opened the floor to any questions or comments.

Q – I've worked in youth democracy for over ten years and have learning disabilities - why do you not start from education up rather than from adult social care. I believe that it is wrong to tell people they have learning difficulties at such a young age when neither they nor their parents are in a position to be able to understand this at such a young age. We need a system that works within education and provides one to one support.

A– The phase of young people moving from one service level that they have been used to as children and young people into the service that adult social care provides, this is called transitions. It is supposed to be streamlined as much as possible, something that we are very conscious of and what we will be doing with younger people as they come through into adult social care is employing this kind of approach, which is trying to identify from the very start what kind of outcomes they are after and what their lives would like to look like using support, planning and methodology; using the personal budget and a more innovative approach to what the solutions could be. If someone wants to get education, get a job, we should be putting a support plan into place that helps them to meet that. It is about identifying these kinds of things that I believe that PPF can help with.

Q – As much as the services mean well they tend to approach individuals with what they think that person needs rather than spending time listening to that individual saying what they need and want.

A – PPF is about dealing with those types of issues; we need to change the culture / attitude / language – all of this needs to happen to be able to get them to start to look at things through that person's eyes. The Council is particularly keen on the role of what are known as user led organisations, this means acknowledging people who have experience of the condition / disability, are actually the experts and there are organisations out there that are run by those experts and think that we need to actively help them provide information, advice, advocacy even more than they do currently, acknowledging.

Q – With all due respect I find that people who say that they are experts are not always right, the people who have the expertise are those people who have had experience of the issues, people like myself and Theresa they are the experts not the PCTs.

Q – Can I suggest that we actually ban the use of the word expert? I think that to try and move from the notion that the experts are the consultants, professionals etc simply by saying that we are the experts actually still presents something odd, you can get along without the word expert. With regards to the jargon buster, I do not think that the expression 'Jargon Buster' is terribly useful for ordinary people either. These are the terms in use. I have trouble with the difference between advocacy and brokerage. In both I have trouble with who is being your advocate and who is being your broker and are they people within PPF, which is I assume within Adult Social Care? Or are they people outside? Because if they are within are they not advising you and helping you with one hand and the other hand is the hand that has the money? And is there not some difficulty in that?

A– This is a very important point and may have touched on some of the questions that other people may have about this. It is not the first time that I have had a

question about this. It is fundamentally important that we understand that different people working inside statutory adult social care and outside in the voluntary sector, for example, have different roles around advocacy and possibly around support brokerage, support planning. We need to make sure that people know they have a choice and that they may choose to work with adult social care, with a social worker and they may find that service gives them what they need and what they want. We still need to make sure that we are working with the voluntary sector and user led organisation outside of social services to make sure that they are ready and willing to help provide advice. An independent advocate should be someone who is entirely independent of all financial aspects.

Q – Many people do not realise that in voluntary sector organisations, not all roles are carried out by volunteers. Another thing is in your last case study you were talking about someone who is using their personal budget to pay for transport to a hospital. In a situation I've come across someone who requires regular hospital visits and therefore requires transport to hospital, does not have anyone to go with them. Once at the hospital they are reliant on the hospital reception volunteers to take them to the necessary departments; what this person said was that it would be good if they could use their personal assistant to accompany them on medical appointments as they currently find that they are being called for their appointments by the consultant and they do not hear them. However, we were told this was a health need so social care shouldn't be providing that service. What I would say is that there needs to be less of a separation between health and social care - it should be more about this person being able to access their daily life. If using a personal assistant to go with them to an appointment is much more effective than someone at the hospital just guiding them to the correct department, then that is much more effective.

A – That is a really good point. The answer you were given effectively describes that challenge about health care services being free at the point of delivery and social care services currently being funded through the mechanisms that are limited and how you will notice that when PPF first started it was all about individual budgets and pulling in different strands of funding and it would all come around that one individual, which is massively difficult to sort out because of the way that funding happens. This is why we have moved to personal budgets at the moment and it is about adults being in control. There are various different budgets, the community care budget, supporting people funding – receiving working / housing related support and there is a big debate as to whether this can be included in the personal budget. Is this a good idea or not now that the ring fence around this has been moved. This is complicated but it is not for want of putting people in a scenario where the situation revolves around the individual, rather than the individual revolving around it.

Q – I just wanted to make a slightly different point but it is one which I think is a real dilemma for you. I was thinking about integration between health and social care, which is clearly a good idea as it's your aspiration to be universal. I think if you are dealing with some of the self funders and you are going to alter the culture very significantly, at a rough calculation there are over 70,000 people over 75 and probably 20,000 plus who are over 85, I am wondering how you are going to prioritise your advise between those who actually need a personal budget from you and those who need your help and advise in putting a budget together.

A – How are we going to manage the volume that potentially this symbolises and this is where we need to work in partnership with other agencies about information, advice and support and how we enable access to that. It will not always be appropriate for that to be handled by adult social care or people employed by us.

Q– Who should handle this then?

A – There are certain benefits to helping people in the longer term.

Q – In our experience trying to attract more funding will allow us to support someone to achieve an independent way of living, whether by having an advocate or a befriender or someone to mentor someone in order to be able to access and attend their hospital appointment. If, for example, their appointment is at 2pm, they have to rely on local hospital transport charity which will pick them up at 9am. We have been turned down for funding in recent months, as this is for mental health users but we are talking about social needs; the goal posts have been moved. The funding criteria is a holistic thing but we have been turned down with ‘sorry you can’t have your funding because that’s healthcare’. You try and argue your case but it’s so difficult. My concern with this is about the eligibility criteria, the assessment process stays the same but the goal posts have changed therefore your eligibility to receive that personalised budget and to achieve the service that you want to choose all of a sudden you do not get it.

A – Does everybody understand the eligibility criteria issue? Eligibility in terms of better access to care - each local authority gets to set their eligibility criteria for their services that they fund through the community care grant. We do this because we need to make sure that we target people who are most at need in the community and we need to ensure that we have enough funding to do that for all the care packages. What PPF expects us to do is make sure we balance our investments for people who fall outside of those criteria, i.e. people with low and moderate needs. There needs to be enough service provision with enough of a range of services to meet that range of needs. Obviously the challenge with that is that we still have to work within the same resource envelope that we have always had to work in and we need to manage how we use that money along that section of need. We have always had to do that; we will always wish to work with the local community to make sure that we do that in the best way possible. It is hard to prioritise as there is also an expectation that we demonstrate shifting of resources around that spectrum, which is why I mentioned supporting people as well in terms of a large amount of money. Eleven million pounds goes into housing related support that enables people to stay within the community, outside of the community care budget. It is how we join up our planning and commissioning of services in that area to meet as wide a range of needs as possible. This is not a simple thing to do, since PPF started we have also moved into an economic climate that is not that helpful and that will affect public services. We will do our best with this.

Q – I’ve been to the Brighton Big Care Debate which is a discussion about a green paper about funding and reallocation and how funding will need to change. The emphasis that it will put on everyone with the ageing population is going to be to turn it into a pot and they are looking at three options and the future of funding. More information is available on the website. The Government is aware there are a growing number of elderly people with a growing number of needs and there are

limited resources - how is this going to be funded and how is this going to be supported.

A- I know that the LINK are probably right on top of that and the options as they have been working with the East Sussex Seniors' Association and have been involved in the considerations around what those options feel like and what are the best ones. This does not change the on-going agenda around personalisation and the way that services need to be responding more. People have big expectations around the nature of the services that they want, this will be a change that will occur over a longer timescale.

Q- It could be that you take on the role as commissioners rather than providers; the way that funding is distributed is completely different and unrecognisable to what we have today.

A - PPF heralds that changing relationship already in that Local Authorities are commissioners of services and also allowing individuals to commission their own services. There is a whole relationship change between us and service provision.

Q - With the wide-scale abuse of the benefits system, the Government are talking about reducing / stopping benefits and forcing everyone into work. The minority are spoiling it for the majority who, due to access and disabilities find it very hard to get into paid employment. It may be a need to move to a situation more like the USA where legislation has changed so that all efforts need to be made to allow someone with a disability to be able to find paid employment and that the employer needs to do everything in their power to facilitate this happening.

A - With the learning disability commissioning strategies it is one of the agendas around where people need that support to get into employment and working with employers to enable that to happen. That is something that is very clearly on the agenda.

Q - I am still finding the 'Jargon Buster' a very useful document in many ways but suddenly it starts to talk about 'us' and 'we' and you think ' who are you?' What is PPF? Is it for example a budget? Is it a three year project/initiative and will the money disappear? Or is it something else and is it meant to be permanent? If it is one of these things, then it needs a very succinct explanation. Is the money ring fenced by government? Is it formula based according to the number of older people? I really think that it would be tremendously useful, even a first step for people who come to a meeting like this, to explain what PPF is.

A -It is a policy not just an initiative and because it works across so many areas of service and the change that it heralds implies many different changes about the way we in adult social care currently do things, it is hard to distil it. When we talk about 'we', the concord for that was signed up by some eighteen national government departments / agencies from health through to social care and the department of work and pensions. It is a partnership agenda that is being led by adult social care. It is complex but it is about saying that it is not just us that can do this.

Q - What we will be looking at doing is describing what happens to you as a service user when you come to the door and what should happen next so that people can see it in a very quick and easy read format. We will be publishing that

in due course. This information is all currently available on our website and we would appreciate all feedback.

Q – My colleague signed up to this event and does not have e-mail or access to a computer; there are a large number of people who do not have access and who are not computer literate, we forget that when we try to disseminate the information.

A – IT does not give the answer to everything and we do need to get support to people. We have physical information as well as having people available on the telephone. Website documents are starter documents and will be developed into a hard copy.

Q – When was PPF first launched? Only recently done in East Sussex but this is already being done successfully in other areas why is it that Adult Social Services are doing a pilot when this was initially piloted over two years ago?

A – Although the idea of the personal budgets was initially piloted two years ago the results of this were published in the Ibson Report (access to this report is available) which gave a detailed breakdown of people's experiences of this, but also highlighted a large number of issues. Therefore, all Local Authorities are different in their structure that needs to be considered before this can be implemented county wide. Plans are in place to meet the milestones set by the Department of Health. It is not without its challenges but we will get there.

Q - If people do not want Personalised Budgets but have Individual Service Funds (ISF) what plans are there to ensure service is value for money and safeguarding of individuals, etc?

A – This is something that seems like a good idea but may have a downside. We do need to work out the details of ISF's. We are building it into our requirements. We are currently retendering home care – making sure that there will be sufficient services and diversity. ISF working with home care agencies, how they make their services more personal, this is one element that we use to encourage this to happen. We need to put accounting mechanisms in place with those providers. One idea is that there is a support plan with very clear evidence of what money is going towards and making sure that providers are able to do that with us. Needs to be balanced out must ensure it does not increase cost or decrease availability of money for care or that the costs of managing money for those who cannot do it themselves does not decrease availability of funds for care.

Meeting Closes – Maureen thanked everyone for attending, for the high level of participation and also asked everyone to please try and stay in contact with the LINK.

A brief presentation was given by the 3T's project (Teaching, Trauma and Tertiary care) looking at the redevelopment of the Royal Sussex County Hospital in Brighton during the refreshment break. The 3Ts programme will replace some of the oldest buildings in the NHS and bring our specialist and trauma services together on one site to treat the most seriously ill and injured patients from across Sussex and the South east of England.

Patient & Public Design Panel

- Would you like to represent local patients on matters relating to the Royal Sussex County Hospital redevelopment?
- Have you been a patient (or patient carer) at the Royal Sussex County Hospital or Princess Royal Hospital in the past 12 months?
- Do you have a particular interest in building design and layout?
- Are you able to attend quarterly meetings?

If you can answer YES to the questions above, you may be interested in applying to become a member of the Hospital Redevelopment Patient & Public Design Panel.

If you are interested in applying to join the panel or would like to find out more, please contact:

Dr Anna Barnes, Associate Director, 3Ts Programme

Email: anna.barnes@bsuh.nhs.uk

Post: Office & Governance, Royal Sussex County Hospital, Eastern Road, Brighton, BN2 5BE