

East Sussex LINK

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

Your voice for health and social care in East Sussex

“Our Core Purpose is to work with partners to improve Health and Social Care services for the people of East Sussex”

YEAR 2 ANNUAL REPORT: 1 APRIL 2009 – 31 MARCH 2010

“Building relationships and partnership working”



East Sussex LINK

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The LINK Host is East Sussex Disability Association (ESDA) Registered Charity Number 1042071
Company Limited by Guarantee No. 2979027 Registered in England and Wales

Developing health and social care services around you

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This document is available in alternative formats – please contact the LINK office

1. Introduction:

We are delighted to introduce East Sussex LINK's annual report for 2009/2010

During the year we have carried out 5 meetings in public looking at the Transformation of Adult Social Care under the Putting People First Agenda and Mental Health concerns of those using services.

Our Host team held 9 summer road shows raising awareness of the Link and gathering views and experiences as well as delivering training for new people to become actively involved with the LINK.

We have had significant success this year in building relationships and working with our local Primary Care Trusts, National Health Service Trusts, Local Authority, social care providers and Overview and Scrutiny Committees to improve outcomes for people. Working in partnership we have looked at 3 key issues that you told us were important to you including: day services for older people, delays to breast screening programmes and food and nutrition in hospitals.

Our next big challenges are building upon those relationships to influence the commissioning of services, making sure people involved with the LINK have the necessary skills to be able to represent the LINK and visit services to continue to look at local concerns. This is what we will be concentrating on in the coming year.

Please sign up for our newsletter if you would like to be kept informed of our work. To do this simply contact info@thecountylink.net,
(See our alternate methods of contact at the beginning of this report)

If you would like to find out more about our work or get directly involved in it (in any way that suits you) please contact Elizabeth Mackie using any of our contact methods.

If your organisation would like to hear more via a presentation or by attendance at one of our events we would be delighted to hear from you. Please contact the LINK office on 01323 514510 or email info@thecountylink.net

1.1 Facts and Figures

Host Organisation:

East Sussex Disability Association (User-Led Organisation)
1 Faraday Close
Eastbourne
East Sussex
BN22 9BH
Telephone: 01323 514500
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Email: info@thecountylink.net
Web: www.thecountylink.net

What is the Host's Role?

The role of the organisation employed to support the LINK include:

- Telling the community about a LINK and encouraging people to get involved
- Advising the LINK in its work and activities
- Providing office support and helping the LINK to develop clear systems
- Managing the LINK budget and recording its activities
- Letting the community know about what the LINK is doing and asking for their views
- Reporting the progress of the LINK to Government (Department of Health guidance)

Current Host staff and contact details:

LINK Manager: Elizabeth Mackie

Email: manager@thecountylink.net

LINK Administrator: Debbie Harris

Email: info@thecountylink.net

LINK Development Worker, Lewes and Wealden: Vacancy

Email:

LINK Development Worker, Hastings and Rother: Jan Cutting

Email: jan.cutting@thecountylink.net

East Sussex LINK also has a website www.thecountylink.net where you can access up to date information and details of any reports.

The LINK is also on social networking sites:

Twitter: www.twitter.com/LINkeastsussex

Facebook: www.facebook.com/eslink

The LINK office is open from Monday – Friday; 9am – 5pm and paper reports are available at the LINK office:

Operational model of the LINK (Core Group)

Those involved in making relevant decisions are:

- Raymond Barrett
- Janet Colvert, Chair – Rother District
- Ivy Elsey
- June Jarrett
- David Lawrance – Lewes District
- Maureen Lawrence
- Anthony Moore
- Brian Rockell – Hastings District
- Margaret Stanton MBE – Eastbourne District
- Sue Weiner – Wealden District

And from the Community & Voluntary Sector

- Perry Aldred, East Sussex Crossroads Carers Forum
- Dominique Corbett Friends Families and Travellers
- Tim Furlonge Hastings Citizens Advice Bureau
- Alan Keys Vice Chair, Sussex Heart Network
- Ambrose O'Boyle Hastings Rainbow Alliance (Lesbian, Gay, Bisexual and Transgender Forum)
- Baldev Soni Sussex Indian Punjabi Society

The above 10 individuals and 6 members from the Community and Voluntary organisations make up the Core Group.

The Core Group welcomed Brain Rockell from Hastings as a member in December 2009 and extends its sincere thanks to Geoff Thomas and Maureen Lawrence for their valued contribution as Vice Chairs for year 2008/9.



The Core group 2009/2010

Next LINK election for the individual places on the Core Group will be October 2010.

LINK Representatives Authorised to enter and view services are:

- David Bold
- Janet Colvert
- Ivy Elsey
- Adrian Fairhead
- June Jarrett
- Liz Lash
- David Lawrance
- Maureen Lawrence
- Margaret Stanton MBE
- Vin Tapp
- Sue Weiner

1.2 Membership

Total number of participants Year 2 – 684

Total number of participants Year 1 – 175

Number of **active** members involved in Management Boards, sub groups, project groups, representing the LINK externally and Authorised Representatives – 40

East Sussex strongly advocates the flexibility of participants to dip in and out of the LINK and that the LINK is not a membership forum which people have to join in order to be involved. We have:

Informed Participants: receive information about updates and thematic interest including people who interact with the website and social networking sites.

Occasional Participants: respond to a particular issue, workshop or meeting and opt in, examples here are themed meetings in public with focus on Mental Health issues and Putting People First

Active Participants: have a journey to tell, initially respond to information they have read or picked up in the community, want to become more involved, attend Introduction to LINK workshops, access training to build up skills in representation and or visiting services, become involved in the core group/sub group activities.

The newly developed bespoke database tracks individuals and groups/organisations movements between the three categories. Current interest of participants is divided into:

Health: 32.1 %

Social Care: 28.5 %

Combined interest: 39.4%

Gender Male 215 Female 332 not recorded 137

Cultural, ethnicity, disability and sexual orientation statistical data

98.5% preferred not to say

(The host team are working towards using Stonewall publications to encourage individuals to disclose “about me” information and the importance of capturing this data)

The number of interested groups which represent under represented sections of the community.

600 groups and organisations receive information about the LINK

148 interact with the LINK through networks, meetings and representation forums.

The LINK is supported by a local User Led Organisation. It is also a member of the countywide representation forum SpeakUp, through these networks the LINK is able to ensure they are fully inclusive. Evidence how this works for the LINK will be highlighted elsewhere in this report. To reach our very diverse community the most successful method has been through networking and joint working.

1.3 About our Community

East Sussex has a population of just over half a million, covers an area of 660 square miles and includes the districts of Eastbourne, Hastings, Lewes, Rother and Wealden. It has a coastal strip of seaside towns and large rural areas.

Elderly people make up a significant percentage of the population. East Sussex has the highest percentage of very elderly residents of any county in England – including the two categories of over 85 and over 90 years old. It also has the second highest rate of natural decrease in population (more deaths than births) of any shire county in England, in relation to the size of its population.

Both of these factors impact the priorities for the LINK from gathering the views and concerns of elderly people, especially those living in rural areas of the county and facing the transformation of the way services will be delivered under the Putting People First Agenda.

The LINK has strong representation with the senior forums and voluntary organisations supporting older people in East Sussex.

Other populations and groups within our county that engage regularly with the LINK are:

- Sussex Indian Punjabi Society who attend monthly core group meetings.
- Lewes Prison Health, Equality and Diversity Team – the host team are setting up a joint working team to look at key findings:
High volume of prisoners with mental health issues, lack of psychological/talking therapies
people with learning difficulties in the criminal justice system being identified post sentencing
- Lesbian, Gay, Bisexual and Transgender (LGBT) Equalities Forum through Hastings Rainbow Alliance attends Core Group Meetings – key concerns logged include high rate of suicide attempts in young gay men
- Friends Families and Travellers attend core group meetings; assist the LINK with cultural awareness training and in facilitating visits to traveller sites. (Further reading on this work is featured as a Case Study page 23)
- Carers organisations attended 5 themed meetings in public
- Local mental health voluntary groups and organisations engaged with the LINK at their meetings in public looking into mental health issues across the county. This also provided opportunities to network with local interagency mental health user groups.



- Representatives from the Disabled Peoples Participation Group and the Involvement Matters team, (East Sussex County Council, Learning Disability Partnership Board) spoke about their experiences and journeys into personalisation under the transformation of social care services at a meeting in public.
“My journey into personalisation” Tim Sully at Meeting in Public 25th February 2010

- Locality based Interfaith Forums – engage with the LINK via representation at quarterly meetings
- Young people are beginning to engage with the LINK through social networking sites and via local Parent Link networks.

In East Sussex the most successful methods used to engage with people for this year has been:

- Themed Meetings in Public
- 120 people attended Mental Health focus meetings (made up of statutory partners individuals and groups and members of the public)
- 13 completed questionnaires to voice their comment in advance of the meetings

Key information gathered:

- Access to Psychological Therapies – both for people living in the community and the prison population
- Access (Community Transport) to Day Services Review, people felt it was a vital resource and the review needed to be extended - Achieved through work with Adult Social Care
- Closure of Woodlands Unit – Statutory Partners used the LINK as a platform to update the community on any progress/outcomes of the Investigation – the key concern voiced was where and how other users had been placed across the Trust’s geographical boundary without consideration to travel, cost and maintaining contact with family and significant others.
- Implementing the new Dementia Strategy
- Those with mental health in the criminal justice system (including people with learning disabilities)
- Exploring new ways of engaging with consumers through technology – Patient Opinion a web based interactive site for people to tell their story or leave a comment. The Trust, who are signed up to this resource can also respond directly in real time to those comments and the LINK is alerted to comments being posted in our area.
- The added value from hearing personal stories as a way of engaging is being recognised as a valuable resource of involvement.
- A further 127 people attended Putting People First focus meetings (made up of individuals, statutory partners and groups)
- Summary of what people told the LINK – the attendance from Putting People First team at all these meetings has been appreciated; the information provided was excellent for professionals but not “user friendly” for the average citizen

Representation at meetings, Boards - Total 61 meetings attended by 18 active participants confirmed to represent the LINK.

Networking, where strong networks exist, using those forums to share information, check for duplication of work, gather views and experiences and feedback outcomes - Total 73 Networking meetings

1.4 Training

The host team support the LINK to identify and deliver training to participants as part of a Training Sub Group. This includes members, Active Participants and the Host Manager. The LINK also has a budget for meeting their training needs within their allocations for governance arrangements.

Training this year covered workshops on:

Introduction to LINKs Workshops – Total of 5 Workshops throughout the year for individuals and organisations just starting to engage with LINK and wanting to learn more about how and why to get involved. This training is facilitated by the Host team and LINK members – Total of 28 new active participants/representatives accessed these workshops.

Understanding the Role of LINK Participants/Members and the Host team – Development Day, building relations – April 2009

Understanding the Role of Authorised Representatives (to enter and view services) two sessions have been delivered by the Host team with LINK members – bespoke modular training offered to individuals interested in becoming an Authorised Representative. Total of 6 new Authorised Representatives.

LINK Enter and View Train the Trainer – Host Manager attended to deliver in house training to LINK participants.

Support from N I C E for LINKs June 2009
Establishing dialogue and discussion with NICE



Safeguarding Vulnerable Adults two sessions have been accessed this year (This training is accessed through the Local Authority and is mandatory for all Authorised Representatives wishing to enter and view services)

Equality and Diversity Training – March 2010 (for all participants and members who take part regularly in LINK activities)

Understanding Cultural Differences of Gypsy and Roma local population was offered to members and participants and the voluntary sector <http://www.gypsy-traveller.org/>

Deprivation of Liberties Awareness Training – identified for Authorised Representatives to gain a greater understanding of the Mental Capacity Act when entering services.

Working Together to Safeguard Children

LINKs and Care Quality Commission Working Together Workshops – members and host team are part of the LINKs Advisory Group

2. What we did

2.1 *Building Relationships and Partnership working.....*

Examples where the LINK continues to develop relationships with statutory providers and where these relationships have led to joint working:

Mike Wood, Chief Executive, East Sussex Downs and Weald Primary Care Trust and Hastings and Rother Primary Care Trust commented:



‘We enjoy a close and productive relationship with the East Sussex LINK and really value the role they play in ensuring that the views of patients and the public are fully taken in account by the local National Health Service.

For example, over the past year members of the LINK have been involved in inspecting local community hospitals to ensure high standards are maintained, and also taken a keen interest in areas including children’s physiotherapy and screening for a number of diseases.

We look forward to this continuing in years to come as we face the challenge of working to improve the health and well-being of people living in East Sussex, whilst using our resources as effectively as possible.”

Keith Hinkley, Director Adult Social Care, East Sussex County Council added:



“The LINK is an important voice for service users, carers, residents and voluntary organisations on health and social care issues that matter to them. Having an independent organisation scrutinise how we plan and deliver services is new to Adult Social Care and is welcomed.

Two years after its formation there are now many examples of how the LINK is working effectively with us. These include:

- A LINK representative on all our Partnership Boards which plan services and provide strategic leadership across East Sussex.
- During 2009/10 the LINK, through discussion and presentations at their local ‘Meetings in Public’, has helped us get the messages across to the residents about significant changes to our service delivery as we implement the national ‘Putting People First’ agenda and has ‘busted’ some of the myths about what this would mean.
- Clear protocols have been agreed which provide evidence that effectively working together has resolved care issues, both for individuals who need help and groups such as addressing transport issues for those attending a day centre in Crowborough.

In the coming year we look forward to working with the LINK to help it further develop the skills and experience base of its participants and widen the range of people and groups who are involved. The organisation now has the structure in place to increase the scope and range of its work.

Adult Social Care continues to support LINK activities; listen to what residents say about health & social care; improve our services in response to issues raised; respond to requests for information; and promote the LINK and its activities to service users, carers and staff at all levels”

The Commissioning Agenda

Decisions within the National Health Service on which services to buy, how and where they will be provided are now made by primary care trusts. They operate under World Class Commissioning guidelines and are required to consult public and patients as part of this process. Closer cooperation with social services to improve care in the community and developments in practice based commissioning are factors in moving some health care away from the district general hospitals.

In the autumn the Government instructed the National Health Service to plan for reduced spending of 15-20% over the next three years. Against rising demands that represents a serious funding problem with potential threats to front line services.

The LINK has representation on the Patient and Public Involvement Steering Group and Practice Based Commissioning Committee for both Primary Care Trusts but regards the level of consultation on planning of the services to be commissioned as somewhat deficient. We believe there is a role to be played in representing the views of the community when difficult and complex decisions are being made. Accordingly, we are involved in discussions with the Primary Care Trusts about how we can best contribute directly or in association with other patient groups, where they may have greater expertise. We expect to move forward quite quickly and would welcome hearing from any LINK members, who have relevant knowledge to offer.

Alan Keys, Vice Chair

South East Coast Ambulance Trust (SECAMB)



Working across geographical boundaries

As a LINK we have engaged regularly with SECAMB as it moves towards Foundation Trust status.

SECAMB has a pro-active policy of public engagement including its own Public Opinion Group and Patient Liaison Group. David Bold and Brian Rockwell have now been appointed by the LINK as their appointed representatives to SECAMB. We are conscious that SECAMB, covering all areas of Sussex, Kent and Surrey, also embrace 7 LINKs in these counties. Many of the issues on which the public take an interest, cross these boundaries.

East Sussex LINK has recently agreed to spearhead an Ambulance Focus Group engaging with all of the LINKs in the South East Coast Counties so that LINK's collectively, as a statutory body independent of the Trust, can develop its relationship with SECAMB and discuss and promote common issues.

We shall meet with other LINKs shortly to develop this proposal.

Brian Rockell LINK Core Group, Hastings District

The Health and Social Care Act 2008 says the Care Quality Commission must listen to and work with LINKs,

LINK members and the Host Manager are part of the CQC LINKs Advisory Group and contribute to meetings and workshops nationally as well as working locally with our area manager sharing information about services. Local Assessors have also attended our meetings in public as part of their role in listening to communities.

The work of the Advisory Group includes:

- Helping to develop how health and social care services are regulated.
- Having regular contact with local CQC staff
- Looking at ways to work with CQC on driving improvements i.e. Comprehensive Area Assessment - contributing information about care services to overall assessments of the quality of all local services
- Suggest ideas for managing information sharing with CQC and LINKs

An active LINK participant has been recruited to the recently formed Voices for Equality Diversity and Human Rights Group with the commission.

Jose King, Involvement Officer. Involvement Team, Care Quality Commission adds

“The Care Quality Commission has a statutory duty to 'have regard' to the views of LINKs. We welcome this duty.

In 2009-10 we have been establishing contact with all LINKs across the country, to start to work together to identify poor care and drive improvements in health and social care services. LINKs have started to work with CQC in a range of ways, including:

- contributing to our consultations
- joining our national LINKs advisory group (the East Sussex LINK Manager is a member of this group)
- submitting information from local people about the performance of health services to help us register and monitor the National Health Service under our new registration system, including enter and view reports
- informing service inspections of adult social care
- building local relationships with CQC staff in their area to agree ways of working together and sharing information.

CQC is starting further development work with LINKs in 2010-11 to explore better ways of sharing information between us, and to involve LINKs more directly in our assessments. We recognise the important role that LINKs play in making sure the voices of people are heard and taken into account in improving health and social care services.”

2.2 *How those relationships led to Joint working.....*

Maternity Services Development Panel



East Sussex LiNK agrees with the Primary Care Trust's commitment to the development and delivery of flexible, accessible, individualised maternity services to meet the needs of women, their babies and families.

As Representatives in the community we have been part of the Development Panel with a brief from the Reconfiguration Panel, set up by the Secretary of State, to ensure Consultant led services continue to be available on two hospital sites (Eastbourne DGH and Hastings Conquest).

This Panel has met for over a year and the document "Maternity Services Strategy 2009-2012" has now been published. In order to put the plan into practice a succeeding body called 'East Sussex Maternity and Newborn Services Clinical Implementation Group' is now in place and is responsible for ensuring the recommendations happen.

We are pleased to report to you that LiNK has a place on this group and will continue to receive and make your views known at that meeting. LiNK will continue to liaise with the East Sussex Overview and Scrutiny Committee (HOSC) who are providing external scrutiny and challenge where necessary.

As always, we need your views and comments if we are to truly represent you: there are a number of ways in which you can contact us contained within this Annual report.

Maureen Lawrence, LiNK Core Group Member

The Productive Ward

For the last two years I have been visiting wards in both the Conquest Hospital and Eastbourne District General Hospital to see how this initiative can help the staff to make best use of their time and resources, to work together as a team to identify practical ways of making life in their ward better for the staff and most importantly the patients.

Wards can bid for funding to make changes which will then be monitored to ensure that they are of lasting benefit. Good ideas are shared at a monthly meeting and staff visit each other across both sites to share good practice. The intranet site enables wards to make use of furniture and equipment which is redundant to another ward.

Some of the changes I have seen over the two years include vastly improved storage systems which have added greatly to a more professional appearance have freed up space in corridors, and resulted in a huge increase in the time that Health Care Assistants can spend on patient care.

Increased analysis of patient falls has resulted in changes of positioning of beds and equipment and additional sockets to prevent trailing leads as wards have an increasing amount of electrical equipment in use.

Monitoring of drug storage and in some wards a quiet space to restock the trolleys has been valued. Others have revamped patient record storage, making life more efficient for both Doctors and Nurses.

As this is a rolling programme, and each ward can use its own initiative to meet its own needs, each ward makes its own improvements in the order that is appropriate to its own specialism and its own space. Pace of change and priorities vary accordingly and all are carefully monitored by the two project managers. As with all such projects, the more the team puts into it the more they and their patients benefit

What is my role in this? Well, I learn a great deal about the details of managing improvement in busy wards in a time of great changes in Health delivery. When staff talk to me about what they have done over the last six months, it is great for them to realise how far they have improved and the importance these efforts make to their patients' wellbeing as well as their own and I am able to tell others. This is just one kind of monitoring that the LINK undertakes and sets out to be positive and informal.



Janet Colvert, Chair LINK Core Group, Rother District

Patient Environment Action Team:

Visits were made to Eastbourne District General Hospital and Conquest Hospital in Hastings as part of this years planned inspections.

LINK also monitors action plans for implementing recommendations as part of this role.

An example of where the LINK has used those relationships to share the views of the community and to influence service change and improvement.

Sussex Partnership National Health Service Trust

In recognition of our Independent role Alan Keys has chaired the Sussex Partnership Trust's consultation.

2.3 Management of Information



At the LINK we have always listened to local people and are aware of what they want us to do.

It became apparent that many people did not have access to a computer and those who did prefer to read from a printed sheet to enable them to absorb the content of the email and attachments.

With this in mind we decided to develop an Information Bank which would be accessible and indexed and would empower all the LINKs in their work.

We have purchased two laptops available to the computer literate at all times and 31 sectioned box files all numbered and sub-divided.

Titles include minutes of all Primary Care Trust Board Meetings – Maternity Reports, National Health Service & Local Strategies, Public Patient Involvements, Community Centre and Volunteer Partnerships, SECamb, etc.

Reports are archived after 2 years and replaced with current papers.

Every month a list of reports back from accredited LINK representatives are emailed and made available in the Information Bank.

Margaret Stanton, MBE, LINK Core Group Member, Eastbourne

3. Summary of Activity

At the LINK we have always listened to local people and are aware of what they want us to do.

- Continue to visit hospitals and care services in coordination with our partners and when appropriate, responding to the community.
- Devise and offer training to enable more citizens to become actively involved in their LINK
- Provide diverse forums for Commissioners to receive the views and comments about services from local people
- Ensure patient and public involvement is embedded in action plans in a timely and jargon free style
- Inform the community of the outcomes achieved by LINK
- Using our networks and representation to influence providers and commissioners of services

3.1 Requests for Information

Adult Social Care:

Communication Portal established for LINK and Adult Social Care to log communications:
Taken from Quarterly Reports 2009/10

- IR 32/33: Hospital Car Parking Fees – ongoing
- IR15: Health inequalities for people with learning difficulties – outcome LINK Representative offered place on Learning Disability Partnership Board.
- Requests to see policies embedding the Duty to Involve:
Duty to Involve: Guide 18 25/08/09 - Response with East Sussex Consultation & Engagement Strategy & brief for strategic review of engagement 02/09/09
- Requests in relation to Issue IR67 Day Care Services for Older People Review – Is the LINK satisfied the views of individuals, families, carers and the community regarding directly provided services, including the Isobel Blackman Centre, have been taken in account?
- Consultation plans relating to changes in older peoples day services during their own directly provided services review
- Request for Putting People First demonstrator site to be in Hastings 13/10/09
- LINK powers to enter & view
Request to visit Moreton & 2 other day services 19/11/09
- Transport Issue re day centre in Crowborough 10/12/09 - this was resolved once the issue was highlighted to Adult Social Care.

Providers of Primary Care Services:

Communication Portal established within Primary Care Trust to log communications:

- Clarification on delays for Children accessing Physiotherapy
- Fair access to screening programmes for those without a permanent postcode:

What policies are in place to ensure all members of the community are included in screening programmes?
How is information disseminated to travelling communities at sites in East Sussex?
What is the take up rate?
Is this the same process for all primary health preventative initiatives i.e. the LINK have generic feedback around Bowel Screening, would travelling communities be included in that programme, the same for Breast Screening etc.
- Access to National Health Service Dental Services for those without permanent postcodes
- Access to walk in centre for homeless people
- IR47 Infection Control MRSA and other Hospital Acquired Infections (Request a summary of MRSA and other Hospital Acquired Infections statistics and outcomes)
- Information regarding delays to breast screening programme
- IR68 Urgent Care Action Plan being implemented without patient and public involvement
- IR61 GP Appointments_– inconsistencies with appointments booking scheme (pre Book System being available) Is this happening in other surgeries? LINK are currently researching this issue.
- Requests for copies of quarterly minutes from Patient Advisory Liaison Meetings

From Providers of Mental Health, Learning Disabilities and Prison in reach services:

- Transport to Mental Health Day Care Centres in East Sussex –in partnership with Adult Social Care this issue was investigated and transport services were agreed to be continued.
- Requests for updates on the closure of Woodlands Unit in Hastings, together with proposals for the service provision when unit reopens. Updates provided at LINK meetings in public.

Good practice protocols for joint working are currently being reviewed

3.2 Enter and View

Review of Nutrition, Hydration and Feeding in Acute Hospitals



East Sussex LINK has been commissioned by the Health Overview and Scrutiny Committee to gather the views of people in our local hospitals regarding the food they are offered during their time in hospital. This is a very interesting piece of research and 8 Authorised Representatives are pleased to be carrying out visits to Stroke, Medical and Surgical Wards at Eastbourne District General and Hastings Conquest Hospitals. The visits are being made at all the mealtimes, breakfast, lunch and supper in order to get an overall picture of acceptability of the food and drink provided, together with the important issues of presentation and assistance to patients to consume their food and drinks.

During May the Report will be written and presented to the Health Overview and Scrutiny Committee, Nutrition and Hydration Review Group, for their consideration.

This review is being undertaken in conjunction with Brighton & Hove and West Sussex LINKs who will report back to the Health Overview and Scrutiny Committee in June to give an overall picture for Sussex Hospitals.

Pilot Visits to Adult Social Care Older Peoples Day Services



Visits were made to 3 older people's day services as part of a wider investigation to gather views and experiences from individuals who use the service, their carers, staff and in Hastings the voluntary and community sector about their involvement in the consultation process

Services visited:

- Uckfield Club – Uckfield
- Phoenix Centre – Lewes
- Moreton Centre – Hastings

3.3 Reports and Recommendations

Three reports are currently being drafted:

- Joint Review with HOSC looking at Food Nutrition and Hydration
- Older Peoples Day Services – consultation process
- Delays to Breast Screening Services for 9,500 women in East Sussex.

3.4 Working with Scrutiny Committees

The Chair of LINK Core group sits on both the Health and Adult Social Care Scrutiny Committee.

- There have been no formal referrals to Overview Scrutiny Committees this year.

Key Achievements: LINK continues to build on the established relationships as evidenced by members:

“This year, East Sussex Health Overview and Scrutiny Committee (HOSC) has built on its good relationship with the LINK through joint work on our review of nutrition and hydration in hospitals. The group of local councillors leading the review has commissioned LINK representatives to visit hospital wards around mealtimes to assess the support patients receive to eat and drink. The findings from the visits will help HOSC assess how well hospitals meet patients’ nutritional needs and make any appropriate recommendations for improvements. This project is a great example of the HOSC and LINK roles complementing each other and working together on behalf of East Sussex residents”

Councillor Sylvia Tidy, Chairman, East Sussex Health Overview and Scrutiny Committee

Adult Social Care Scrutiny Committee and the LINK

“The Adult Social Care Scrutiny Committee has valued the input it has had from the LINK co-opted member over the past year. By having a direct contact with the voluntary and community sector across East Sussex, the co-opted LINK member has been able to bring a different perspective to discussions at committee meetings and provide an insight into the local issues that residents are raising with the LINK.

As a member of the review board scrutinising the development of the Community Equipment Service, the co-opted LINK member has also been active in raising issues as this work has moved forward.”

Councillor Joy Waite, Chairman, Adult Social Care Scrutiny Committee

HOSC RURAL HEALTH EVENT – November 2009

Investigating National Health Service delivery in rural East Sussex

East Sussex Health Overview and Scrutiny Committee (HOSC) wanted to build a clearer picture of rural health services provision and accessibility. It wanted to determine whether services are meeting people’s needs; the extent of local support in place to facilitate access to services; and whether there are any issues that merit further investigation.

East Sussex Link was invited to present comments and experiences gathered relating to rural health issues.

The aim of the event:

- To investigate how health services are planned, commissioned and delivered in rural East Sussex
- Give delegates an opportunity to feedback and suggest areas for attention, including more in-depth review by HOSC
- Showcase what is happening in East Sussex and other counties

Presentations included:

Rural East Sussex Jeremy Leggett, Chief Executive, Action in Rural Sussex

Jeremy provided an overview of the key challenges facing rural communities in East Sussex. He covered three main themes: choice, access and rural deprivation. He highlighted specific health related issues e.g. rural health inequalities and the impacts that trends and shifts in health services are having.

Community Health Services in Rural East Sussex, Alice Webster, Head of Unscheduled Care, East Sussex Community Health Services

Alice covered the complexity and key challenges of providing community health services in rural East Sussex e.g. accessibility, economies of scale, viability, quality, liaison with health agencies based outside East Sussex.

Rural service users' experiences – Host Team, East Sussex LINK

The team presented a range of issues and concerns gathered by East Sussex Link from health service users in rural East Sussex. Issues include: the (in)accessibility of mental health services; out of hours GP services; information through National Health Service Direct; non-health service decisions that affect people's health and wellbeing e.g. social housing; and transport.

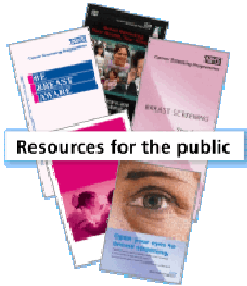
A Report is included in HOSC Annual Report

<http://www.eastsussexhealth.org/pdf/Annual%20report%200910%20FINAL.pdf>

Following on from this event, the LINK team were invited join a partnership Navigator services, Action in Rural Sussex, Pensions Service, Hastings & Rother Primary Care Trust and Age Concern to pilot a series of rural road shows throughout the county to continue to gather comments and experiences.

4. Demonstrating Impact

4.1 Delays in Breast Screening



In the autumn of 2009 the LINK became aware that the government requirement of a 3 year cycle inviting women for Breast Screening had been seriously delayed in several areas of East Sussex.

Following communication with the Primary Care Trust it became apparent that the problem had been ongoing for many months and was the result of a move in premises, problems in recruiting radiographers, a requirement to provide additional training for newly appointed radiographers and some issues around administrative delays.

The issue was picked up by BBC in April 2010 and we were invited to provide interviews for local TV and radio. Following some high profile reporting the LINK met with the Primary Care Trust where we were given reassurances that in spite of the ongoing difficulties of recruitment and training the Primary Care Trust are confident that all delays would be resolved by September 2010. The agreed actions include:

- The problem would be escalated to the Chief Executive
- Women will be informed if further delays occur
- A static scanner at Eastbourne District General Hospital would be used to prevent further problems with the next round of screening
- The LINK would review progress in October 2010 to check that all delays have been overcome and there is no slippage in the new screening round.

Sue Weiner, Core Group member

<http://www.cancerscreening.nhs.uk/breastscreen/>

4.2 Added Value of LINKS powers to enter services:

During a planned coordinated visit to an Older Peoples Day Service, the lead representative identified that the service being provided as a temporary measure, was not ideally suited to the needs of the older people using the service and took appropriate action to request a review of the service. This request to the service provider was complied with fully and the LINK and services provider are discussing options for the future.

4.3 Networks working together to achieve good outcomes:

Not all in our county would acknowledge East Sussex Fire and Rescue Service (ESF&R Service) as having a key role to play in preventing vulnerable adults in the community becoming a statistic.

The LINK has promoted East Sussex Fire & Rescue Service campaign “Who Cares?” when networking and planning public engagement events.



As a direct result of networking the LINK has used these networks to assist 2 very vulnerable members of the community in critical need, to receive the help and support they needed.

[East Sussex Fire & Rescue Service... Who Cares? Campaign](#)

4.4 The Value of LINKs supported by a user led organisation

In East Sussex the LINK is supported by a local User Led Organisation (ULO). This has attracted national interest from other User Led Organisation's. The host team were invited to facilitate a workshop at the National User Led Organisation Conference in March 2010 to share good practice with other organisations and to demonstrate by supporting a LINK, how they can benefit the community.

It is the values of ULO's namely peer support, valuing diversity and human rights and the wealth of knowledge ULO's have within Third Sector networks and how they can be replicated in building a LINK, which benefit the operation and structure of the LINK.

These values add to those already adopted by LINK e.g. Nolan Principles, transparency and equality.

Article Published:

LINKs and User-led Host Organisation - a vision from East Sussex

Introduction:

The vision is close to being realised.

East Sussex Local Involvement Network (LINK) Host organisation, East Sussex Disability Association (ESDA) meets twenty of the twenty-one strands required for User-led Organisation (ULO) status.

A user-led organisation is one where 'the people the organisation represents, or provides services to, have a majority on the Management Committee or Board, and where there is clear accountability to members and/or service users.' However, there is no one model for ULOs,

What does this mean for LINKs?

Putting into practice the values and functions of a ULO, especially around equality, diversity and human rights in representation on the Core Group.

In East Sussex the Governance Group is formed of ten individuals from across the diverse geographical areas of our county with an interest and experience in health & social care services and six members from the Community and Voluntary Sector.

The six members from Community and Voluntary Sector add to the diversity of the Core Group with representation from Sussex Indian Punjabi Society, Friend Families and Travellers, Citizens Advice Bureau (Social Policy coordinator) Lesbian, Gay, Bisexual, Transgender community, Sussex Heart Network and a local Carers' Organisation.

Collectively they all share the same passion about involving local people in the planning, commissioning and delivery of local services to achieve quality outcomes.

The value of local knowledge, direct experience and peer support that ULOs can provide is now widely accepted and our LINK recognises the many advantages of working in partnership with a User-led Organisation and harnesses that partnership as a platform to achieve those quality outcomes for people.

Another key factor in building a cohesive LINK on the foundation of a ULO is a proactive Local Authority that embraces change, opens doors to new ways of working and shares the same vision that local communities determine and shape the future of health and social care services

Elizabeth Mackie, LINK Manager (Host)

4.5 Case Study

Working together on community issues

Friends Families and Traveller Project Remit with Department Of Health:

<http://www.gypsy-traveller.org/>

Introduction:

Friends, Families and Travellers is a nationally recognised voluntary organisation which serves the whole spectrum of the Traveller community, both traditional and new, settled and on the road. We run a national helpline covering evictions, harassment, planning, employment, benefits, education, health and civil rights, discrimination and legal representation. Friends, Families and Travellers are also active in community support, research, monitoring, mediation and policy development at local and national levels.

Friends, Families and Travellers have been awarded three year funding by the Department of Health to work across three Strategic Health Authority areas to help join Gypsies and Travellers into the consultative and participative mechanisms being rolled out by the National Health Service. The project will be led by myself, Liz MacPherson, Zoe Matthews (Health Improvement Manager) assisted by Avril Fuller (Community Outreach Worker) and Chris Whitwell (Director of Friends, Families and Travellers).

The Strategic Health Authority areas selected are the South East, The South West and the East of England. We will also be working with partner organizations in the South West and East of England areas, specifically the Ormiston Trust in the East of England and Travellerspace in the South West.

I am hoping to pass on this information to all the Primary Care Trusts in each region and identify one or two in each area that are willing to work with us on an intensive basis to assist the objectives of securing better Gypsy and Traveller engagement in Local Involvement Networks, commissioning Fora etc. We will then seek to identify, train, support and mentor individual volunteers from the travelling communities to participate in the various National Health Service involvement mechanisms. They will also be supported by our partner organizations. In this way we hope to develop 'centres of excellence' for Gypsy and Traveller involvement, that can then share the experience and knowledge of the good practices that they have developed with other Primary Care Trusts in the Strategic Health Authority area. We have some modest funding to support the individual Gypsy and Traveller volunteers and to pay for the input of our partner organizations.

How we are working with LINKs regionally and nationally.....

My name is Avril Fuller my role is Outreach Worker. I sit on the Brighton and Hove Steering Group and take part in the Sub-Groups, also an Action Group.

Outreach and Engagement is being achieved via joint home visits with LINK Development Workers. We aim to go out once a month and to engage Traveller's on the Sub or Action Groups. Development Workers give a training presentation about the LINKs to groups of Gypsy/Travellers that are looking to engage with LINKs Groups in local and other Regions.

The feedback was very positive with Travellers wanting to engage with LINKs in local and other regions.

I have also engaged a Gypsy/Traveller, Dominique, onto the East Sussex Core Group. I sit jointly on this group, too.

I will be looking to establish Outreach visits with the new Development Worker to engage with local Gypsy/Travellers.

The engagement so far with the West Sussex Stewardship Group, has been via joint home visits with Development Worker for the LINKs Group, we are looking for Travellers to form a Sub Group to put forward their Health and Social Care concerns.

In the South West of England FFT met with a Community Development Worker, Penny Dane, from Devon. Penny was already doing developmental work and awareness training. One of her trainings, with her colleague Lizzie Issac who is a Gypsy/Traveller, was to the Devon LINKs Group; they have since been in contact with us. Penny and local Gypsy/Travellers have produced a Resource Pack about local services.

We engaged Penny to deliver training on PowerPoint Presentations for four Gypsy/Travellers; this was Cultural Awareness Training (Train the Trainers). I have met and spoken to the Taunton LINKs Workers, and in turn introduced them to some of the local Romany Gypsy/Travellers.

I have been in contact with the Bristol LINKs they have done joint outreach home visits and their engagement with the local Gypsy/Travellers was achieved by visiting with a local Community Development Worker Annie Crocker, who is a Gypsy/Traveller. The local Primary Care Trust is producing an A-Z directory on services. We have made contact and identified travellers that would like to engage with LINKs in this area, I also have contact details for South Gloucestershire LINKs Group.

The other area is Cambridgeshire and Norfolk; again we have Gypsy/Travellers that would like to be part of the Cultural Awareness Training (Train the Trainers), also to engage with their local LINKs Group.

Supporting LINKs to work with our community

Friends Families and Travellers (FFT) were invited to deliver a Cultural Awareness Training Session about Gypsy and Traveller History and Culture to the East Sussex LINK Core Group on the 1st March 2010.

Delivering the training on behalf of FFT was myself, Liz MacPherson (Training Officer) and Avril Fuller (Mental Health Outreach Worker) We were also lucky that Dominique Corbett, Romany Gypsy and member of the LINK core group was also able to help us out at the training despite being heavily pregnant with her fifth child.

Everyone started by introducing themselves at the beginning of the session, and explaining a bit about their background and how they had come to be a member of the

Core Group. It is always interesting to hear how people's different paths have ultimately led them to the same place!

The session began with a PowerPoint presentation which comprised of ten slides. I gave an overview of Gypsies and Travellers history, and their culture and beliefs. The slides then looked at the chronic social exclusion that Gypsies suffer from, looking more in depth at one strand of this which are the very poor health outcomes that are typical in the Gypsy and Traveller community. The Core Group were amazed to hear that life expectancy in the Gypsy Traveller community is between 10 and 25 years lower than the settled community, and that mothers are 20 times more likely to experience the death of a child than mothers from the settled community.

The presentation then focused on Gypsies and Travellers experiences within the health care system, and how it can be difficult for them to register with GP's, often having to depend on Accident and Emergency or attending a clinic as a temporary patient where there is no continuity of care, and no access to healthcare screening. Lastly the presentation focused on what works with regard to improving health outcomes for Gypsies and Travellers, and how East Sussex LINK could take their work forward in this area.

After the presentation the Core Group split in to sub-groups in order to discuss what they had just heard and seen. They were also very keen to hear from Avril and Dominique about their own personal experiences as Sussex Romanies, and how Dominique juggled being full-time mother of 4, alongside training to be an accountant and acting as the Treasurer to Marshlands school PTFA.

Following a lively discussion the group watched a DVD called Sticks and Stones which touches on the lives and experiences of a range of young Gypsies and Travellers. The Core Group were shocked at how frequently these young people were on the receiving end of racist taunts and attacks, both at school and in their home towns and villages; and the point was further reinforced because the majority of the film was shot in Sussex and featured local Romany Gypsies.

All in all it was a very productive and interesting morning, and I would like to thank the Core Group for their interest and what they themselves brought to the session by way of insights and reflexions.

Liz MacPherson April 27th 2010

5. Our Finances

INCOME AND EXPENDITURE

The host report all financial activity quarterly to the Local Authority.

Financial report 2009/10

Income	£
Income from Department of Health via ESCC	200,000
Project reserves brought forward	19,724
General reserves brought forward	9,285
Total Income	229,009
Expenditure	
Start up Costs	4,167
Staff	101,214
Support Costs	14,788
Running Costs	29,525
Governance	19,589
Projects	3,231
Total Expenditure	172,514
Excess Income and Reserves over Expenditure	56,495

This years LINK accounts show that there was an excess of income and reserves brought forward over expenditure of £56,495.

Reserves Brought Forward

General reserves brought forward of £9,285 were allocated as follows:

Start up costs (Database)	4,167
Running costs	4,667
Governance	451
Total allocation	9,285

Project reserves brought forward of £19,724 were allocated as follows:

Offset against overspends on running/governance costs	16,493
Spent on projects in year	3,231
Total allocation	19,724

Reserves Carried Forward

Reserves carried forward for the year will be as follows:

Project Reserves carried forward	31,895
General Reserves carried forward	10,400
Total Reserves carried forward	42,295

Budget compared to actual performance during the year

Due to pressures on budgets during the year, it was necessary to reallocate budgets between some budget headings in order to meet the costs of operating the LINK.

There was an underspend on staffing costs during the year due to one Developmental Worker and one Administrator vacancy at differing times of the year. These have been recruited for in 2010/11 and appointments are being made. In the interim, contract staff have been employed and the net underspend on these costs has been carried forward to 2010/11 to cover increased costs regarding staff recruitment.

There was an overspend on governance costs and some of this was covered by an offset of project funds as it was felt that some of the governance costs were related to specific projects.

There was also an overspend on running costs which was again partly covered by the offset of project funds.

Monies spent on projects during the year were covered by project reserves brought forward. As a result no expenditure came directly from the reserve for projects and so the 2009/10 budget of £31,895 has been carried forward so that it is available to spend on projects in 2010/11.

6. Next Steps – Looking ahead to the next 12 months

- Influencing the Commissioning Cycle: A key priority would be to demonstrate how public involvement can have a measurable impact on commissioning outcomes
- Identifying lead personnel to engage with LINKs around providing information to inform Joint Strategic Needs Assessment are a priority.
- Strengthening working relations with Care Quality Commission
- Build upon relationships established to work together with our partners in achieving better outcomes for people.

The LINK has commissioned the following project looking into Wheelchair Services

WHEELCHAIR REVIEW - MAY 2010 - JANUARY 2011

Following complaints by wheelchair users and carers of long waiting times; restrictive eligibility criteria; lack of opportunity for user involvement; difficulty in contacting the service; poor repairs and a lack of understanding of the fact that without their wheelchairs service users are unable to participate in normal life the East Sussex LINK has responded by setting up a review .

The Review Report will be titled "WITH OUR WHEELCHAIRS WE ARE ENABLED: WITHOUT OUR WHEELCHAIRS WE ARE DISABLED"

Members of the Steering Group are Matt Colliard, Shirley McCall, Pat Newton and Kevin Towner with Pat Newton as Lead and Principal Contact and Elizabeth Mackie as Project Manager. A research consultant is to be appointed.

Recruitment of participants is through newspaper publicity, Facebook and the newly launched LINK Wheelchair Users Web Forum. The Wheelchair Service has agreed to support a mail out .Evidence will be taken from the Wheelchair Service, wheelchair users, their carers, organisations and care homes. Recruitment closes September 2010 and consultation closes November 2010.

The review is particularly considering and making recommendations on current performance against relevant performance indicators

- The ability of the Wheelchair Service to respond to the varied needs of people with disabilities.
- Whether requirements for involvement of service users and partnership working are met
- Whether current process management and multiplicity of work centres adversely affects performance
- Whether sufficient recognition is given to the effect of wheelchair service performance on the lives, health and welfare of disabled people.
- Whether service policies, funding and management successfully prevent health inequalities for disabled people

Consultation is by questionnaire, interview and the LINK Wheelchair Users Forum and runs between May 2010 and November 2010. The report will initially be presented to the LINK Core Group and then as report to the community in February 2011 and finally to the East Sussex Improving Life Chances Board in March 2011. Because the impact of additional funding allowing the employment of an additional therapist will not be apparent during the consultation period a supplementary report may be required later that year.

The Web Forum is at

<http://uk.groups.yahoo.com/group/LINKWheelchairUsersForum> and the introduction to the Forum is -

Only wheelchair users and their carers can fully understand that a malfunctioning wheelchair or lack of a wheelchair at all is just as disabling as any physical impairment. Without our wheelchairs we cannot have a normal life or take our proper place in the community. We read of initiatives to improve the lives of disabled people but we know that we have no chance at all unless we are supported by a well resourced efficient wheelchair service. We read of care pathways but are they accessible pathways or are they rocky roads full of pot holes?

Pat Newton.26.Apr.2010.

wheelchairs@thecountylink.net

Further Projects the host team is researching for the LINK include:

- Health inequalities within the prison population (including people with learning needs in the criminal justice system)
- How services meet the needs of people with long term conditions

Please contact Elizabeth Mackie, Manager with your comments or experiences.

7. Summary

7.1 What we achieved

- Sharing views and comments of local people at 5 meetings in public
- Recognition for supporting LINK as a User Led Organisation
- Raising the profile of delays to breast screening programmes for 9,500 women
- Representing patient and public views on the reconfiguration of maternity services
- Undertaking commissioned work from Health Overview and Scrutiny Committee to enter and view services
- Piloting visits to Older Peoples Day Services
- Working in partnership with Health Overview and Scrutiny Committee on rural issues
- Strengthening relationships with Care Quality Commission
- Working in partnership with Voluntary & Community sector on rural issues
- Representation and recognition on boards and partnerships throughout the county
- Increased number of participants receiving information about LINKs
- Building capacity of volunteers to actively become involved with LINK

We will continue to develop and encourage further partnership working to achieve better health and social care outcomes for local people.

Thank you to EVERYONE for their involvement in East Sussex LINK this year and we look forward to another successful year.