



Lambeth



2009-2010

Involving Disabled and Older People – Annual Report



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User Involvement Worker -
Disabled and Older People

Introduction

Older and disabled people have strong views on topics such as transport, housing, access and disability discrimination but often find it hard to get someone to listen to them or take responsibility for addressing the questions to which they need answers. The role of the User Involvement Service is to strengthen the voices of older and disabled people in Lambeth and to ensure that service providers hear them.

of the Local Strategic Partnership – Lambeth First.

Lambeth First brings together all the major statutory authorities that work in Lambeth together with local business, the local voluntary and community sectors and service providers. Its role is to enable these organisations to work together to develop a long-term vision to improve the quality of life and services in the local area.



DASL and Age Concern Lambeth's User Involvement Service works with and on behalf of the Older People's Partnerships Board and the Physical and Sensory Impairment Partnership Board which are part of the Lambeth First structure.

The service employs a range of methods to build and support user involvement in:

This is a combined user involvement service for disabled and older people, which is jointly managed by DASL and Age Concern Lambeth working jointly to deliver user involvement in a wide range of important strategies and service developments.

The User involvement Service is commissioned and funded by Lambeth Council and NHS Lambeth on behalf

- The evaluation of services
- Consultation on changes to services
- Membership of Committees and Boards
- The design of services.
- Co-production in the delivery of services.
- Independent forums and user led organisations.

This list is not intended as a hierarchy of activities. Users feel disempowered for many reasons and a range of approaches is needed to overcome this. For user Involvement to be effective and sustainable it has to be honest about its limitations, particularly regarding how decisions are made and the degree to which service users can influence them. Thus, to present a situation as, say, a co-productive relationship when the reality is that of a consultation, not only leads to confusion but can undermine future user involvement by creating distrust.

The User Involvement Service is staffed by myself, Richard Farnos with the assistance of a part time clerical support worker (approximately one day a week). The support worker was Petrina Hughes up September 2009. Petrina was promoted as Age Concern Lambeth Volunteer Co-ordinator and Diana Amaechi became my support worker from December 2009.

I would like to thank the all disabled and older people who have been involved in the project in one way or another. I would also like to thank the following volunteers whose support has made this work possible:

- Anne Curnow-Denison
- Barbara McLaughlin
- Brenda Collins
- Cheryl Griffith
- Chin Ong
- David Hart
- Ellen Lebeth
- Graham Peck
- Jeff Dorne
- John Pryer
- Joseph Mullen
- Lino Diogo
- Liz Azubuike
- Lynda-Anne Garwood-Warren

- Mohammed Khan-Lodi
- Ray Ludford
- Sean McGovern
- Sohret Pirefendi
- Susan Hamilton
- Sylvie Kone

The following is a review of our work from April 2009 to March 2010 that directly involved older or disabled people. Internal administration, staff training and event attended that did not involve users have not been included. Areas of work have been grouped under the methodologies adopted as can be seen below:

Service Evaluation

- Intermediate Care - Lay Assessors Project

Consultation

- Older People's strategy
- Physical and Sensory Impairment Strategy
- Guys and St Thomas Communications Strategy
- Dental Strategy
- Green Paper on Social Care

Boards

- Older People's Partnership Board
- Physical and Sensory Impairment Partnership Board

Service Design

- Transforming Equipment for Daily Living
- Reviving the Goldies Group

Independent Forums

- Lambeth Pan-Disability Forum
- Lambeth Forum for Older People
- Gruppo Girassol

Service Evaluation

Intermediate Care Review - Lay Assessors Project

As part of their review of their Intermediate Care Strategy, Lambeth Primary Care Trust commissioned Age Concern Lambeth to undertake research to explore the experiences and views of service users.

The methodology used was a form of peer research, an approach which involves peers of service users both in the development of the project and in conducting the interviews. In practice Lay Assessors are volunteers made up of a mixture of users, carers and potential users. They visited people in their own homes or in an agreed neutral environment (e.g. Age Concern Lambeth offices) to gather their opinions of the Intermediate Care service.

At the interviews with service users Lay Assessors worked from a semi-structured questionnaire. While this set of open and closed questions gives structure to the interview, it still allows the Lay Assessors to depart from the script when they feel the interviewee raises an unexpected but relevant and interesting issue.

Due to the severe cold weather in January 2009 which placed exceptional burdens on Acute and Intermediate Care Services. It was agreed with NHS Lambeth that interviewees should be taken from users of the services in the period September to December 2008. Of the approximately 250 letters that were sent only twelve were able to be involved. There were two focus groups made up of 6 to 8 people that included service users and the Lay Assessors,.

All but one contributor interviewed felt



that they were involved in decisions that had been made about their care and felt their wishes had been respected. A few of the contributors “had to fight” to get referral to Pulross Intermediate Care Centre or Lambeth Community Care Centre.

All Intermediate Care Services were well appreciated and often regarded with affection by service users. All contributors were satisfied with the medical treatment and support received in the Care Centres or at home.

The vast majority of service users felt that the staff were professional and friendly. There were no major complaints about the physical state of Care Centres and no complaints at all about cleanliness.

Despite the good experiences that people who had used the services of Supported Discharge and Rapid Response Teams, only two people out of the ten asked felt that the support given at the centres could have been provided at home, nor was there any great desire for returning home earlier. All eight that felt that they couldn't have returned home earlier also wouldn't have wanted to return home any earlier.

The reason why people were reticent to use the services provided by the Supported Discharge and Rapid Response Teams were explored to a greater depth at the focus groups. It became apparent that this concern was largely perceptual with concerns around safety at home and due to some confusion with homecare services provided by Lambeth Council's Adult and Community Services through agencies. Moreover, staying at the Lambeth Community Care Centre or Pulross Intermediate Care Centre gave some very isolated people social interaction in a caring environment:

The report came to a number of conclusions and made recommendations including:

- There needs to be better coordination between the various Intermediate Care teams, and with hospitals
- There was significant evidence of lack of awareness of the range of services provided by the Intermediate Care teams – most notably medical staff in acute services.
- There needs to be greater knowledge of the support services available from Age Concern Lambeth and other voluntary sector organisations in Lambeth.
- There needs to be greater efforts made to have consistency of staff visiting people in their homes
- There is a desire for greater use of assistive technology among service users
- There should be consideration of the development of some sort of 'home from hospital' scheme where volunteers work alongside members of the Intermediate Care Service to help service users in the transition from institutional care to home.
- It is important that Care Centres ensure that all meals have at least one option that is suitable for anyone with any dietary restrictions.

The Lay Assessor report is due to be incorporated into a wider review of the Intermediate Care Service. We also await NHS Lambeth's responses to the recommendations in the report.

Consultations

Older People's Strategy

The Older People's Strategy had been well advanced prior to April 2009. Indeed, the end of April marked the conclusion of the formal period of Consultation.

The role of the strategy sets the workplan of the Older People's Partnership Board for the period 2009-2014. It is also a commissioning strategy for the development of services in this period



The strategy covers a range of topics including:

- leisure, cultural and community facilities
- transport options
- housing and adaptations
- help at home
- looking after your health
- personal and community safety

The User Involvement Service organised two events in April 2009 which sought the views of seldom heard groups including older Lesbian, Gay, Bisexual and Transgendered people and of Portuguese elders who were members of Gruppo Girasol.

These meetings were productive in illustrating the need for flexibility of services to meet the needs of smaller minority ethnic communities and older LGBT people. For example it was felt that there was the need for a more coherent policy of translation services

The Older Peoples' Strategy has been finalised and published under the title **Positive Ageing**. A workplan has been developed to implement the commitments made in the strategy including those for user involvement.

Physical and Sensory Impairment Strategy

The Physical and Sensory Impairment Strategy has been a significant part of my work over the last year.

Like the Older People's Strategy, the Physical and Sensory Impairment Strategy will set the workplan for the Physical and Sensory Impairment Partnership Board over the next four years and underpin the commissioning of services in this period

The strategy covers a range of topics grouped into six themes:

- Employment, training and volunteering
- Being healthy and independent
- Information, advice and advocacy
- Housing
- Transport, access and mobility
- Personal safety and crime
- Leisure, culture and community facilities.



- 4/2/10 PSI Workshop on Housing
- 10/2/10 Sickle Cell Workshop
- 23/2/10 Deaf and Hearing Impairments workshop

In addition we developed a questionnaire that was sent with a special issue of DASL's Newsletter *The Mole* to all DASL members. We received 32 replies to our questionnaire. All raised important concerns and made interesting and constructive solutions

A key issue raised was the inflexibility of services in relation to the needs of people with fluctuating conditions such as sickle cell disease and the lack of a 'pathway' from diagnosis onwards with people having to constantly reinvent the wheel or fight the same battles to access services.

For example, members of the Sickle Cell Society reported that it was virtually impossible to get support in the home without first having reached a crisis point requiring hospitalisation. Earlier, lower level intervention could often prevent such attacks and would prove less distressful for the affected person and their families, and, ultimately, cheaper for service providers.

Following the conclusion of formal consultation at the end of February the Strategy will be redrafted and published with an action plan later in 2010.

Between April 2009 and April 2010 there were two stages of consultation for the Strategy. The deliberative stage – where the consultation sought views and ideas about priorities; and the formal consultation – where people were asked their opinions on the proposals in the draft strategy.

The User Involvement Service worked alongside the Council's Communication departments and organised or assisted in the following consultation events:

- 6/7/09 Deliberative Stage launch
- 31/7/09 Voluntary sector workshop
- 6/8/09 Headway Group
- 6/8/09 Lambeth Pan-Disability Forum meeting
- 7/8/09 Lambeth Resource Centre
- 18/8/09 Latin American Disabled People's Project Group
- 1/12/09 Formal Stage Launch
- 4/12/09 Workshop at DASL AGM
- 11/1/10 Transport Workshop
- 18/1/10 Health and Social Care Workshop
- 28/1/10 Housing Workshop

Guy's and St Thomas' Communications Strategy

The User Involvement Service was involved in helping Guy's and St Thomas' NHS Foundation Trust develop a Communications Strategy.



We recruited members to two focus groups – one made up of people who had recently been in hospital (although not necessarily Guy's and St Thomas') and one of Portuguese elders drawn from Gruppo Girasol. The meeting was facilitated by staff from the trust.

Green Paper on Social Care

See Independent Forums – Lambeth Forum for Older People

Boards

Older People's Partnership Board

User representatives on the Older People's Partnership Board are elected from organisations that are representative of older people in Lambeth rather than simply 'interested individuals'. At present there are four representatives:

- Mohammed Khan-Lodi - **Lambeth Forum for Older People**
- Ellen Lebethe – **Lambeth Pensioners Action Group**
- Sohret Pirefendi – **Expert Patient User Group**
- Lynda-Anne Garwood-Warren– **Sheltered Housing Forum**

Before each Board there is a user representatives' meeting. At this meeting the items that are to be discussed at the Board are reviewed to ensure that service user representatives are clear what the discussion is about and are able to access support and further information to be able to make their contributions effectively.

Physical and Sensory Impairment Partnership Board

User involvement in the Physical and Sensory Impairment Board is less well developed.

As with the Older People's Partnership Board the intention is to have representatives of disabled people in Lambeth rather than simply 'interested

individuals'. However, this is more complex to achieve as there are many different impairment and condition-specific groups which fall within the Board's remit.

To overcome this challenge we are creating a "pool" made up of representatives from the various user and support groups in Lambeth. As with the User representatives' meeting for the Older People's Partnership Board the pool will meet up prior to every Board to discuss the items on the agenda. Where it differs is that, depending on the business due to be discussed and the expertise of pool members a varying delegation from the Pool will be nominated to attend the Board. The pool has the advantage that it takes some of the pressure off individual representatives and allows them to specialise in area of interest to them.

As the Physical and Sensory Impairment Strategy is not yet in place it has been agreed to postpone recruitment to the pool until a review of the Board structure and membership, including its sub-committees, has been completed.

Currently there are three interim user representatives on the Board:

- Anne Curnow-Denison – **Bowley Close Rehabilitation Centre user Group.**
- Brenda Collins / Ray Ludford - **Lambeth Pan-Disability Forum**
- Barbara McLaughlin - **Direct Payments User Group**

Service Design

Transforming Equipment for Daily Living

A large amount of my time has been devoted to the Transformation of Community Equipment project (which has now been renamed as the more user friendly Equipment for Daily Living). This has included regular meetings of the Work Group Leads, and the Project Board and some attendance at the retail group meetings on behalf of Age Concern Lambeth.



Lambeth Council and NHS Lambeth are reorganising how people get their equipment for daily living. This equipment helps people or their carers with everyday tasks and is sometimes referred to by different names, such as

“assistive technologies” or “community equipment” or “Telecare.” It ranges from items such as raised toilet seats & commodes to white canes, medication reminders & falls detectors.

Currently, people get this equipment delivered from a central store after they have been assessed by an occupational therapist, district nurse or another ‘trusted assessor’. From mid 2010 it is planned that people will be given a prescription which they will redeem at a local accredited shop – as if picking up a prescription for

medicine from a doctor. Who is eligible to get free equipment from the Council and NHS will not change, nor will how people are referred or assessed. However, how people get the equipment will change with the move to what is called a ‘retail model’

My principal involvement has been to help develop the user involvement workstream including the development of a questionnaire sent to previous users of the community equipment which was followed up by a focus group that will explore any issues that arise out of the questionnaire and look at the proposed

leaflet, posters and other communications. In addition, the Lambeth Forum for Older People and Lambeth Pan-Disability Forum have been kept abreast of developments and acted as a sounding board/reading group for the development of leaflets.

Everyone involved in the project has been encouraged by the response of existing and potential service users which has been almost entirely positive. People welcome the opportunity to see equipment prior to taking it home, support the notion that such equipment should be 'normalised' and seem willing to organise their own deliveries. Moreover, in response to service user concerns about people who fail to pick up prescribed equipment, the Project Board has agreed that prescription will only last 28 days, thus building in an automatic review with uncollected prescriptions being referred back to the assessor.

Reviving the Goldies Group

I have been involved in the discussion around the development of an 'Opening Doors' project in South London – that included discussion with GMFA (the gay men's health charity) in August 2009. This has somewhat been eclipsed by wider developments with the aspiration to organise and get funding for a London-wide Open doors Project with Age Concern Lambeth acting as host for south London.



Nevertheless, as part of the development of the Vida Walsh Centre in Brixton, I organised a focus group of previous 'Goldies' members on in February 2010. Although the meeting had limited outcomes a number of number of decisions were made:

- The majority were happy with the name 'Goldies'
- They welcomed the idea of regular coffee mornings. The Goldies Coffee Morning will be launched on 15th June.
- They suggested that we should encourage other local LGBT groups to provide activities during the Celebrating Age Festival
- That Lambeth Archives should be asked to launch an appeal for Lambeth LGBT memorabilia during Celebrating Age for a display in LGBT history month.

Independent Forums

Lambeth Pan-Disability Forum

With my assistance the Lambeth Pan-Disability Forum was formed on 1st April 2009. The need for such an organisation became apparent from contact with local disability activists, not least the late David Hart, and through identifying existing user and support groups. Most existing groups were 'condition' specific and orientated to the work of national charities, or particular services – such as those provided at the Bowley Close Rehabilitation Centre.



The aim of the Lambeth Pan-Disability Forum is to seek to represent disabled people and issues that are common to many if not most disabled people regardless of impairment or condition—hence the phrase 'Pan-Disability.' Issues can include the obvious such

as transport or social care services to less featured but equally important ones such as crime or being a disabled parent

Despite having no formal funding the Forum has been very active. With my support it organised a hustings for the European election and in October 2009 they collaborated with the planning department of Lambeth council in a bus stop audit in Streatham Vale. More recently, they have been involved with constructive discussion with the Lambeth Events Department to help make the Lambeth Country Show more disabled friendly.

In addition, the Forum has organised a consultation meeting on the Physical and Sensory Impairment Strategy and held meetings on Personalisation of social care services, Lambeth Council's Single Equality Scheme, the development of Lambeth Centre for Independent Living and the Introduction of the retail model into Equipment for Daily Living.

They have also made written responses to the Physical and Sensory Impairment Strategy and the Department of Transport consultation on mobility scooters and powered wheelchairs.

Currently there are 34 members of the Forum. The membership and the Committee is representative of the ethnic diversity of the Borough. There is, however, an imbalance in membership in terms of disability. The majority of members either have physical impairments or mental health issues or both. Only a couple of members are blind, or visually impaired, or have learning difficulties. There are no deaf members or members with declared hearing impairments.

This problem has been recognised and the Forum will tackle it by improving the accessibility of meetings, for example by providing British Sign Language interpretation. This is, however, dependent on the outcome of the Forum's recent application for a Grassroots Grant from the Capital Community Foundation.

Lambeth Forum for Older People

It has been a difficult year for the Lambeth Forum for Older People. The Committee has reviewed its policies and procedures and some of its officers have had serious ill health.

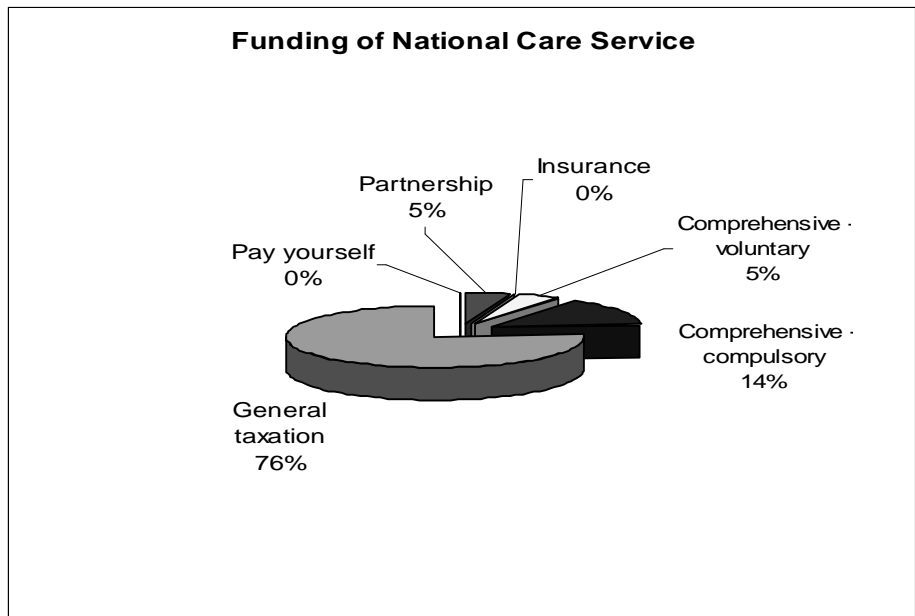
Nevertheless, with my support which has included the organising of an 'away day' and training event for the

Committee in association with Age Concern London and Help the Aged, and mentoring work with the Forum's secretary, Cheryl Griffith, and Mohammed Khan-Lodi who took over as chair in December 2009, the Forum has managed to organise a range of activities.



There are around 150 members on the data base although attendance at meeting fluctuates between 10 and 40 people. General Meetings have covered a diverse range of issues including End of Life Care, Polyclinics, Public Transport, Equipment for Daily Living and the Older People's Strategy. The Forum also organised a coach trip to Eastbourne in the summer and a New Year Party at the Vida Walsh Centre in Brixton. Finally, a regular newsletter called "The Lambeth Sage" has been established.

The membership and attendance at General Meetings reflect the diversity of the borough. However the membership of the Committee is largely male with only one female member. The Committee is resolved to tackle this problem and to generally increase membership by working with other groups in the borough.



Perhaps the highlight of the year was the meeting on the Green Paper consultation on the future of social care called ***Shaping the Future of Care Together*** which was jointly organised with Age Concern Lambeth and Lambeth Pensioners Action Group.

At a packed meeting held at the Woodlawn's Centre in Streatham on the 20th October 2009, the Green paper proposal to introduce a National Care Services was welcomed. It was particularly felt that there was a need for common national assessment standards where the care needs are assessed in the same way in all parts of the country.

There was also a view that the level of support expected should be the same in all parts of the country, and in order to achieve this, the allocation of resources should reflect local labour market conditions, for example taking into account the higher wages needed in London.

The greatest area of concern at the meeting was how a new National Care Service was to be funded. The option of an insurance scheme was not

favoured and there was unanimous opposition to the abolition of Attendance Allowance or any other disability benefit. The vast majority of people at the meeting felt that general taxation was the only workable and fair way of paying.

Gruppo Girassol

Gruppo Girassol was set up by Francesca Valerio, the original 'Have Your Say' project worker for Age Concern Lambeth. She identified that, within the Portuguese community in Lambeth, older people (those over 55) were isolated, frustrated and unable to access services. Many older Portuguese are unable to speak English; this means that when they have to engage with statutory services they meet an immediate language barrier.

The group meets at Lingham Court Extra Care facility, the room is free and the staff provides tea, coffee and biscuits. The group uses a paid translator, Lino Diogo

There have been several attempts to support the group to clarify its purpose and set some practical goals but this has not yet been achieved. This lack of focus and clear function has contributed to the fall in attendance from 8 to about 4 regulars.

The group enjoys hearing from people



about services available and over the last twelve months, the group has had a meeting with Vivienne McKnight from Lambeth Housing, representatives from both NHS Lambeth and Lambeth Community Health who, among other

things, explained the 'Message in a bottle' scheme.

The group was also involved in the review of Guy's and St Thomas' communication strategy and the Older People's Strategy consultation. Discussion at the latter meeting was quite heated although a number of important issues were raised including the need:

- for a more coherent policy of translation services
- to employ Portuguese speaking staff in frontline positions
- for English classes with a Portuguese speaker.
- for a Portuguese speaking advocacy worker
- to support and develop a Portuguese community group.

Along with Sue Taylor from Age Concern Lambeth I took some members of Gruppo Girasol and some Somali elders on a trip to Kew Gardens June 2009.

The Year Ahead

The coming year is likely to prove hugely challenging. Lambeth's Labour administration seeks to transform services in the Borough through a "Co-operative Council Model". First trailed in the Guardian in February 2010, this would involve residents in taking on a bigger role in running and shaping local services. The model seeks to apply the co-operative principles of fairness, accountability and responsibility across a broad range of services.

This vision for Lambeth runs in parallel with the new Conservative and Liberal Democrat Coalition Government's concept of a "Big Society" which aspires to a revival of 'civic society' beyond that of local and central government. Both notions appear to have potential benefits for older and, particularly, disabled people offering the possibility of them being able to play more integral parts in the life of the community.

All this, however, is set against the background of major cuts to the services provided by, or funded by, local authorities. The principles of a 'Co-operative Council' may help to balance some of the effects of the cuts in services that are inevitable. However, there is also a risk that there will be insufficient resources to enable user involvement initiatives to be supported effectively and good ideas will not be able to be delivered. .

The word 'co-production' is likely therefore to be the buzzword of the year, for whether it is the formation of co-operatives or civic institutions, the active involvement of service users is



Essential. For this to work, not only must there be equitable relations between service users and service providers, but there must be support for the dialogue which user representatives and 'citizen leaders' need to have with other service users and residents. The United Kingdom Disabled Peoples Council has recently produced a manifesto which, in its section on 'Voice and Co-production' argues the following:

"The views of carers, disability charities and other service providers are part of co-production, but it must be recognized that they have their own vested interests. Therefore we demand that:

- *Government recognises the importance of the representative voice of disabled people.*
- *Other members of the third sector work with us in co-production and as full allies to*

our objectives of equality, rights and justice for disabled people. Professionals should be a resource but Disabled People have the authority over our own lives.

- *The voice of disabled people, through our own representative organizations must be in the lead and financially supported in all policies and programmes that directly affect us”.*

Workplan

Below is the current workplan for the Age Concern Lambeth and Disability Advice Service Lambeth User Involvement Service for the period April 2010 – March 2011. I will be seeking to deliver this by working closely with older and disabled people and partners from the statutory and voluntary and community sectors.

Older People’s Partnership Action Board

- Support Board user representatives group and develop and support individual representatives including the user co-chair
- Attend Strategy Executive Group

Physical and Sensory Impairment Partnership Board

- Attend Board Planning Group to advise on user involvement issues
- Identify and support Board user representatives
- Support users in current and future Board work stream groups as required

Involvement of disabled and older people in Lambeth Link

- Take a lead in engaging with Lambeth Link and Age Concern Lambeth as the host organisation regarding the involvement of disabled and older people
- Follow up work arising from recommendations of the Link in relation to disabled and older people



Supporting the development of effective models of co-production to involve disabled and older people

- Contribute to training of users in key skills (e.g. being a representative, community advocacy, lay assessment) across Lambeth Strategic Partnership structures
- Contribute to the development of models of peer support as part of the Personalisation agenda
- Research and report on good practice in co-production and

involvement of disabled and older in other authorities

- Support disabled people's involvement in the development of a Lambeth Centre for Independent Living



Redesign of Day-care: Mental Health of Older Adults (MHOA) Services

- Arrange a general meeting with day hospital users to feed into the wider Older Persons agenda
- Increase involvement of older people with mental health needs
- Involvement in the LINK Task and Finish Group on MHOA

Review of general older persons day services

Review of Lambeth Resource Centre

- Involvement in working group to implement review recommendations.

- Discuss ongoing role in supporting user voice at LRC

Intermediate Care Strategy

Coordinate a lay assessment project with users of Lambeth Community Care Centre

Re-ablement Strategy

Coordinate a Lay assessor project for Integrated Enablement Team pilot

Transforming Equipment for Daily Living

- Attendance at Project Board as required.
- Involvement in communication with service users about the 'retail model' service and assessment of early performance

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