

PROJECT SUMMARY

Project Title: Service User Involvement	Date Project started: 2003
Project Lead (MI): Gaynor Smith	Date Project closed: 2008
Project Lead (Other): Disability Advice Service Lambeth Blackfriars Settlement	

Brief description of aims of project:

This project aimed to enable people living with stroke to develop, deliver and influence local services.

Reason for change:

People living with stroke reported that the life-changing impact of stroke was poorly addressed by health and social care services. There was a need for people with stroke to be able to have significant influence on statutory service provision, promoting approaches to 'disability mastery' and identifying a wide range of resources and opportunities for people living with stroke.

What we did (action taken):

Over the past three years the Modernisation Initiative has piloted a range of approaches to service user involvement, engaging over 70 people affected by stroke in Lambeth and Southwark. Their involvement has been wide ranging from consultation to strategic planning with providers, from one-off focused involvement e.g. in patient information, to becoming peer supporters. Involvement has spanned the care pathway from prevention to long term support, with neutrality of the MI and the users it has engaged being an essential characteristic.

Impact, display data baseline to current:

- A series of Join In consultation events.
- 16 peer supporters trained.
- 48 service users have received peer support
- Engagement of over 40 people living with stroke in the development of “Learning from people who have had strokes” - User defined good practice guidance for delivering stroke care with accompanying DVD featuring service users telling their stories. This resource was used to identify a number of areas for service improvement as well as a basis for running training and raising awareness events.
- A group of service users and professionals worked together on the development of a range of patient friendly stroke information resources (stroke patient held handbook, picture menus for stroke units, resources for parents and children living with stroke).
- A group of trained people living with stroke experienced in delivering training and stroke awareness events.

Outcomes / Learning:

There are a number of potential barriers to involvement for people living with stroke (communication, memory, multiple health problems, mobility, confidence, transport). Traditional involvement approaches, such as one off consultation events and representation on local boards had been largely unsuccessful in engaging stroke service users. Ongoing mechanisms used by the Modernisation Initiative to bring people together to network and grow confidence and involvement skills facilitated involvement.

Lambeth and Southwark now have a large group of skilled people living with stroke who keen to set up a local Stroke User Involvement Network and have taken an active role in developing the proposed model.

Local service providers and commissioners are aware of the benefits of user involvement in stroke care and committed to developing mechanisms for sustaining involvement post Modernisation Initiative.

How has change been sustained:

Lambeth and Southwark Primary Care Trusts, together with Guy's and St. Thomas' Charity, have committed to supporting the development of a local Stroke User Network to sustain the innovative and far reaching methods of engagement achieved by the MI, and, in addition, facilitate a new phase of development in these approaches. This new phase will aim to embed the Network, hosted by Disability Advice Service Lambeth and

Blackfriars Settlement, in the local community, enabling people who have experienced stroke to participate more fully in mainstream activities, and engage with the plurality of agencies that work with people with stroke.

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