

Appendix E: Summary of consultation and engagement activity with people with physical disabilities and their carers regarding physical disability services.

Introduction

This report summarises the findings from a period of engagement and consultation with service users and carers during the development of the strategy: Choice, Independent Living and Personalised care: A strategy for Physical Disability Services 2009-2012.

The strategy is a joint strategy between the Brighton and Hove City Teaching Primary Care Trust and the Brighton & Hove City Council to improve opportunities and support services to people with physical disabilities

Background

The strategy has been under development for over two years. At the start a Physical Disability Strategy Steering Group was established to help develop the strategy. This group included cross representation from statutory and 3rd sector organisations including service user representation from the Federation of Disabled People.

During the lifespan of the steering group a range of outreach work was carried out to discuss the developing strategy. This included:

- Discussions with 3rd sector organisations, service user representatives and advocacy groups on existing services and care pathways. During this time meetings were held with the Federation of Disabled People, the Multiple Sclerosis Society, Headway, the carers Centre and Sussex Acquired Brain Injury Forum (SABIF).
- Meetings with special interest groups and specialist workers were held including: the Disability Access Advisory Group and the Disability Equality Scheme Steering Group and the Disability Service users Group.
- Promotion of the developing strategy at wider events relevant to people with physical disabilities and their carers. This included: the Independent Living Day event, Carers Centre launch, Neurology network launch, and the Sussex wide steering group for neurorehabilitation

Also informative to the development of the strategy were the following workshops and events:

Integrated Service Improvement Plan process led by the Strategic Health Authority. This involved a series of workshops with representation from across the local health authority and 3rd sector to scope local priorities and assess the benefits of service priorities.

Response and recommendations:

The identified priorities have been incorporated into the strategic objectives and identified projects

PCT World Class Commissioning - consultation events

The PCT hosted 2 events in July and September which provided an opportunity for wider discussion of the priorities for the local health and social care economy.

Response and recommendations

These events have informed the PCT Strategic Commissioning Plan and annual operating plan. The Physical Disability Strategy is in line with the overall strategic direction of the PCT as outlined in the Strategic Commissioning Plan.

Report for Sussex-wide neurorehabilitation Commissioning Framework: Involving service users and carers in the development of a Sussex-wide Commissioning Framework for adult neuro-rehabilitation (June 2008)

This is a report of the findings of a series of local semi structured interviews with service users and carers with experience of stroke or acquired brain injury.

Response and recommendations:

Conclusions from the consultation have been included within the final Sussex-wide Commissioning Framework and will be taken forward through the PCT commissioning plan and monitored by both the Sussex-wide Commissioning Group and the city's Physical Disability Steering Group.

Equality Impact Assessment an initial Equality Impact Assessment screening on the strategy was undertaken and recommendations were received with regard to specific language and format of the document. A glossary was requested to support the final document and a full EIA was recommended on the action plan

Response and recommendations

A glossary to the strategy is attached at Appendix A. The draft document was reviewed and language changed as recommended. A full EIA on the strategic action plan is to be completed on the 23rd February 2009

Formal Consultation period October 2008 - February 2009 :

From October 08 the PCT led a formal consultation period, planned in partnership with the Local Authority and The Federation of Disabled People. This included:

- A wide mail-out of the draft strategy to the 3rd sector, communities of interest, service user groups and email correspondence with individual service users (list of recipients included in Table 1)
- Inclusion of the draft document on the Local Authority and Federation of Disabled Peoples' website
- Tabled discussion at the International Day for the Disabled on 3rd December 2008;
- A service user consultancy group facilitated by the Federation of Disabled People on request of the Disability Equality Scheme service users group (1 meeting held but agreed follow up meeting postponed due to inclement weather and difficulties with travel: email responses received instead)

Outcomes from engagement and consultation - How well are service users and carers needs being met?

As a result of the above consultation period service users and their carers have identified the following concerns and priorities for further service improvement

1. The importance of a social model of disability

Service users have commented that the draft strategy needs to be more strongly rooted in the social model of disability and have felt that the draft document by its reference to specific conditions, individual services and use of terms such as severe, moderate disability and complex needs maintains a medical model of disability.

Service users have requested that reference to specific conditions, and terms as above are removed from the document to lessen the medical model of disability and to ensure that the strategy is relevant to all people with a physical disability

Response and Recommendations:

The draft document has been reviewed - the social model has been further defined, and emphasised within the strategy as the foundation for future plans Reference to specific medical conditions, services and levels of disability have been minimalised.

The title of the document has been revised to reflect principles of the strategy and direction of travel.

2. Increased involvement in decisions about services

Service users have expressed their desire to have ongoing involvement and engagement in the planning and decision making processes for service improvement.

Response and Recommendations

Strengthened involvement and engagement is included as a key objective within the strategy and specific tasks are incorporated within the strategic action plan. We will be working with service users to agree a model to ensure on going involvement and engagement. Also during 2009/10 consultation will take place to determine the future model for a service user led centre for independent living.

3. Improved access to clear and joined up information services

Service users have emphasised the need to know what services are available for information services that are responsive to the needs of vulnerable adults (e.g. people with sensory impairment) and for clear advice re: entitlements.

Response and Recommendations

Improving access and further integration of information services are incorporated within the strategic action plan. The PCT is working with the Federation of Disabled People to ensure a joined up approach to improving information services. A key action of the action plan is to improve access to advocacy services.

4. Improved access to services including primary and specialist health services, and appropriate housing - people have told us of long wait times for home adaptations and Occupational therapy assessments. The difficulties of attending health appointments and of the need for improved access to GP surgeries, dentistry and specialist health services

Response and Recommendations

A number of key actions are included within the action plan to address these issues of access. The Physical Disability steering group will be tasked with ensuring a joined up approach to these issues of access and wait times.

5. Management of disability needs during hospital stays and at discharge

Consultation has highlighted the need for improved care planning for disability needs during hospital stays and for early and improved discharge planning: including an assessment of carers needs and the needs of disabled people with caring responsibilities.

Response and Recommendations

Management of hospital stay and discharge is incorporated within the strategic action plan.

6. Improved taxi and bus transport – improved access to appropriate and affordable transport is a priority for service users

Response and Recommendations

A review of accessible transport is included as a key action within the 3 year action plan

7. Recognition and improved support to carers -

Increase recognition of carers role and importantly at transition points including hospital discharge.

Response and Recommendations

Strategy amended to ensure carers needs included within key service improvement areas and links made with the developing carers strategy.

