Disability Focus – About Me (Health Passport)

Background

The principal objective of Disability Focus is to enable disabled people to raise their concerns and issues and make their voices heard, and for those in statutory organisations to listen to those voices and take note of their concerns and issues.

It is a partnership event designed to bring together disabled people, their family carers, representatives of disability organisations and representatives of statutory organisations in Suffolk.

Each year, delegates have the opportunity to think about their big issues – getting information, getting around, keeping safe and having enough money. Whilst the results indicate continuing year on year improvement, comments made by delegates indicate that there are still many barriers to the effective inclusion of disabled people in our communities. There are many specific examples of such barriers within the detail of the full reports from each event which are widely circulated.

Suffolk Disability & Health Action Group

The Suffolk Disability & Health Action Group has been established since 1996 and is set up to promote the good health of disabled people and to improve outcomes by ensuring services that affect the health, well-being, and independence of disabled people are fully accessible to them. It is supported financially by the Ipswich & East Suffolk and West Suffolk Clinical Commissioning Groups. Membership includes Patient Leads from the Ipswich & East Suffolk, West Suffolk and Gt Yarmouth & Waveney Clinical Commissioning Groups, the Ipswich & West Suffolk Hospitals, Suffolk Community Healthcare, individual disabled people and their family carers and representatives from disability organisations.

About Me

At Disability Focus in 2016, following comments and requests from delegates, an action point was made which related to disabled people being able to easily give health and care professionals information about themselves and their care needs as detailed below:

Action Point: To continue working on the proposal to extend the use of the Health Passport, already used by people with learning disabilities in the Ipswich and West Suffolk hospitals, to any disabled person who has contact with health and care professionals.

Outcome: The Health Passport will be adapted for use by any disabled person and recognised by health and care professionals.

Made by: Suffolk Disability & Health Action Group

This action point was already being progressed by the Suffolk Disability & Health Action Group and has been further developed through coproduction with a group of disabled people.

In order to develop a simple document that could be used by any disabled person to help them inform health and care professionals of their care needs and their wishes, the Suffolk Disability & Health Action Group reviewed a number of 'Health Passports' and 'This is me' documents that are already in existence in the country and in use by certain groups of disabled people such as people with learning disabilities and people with Alzheimer's Disease. The Health Passport currently in use by people with learning disabilities at the Ipswich and West Suffolk Hospitals was chosen as the basis for a Health Passport for any person with a disability in Suffolk.

This document was then shared with a group of disabled people to check the content and to expand it where necessary so that it covered the needs of the majority of disabled people and addressed their mutual experiences in receiving care and treatment. It was felt that the name 'Health Passport' was not particularly helpful and it has been agreed that the document would simply be called 'About Me'. The document was then reworked and sent to members of the Suffolk Disability & Health Action Group for their comments.

It has been agreed that 'About Me' will be made available through a link published on a number of websites in both the statutory and voluntary sectors in order that it can be downloaded and completed by the disabled person and/or their family carer. No funding is available for printing hard copies of 'About Me'. Mid Suffolk Axis has kindly agreed to host the link but the introductory wording is only in draft form at present. The link is:

http://midsuffolkaxis.onesuffolk.net/news/about-me

Currently, the Suffolk Disability & Health Action Group is seeking endorsement of the use of the 'About Me' initiative from the Clinical Commissioning Groups, Acute and Community Hospitals, Community Healthcare Services and GPs in Suffolk.

This is important as disabled people have told us that currently health professionals do not always read or take note of their current 'Health Passport' type documents resulting in the frustration of having to repeat their needs over and over again.

How can you help?

Endorse the 'About Me' initiative by:

Allowing the Suffolk Health & Disability Group to say that your organisation endorses the initiative in its publicity;

Helping to publicise this through your publications and information sent out to the public and to GP surgeries and to services that you may commission;

Including the link to 'About Me' and your endorsement on your websites.

Suffolk Disability & Health Action Group March, 2017