

Service User and Carer Report

Improving Access for People with Learning Disabilities

Introduction

A number of focus groups were set up to gain the views, experiences and opinions of people with learning disabilities and their carers as part of improving the access to primary care for people with learning disabilities.

Methodology

Four focus groups were set up for service users in County Durham and Darlington with 29 people with learning disabilities attending in the following locations:

- Easington
- Durham and Chester le Street
- Bishop Auckland via Innovations
- Darlington

The group were supplemented by a one to one interview over the telephone with a person from Darlington.

Five focus groups were set up for carers supported by the local carers centres. In total 19 carers attended with 6 support staff in the following locations:

- Derwentside
- Sedgfield
- Easington
- Dales
- Durham and Chester le Street

The focus of the questions for the group were:

- Experiences of primary care services
- Annual health checks
- Health action plans
- General health promotions

The groups were facilitated by Catherine McBride and Martin Howe from Assura Derwentside LLP.

Key findings

1. Experiences of Primary Care Services

There were a number of themes:

- The groups found GP practices helpful with comments including;
‘They make time for me’
‘They are polite’
‘They make people feel comfortable’.
- One carer described how the practice makes adjustments with the appointment system for his son to prevent long waits.
- It was discussed in a couple of the carer forums that for some people with learning disabilities their health support has been consultant based at one of the North East hospitals from an early age and as a result practices do not know them well.
- One concern was the lack of continuity of care for certain people with their GP’s and locum doctors who may not have met or know the person well enough and this means going through past personal and medical detail.
- Some carers had felt that their voice was not always heard and that vital information could be missed during consultations. This was in part due to staff involving the person with learning disabilities as the focus of the consultation. One carer used an example of between 10 -12 professionals missing her daughter’s diagnosis over an 11 year period which in turn made her question her own judgement.
- The transition period was identified by carers as a critical period in

health provision. The school environment provided lots of health service provision which changed when leaving school into adult services. One example given was the difficulties one parent experienced in getting her daughter weighed.

- Carers found a lack of information regarding new or existing services. It was felt that this was compounded by organisational restructures and change in personnel. A couple of examples given were not knowing about the Independent Living Fund and local epilepsy services.
- Members of the groups regularly use dentists, chiropodists and opticians often with support and there were no areas of complaint or difficulty.
- There was a suggestion to meet in one year's time to review progress made and share further experiences around health checks.

2. Annual Health Checks

Service users who had received an annual health check in the groups were:

Darlington – 4 out of the 5 people had an annual health check and the fifth person had an appointment for mid June. They lasted around 20 to 25 minutes and some of the actions included:

- Receiving a membership card for the Dolphin Centre to use the gym at a reduced cost.
- One person has been referred to hospital
- One person has now got glasses following a referral to the optician and 'can see clearly now'
- Regular blood tests and BP checks are taking place
- Advice on healthy eating

The support to attend the health checks was from family members, staff and members of the health facilitation team.

Bishop Auckland – 4 people had annual health checks. The checks had taken from 40 minutes to one hour and were felt to be thorough.

Durham and Chester le Street – none

Easington – none

A couple of carers had experienced their son or daughter receiving an annual health check and felt they had been thorough and had identified health needs and other services were being accessed as a result. A couple of actions were:

- One person having their ears syringed
- One person being referred to a dietician

3. Health Action Plans

A percentage of the service user groups had Health Action Plans:

- Darlington – 5 from 5
- Innovations – 5 from the 12
- Durham and Chester le Street – none of the group but plans were being developed in the day service and some people who attended Empower had Health Action Plans.
- Easington 9 from the 12

Some key themes were:

- A number of referrals had been made to primary care services such as opticians, dentist and chiropodist.
- Many examples of activities to improve health including exercise and healthy eating courses.
- Some referrals to specialist support services such as speech therapy, occupational health and physiotherapy.
- In the Easington and the Durham and Chester le Street localities the plans were developed within the day services with support from the health facilitation team.

One lady explained some of the changes she has made as a result of the plan. These included:

- Attending the gym twice per week
- Attending the doctors more regularly
- Looking after herself in a better way

Carers felt the health plans were useful in collecting all the health information into one file but there was uncertainty about whether their family members had plans. One carer expressed her concern about

whether Health Action Plans would capture the information needed for a person with severe and profound learning disabilities.

4. Health Promotion

There were lots of discussions about activities people undertook in day services to promote healthy lifestyles often following an initial assessment. These included:

- Swimming
- Football
- Healthy eating courses
- Lifestyles advice on losing weight and smoking
- Gardening
- Marshall Arts
- Walking (including developing independent travel)
- Gym including having a healthy diary

It was also discussed how different groups focused on health topics and brought in speakers on specific topics. Some carers groups felt the day services had changed over the years in promoting healthy lifestyles which had physical as well as mental well being and self confidence benefits.