

**Visit to Grampian by Communication sub-group of Lothian
Learning Disability Review
13th February 2006**



The communication sub group met with Susan Carr Joint Learning Disability Partnership Manager and service users and carers from Grampian on 13th February 2006 in order to find out how service users and carers had been consulted about the Grampian Learning Disability Strategy.



Background

Grampian's last Learning Disability Strategy took place in the mid 90's. It only looked at services for adults and did not include children. Service Users were only involved during the strategy. There was no follow-up involvement.

In 2003 a new Learning Disability strategy was begun. After the strategy was finished, service users continued to be involved in the Implementation groups.

Consultation

Service users were involved in a number of ways:

There was a **big event** in the Beach ballroom in Aberdeen the day-time and an **evening event** at Park House Centre. Only about 15 people came to the event in the Beach Ballroom and about 25-30 people came to the event at Park House. The day time event attracted some people who were not using services for people with learning disabilities.

The events were organised with stations around the room for different topics:

- Employment, education, leisure opportunities
- Profound. multiple learning disability
- Autism
- Advocacy, advice, information
- Transport
- Health services
- Paid staff & family carer training
- Residential & respite care
- Day services
- Direct payments
- Children
- Any other ideas
- Education
- Employment
- Verbal and non-verbal language and communication
- Social activities
- Environment
- Moving on to other services and stages in life

People were also offered **individual consultations** either by phone or visit.

Questionnaires were also sent out. They asked:

- What is good about the services you get?
- What would make them better?
- What new services would you like to be developed?

Questionnaires for service providers which asked similar questions were also sent out.

Learning Disability Group of Aberdeen



Following the event, a reference group was set up. People with learning disabilities volunteered to be part of the reference group. The group like to take on concrete tasks such as:

- Consultation on symbols for leaflets etc.
- Symbolised consent forms

Feedback from the Consultation

The Grampian group said that it is very important to provide feedback and results to the people who have been consulted

Everyone who left their details was contacted at least 3 times afterwards. They were sent copies of the draft strategy for comment and copies of final strategy were sent to them.

Recommendations

At least 10 of the 40 recommendations in the strategy were made by service users and carers.

PAMIS

PAMIS were involved in the review. They provided personal 1-1 consultations with parents. They were able to identify common themes.

They are currently involved in:

Working on a specific strategy for people with PMLD

Identifying the numbers of people with PMLD. The geography makes it difficult to meet individual needs.

A pathway, looking at current services and identify gaps.

Planning by identifying youngsters coming up to transition.

Working with services and families on transition & planning –PAMIS have a model for transition for young people with PMLD.

Service User and Carer Group

A Service User and carers group was set up in order to put together the information on

Quality Indicator 1 in preparation for the QIS visit. This group have continued to meet. They raise Grampian-wide service issues

Membership of the group consists of: a geographical rep, service users/ carers/ professionals (about 17 members) It now includes children as well as adults.

Aberdeenshire

Aberdeenshire had 6 local consultation events with a similar programme to that of Aberdeen with facilitated workshops and a scribe

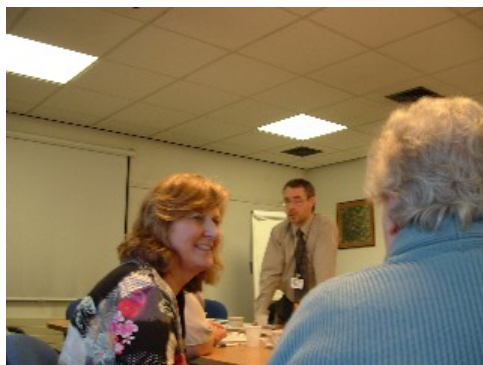
Children

There was an information event for families of children with disabilities (at a week-end). It comprised:

- 50 information stands
- A little interview room where kids could go and speak to a video camera and The Big Brother chair
- Entertainments for children
- Questionnaires for parents

In addition, twice yearly week-end workshops are held for parents. These have provided training in topics such as: How to have a good meeting, Guardianship and Sexuality and Autism

A video was made at the last meeting about how parents felt. It is now being used for training.



A summer holiday play schemes consultation for children aged 6-18 years has taken place. It was recommended that an independent person should carry out the consultation so that the parent or carer does not speak for the child.

Many children were found to be lacking in confidence. Drama classes seem to have helped the children to put their point of view across.

The next consultation is likely to be on respite services.

Tips

Consultation needs to be part of a social event with something for the people who come along such as refreshments or entertainment.

It requires a lot of preparation

Autism Strategy Consultation

- This involved:
- Questionnaire
- Workshops
- Stickers on the walls at the consultation event for comments
- Copies of Strategy-bullet points for tip boxes

(DDA) Training

Learning Disability awareness training is provided to the acute hospital.
A service user and carer are involved in the training

Hospital Booklet

Service users have produced an accessible information leaflet with photographs with information for people who have to visit hospital.