

CONSULTATION QUESTIONS

Progress and Challenges

Q.1 Do the findings of the evaluation broadly reflect your views about services for people with learning disabilities/carer?

Yes No

Yes, Quite a lot has been achieved in Fife which has been beneficial to people with learning disabilities/PMLD/ASD. It is very satisfying to see how service users and carers were closely involved in making decisions throughout.

Q. 2 Can you give examples, either locally or nationally, of what you think has worked well over the last 10 years of *The same as you*?

The closure of Lynebank Hospital has to be one of the highest achievements since the Same As You programme started. It has been very clear after working alongside so many of the people who were confined to the hospital that they should not have been there. Their contribution since their discharge to the decision making on committees, working groups etc has been quite remarkable.

The empowerment of the service user and the carer has been appreciated by the carers who have become involved in committees and working groups where in some cases they have chaired the meetings.

Local Area Co-ordinators was without doubt a first class programme which some regions have adopted. Unfortunately in Fife this has not happened.

Personal Centred Planning was also a helpful programme which gave service users the opportunity to express their desires for the future. In my family this was one of the foundation stones in moving our son on to independent living.

Good Practice – Organisations

Q. 4 Can you provide examples of what you have done over the last 10 years, within your organisation, to improve services and access to services within your local area?

My role in the organisation has been carried out as a carer. It has been very gratifying that carers such as myself have been offered the opportunity to give positive input.

See Question 5 for further information

Q. 3 Can you give examples of issues in current work and/or policies that still need to be addressed?

Employment is something that many people with learning disabilities .ASD feel they want. Those that have that opportunity now appreciate the fact. Fife has been active in trying to place people in employment. The setting up of the Media Solutions Project within the Social Work Service has proven a great success and employs 13 people with learning disabilities.

It is sad to know that several years past employment was available within the Adult Resource Centres but that came to an end without explanation. Carers often raise this but satisfactory responses are never given. It was in my opinion based on Health and Safety issues. The Health and Safety legislation is sadly used in some cases not to do something instead of investigating how activities could be carried out within the law. Is this the case here?

Future Priorities - Healthcare

Q.6 What still needs to be done to ensure that people with learning disabilities have access to better and more appropriate healthcare?

During the Same As You Project the Good Healthcare for Life Working Group recognised that there was a particular problem when some people entered hospital. A proposal to train nurses and in particular Auxiliary Nurses was never taken up. Still, on many occasions carers have to spend many hours in hospital caring for their family member as there is insufficient support on the wards.

More has to be done to highlight the need for exercise and healthy eating to prevent heart disease.

Fife does have good sports facilities and at least in one area these facilities are offered once a week for people to go and get exercise. One of those incentives is to supply transport which has been the policy in Fife. Future policy may deem that this be removed to save money. This will certainly reduce the ability to access such facilities by many who have a learning disability.

Good Practice - Individuals

Q.5 What have you done, as an individual, to make positive changes within your local area?

As a carer I have been heavily involved in the Same As You Project being a member of working groups and chairing the Good Health Care for Life working Group. Also a member of the Same As You Project Committee.

As chair of the Good Health Care for Life Working Group I led the team to work on a number of projects. Liaison Nursing which has now been expanded to cover Liaison Nursing for acute and primary care patients.

A cookbook promoting healthy eating was produced for people with learning disabilities.

Work was also done to promote the need to address the problem of dementia in people who suffer down syndrome. Clinics have now been set up in Fife although not directly from that work but I am sure it had an influence.

I was also involved in the setting up of the Local Area Co-ordinators which sadly has not been established as I would have wished as a carer.

A book "Thinking Ahead" was introduced to Fife after I had seen it in Glasgow. Working with the Supported Living Working Group it was made available to all carers who cared for people with learning disabilities/ASD in Fife after being edited to make it relevant to Fife.

In the latter days I have transferred to Chairperson of the Carers Working Group and have or am presently working on issues including carers assessments, appropriate adults, adult protection training for carers and planning a conference called "When I Am Not Here" which will address the planning needed for family members who have a learning disability after the carer is no longer able to care.

Future Priorities – Independent Living

Q.8 What still needs to be done to ensure that people with learning disabilities are able to live independently?

There will be a number of reasons why people with learning disabilities do not move on to independent living. In my experience one main one is fear for the cared for person.

Moving people forward is not an easy task and there are many aspects which have to be addressed.

In Fife, I with my Carers Working Group are to address the problem by organising a “When I Am Not Here” conference in November 2012. Workshops covering Guardianship, Power of Attorney, Bereavement, Housing Options, Circles of Support, Wills and Trusts will be held. This is being organised in partnership with Equal Futures who wished to run a similar conference.

However people must be seen as the priority and not a budget of various departments. People who move forward towards independent living should have had a risk assessment carried out. This should be realistic and the options to make that person safe should be acceptable to that person and their carer. Reliance on technology for safety should not be relied upon without the approval of all parties.

Future Priorities - Education

Q.7 What still needs to be done to ensure that people with learning disabilities have access to better educational opportunities?

Excellent work is carried out in Fife for those with learning disabilities. Unfortunately there is a lack of communication between the colleges and the carers. It appears that the colleges fail to understand that behind most students with a learning disability there is a carer who also has a life to manage at work, at home, or with the rest of the family.

Although offered the opportunity to attend Committees where items discussed are relevant to their work is discussed rarely do they attend.

Although the subjects offered by local colleges are very good more should be done to teach the basics which would help the student greatly. Simple arithmetic, reading and writing would be helpful. At one time an evening class was available for those subjects but was discontinued.

More guidance should be given to students when courses are made available. Choice is a great thing to have but for many a little guidance could result in a better value in learning for the student.

Carers should be given the opportunity to hear of the progress being made by the student and be given advice as to how they can help. Some would be pleased to do so!

Thank you for taking the time to read the consultation document and taking the time to respond to the question. Your continued input and support is vital in ensuring that we continue to close the inequality gap that people with a learning disability face daily.

All completed questionnaires should be returned to Sarah Grant either by e-mail or at the address below. The closing date for responses is 30th September 2012.

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Future Priorities – Employment

Q.9 What still needs to be done to ensure that people with learning disabilities have access to better employment opportunities?

This has always been a very difficult area for people with learning disabilities. I have not had enough experience in this field to make valid comment above those made in Question 3. However it is my opinion that for many legislation is a barrier to the employment of these people. Health and Safety and Employment Law are two which may be the major blocks.

My response in Question 3 shows how for some reason the people are refused the opportunity to do meaningful work. If this is the case within Fife Council what hope do we have in the private sector.

Future Priorities

Q.10 What other future priorities do we need to focus on? (Please list these in order of importance with the most important first)

The new proposal to Integrate Adult Health and Social Care will be interesting and should give more opportunities to develop services without the “them and us” attitudes which come to the surface from time to time. “Who pays” should not be a major issue.

It will be important however to continue to involve the service user and carer at a high level in the process of decision making.

Sarah

*I have also submitted
this response to Fife
Council who are also
collecting information
use this if you think
it OK for a person to
respond twice.*