

## ***The same as you? – Consultation***

*The Same as You?* (SAY) is the policy that was launched by the Scottish Executive in May 2000 to review services for people with learning disabilities and people on the autistic spectrum. It contained 29 recommendations intended to drive a change programme which would improve services.

In 2010 the Scottish Government set up an Evaluation Team to find out how the lives of people with learning disabilities and/or on the autistic spectrum and their families have changed since the launch of SAY?

The evaluation process highlighted a number of areas where further work was still required, for example:

- Healthcare
- Education
- Housing
- Employment

In order to enable service users and carers within West Dunbartonshire to participate in responding to this consultation, an event was held in Dumbarton Burgh Hall on 20<sup>th</sup> September. The aim was to facilitate a consultation that enabled as many service users as possible to take a meaningful part and to give their views. We did this in a variety of ways:

- In order to remind everyone about the recommendations of SAY the Good Life Positive Attitudes Group produced a light-hearted presentation illustrating the changes that had taken place locally as a result of SAY.
- The Advocacy service produced a multi-media presentation that covered the time since SAY was published. This helped service users to be aware of the time scale being discussed.
- The Speech and Language Therapy team adapted the questions from the Government consultation and provided visual support to make them more meaningful and clear. They also used Talking Mats to offer service users an alternative way to express their views.



Of the 582 people with a learning disability known to the CHCP, 57 attended the event.

Carers were consulted in two ways. Postal/online questionnaires were sent to 150 carers and focus groups ran concurrently with the service users' consultation.

The resulting report that was sent to the Scottish Government combined both the views of service users and carers and was tied together by an introductory overview and conclusion provided by the Learning Disability Service. The following is a summary of the report. If you are interested in reading the full report, please contact Robynn at [robynn.mccrossan@west-dunbarton.gov.uk](mailto:robynn.mccrossan@west-dunbarton.gov.uk) or on 0141 562 2331.

## **Progress**

Much has changed for people with a learning disability since the publication of *Same As You*, including a greater emphasis on listening to the views of service users.

National Progresses include:

- Hospital discharge programme
- Development of Housing Support Options
- Personalisation of services
- Service user involvement and personalisation

## **Challenges**

- Many people with a learning disability feel that they still face barriers created by the attitudes of others, which prevent them from making a meaningful contribution to their local communities.
- Reasonable adjustments need to be made to the way services work, and to the kind of information they provide in order to improve access for people with learning disabilities.
- Accessibility of public transport continues to be an issue.

## **Good Practice Locally.**

- Joint Health and Social Work LD team
- Local Area Co-ordination
- Independent Advocacy
- Housing support
- Employment Services
- Day Opportunities developed so there are fewer building based services and a wider range of opportunities
- New respite centre
- Short breaks
- Development of service user networks that are involved in planning services and providing feedback
- C21 health checks

## Views of Carers

- We are consulted more often, and suggestions and comments taken on board.
- Positive changes have been made to day services following consultations with service users, families and carers.

- The integration of health and social care services has benefitted carers and service users.
- The support and training received from the carers centre is to be commended.
- Public transport is improving, but there is a need for more wheelchair accessible buses.
- We feel the social workers in the learning disability team do a good job.

### **Future Priorities - Healthcare**

- Continue to improve access to community / primary health care.
- Work to improve participation in national screening initiatives.
- Improve communication about health issues with people with a learning disability and their carers.

### Views of Service Users

#### Access to Healthcare

The majority of service users could not access primary care without support.

- 12 people said they did not understand their Doctor.

#### ***“Cut down on the mumble jumble.”***

- 7 people said their Doctor did not take them seriously, listen or understand them.
- 6 people said that their Doctor did listen and take them seriously.
- Some reported that their Doctor spoke to their family member/Support Worker rather than them and some felt rushed.

#### Living a Healthy Lifestyle

Most people said that their knowledge about living a healthy lifestyle came from family, friends, support workers or health professionals, not from health promotion campaigns. Barriers to healthy eating were :

- Family member chooses what I eat and/or does the shopping (7).
- I need to learn how to cook (5).

26 people reported doing some form of exercise, 9 said that they didn't.

***“I used to go to the gym but stopped doing it. Lost interest because I was always on my own. Need more support.”***

#### Views of Carers

It was agreed that better communication with hospital staff is needed, and several of the carers suggested that the use of a “communication passport” that would show health staff the best way to communicate with the individual with a learning disability.

Although it was discussed that personal care needs must be met, and more compassion needed regarding patients with profound needs, it was felt that there has been an improvement in the delivery of health care since 2000.

## **Future Priorities - Education**

People with a learning disability still suffer from low expectations of educational achievement. There needs to be better continuity and planning so there is clear direction and a stop to regarding college attendance as an end in itself. In addition, there needs to be improved access to mainstream courses.

### Views of Service Users

- 14 people said they liked school, particularly seeing friends (3).
- 16 did not like school, due to boredom, the lack of support from teachers and being bullied .
- 5 people said they didn't like college as it was too loud/busy and that they no longer saw their friends from school.
- 12 people said they liked college, most because they made friends
- 6 people who didn't attend college said they would like to.
- 15 people stated that what they could learn at college was limited and would not help them to get a job.
- 3 people have gone to college for many years, often repeating the same courses.

***“If you have done all the courses, what else can you do? There is no use doing them again.”***

- 6 people stated that they liked or preferred learning in the community such as with their support workers/family at home.
- 4 people reported that they learned at work.

***“I have done CLAN, I graduated last year. Really enjoyed it.”***

### Views of carers

It was agreed that service users could probably receive a better level of education if classes/courses were delivered within day centres. It was also agreed that more appropriate courses could be delivered i.e. Life Skills, Cookery, Money Handling, etc.

***“Some colleges are not set up for people with autistic spectrum disorder”***

Carers also discussed the fact that it is always the same college courses that were available, and that there needs to be more of a variety of courses for people to attend, for example art, music therapy, etc.

The possibility of working more closely with schools was also discussed, and spending more time on the basics of education:

- Reading
- Writing
- Arithmetic.

## **Future Priorities – Independent Living**

- Promote Self Directed Support, peer support, greater involvement of service users in recruitment and clearer planning strategies with housing developers.

### Views of carers

Housing to be appropriate to the clients needs with the necessary support and supervision in place.

*(Note: Service users were not asked about this issue at the consultation event as it was discussed at last year's event. Instead of reduplicating, more time was spent discussing the other topics).*

## **Future Priorities – Employment**

There needs to be a national lead in ensuring that people with a learning disability have access to the full range of employability projects which are currently in place.

### Service Users Views

- 11 people said they had a paid job, all part-time.
- 12 people who did not work said they would like a paid job, 9 did not want to work.
- 8 people had paid employment in the past.
- 2 were asked to leave because they were being bullied or they didn't have enough support at work.
- 2 had been made redundant.
- 11 people stated they were worried about their benefits being cut if they worked.

***"I worked in Remploy for five years but it closed down. They should have kept it open. We're all unemployed now."***

***"I used to answer the phones...and I miss it. I'm on my own so I miss it."***

### Views of Carers

Carers believed that there has to be appropriate employment support.

Carers felt that employers still had to be encouraged/persuaded to employ someone with a learning disability.

## **Future Priorities - other**

- Remove current barriers which inhibit full community participation.
- Make better use of mainstream community resources.
- Personalise services.
- Make public transport fully accessible.
- Continue the positive developments in integrated Health and Social Work Services.
- Improve access to, and communication with, Primary and Acute Health Care.
- Reduce reliance on written communication and further implement Inclusive Communication.
- Develop clearer planning processes between all agencies for supporting people with complex challenging behaviour.