

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

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.

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 20/9/12. This was hosted by Lomond and Argyll Advocacy Service, and planned by a steering group that included wide representation from learning disability services. 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.

The planning group felt that the method used by the SAY evaluation concentrated on mildly disabled service users, excluding those who have communication difficulties, particularly those whose understanding of language is impaired. Whereas speech difficulties may be readily apparent, problems with understanding are more easily hidden. Nonetheless, most people with a learning disability struggle with communication at some level. This is particularly true when the consultation involves abstract concepts. In addition, few people with a learning disability are able to read and write to a level that would make this a possible alternative. Much of the planning of the West Dunbartonshire consultation event centred on seeking to overcome these difficulties.

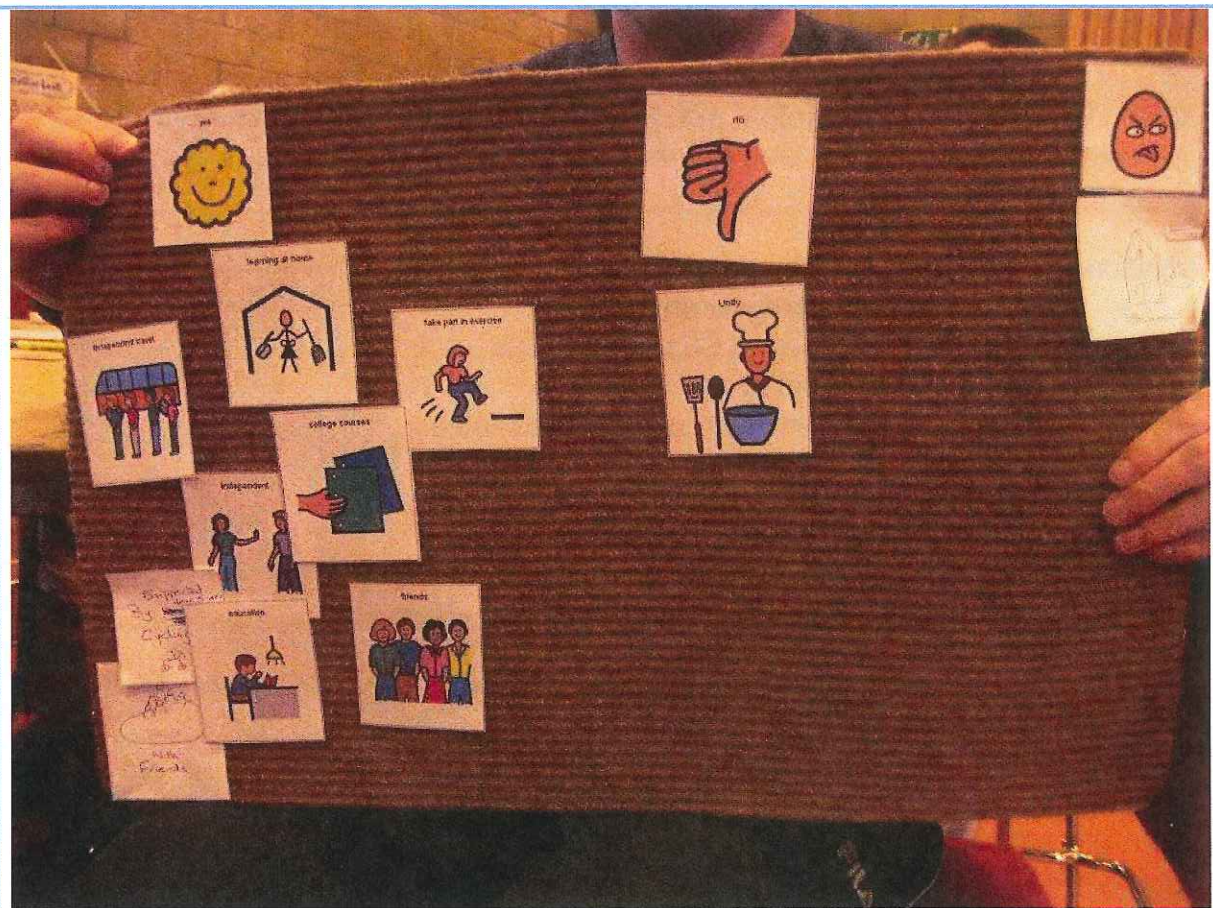
This was done in the following ways:

Local Area Coordination worked with the GoodLife Positive Attitudes group of service users to produce a presentation that reminded everyone about the recommendations of Same As You and changes that had taken place locally as a result.

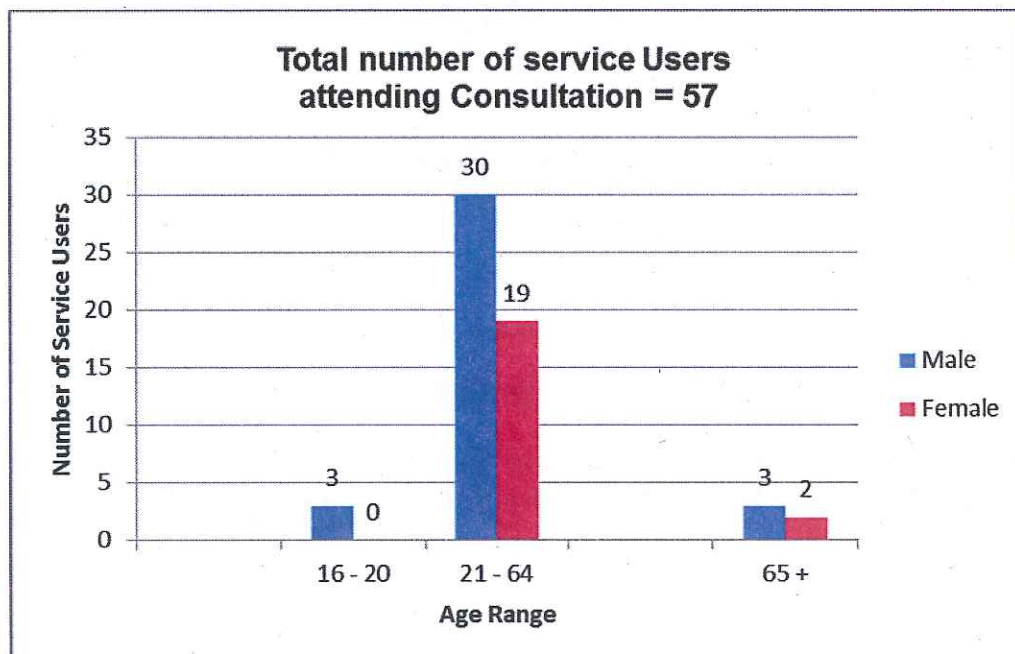
An Independent Advocacy worker produced a multi-media presentation that covered the time since Same As You was published. This helped service users to be aware of the time scale being discussed.

Speech and Language Therapy rephrased the questions in the consultation to make them easier to understand. Members of the LD team volunteered to facilitate small group discussions at the consultation, and to record service users spoken responses.

Speech and Language Therapy also used Talking Mats to enable service users who are not able to take part in group discussion to give their views. This is a visual method using symbols. This method was available on the day to anyone who wanted to use it. Here is an example of a completed talking mat:



Independent Advocacy workers and Local Area Coordinators provided a Feedback Frieze where anyone attending the consultation day could add a comment. Of the 582 people with a learning disability known to the CHCP, 57 (9.79%) attended this event. The distribution of age and gender is shown in this table.



Carers were consulted in two ways – postal/online questionnaire sent to 150 carers and focus groups that ran concurrently with the service users' consultation. The responses in the remainder of this questionnaire are the results of these consultations.

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?*

Nationally,

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

For local initiatives, see Q 4

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

- Many people with a learning disability feel that they still face barriers created by the attitudes of others. They feel that they could make a far bigger contribution to their local communities if these barriers could be overcome.
- It can be difficult for people with a learning disability to access services. This is not now about physical access, which is greatly improved, but about understanding how to use services. Reasonable adjustments need to be made to the way services work, and to the kind of information they provide.
- Accessibility of public transport continues to be an issue.

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?

- Joint Health and Social Work LD team, co-located.
- 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

All the carers that attended both focus groups agreed that they are being consulted with more, and that their points and comments are being taken on board. All participants agreed that the development of the new respite centre at Dunn Street was built on the back of consultation with all suggestions taken on board.

It was also agreed that there has been positive changes to day services following consultations with service users, families and carers.

Participants commented on the integration of health and social care services, and feel that this is benefiting them and the service users, and will do more so over time.

It was also commented on about the support received from the carers centre, and the centre providing training to receive new skills which help the carer to support the person they care for more effectively.

One participant commented that the clinical support worker liaises well on behalf of her son, preparing and planning appointments etc.

It was agreed that public transport is getting better, and has improved since 2000, but there is a need for more wheelchair accessible buses.

Several participants also commented on having a great experience with the social workers in the learning disability team.

Good Practice - Individuals

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

See above.

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?

- We need to continue to improve access to community / primary health care.
- We should work to improve participation in national screening initiatives
- We should improve communication about health issues with people with a learning disability and their carers.

Views of Service Users

The majority of service users could not access primary care without support. This is true of every step of the consultation process, from making an appointment to taking medication. Most people said that they would never go in to an appointment without a carer / family member.

Understanding the GP

- 12 people said they did not understand their Doctor.
- 7 of these mentioned that this was because of the use of jargon/complicated language.
- 4 people said they relied on their Support Worker or family members to help them understand.

“Cut down on the mumble jumble.”

Being taken seriously/listened to by the GP.

- 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.
- 5 people reported that their Doctor spoke to their family member/Support Worker and not them and they didn't like this!
- 2 people said they felt that they were rushed and suggested that a longer appointment would be better.

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. Most people knew that eating fruit and veg was a good thing, but other health knowledge was limited. The most common barriers mentioned to health eating were :

- Family member chooses what I eat and/or does the shopping (7).
- I need to learn how to cook (5).
- I need support to learn how to shop for healthy food (4).
- Cakes/chips are tasty (2).
- Poor availability in the local area. ***“Mostly chips.”***

“I don't know how to cook really. I'd like to learn. I live out of a tin or freezer.”

“Chips are nice and tasty.”

“The supermarket’s so big I get lost.”

Exercise.

- 26 people reported doing some form of exercise.
- 9 people said they didn’t exercise as they had no interest or that they used to but stopped.
- 4 people stated that they’d like to do more exercise.
- More support is needed to exercise.

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

“Nobody is here to take me to dance class!”

Views of Carers

The participants felt that carers need to be able to give more input into health decisions. Carers feel that they are getting less say and that decisions are being made without the carers knowledge.

It was also agreed that better communication with hospital staff is needed, and discussed the possibility of using a “communication passport” that would show health staff the communication limits of the service user. Although it was discussed that personal care needs must be met, and more compassion needed regarding patients with profound needs, there has been an improvement in the delivery of health care since 2000.

Future Priorities - Education

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

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

School.

- 14 people said they liked school, particularly seeing friends (3).
- 16 did not like school, reasons given were being bored (1), the lack of support from or being punished by teachers (4) and being bullied .

- One person stated they liked mainstream primary school but hated their Secondary special School.

“I used to get picked on because I... used a different bus and I wasn’t as clever as them. Having to go to a different class. This made me feel ostracised, put away. I didn’t get to know people or they me. I didn’t like school, I learned more when I started work.”

College.

- 5 people said they didn’t like college. Reasons given were that it was overwhelming, frightening, too loud/busy (2) and that they no longer saw their friends from school (1).
- 12 people said they liked college, reasons given were that they made friends (10) they were respected and not bullied there (3), they liked learning (2), that tutors were good (1) and some just liked it!
- 6 people who didn’t attend college said they would like to.

Negative experiences and barriers.

- 6 people identified travelling to college as being a problem.
- 2 people said they didn’t get enough support at college.
- 15 people stated that what they could learn at college was limited. The reasons given were there were fewer courses available (2), that there were cuts and closures (3), not being allowed to choose their own courses (2) or having gone to college for years and/or repeating the same courses (3). One man has been going to college for 23 years!

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

College as preparation for employment.

- 2 people reported that the skills they learned at college helped them to get a job or volunteering opportunity.
- 5 people thought that going to college would help them get a job.
- 14 people said they did not think going to college would get you a job.

Learning in the Community.

- 6 people stated that they liked or preferred learning in the community such as with their support workers/family at home (5), at Skypoint Unit (2), at local the Day Centre or Community Learning Centre (3) and with Community Literacy And Numeracy (CLAN) (7) which was described as being an outreach project and received particularly positive comments.
- 3 people said they would like to learn through a mixture of college

AND at the local Day Centre with a tutor coming to visit them there.

- 4 people reported that they learned at work.

"I have done CLAN, I graduated last year. Really enjoyed it."

Views of carers

Participants discussed the most effective way to deliver education, and agreed that it doesn't have to be college centred. 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"

Participants also discussed the fact that it is always the same college courses that are 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

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

- Promote Self Directed Support in a creative manner separate from budget processes.
- Promote peer support
- Promote greater involvement of service users in recruitment.
- Clearer planning strategies with housing developers to ensure suitability for people with multiple disabilities.
- Better use of smart technology.

Views of carers

All participants agreed that the housing would need to be appropriate to the clients needs and that the necessary support and supervision would need to be in place to allow clients with a learning disability to sustain their own independent living.

One participant expressed concern that the service user wouldn't have the proper support when out and about, and independent living would also have to cover when the service user is out of their home and in the community.

Future Priorities – Employment

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

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. Too often people with a learning disability are seen to be too far from the employment market and are viewed as likely to present poor outcomes for employability services.

Service Users Views

Paid Employment.

Currently

- Of the people attending the consultation day, 11 said they had a paid job. All of these were part-time jobs.
- 4 people said they enjoyed work and would like to work more hours.
- 12 people who did not work said they would like a paid job.
- 9 people who did not work said they did not want a paid job.
- Of those in paid employment, 5 said they had spent between three and ten years in that job.
- People worked in a variety of places but the top employers were Charity Shops (4) and West Dunbartonshire Council (3).

Previous employment.

- 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.

“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.”

Barriers to gaining paid employment.

- 11 people stated they were worried about their benefits being cut.
- This stopped 7 people from working at all and 3 people from working more hours even though they wanted to.

“Employers see the disability not the person!”

“If you live in your own house working or volunteering affects your benefits.”

“The Government should stop forcing people with disabilities to work. Not easy getting back on benefits, I had no money.”

Views of Carers

Everyone agreed that there would have to be appropriate support with employment for the employee with learning disabilities. It was agreed that linking with Work Connect would help oversee support, safety, etc.

Participants weren't sure if it is easier now than in 2000 for an adult with a learning disability to gain employment, they felt that employers still had to be encouraged/persuaded to employ someone with a learning disability

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)**

- Remove current barriers which inhibit full community participation.
- We need to make better use of mainstream community resources in all walks of life.
- Personalisation of Services.
- Public transport needs to be fully accessible.
- Continue the positive developments in integrated Health and Social Work Services.
- Improve access to and communication with Primary and Acute Health Care.
- We need less reliance on written communication. The lack of progress in implementing Inclusive Communication is disappointing.
- Develop clearer, more robust planning processes between all agencies for supporting people with complex challenging behaviour.