

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

The content of the findings were broadly seen as the views of our members who are both parents and people with learning disabilities.

However there are particular concerns about wider policy issues which are having an impact. Firstly, the planned changes to the benefit system. Many people are fearful and anxious about the pending changes.

Secondly, the major policy decision that colleges will only offer places which have employability outcomes has had a knock on effect which has excluded and prevented older adults with learning disabilities to take up college courses. In Edinburgh the introduction of the New Edinburgh College which has drawn in Telford, Jewel & Esk, and Stevenson Colleges into one large college. There has been a substantial reduction in places available more than 50% reduction. This has left people isolated and staying at home during the day with their elderly carers and as a consequence the loss of day time respite for carers.

Lastly, the introduction of eligibility criteria which was specifically in used after the introduction of free personal care for the elderly. This has had an affect on people accessing services who have learning disabilities and wanting to continue to develop their independence from their older carers.

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 following comments are from parents and people with learning disabilities at our consultation event.

- Consultation Reports and things that have worked
- In relation to Carers issues – reflected views well
- Daughter moving on soon – surprised she is so keen - working out in long term
- Local authority has agreed some support for older carers
- Good we have LACs - does depend on who you get

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

The following comments are from parents and people with learning disabilities at our consultation event.

- Some things have gone backwards – I feel like “policeman” having to monitor service. Son’s needs have increased – but no additional funding to support him. Service getting diluted - carers having to fill gap.
- Day activities have “fallen apart” (for 1 person) – café closed Stuck wandering around shopping centres. Now have a DP
- Day Centres had “bad press” – but were a bit of a lifeline for parents.
- After school – are there genuine choices??
- Each individual is different – one side does not fit all
- Other changes have cut across SAY ideas i.e Eligibility Criteria, ILF
- Charging Policies
- Not everyone could answer these questions
- We don’t have the capacity to explain this to people
- Should have someone to go and do consultation
- Needs to be more visual
- I go to Fisherrow ... I drink coffee? Hang on! Not JUST THAT !! I only get it once a week and sometimes it just gets taken away
- Does it reflect your views?
- Put from pillar to post
- These figures can’t represent whole of Scotland
- People want their own Specific funding... not a project being funded
- Find Funding yourself!
- Most people share housing - whether that’s more aboutFUNDING !
- “Do you think it’s right for everyone else to pay for your daughter?”

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?

EDG has developed the Big Plan – a form of large group person centred planning with 8-10 individual and their families at one time. This has been particularly helpful for young people and their families who are in the transition from high school to adult life. However, it has also proved very useful for older individuals who want to make positive changes in their lives also. The Big Plan offers an exceptional opportunity for communities to get involved in supporting the aspirations of young disabled people who want to make their contribution. We have begun to pilot the Big Plan approach as a first step in people deciding how they want to Self-Direct their own support.

EDG continues to practice and build best practice around person centred planning in the east of Scotland and more widely especially using MAPS and PATH

We have been committed to promoting ABCD approaches to community building for people with learning difficulties and their families. In particular, EDG set up a very successful Community Circle in North Edinburgh which is diverse in membership but includes some people with learning difficulties at its core.

EDG has become a Remote Reporting Centre and in partnership with People First has been supporting people with learning difficulties to work with primary school children to challenge hate crime.

For the past 5 years our SOFI Project (initially with Lottery support and currently funded by the City of Edinburgh Council) has allowed us to support older families in a uniquely person centred and flexible way – ranging from advice and information, to person centred planning, to brokerage around services and funding.

Good Practice - Individuals

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

Please provide any comments and/or examples 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?

The following comments are from parents and people with learning disabilities at our consultation event.

- Access to Healthcare
- If you have a good GP practice – works well
- ENT was a disaster initially –but works if you get liaison nurses involved
- Importance of healthy living - balance between choice and keeping well
- GPs liaising with learning disability teams
- Problems with communication between health professionals sometimes
- Son sometimes does not have support staff to take him to hospital appointments. Lack of flexibility
- Since Centre closed - have to now buy meals out – costs more and food maybe
- Missing friends from centre?
- Learning Disability Teams in Edinburgh have been “really, really good” – helped people’s health
- Work with GPs to do Annual Health Check
- “My doctor is good – helps me”
- When I visit hospital I was treated good – I use a

- wheelchair to be safer... because I have epilepsy.
- Do people need help to get to health appointments? Shouldn't be just down to carers/parents...
 - Day Centre – work on healthy living, Managed to find a few good Keep Fit Classes ... not too quick. Have found some good inclusive ones. Good Zumba Class in Musselburgh. 1 person goes to Weight Watchers
 - Dieticians not taking referrals for losing weight.
 - Person likes to help people in wheelchairs
 - Can access a Rosemary Conley Fitness programme through GP / NHS now
 - Often Support time is so brief – hard to support people to cook healthy meals
 - Funding situation has got WORSE in past years
 - Individuals and families budgets stretched to pay for healthy activities i.e. support time to attend GP appointments
 - Is General Population less healthy too?!
 - Important not to forget emotional health too
 - Appointments have been better – FAIR leaflets have helped.
 - There is an improvement in diagnosing health issues... but issues getting to hospital
 - More leaflets on procedures?
 - Depends on whether Doctor etc. have met person. Having to re – tell stories
 - Very different experiences from parents/carers of people with autism were shared. i.e. fasting, not given early appointments, lots of people taking histories
 - Families, support staff being asked to stay with patients throughout. Like they don't want to do their part of their job
 - Royal Blind School – some young people not from Edinburgh no records
 - Sometimes difficult transition to adult health services (Emergency over 14 adult services)
 - There are lots of possibilities about health services being available to special schools – but makes the transition to adult services more of a challenge when it comes

Future Priorities - Education

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

The following comments are from parents and people with learning disabilities at our consultation event.

Lots of college places have been lost
I enjoy college – Life Skills
Tutor comes to us but funding has been cut
Lots of cutbacks
Classes fill up quickly
Places limited
Oversubscribed.
No direct link between college and then getting a job.
Repetitive – not moving on – no progression
Good transition at Edinburgh Blind School – College
Young People don't get enough support
Quality of transition changes depending on area! (Nationally)
25 years ago - transition was non – existent
School Day Centre only options
Education / Learning - Less courses available
Courses repetitive – 3 years in a row
Done all the courses! Now nothing available
In 12 years – Things originally improved but now have got worse
My daughter has a paid job – Part time half day a week
Changes at workplace mean my son has lost work
Some support available
Good experience of Engine Shed but this is only a training place for three years
Son had a great job with good team support but Tesco takeover changed everything
Money is not always the driver for getting a job
Workers are needed
Employers today don't have the time to support people properly.
Funded Support
More Support is needed – all the way along the line
More barriers in place – needing certificates to be able to do a job
College places aren't tailored to people and their needs
Not flexible enough
Some employers better than others

Future Priorities – Independent Living

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

The following comments are from parents and people with learning disabilities at our consultation event.

It is not one size that fits all
Need confidence in the care support they get
Before leaving home BUILD CONFIDENCE
After you've left home BUILD CONFIDENCE
My son's funding has not changed since 2003
Independent living must be based on choice and individuality
DURING THE WEEK EVERY DAY SOMETHING
WORTHWHILE - GARDENING, VOLUNTEERING, OLIVE TREE
CAFÉ (NOW CLOSED) EDUCATION COLLEGE BEING PAID
More Opportunities for employment TEAM
CHOICE NOT GREAT BIG GROUPS
Right person for the job (supporting)
FLEXIBILITY OF SERVICES
L'Arche subsidising local authorities
Independent Living should not automatically mean living alone
WHAT IF? Conversation Planning for us not being able to help
our son
Emotional Blackmail on parents from the Social Work
Department.
The whole point: you NEED FLEXIBILITY of SERVICES
People need EMOTIONAL SUPPORT when they begin to live
independently
HARD TO FUND
Different types of support
RIGHT TYPE OF SUPPORT
HAVING A BABY YOUR CHOICE
Some people don't get funding because they are deemed 'too
able'...
HAVE A BABY
Ambulance
GIRLFRIENDS AND BOYFRIENDS
My girlfriend had a flat
On my own with other flatmates
What needs to be done to help people with learning difficulties
live more independent lives?
More preparation before journey
PREPARATION:
Children/young person
Parents

Disability doesn't stop at 16...Why do services?

Funding

In Sweden they have a good system

PAY MORE TAX

DEPENDS ON QUALITY OF S.W SOCIAL WORKER

Need a list of good builders

Need experience of being away from home

Moving on...

Skills to move on

BEING PRODUCTIVE

Nobody should have to sit drinking coffee everyday

People are restricted when still at home... don't even make a cup of tea...or school is next best

Need to get money to get the Specific Support you need

Future Priorities – Employment

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

The following comments are from parents and people with learning disabilities at our consultation event.

Real Jobs (Action Group) funding cut
It's very difficult for people to get jobs if they need support
More support needed
"I have a voluntary job three days a week in the café"
Gardening Money would be good
Lots of people working in Charity Shops
Voluntary opportunities but not paid work
Costs for people with learning difficulties (going out for Lunch) not subsidised
Would like to get a paid job – ASDA
People coming together, social, cultural (needs to be more options for this)
Very few jobs that transpire into jobs
Employers don't recognise people's skills and gifts
Need more incentives for employers
Support. A lot of work is needed with employers. We use employers' time and again but also look for new employers
People don't know what is available
Supported employment is difficult to get
More jobs available from the council not private employers
Employers are scared, legislation needs to change
Being at college was an achievement
No link between college and jobs
Impact on benefits if paid
Money that is earned doesn't seem right - £15 for two days
Employers could let others know Success Stories
It can be a long process but worth it!
Better process – Building for support

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)

Please provide any comments and/or examples here

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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