

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

There is a substantial caveat to our Yes response above:

- ◆ The evaluation interviews of people with learning disabilities and carers were carried out in the spring of 2011.
- ◆ This coincided with or came shortly after the setting of significantly tighter eligibility criteria for statutory services for people with learning disabilities. The effects of these changes are only now being felt as assessments are carried out.
- ◆ Under the new criteria, only those with severe or critical needs are eligible for services. Those with moderate needs will have services withdrawn.
- ◆ It is difficult to estimate what proportion of the total number currently receiving services is represented by those with moderate needs, but if it is roughly analogous to levels of disability it could be up to 50%.
- ◆ This casts the evaluation in a new light: whatever the adequacy or failings of current services, and whatever action is taken to improve them, a very large proportion of those with learning disabilities will not benefit because they are, or will become, ineligible for those services.
- ◆ The Same As You? was written in an environment which assumed that everyone who needed services would receive them, but this is no longer the case.
- ◆ We feel that the TSAY review needs to acknowledge this change: The Consultation Report makes only very brief reference in passing to eligibility criteria in relation to transport (p.24) and Work (p.60).

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 employment support provided by Ways2Work in the Scottish Borders has made securing paid jobs a realistic ambition. Interest Link has employed 7 staff through this route since 2007.

The building of houses in which 4-5 service users can have their own flat,

but where there is also a staff flat or office has worked very well in Kelso.

Borders College Access to Learning courses have served young people very well in preparing them for an adult life that is as independent as possible.

Interest Link Borders has operated across the Scottish Borders since 2002 and has provided over 650 befriending links to around 340 children, young people and adults with learning disabilities: a full description is provided under Q.4.below. Now that eligibility criteria have been tightened, we are the main source of support for people with low or moderate needs.

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

Community and social involvement

SAY Recommendation 15: Local authorities and health boards, should both examine what they provide and develop more modern, flexible and responsive services which support people in the community through employment, lifelong learning and getting them involved socially.

SAY Recommendation 21: There should be a long-term programme to promote public awareness about learning disabilities and including people with disabilities in the community. This should include programmes from the earliest years of education. The new centre for learning disability could be responsible for taking this forward.

Our experience is that contracted services using paid care staff cannot achieve real community involvement for a number of reasons:

1. At an organisational level, contracted care providers are (rightly) focused principally on service users care needs. It is difficult for them to focus on providing social relationships as well.
2. Contracted staffing levels are usually sufficient to provide a safe and diverse buildings-based service, but are not adequate to enable significant community involvement on a 1:1 basis.
3. Where 1:1 community support is available, service users are usually asked to pay their support staff's activity costs and are well aware that there is a formal contractual relationship with staff, who are not there purely out of choice. As a result the relationship is not a normal social friendship on which further social relationships in the community might be built.
4. These elements are even more relevant in children and young people's services, where there will always be an age disparity between service users and staff.
5. Eligibility criteria now restrict statutory contracted services to those with severe and critical needs. This will leave an even larger percentage of people without support for community involvement.

This is no criticism of these staff-delivered services, it is simply a reflection of their nature and the fact that normal social relationships and community involvement are difficult to deliver.

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?

Interest Link is an unusual organisation, in that it delivers its services entirely through volunteers and is focused principally on social and community involvement. Because of this, the response below gives a full description of the organisation and its services as background information.

Aims, Objectives and Projects.

- ◆ Interest Link Borders aims to improve the quality of life of people with learning disabilities and their carers in the Scottish Borders through volunteer befriending.
- ◆ We are a local charity, founded by carers in Berwickshire in 1990. We expanded to cover the whole of the Borders through four branches covering Berwickshire, Central Borders, Roxburgh and Tweeddale in 2002.
- ◆ We hold the Approved Provider Standard for Befriending Services and the Queen's Award for Voluntary Service.
- ◆ We have 340 registered service users and 200 volunteers and have created over 650 befriending links since 2002.
- ◆ In the year April 2012-March 2013 we aim to run the following projects, which are developments of our previous work.
 - ❖ Our Children's and Young People's Project will benefit 86 service users aged 8-25. It will concentrate on personal development at a key time of transition, aiming to complement the Curriculum for Excellence and Getting it Right for Every Child. There will be around 46 1:1 links and 40 links in groups.
 - ❖ Our Adult Project will benefit 140 adults with learning disabilities. It will provide around 105 longterm 1:1 befriending relationships, and around 36 short-term links, mostly in groups.
- ◆ Our services will be free of charge apart from activity costs such as cinema tickets or refreshments. We pay all volunteer expenses.

The need for our services.

- ◆ People with learning disabilities have a significant, lifelong condition that starts before adulthood, affects their development and means they need help to understand information, learn skills and cope independently. Cerebral palsy, down's syndrome and autistic spectrum disorder are the most common causes.
- ◆ The Same As You? highlighted that people with learning disabilities usually have no social contacts outside their family, day centre or school and no experience of forming normal social relationships. However they have the same social needs as their non-disabled peers and the same need to pursue their interests, participate in community activities, make choices, gain skills and develop independence.
- ◆ There is also a need for high quality respite for carers of people with learning disabilities, as identified in, for example the Carers Strategy for

Scotland.

- ◆ Our feasibility studies, independent evaluations and evidence from other organisations confirm that this need is felt strongly in the Scottish Borders, and that there are no other services in the area addressing it.

How our services are delivered

1:1 links

- ◆ Service users of all ages are matched 1:1 with volunteers who share their interests, are usually of a similar age (although our childrens' links sometimes involve adult volunteers) and meet up with them regularly.
- ◆ Activities are chosen by service users and volunteers and will usually take place in the community. Typical activities will include going to the cinema, cycling, local events, walks, shopping, going for coffee, arts & crafts, golf, swimming or football.
- ◆ Activities usually last for around three hours and can be weekly, fortnightly or monthly.
- ◆ Because of the nature of learning disabilities, relationships can take several months to fully develop. Once established they are very precious and accordingly we aim for longterm sustainability, with adult links often lasting up to 5 years and as long as 10. Childrens' and young peoples' 1:1 links are often shorter because of the changing lives of younger service users and volunteers.

Befriending Groups

- ◆ All branches run young people's groups and some run them for children and adults.
- ◆ As well as being fun, the groups build confidence and help develop the ability to interact and communicate as part of a group.
- ◆ Groups usually have roughly equal numbers of volunteers and service users and all the members are as close in age to each other as possible.
- ◆ The groups meet up regularly, usually on a weekday evening, and are supervised by an Interest Link staff member.
- ◆ Group members decide what they want to do, and as well as fun social and leisure activities, they often do personal development projects involving, for example, music, art & crafts, drama and outward bound activities.
- ◆ Children and young people usually stay in a group for two years, after which they can move to an older group or be linked 1:1

Why befriending is the most effective way of meeting the need:

- ◆ Service users' relationships with their volunteers have a very special quality, because the volunteers are there purely out of choice. This is often the only such relationship a person with learning disabilities has and makes a huge impact on their quality of life and outlook.
- ◆ Volunteers are drawn from service users' communities and are the ideal agents to enable their participation and integration in those communities.
- ◆ Unlike services using paid staff, the vast majority of volunteers in the Children and Young People's Project will themselves be children and young people, making relationships with service users more natural.

Expected Outcomes from our work (percentages are drawn from 2010 independent evaluation, and we would expect to match or surpass these in future work)

- ◆ People with learning disabilities will have improved confidence (91% of people interviewed), self esteem (87%), life skills (88%), physical wellbeing (46%) & mental wellbeing (76%).
- ◆ Family carers (66%) and referrers (100%) will find that befriending links relieve pressure and help families to cope, making family life more sustainable.
- ◆ 100% of volunteers will report a high impact on their awareness and attitudes to learning disability
- ◆ "Because befriending relationships are often very public e.g. in night classes, swimming pools, snooker halls, restaurants and cafes etc., this means that the profile of people with learning disabilities is raised as they undertake the social activities which many take for granted."

Unit Cost and Social Return on Investment (SROI)

- ◆ Our services cost around £1,150pa per befriending link/£16.40 per hour. Average UK cost of comparable short break respite is £20 per hour. (PSSRU)
- ◆ When asked to put a value on our befriending links, family carers generally responded that they were priceless. Asked if they were comfortable with a value twice that of a service delivered by paid staff the answer was yes.
- ◆ Relevant SROI proxies include:
 - ❖ Sustaining family home care saves £20,000-£69,000pa per person (PSSRU)
 - ❖ Benefits of short break services for a disabled child are at least £2,505pa (NPC)

Governance, Management, Monitoring & Funding

- ◆ Our Board of Directors and Branch Committees are made up of elected service users, volunteers, carers and representatives of statutory and voluntary care services.
- ◆ Our services in each of the 4 branch areas are delivered by a Branch Co-ordinator, assisted and advised by their Branch Committee and an assistant. All non service-delivery tasks, such as fundraising and financial administration are centralised and carried out by a Project Co-ordinator. This leaves the Branch Co-ordinators (who are line-managed by the Project Co-ordinator) free to concentrate on registering service users, recruiting, checking and training volunteers and creating and supporting the befriending links.
- ◆ We gather baseline and annual monitoring information internally and each branch keeps a database and submits a bi-monthly written report. This combines with 3-yearly independent evaluations as the basis for the project planning process.
- ◆ We are funded by Charitable Trusts, Scottish Borders Council and Big Lottery Fund.

Good Practice - Individuals

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

N/A

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?

This is not an area Interest Link is involved with.

Future Priorities - Education

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

We work closely with local primary and secondary schools and, together with Borders College, they appear to do an excellent job at preparing children and young people for adult life. There are indications that the number of college places available to young people with learning disabilities after they leave school may be reduced. This would threaten a key element of the process of making them as capable as possible of leading an independent life.

More could be done to develop social skills and broaden the horizons of children and young people's: Interest Link's groups have the feel of mainstream youth groups as there are often more volunteers than service users. This is usually the first such experience service users have had and gives them confidence that they can be part of a group of their peers "the same as you"

On the adult side, Interest Link's Buddies service has enabled around 40 adults with learning disabilities to attend mainstream evening classes with the support of volunteers. The presence of a volunteer ensures that class tutors do not have to spend more time on the person with learning disabilities than on any other student, and this has been one of the keys to success. The service is attractive to volunteers and fairly easy to run and could be copied in other parts of the country.

Future Priorities – Independent Living

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

Self-directed Support needs to be implemented nationally.
Social and community relationships need to be built up.

Future Priorities – Employment

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

Supported employment services (such as Ways2Work in the Borders) and social enterprises (like Kingsmeadows Catering and The Green Team) have proven effective in the Scottish Borders.
Advertising can have an impact on employers' attitudes
Local employers have to be courted assiduously and trust built up.

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)**

Self-directed support must be implemented fairly and consistently across Scotland. Implementation in England has been a drawn-out affair with a difficult transition to the new systems. This should be avoided in Scotland.

Development of social relationships and community involvement:

- ◆ Our independent evaluations are clear evidence of the enormous impact on quality of life that befriending can have for people with learning disabilities and their carers.
- ◆ Our service has broadened and grown to become an established part of the care landscape in the Scottish Borders and is of a sufficient size to have a significant impact (we support around 230 people each year).
- ◆ We felt there would be enormous benefit if our service was replicated in other parts of Scotland: At the moment, provision is very patchy, with Interest Link accounting for around 25% of all learning disabilities befriending links.
- ◆ Because befriending is relatively low cost and funding can be raised from the Lottery and Trusts, it can be developed as a support service for the large numbers of people who will be outside the new eligibility criteria.
- ◆ Of the future priorities identified by the TSAY evaluation, befriending has an impact on Children and young people, Choice and control, Support for families and carers and Public attitudes