

## 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

Please provide any comments, evidence and/or examples here

**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?***

Please provide any comments and/or examples here

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

Please provide any comments and/or examples here

The group mainly composed of professionals said:

- The impact of welfare benefit changes
- The voluntary jobs 'merry-go-round'
- The challenge of providing meaningful employment for people with learning disabilities.

### 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?**

Please provide any comments and/or examples here

### 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?**

Here is the graphic of the responses to this question at the Perth SAY Event. The points on the graphic were chosen as the most important points about healthcare by each of the four groups which participated in the event.



Please provide any comments and/or examples here

Here are comments made about health by individual groups:

The group of people with learning disabilities said:

- I manage my own GP appointments and my prescriptions
- One GP I met did not know anything about learning disability.
- Some GPs are excellent. Giving time to the person is vital. GPs need to listen and respond.
- Health services need more education.
- Specialist clinics and centres can be very supportive.
- Sometimes health services, including generic health services do not know much about people on the autism spectrum.
- Staff at Ninewells are being given advice about customer care and how to be supportive
- If training has started, we need to see if it is working.
- Tools like “All about me” can help health services to understand but we need to make sure that health professionals are aware of these and the value of these.
- Mental health for people with learning disabilities and people on the autism spectrum must be considered. People on the autism spectrum can fall between learning disability and mental health services, so they don't get the support they need.
- Everyone in health should know about Adult Support and Protection.
- If you don't have a diagnosis, it can mean you don't get help. It can be hard to get a diagnosis of being on the autism spectrum.
- We need better, accessible health information in easy read.
- It's everyone's job to support people with learning disabilities.

People with learning disabilities said the following about healthy living:

- Staff can help to find out about opportunities.
- Groups can help me to be healthy but I am not sure if I can carry on without the group.

- The Special Olympics helps me to be healthy.
- We need GPs, health workers and support workers to work together.
- I want to learn to cook more healthily.
- I need to hear about other people's successes. This helps me.
- It can be hard to be healthy when being sociable revolves around food.
- The support you get to be healthy can be a postcode lottery.
- People need to remember to wash their hands to be healthy.
- Support workers should support me to be healthy but they should not do it for me.

The groups mainly composed of professionals said:

- GPs do not have the time/patience to spend with people with learning disabilities. We must build people's capacity to attend the GP and make GP services more accessible through training and changing policies (although one person thought that there was not much interest from GPs). Other services need to build relationships with GP practices. All practices should have an identified person with responsibility for people with learning disabilities, but not all do. In hospitals, there should be Disability Liaison Teams and people should know about them.
- People with learning disabilities can be very vulnerable in hospitals.
- If acute admissions can be anticipated we should invest in planning and training staff. Hospital staff do not have the time, resources or training to support people in hospital. This can mean that people with learning disabilities engage in behaviour which is viewed as challenging. There needs to be some discussion around the role of social care support workers in hospital.
- Health services need to engage in better planning and communication – communication booklets and health passports for planned admissions can be useful if health staff know about them.
- Health transitions from children's to adult services can be as challenging as social care transitions. The GP is not always central. The expertise held by the paediatrician is often lost. Resources can be so scarce that carers have to step in.

- With respect to guardianship, services are not always respecting the principle of the least restrictive option. There are cultural issues and rights issues involved here.
- If a person has complex health needs, all the support time is managing that and there are disputes on who should fund.
- Doctors at medicals for ATOS don't listen and don't identify needs.
- There seems to be a lack of communication between the different specialisms; this is especially evident in medication practice between neurology and psychiatry.
- Some consultant psychiatrists are very risk averse. Risk needs to be managed positively.
- There are strict eligibility criteria for access to learning disability services; the SAY definition of learning disability is not being applied, meaning that some people will be missing out on assessments.
- Specialist health teams are very confident but other parts of the services are not. Specialist health teams need to act as brokers, as conduits for information.
- Early onset dementia in people with learning disabilities is not being diagnosed, so additional resources cannot be accessed. We need to do baseline assessments of people with learning disabilities – we could do these when people register with a GP. What are the accommodation and support options for people with learning disabilities and dementia (especially when people are under the age of 60).
- Continue to work to make NHS 24 more accessible.
- Good practice and planning do exist – we need to learn from this!
- Technology can be a barrier if data systems do not match.
- But some people have a poor GP service with changing personnel, so they end up accessing specialist services instead, which is sometimes not ideal.

The following points were made by carers or about carers' health:

- We need to consider the whole family – identifying carers is important and needed for prevention work.
- Health is not just about managing physical health. My daughter's has complex needs; she is kept physically well but at the expense of any activities or skills development. When she is in hospital, I have to stay with her and care for

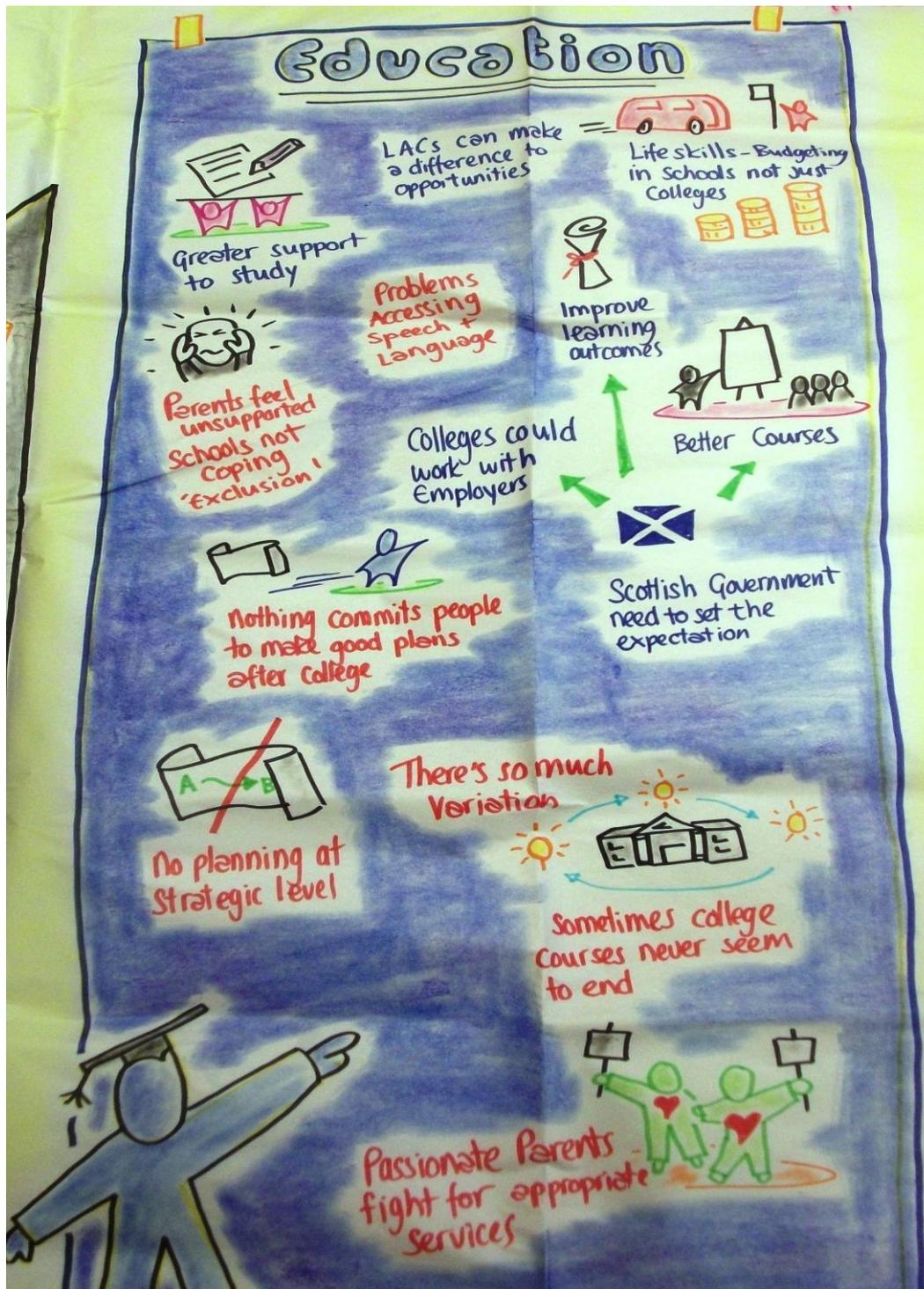
her more than I do when I am at home.

- Local authorities and health boards must work together regarding the health of carers
- It's important to have confidence and a good relationship with GPs – both for carers and the people they care for. Sometimes generic health services do not listen to advice from carers
- Carers must be asked what they want and need.
- There should be a website for information which is accessible to carers.
- For some people, hospital care has become more person-centred.
- Health care can still be a lottery and is not consistently good.
- Expectations and entitlements have improved.
- Community Learning Disability Nurses can help in arranging changes to support.
- Things have got better, but there is still more to do.

## Future Priorities - Education

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

Here is the graphic of the responses to this question at the Perth SAY Event. The points on the graphic were chosen as the most important points about education by each of the four groups which participated in the event.



Please provide any comments and/or examples here

The group of people with learning disabilities and family carers said:

- Start by building people up, not by putting them down.
- One person had progressed from a special course to a mainstream course. Another person had attended special school and her teachers had treated her as 'herself' which meant that she went on to have a full life and a job. Someone else went to hospital school.
- People need support to study and what is available is not always enough.
- Life skills and budgeting should be taught at school to everyone, including people with learning disabilities.
- People get bullied at school. Sometimes the bullies are other people with learning disabilities, sometimes they are other young people, sometimes they are teachers.
- There might be limits to what a person can learn but they should still have involvement with support.
- Awareness of disability is important but everyone should get the same chances.
- People who don't need as much support should not be left out.
- People need more social support, especially places to go.
- Courses never seem to end and always stay the same.

The groups of professionals said:

- Mainstream education is good for inclusion but not for learning.
- It is not appropriate for education to stop at 18 for some people with learning disabilities. Some people need more continuity.
- In Perth and Kinross there is a dedicated Transitions Team which acts as the one point of contact for all schools.
- The challenge for local authorities is to meet the differing expectations of younger/older families.
- Involvement tends to be done to the professionals' agenda so groups do not last a long time.
- Drama and singing can make a big difference to people's communication.
- There is little planning at strategic level for the transition

between primary school and secondary school or for the transition between secondary school and college.

- People need good information about options. There are some good example of this, like Transition Teams.
- There is a lot of variation across Scotland.
- College courses have been cut, but this might be a good opportunity to change the curriculum to outcome focussed planning.
- Specialist teams with multi-disciplinary staff can help to get things done by working in a joined up way to resolve problems. But what will happen with health and social care integration?
- People need advocacy to support transition.
- Good foundations are needed for lifelong learning and skills acquisition.
- We need more teachers in classes and more models of support.
- Exclusions or truancy can make later life difficult.
- The language about people with learning disabilities in children's and adult services is quite different. The assessment plans used in adult services are very different to the ones used in children's services under 'Getting it Right for Every Child.'
- The Scottish Government needs to set the expectations about what college should be like.

Carers said:

- It is hard to get information about any level of education.
- It is hard for parents to negotiate education systems, even if they are articulate and confident.
- Parents feel unsupported by education systems, especially if schools are not coping.
- There is so much talk about the 'exceptional' needs of the child, which contradicts the inclusion message.
- The curriculum seems to vary a lot between areas.
- College means a lot to people with learning disabilities, but we need to plan for what happens afterwards.
- Who pays for the health and social care support for a person to attend college?
- People with complex needs and profound learning and multiple disabilities have the right to opportunities too.
- Choice of school is a good thing but choices might be limited due to your location.

## Future Priorities – Independent Living

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

Here is the graphic of the responses to this question at the Perth SAY Event. The points on the graphic were chosen as the most important points about independent living by each of the four groups which participated in the event.



Please provide any comments and/or examples here

Points made across the four groups included:

- Independent living works well with good support.
- How do we manage demand for accommodation? Waiting lists are frustrating and overlong. With high demand, prioritisation is also difficult.
- People need choice about where to live and they need skills and support. People need advice. It can be expensive so people need skills to manage money.
- “Someone I know has a house shared with two other people with support, her activities are planned for around the things she likes to do. She was in a long stay hospital. She has blossomed as a person and likes to do things for herself. Some really good things have happened for some people. We must continue working to make sure people with all needs get ‘The same as you?’
- Independent shouldn’t be all or nothing – people should get support to live independently
- People need support to make friends, to build networks of support – like Equal Futures – Circles of Friends, Dates N Mates
- We must keep challenging expectations of society at large. There is still a long way to go for public attitudes to improve.
- Harassment is still a problem which can get in the way of people living independently. We need education in schools and spearheaded by celebrities to show that certain language is unacceptable.
- We could do more with new technology.

The group mainly composed of professionals said:

- People need support to live independently. Don’t change people’s packages. It’s also hard for new people to get appropriate packages.
- We need to build people’s capacity to live independently.
- We need to think of creative ways to address the cuts. There are good examples locally.
- Working and being involved in the community are ways to live independently and help people to have fulfilled lives.

There was some discussion in the professionals’ group around self-directed support:

- Health and social care staff need training on SDS.
- SDS should open up opportunities for individuals but we must be careful that people are not exploited. There are Adult Support and Protection issues. How can we ensure that vulnerable people are protected? Carers must be PVG'd – it is a concern that they are not. People need advice and support to choose their carers. There are significant implications to becoming an employer under one of the options.
- People need unbiased information. People need good advice and support, for example from advocacy services.
- SDS can mean there is more choice in who supports you. It must be a real choice.
- SDS has huge implications for organisations which have spent resources training support workers, who may then go on to be employed by individuals privately – someone else disagreed with this and cited the different options for SDS.
- Who will regulate SDS packages?
- People who do not have capacity might miss out – although someone else disagreed with this and referred to the different options

## Future Priorities – Employment

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

Here is the graphic of the responses to this question at the Perth SAY Event. The points on the graphic were chosen as the most important points about employment by each of the four groups which participated in the event.



Please provide any comments and/or examples here

People with learning disabilities said:

- One person had the experience of doing some voluntary work on a short term basis, but needed support to be in a workplace. There should be more employment support services so people can get support in work.
- It's hard to get a job at the moment.
- Remploy services are being reduced or closing and people who used Remploy have been offered placements not long term employment.
- People like volunteering and volunteering is important.
- There is not enough support to find a job.
- Some people feel stigmatized if they have benefits or they do not have a job.
- Sometimes carers can be a barrier to employment because they worry about money or how the person will cope./

The group mainly composed of professionals said:

- There is a successful supported employment service in Stirling which works with employers.
- In Aberdeenshire there is a focus on people who want to work, but not everyone is eligible for the supported employment service. There is also a peer mentoring system in place.
- There is a supported employment unit in Dundee attached to the mainstream unit.
- Jobs now expect a range of skills for a range of tasks so people need a range of support. Rigid job descriptions can get in the way.
- Local authorities should offer jobs opportunities to people with learning disabilities. Or they could offer work placements . How many people does the Scottish Government employ?
- We need wider apprenticeship schemes.
- Mainstream employability services are not skilled up. Supported employment is more effective but it takes time.
- Social enterprises might be part of the answer. In Dumfries and Galloway they are looking into opportunities for microbusiness. In Perth and Kinross, students in the new school do catering at the cafe (15-18 year olds) to give them experience of a job. However, it takes time to set up social enterprises – 6 months seed money will not be

enough.

- Benefits can be a barrier to work.
- Creative solutions are needed; solutions which are person-centred are needed.
- Unemployment is an issue for everyone now, especially young people.
- Employers need support. They are afraid that they will not support someone properly or that someone will not be productive. Employers should understand that people can make a real contribution; that people have skills and abilities. Case studies could help. Employers need incentives. Equal opportunities need to be supported from the national government level.
- Education and employment skills need to join up – people should be learning skills for employment even before transition begins.
- Jobs are so important to helping people to make friends and building well-being and confidence.
- Lots of small workplace opportunities increase the size of the available pool of opportunities.
- People with learning disabilities should have the chance to develop on their roles.
- There should be some research on how many major employers hire people with learning disabilities.
- How can we police whether or not people are being employed?

### **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

People who do not need a lot of support can still be vulnerable if they don't receive the little support they do need. To access support adults need 'labels'. Support must be about needs and not about funding streams. There is a balance needed between high end crisis needs and prevention.

Carers said:

The whole family needs more consideration in plans and policies

People need help before a crisis – crisis cannot be avoided altogether but sometimes it can.

Respite and short breaks

Social workers must improve communication and be more available