

## 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

By promoting people's right to live 'the same as you', the policy has helped to embed human rights in a meaningful way whereby the rights of people with learning disabilities are taken more seriously. This message has positively influenced the culture of all services and people are more likely to be treated with respect and dignity. Workers are mindful of supporting realisation of rights and responsibilities through positive risk enablement and helping people to be active citizens, regardless of the level support needs an individual may have.

Whilst we agree broadly with the findings of the evaluation and feel that SAY has had a positive impact on how people with learning disabilities and those diagnosed on the autistic spectrum are perceived and supported, we also agree that more work needs to be done.

Setting a deadline may have speeded up the process for long-stay hospital closure; however the success of this policy cannot be directly attributed to SAY as this was already underway prior to the review. SAY observed that the pace of change in Scotland was slower than in rest of the UK, with significantly more resources tied up in hospitals than in the rest of the UK. This has shifted, and resource transfer to local authorities from health boards has steadily increased to support more community-based services commissioned by local authorities. However, higher levels of health expenditure still go on inpatient services, than on outpatient and community based support (see. [http://www.isdscotland.org/Health-Topics/Finance/Costs/Costs\\_R300s\\_2010.xls](http://www.isdscotland.org/Health-Topics/Finance/Costs/Costs_R300s_2010.xls)).

In addition, most local authority resources for people with learning disabilities continue to be invested in commissioned services rather than individualised support or direct payments.

There are no easy solutions, but it is to be hoped that SDS and a refreshed and more action-focused SAY strategy will help to move things forward further.

**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 long stay hospitals locally have closed. Individuals are given more independence in relation to accommodation, finance and life opportunities, all of which have been extremely positive.

Services have improved over the past ten years and are much more focussed on supporting individuals to achieve their goals, and expectations

of what people with disabilities can achieve have changed. People working in services are more likely to be solution focussed, less fearful of failure, and open to help an individual explore new challenges and learn from new experiences.

Day services have been very innovative and more outward facing. The development of more community based work experience and training facilities for people with learning disabilities has helped to reduce segregation, supporting more positive perceptions of the contribution people with disabilities make.

Nationally, there is a greater awareness of the needs of people with autism and a better understanding of how specific conditions affect the way people understand and get by in the world. This has reduced the stigma associated with particular diagnoses and families appear more comfortable in talking about both the positive and challenging aspects of their experience, advocating on behalf of their relative and working with services to make things better.

People with learning disabilities and autism are more aware of their rights and more likely to expect these to be respected.

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

SAY recommended that local authorities, health boards and primary care trusts prepare 'partnership in practice' (PIP) agreements for learning disability services in their areas. Whilst most areas produced 'PIPs' or joint strategies, the status of these was never very clear and was further complicated by subsequent guidance from the Improvement Service on joint commissioning.

In 2009, the Scottish Government published *Commissioning for Personalisation* as part of the *Changing Lives* programme. This stressed a need to shift towards 'co-production' and approaches to delivering support that; "*enable(s) the individual alone, or in groups, to find the right solutions for them and to participate in the delivery of a service. From being a recipient of services, citizens can become actively involved in selecting and shaping the services they receive.*"

(see <http://www.scotland.gov.uk/Resource/Doc/269193/0080033.pdf>). Much of the current guidance on joint commissioning is focussed on the needs of populations rather than on person centred commissioning and there needs to be greater support for developing local approaches to bring joint commissioning closer to individuals.

In England and Wales, the white paper *Valuing People* placed stronger obligations on public services to pool budgets and work together involving stakeholders, including people with learning disabilities and informal carers in Joint Commissioning Boards. There is still no joint funding and commissioning of care packages and therefore tensions between the local authority and the NHS continue, which is to the detriment of service users. The current integration agenda is welcomed, but the focus is on older

people and this might not be the right approach for people with learning disabilities. The Scottish Government may want to consider supporting local Joint Commissioning Boards for learning disability services, where all stakeholders, including those directly affected by services, work together to agree where to invest resources locally.

Some agencies still tend to be very protective of individuals with learning disabilities and reluctant to allow them to make choices about the risks they take. A clearer emphasis on a rights-based approach, running through all relevant policies and guidance, may help shift the focus.

There are tensions in approaches being taken in both health boards and local authorities to drive forward improvements. Often these are focussed on reducing variation and streamlining processes to achieve efficiency savings. This does not sit easily with the drive to personalise services and promote better outcomes for individual people, where success will depend on flexible and responsive systems that are more tailored to individuals.

The extent to which public bodies involve people with learning disabilities can still be improved. Not all authorities in Scotland routinely produce easy read information and by contrast, partnership boards south of the border increasingly produce information in a range of formats, including video and audio. Additional funds have been made available to NHS boards to improve information and we believe local authorities should have similar support.

We are very supportive of the SDS agenda and see a need for continued support to help people with disabilities, families and other agencies to understand and embrace this. The guidance on direct payments and data collected on uptake of direct payments conflated this with 'self-directed support' which has helped perpetuate misunderstandings and misinformation. We are also wary of SDS becoming overly-complicated.

Although much of the early work on person centred planning took place in Scotland, subsequent development and use has been very patchy over the past ten years. There is plenty of evidence to show that person planning and associated work to develop circles and networks of support is cost effective and produces better outcomes, yet this is far from being a default model. This may be partly down to the increasing workload of care managers and other workers, with the ongoing demands to produce management information and implement new policies. This leaves limited space for developing person centred plans for people. When SDS is implemented, its success will be partly dependent on the quality and detail of planning undertaken with individuals and more resources need to be directed in this area.

In Aberdeenshire we commissioned a survey to explore community readiness for more community based integrated day services and although there was a great deal of positive support for this there was also a deep undercurrent in the comments reflecting individual prejudices, fears and lack of understanding. Negative perceptions of people with learning disabilities continue to be perpetuated in the media and in popular culture and discriminatory attitudes towards people with learning disabilities expressed

by public figures too often go unchallenged.

Welfare benefits reforms are already having a major impact on people. Some have lost housing benefit and this poses a risk to independence.

### **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?**

Significant work has been done in Aberdeenshire in day services to develop a wide range of purposeful options. In Aberdeenshire, our day services have very good relationships with local communities and work in partnership with local agencies and groups to support new opportunities. Day activity options have increased greatly and are moving away from traditional day services to skill based opportunities, enhancing the lives of those who attend.

There has been investment in developing projects in the community which has raised the profile of what people with disabilities can contribute to their communities and provided the opportunity to gain real skills as a stepping stone to employment and employment type activities. This has included commissioning alternatives to day services.

Employability services have undergone a major redesign with employability officers being up-skilled to deliver improved services through an integrated model which has increased capacity, focus and outcomes.

There are many examples of local initiatives across Aberdeenshire. Banff Inclusion Project brought together a local youth group and people with learning disabilities to explore opportunities and promote positive relationships. Cafe Connect in Fraserburgh is on a local high street and provides work and training opportunities for people with disabilities, as well as services to the wider community such as maintaining the community webpage. The Pitscurry project provides opportunities and training in a rural location, in horticulture, woodworking and arts and crafts for around 100 people, whilst also supporting wider environmental initiatives and awareness-raising to people across Aberdeenshire.

Currently a major redesign project is being undertaken to take day services to the next stage of community integration and inclusion. The project plan is being developed at grassroots level with service users and family carers being involved in determining what needs to be done through an extensive range of community based events.

We are very involved in local community planning initiatives. We undertook a series of Inclusion in Mind events across each local area that supported people with learning disabilities and those with mental health problems to evaluate how inclusive services and their local communities were. This has led to a number of specific projects and also raised awareness, helping local planners and providers to consider the needs of people with learning

disabilities in their communities.

There has also been major investment in resourcing the development of a 'Shared Lives' Adult Placement Scheme, to deliver short breaks and day services in the community. This scheme has been shown to support good outcomes for those who use it.

We have worked with service providers to develop a range of supported living options. Supported living options have increased and more individuals now have their own tenancies. We are developing more supported living tenancies for people who challenge services and who would have otherwise lived in institutional settings. Projects have focussed on supporting people who were 'placed out of area', some of whom resided in private hospitals, to allow them to live in their local community.

Social opportunities have focussed more on choice and developing independence, such as drop-in groups and peer support, rather than on 1-1 social support which never really achieved what it was planned to.

We have a good track record on supporting individuals to access direct payments, but recognise more can be done. An In Control pilot has allowed us to achieve a better understanding of how self-directed support can work for individuals and we are working with the independent sector to further develop and promote SDS.

Care Managers are highly skilled and encouraged to continue their professional development so that they can provide a good service. We have developed more outcome focussed assessments and Care Managers have received comprehensive training on this. Care Managers have undertaken training to improve risk assessment so that people are supported to be more independent and make positive choices. Adult protection is now taken more seriously and we have robust mechanisms in place to identify adults at risk of harm and work in partnership to keep them safe, whilst seeking not to compromise independence.

We work in partnership with NHS Grampian to provide person centred support to individuals and practitioners have excellent relationships with local allied health professionals in their areas. This means that people can access specific support such as Speech and Language Therapy, relatively quickly and recommendations made are reflected in people's care plans and the day-to-day support they receive.

We now have Local Area Coordinators in each of the three learning disability community support teams and in children's services. Local area coordinators have worked proactively with families in their areas, for example, a 'letting go' group has been established to support parents to think about what will happen through transition to adult services.

Health information has improved and NHS Grampian has invested in developing easy read materials. We are in the process of developing easy read versions of all our key policies relating to adults with learning disabilities. We have a way to go in improving access to information; however there are increasingly more examples of good practice. For

example, we produced a video with people with learning disabilities to support awareness-raising about our day services review.

We have consulted widely with individuals and carers about the opportunities they want and have sought to integrate these into our planning processes. There has also been significant investment in delivering citizen leadership training across Aberdeenshire and promoting self advocacy.

### **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?**

The reception of adults with learning disabilities in mainstream hospitals is still inadequate and we are told that parents/carers are sometimes frightened to complain for fear of poorer treatment for their son/daughter. The introduction of the liaison nurse in ARI has greatly improved elements of this; however, not all hospital staff have adequate awareness or understanding of the needs of people with learning disabilities and their families and communication is an issue. Consultants from different specialisms do not always appear to work together to provide the best possible care to a patient with learning disabilities. This can result in delays in diagnoses and treatment of physical conditions.

Whilst specialist advice and treatment is essential for some people, for example in ensuring the safe handling and feeding of those with PMLD, we still encounter a tendency for some NHS staff to be risk averse and there needs to be more support for positive risk taking to enable people with health care issues to be supported in a realistic and inclusive way, that takes a more holistic account of quality of life.

Psychology assessments sometimes focus too heavily on negative reputations rather than on an individual's strengths and aspirations. This can lead to overly restrictive regimes that can exacerbate problems and perpetuate self-fulfilling cycles. There can be overemphasis on 'forensic' needs, which can lead to people being inappropriately labelled.

Inpatient Assessment and Treatment services can be a frightening experience for people and reception needs to be more sensitive and personalised. It is not uncommon for a person's condition to rapidly deteriorate on admission to hospital, which can lead to delays in recovery and subsequent discharge. On discharge, people do not always receive adequate aftercare and support.

We still encounter some discrimination around sex education and the view that people with learning disabilities need to have capacity assessments prior to supporting them to learn about safe sex.

The mismatch between Health and Social Work eligibility criteria is a problem. We would like more flexibility from health services to deliver specialist support to those who need it, rather than based on IQ, as some people, such as those with autism, do not always meet this and subsequently lose out, or only receive additional support if they development mental health problems.

Whilst the local authority receives some funding from Health in the form of resource transfer to support services for people in the community, direct accountability for how this is allocated lies with the local authority. This can mean that Health recommendations about support to individuals do not always take sufficient account of cost which can impact on relationships between health and local authority workers, who are required to deliver best value. At times this can be to the detriment of people with disabilities who may subsequently experience delays in a support package being agreed and implemented. There needs to be more transparency with regards to Health resources so that these can be effectively pooled with local authority funds, to enable us to work together to agree joint individual budgets that can be used to develop truly person centred and holistic support for individuals.

### **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 Additional Support for Learning Act has been excellent in terms of supporting all learners and helping educators to focus more specifically on the additional support required, rather than the disability, reducing assumptions about what children and people can/cannot achieve. A downside of this has been less clarity in relation to identification of those with learning disabilities. This has been an issue for some young people coming up to school leaving age where adult services are not always notified early enough and consequently planning for the future does not always happen timeously. Specific GIRFEC guidance linked to ASL, setting out more clearly the role of the Lead Professional and Named Person in relation to a child with disabilities and specifically regarding children and young people in transition, would be helpful.

The experience of children and young people in education varies considerably. Some schools have worked very hard to integrate children with learning disabilities and provide access to a broad child-centred curriculum. However, a focus on attainment can make it difficult for schools to foster the achievements and confidence of children with disabilities. Reduction in the numbers of classroom assistants can have a detrimental impact on those requiring additional support and schools need more access to a range of resources such as technology that can assist communication.

Whilst there are a range of initiatives and organisations, such as Lead Scotland, which aim to support lifelong learning for people with disabilities, these are not very joined up. Unless organisations have a clear national remit and high profile or are specifically commissioned, we often don't know about what they can offer and this can lead to patchy and uneven development of schemes.

College extension course, whilst intended to be skills based, are often not and do not adequately prepare individuals for employment. Colleges need to make more progress in understanding and providing for the needs of students with disabilities. Limited recognition of communication issues, the environmental adjustments required for some students and the possible behaviours some adults may display (usually as a result of the former), too often results in exclusion.

Further education colleges need to be more outcomes focussed and help develop individual pathways for students to access work or volunteering after completing courses. For some, an outcome-focus is results-driven and whilst this may help improve standards, this can also lead to short-sighted planning where a positive result is recorded if a young person goes on to a placement regardless of whether this breaks down or what happens to the person next.

Universities often have excellent resources and can offer great opportunities for young people to learn life skills and encounter new experiences and universities could be encouraged to widen access to these resources and develop specific schemes for young people with learning disabilities.

### **Future Priorities – Independent Living**

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

Whilst many people discharged from hospital have been able to live more fulfilling lives, a number of people moved to new forms of institutional settings and continue to be isolated within their local communities. Even where people have their own tenancies, the way different organisations support people, is not consistent and supporting people to maintain and develop their skills should be a clear outcome of any support work being undertaken.

*Supporting People* enabled many more people to achieve greater autonomy in their day-to-day lives and enjoy the rights associated with having a tenancy. When this policy ceased, the process of deregistering care homes slowed down and too many people still live in, and continue to be 'placed' in care homes.

There is a concern that insufficient funding precludes the development of a range of appropriate independent living options for people and there needs to be closer working with housing providers to see if we can develop affordable, local housing options that facilitate peer support, such as



## Neighbourhood Networks.

There is particular concern about the impact of Welfare Reform, which poses a significant challenge to widening housing options for people with learning disabilities. The Housing Benefit cap will seriously limit the options we can offer people and make creative, person centred outcomes harder to achieve. Loss of ILF will mean more people will require increased input from local authorities and potentially have less independence.

The Joint Committee report on the Human Rights of Adults with Learning Disabilities in the UK 2007/08 (see <http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/40/40i.pdf>) highlighted that people with learning disabilities are more vulnerable with respect to safeguarding their rights than most of the UK population. This is backed up by high profile abuse enquiries, and evidence that health and residential settings are not always safe. The Winterbourne View scandal reminds us of the need to continue to seek more inclusive ways of supporting people with learning disabilities and in particular those with complex needs and challenging behaviour whose interests are not inevitably best serviced in a 'specialist' or secure service.

There needs to be greater education about independent living and what it can mean, to avoid 'all or nothing' approaches. Many people do not know about the philosophy behind IL and assume it means leaving people to look after themselves, inevitably living alone, rather than being about focusing assessment and service delivery on enabling people to control their services as much as possible and to live with dignity in the community. In order for this to happen, our communities and services need to be more open and accepting. There are specific things such as work to ensure that transport services are accessible to people with learning disabilities (this means improving driver's training and signage etc), but we still need to get better at listening to people. More support to develop self-advocacy, peer support and mentoring would be beneficial.

Some family carers need more support to embrace the concepts of SAY. Families can be understandably worried about the risks to their relatives in the community and can consequently be very protective and sometimes unwilling to support positive risk taking. Some parents have become accustomed to doing everything for their son or daughter. There are some adults who have learnt many skills whilst at day services or on short breaks who don't get the opportunity to use and develop these skills at home. This can reduce people's chances of developing more skills and experience.

Some families have not received adequate support in the past and do not always get the right information to help them when they need it. For many families, this has encouraged them to be proactive and often to become experts in their relative's condition and on innovative practice, as they have sought solutions. Whilst we do work much more in partnership with carers, we may not always pay enough attention to the expertise they have and carers do not always feel that all professionals pay sufficient attention to the knowledge they have, for example about how their relative communicates. Carers assessments have improved but can prove difficult for some carers since these don't automatically lead to services.

## Future Priorities – Employment

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

Widening access to employment requires continued and concerted effort on the part of all stakeholders. There may be a need to explore positive discrimination, through public bodies' equalities duties, possibly requiring them to evidence specific efforts to recruit people with learning disabilities.

Young people with learning disabilities do not seem to be routinely considered in initiatives such as internship and apprenticeship schemes and more work could be done to explore this area. Other organisations such as trade unions could be encouraged to think more broadly about their role in promoting the rights of those excluded from employment as well as protecting those of people who already have jobs.

There needs to be more targeted effort to engage with employers who will be more concerned about economic than social benefits and may not appreciate how these are linked. Employers struggle to give the time required to work with an adult with a learning disabilities in workplaces and this has become worse since the recession. Increased funding to support an employee or tax breaks for employers may assist. A focussed approach to developing more volunteering opportunities within companies to allow people with learning disability the chance to try would be a beneficial. In addition, publicity at a national level about what people with disabilities can contribute - directed towards employers – would be helpful.

Many people are put off working for fear of the impact on welfare benefits. This has become more of a concern for people with the introduction of Work Capability Assessments and Welfare Reform. The focus on capability to work also risks being detrimental to those who want to work but are not deemed capable. Determining capability is impossible without reference to the type of work that might be available and for people with learning disabilities the issue is very complex. Some people's learning disability can affect their motivation to work whilst they may appear physically able. It is far more productive to focus on developing a range of opportunities for people who *want* to work rather than on those we think *ought* to work.

The Scottish Government needs to monitor the impact this is having on people with learning disabilities and seek to ensure that this does not negatively impact on making further progress through SAY.

## 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)**

1. Maintain the ethos of the Same As You, with greater emphasis on the rights of people with learning disabilities, including making choices and taking risks;
2. A national drive to improve public perception and culture about what people with disabilities can contribute to communities;
3. Higher profile for SDS to encourage greater buy-in from families, support people to look at outcomes they want to achieve and promotion of person centred planning to make SDS work for people with learning disabilities;
4. Support and guidance to develop local joint commissioning closer to people requiring support and linking to SDS;
5. NHS to adopt SAY guidance on eligibility for specialist health services;
6. More support to develop self-advocacy and peer support;
7. Monitor impact of welfare reform;
8. Guidance on GIRFEC for children and young people with learning disabilities, including the role of the Named Person and Lead Professional, with a focus on the pathway to receiving support as an adult;
9. Focus on prevention, supporting people to develop practical skills and build and maintain lasting relationships;
10. Support to improve information and involve people with learning disabilities in planning and development;
11. Widening opportunities for people with learning disabilities to access training, apprenticeship, volunteering and employment with personalised support and incentives for employers;
12. Community development to support more people with learning disabilities to be integrated into mainstream community activities;
13. Development of appropriate housing such as extra care housing for these that could benefit;
14. Healthcare modernisation, supporting more holistic approaches that can help more people to manage their health care and take positive risks;
15. Better training and clear standards for healthcare staff in how to support people with learning disabilities in hospital.