

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

Yes, ADSW would agree that the findings of the evaluation largely reflect our views. It is clear that there has been considerable improvement in the quality of lives of people with learning disabilities since SAY was initially published and that there is now much more support for them to live in their communities and to achieve greater independence.

However, the views expressed in the evaluation by people with learning disabilities themselves tend to reflect the opinions of people with a higher level of capacity and a greater ability to articulate their views. This means that those people with more severe learning disabilities do not have their views expressed here other than through their carers. While we fully respect the importance of carers' views and the key role they play in supporting people with learning disabilities, we should nevertheless recognise that their views are not necessarily the same as those they care for.

Funding issues are not explored in a way that reflects their key importance for the future of the learning disabilities strategy, particularly in relation to pressure on public service budgets and the impact of cuts. Greater consideration should also be given to future demand, taking into account the increasing numbers of people with learning disabilities requiring care, ageing carers, and recognition of the increasing role that health problems will play as a consequence of people with learning disabilities growing older.

Welfare reforms will have a considerable impact on people with learning disabilities. This is a critical issue which is not addressed to any meaningful extent in the evaluation

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

- The setting out in SAY of a clear direction of travel for people with learning disabilities was of key importance in establishing new standards, increasing expectations, and in creating the climate and political backing for change.
- It encouraged a partnership approach between agencies, particularly health, social work and the third sector.

- It contributed to the further reduction in the number of people living in a hospital setting.
- It has helped to improve health outcomes for people with learning disabilities
- It increased the variety of support available in accommodation, day activities, and respite.
- It encouraged councils to listen more to the views of carers and people with learning disabilities themselves.
- It helped to create new, more imaginative, person-centred resources
- It recognised the importance of supported employment, further education and training, even though this part of the strategy has had limited success.

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

- **Funding.** Most of the major developments in housing and support models have been funded by Resource Transfer and Transitional Housing Benefits. ILF has also been a key resource but has been stopped. There are no new funding streams available, and it is expected that people with learning disabilities will be adversely affected by welfare reforms. This means that there will be fewer resources available to meet increasing needs, an issue that requires to be addressed within any new strategy.
- **Employment** – a policy on the creation of job opportunities and on supported employment is required if this issue is to be addressed seriously. Statutory agencies could, for example, be encouraged and incentivised to create such opportunities, and thus to lead by example
- **Autism.** The new Scottish Strategy for Autism gives an opportunity for the statements around autism in the original SAY to be revisited and clarified. *ADSW recommends that any new learning disabilities strategy should address the needs of people with autism who also have a learning disability, and to state this clearly in order to avoid confusion.*
- **GP's role.** It would be helpful for the future strategy to recognise and clarify the role of GPs in dealing with people with learning disabilities.
- **Adults with Incapacity.** There are issues around the use of AWI/Guardianship for people with learning disabilities which ADSW would be happy to discuss in greater detail.
- **Further education** – it is clear that the recent changes around further education have not adequately addressed the particular needs of people with learning disabilities, and therefore the opportunity should be taken to set out the position in policy terms.

- **Adult Support and Protection** – this is mentioned in broad terms, but it may be helpful to specifically address the particular problems that people with learning disabilities face in relation to ASPA, including their increased vulnerability to physical, sexual and financial abuse.
- **Transport** – there remains a need for suitably adapted transport to be available at the right time to enable people to access the community/services themselves.
- **Crisis response.** The ability to respond quickly in a crisis situation is becoming an increasingly critical issue. This points to the need for advanced planning with families in particular and to the availability and flexibility of services available to respond in a crisis.

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

As this is an ADSW response covering all of Scotland, examples are too numerous to detail in this section. However, in general terms, key developments have been around:

- Transitions planning and improved liaison/communication between children and adult services.
- Fully integrated health and social work learning disability teams
- Better assessment of need on a multi-agency basis, improved risk assessment and planning, and more accessible integrated IT systems suitable for the sharing of information between agencies.
- The development of person-centred plans.
- The setting of clearer outcomes and expectations within care planning.
- Examples of effective commissioning of a range of services.
- Improved care management arrangements on a multi-agency basis.
- Better contract compliance and more effective partnership working with external care providers.
- Improvements to day services and respite.
- The development of more local resources, enabling people with learning disabilities to live in their own communities and to remain closer to their family networks.
- Councils should be encouraged to continue to enable the development of local community resources, similar to the LAC model but not necessarily uniquely so.
- A variety of initiatives aimed at improving health
- Examples of imaginative use of Direct Payments and Self-Directed Support.
- Creation of service users and carers groups, and their active involvement in planning, strategy, and the design of future services.

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

Not applicable

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?

Please provide any comments and/or examples here

- Greater clarity is required around the role of GPs in relation to how they address health issues for people with learning disabilities on their registers (they receive additional payments for this but little or no evidence of outcomes or strategy to support this).
- Hospital Information Booklets have been piloted in some areas. These typically contain personal information about the individual with learning disabilities and provide advice on how they should be treated in the event of being admitted to hospital. These could be cited as good practice exemplars and other areas encouraged to adopt them.
- Health initiatives, such as bowel screening, require to be adapted so that they can be understood and accessed by people with learning disabilities.
- In some areas, specialist learning disabilities nurses adopt a health improvement approach involving, for example, linking with day and respite services or supported accommodation to provide advice to staff, detect early signs of problems, and encourage healthier lifestyles. This is a departure from the traditional individual health deficit model and moves nursing in the direction of prevention rather than cure.
- In some areas, basic health checks designed specifically for people with learning disabilities have proved effective in early detection of conditions, allowing effective preventative treatment to take place. This approach should be encouraged/rolled out across Scotland.
- Improving GP appointment systems to allow more time and better response to people with learning disabilities

- Increase the use of anticipatory care and “end of life” plans
- Provide more training for staff in awareness of adult protection and AWI issues.
- Provide guidance for Dentists, Opticians, Pharmacists etc on best practice in dealing with people with learning disabilities
- Provide access to well man/woman clinic

Future Priorities – Education

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

Please provide any comments and/or examples here

- As stated earlier, it is clear that the recent changes around further education have not adequately addressed the particular needs of people with learning disabilities, and therefore the opportunity should be taken to set out the position in policy terms, and to clarify how people with learning disabilities can benefit from FE.
- FE courses offered are increasingly vocational. This can exclude many people with learning disabilities who have fewer prospects of achieving employment and have traditionally accessed FE in order to gain life skills. Colleges themselves are increasingly unclear about their role in educating people with learning disabilities and this point should be addressed in policy terms.
- It is unclear whether FE colleges or social work have the responsibility for providing additional support and care for people attending college who have additional needs. This can and does result in the exclusion of people with learning disabilities from college placements.
- The grouping together of several FE colleges to provide particular courses on one single site can also exclude people with learning disabilities who are effectively debarred from attending because of travel difficulties.
- The proposed integration of adult health and social work presents a risk of losing established transition arrangements between children and adult services, particularly the contribution and specialist knowledge from schools. The issue of transitions for people with learning disabilities should be addressed as a priority

Future Priorities – Independent Living

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

Please provide any comments and/or examples here

- As highlighted earlier, most of the major developments in housing and support models during the past 10-15 years have been funded

by Resource Transfer and Transitional Housing Benefits. ILF has also been a key resource but has been stopped. There are no new funding streams available, which will severely restrict our ability to build or acquire new tenancies and to staff and resource them appropriately. This is a major issue which has the potential to reverse much of the excellent progress made under SAY.

- There is a need to address strategically the issue of emergency provision when, for example, a carer dies or is admitted to hospital. For single authorities to set aside beds for use in an emergency would be prohibitively expensive, and may therefore indicate a joint resource between partner authorities is required.
- The appropriate and inappropriate use of telecare/telehealth should be explored in terms of practice examples. This would have to deal with difficult issues such as tracking devices which may enable some people to go out independently, but can be seen as infringing an individual's rights.
- There remain too many large group homes which, can lead to institutionalisation and, as we have seen from Winterbourne View, to abuse. However, they have the advantage of generally being available for use in emergencies.
- Providing 24 hour individualised support to single people with learning disabilities living in their own homes is prohibitively expensive. It is also questionable in real independence terms given that most contacts are with paid employees rather than with peers. Clarity and guidance around this issue would be appreciated.
- Welfare reforms need to address the issue of housing benefit for people with learning disabilities where payment will be made for only one bedroom: additional care needs often require that an additional bedroom is made available.

Future Priorities – Employment

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

Please provide any comments and/or examples here

- It should be recognised that this is the area within SAY where the least progress has been made, from which it can be concluded that local solutions and initiatives have not been effective and that a national policy directive is now required. Should employers, for example, be required by the Scottish Government to provide supported employment for a certain number of people with learning disabilities, and if so how would they be held accountable for performance? What incentives would employers be given and how would this be supervised to ensure proper compliance?

- Should statutory agencies be the starting point for such an initiative?
- The requirement for school pupils to undertake work experience does not appear to apply to children with learning disabilities. This anomaly should be addressed within a revised policy.
- Project Search has frequently been cited as a good practice model for the support into employment of people with learning disabilities. The possibility of rolling out this model across Scotland should be explored.

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

- The issue of funding and resources for the next 10 years needs to be addressed as a matter of urgency.
- While recognising that there have been a number of positive aspects to eSAY statistical returns, particularly in encouraging partnerships to actively address the key proposals in the original SAY policy, many elements of eSAY are flawed and can produce misleading, inaccurate results. The usefulness of some of the measures is questionable. The opportunity should be taken to completely revise the process and, if it is to be replaced, to introduce a more relevant and effective system of performance reporting.
- A criticism of SAY is that it places too much emphasis on the needs and aspirations of people with mild/moderate learning disabilities, and does not address the needs of people with severe to profound learning disabilities who, ironically, tend to have the highest cost care packages. They are also the people most likely to require hospitalisation or to live in more institutionalised forms of care. The opportunity should therefore be taken to look in more detail at their particular needs, the models of care best suited to them, and the cost implications of this.
- Scottish Government guidance on Eligibility Criteria should be examined in the context of learning disabilities, in particular that it does not encourage a preventative approach.
- The issue of older carers should be addressed separately within any revised policy – see the 'Running Out of Time' campaign.
- Councils should be encouraged to continue to enable the development of local community resources, similar to the LAC model but not necessarily uniquely so.