The Stroke Association

Are you generally in favour of the Bill and its provisions?

Yes, we are generally in favour of the Bill. We stress however that implementation must follow all three principles to be successful in securing greater control and choice for people who use support services.

We believe that the Bill should include specific reference to access to independent advocacy for people offered self-directed support (SDS). An effective independent advocate will work to ensure that; an individual's rights are upheld, that they make informed decisions, they understand the consequences of their decisions and that they are fully involved in decisions that affect them.

What are your views on the principles proposed?

We are strongly in favour of the three principles. We believe that all three principles are necessary. We take this opportunity to give a strong message that stroke survivors and their carers must have readily available information and support to access SDS that is individually tailored round their communication needs. Only with truly informed choice will the principles be upheld and followed.

It will be important that effective evaluation processes are in place as the Bill is implemented to ensure that these principles are being maintained.

What are your views on the four options for self-directed support proposed in the Bill?

We are generally in favour of the four options. Given the nature of stroke and the individual's unique journey to recovery we would wish to stress the importance of reviewing the person's delivery preferences at agreed intervals, especially during the first year following stroke.

4. Do you have any comment on the proposal that the self-directed support options should be made available to children and their families?

We would wish to see all of the options available to child stroke survivors and their families.

5. Are you satisfied with the provisions relating to the provision of information and advice?

Although we are generally satisfied with the provisions relating to the provision of information, support and advice, we strongly feel that this must be properly resourced and accompanied in implementation by practical guidance and support for relevant staff. We stress the importance of getting
communication right for each individual to ensure that the choices people make in relation to SDS are truly informed. We would like to see a right to access independent advocacy for anyone considering SDS and especially where people have cognitive and/or communication difficulties.

For stroke survivors it would be important that relevant staff have training, which includes the direct input of stroke survivors, on the wide ranging effects of stroke with particular attention to communication needs. We also feel that all stakeholders should be better aware of the supports and agencies, such as independent advocacy, that stroke survivors could access to help them with the whole process from first contact through to assessment, decision making and any resulting challenges.

6. Are you satisfied that the method for modernising direct payments in the Bill will result in the change that the Government seeks?

We are generally satisfied that the method of modernising direct payments in the Bill through secondary legislation and regulations will result in the changes the government seeks.

It will however be important that adequate safeguards are in place to ensure that local authorities do not use their ‘discretion’ in ways that impact unfairly on the individual’s right to determine their own support. We feel strongly that the discretion available to local authorities should be limited and that clear guidelines must be included in the regulations.

7. Do you have any views on the provisions relating to adult carers?

We are pleased that SDS options will be offered to carers. We think that clarity is required between the needs of the carer and the cared for person. Agencies offering help with SDS processes should have policies in place to both reduce potential conflicts of interest and to minimise their effects.

The Policy Memorandum states in relation to Island communities where there is a limited supply of appropriate care and support providers and where there are suitable family carers who are willing to become paid employees for the supported person, that under the more flexible SDS approach paying family carers may be a way forward for some individuals.

We are aware that some stroke survivors and their unpaid carers are reluctant to seek support. If the possibility of employing a family carer was advertised, more stroke survivors and their families may come forward for at least an assessment for community care support. Under the regulations the decision on whether or not to sanction the employment of a close relative will continue to rest with the local authority. We welcome this safeguard. We would add that where an option to pay a family carer is under consideration, the person should be offered the additional safeguard and support of an independent advocate. We would wish to see this enshrined in the Bill as a right.
8. Do you agree with the approach taken by the Scottish Government not to place restrictions on who may be employed by an individual through the proposals in the Bill?

Yes we are in favour of this approach. We feel it is important that stroke survivors and carers can choose the people and the agencies that provide their support. It will be important to ensure that safeguards are in place to ensure that individuals are not coerced when coming to their decision. This is in line with the Stroke Association policy and practice in person centred approaches and our belief that equality means shared rights and responsibilities.

9. Do you have any views on the assumptions and calculations contained in the Financial Memorandum?

We welcome the recognition given to the importance of addressing costs indirectly associated with the Bill implementation if the transformational changes are to be made to the culture, systems and approaches relevant to social care.

Linked to our responses to questions 2 and 5 we are concerned that if adequate resources are not invested in ensuring that people affected by stroke receive information about SDS in a way that is tailored to their individual communication needs they be indirectly discriminated against when this Bill is implemented. We recognise that funding has been identified for both workforce development and information and advice we will be interested to find out what positive impact this investment will have on people affected by stroke.

Independent advocacy will have a key role to play in supporting people affected by stroke to access SDS. The Stroke Association is delighted to have received Scottish Government funding to help increase awareness amongst stroke survivors and carers about SDS and the capacity of independent advocacy organisations to support people who may need their support to access SDS.

There has been a growing recognition within national policy and legislation about the important role that independent advocacy can play in relation to equality of opportunity. We would like to see access to independent advocacy specifically mentioned within the Bill, separated out from the provision of information and advice about SDS.

10. Are you satisfied in the assessments that have taken place in regard to these matters and in the conclusions reached by the Scottish Government?

We have some concerns about the assessments laid out within the Financial Memorandum. In particular, ‘the Stirling study noted the importance to SDS users of investment in advice and advocacy services’. Across Scotland the investment in independent advocacy focuses strongly on mental health and
learning disabilities. There continues to be very little independent advocacy available to people effected by stroke or other physical disabilities.

The Stroke Association project mentioned in question 10 will help to increase the skills, knowledge and confidence of independent advocates to work effectively with stroke survivors. However, without increased investment in direct advocacy provision the ability of stroke survivors and their carers to access it will continue to be severely limited.

We agree that local authorities will not be required to set up or invest in a significant number of new organisations to meet the advocacy needs of people looking to access SDS, however, there will be a need for increased funding to enable existing advocacy organisations to respond to the potential increase in demand and to extend the 'client groups' they currently work with as necessary.

11. Do you have any comments on any other provisions contained in the Bill that you wish to raise with the Committee?

Stroke is a condition where many survivors are likely to require combined health and social care supports in order to make the best recovery and build a good life following stroke. This is especially true on discharge from hospital. The stroke association are pleased to see that two pilots have taken place in joint health and social care SDS approaches. We understand that some stroke survivors have benefitted from this pilot work and that the outcomes are positive. We feel the Bill gives an ideal opportunity to support joint working especially around long term conditions such as stroke. It will require more effective partnership working across services to develop a system for enshrining choice and control for those who require both health and social care. We think there should be a combined duty on health boards and local authorities to consider SDS for people with long term conditions from first discharge onwards. Outcomes focussed assessment is applicable to health elements of an overall recovery and/or condition management programme and self management processes should surely be linked to SDS from the outset.

Given the limited capacity within the NHS to delivery longer term rehabilitation services e.g. physiotherapy, speech and language therapy to people affected by stroke we feel that people should be able to use their SDS funding to buy this service from a private or third sector provider.

The Bill says that individual should be empowered to play a full and equal part in informing the initial assessment of need. The assessment is crucial in giving people the opportunity to think through and discuss their care needs and aspirations for the future. It is the building block for agreeing outcomes. The stroke association is aware that some people have not been aware that an assessment is taking place. We would wish to see very clear guidance accompanying the Bill in implementation about both social care and joint health and social care assessment. We welcome the outcomes focussed assessment model Talking Points and the provisions made for training staff in
this approach. We would hope implementation of the Bill will not lead to people being assessed by numerous agencies to determine their social and/or health care needs.

The Stroke Association
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