Social Care (Self-directive Support) (Scotland) Bill

NHS Lothian

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

I am in favour of the Bill and its provisions.

2. What are your views on the principles proposed?

I fully support the principles, but would prefer to see those principles enhanced with regard to the responsibility of the local authority, or agency with delegated responsibility, to ensure that the individual is provided with support and information appropriate to them to facilitate engagement and informed decision making.

I would wish to see further clarification of the application of delegated powers under the proposed health and social care partnerships in order to ensure that access to services using SDS is applicable to services provided by the partnerships.

In addition, I recognise there will be services which will not be appropriate to be delivered through all of the SDS options. However by encouraging “involvement”, “informed choice” and “collaboration” individuals should be fully involved to the appropriate degree in decision making.

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

I agree that the range of options offers a high degree of flexibility and choice and takes into consideration the degree of control an individual may wish to take and their willingness or capacity to manage that option. The inclusion of Option 4 may be most instrumental in increasing the uptake of the Options 1-3 as it allows individuals to tailor the degree of control they wish to take.

However, providing appropriate support to make an informed choice is of central importance.

4. Do you have any comment on the proposal that the self-directed support options should be made available to children and their families, together with the proposal that the degree of control a child may have over the process should vary with age?

I agree that the SDS options should be made available to families. The child or young person should be engaged in any decision making regarding their care package as appropriate to their age & capacity. GIRFEC principles must be applied to ensure that the young person is involved in full and informed planning regarding their transition to Adult Services.
Specialist Independent advocacy for children would ensure that the child’s views are heard, to ensure protection of their views, particularly where the wishes of the child differ from those of the parent / carer in terms of how their care is delivered.

The UN Convention on the Rights of the Child defines ‘child’ as a person under the age of 18, and encourages countries that have a lower age of majority to increase their level of protection until age 18. The promotion, protection and fulfilment of children’s rights under the Convention should be visibly obligatory in this bill, and incorporated into any monitoring framework.

In relation to the Bill, attention to equality in children’s rights should specifically consider issues of gender and ethnicity, freedom of expression, and ‘respect for the views of the child’.

In addition, I suggest that Section 21 in the delegated powers memorandum, where it describes the power to disapply SDS to certain services for children and / or adults, should be revisited. The statement claims that Ministers do not consider that it is not necessary that this power is applied to services to carers. However, there may be cases, particularly in regard to young carers, where the needs of the young carer may well be complex and involve an element of child protection.

Therefore, I suggest that whilst it may be inappropriate for direct payments to apply to all services, the principles of engagement and empowerment, plus the remaining 3 SDS options may well be absolutely fundamental in providing the individual with the flexibility and services they require to continue with their caring role, should they choose to do so.

Again the provision of independent advocacy for the young carer would be fundamental to this process.

5. Are you satisfied with the provisions relating to the provision of information and advice, together with those concerning the support that should be offered to those who may have difficulty in making an informed decision?

I agree that an individual’s capacity should not limit their ability to engage in these processes. Therefore, information re the SDS options should be made available in the appropriate way to enable the individual to engage.

Adults and children who require support to make decisions on the options should not be disadvantaged by this. The Bill notes the importance to self-directed support users of investment in advice and advocacy services. This is in line with guidance on the Patient’s Rights Act (2011), “Patients are provided with such information and support as is necessary to enable them to participate in decisions regarding their health & wellbeing”, therefore, as noted earlier, if / when the application of SDS is applied to services provided via the integration agenda and the health and social care partnerships, it is
recognised that the principles of engagement should be ones that are already embraced by the original agencies.

In addition, I suggest that it may be helpful to reinforce that the information needs not only to ensure that the individual is informed to make choices and act on those choices in relation to their chosen SDS option, but that they or their proxy are clearly informed of their rights for review etc, and that where necessary this is revisited within times frames that are supportive to the individual.

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

I am concerned that the Bill makes no provision to create a mechanism to enable a Direct Payment to be made from the NHS to the individual, therefore excluding those individuals whose care package is solely funded by health from that SDS option.

For example, those individuals whose care is the responsibility of NHS Scotland, as guided by the NHS Continuing Healthcare CEL 6 (2006) may appropriately direct their own care should the SGHD choose to extend SDS to individuals whose service is provided from within this framework.

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

I recognise the impact of caring on an individual’s health & wellbeing; and agree that enabling an SDS package to be made available to carers will go someway toward alleviating that impact. This could be agreed through the mechanism of existing carer’s assessments. Provision of advocacy to carers could be enhanced to support carers in considering how services via the SDS options could support them in their caring role.

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?

I do not agree with this approach.

There are unresolved difficulties with the Protecting Vulnerable Groups (PVG) Scheme, targeting empowerment and control at people who, by definition require support services, without resolving the issues around vulnerable people becoming employers is unadvisable.

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

I am concerned that although the evaluation of the Local Authority SDS test sites highlighted the need for leadership to drive SDS forward, there has been no resource allocated to Scotland’s Health Boards in–line with the funding
provided by Scottish Government to Scotland’s local authorities, providers & user groups in 2011.

I, therefore, suggest that a significant investment in the NHS by Scottish Government is required to enable the transformation of culture, systems and approaches towards SDS. I would suggest that paragraph 135 of the Explanatory Notes which suggests no costs to NHS Boards for the release and backfill of the estimated 22,000 staff is unrealistic.

In addition, I suggest that if Scottish Government wishes to provide information and culture across the NHS in Scotland there needs to be recognition that 1 day training per staff member is entirely insufficient to enable the required understanding or embracing of the complexities of SDS.

Perhaps there may be an opportunity through the rolling out of the training and awareness of the Patient Rights Act (2011), to add linkages between the principles of involvement and engagement, and begin to introduce SDS as a concept to NHS staff nationally.

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?

I am satisfied with Scottish Government’s assessments, but would suggest that further work in this area is informed by the findings on the data being collected by the Health Analytical Services Division in respect of evidence on how this might work for the population groups mentioned in section 59 of the memorandum as the EHRC and other bodies in Scotland and England have published reports and evaluations that raise concerns about the universal applicability and equal outcomes for this model of care. Scottish Government must ensure through training of staff and information & advice that everyone is aware of SDS and can make an informed choice regarding which of the 4 SDS options best meets their needs.

A robust monitoring & evaluation tool will identify gaps in up take, and underlying issues of inequality, and enable organisations to adjust how information is made available to ensure a wider awareness of SDS.

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

The title Social Care (Self-directed Support) (Scotland) Bill clearly places the emphasis on Local Authorities, and not the NHS.

I suggest that for SDS to be implemented fully and have maximum benefit for the adults and children supported by our respective systems the same duty placed on Local Authorities must be placed on NHS Scotland, not merely as a delegated power in regard to social care duties as stipulated in the Bill.
There is recognition that this will require a significant investment by Scottish Government in Health Boards to support training and systems change, and therefore also suggests that the forthcoming and evolving integration agenda perhaps offers a vehicle to make the duty of SDS more explicit on the proposed Health and Social Care Partnerships.

NHS Lothian
19 April 2012