VOCAL – Voice of Carers Across Lothian

VOCAL – Voice of Carers Across Lothian – contributed to the following submission on the Social Care (Self-directed Support) Bill through carer consultation, carer focus groups, Board and staff meetings and through public events to the submission below, which was also submitted by the Coalition of Carers in Scotland.

VOCAL supports all the key issues raised in this submission which evolve directly from the experience of carers of people with support needs.

Background Information

There are over 660,000 unpaid carers in Scotland\(^1\) who save the government £10.3 billion pounds every year, equivalent to more than three quarters of the entire budget of NHS Scotland\(^2\). Of these, 115,000 care full time, without pay, for over 50 hours a week – roughly equivalent to Scotland’s total paid care workforce\(^3\). With our increasingly ageing population, the number of unpaid carers is set to grow, with society becoming ever more dependent on their contribution to health and social care delivery.

With the current move towards shifting the balance of care to care at home, family members, relatives and friends will play an increasingly central role in the care and treatment of people who are frail or live with long term conditions, illnesses and disabilities. The current shift towards more personalised, self-directed support is not achievable without the support and participation of these unpaid carers.

1. Key Recommendations

1.1 We welcome the Self Directed Support Bill. The Bill is a positive step in bringing together and extending legislation in relation to self-directed support and in ensuring there is greater clarity and easier access to direct payments and other delivery mechanisms.

We agree with the four options proposed replacing the original proposal for people to ‘Opt Out’ of self-directed support. While direct payments provide an opportunity to extend choice and control to service users and carers, it is also important to recognise that many people are satisfied with their current provision and that wanting to retain existing arrangements is a legitimate choice. The four options provide a better balance in allowing people to determine how much involvement they want in the design and management of the services they use.

1.2 While we support the Bill we feel that it could be significantly strengthened in some areas, particularly in relation to:

\(^1\) Scottish Household Survey 2007/2008
\(^2\) Valuing Carers, Carers UK. 2011
\(^3\) Census 2001
• recognising carers as equal partners in care
• ensuring carers have equal access to support across Scotland, including through the provision of a direct payment
• extending the ability for people to employ a relative through a direct payment.

1.3 We also have concerns about the implementation of the Bill and the need for clear guidance and direction to local authorities in relation to adhering to the principles of SDS, ensuring there are robust and fair processes and timescales in relation to implementation and that outcomes for service users and carers are clearly recorded, monitored and evaluated.

2. Recognising Carers as Equal Partners in the Provision of Care.

2.1 We welcome the recognition of the key role that carers play in the provision of health and social care in Scotland

‘Without the contribution of Scotland’s carers the health and social care system would be unsustainable.’ (Social Care (Self Directed Support) (Scotland) Bill, Policy Memorandum)

2.2 The Community Care and Health Act, 2002 (Supporting Guidance) recognised carers for the first time as ‘partners in care’. The Scottish Government and COSLA extended this by recognising carers as ‘equal partners in care’ in ‘Caring Together’ Scotland’s Carers Strategy, 2010. While the SDS Bill acknowledges the vital contribution carers make it falls short of recognising them as equal partners. The Minister Michael Matheson MSP, recently stated that the shift towards SDS is one of the most significant developments in social and health care provision for the last decade. The role carers will be required to play in the success of this service redesign cannot be understated. It is therefore imperative that the principle of acknowledging carers as equal partners is embedded in the Bill and accompanying guidance.

3. Direct Payments for Carers - Duty versus a Power.

3.1 The Bill provides an opportunity to not only recognise carers, but to ensure they are appropriately supported in their caring role. As stated in the policy memorandum:

‘The Bill helps to deliver the strategy by providing a power to local authorities to release support to a carer following a carer’s assessment. No specific power exists for this at present although in practice authorities can and do provide a range of services and support to carers’

3.2 Despite the growing recognition of the contribution carers make to health and social care provision, carers have never had a right to access support to assist them in their caring role. The SDS Bill provides the opportunity to rectify this by placing a duty rather than a power on local authorities and new joint health and social care structures to provide carers with support following
an assessment.

3.3 While it remains a power there will always be very diverse practice and interpretation across Scotland’s 32 authorities and a danger to perpetuate current inequity and the postcode lottery of provision and eligibility of service users and carers.

3.4 At the moment the Bill proposes that the power is enacted following a carers assessment, thereby only providing carers with services they are assessed as needing. We propose this should be a duty in the same way as it is for service users who are assessed as needing a service and fit the local eligibility criteria. Failing to extend this duty to carers to apply in the same way as it does for service users could be prone to interpretation as discriminatory practice.

3.5 Local authorities will interpret a Power in different ways leading to inequity for carers across Scotland. It will result in some carers being able to access services and a direct payment following an assessment, while others with the same level of need will be denied the same rights. Until supporting carers is a statutory duty carer support services will always be vulnerable to cuts, particularly given the current and future pressures on health and social care funding.

3.6 The economic benefits of providing timely, preventative support to unpaid carers has been recognised by the Scottish Government and needs no further explanation. It therefore makes no economic sense to place restrictions on providing this support to carers following an assessment of their needs.

3.7 It is important that the needs of carers are recognised within the assessment process for SDS for the person they care for. Local authorities need to avoid the danger of making assumptions about a carers ability and willingness to contribute to care. It is also important to recognise and resource carer support. However, this should not be included in the cared for person’s direct payment as happens in some local authorities, as this can produce a conflict of interest. For example we have evidence of carers reducing their short break provision in order to be able to direct more resources to higher cost services for the person they cares for, despite the impact on their own health and wellbeing. Similarly, this situation could work in reverse with the cared for person resenting the use of ‘their direct payment’ for carer support. There cannot be a presumption that the needs of carers and the person they care for are always in alignment. This is why it is essential that carers are able to access a direct payment in their own right.

4. Carers Assessments and Considerations Relating to Carers Accessing a Direct Payment

4.1 It is important to strengthen carers’ assessments to ensure effective implementation of carers ability to access a direct payment. There are many excellent examples of outcome focused carers assessments, such as Talking Points, but these are not in place in all areas of Scotland and uptake for
carers assessments is still poor. Evidence from many local authorities suggests continuing low level of carer assessments, which would undermine the intention of new legislation. Further investment is required to ensure systematic practice is in place in every local authority.

4.2 Scotland has an enviable network of local carer organisations that provide early preventative support services to carers, such as information, advice and advocacy, emotional support, training and access to short breaks, as well as increasingly personalised and person-centred planning in care planning. In almost all cases these services are free to carers and do not require the involvement of statutory services. This existing infra-structure of ‘universally accessible provision’ must be retained.

It is imperative that direct payments for carers enhances and complements existing services by extending the type of support carers can access, for example by allowing carers to design more personalised short break services or access support with practical household tasks. Direct Payments for carers must not be seen as a replacement for existing carer support services, which remain the mainstay of direct carer support and are vital in protecting and promoting carers health and wellbeing.

4.3 Carers who receive a Direct Payment should be adequately resourced and supported by an independent organisation, such as InControl, to ensure there is no additional burden placed on them in regard to accessing and managing their Direct Payment.

4.4 Providing carers with access to training should continue to be a priority for the NHS and other partners, with carers being able to access free training, such as moving and handling and training courses such as ‘Caring with Confidence’ This should not be funded through Direct Payments to carers.

5. **Employing a Relative Through a Direct Payment and Community Development**

5.1 At the moment the restrictions placed around employing a relative through a direct payment, which directs local authorities to only permit it in ‘exceptional circumstances’, mean that many people who would choose to employ a relative are unable to do so. The SDS Bill acknowledges that this is often the best course of action for people and is likely to produce the most positive outcomes.

‘Local authorities should be empowered to allow the employment of close family members where this is the supported person’s and carer’s informed choice and where it is appropriate to do so. The Bill therefore contains a power for Ministers to issue regulations in order that they can guide authorities who may need to sanction such arrangements.’ *(Social Care (Self Directed Support) (Scotland) Bill, Policy Memorandum)*

5.2 We welcome the move to free these restrictions making it easier for people to employ a relative where it is in their best interests to do so. But we argue strongly, that legislation should not simply extend the power of local
authorities, but instead extend and embed the right of service users to request the employment of family members. Where service users request the use of direct payments for the employment of family members or relatives, local authorities and future joint planning and commissioning structures should have a duty to consider and respond positively to such requests, and where such requests cannot be granted they should offer clear reasons why the proposal would not be considered to safeguard the care of the service user.

We believe that Ministers should develop clear regulations which adopt such a universal approach to the employment of relatives which not simply focuses on the powers of local authorities, but strengthens the right of service users to request a particular form of care provision. A Scotland wide framework of safeguarding criteria to protect vulnerable adults and ensure care criteria are met will be important.

5.3 There are many examples where employing a relative is the only available or desired option for people. The SDS Policy Memorandum touches on this issue:

‘Self-directed support may, therefore, offer a solution 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’ (Social Care (Self Directed Support) (Scotland) Bill, Policy Memorandum)

The Coalition of Carers in Scotland recently held several information events for carers in relation to Self Directed Support. In both island and rural and remote communities, such as Shetland, Angus and Aberdeenshire we found examples where recipients of direct payments were unable to access a service by recruiting a P.A or using the services of a care agencies because the area they lived in was too remote to sustain such services. The only way they were able to use their direct payment was by employing a relative.

5.4 There also needs to be a clear strategy and investment in community development to ensure that SDS is able deliver greater choice. Those living in rural and remote areas, from BME communities or looking after people with complex conditions report finding it difficult to employ PAs or purchase services from agencies. While this situation exists SDS cannot deliver on its promise of promoting greater choice and flexibility. It may be that over time services will evolve to fill this gap, however, initial investment is required to lay the foundations for this shift.

5.5 Many conditions result in challenging behaviour, or anxiety associated with unfamiliar people. In these circumstances the best outcomes for the service user are for care to be provided by those people, with whom trust has already been established. For example, carers looking after someone with dementia have told us that where care is provided by a care agency there is often a lack of consistency in the staff delivering care, which is upsetting and confusing for the person with dementia. In one situation the carer told us that the local authority had withdrawn a service as her mother had become aggressive as she was upset at the number of strangers providing her with
personal care. Their solution was to place her in residential care. However, by employing a relative through direct payments her mother was able to remain in the home and was no longer anxious or aggressive.

5.6. An additional group which often struggles to access appropriate support services are people from BME communities. We recently undertook some joint research with a member organisation (MEAD) around the needs of carers from BME communities in rural Perthshire. We found that one of the biggest barriers to people accessing care was language difficulties and a lack of access to interpreters. Respondents to the survey indicated that an interpreter was available in only 28% of cases. This was the same both for those trying to access an assessment and those wishing to take up a service following assessment. Unless language and cultural barriers are addressed by mainstream services, employing a relative through a direct payment is the only suitable option for many from BME communities.

6. Issues Relating to Implementation

6.1 The success of the SDS Bill in increasing choice and control to individuals and enabling them to access more personalised, outcomes focused support is dependent on the government issuing clear guidance and regulation to local authorities. At the moment local authorities have been very inconsistent in their approach to the implementation of SDS, which has resulted in some people having a negative experience. It is essential that the Bill is supported by strong guidance ensuring that local authorities adhere to the principles of SDS, that there are robust and fair processes and timescales in relation to implementation and that outcomes for service users and carers are clearly recorded, monitored and evaluated.

6.2 SDS is being implemented at a time when local authorities are facing financial pressures and are seeking to identify savings. It is essential that in implementing SDS local authorities do not view this as an opportunity to introduce cuts to services. The government will already be aware of Glasgow’s policy of introducing personalisation and SDS alongside cuts of approx 20% to individual care packages. This goes against the principles of SDS and reduces choice, forcing people to make difficult decisions in reducing the level of services that support them and narrowing the opportunity to identify new and more innovative models of support.

6.3 In addition, local authorities must not make presumptions about the type of support people will wish to access. Some local authorities have funded SDS by firstly closing more traditional support services such as adult resource centres and residential respite units in order to shift resources towards individual budgets. However, this removes the choice for people to choose more traditional service models, which may produce the best outcomes for their individual circumstances. Choosing to maintain an existing care package rather than moving to something new must be viewed as a legitimate choice.
6.4 The process for implementation needs to be clear and robust, guidance needs to ensure that best practice is adhered to, particularly in the following areas:

- Developing an assessment process which is person centred and outcome focused. Lessons must be learnt from the poor SEQ process developed in Glasgow.
- Involving carers as equal partners in the assessment of the person they care for.
- Ensuring there is a robust review process which monitors outcomes.
- Ensuring local authorities develop Resource Allocation Systems which are clear, equitable and transparent and adhere to universal standards
- Ensuring there are appropriate timescales for implementation so that local authorities do not adopt a whole system approach as they have done in Glasgow to the detriment of the individual. There needs to be sufficient time for information dissemination, consultation, for outcome plans to be developed in partnership with the appropriate people. Risk enablement processes need to be thorough and there needs to be ample opportunity for people to take time to be creative in their thinking when it comes to the development of their care plans.

6.5 Information provision and support is at the heart of the successful implementation of SDS:

‘Individuals and families must understand the responsibilities that come with the choices available to them, particularly in managing and choosing to take risks.’ (Social Care (Self Directed Support) (Scotland) Bill, Policy Memorandum)

Service users and carers must have access to independent support agencies who are able to assist and empower them in making decisions and understanding the responsibilities inherent in accessing a direct payment, such as managing payments or employing people. Local carers centres may also play an important role in disseminating information and providing training. For example specialist staff are already employed by local carer organisations in Dundee and Midlothian to assist in the implementation of SDS and several local carer organisations have run awareness events and training to increase carers’ awareness of SDS.

7. Charging Carers

7.1 As previously stated carers have been recognised in legislation as ‘partners in care’ due to the significant contribution they make to the provision of health and care services in Scotland. The cost of replacing care provided
by carers in Scotland is estimated at over £10 billion each year.\textsuperscript{5} Carers must be viewed as contributors to care provision, rather than as service users. They should not be expected to contribute financially to the cost of services provided to the person they care for, or to the cost of services which enable them to continue in their caring role.

7.2 Section 16 of the Bill must therefore be amended in line with this principle:

Section 16 amends Section 87 of the 1968 Act (authorities' power to charge for services or support). This has the effect that authorities may charge for support provided to carers under section 2 of the Bill. (Social Care (Self Directed Support) (Scotland) Bill, Explanatory Notes

If you require any further information, supporting evidence or wish to consult with our members in relation to any of these issues, please don't hesitate to get in touch.

Voice of Carers Across Lothian
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\textsuperscript{5} Valuing Carers, Carers UK, 2011