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

The MS Society welcomes the Bill on Social Care (Self Directed Support). We believe that legislation is needed to reflect the changes in policy towards person-centred and outcomes-based social care. Self Directed Support is a vital part of independent living; allowing people with MS to fulfil their potential and to fully contribute to their communities. We welcome, therefore, any attempt to increase choice and control for people with MS.

Whilst new legislation is an important step forward, previous legislation on direct payments has shown that legislation alone will not meet the government’s policy aims to make social care more person-centred. It is important then that this legislation is supported by other activity.

As it stands, the Bill lacks clarity on a number of issues which will be crucial if meaningful choice and control is to be delivered to people affected by MS. It may of course be out of the Bill’s scope to address such issues but in our experience these factors will play an important role in ensuring people with MS are given real control over their support.

- **Training:** Will training on SDS be compulsory and who will be trained? Many local authorities in England have trained only their senior managers, rather than professionals who work directly with supported individuals and who often inform and influence decision-making. It is also important that training on SDS is consistent across all local authorities. We have noted that in England local authorities have interpreted SDS differently and incorporated these differences into their training. This has lead to inconsistency across local authorities where an individual in one local authority area has the flexibility to use SDS in a way which might differ to somebody in a different area. It may be worth thinking about a national programme to ensure consistency and fairness.

- **Service users as employers:** Support packages for individuals must contain a contingency fund to cover additional costs such as insurance, recruitment and emergency cover. People cannot take on the responsibility of being an employer without this in place. It is important that contingency funds are accompanied by clear guidance on when they can be used. It may also be worth considering including the ability for the fund to be used flexibly to cover unexpected changes in condition. This is particularly important to people living with MS, which is a fluctuating condition. It is also important to ensure that there is sufficient assistance available to an individual to understand their liabilities as an employer and take the right steps to cover themselves.

- **Consistency:** Will the variation in charging be addressed? Will the assessment process be the same across the country? Will support packages be transferable across local authorities? These concerns can have a significant impact on where a person can live and work. Allowing
packages to be transferred across local authorities, for instance, is important in terms of social mobility and equality. We of course, understand the importance of local democracy but when does acceptable variation become inequality? A caller to our helpline recently asked, “Where is the best place to live in Scotland if you have MS”?

- **Monitoring**: We would like some assurance that the enforcement of the Bill will be monitored. We believe there are opportunities to work with the voluntary sector in this area. If support is to be outcomes-based, SDS must be implemented flexibly. We believe, for instance, that people with MS should be able to use their direct payments for short breaks. It is important that local authorities see short breaks in a flexible manner, allowing people with MS and their carers to take breaks in the same way as the rest of the population do. Short breaks are a very important mechanism for supporting carers and enabling them to continue in their caring role.

2. **What are your views on the principles proposed?**

The MS Society strongly believes that individuals should be able to choose the support that is right for them, at the right time. This is particularly important for individuals living with MS since MS is a fluctuating and unpredictable condition; some people with MS may require support sporadically and sometimes perhaps quite suddenly. People with MS then require a social care system that is responsive and flexible; one that enables them to decide what support they need, when it is to be delivered and by what means. It is crucial to this process that the individual receives quality information about what choices are available to them and that they receive the necessary support to maintain the chosen support option. We agree, therefore, with the general principles outlined in the Bill.

We believe, however, that it would be worth making reference to how SDS options should be applied with flexibility and creativity. We also note that an individual must be provided with assistance that is “reasonably required”. We are concerned that the term ‘reasonably’ may be interpreted differently by local authorities. Assistance that is required for an individual to express their views or make an informed choice should be provided.

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

The MS Society agrees with the Bill’s assertion that the status quo cannot continue; that is, people should not be subject to the traditional ‘default’ of a local authority arranged service or a decision-making process which is ‘state-owned’. We also strongly support the assertion that individuals should expect choice and control over the support they receive – including the choice to have their support arranged by their local authority if they wish (option 3).

The MS Society fully appreciates the value of direct payments (option 1) and understands the positive impact they can and have had on the lives of people living with MS. Many of our members have described how direct payments
have enabled them to take-up employment, education or social opportunities that would previously have been unavailable to them. Our members have also described how direct payments have allowed their close relatives and friends to become family and friends again – rather than unpaid carers. Direct payments then can have a huge impact on the quality of someone’s life and their ability to participate in society.

Increasing the take-up of direct payments in itself, however, will not provide genuine choice for all. For direct payments to work in the way the government intends, local authorities must apply this option in a truly flexible way.

We are concerned that the language used in the Bill does not adequately express this desired flexibility. At present, direct payments are defined in the Bill as “a payment...for the purpose of enabling the person to arrange for the provision of support by any person (including the local authority)”. The Bill’s accompanying policy memorandum, however, states that “money can be spent however the individual chooses provided it meets the agreed outcomes in their care and support plan”. This latter definition appears to us more flexible than that in the Bill itself, which seems to imply that a direct payment will be used to fund a personal assistant. We would argue that this will not and should not always be the case.

We would advocate a similar approach when applying options 2 and 4. It is key that local authorities interpret these options in a flexible manner. In addition, it is crucial that the very idea of flexibility and what that entails is delivered in a consistent way across Scotland. At the moment, what a direct payment can be used for is interpreted differently across local authorities. For instance, in one local authority it is currently acceptable to use a direct payment to pay for costs associated with keeping a canine partner. In another local authority, however, using a direct payment for this purpose is deemed inappropriate. Our members in England are experiencing similar issues – what is deemed acceptable in a care plan often comes down to the views of individual social workers. We believe this is unacceptable.

It is important to remember that there may be occasions where care plans will change until the right combination or balance of support services in place. People should be given the opportunity to try packages and change their mind if necessary.

We would also be interested to know how the choices outlined in the Bill could be accessed by current recipients of support. A number of our members have not heard of Self Directed Support and believe it would be ‘a hassle’ to find out about and arrange. We are interested to know, therefore, how local authorities will actively promote these options with existing service users.

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?
The MS Society believes that SDS options should be available to children and their families. We also feel that young people should be encouraged and supported to manage their own support as early as feasible for that individual. This enables the young person to be able to make their own decisions on the type of support they want and how they want that provided. There would of course need to be someone to oversee such decisions (probably the parents) and ensure that the young person’s needs are being met. However being able to manage their own support package is a big step towards independence for many disabled people.

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?

The MS Society believes that for choice to be meaningful individuals must be provided with clear and objective information about the various possible support choices. We also agree with the Bill's assertion that local authorities must promote self directed support options. We are interested, however, in how this provision would be monitored and what would be deemed quality information and promotion? Only when individuals are given clear, quality information will choice be truly genuine.

Both promotion and information provision will require ‘cultural change’ from local authorities. Some people with MS have not heard of SDS and some of our members have told us that they have never been offered a direct payment, despite local authorities having an obligation to do just that. Other people with MS have told us that their social worker advised them that direct payments “are not right for you”. Some people with MS told us that they received information on direct payments through searching on the internet or approaching voluntary organisations. Others have told us that they had to ‘fight’ or ‘struggle’ to access direct payments. Often the information available has depended on the enthusiasm of the local authority or the enthusiasm of individual social workers.

Training of all staff, therefore, will be crucial to the success of SDS. It might be useful to include some guidance around minimum training for staff. In addition, it would be useful to set out what support individuals can expect from their local authority once they have chosen a support option. Experience from our members in England has shown that in the main the best support comes from organisations of disabled people – such as the Centres for Inclusive/Independent Living.

There is also a need to ensure proper support systems for individuals who are having difficulty in retaining information either temporarily because of their condition, such as during a relapse, or who need ongoing support to make informed choices. Advocacy is crucial to ensure that all people are able to have access to services which enable them to make informed choices in how their support is provided. Such support and advocacy should be provided as a right not as an optional extra if the LA want to provide such a service.
6. Are you satisfied that the method for modernising direct payments in the Bill will result in the change that the Government seeks?

The MS Society agrees with the need to reform current direct payment law. However, as previously stated, legislation alone will not necessarily effect the change in social care that the government seeks. Real change will come from how the local authorities interpret direct payments and how flexible they are in applying direct payments. This flexibility must be applied consistently across the country.

In this section, it is also important to make reference to the employment of personal assistants. We know that many people using direct payments experience some anxiety about becoming an 'employer' and the responsibility that this entails. Whilst it is of course important that individuals are aware of their responsibilities it is equally important that they understand support is at hand.

Such support for direct payments should not only be available for ‘setting-up’ the arrangement but should be available to individuals on an ongoing basis. People should have the ability to ‘dip into’ support services as and when they feel they need it. People will be less inclined to take up direct payments if they do not feel that the support services are adequate or available to them in times of need. It would be helpful if minimum criteria is established to ensure that all people taking up this service have access to support and services that would enable them to have real choice and control over their support.

Importantly, people with MS have suggested that for them to have genuine choice and control over their care, there must be appropriate services for them to choose from. In some parts of Scotland, for instance, there is limited choice for those who wish to access short breaks.

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

The MS Society believes that carers make a huge contribution to Scottish society and agrees with the Bill’s assertion that without unpaid carers Scotland’s health and social care systems would be unsustainable. We support the provision to allow SDS to apply to carers. We believe this is sensible and just. We would ask for clarity, however, on what this will work in practice – how will a direct payment for a carer differ from a direct payment paid to the person they care for. Would they be paid through the same budget?

We would also stress again that for the Bill to effect genuine change, the carer must be provided with quality information prior to making a choice and effective support once that decision has been made. SDS options for carers, like the cared for person, must be applied with flexibility if they are to provide genuine choice and control.

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?
Many of our members have suggested to us that SDS options would have a positive effect on their personal relationships by allowing their close relatives or friends to become just that again – e.g. they would use their SDS to employ a personal assistant in place of their relative being an unpaid carer. However, we are aware that in certain situations – perhaps due to culture or geography or where privacy and intimacy is paramount - it may be preferable for an individual to use their direct payment to employ a relative. For instance, in rural communities where there may be a lack of suitable employees, or where an individual needs end of life or respite care. We are aware of course that this is a complicated issue. There is the issue of benefits that are affected if a family member living with the individual is paid for the caring and also the issue of control and pressure. One might argue, for instance, that it is very difficult to fire your mother! Employment of family members therefore must be an arrangement then that both the individual and carer are happy with.

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

The MS Society agrees that service re-design is essential in the face of demographic changes and financial pressures. The Society is not in a position to comment fully on the investment laid out in the Financial Memorandum and how this might feasibly fit with the changes to be made by local authorities. We agree with the Memorandum’s assertion that some local authorities will have to make more changes than others, meaning the financial implications for authorities could vary considerably.

The MS Society of course, appreciates the difficult financial position of local authorities, particularly in light of the UK government’s changes to welfare and benefits. We believe this situation, however, offers an opportunity to think and act differently with regard to health and social care. It is more important than ever that resources are used as effectively as possible. We agree that Self Directed Support provides better outcomes for individuals and as a result provides better value for money. Whilst SDS is not about cutting costs, in some instances it can directly reduce costs for local authorities. For instance, one member described how prior to direct payments, they were forced to use respite centres providing 24 hour care in set blocks of time. However, the member might only require overnight care meaning 12 hours of care was effectively ‘wasted’. With direct payments the member was able to arrange support when she needed it – meaning either a saving for the local authority or double the amount of care for the member.

A cultural change within local authorities will be vital if genuine change is to be effected. It is important then that adequate resources are allocated to provide training to all those who need it – including those professionals who have direct contact with supported individuals.

10. Are you satisfied in the assessments that have taken place in regard to equal opportunities, human rights, island communities and sustainable development and in the conclusions reached by the Scottish Government?
We are satisfied with the conclusions reached by the government. We agree with the assertion that Self Directed Support may not address all of the challenges faced by those in Island or rural communities. However, we are supportive of the government’s belief that SDS offers the opportunity for flexible and creative solutions. We also believe the opportunity to employ family members, where appropriate, may offer an alternative where there is a lack of suitable carers.

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

MS does not adhere to department boundaries. MS can cause symptoms which require medical treatment but these symptoms will also impact on services beyond health. MS can lead to mobility issues, for instance, which may require housing adaptations, or mean that the individual needs assistance to carry out day-to-day tasks. Similarly, mobility factors may make using public transport difficult which could affect an individual’s ability to work or to study. It is vital that needs are looked at holistically and that support is based on outcomes and not service-provision. Achieving this will require professionals to work together across bureaucratic boundaries. It is important to people with MS that those professionals have the specialist knowledge necessary to assist them in making the most informed choices and supporting them in doing so. We, of course, realise that this Bill has limited scope and we support the effort to promote SDS across different services. This is particularly important as closer integration of health and social care services is envisaged. A project involving people with MS in NHS Lothian may provide evidence as to how successful health outcomes can be achieved through SDS. An evaluation of this test site is expected to show the positive impact of SDS for those with complex needs.

About MS and the MS Society

- Multiple sclerosis (MS) is the most common disabling neurological condition affecting young adults, and more than 100,000 people in the UK have MS.
- The MS Society is the UK’s largest charity dedicated to supporting everyone whose life is affected by MS and exists to help people living with MS across the UK by funding research, providing high quality information and support and raising standards of care.

Multiple Sclerosis Society
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