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

PAMIS

Response from PAMIS

PAMIS is a voluntary organisation that supports people with profound and multiple learning disabilities (PMLD), their families and carers.

People with profound and multiple learning disability have profound learning (intellectual) disability, the majority will have physical disability (lifelong wheelchair users), sensory impairments and very complex health care needs. Health difficulties include: severe epilepsy; chronic respiratory difficulties; gastro-intestinal difficulties; problems with eating and drinking, and many more. Their communication is usually non-verbal.

Views on the Bill as a whole

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

Yes we are in favour of the Bill and its provisions. 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.

General principles underlying the Bill

Section one of the Bill proposes three principles, which are described as “the general assumptions under which professionals and individuals should operate.” (Policy Memorandum, para 17). The principles encourage “involvement”, “informed choice” and “collaboration”. Local authorities would have a duty to have regard to these principles when carrying out their functions under the Bill.

2. What are your views on the principles proposed?

The principles proposed seem to be very positive on paper. However, as an organisation that supports people with profound and multiple learning disabilities (PMLD), we would want to stress the high level of medical and personal support that a person with PMLD needs on a 24 hour basis. Because of their complex needs and limited understanding, families with relatives with PMLD are usually the ones responsible for ensuring that their relatives’ needs are met and that appropriate services are in place for them.

Because of this, families need to be assured that there is clarity in their informed choices to ensure an outcome for their relative with PMLD based on their level of need, and that this is reflected in the budget they are set so that the appropriate care they need can be “purchased”.

We are encouraged by the principles that promote involvement and collaboration. Unless these principles are maximised by local authorities people with PMLD will not benefit from SDS.

With this in mind, carers must be included throughout the SDS process. Involvement, collaboration and inclusion are particularly important to people
with PMLD and their carers because packages of support are so specialist and at times very complex in their delivery.

Options for self-directed support

Sections 3-4, 6-12 and 17 of the Bill contain the core self-directed support provisions. Included are that the local authority must offer an individual four options in how they would like to direct their support – “direct payment”; “direct available resource”; “mix of approaches”; or, “local authority arranged support”. The provisions would relate to adults assessed as requiring community care services, and also children and their families where a local authority decides to provide services under the Children (Scotland) Act 1995. Other provisions include that individuals must be provided with information and advice to help them make that choice, and those who may have difficulties in making informed choices are provided the necessary support to do so.

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

We feel that it is very good that local authorities now have a duty to offer four options, thus providing a variety of approaches to service provision.

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. 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.

However, we want to ensure that each option, and its pros and cons, is clearly laid out to service users – or to families, as they will generally be the people needing to organise services and make decisions for their relatives if they have PMLD. We also want to be sure that these families are fully involved in the process, and that they are properly informed, so that they can make a clear choice on which option is best for their relative.

Families may also need help and support to make the best decisions, so we want to see organisations who can provide this support highlighted to them as early on as possible, so that they are not left to struggle with planning/decision making alone.

One thing we feel should be highlighted to families who have a relative with PMLD is that, if they go for the option of recruiting a PA for their relative, there will be a need to train that PA– because of the specialist health and medical needs of people with PMLD.

Families should also be made very aware that they can change between options if their chosen option isn’t working for them and they want/need to try an alternative approach eg if they try managing a direct payment and it doesn’t work for them etc.

Families must feel supported throughout all stages of this process, particularly while trying to adapt to the changes involved. Personalisation and self directed support should, after all, be about adapting to a person’s needs, rather than the person having to adapt to services that are available.
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?

PAMIS supports families who have a relative with PMLD of any age, so many of these are children i.e. under 16 years of age. However, because of the limited capacity of most people with PMLD, these children are unlikely to be able to exercise the type of control referred to here. However we would welcome this opportunity for other children with learning disabilities who may be more able.

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 principle of providing information and advice proposed here is an essential one. Clear and appropriate information is vital to anyone needing to understand the concept of self directed support, as well as the intricacies of the self directed support process, and what decisions to make.

In addition, as we have mentioned previously, the organisations that can help provide support to families with regard to SDS, need to be highlighted to them as early on in the process as possible.

We also want to see consistency in the provision of information and advice across all local authorities. We believe that families in all areas should have access to the same level of support and advice, to make the best possible decisions for their relative, so that the best possible services are provided for them.

At PAMIS we focus on training, consultation and inclusion for the families we support, and would be encouraged if local authorities focused on frequent training of their staff in order to support service users in the many changes ahead.

Direct payments

The Bill seeks to modernise and consolidate current legislation on direct payments, in order to make it more flexible to respond to individuals’ needs. Whilst local authorities would retain a range of duties and powers, the Scottish Government does not wish these to impinge on people’s ability to determine their own support. However, section 13 of the Bill would seek to do this through secondary legislation by granting Ministers powers to introduce regulations, rather than setting this out on the face of the Bill.

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

Modernising direct payments and allowing close family carers to be recruited as PAs for their relatives seems to us a positive step forward with regard to extending the level of appropriate support a person with PMLD receives.

At present, the majority of people with PMLD are supported by their parents for the majority of their day, resulting in isolation for both the ‘cared for’ and...
the carer. The isolation can occur from the high level of support the person with PMLD requires, and the lack of training that an ‘outsider’ can bring, thus creating a lack of trust in using outside agencies/PAs. So the possibility of recruiting another close relative to shares this understanding and experience to help in this care role is very welcome.

Rather than making it difficult for carers to get this type of support, we should be rewarding and valuing the knowledge and care skills they can bring to their relative with PMLD.

There is a need, however, to stress to families the importance of tracking and managing direct payments, and the level of input required by carers to manage appropriately this method of service provision. Account needs to be taken of the amount of time and commitment needed by a carer to manage a direct payment. Full support needs to offered by local authorities and supporting agencies on a regular basis to make this a viable, and successful, option for families.

**Adult carers**

Currently, adult carers of other adults or children are entitled to have an assessment of their needs. However, section 2 of the Bill proposes that local authorities should have the power to provide support to a carer on the basis of that assessment. Where a local authority decided to provide such services, section 6 would require it to offer a choice of the four self-directed support options to the adult carer.

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

We want to see the provision of services for carers, following a Carers Assessment, as a duty for local authorities, not just a power or recommendation. At present a Carers Assessment is often requested by a carer but it does not automatically lead to any provision of support for the carer, or any increase in support if this is required. Families with a relative with PMLD on average provide at least 10 hours a day of personal care for their relative, on top of day to day care, so carers desperately need support and respite if they are to continue with this role. Many of the families we support have a limited quality of life and many health-related issues as a direct result of the care they are providing for their relative on a day to day basis.

We would also want assurance that carers will always be offered a Carers Assessment, as we still hear of situations when one has never been offered, or one has been requested or offered, but never provided.

We also want to see consistency in the provision of services for carers across all local authorities. We believe that families in all areas should be able to receive the same level of support, as befits their needs, regardless of where they live.

**Individuals’ responsibilities and risk enablement**

The proposals in the Bill could place a significant amount of responsibility on individuals and their families, particularly in managing risk. The Policy Memorandum (para 26) accompanying the Bill makes particular note of the current ability of people to employ personal assistants through the use of direct payments (option 1 in the Bill). Whilst the Bill does not place any
restrictions on the categories of people that may be employed by an individual, the Scottish Government would publish statutory guidance which would cover ensuring individuals are aware of their duties as an employer and the risks in not adopting safe employment practices.

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 think there is merit in individuals being able to choose to employ a family member as their PA. By being able to employ a family member, who usually has the specialist knowledge/training and a positive relationship with their relative, effective support can be provided.

But again, the Government needs to be very aware that, because of the high level of medical, specialist and personal support, required over a 24 hour period, that greater costs will almost always be incurred, whether recruiting a worker from an agency, or a PA. Both will be carrying a high level responsibility for specialised care, and will need to be appropriately trained in moving and handling, as well as sometimes in the use of epilepsy medication, gastrostomy feeding, specialist communication etc. Many PAs and caring organisations are ill equipped to take on board the level of care this group must receive, without specialist training. In many cases, a person with PMLD will require the care of 2 workers at the same time, which obviously comes with an additional cost.

Financial Memorandum
The Financial Memorandum accompanying the Bill sees much of the Bill being cost-neutral in the long term. However there is an acceptance there will be transitional costs associated with transforming the culture, systems and approaches to social care provision as a result of the Bill and the Government’s wider strategy.

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

We have concerns over the Transformation costs allocation of funding for local authorities. £24 million is to be granted over 3 years, peaking in year 2 and then declining. The evidence from the test sites project run by the Scottish Government was of a much slower scale development over the 2-3 years that it ran for. Only a small number of people in each local authority (50-100) were enabled to take up Self Directed Support options, despite funding of £0.5 million per year being made available to each local authority. The amount proposed is less than this, if the £24 million is split evenly between local authorities.

As a result we believe the expectations of this policy and Bill need to be clearly stated as significantly less than full scale transformation - or the amount of funding made available to support the change process needs to be increased.

We think it is a mistake for the Financial Memorandum not to look at what will happen with the Independent Living Fund (ILF). The existence of the ILF has been important is supporting the move towards SDS. For individuals
managing this contribution to their care, it has helped them become more confident in managing the local authority contribution in Direct Payments.

The ILF is closed for new applications but the latest statement on the Fund has guaranteed a degree of security to it for the remainder of this session of the Westminster Parliament (expected to be 2015). In Scotland in 2009 ILF spent £60 million.

A long term proposal to transfer ILF funds to local authorities may be put out for consultation shortly. This will be aimed at the English proportion of the fund but will have implications for Scotland. For Scotland the fund is likely to be transferred to the Scottish Government to manage, who would then be able to decide the appropriate placing within a Scottish context. They may be able to choose to transfer it to local authorities or not.

We have a number of real concerns over such a transfer to local authorities:

- The value of additional funding may be lost amongst the much bigger pot of social care spending
- There is no statutory right to “independent living” so the money will be directed towards basic care needs
- There may be reductions in the level of support enjoyed by recipients as there will no longer be a necessity for a minimum care package to be in place for ILF eligibility
- The ILF money may eventually be lost entirely to the social care budget as it may not be ring-fenced.

Our view is that the ILF should continue to exist as a ring-fenced fund, managed by the Scottish Government, and use its resources to complement local authority spending on social care services. The ILF is a relatively small contribution to social care. In 2009 local authorities spent £840 million on social care for people with learning or physical disabilities – 14 times as much as the £60 million contributed by the ILF. Its funds would be better used to support people who already received a social work service but were in need of further support to improve their quality of life. Funds could be allocated following assessment by ILF assessors to meet quality of life outcomes, perhaps guided by the Talking Points model.

This would mean that, where people were having their basic needs met by the local authority, they could apply to get additional help from the ILF to:

- Live safely and securely in their own home
- Have meaningful things to do in their lives
- Make, keep and sustain friendships
- Keep in good health and well being.

The Policy Memorandum (para 52-63) accompanying the Bill outlines the assessments made by the Scottish Government on the potential impact, if any on equal opportunities, human rights, island communities and sustainable development.

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?
It is very positive that the Bill will give as much information to service users to make informed choices, and we hope that the core values and principles of the Bill will enhance service users’ lives.

However, we must take into account the amount of support a person with PMLD requires, and we assume that the necessary Equality Impact Assessment took into account this widely unrepresented group.

Other matters

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

With regard to how actual budgets are worked out for individuals, we feel that if a RAS (Resource Allocation System) is to be used by a local authority for this, then it should include medical and health needs, which are a large part of the support required to people with PMLD.

We also feel that all local authorities should use the same calculating measures/techniques when allocating budgets, so that people with PMLD and their families can receive the same level of service in all parts of the country.

PAMIS
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