

Long Term Conditions Alliance Scotland

Response to Proposals for a Self-Directed Support (Scotland) Bill

23rd June 2010



LTCAS welcomes the opportunity to respond to the Scottish Government's proposals for a Self-Directed Support (Scotland) Bill. LTCAS commends the Scottish Government for addressing the low numbers of individuals taking up self-directed support in Scotland and its aim to reduce any barriers by updating existing legislation. We believe that self management is an integral part of the Self-Directed Support Bill and should be reflected throughout.

Self management can be defined as a person-centred approach in which the individual is empowered and has ownership over the management of their life and conditions. When people can manage their condition(s) effectively, they have a higher quality of life, reduced complications and use of services, and are more likely to be economically active.

Self management should remain a priority for the Scottish Government in order to address the growing challenge of long term conditions. The Scottish Government should use the opportunity of the bill to consolidate the links between self management and self-directed support and to promote the strategy further. We strongly support the ethos of the guiding principles (better outcomes for individuals, choice, participation, mutuality and equality). This ethos strongly mirrors the principles of the self management strategy for long term conditions in Scotland. We recommend that these links are made clearer within the bill or the Policy Memorandum that will accompany it.

The bill must ensure that links between other key policy agendas (relating to health and social services) are properly established if its intentions are to be realised.

For self-directed support to be successful, self management must not be taken to mean 'going it alone' or act as a replacement for services. It must ensure that it offers high quality guidance, support and advocacy to individuals with varying levels of support needs. Furthermore, cross-sector training (with self-directed support, inclusive/independent living, self management, recovery

and human rights at its core) is essential for the bill to push the necessary cultural change within healthcare and social services.

Consolidating Existing Statute

LTCAS agrees that the existing legislation on community care should be brought into the 21st Century through the Self-Directed Support (Scotland) Bill.

Consolidating the existing laws on Direct Payments to one piece of statute is welcomed as a means for both clearly defining and promoting self-directed support.

Although LTCAS strongly supports the guiding principles (better outcomes for individuals, choice, participation, mutuality and equality), we recommend that self management is clearly emphasised within these values. Self management should be an overarching theme within the bill and thus form the link between each of the guiding principles.

Setting the Framework for Self-Directed Support

Legally defining self-directed support is welcomed by LTCAS. We are pleased that the Scottish Government has actively consulted disability organisations. This follows the very ethos of self management and ensures that a definition for self-directed support is sought, rather than imposed on the people it relates to.

We broadly support the bill setting parameters for the Scottish Ministers to amend the bill and to allow for combining social and health care into one direct payment. In addition, we would strongly welcome the bill's attempts to better integrate health and social care both at a policy and service-delivery level. The Scottish Government should also ensure that self-directed support and the new Healthcare Quality Strategy are linked up, especially in its approach to person-centredness.

LTCAS strongly encourages a framework within the Bill to allow for Ministers to create pilot areas for extending self-directed support and direct payments to areas beyond social care. It would be helpful if the learning from the pilot being developed with NHS Lothian could be widely shared.

Moving from Opt-in to Opt-out

LTCAS believes that self-directed support should be the norm in the future. We see an opt-out approach as a positive step towards achieving this goal. As the uptake of self-directed support has been low in Scotland, we believe that a more radical approach is required to move the agenda forward. Opt-out would be a good way to ensure local authorities make individuals aware of their choice to receive direct payments. Legislation should guarantee that local authorities provide the individual eligible for direct payments with unbiased support in order to make informed choices that best suit their personal needs.

Monitoring will be required to determine the impact of the legislation and how well it is being implemented. Increasing the level of advocacy, as described in the draft self-directed support strategy, is an important role for the voluntary sector to pursue.

It is essential to ensure that no individual's health and well-being is neglected through a lack of available guidance and support. However, it must also be understood that part of self management is people being allowed to make their own decisions and set their own priorities.

People who Lack the Capacity to Consent

The Scottish Government has understood that the current process to obtain guardianship orders is overly lengthy and bureaucratic. LTCAS believes it is essential to self-directed support that this barrier is overcome. Although we are keen on the idea of facilitating direct payments access for carers, new legislation must have effective safeguard measures in place.

We believe that the best method for improving access to direct payments would be by expanding the Access to Funds scheme (point numbers 47/48). The reason being that the established body, the Office of the Public Guardian (OPG), can most effectively monitor 'withdrawers' to protect individuals from fraud or misconduct. Amid growing budget costs, we warn that the OPG will need to secure the appropriate level of funding in order to act as an effective protection mechanism.

Extending Eligibility:

(i) People who are granted a leave of absence while subject to a Compulsory Treatment Order

LTCAS sees the extension of eligibility for direct payments to those with a Compulsory Treatment Order (CTO) as a positive step towards diminishing the social exclusion of people with mental health problems. Here, the voluntary sector should be supported in the key role it can play to ensure that those individuals with a CTO are given the additional support they need to effectively manage an individual budget.

LTCAS believes there should be a consistent approach throughout Scotland. Therefore, we believe there should be prescriptive measures set out for local authorities in this section of the bill. We are wary of the bill giving local authorities the power to decide whether to continue direct payments to this group of people and feel that this could be more appropriately decided by a multi-disciplinary body.

(ii) Residential Care

LTCAS supports the removal of the current restriction on the use of direct payments for residential care if certain conditions are met. Firstly, that the National Care Home Contract rate applies to those purchasing their own care. Secondly, that if this lower rate does not apply, individuals should be made fully aware of this when offered direct payments. Lastly, that the perceived burden (for example, the responsibilities and paperwork that come with entering into a contract with a care home) are overcome through additional expertise and support for this group of eligible individuals.

LTCAS is optimistic that direct payments would improve the quality of residential care and discourage extortionate care rates through improving the ability for individuals to choose their care.

(iii) Unpaid Carers

LTCAS agrees that there needs to be improved access to direct payments for unpaid carers in their own right. In times of falling public funds, there is a risk that an even greater reliance is placed upon unpaid carers. There must be appropriate support so that people are not forced into caring arrangements with family or friends where this is not what they want.

Unpaid carers should be recognised for the vital role they play in caring for many people with long term conditions. As unpaid carers often themselves live with long term conditions and experience greater barriers to accessing healthcare. Receiving direct payments could help diminish these barriers and also allow greater access to respite. This will help carers to protect their own mental, emotional and physical health and enable them to continue in their role. These principles should guide the new legislation.

Further recommendations:

(i) Link with self management

As highlighted in our May 2010 response, we recommend that the link with self management should be made more explicit in a Self-Directed Support (Scotland) Bill. Determining self management, and the role of self-directed support within it, would further the self management strategy for Scotland and play a key role in engaging health staff in the self-directed support agenda.

(ii) Budget and Funding

It is crucial that support mechanisms, for those eligible for self-directed support, cater to those with wide-ranging needs. Funding should appropriately reflect this. If not, there is a danger that those with complex needs will miss out on the benefits of the proposed bill and become further segregated in society. The bill and strategy should be face continual monitoring through an Equalities Impact Assessment.

(iii) Joined up

LTCAS reaffirms that the final strategy should contain plans to work with staff from across sectors, unpaid carers and people using services, to explore and address the issue of risk. This should include linking to the Scottish Patient Safety Programme and the safety strand of the Quality Strategy, as well as continuing to reflect the move towards self management and person-centred approaches.

The bill must attempt to encourage cultural change in the health and social services to help solve reluctance to self management and self-directed support. The self-directed support strategy can only succeed in combination with training and engagement with staff from across sectors.

About LTCAS

The Long Term Conditions Alliance Scotland (LTCAS) is an independent charity funded by the Scottish Government. LTCAS has over 170 member organisations from across Scotland and aims to ensure the voice of people living with long term conditions is heard by policy makers and service planners.

LTCAS' vision is for a Scotland where people with long term conditions enjoy, not endure, full and positive lives, free from discrimination and supported by access to high quality services, information and support.

LTCAS would be very happy to discuss any of these issues further.

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