

CONSULTATION QUESTIONS

Question 1

What aspects of the current ILF worked well and what elements did not work so well?

The Neurological Alliance of Scotland welcomes the intention of Scottish Government to continue funding current recipients of ILF to the same level of award and for the opportunity to input to the future developments regarding distribution of monies once no longer needed by current recipients.

Neurological conditions can affect all ages and can begin at any time in a person's life. Some neurological conditions are life-long and may be present from birth, such as Spina Bifida or cerebral palsy. Other conditions such as Alzheimer's and Parkinson's disease will affect mainly older people. Some neurodegenerative conditions, such as multiple sclerosis and motor neurone disease, occur mainly in adulthood and are progressive meaning that that a person's ability to live independently eventually becomes difficult and they will rely more on appropriate services to assist them.

Many people with neurological conditions have major disability and are eligible for additional support via ILF. ILF has been crucial in providing these people who have high support needs which are often complex, with the ability to participate in society and live as independently as possible. Many people with neurodegenerative conditions need constant help with personal care and would not be able to live independently without the flexible support of ILF money. ILF has been particularly helpful due to its flexibility and responsiveness. Payments can be used to respond to changes in circumstances and to plan support based around fluctuating needs.

We believe that as a nationally administered resource, ILF has allowed people to take a more preventative approach and is co productive. People with complex neurological illness are more able to ensure their personal care needs are met, informal carers do not suffer burn out and services they access are more appropriate to their needs. For example, younger people should not be forced to access services that are not age appropriate such as day centres or residential care services which are tailored to the needs of older people.

Question 2

Should the money that becomes available after existing ILF recipients no longer need it be used in the same way for others in the future? If so, why? If not, how else might the money be used?

We believe money that becomes available should continue to be available for use by others and should be ring fenced to ensure that its portable, flexible and preventative aspects are not lost.

If devolved to Local Authorities, ensuring equity of access and avoiding localism is unlikely to be guaranteed across Local Authority areas. The

direct payment of ILF money is a major benefit of it and allows for the flexibility required to meet individuals' needs. We feel it is important that support is nationally distributed and awarded through co-produced assessment. We therefore feel that the new Fund would be best distributed via the Third Sector rather than Local Authorities.

Question 3

If the available resource is simply that which is transferred from the Treasury, how would you like to see it used if it was not to be a continuation of the existing approach?

We understand that a Scottish ILF is not seen as sustainable and innovative approaches must be delivered to ensure that people have the support they need to live independently and are able to participate fully, however we .

It will be important to ensure that the amount of money transferred from the treasury reflects the current and future demand for its use.

We would support the new fund allowing for some preventative spend on lower levels of need. Funding made available to start projects enabling people to remain active within their communities would be welcome, for example self management projects and peer support projects. However, we believe it is most important to preserve the overarching principles of ensuring those with the highest need such as those with neurodegenerative conditions receive the support they need to remain as independent as possible.

Question 4

What innovative ways might there be for increasing the overall amount of money in the pot?

The ILF model and its fair and flexible delivery helps to meet the complex needs of those who receive it. We believe the model should not be substantially altered.

It may be that some resource can be allocated to people with lower level needs to enable them to remain active in their communities, access employment and subsequently avoid main stream support services for longer.

In the case of some neurological conditions, for example MS and Dystonia, supported self management and the ability to access low level support services such as complementary therapies and exercise programmes may mean that the individual remains active and reduces their need for more intensive support services. This may help to shift the emphasis from waiting for peoples support needs to increase before they can access a service.

Use of money to encourage and enable people to make use of technology and equipment that can allow them to retain independence would also be welcomed. For example, support for light writers for people with Motor

neurone Disease to support communication.

We believe that the model of delivery will be crucial in generating efficiencies. We do not think that a proposed Local Authority model will be the most efficient and would support a third sector partnership distribution.

Question 5

With any available resource, where is the most effective area to target resources which can have the biggest impact on an individual's ability to live more independently?

The Neurological Alliance of Scotland feels it is important that support from the new fund has the flexibility to meet individuals' needs. Ongoing long term support is crucial for many with neurological conditions with severe disability enabling them to live independently. We understand the financial impact of this but believe that short term models of support do not allow for people to retain independence and consequently are likely to require more intensive support in the long term.

The nature of many neurodegenerative conditions means that high levels of support with personal care are necessary. For many people ILF funding purchases similar services as those accessed via Local Authority funding but at a level which allows them to stay in their own home – for example buying in night time care.

We believe that it is important that people are given a range of options so that they can flexibly target resource in order to maximise their independence and meet their individual needs. Whilst for some, for example some people with relapse remitting MS, short term intensive support may be helpful. However those with progressive neurodegenerative conditions will require longer term support as their support needs increase.

Question 6

Once funding has been devolved to the Scottish Government, which option do you think will be most appropriate for Scotland?

The Neurological Alliance of Scotland would support Option 4, a new national trust or partnership within the third sector, which we believe would be the most appropriate model for Scotland and would retain aspects of what has worked well with the ILF.

We believe that the administration of the fund on a national basis would allow for more equitable distribution as it could employ national eligibility criteria that would support and deliver independent living and retain portability. Furthermore a nationally delivered fund would allow for a co productive system ensuring that funding provision is based upon need.

Question 7

To assist with our partial Equality Impact Assessment in relation to the future development of a sustainable Fund to support disabled people in Scotland to live independently, please describe any equality issues (in relation to age, disability, sex, sexual orientation, gender re-assignment, race, religion or belief, pregnancy and maternity and marriage and civil partnership) that you feel may arise and suggest ways in which these could be addressed.

No Comment