

CONSULTATION QUESTIONS

Question 1

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

The ILF has enabled our son Stephen whom is aged 44 to continue to live in the Community, without ILF Stephen would almost certainly have been facing the prospect of residential care for the remainder of his life. Although profoundly disabled and needing constant care and support Stephen has an active brain and both wants and needs a quality of life which he can only have if living with his parents in surroundings which he chooses in conditions which he chooses. The ILF has not only enabled this to take place but has also allowed Stephen the flexibility to employ the people he wants as personal assistants and to dictate when and where he wants to do things and with whom rather than being dictated to by others and having to fit in with other people routines rather than his own, when he wants to go to bed is his choice not others. The future for Stephen after the cessation of ILF is looking particularly poor as both his parents are now pensioners and will not be able to cope with both the physical or financial demands which will arise, there is also an unsure future for the personal assistants who he currently employs who will find themselves out of work.

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?

Any finances which are currently ring fenced for the support of severely disabled persons should continue to be used for that purpose. People who have severe disabilities do not choose to be in that situation and face lifelong handicaps both in the way that support systems operate (people have to fit in with what is readily available with the systems not being flexible enough to accommodate their needs and as a result financial pressures are created on the person with a disability and their Carers.

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?

The resources which are being transferred are being transferred to continue the work of the ILF at least for a 12 month period and as such must be used for that purpose. For Stephen and many other ILF recipients without this measure of support their lives will be damaged and the resultant costs to Local Authorities in meeting his needs will be very expensive and Stephen's quality of life will suffer.

Question 4

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

Increasing the amount of money for people who have a disability will be difficult unless resources are made available from elsewhere in the Government's budget such as Defence / Roads and Transport where a very large amount has recently been spent on the Edinburgh tram project (this alone would have been sufficient to continue with a form of ILF for many years).

If the Scottish Government is genuinely interested in supporting people who are highly vulnerable and disadvantaged then resources can be found BUT the willingness to do this has to be present.

It should be remembered that Carers such as ourselves already save the UK Government many billions of pounds each year.

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?

Making available resources, as the ILF has, directly to severely disabled people who know better than anyone else what their needs are. This allows the resource to be targeted in a more efficient manner and is cost effective as it eliminates most of the administration costs as the individual manages the monies themselves in a way that is flexible and targets each individual's needs as no two people's support needs are similar.

Question 6

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

Maintaining a Scottish equivalent of the ILF as history shows that it has eliminated the need for residential care for almost 20,000 people during its lifetime, even allowing that only a quarter of ILF users may require residential nursing care at a cost of £850 per week (UK average fees for nursing care) the resultant cost would be in the region of £221 million pounds each year, almost 60% of the £360 million pounds each year that the DWP claim would be saved by scrapping the ILF, to say nothing of the destructive effects on people's lives.

More importantly the Independent Living Fund has allowed people who have a severe disability the opportunity to continue to live a life which is controlled by themselves and as such has a quality which otherwise would be denied them.

It is essential that people in authority listen to people who have a disability and their Carers and not just their accountants, nobody who has a severe disability wishes to be disabled and they already face difficulties each day of their lives without the worry and threatened future which is being forced upon them.

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.

To our knowledge people who have a disability are already subject to inequality and the very fact that we are completing this questionnaire only strengthens that feeling.

Many years ago two young boys were passing my son who was in his wheelchair and one of the boys was staring at my son then the boy came up to his friend and said "don't do that if everyone was in a wheelchair we would be disabled". Those simple words from a child have stuck with us throughout the years as it puts in a nutshell the way that Society views what is normal and acceptable, again if indeed everyone was a in a wheelchair then we would not be completing this questionnaire.

"Out of the mouths of babes ?."