

CONSULTATION QUESTIONS

Question 1

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

The fact that ILF enables a great number of disabled people to lead more independent lives is a real plus. Without the additional ILF funding it is unlikely that so much could have been achieved and maintained by Scotland's Local Authorities. The problem with the ILF funding was the limited extent of the fund and that so many people who would have gained from it were not able to access it. To those looking in from the outside it would seem that the fund has great inequalities but to those who have been able to draw on the fund it has been a life saver. It is a fact of life that the fund could never have enough money given its widened remit. What has happened is that those, with perfectly legitimate needs, have been unable to access the fund in recent years and this has left many of them unhappy and feeling cheated. However for those who have been funded the latest changes have brought great doubt and worry about the future. The fluctuating nature of the fund has therefore brought about a great deal of unhappiness and unease from both sides of the equation. For my daughter and our family ILF changed our lives dramatically for the better. It would be difficult to put into words how valuable it has been to us and what a terrible blow it would be if the funding was to be reduced or stopped.

The assessment and monitoring procedures were efficient and well maintained. The ILF staff were very professional and seemed to work well with the local authority. The changeable nature of government policy towards public services and this fund in particular was a destabilising factor and more certainty in the longer term would have been welcome. Short-termism is an issue that always causes unease particularly when long-term solutions are being sought.

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?

Our severely disabled daughter lived with us at home for 32 years. The level of care required placed a physical and mental burden upon our family and also limited our daughter's opportunities. As our other children left home and as we became older and less physically able our thoughts continually turned to our daughter's long-term needs. We have suffered with both mental and physical problems and these were only going to get worse over time. Having now placed our daughter into a home of her own where she has settled well and is happy my family has experienced the great benefits that the change has brought about. I am sure that there are many other families in Scotland who would experience life-changing benefits if a similar service was available to them and I would argue strongly for any extra funding to be used in the same way that it has for my daughter and our family. My worry is that funds that are freed-up are spread too thinly to make any real difference to those in greatest need. I would rather that the

funds were used for those in greatest, and most critical, need and not dispersed more widely to those with less significant need. I know this might be looked on as selfish but I actually believe that is the most pragmatic and realistic solution. There will never be enough money to satisfy everyone and the politicians' perspective may be to upset as few people as possible rather than to defend a decision to be more targeted. I believe the right approach is to focus on greatest need particularly as those in greatest need often come from the lower socio-economic groups. Past experience leads me to believe that such groups are often unaware of funding paths and that they can find it difficult to interact with officialdom or to make a persuasive case. That doesn't make their need any the less. I read your paper with interest and could not disagree with any of the case studies you highlighted. However I would argue that some of them are less about crucial need and more about desires. That said if the funding was available we should of course do them all. The fact that it is not suggest that we should cut our cloth. I believe that should be based on extreme need and not on marginal improvements. That is where I believe the limited funds should be focussed and that this should be spelt out so that everyone understood why the funds were being used in such a way. No ambiguity.

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 Independent Living Fund's ambition was, and continues to be, a very worthy one given the greater desire to get the disabled out of dark rooms and back into the community where they belong. The existing approach is only limited by the funds available and it is, I believe, something that the Scottish Government should not only aspire to but take on to a higher level. There is a great need for such a service and I can confirm the life changing benefits it achieves. I believe that it would be an act of the gross folly and betrayal should the Government of Scotland abandon this flag ship service.

Question 4

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

There is no obvious or easy answer to this question given the pressures on Government from every quarter and the cost of providing such services. The funds are already inadequate given the overall need and the only way I can see of increasing the fund to some is to deny it to others.

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?

There are some individuals who are, like my daughter, severely disabled. For them it is not a matter of having a social life but more fundamentally about having any quality of life at all. As you would expect from my point of

view I see support for them as the priority. Allowing them to live in their own home with the support that they need should be seen as a basic human right. By its very nature this is the most expensive end of the programme of assistance but I believe the truest to the philosophy of the ILF. Adjusting lives in the margin to make them better would be welcomed by everyone and for many arguing against it would be seen as politically unacceptable. We seem to be living in a society where everyone expects everything and that limits are somehow not acceptable. Many politicians seem to find it difficult to say no but I am afraid that sometimes hard decisions need to be taken. We are now at crossroads with this fund and I believe it is for politicians to take the hard decision and then to stand by it. For me that is to communicate clearly what limited monies are available and how they are going to be used. It is better to be honest up front than to build up hopes that somehow a magic wand can be waved and everyone will get something. Spreading the fund thinly is no answer and it just ducks the hard decisions.

Question 6

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

Two of the options would seem the most likely given the disadvantages you highlight. These are local authorities taking on the role or a new trust involving the third sector. Personally I favour local authorities taking on the role with an inspection and oversight role be handed to the Care Commission who would cover Minister's on-going interests. I would worry about the time it would take to set up a trust and also the make-up of such a body. I feel it would be dragged apart by diverse interest groups seeking funding for their own areas and as such would lead over time to the fund being so widely dispersed that it served no really useful purpose and just became another income stream for those on disability benefits. It seems to me that local authorities are best placed to see and understand the real need in their client base and that they would use the funds in the areas of greatest need. A major issue would be the ring-fencing of the fund given that it could easily be lost in the huge social care budgets. Equally it would not be fair of local authorities to reduce their social care budgets taking account of this funding stream. These are not easy issues but I still believe that a unified service will lead to the most efficient and effective use of the funds.

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.

If the fund is truly based on greatest need, and that criterion is properly

applied, I can see no equality issues arising. A persons' gender, age, ethnicity, etc. should play no part in the process. The argument that might surface is how disabled is disabled. In other words is being blind more of a disability than being confined to a wheelchair etc. Professionals across the sector have been struggling with such issues for years so this is nothing new. They have systems of scoring need and whilst it is not always a comfortable process to go through it at least has a degree of fairness and consistency to it.