

Oxfordshire Family Support Network

Changing Scenes project,

Reg. Charity No 1143367 Co. Ltd By Guarantee: No 7583197

Jan Sunman, project Leader: 07596 784947

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06/10/12.

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To Whom This may Concern.

Please find enclosed our comments to the consultation regarding the ILF. We are sorry that we are sending this in right at the end of the consultation process, but circumstances were against us. We really hope you have time to look seriously at our comments.

The Oxfordshire Family Support network is a charity that was set up by family carers of people with learning disabilities. The organisation also works closely with other organisations in Oxfordshire, such as Carers Oxfordshire and local Mencap groups. It supports the families and carers of people with learning disabilities. The 'Changing Scenes' project is a recent project set up with the support of funding from Comic Relief. It aims to support older carers aged 60 plus, in the community.

We discussed the consultation questions at a meeting of our group, and took on board comments from service users and their families and carers, and from professionals. I also contacted individual older carers and a professional within Age UK.

I hope we have a comprehensive document for you and am only sorry our group was not in existence sooner, so that we could have got our comments to you earlier.

I am one of the carers involved in the Changing scenes Project.

Elaine Walker.

Elaine Walker

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P.S. You may receive this document electronically, but I've sent you a paper copy to cover all bases.

Question 1

Do you agree with the Government's proposal that the care and support needs of current ILF users should be met within the mainstream care and support system, with funding devolved to local government in England and the devolved administrations in Scotland and Wales?^[7] This would mean the closure of the ILF in 2015.

No.

However, the reality is that this will happen, and there needs to be checks and balances built into the process to ensure the best possible outcome; i.e. the social services have the mechanisms in place to ensure continued assessment of people's needs and the resources and infra-structure to deliver, and the recipients are kept well informed and are not missing out on financial support because of ignorance on their part, or on the part of the social services. We would like to ensure that any re-assessment of need is done in a fair and transparent way, with clear eligibility criteria, with rights of appeal. We wish to see reassessment that is genuinely needs led, rather than resource driven. We would like to see ring-fencing of this funding within the local authority to safeguard the needs of these very vulnerable service users, who, in order to receive ILF in the first place, have to demonstrate very high levels of need. We also would welcome the flexibility to ensure that if people move from residential care, that they could then apply for support to ensure that their high support needs can be met properly within a community setting e.g. if in supported living. The recent events at Winterbourne, also suggest that funding needs to be made available to support vulnerable adults with behaviours that challenge and who have mental health needs. This points all the more to maintaining specific, ring fenced funding like ILF.

Question 2

What are the key challenges that ILF users would face in moving from joint ILF/Local Authority to sole Local Authority funding of their care and support needs? How can any impacts be mitigated?

There is a fear that funds will not be ring-fenced, and that financial support will be eroded and cut. Our group have suggested that an Independent Monitoring Panel should be set up in each area of the country. This should be a service user reference group. The remit should be to ensure that each authority is delivering the funding that until now has been delivered by the ILF. Recipients of the ILF, or their carers or advocates should make up the panel. The council should liaise with the panel and it should be facilitated by the council, so the council will fund a venue for the meetings, and fund a clerk to minute them. The government could consider using the user-led organisations that identified both as useful in implementing personalisation locally and in engaging with hard-to-reach groups.

One of the greatest challenges is to ensure that people continue to receive the right level of support to continue to live in the community with dignity and are supported to be able to have a life like other people that supports them to meet their aspirations. This funding currently makes that possible for many.

Question 3

What impact would the closure of the ILF have on Local Authorities and the provision of care and support services more widely? How could any impacts be mitigated?

24. We know that the closure of the ILF would be more difficult for those Group 1 users who are not currently receiving any Local Authority funding, and who in some cases have little experience of the mainstream care and support system. It is important that those users engage with the local authority care and support services for which they are eligible.

Without putting too fine a point on it, we think panic and distress may ensue. This would not be an unreasonable response. The social services have an enormous responsibility with regard to social welfare and support. Their budget is constantly being cut and guidelines and criteria change all the time, as does legislation.

An example of this has been the implementation of the self-directed budget. So many people are being 'sold short' on this because care managers do not fully understand the mechanics of it. Many carers have no help or information when drawing up a support plan and are unaware of the brokerage system, etc. and other agencies who are there to support them. Access to independent, unbiased advice is not readily available and many carers are still very confused about how personalisation works. We feel that it is very important that care managers and social workers understand the funding process and understand community care legislation to ensure that service users receive the funding that they require.

We believe that impact assessments should be carried out on each individual, to monitor what would happen under various scenarios.

If ILF were totally lost for each individual and not replaced, what would happen?

What would be the impact of losing different percentages of funding?

What would the impact be on other services, such as health services, if ILF was not replaced in full for each individual and what would be the overall impact on the Local Authority?

Will the emerging new health commissioning structures, such as Clinical Commissioning Groups have taken into account the impacts on their commissioning of services if ILF goes?

What will be the impact if ring-fencing is lost on those with the highest levels of need?

Will there be a disproportionate impact on people from very disadvantaged groups, such as those from BME communities?

Will any replacement funding recognise not just the needs of people with severe physical disabilities but also those with severe and profound learning disabilities or autism? The recent proposed changes to DLA show a depressingly low awareness of the needs of people with learning disabilities and we would not want this proposed change to ILF to also adversely impact on those who have learning disabilities.

Question 4

What are the specific challenges in relation to Group 1 users? How can the Government ensure this group are able to access the full range of Local Authority care and support services for which they are eligible?

25. The Government remains committed to funding current ILF care packages until 2015. But we know that it will take some time to manage the move to sole local authority funding. It would be necessary to start such a process well in advance of 2015. This consultation is only the start of a process of working with users, Local Authorities and the Governments of Scotland, Wales and Northern Ireland.

Information needs to be made available to all.

Careful assessment of needs would be vital, and advice and help in drawing up comprehensive support plans that are tailor made for each individual. Transitional funding will need to be made available to ensure that people who have high support needs are not losing out on vital services.

We would suggest that there needs to be a dedicated multi-professional team, skilled in supporting people with physical and learning disabilities, in each authority who work on these transitions to ensure that people who have ILF do not have their care and support de-stabilised.

Question 5

How can DWP, the ILF and Local Authorities best continue to work with ILF users between now and 2015? How can the ILF best work with individual Local Authorities if the decision to close the ILF is taken?

Communicate and listen. Please have a workable strategy in place in good time so that chaos does not break out at the last minute.

Work effectively and closely with service users and carers and actively seek their views. Measure impacts of changes and make sure that the Local Authority and Health and Well Being Board are required to monitor the impacts. Engage with local Health Watch as the local health and social care watchdog, to ensure that people are being listened to. Use local carers organisations to monitor impacts on family carers of these changes.

Anything else you would like to tell us about

Is there anything else you would like to tell us about in response to this consultation?

The criteria used to access ILF funding changed dramatically about 3 years ago, excluding the majority of people with learning disabilities who would have previously been eligible. We would like to think that this criteria could be reviewed and adjusted so that not only the people who currently receive funding from the ILF do not lose financial support, but those who currently do not meet the criteria may also be included in the new system of funding. We would also like flexibility so that if people's needs increase or change, they can receive extra support quickly, with a clear and rapid decision-making process.

- 4 Support for ILF users from 2015

- 6 Impact and Equality Impact Assessment