

**A SUMMARY OF
ADULT SOCIAL CARE
INCOME REVIEW
CONSULTATION FEEDBACK**

**A REPORT OF THE SERVICE USER AND
CARER REFERENCE GROUP
DECEMBER 2008**

1. BACKGROUND TO THE REFERENCE GROUP

A number of Service User and Carer led organisations and groups were invited to send representatives to form a Service User and Carer Reference Group to oversee the consultation with Service Users and Carers on the issue of the Income Review.

Five organisations were able to nominate a representative who could commit the time required and the group initially met on the 4th July 2008. The organisations and groups that were represented are as follows:

Alliance of Service Users and Carers
Independent Disability Council (Leeds)
Leeds Local Involvement Network Preparatory Group
Learning Disability Service User Reference Group
Older People's Reference Group

The Reference Group was chaired by a Service User and Officers of Adult Social Care Services were in attendance as advisors.

2. THE REMIT OF THE REFERENCE GROUP

The Terms of Reference of the Service User and Carer Reference Group were agreed at the first meeting of the group on 4th July 2008. These are attached for information.

The starting point for the work of the group (and the consultation) was not whether people should contribute towards the cost of the social care services that they receive, but how and how much they should contribute. Leeds City Council were looking to consult on how it could increase the contribution it received from users of non-residential social care services and also produce a more "fair and equitable" policy.

At this point we would like to state that by agreeing to be members of the Reference Group and agreeing to the Terms of Reference it did not mean that we agreed with Leeds City Council on seeking to increase the charges for services, or that we agreed with charging for services. The position of all the members of the Service User and Carer Reference Group was that all services should be free of charge.

However, we agreed to work with Officers to look at this issue for the following reasons:

- We believed that this was an opportunity to influence the Council in shaping a revised Fairer Charging Policy.
- We believe that people should be involved at the earliest stage possible in determining policies that affect them.
- We thought that as individuals we had something to add to the process either through our experience as a Service User or Carer or through working with a number of vulnerable people who use these services.
- Also, Officers of the Council stated that the previous consultation that was undertaken in 2002 and 2006, where the clear outcome was that people did not agree with charging for services, would form part of the report to Executive Board.

3. THE WORK OF THE REFERENCE GROUP

The Reference Group first met on the 4th July 2008 and then met on another 5 occasions up to the 11th September 2008 to prepare for the consultation.

We met again on three occasions between the 7th and the 17th November 2008 to receive the feedback from the consultation and to prepare a report based on the feedback.

Additionally, we completed an Equality Impact Assessment on the potential Fairer Charging policy and the Income Review consultation. This took place on the 1st and 10th October 2008.

The Reference Group agreed to work at a fairer way to look at Service User finances in the assessment process and then to work on providing information to people about these proposed changes and to ask them what they thought of them.

During the course of the meetings with Officers of Leeds City Council we were able to change and influence the proposals around charging and the consultation process. Some examples are as follows:

- ✚ Officers were looking at implementing the Charging for Residential Accommodation Guidance (CRAG) in relation to how they would take savings into account. We were clearly against this as we thought that it was not fair for people living in their homes who have costs associated with living in their own homes that CRAG did not recognise. So, we got officers to agree that people should have a higher amount of savings before it is taken into account in assessing their contribution towards the services that they receive.
- ✚ Officers were looking at whether to have a maximum charge or not and if they had one at what level should it be set. We heard that a number of other Local Authorities do not have a maximum charge and people (who can afford it) pay the cost of all the services that they receive. Also we heard that nationally, the average maximum charge is £170 per week. Increasing the maximum weekly charge from £88 to £140 was the figure that was proposed in the consultation, though we would have preferred a lower maximum charge to reduce the impact on service users. Officers did however ask us to note that a maximum charge of £140 per week would affect very few people living in their own homes.
- ✚ We heard from Officers that a number of other Local Authorities take 100% of people's disposable income. We reached an agreement on a fundamental principle with Council Officers that they would not take into account 100% of people's disposable income. What the end result was on this issue was that three levels of disposable income were included in the consultation.
- ✚ We had some lengthy discussions about what information should go out to people and in what format and what the questionnaire should look like. We knew that the subject matter would be a difficult one to get across easily to people but that people did need enough information in order to consider how the proposed changes may affect them and to form an opinion on this. The resulting information and questionnaire that was distributed to Service Users

and other interested parties, we understood was a compromise between transparency of information and being easily understood by (all) Service Users.

- ✚ However, with Officers we did take steps to ensure as far as possible that the whole consultation process was supportive to Service Users, Carers and other interested parties and in pursuit of this a number of arrangements were put into place:
 - We worked with Leeds Advocacy to produce both easy read and pictorial versions of the documents. We would like to take this opportunity to thank Leeds Advocacy for their valuable work in this area.
 - We asked a few key organisations to provide support to people if they needed it to either understand the information that was sent out to them or to help them complete the questionnaire. We would like to thank Age Concern and Leeds Advocacy for agreeing to undertake this support work.
 - Adult Social Care provided a freephone helpline for people. People could use this helpline to complete a questionnaire over the phone; obtain assistance in understanding the documentation; and request a home visit to help complete a questionnaire.
 - Officers of the financial assessment team visited people in the community to assist them in completing a questionnaire. This service was available to anyone who requested it.

- ✚ We also supported the use of a Prize Draw in the hope that this would encourage people to participate in the consultation.

The result of our work was a questionnaire (in a variety of formats and languages) and a set of information documents that were sent to all users of the following services:

- Home Care
- Day Services
- Supported Living
- Supporting People
- Meals at home
- Sitting Services
- Family(adult) placement
- Direct Payments
- Respite Care
- Transport to services

This was also sent to a large number of voluntary, faith and community organisations; Elected Members; Officers of Leeds City Council; and was available on request for the general public.

4. OUTCOMES FROM THE CONSULTATION

In this report we want to focus on the comments that were received by people completing their questionnaires as this tells the story as to why people agreed or did not agree with the options put forward by Leeds City Council.

The key themes that we have taken from this consultation are as follows. If you wish to have details of all the comments that were received then these are available from **Janet Somers, Adult Social Care Services, 0113 2477443.**

i) A number of people stated that they should not have to pay for these services.

As stated above, this would also be the view of the members of the Service User and Carer Reference Group.

Generally, people who made this type of comment felt that it was not fair for people who had worked all their lives and saved are then penalised.

Some views were expressed that the money they pay in Council Tax should pay for their services; or that the Government should ensure that they have enough pension etc to pay for their services; or that the Council should find the money from other parts of their budget. These are not new issues and are some of the issues that we raised in discussions with Officers of the Council. Other suggestions include:

“Maybe a way forward rather than putting it in the service user would be to try to reduce the cost of the service through streamlining it not an inferior service.”

“There should be less spent on management...too much money is wasted on functionless administrators.”

“The Council should look at alternative plans which cost less including other agencies delivering the services.”

However, other people thought that more money should be invested in social services to keep the services in house.

A relevant observation was made by one respondent:

“...And as LCC knows people cannot live without the services provided. Therefore people have no choice but to try and find the extra money.”

People should not think that it is a choice between either paying the extra money or not having a service. This is something that the Council needs to look at when implementing any potential changes to the Fairer Charging Policy. Similarly we are concerned that some people said that they would cease their services if they had to contribute more. The policy should be carefully implemented and monitored to ensure that vulnerable people continue to receive the services they need irrespective of the charging policy in place.

ii) A number of people commented that they could not afford to pay more or want to pay more.

The information sent out did state that people will only pay what they can afford to pay, and everyone will have a financial assessment before any charges are made or increased, however, people seemed to be saying this at the same time as commenting on the fact that everything is more expensive and that they have little enough income as it is. So, the message seemed to be more about people thinking that if they do pay anything at all now, then they pay enough.

“Obviously I don’t like the idea of paying more – as this is on top of the rises in food and utility bills etc.”

Older people who made comments were more likely to state that they were struggling financially and that living in their own home was a struggle. Some people who responded went on to say that they have to choose whether to be warm or whether to eat.

“I am happy paying £26.96 per month and no more.”

“Maybe spend a little less on the show off stuff and more on basics. In 2008 electricity has gone up 250% gas is up 143% and everything else is up at least 10%, benefits went up 3.3% - heat or eat is the reality.”

iii) Some people did agree with contributing towards the cost of their services.

However, this was not the majority view. What appear to be the key messages from these comments are keep any increase small and use it to improve services.

“I think everyone could pay towards transport.”

Some comments agreeing with people contributing towards the cost of the services that they receive and increasing the level of contribution was made by people who do not receive or pay for services:

“Several of my answers are “don’t mind” at the moment. I don’t mind because I do not have to pay for the services. I might mind very much if suddenly I have to pay £140 a week on top of the much publicised rises in energy costs.”

The majority of people in Leeds receiving a service will not have to contribute towards the cost of providing those services. ***We cannot identify whether the service users that have completed the questionnaire (and provided comments) are affected or not by the proposed changes.*** This should be a consideration when looking at the consultation.

iv) Some people raised the issue of the inequalities in the benefits and allowances system, raising concerns that any proposed changes would hit some people more than others.

The issue here is that younger adults receive less benefits and allowances (no winter fuel payment for instance), than older people and therefore they perceive that any proposed increases would be less fair to them.

“If further increases are applied most of my son’s disposable income will not be sufficient for his living needs. As a parent and carer our son is already being supported by our finances. When my husband retires shortly this will create financial difficulties for us as a family.”

The points that we would like to make in relation to this issue is that all people on benefits do not receive the same amounts and younger people generally receive less than older people; plus people’s perception at the current time is that any proposed changes are not (generally) fair and equitable (which are some of the reasons that the Council gave for undertaking this piece of work) and that they will have to contribute more. People’s anxieties about money and charging have probably resulted in them missing the issue about people only contributing what they can afford to contribute after a financial assessment – but perhaps Service Users’ views about what they can afford and what we think they can afford are very different.

v) Any specific comments about carer’s services were quite clear in their message, that is that Carers should not pay for the services that they need.

The view from the consultation, and one that we would endorse and recommend, is that Carers provide a valuable (often unseen and unacknowledged) service and that without them the burden on Council’s to care for people would be much greater. The majority view from people who made a comment about carers services was that these should be delivered free of charge. Any proposals to charge for carers’ services may be seen as punitive and would be a deterrent to using services.

There are two comments that seem to sum up people’s attitude to charging carers (or service users) for services to carers:

“Anything that relatives have to pay in order for them to have a break from caring I totally disagree with. By caring as they do, they save the country millions of pounds.”

“I agree that some of the services we can pay for. But bare in mind we carers can’t enjoy holidays when we want, and our income is taken up with paying for facilities we cannot take care of ourselves. The whole problem of finances leaves us completely stressed, in the end we will just have to use less of the service and carers suffer more stress.”

vi) There were a number of comments about services themselves.

There was a mix of comments about services. A number of people valued the services they received and were happy with the quality.

“The home care service is worth every penny we pay for it. It provides me with peace of mind and is better care than my mother received in a nursing home on transition from hospital.”

However, there were negative comments about the same service:

“Home care – paying for a service that misses average 20 or so visits in a year because of staffing issues is not my idea of a good service. I would categorically refuse to pay a penny for a service on the current basis and I don’t see that paying a small amount would change the efficiency of the service as the service provider would still be paid the same.”

In most instances we cannot identify the provider of the services and in some instances people have not mentioned the service that they are happy/unhappy with. However, we have been assured that all comments will be passed on to other areas in Adult Social Care.

It should be noted that the number of positive and negative comments received about services was roughly equal (22 to 18 respectively).

vii) Lastly a number of people found the questionnaire and the information difficult to understand.

Some of the comments related to the fact that the questionnaire asked questions relating to a range of services and some people felt that this was not relevant to them. However, in the main a number of people felt that the subject matter was too difficult to fully understand. However, these people had completed the questionnaire on their own or with assistance.

“I don’t pay for home care at the moment most of the questions do not apply to me and I do not understand them.”

As we noted above, we and Officers of the Council acknowledge that the subject matter was complicated and not the easiest of subjects to try and translate into easy read. Officers have taken these comments seriously and will consider how it can best communicate such difficult subjects in the future.

5. CONCLUSIONS AND RECOMMENDATIONS

The work that we, as members of the Income Review Service User and Carer Reference Group have undertaken with Officers of Leeds City Council has produced some valuable results in terms of what people think about charging for services and something about the value of those services themselves.

If Elected Members and Officers of Leeds City Council can take some things away from this, then we hope they would be the following:

5.1 Listen to what people have told you. Not only is consultation expensive and time consuming, but you can also gain the trust of the people who participated in the consultation and the wider service user and carer populations if you listen to what has been said.

5.2 *There are some clear messages from this consultation process and they are that generally people do not think that they should pay for the services that they receive, but those that accepted that there should be a payment want to see only a small increase in their contribution and that the additional money that this generates should go back directly into the services that they receive. There is also an element of trust here, as some respondents did not believe that the money would be reinvested in these community services.*

5.3 *Do not just agree the changes to the Fairer Charging Policy and then think that your job is done. Think about how you communicate with people (not to raise anxiety) and also how you will monitor the effect that any proposed changes has – will people stop their services?; will it have a detrimental effect on people’s lives – this is as much about perception as well as how it has practically affected them.*

We would also ask Executive Board to pay attention to their public body duties (both general and specific) as defined in the Disability Discrimination Act legislation (Disability Discrimination Act 1995 and as amended 2001 – 2005). Some of the essential elements of the public body duty that are of particular relevance to the Fairer Charging Policy are:

- *The need to promote equality of opportunity between disabled people and other people (general duty)*
- *The need to take steps to take account of disabled people’s disabilities even if this requires more favourable treatment than others (general duty).*
- *(Arrangements for) assessing the impact of activities of the authority on disability equality (specific duty).*

We hope that the work that we have done has been useful and that our collective experience and knowledge has brought benefit to the consultation process on behalf of Service Users and Carers.

In addition, it should be acknowledged that we feel this process has been an example of `Best Practice` in the meaningful involvement of service users and carers and that it represents a positive model that should be shared and promoted across all services within the City Council. We feel that Leeds Adult Social Care Services and all of the Officers involved should be congratulated on their facilitation of this process and their openness, honesty, leadership, accountability, objectivity, integrity and professionalism that delivered a process that was meaningful, accessible and inclusive to the needs of service users and carers within Leeds.

REVIEW OF SERVICE USER CONTRIBUTIONS SERVICE USER AND CARER REFERENCE GROUP TERMS OF REFERENCE

Purpose/Background

The Council is reviewing the income it receives from service users for non-residential adult social care services, that is:

- Home Care
- Supported Living Services
- Day Services
- Transport to Day Services
- Respite Care
- Family Placement (adults)
- Sitting Services
- Direct Payments

Non-residential services are a cornerstone of our strategy to support people in the community. For many people it is the key to enabling them to remain independent and in their own homes. It is very important that the services are properly funded. The contributions made by people who use these services are an important part of that funding.

The Council has to inform all users of the above services of its intentions and the potential impact it may have on them, as well as asking these people their views on its proposals.

Objectives

The Reference Group will work together to oversee the engagement of Service Users and Carers in this process.

Scope

1. The Reference Group will produce a set of preferred charging options that will then go out for consultation to service users, carers and other interested people and organisations.
2. The Reference Group will advise Officers on the appropriateness of the information to be provided as part of the consultation process for the target audience in terms of accessibility and completeness.
3. To advise Officers on the format of the questionnaire
4. To receive feedback from the consultation process
5. To provide a report to the Income Review Project Board on the outcome(s) of the consultation which will input to shaping the final proposals.
6. To complete an Equality Impact Assessment for the Income Review
7. To oversee and facilitate the allocation of funds to small community organisations to engage with Service Users who may not otherwise engage with the City Council.

Membership

Membership of the Reference Group is based around representatives of a number of selected service user and carer organisations/forums. Service Users will form the majority membership of the Reference Group.

Officers of the Council, representing the Income Review Project Team, will act as advisors to the group and support members in fulfilling their role.

The Reference Group will operate with due regard to all appropriate equality requirements.

The Chair of the Reference Group will be elected from the members at their first meeting.

Decision Making

Decisions will be based on a consensus wherever possible. Where a consensus cannot be reached, decisions will be put to the majority vote. Officers do not have a vote.

Time Span/Meetings

The Reference Group will meet in the first instance on 3 occasions between 4th and 11th July 2008. The consultation process using questionnaires will take place between mid August and mid-October. The Reference Group will need to meet at least once following closure of the consultation process, probably before the end of October 2008, in order to report on the findings.