

Personalisation Agenda

Consultation with Carers of Leicestershire

March 2009

**Jenny Darlow
Carers Information Worker
CLASP the Carers Centre**

Carers Consultation on Personalisation Agenda

1. Introduction
2. Background
3. Consultation Sessions
4. RESULTS
 - Topic 1 – Information needs
 - Topic 2 – Support with the process
 - Topic 3 – Thinking “outside the box”
5. Questions from Carers
6. Conclusions and recommendations

Appendix

- A. Copy of the presentation
- B. Workshop results from each area
- C. Results from evaluation forms.

1. Introduction

The consultation process outlined in the following report has been conducted to research carer's opinions on the new government initiative 'Personalisation Agenda'. This aims to put individuals before systems enabling them to take responsibility for themselves, and to give them choice & control over the services they use and how money is spent on their care.

The following report will look at the results of eight consultation meetings that were held between January and March 2009.

The meetings consisted of a presentation outlining the background of the Personalisation Agenda and what it means for carers and service users. Following the presentation there were discussion groups looking at information, support through the process and at 'outside the box' ideas of services that carers may wish to use.

The report will then look at questions that have arisen from these discussions and which the County Council may wish to address as part of their ongoing communications with carers and service users.

Finally the report will look at conclusions and recommendations to be made from the results.

2. Background

In 2007 the "Our Health, Our Care, Our Say" introduced the concept of the Personalisation Agenda with its seven main outcomes ranging from improvements in health and well being and quality of life to commitments to providing greater choice and control.

This was followed in 2008 by "Putting People First" a paper which sets out how social care is to be transformed and which calls for carers to be treated as "experts and care partners" (except where their views are opposed to those of the service user).

Finally in 2008 the National Carers Strategy highlighted the Personalisation Agenda calling for a new deal for carers with integrated and personalised services at its heart.

This new Agenda aims to provide a new more individualised way of providing social care and other public services, giving service users and carers more freedom to choose services that fit their individual circumstances.

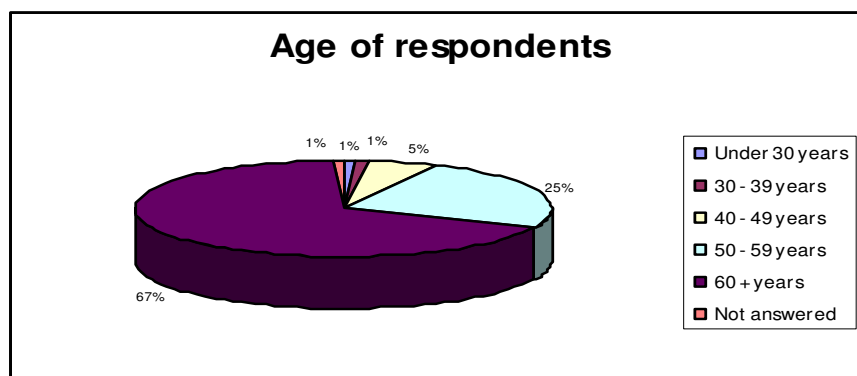
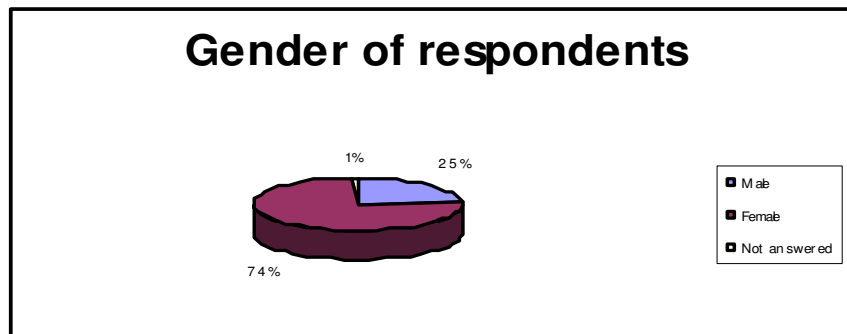
3. The Consultation Process

A total of 8 consultation meetings were held at strategic locations around the county of Leicestershire. The chart below shows where these were and the number of people attending each meeting.

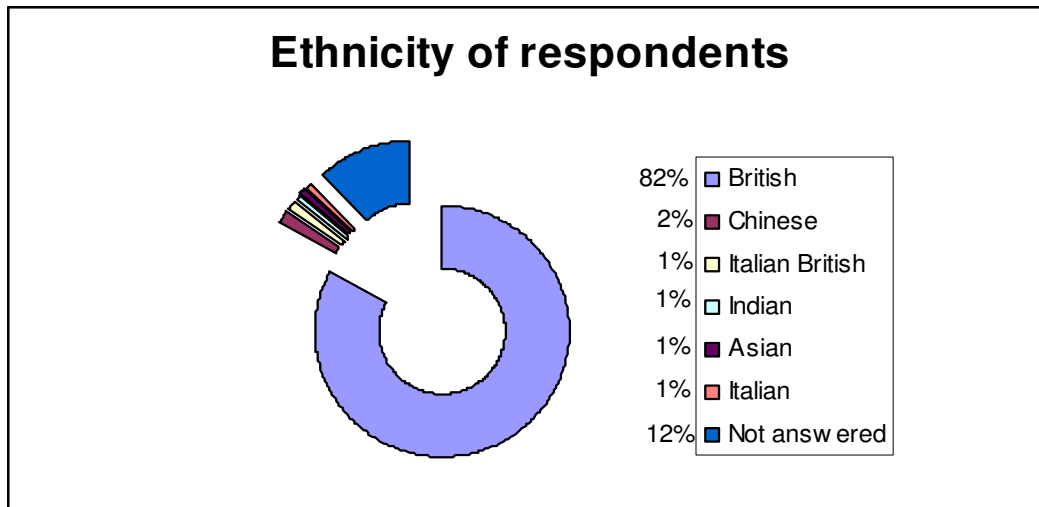
Location	Number of People Attending
Hinckley & Bosworth	32
Oadby & Wigston	25
North West Leicestershire	25
South Leicestershire	24
Melton	60
Charnwood (1)	13
Charnwood (2)	10
Blaby	19
Total	208

The consultation meetings proved very popular, as many people were obviously concerned about how this new system will affect them and the people they care for. The majority of people attending were carers, though some interested professionals from the voluntary and statutory sectors came along.

Of the 208 attendees 110 filled in an evaluation questionnaire. From this we can see that 74% of respondents were female and that 67% were aged 60 years or older.



The evaluation forms also revealed that 82% of the respondents were British.



Although of the 110 replies received 72 people (65%) classified themselves as belonging to the Church of England there were 8 other religions represented.

Religion	Church of England	72
	Roman Catholic	9
	Methodist	3
	Baptist	2
	Agnostic	2
	Hindu	2
	United Reform Church	1
	Muslim	1
	Buddhist	1
	Not answered	17

Other results from the evaluation forms showed that

- Approximately 70% of the respondents felt they knew nothing or very little about Personalisation Agenda before the meeting and approximately 70% felt that they knew a lot more after the meeting.
- Approximately 80 % found the presentation informative
- Over 90% were satisfied that they were given enough opportunity to express their opinions.

For full evaluation questionnaire results see appendix C.

4. Results of the Discussion Groups

Topic 1 – Information needs

When? Where? What sort? What Format?

Carers were asked to discuss what information they felt they needed from the County Council in order to make the transition to this new system easier.

From these discussions there were definite themes that emerged in every area.

The most important thing for the majority of carers was that they did not want to feel as though they were being 'left on their own to get on with it'. They wanted to be able to speak to a real person, whether face to face or on the telephone, someone that they could possibly build a relationship with, who would understand them and would have a wide knowledge and range of information of what is available for them.

When do they want information?

The simple answer to this is that they want information to be readily available all of the time. As one carer put it "...when help is needed and at any and all stages in between..."

For new carers it was felt that people should receive information about being a carer, about the personalisation agenda and about what services / benefits etc are available to them as soon as they become a carer. There was however concern that being swamped with too much information "all in one go" and then being left on your own would not be beneficial.

For existing carers there was much praise for the fact that they were being included, through this consultation process, in the transition to personalisation. They hoped that this consultation or at least information sharing would continue throughout as this is obviously a huge change for them. As a carer in Oadby pointed out it is also useful to have relevant information about changes in advance so that they have time to really understand what the changes mean and how they affect them and their situation.

For a lot of them the idea of taking responsibility for sourcing services and employing people / agencies was daunting and many felt that knowing the right information was readily available whenever they might need it would bring some peace of mind.

As one group in South Leicestershire said there is not an unrealistic expectation of having someone there 24 hours a day but they would like to know that for at least a few hours a week there is somewhere that they can go, or phone where they can talk to someone and be given the information that they need.

Where do they want this information?

Again the simple answer is that they want information to be available everywhere.

For information about the Personalisation Agenda it was suggested by more than one group that there should be a wide reaching media campaign, much along the lines of the current one for Stroke Awareness.

On a more local level it was felt that the County Council could make carers aware of the changes through local TV, local radio, free and local newspapers, the Leicestershire Matters magazine, in libraries, GP surgeries, Hospitals, Dentist surgeries, through voluntary organisations, through carers groups, on different websites etc

With regard to ongoing information for carers and service users about the services available for them to use and to help with any problems they have, a popular suggestion that again came up in several discussions was the idea of having a 'one-stop-shop' or central brokerage centre.

This would be somewhere local to them where they could drop in and speak to someone to gain the information that they required.

There was concern that the people in these drop in centres would need to be fully trained and that if they did not have the information themselves they would be able to signpost carers directly to someone that did have that information so that carers weren't just being passed around endlessly.

The 'one-stop-shop' may also be used as a meeting place for carers so that they could give each other support and pass on their knowledge by word of mouth.

A variation on this theme was that carers should be given the option of having someone visit them at home. This was not only to impart information but also as a general "how are you doing?" check. This, it was felt would reduce the feeling of isolation for those who found it hard to get out.

Another suggestion was that instead of or as well as a physical drop in centre there could be a helpline set up to offer information over the phone. This would mean that carers were still able to gain information, guidance and support from talking to a person but, especially for those in very rural locations they would not have to make a special journey which could be time consuming and costly.

Almost every group, when discussing this topic suggested that they would like to have information available in their GP surgery. For some this meant a dedicated member of staff who is trained in carer's issues and has a good level of knowledge. For others this was a stand or display of information that was kept up to date and notified carers of any changes that they needed to be aware of. It was suggested by a carer in Melton that this could build on the Hinckley & Bosworth Model of having a link worker in every surgery.

The chart below shows the wide range of other locations that carers felt were good places for them to pick up information.

Hospitals	Libraries	Community Centres
Voluntary Organisations	Schools	Chemist
Churches	Parish Halls	District Council Offices
CLASP the Carers Centre and others carers organisations	Pay points (where you pay your bill)	Post Offices
Mobile Libraries	Information Bank	Social Worker if their role is expanded and they are fully trained.
Carers Development Workers	Websites – different organisations	Carers own website
Through the post	At meetings arranged by the County Council	Database for local areas
Word of mouth	Parish Councillors	Local press
Supermarket notice boards	Charity shops	Local shops
Voluntary and community groups	Emails	Social Services
Service providers	Garden Centres	Community Notice Boards
Dentists	Opticians	Podiatrists
Town Hall	Health visitors	A monthly magazine for carers
Postcards to tell you of new developments / contact information	Citizens Advice	Welfare Agencies

What sort of information do carers want?

Carers want more information about the Personalisation Agenda. This consultation process has raised their awareness of it and given them a basic understanding but as the scheme unfolds they want to be kept fully informed of what is happening and how it affects them.

As part of this many carers have expressed the wish to receive free training on such topics as

- How to manage a budget?
- How to choose the right service?
- How to manage people / HR issues
- Legal requirements?
- Assertiveness training
- IT training

Without this information being given to them freely and accessibly many felt that personalisation would become more of a burden to them and would increase their stress levels. Carers who have had some experience with Direct Payments were all very positive about the advice, information and support that they had been given and once through the initial stages felt very happy with the outcomes.

Once the transition has occurred there is again a distinction between what information new and existing carers would need.

For those becoming carers it was felt that at the beginning general information is required about rights and entitlements (benefits services) what is out there and how to get it. Also they need to be told about any support groups that are available for them to join.

For all carers, information is required on a wide range of subjects, such as

- What services are available to them?
- Where these services are?
- How do they access them?
- Are they trustworthy?
- Are they getting the best value for money?
- How do they employ people?
- What happens in an emergency? If the person you employ is not available?
- Personal needs – adaptations, equipment, nursing services
- Benefits
- Support groups
- Sitting services – are these paid for by the carer or the service user?
- Respite

This list is not exhaustive but it does give a sense of what carers feel they are being faced with and the importance of ensuring that the right information is available to them when they need it. Without this there was a general feeling that the whole system would fall apart.

What format would carers like to receive information in?

As stated previously the majority of carers wanted to be able to receive their information from a person either face to face or over the telephone. Having said that though they did realise that there would be advantages to receiving information to read through and to make informed decisions.

Information in a hard copy format was favoured but this ranged from sign posting leaflets to all encompassing 'Yellow Pages' style directories. This diversity in the format of information also carried through into how much information they wanted to receive at any one time.

Some people wanted small booklets and not too much information all in one go whilst others wished to have it all there in front of them so that they could compare.

Two of the most popular ideas were that of a Directory of Useful Telephone Numbers and a Carers Information Pack.

The directory would include contact numbers that they could phone to get general information or where they could be sign posted to the relevant organisations.

The information pack would have information about carer's rights and entitlements and about support / back up support. It was suggested that these may be available from GP surgeries.

Almost every carer was adamant that any information produced needed to be in simple language with NO JARGON. It should be available in different languages, in Braille, in large print, and on audio and alternative formats may include CD ROMs, DVD's, or on websites.

One suggestion from a group in Charnwood was that websites were fine for back up but you can't ask it questions. A reply to this was that a website could have a page of most frequently asked questions and answers.

One of the main concerns of carers with regard to information was the quality and consistency of the information they received. This was important whatever format it was received in, but maybe especially when information was received in person. The need to have people that genuinely care, take pride in their work and are positive about information was seen to be of the utmost importance. The carers felt that they need reassurance that anyone giving them information will be properly trained and will have up to date knowledge. At the moment the information they receive changes depending on who they talk to.

Overall information was seen by carers to be of vital importance. It was felt that alongside other support, if they receive the right information at the right time in the right way they will have more confidence to embrace personalisation and if not there was concern that they could end up with much less time and much more stress.

Topic 2 – Support through the process

What support is needed to help with self assessments, finding out about and setting up services, recruiting staff, human resource issues, payroll / tax, insurance, general administration and Criminal Records Bureau checks?

Following on from the discussions on information needs carers were then asked to think about what support they felt they will need to make the personalisation agenda work for them.

Overall carers were optimistic about the Personalisation Agenda and welcomed the principle of a personalised approach but had some concerns

Self Assessment

The first big issue raised by just about every group was the self assessment form. There was a lot of concern about understanding the form and filling it in correctly on their own. Many wanted the form to be as short as possible, with no need for filling in repetitious information. They also wanted it to be in simple language with no jargon.

One specific part of the form that concerned them was that where they may be asked to identify what they do. It was suggested that they keep a diary of their activities to help them to start to think about what they actually do (it has been found that many carers do things automatically not realising that they are part of their caring role) but for many carers this seemed like an additional task eating into what little time they do have. Many groups agreed that one way round this would be for the form to list a number of core activities and they could just tick a box to confirm they do that. In addition to this there could be space where they could add any extra activities that they feel they perform.

Over and above these concerns though was a fear that if they didn't fill the forms in, in Social Services' format i.e. using the right or key words then they would be penalised and may miss out and receive less money for the person that they care for.

In order to reduce the risk of this it was felt by many that although they would fill the form in they would want a professional who understood the system to go through it with them or check it before it was submitted.

In Charnwood it was requested that service users / carers should be sent a copy of the final version, and it was also suggested that self funders should also be offered assessments.

In South Leicestershire the carers wanted to be including in the production of the new forms.

Money

Once they've filled the self assessment form in there was an interest to know how their entitlement would be worked out and there was an expressed need to receive the financial details of the Resource Allocation Scheme (RAS).

The underlying concern appeared for many to be that Social Services costs for services would be lower than what they would be able to buy them for as individuals or that the money they were given would be based on the cheapest options available.

This would lead to a short fall in money the consequence of which would be that the service user would not be able to receive the same amount of care.

In addition to this there were a number of groups who wished to be given long term funding so that they could plan better for future care and respite breaks. An example of this was one lady who felt that she needed to know what money she would have available in 6 months time as she had to book her holidays so far in advance otherwise there were no respite places available.

Support or Brokerage

Although aware that there are different options for managing their care package for many of the carers taking part in this consultation there is real concern that personalisation will be an extra burden with which they do not feel equipped to cope.

One of the solutions that was suggested several times was that of brokerage. The idea of having a central point, a company or organisation etc that will not only be a central reference point for information but will also take responsibility for managing the care package was seen by many to be very appealing. Having a brokerage company that they could build a relationship with, who would understand their particular situation and who take on all the administration, HR, financial and legal duties was thought to be a very useful option.

For those who wished to retain more control over their care package it was felt that there was still a need for support when setting up services or when circumstances change. This support could come from the Direct Payments team, Social Services or from service providers. Those who have already had experience of Direct Payments were very positive about the support that they have received though the question was raised that as the number of people taking up Direct Payments increases will the resources be there to support all those that need it?

It should be noted that the definition of support varied from help with form filling to ongoing training on issues related to running their 'micro-business'.

Overall there was some concern that there are a limited number of Social Care Services available and there was some uncertainty about how much choice there

really will be. A group of carers in Melton stated that they "...need a good range of locally based services."

Continuity / Consistency / Quality

Another of the major themes that emerged from the discussions is that of continuity, consistency and quality. Currently many people have a number of people that they deal with or who come into their homes to provide care and yet it is not always the same people and so not only do they not build up trusting relationships but they also don't have a consistent quality of care.

The wish of many is that they will be able to employ a small number of people who will be professional, conscientious, trustworthy and with whom they will be able to build a real relationship with the person they care and themselves. This would lead to the service user and carer getting the standard of service that meets their individual needs.

In order to get this calibre of person several carers felt that it would be important that they could pay care providers a decent salary. And their concern was that they may not have enough money.

Some carers questioned whether the Personalisation Agenda could adequately provide safeguards to ensure the safety of the service user and minimise the risk of exploitation or abuse.

Inter – Agency Communication

For the Personalisation Agenda to succeed in making people feel like individuals rather than statistics it was felt by many that carers expertise will need to be recognised by professionals.

Part of this recognition it was felt would come from being included in decision making regarding the person that they care for. There also needs to be more communication between the different agencies involved so that carers aren't expected to spend so much of their time repeating themselves and filling in the same information on endless forms. The main agencies that carers felt should be working together to provide a joined up service were health, social services, GP's, community services, voluntary organisations and the carer.

There should also be more co-operation between services from different geographical areas within the county and between Leicestershire and surrounding counties as not all carers lived in the same district or county as the person they cared for

Respite

Finally carers felt that they would need support with regard to respite. Carers in North West Leicestershire and South Leicestershire all called for more age appropriate respite services for the service user. One lady cited the example of her husband who is in his 40's who had suffered a stroke and had difficulty communicating. She went to pick him up from his respite service to find he'd been sat with a number of people aged 60 years plus listening to Englebert Humperdinck, He was a lifelong heavy metal rock music fan.

Again there was concern that there are not enough age appropriate respite services available and so carers need help in finding services that are available that they can book at relatively short notice.

Another form of support that many carers expressed a wish for was befriending. Befriending will give them an opportunity to meet and talk to other carers and a break from their caring role. The same was said of support to find carers support groups.

Other general comments that were made as part of this discussion were

- Young carers should be informed and involved.
- Social Services staff training re carers should be ongoing and carers should be included in the delivery.
- Carers should still receive carers allowance when they reach pensionable age even if they are entitled to a full state pension.
- It's better to build on a relationship with social services but change the emphasis from being told what they think you need to what you actually require.
- There is a need for independent mediation between carer and service user when required.

Topic 3 - “Thinking outside the box”

The final topic that people were asked to consider was that of what things that are not normally offered would they like to make their life and their caring role just that little bit easier or more manageable. This involved “thinking outside the box” and thinking about themselves and for many carers this was quite an alien concept.

Social Activities with friends / hobbies/ trips out	14
Concessions on travel	12
Pampering	8
Social Activities with other carers / befriending – free or cheap	7
Holidays or weekends away with or without service user	6
Home based respite	6
Concessions on leisure	6
Help around the house – for things carer no longer has time to do	5
Someone to do small DIY jobs around the house / gardening	5
Free training / courses at college	4
More flexible ‘appropriate’ respite	4
Emergency cover	4
Time to spend with other family members or family as a whole	4
Driving lessons	2
Me time	2
Assistant to join family on break / holiday to support cared for	1
List of transport companies with wheelchair access	1
Still need benefits when cared for in hospital	1
Outings for the cared for person	1
List of hotels that suit cared for needs	1
Sorting out higher residential charges for self funders	1
Stress awareness / recognition of the stress caused by caring role	1
Free phone calls – for all the bureaucracy	1
Interpreters	1
Radar keys	1

The chart above shows the ideas suggested and the number of times they came up. There were very few ‘extravagant’ suggestions and many of the same ideas came up.

Questions raised by carers

Throughout the consultation process there were a number of questions that were raised by carers that did not necessarily fit into the topics under discussion but which the County Council may wish to address.

- Having personalised services is likely to cost more, where is the money for this scheme coming from?
- What happens if you run out of money?
- Will there be enough resources for this?
- Could information about service user be stored between agencies so that there is less need for repetitious paperwork?
- What will happen to those services already in existence? E.g. Day Centres
- Do all receipts have to be kept and produced for audit?
- How do they afford quality, trained, respectful staff unless they can afford to pay them a good wage?
- Who pays for CRB checks?
- What is the appeal procedure?
- Who will regulate care homes with regard to the prices they charge?
- How will carers know that service providers are charging a reasonable amount? Will Social Services still need to negotiate prices?
- Why aren't the Government focusing on getting trained people in?
- Who's going to pay me for managing this? Interviewing people, managing staff etc all takes time and energy
- Will Social Workers be trained to understand the caring role?
- If you care for more than 1 person will you only be allocated one sum of money? You have a multiple caring role and service user is treated separately.
- Will pensioners get the budget?
- Will it be means tested?
- What are the timescales?

Information Needs

Conclusions

The main part of the brief from the County Council at the start of this consultation process was to discover the information needs of carers with regard to the Personalisation Agenda.

During the consultation meetings it became apparent that there were two very distinct topics that carers wanted information about.

The first of these was about the Personalisation Agenda as a scheme or process. What is it? What is it about? How is it going to change things? How will it affect me and my caring role?

The second was around finding the services they require for the service user once the Personalisation Agenda is in place.

As the Personalisation Agenda recognises, every case is unique and therefore information needs, to some extent, to be tailored to each individual situation. Having said that however some definite themes and ideas were put forward by many carers.

The most important point made by the majority of carers was that they really don't want to be handed responsibility and then left on their own. They wanted to be treated as equals and have their knowledge and experience recognised by professionals so that they can work in partnership. With regard to the new agenda they wanted to be involved and welcomed this consultation with the hope that it would continue and that they would be kept fully informed. Once the agenda is in place they want information to enable them to set up and maintain their care packages.

For many, the ideal way of receiving the information they require was to have a person, accessible locally, who they could speak to on the telephone or drop in to talk to face to face. Ideas for the latter ranged from a carers drop in centre to a designated carers worker at their GP surgery.

Hard copy information was also thought to be useful as they could take this away with them. This information would need to be available in different languages, font sizes, in Braille or on audio etc. It would also need to be relevant and reliable and of a consistent standard across agencies.

Having information and frequently asked questions available on various websites was thought to be a good idea as a back up but not as the main source of information.

At the point a person is considering taking on a caring role or has just become a carer, information must **always** be available. From that point on, a system should be in place which is flexible enough to allow carers to access information as and when their need arises.

Information needs to be far reaching and relevant. With regard to the introduction of the Personalisation Agenda there was a call for a high presence media campaign.

Training courses were considered a good way for carers to learn how to manage their care packages and all the skills they will need. This will give them much more confidence in their role.

Recommendations

- Treat carers as equals, acknowledge their expertise
- Treat each case individually
- Work together with carers to inform and support them at all stages
- Provide prospective / new carers with information immediately
- Have a flexible approach to information in terms of what is produced and how it is made available
- Provide the opportunity for carers to talk to someone – don't expect them to do this on their own
- Create a 'bank of information' – an all encompassing database / directory from which they can pick out what is relevant to them
- Work closely with GP's and other members of the Primary Care Trust so that carers can be identified and kept up to date with any changes
- Provide information in many formats – from big media campaigns, to leaflets, directories, DVD's, CD-Rom's and in different languages, Braille, Audio etc
- Provide free training for carers on all issues surrounding the Personalisation Agenda and managing their care packages

Support through the Process

Conclusions

As part of the consultation process we also looked at the support that carers felt they would need to help them through the Personalisation Agenda process and make it work for them.

The issue of self assessment was worrying for many carers. Their concerns covered not understanding the forms, to the forms being too repetitious and taking too long to fill in; to the problem of losing out on benefits because their answers did not contain keywords. It was requested by many that a professional help them fill this form in.

Carers were concerned that the calculation of the individual resource allocation would be based on how much it costs the County Council to buy services rather than on what they as individuals could buy services for

There was a call for funding to be agreed for a lengthy period of time as many holiday and respite plans have to be made in advance. E.g. 6 months

Brokerage was seen by many as a way to reduce what they perceived as the extra work that personalisation would make them responsible for. There was the desire to form a good relationship with a few service providers rather than having a lot of people entering their homes

For those managing the package themselves they need support whilst setting up the care package and if and when their circumstance change

Consistency and quality of the service received was highlighted as very important and receiving the same high level of care or quality of information regardless of who they speak to was a big objective

Inter agency communication between Social Services, Health, GP's, Community Services, Carer and other voluntary organisations and the carer was felt would benefit service user and reduce stress on the carer as it would reduce the time spent on 'red tape' and bureaucracy.

Appropriate respite care places were felt to be in very short supply which meant a lot of people either didn't get respite or had to book it several months in advance. There is a need for more appropriate respite places that can be booked flexibly.

Recommendations

- Produce a self assessment form that is short, in plain simple language, contains checklists/ tick boxes, and is not repetitious.
- Provide carers with access to a professional who can help them fill in the form or can check it before submission
- Provide transparent information on the calculations of the Resource Allocation Scheme
- Provide service users and carers with an assurance of their long term funding
- Provide service users and carers with enough money to employ appropriately trained, high calibre service / care providers
- Encourage independent brokerage, whilst at the same time regulating them
- Direct Payments team, Social Services , Health, Service providers, Carer, community and voluntary Organisations need to work together to provide 'joined up thinking' support for the service user and carer
- Set up training and monitoring system to assure quality and consistency of professional service and information providers
- Provide more appropriate respite care places to enable carers to have their own time to pursue their own life
- Provide befrienders for the service user and / or the carer.
- Provide a list of authorised service providers
- Take a lead in developing the new market for individual workers and flexible service providers

“Thinking outside the box”

Conclusions

The most obvious conclusion from this discussion was that carers really are not out to get unrealistic, extravagant luxuries for themselves.

Many of their “outside the box” ideas were not really “outside the box” at all, but were practical things that would either just make their caring role that bit easier or that would give them just enough of a break / their own life to carry on with their caring role.

The most popular wish was that they could have some time to meet up with friends, to pursue their hobbies or go shopping or for a day out. For some this was some time every week and for others, such as a group in Charnwood they wanted two day trips out a year.

This wish was closely followed by concessions on travel. For many carers around Leicestershire living in rural communities makes it prohibitively expensive for them to go out with the person they care for for pleasure. A free bus or train pass or help with taxi fares would be a bonus for trips out but expecting carers to pay for their travel to take the person they care for to meetings or appointments was seen as being very unfair.

Other ideas range from someone to help around the house, do DIY odd jobs, to free phone calls and the continuation of benefits even when the service user is in hospital.

All of these things are aimed to take some of the stress out of what can be a very stressful role. It is acknowledged by many carers that they will always try to carry on in their caring role for as long as they are physically able to and they are not looking for huge rewards for something that they genuinely want to do, but what they are saying is that sometimes they need the focus to be on them not just the person they care for, and receiving something little to show that they have been thought about can make a big difference.

Recommendations

- Treat carers with the respect they deserve and acknowledge that they do not take on this caring role for their benefit but for the benefit of others
- Provide funding for them to get the all important opportunities to do the things we all enjoy – social activities, hobbies, days out
- Provide carers with the same concessions for transport and leisure as the person they care for.
- Provide a list of regulated DIY, Gardening, Decorating, companies
- Provide a list of regulated housekeepers, cleaning and ironing companies
- Provide a list of companies, organisations and venues with wheelchair access
- Provide free phone calls for all the official calls that have to be made
- Contribute to computer / internet / broadband costs and training