Summary of Carers Consultation August 2012

Workshops Summary

Seven workshops were held with carers to seek their views about key issues to help inform the Joint Carers’ Commissioning Strategy. Three additional culturally specific groups were facilitated, with translation services where required, to seek the views of groups that had previously not been fully engaged. These groups were:

- Black and Minority Ethnic (BME) carers (English speaking)
- Carers from the Chinese community
- Carers from Asian communities.

Workshops were promoted through the Gloucestershire County Council (GCC) website, through contracted providers of carers’ services, the carers’ forum, carers’ newspaper, positive caring programme and the community development team. The workshops were attended by 67 carers and were led and facilitated by the carers’ team with involvement of relevant GCC and Health commissioners.

Key issues for consultation

The key areas examined during the consultation were as follows:

- Individual Budgets
- GP Surgeries
- Emotional Support
- Access to Information and Advice
- Short breaks
- Training

Carers were asked to vote about how they felt carers’ voices could be most effectively captured in the future; through Health Watch, county wide groups or more locally.

Carers Views

Individual Budgets

Carers were generally unclear about individual budgets; however, once they were explained more fully, carers identified that having budgets in this way would be beneficial to them. They also liked the idea of having control of how their needs were met. They noted that it would allow them to make different choices and that the flexibility would be positive as it could be a more efficient way of using services. They identified that a mix of individual budgets and organised services may be helpful.
Carers shared their ideas about how they would use individual budgets, these included, cultural activities, gardening, breaks with family, gym memberships, ways to improve well being and reduce stress, joining groups or taking up hobbies of interest or to generally improve their daily quality of life.

There was some concern about how they would manage their budgets and the increasing responsibility they would have. Carers felt that it would be confusing to have separate budgets for the person they cared for and themselves. Some carers felt they would like to manage the budgets independently, others felt having someone to talk it through with would be helpful. Others suggested that having specific people to help them with the whole process would be beneficial; someone who could advise about the process and how the money could be spent. Some carers felt that a single worker supporting them who was knowledgeable and reliable, with an understanding of the needs of carers, would be helpful. Carers also suggested that there needed to be minimal paperwork and bureaucracy otherwise this could act as a deterrent to having individual budgets. Overall carers felt that they needed more information about individual budgets before they would be in a position to use them.

Support in GP Practices

Carers were asked about what support they would like to see in GP surgeries. Overall, carers felt it was important that GPs knew they were carers, but also that just being registered as a carer was not enough. Carers felt that a register was a good way to identify carers but it needed to be promoted. In terms of practical support, some carers had had positive experiences that included flexible, priority or early appointments, double appointments with the person they cared for and health checks. Carers liked the idea of a carer clinic where they could get one to one support and information when needed. They suggested a dedicated person within the practice with knowledge of carers services could help relieve the pressure on GPs. Creating a wider understanding among the practice staff about the impact of caring was noted as helpful, especially in helping carers to feel more confident and be recognised as experts in the situation of the person they cared for and welcomed. A health check was specifically noted as being helpful to support them in remaining fit, well and able to care.

Carers identified that a form of fast tracking referrals from GPs to other health and social care services was needed, as this process was often very slow. Prescriptions for activities were considered to be a good way to support carers. For carers where English was not their first language, support to improve communication and information was important. Some carers suggested that a card to identify them as a carer registered on the carers register would be helpful.
Emotional Support

Emotional support meant different things to different people; however carers identified it was important to their overall mental well being. They identified that a variety of different emotional support was needed and that emotional support made a positive difference in a number of ways, such as:

• helping to give a sense of perspective
• confidence
• reduced isolation
• a safety valve
• reassurance
• spiritual support
• recognition
• opportunity to laugh with other carers
• peace of mind and reduced worries

Carers identified a number of ways in which emotional support could be delivered:

• it could be provided by other carers or former carers
• through the positive caring programme
• through carers workers or counsellors
• family
• faith groups
• more structured carers groups
• peer befriending support

Some groups felt there was a stigma about ‘going for counselling’ identifying confidentiality and peaceful locations as important. Some carers felt emotional support could be provided by telephone or skype.

The most appropriate way of providing emotional support depended upon the type and group of carers. However, a consistent view emerged that carer organisations or other voluntary sector providers would be a possibility and that they could offer oversight for some of the less structured emotional support.

Advice and Information

Carers wanted clear information at the right time. Groups identified that often it was hard to determine what you wanted until you needed it, however information about the support available, their rights and how to complain were highlighted. The need
for this to be presented without complex terminology and in appropriate language was also identified.

Clarity about the different health and social care roles, presented simply, with written copies of reports and information was important to carers. Information about services, organisations and the condition of the person being cared for was seen as particularly important. Some duplication was identified and carers preferred a single point of contact, with a named person. They felt this was a good way to absorb a range of information without being overwhelmed by paperwork. The right time to get information varied greatly, it tended to be individual to particular carers. Some felt that at the point of a crisis was the right time, others when they first become a carer or when a situation changed.

Information at the point of transition from children’s to adult services was highlighted as a gap, as was follow up support to enable carers to revisit or recheck information or advice.

Suggestions for improvements included:

- A card that identified a carer for hospital staff
- Paper copies of discharge plans and assessments
- More information in a diverse range of languages
- Information about carers assessments (and perhaps a change of terminology)
- A central point of contact
- A standard information pack
- Information that is consistent
- Information provided on a one to one basis through an advice worker who could lead the carer through the information.

Short Breaks

Carers identified short breaks as valuable as it gave them time to themselves, enabled them to spend time with family and friends and to recharge their batteries and relax. They identified the need to be able to have some peace and a break from their responsibilities. Carers used the words, “freedom”, “holiday”, “relief” “time for me”. Some carers identified they needed a break from caring, not the person they cared for, and would prefer the flexibly to have a break together with someone to help with the caring. Asian carers felt it was harder to take a break due to some cultural expectations. The types of activities carers identified included having a rest, doing nothing, walking holidays, hobbies, sleeping, relaxation therapies, meeting up with friends and having space.

Training
Nearly every event highlighted the need to have more practical training around handling and lifting and basic first aid. Other areas identified included legal matters, how to deal with emergencies, computer and IT skills and managing diet and nutrition. Carers who had undertaken the positive caring programme suggested a follow up session would be helpful at six monthly or annual intervals, to keep carers’ knowledge current.

**Carers Voice**

The majority of carers preferred a locally based forum which could feed into countywide groups through representatives from each locality. A few carers felt that there needed to be some link to HealthWatch. They were unsure how this would work as they were not clear about the future role of Healthwatch. Chinese carers felt it was difficult to participate in the current forum and would prefer a small meeting where they could understand and participate fully. They suggested that a representative could attend the wider groups and feedback.

**Other issues**

Carers raised a number of issues which related to services relating to the person they cared for. These have been communicated to the relevant service managers, including concerns relating to hospital discharge.

**Young Carers**

The consultation with young carers was facilitated through two workshops. Their views about the skills, knowledge and opportunities that would help them to succeed were sought, as well as their experiences of caring.

**Skills knowledge and opportunities for success**

Young carers identified that they would like to improve their communication skills through improved presentation, good listening skills and interacting with the media. They felt their confidence could be improved through being supported in new situations and they valued positive feedback from adults and professionals. Young carers wanted better access to information, to be directed to where they could carry out research for themselves and an understanding about the range of services available. They felt they needed to know what to do in certain situations and at times would like to be supported through new or different responsibilities. Likewise the opportunity to practice and experiment with new ideas in a safe environment was valued.

Young carers felt their social friendships were important and opportunities to develop these were essential. They required professionals to be people who would inspire them. They wanted the adults in their lives to have realistic expectations about them.
and be someone who was able to listen and understand. Young carers felt they would benefit from time management skills, developing honesty about their feelings and emotions, opportunities to reflect, set goals and targets. Some would like to be more assertive and ‘be a leader’ rather than a follower. They would like opportunities to learn from others and to challenge the accepted ways of doing things to enable ‘more open minded thinking’.

**Availability of support**

Young carers identified a wide range of professionals, voluntary sector organisations and education based support that they felt could help. Their experiences varied with some types of support being patchy. They felt support should be available to them in the following ways:

- Schools including school based peer support
- Gloucestershire Young Carers
- GP surgeries including access to practical support via their GP
- Carers Gloucestershire
- Gloucestershire Young Carers
- Do Care (Agency) Guidepost (Agency)
- Family information service
- Mental Health Trust (2Gether)
- Gloucestershire County Council
- Support to reduce their caring pressures, in-home carers and short breaks
- Emotional support, having someone to talk to and being able to vent their emotions in a safe way
- The media and greater public awareness of illness and the physical and emotional effects of caring
- Family Plans incorporating their whole family’s needs which addressed the range of needs they and they person they cared for may have.

**Conclusion**

This consultation built on previous knowledge gained from other consultations with carers. It will directly inform the joint carers’ strategy. There are key areas which will need further more detailed work, for example, carers’ assessments, the needs of carers from BME communities, carers’ experiences of individual budgets and GP support. The experience of mutual carers has been difficult to gain and would benefit from some focused work.

Gloucestershire County Council and NHS Gloucestershire would like to thank all carers who attended the workshops and contributed to the discussions by sharing their experiences.