

Informing carers

A study based in Newcastle upon Tyne

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Abstracted from the report 'Informing carers: An exploration of the dynamics of the relationship between carers, information, and information providers. A study based in Newcastle upon Tyne.

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1. Introduction

The purpose of this study was to explore the relationship between carers, information and information providers and in doing so, determine the practical and cognitive factors which impact on the effectiveness of this relationship. The study did not aim to prove or disprove a particular question. Instead it aimed to increase existing understanding of the relationship and use this to produce **a set of guidelines to help information providers improve the way they provide information to, and for carers.**

The purpose of the study has been achieved through direct research with carers and information providers by the means of postal surveys, interviews and a focus group. The following section draws together the results of this research to provide a series of conclusions, followed by recommendations. Conclusions are arranged under the individual section headings as used in the chapter on 'Results' in the full research report (available on request – see front cover for details). Each consists of concluding remarks on what are considered the main points of interest. A full summary of key points, from the appropriate results for each section heading, is provided in Appendix A. 'Recommendations' include 'guidelines for information providers' and 'recommendations for further study'.

2. Conclusions

2.1 Carers

It is clear that carers feel that information has an essential role to play in their lives. They identify information as being "crucial", "vital" and "imperative" to them.

Carers want information on everything that might help them but, they place particular emphasis on the importance of getting information on finances, practical help and services, and on being 'a carer'. They place special value on opportunities to meet and share information with other carers, particularly in self-help/support groups.

Carers perceive information as a two-way street. They need to be given information to ensure they receive the help and support they need. They also have important information to give about their own needs and those of the person they care for. However, carers often find they are not listened to or given equal 'information rights' alongside the person they care for.

Status and respect are key issues for carers. They would like to see their 'status' raised so that their own information needs are recognised and they are valued as an important source of information on the person they care for. They also want to be treated with respect for their personal circumstances and for information to be provided in a way that is sympathetic, supportive and respectful of them as individuals.

Carers commonly find that they have to repeatedly ask for, and give the same information to different professionals. This is "exhausting and frustrating". A favourite carers wish is that they could have a single contact person who would satisfy all of their information needs. This person would span all boundaries, including health and social services.

On the whole, carers experiences of information were unsatisfying and problematic. However, a few good experiences were related. Of these, social workers and 'other carers' in self-help/support group settings were most identified as being helpful, effective sources of information.

2.2 Information providers

Information providers commonly experience a number of key difficulties which, they feel, undermine their ability to provide effective information to carers. These are a combination of practical barriers and knowledge barriers. The main practical barriers are lack of time and lack of financial resources. The main knowledge barriers are lack of knowledge of 'pure' information skills and lack of knowledge of carers.

It would seem, from the study, that providing information to/for carers is rarely a job in itself; information providers typically have multiple roles, of which, information is only one. This places stresses on information providers in that the time they devote to providing information to carers must compete with the demands of their other roles. This situation is exacerbated by the fact that carers are not the primary client group for many information providers - so there is a need to find time to learn more about carers but, even less time to do it.

Training was a key theme in the study. It appears that most information providers are providing information to carers without any training or qualifications in information skills. Information skills must be learned on the job and by trial and error. However, it would not be fair to say that information providers are unskilled or that the information they provide lacks quality. Instead the research found that many information providers were very experienced in information giving, often with many years experience of providing information to carers and other groups in some capacity or another. It was clear from the research that information providers often don't give recognition to their past experience of information giving where it has been interwoven into other, broader roles. As a result, many demonstrated a lack of confidence in their information skills and felt that their information role could be done better by a trained information officer.

It is interesting to note from the results of the research that there is an apparent conflict between information providers approach to their work and the practical environments in which they operate. Overall, information providers showed themselves to be committed and dedicated to achieving quality in their work, and sensitive and caring about their users. However, they typically work in environments that do not provide them with the time, financial resources, or training to provide information as effectively as they want.

2.3 Finding information

2.31 Are information providers making the right choices in where and how they distribute information to ensure that carers will find it easily?

The research revealed that there was a mismatch between where information providers choose to site information in public places and where carers most often visit. The results indicate that information providers are focusing their efforts on placing information where they think carers will go 'looking for it', as opposed to placing it in venues where carers may simply come across it. The best example was the 'supermarket' which is the public place most visited by carers but the least used public venue by information providers.

There may be a perception of carers as 'information users' rather than simply as carers. Information users are more likely to recognise their own information needs and seek

information in predictable ways. Carers however, may simply be individuals who do not recognise themselves as carers or know where to go to seek information.

In contrast, the results show that information providers have a good understanding of where, and who, carers go to when they are purposely seeking information.

In conclusion, it would appear that information providers are targeting information more accurately at carers who have identified an information need and are actively seeking to satisfy it, than at carers who have an unperceived information need, such as hidden carers.

2.32 Do Information providers know enough about carers to target them effectively?

There was a wide range of knowledge and experience of carers, amongst information providers. However, regardless of this, almost all information providers felt that they should or could know more about carers. Lack of time was a major barrier to learning more about carers.

Even though many information providers felt they didn't know enough about carers, the majority had no formal in-house definition of a carer, to guide them. This suggests that they must rely on their own, possibly limited knowledge and perceptions of carers to inform the way they create and deliver information to carers.

Information providers were aware that lack of knowledge of carers could undermine the effectiveness of their information to "hit the mark". Many felt that information could be made more effective by involving carers in its design and planning. However, information providers have little or no time to devote to this type of activity.

All information providers demonstrated a keen awareness of the difficulties faced by carers and a sensitivity towards their situation. This may be related to the fact that many of the information providers who took part in the research were carers or former carers, themselves.

2.33 How well do information providers help carers to find information that is for them?

Some information providers signpost carers to written information by using the word/s carer/s and, or, by providing a description of what a carer is but, only a minority do this on a regular basis. Some information providers choose not to do this because they believe carers do not recognise themselves as 'carers', however, most carers said they do in fact recognise themselves under this label.

If carers self identify as 'carers', it is likely that they will look for information that is aimed at 'carers'. Information providers who choose not to label information as being for 'carers' may make it harder for carers to find. However, this can only be a speculative conclusion as there is not enough evidence in the research to prove or disprove this; in addition it must be remembered that all carers who took part in the research were in contact with Newcastle Carers Project and therefore more likely to recognise themselves as 'carers'.

Most information providers use the local media and leaflet racks/poster displays in public places to reach carers with information. This is a good choice as carers regularly use both of these information sources as a means of finding information.

Most carers prefer to be in control of their own information seeking and would like information, advice or training in how and where to look for information, to support them in this. But, the majority said they had never been provided with this kind of help. There is evidence however, that information providers are aware that carers need help in finding information and sympathise with this problem. The results of the research show that the majority of information providers are currently, or have in the past, made efforts to meet this need by providing carers with information, advice or training in information seeking skills. Where information providers are not providing this kind of help, a broad conclusion can be drawn that this is a consequence of lack of resources rather than lack of awareness or sensitivity on the part of information providers. This conclusion draws on other results from the study which highlight lack of resources as a key issue for information providers, along with evidence that information providers are sensitive to, and understanding of the needs of carers and the difficulties they face in finding and accessing information.

2.4 Accessing information

2.41 Delivery & Usability of information

The research shows that information providers have got it right in terms of the delivery of information, its format and level of complexity. The majority of carers want to access information face to face, by post and by telephone, don't need information in special formats and prefer information to be easy to use/quick to get through – and most information providers are meeting these conditions.

However, it must be noted that 'getting it right' for the majority is not necessarily evidence of good quality. Most carers may be able to use information in standard formats but, this still leaves those that can't without access to information which may make the difference between coping and crisis. Information providers may deliver information in every way that carers want but, the service may still be a poor one with, for example, untrained staff or restrictive opening hours.

It is clear from the research as a whole that information providers care about the quality of their information provision to carers. In addition, most information providers have made an effort, at some time, to involve carers in the development of information materials for carers. Therefore, a general conclusion can be drawn, that where information 'hits the mark' it is because information providers are trying to get it right. However, what is also clear from the research is that these efforts are largely informal. Only half of information providers used any formal procedures or guidelines to ensure their information materials are easy to use and read, and are available in different formats on request. This is a concern, as the Disability Discrimination Act requires that information should be available in different formats to meet the needs of disabled people.

In general, the approach to ensuring the quality of carers information seems to be well intentioned but, informal and possibly ad hoc. Information providers should take a more formal approach to quality to ensure that they meet all carers needs, as effectively as possible, as well as meeting legal requirements.

3. Significant themes

3.1 Information provision is dynamic

The research shows us that each element in the relationship between carers, information and information providers is dynamic. Information is subject to change and carers and information providers must both struggle to keep up to date. Both are on a constant learning curve; carers learning how to find and use information, and information providers learning how to provide information. Both are doing this largely without training, learning by experience, trial and error, so that there is no uniformity to the level of skills/experience of one group or the other. Carers and information providers are individuals who each represent their own unique combination of knowledge and experience and their own practical and cognitive barriers to information seeking/providing.

When all of these dynamic elements are brought together they form a relationship which is constantly evolving and contains the element of unpredictability. It is easy to see what a difficult task either information providers or carers have in trying to control it. As a result, it may well be that there is no single solution to ensuring efficient and effective information provision to *all* carers *all* of the time. If both carers and information providers had a greater understanding of this, it might result in a closer, more respectful and possibly more proactive relationship between the two.

3.2 Greater understanding is needed

One of the key messages that run through the research is that information providers care about the quality of the information they provide and about carers themselves. It is interesting that this came out strongly in the research and yet carers said that they *wished* information providers would focus more on them as individuals and treat them in a caring manner, with sensitivity and respect. This suggests that each group may need to know more about each other but, certainly suggests that there needs to be more communication between the two.

Information providers have shown that they are keen to involve carers in developing information materials but, proactive work of this kind is often a low priority. Perhaps, if information providers gave a higher priority to working in partnership with carers, each group would have a more sensitive understanding of the other's difficulties, and this might result in more effective information provision to carers.

3.3 Raise the status of carers

Both carers and information providers made frequent comments about what can best be described as the status of carers. Carers feel strongly that they are not centre stage when it comes to their information needs. Information providers are in agreement, feeling that the profile of carers needs to be raised in general and also in their own work.

It is probably beyond the control of most individual information provider's to ensure that carers receive a higher priority in their work. More likely, this is an issue for management. Organisations need to ensure that if they provide information services to carers, these are sensitive, respectful and well resourced; they should not be a poor man's add-on to services aimed at other client groups.

4. Improving information provision to carers in Newcastle

In the Results section, data from the research with carers was combined with information providers ideas on how information provision could be improved to carers in Newcastle. This provided some clear messages and points of agreement. These are distilled into a series of practical recommendations and guidelines which can be found below (5. to 6.).

5. Recommendations

5.1 Main recommendations

- **Their needs to be greater co-ordination between those who provide information to carers**
 - Local areas would benefit from a central, umbrella organisation to provide a lead on co-ordinating information services for carers, to facilitate networking and training opportunities for information providers, and work to ensure that information providers work in partnership to provide carers with seamless information services.
- **Carers need a single point of contact for all their information needs**
 - There should be a single, centrally controlled carers information service. The foundation of this would be a user friendly electronic information system with the facility to produce hardcopy information. The service should be accessible via the Internet, face to face, by post, by telephone and have access points in all public places. This could be a national or locally operated service.
- **Organisations need to devote more resources to their carers information services**
 - Organisations need to raise the profile of carers in their work. Information provision to carers should not be seen as a low priority or inferior add-on to services for other client groups. Carers should be treated at all times with sensitivity and respect. Sufficient resources should be dedicated to 'carers information' to ensure that individual information providers have the time, finances and know-how to do their jobs effectively, proactively and without undue stress.
- **There should be a more formal approach to quality in information provision for carers**
 - a. There should be a more formal, less ad hoc approach to quality in information provision to/for carers. Applying good practice standards and guidelines would ensure information meets *all* carers needs.
- **Working in partnership**
 - Information providers should work to develop a closer relationship with carers to foster greater understanding of, and respect for, each others role. Information providers should actively involve carers in the planning and development of information materials for carers, to ensure that information really 'hits the mark'.

5.2 Recommendations for improving information provision in Newcastle

➤ **A central focus**

- There should be a single, umbrella organisation to provide a city-wide lead on co-ordinating information services for carers. This organisation should facilitate networking and training opportunities for information providers, and work to ensure that information providers work in partnership to provide carers with seamless information services. It should also act as a central information point, ideally a helpline service, to signpost carers to appropriate sources of information, help and support.

➤ **Seamless information**

- Everyone who is involved in providing information to carers should work together in partnership, with no boundaries between agencies, to ensure a seamless approach to informing carers. There should be a shared information protocol for use by all agencies/groups/organisations who provide information to carers,. This could be a written record of a carers contact with different information providers which would belong to carers. It would allow information providers to see what information had already been provided and the reason for any referral to their service. This would remove the need for carers to repeat their stories or struggle to remember what information they had been passed on to receive.

➤ **A single information resource**

- There should be a single city-wide information service for carers. This should have access points in all public places but, also be accessible face to face, by post, by telephone and via the Internet. The service should be available in an electronic form as well as other formats including a hard copy, pocket sized directory of carers information. The service should be simple and intuitive to use so that it could be used by carers without the need for assistance or training.

➤ **Publicity & Awareness raising**

- There should be a city-wide publicity campaign to raise awareness of carers, help hidden carers identify themselves, and inform carers of help and support that is available to them. Publicity should be regular and ongoing. It should be co-ordinated by a central organisation and promote a single first point of contact (see earlier point: 'A central focus'). Publicity should include a regular 'carers information' column in a local newspaper.

There should be regular carers information events at different locations across the city.

➤ **A closer relationship with carers**

- There should be an expert panel of carers trained and supported to offer advice and feedback on information provision for carers in Newcastle. They would act as a central resource for information providers to draw on, as an easy way of involving carers in the development and planning of their information materials.

Market research should be carried out to find out what information carers actually want and how they want it to be presented.

6. Guidelines for information providers

The following is a list of recommendations, based on the results and conclusions of this study, for how information providers might improve their information provision to carers.

*Each point should be used as appropriate to the remit and circumstances of individual services.

- Carers like to be recognised as individuals outside of the person they care for. Provide information to carers with sensitivity and respect for their individual circumstances.
- Wherever possible give carers equal rights to information alongside the people they care for.
- Prioritise information on finances, practical help/services, and on being a carer as these are the subjects carers most often want information about.
- Self-help/support groups are popular with carers as ways of receiving and sharing information. Whenever possible, provide carers with information on appropriate local carers groups.
- As a general rule, make written information short and quick to get through, rather than detailed and in-depth, as this is what carers prefer.
- Many carers recognise themselves as 'carers'. It is helpful to label information as being for 'carers', to help carers find and identify information that is for them. Always include a description of what a carer is to help those who do not recognise themselves under this label.
- Where possible, involve carers in the planning and design of information materials to ensure that information really 'hits the mark'.
- Provide as much choice as possible in how you deliver information in order to meet different needs. If resources are limited, prioritise offering information face to face, by post and by telephone as this is how most carers prefer to receive information.
- Offer information in a variety of formats to meet different needs. Remember that the Disability Discrimination Act requires that you can provide information in different formats to meet the needs of disabled people.
- Apply a standardised approach to the provision of information to ensure consistent quality and information that meets the needs of all carers.
- Distribute information for carers as widely as possible, in *all* places where carers go. Don't concentrate solely on information/advice/service venues.
- Improve the chances of carers 'coming across' information when they are not looking for it by distributing it in places that are part of people's everyday routines. Carers visit the supermarket more often than any other public place.
- Use the local media to reach carers with information as carers often look there for information that might help them.
- Use leaflet racks and poster displays in public places to reach carers with information as carers often look there for information that might help them.
- If possible, offer carers advice, information and, or training in how to find information. Many carers need and would like to have this kind of help.

7. Recommendations for further study

This study provides an overview of the relationship between carers, information and information providers which could act as the foundation for more in-depth research. In particular, it has produced information on how information is provided but only offers tantalising glimpses of what affects the decision-making process. Further research into this could provide valuable information for organisations on how to standardise and improve the quality of their information provision to carers.

The study also raises questions about the training of information providers. It would seem that there are many people involved professionally in information work who have no training or qualifications in information skills. It would be interesting to find out if this is the case, how big the population is, and what the impact on the quality of information to end users is. It would also be interesting to know what potential there might be for providers of academic information skills courses to tap into this market and make a positive impact on the quality of information that is provided in the community.

Appendix A - Results: Key points of the research

Key points - Carers

- Carers feel that information is crucial, vital and imperative to them.
- Carers want information on everything that might be helpful to them but, particularly about finances, practical help/ services and on being a carer.
- Carers value opportunities to share information with other carers particularly, through self-help/support groups.
- Carers want greater recognition of their role by professionals/information providers. They want equal rights to information alongside the rights of the person they care for, and recognition that they are an important source of information on the person they care for.
- Carers want information to be provided in a way that is supportive, sympathetic and respectful of them as individuals.
- Carers wish that they could have a single contact person to satisfy all of their information needs.
- Carers general experience of information is problematic and unsatisfying.
- Social services and 'other carers', were identified most by carers as 'good experiences' of information provision.

Key points - Information Providers

- Information provision to carers is usually not the only role that information providers have. They commonly have a 'mixed role' encompassing other, often diverse responsibilities/roles.
- Carers are not the primary client/user group of most information providers.
- Information providers primary skills, knowledge and experience do not usually lie in information work.
- Most information providers lack confidence in their information giving skills.
- Information providers commonly do not give themselves credit for past experience of information work because it has not been the main focus of previous roles.
- Few information providers have any training/qualifications in information skills. Most learning is done on the job, by necessity.
- Most information providers would like training in information skills and providing information to carers but, it must be relevant and applicable to their individual roles/work.
- Training in information skills and providing information to carers is a low priority in most information providers organisations/groups, with little or no time or funds available for it.
- Most information providers feel their information role could be done better, faster and more proactively by a trained/qualified information worker.
- Lack of time and money are the most significant barriers to information providers ability to provide information to carers.
- Information providers would like to be more proactive in their information work but are forced, by lack of time and finances, to be largely reactive in their approach.
- Most information providers feel their management/committees support and recognise their information role at a general level but, have little, or no, in-depth understanding of the complexities of information work.
- Information providers are committed to providing the highest standard of information to/for carers but, must work against the odds to achieve this.

Key points - Are information providers making the right choices in where and how they distribute information to ensure that carers will find it easily?

- Information providers emphasise information/advice/service venues as public outlets for distributing information to carers but, carers spend more time visiting places which are part of their day to day routines, such as the supermarket.
- Information providers are well tuned-in, in their perception of where carers are most likely to go when they have a specific information need.
- There is evidence to suggest that when carers don't know where to turn for information, they are more likely to turn for help to a familiar or friendly face, such as their Social Worker or a friend or family member.
- Information providers are better at targeting carers who are actively seeking information rather than carers who have unidentified information needs.

Key points - Do Information providers know enough about carers to target them effectively?

- Information providers are not always experienced and knowledgeable about carers.
- Many are not provided with a formal, in-house definition of what a carer is, to help inform and guide how they provide information to carers.
- Most information providers feel they have a good, general knowledge of carers but, all would like to know more.
- Information providers are understanding of, and are sympathetic of the difficulties faced by carers.
- Information providers are often carers or former carers themselves.
- It is likely that individual information providers must rely on their own, often limited, knowledge and perceptions of carers to inform the way they create and deliver information to carers.

Key points - How well do information providers help carers to find information that is for them?

- Most information providers do not routinely label their written information as being for carers or provide a description of what a carer is.
- It is possible that some information providers think carers do not recognise themselves as 'carers', however, most carers do identify with this label.
- Information providers have correctly identified that most carers seek information in the local media and leaflet racks/poster displays in public places, and are using these as vehicles to reach carers.
- Carers prefer to be self sufficient in seeking information and want information, advice and training in information seeking skills.
- Few information providers, provide information/ advice/training in information seeking skills for carers but, the majority are aware of, and sympathetic to the need.
- It is likely that where information providers do not provide information/ advice/training in information seeking skills for carers, the barrier is lack of resources rather than lack of awareness/sensitivity.

Key points - Delivery & Usability of information

- Most information providers are delivering information to carers in the ways that carers most prefer.
- Carers want information that is easy to use and understand, and quick to get through.
- A minority of carers have difficulties accessing information because of the way it is presented/formatted.
- The effects of being a carer have no significant negative impact on carers' ability to concentrate on, and take in, new information
- Information providers feel a strong sense of responsibility about the quality of their information and the impact of poor quality information on carers.
- Many information providers do not have a formal procedure for providing information in different formats on request.
- Many information providers do not always use clear print or other guidelines/procedures to ensure information is easy to use and read.
- A majority of information providers involve carers, at least some of the time, in the development of information materials for carers.
- Most information providers rely on others to keep them up date about new guidelines/procedures/laws concerning information provision because, they don't have the time or know where to find out about this themselves.
- In general, the approach to ensuring the quality of carers information is well intentioned but informal. Information providers should take a more formal approach to ensure they meet *all* carers needs and meet any necessary legal or other requirements.