

# **Research: Legal Needs of Carers**





Susan Solomon Independent researcher

# **Acknowledgments**

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- · Govan Law Centre
- · Carers Scotland
- Glasgow Association of Mental Health Carers Team
- Glasgow East End Carers Centre
- Glasgow North East Carers Centre

The researcher would also like to acknowledge the participation of carers themselves whose experiences and insights helped produce this report. The reflections in the report are those of the researcher and inevitably, a large volume of qualitative information has been condensed into this report. I hope I have done justice to the participants – any errors and omissions are, of course, my own.

Susan Solomon, is an independent research and evaluation specialist and was commissioned to conduct this research.

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## **Executive Summary**

This report sets out findings of the research and provides conclusions on carers and their legal needs and recommendations regarding setting up a new carers legal service unit within Govan Law Centre (GLC). The research approach is qualitative in approach with key informants including carers themselves, carer support organisations that already have a relationship with GLC staff.

#### **Background**

GLC offers free legal and confidential advice to residents and those working in Glasgow. They have identified an increase in the number of carers that are requesting their legal services and believe there is an unmet need for a specialist legal services unit dealing exclusively with carers issues. Research was commissioned to uncover whether this belief was justified.

#### Methodology

A qualitative methodology was agreed and a total of 17 in-depth interviews were conducted with carers (11), carer support organisations (4), and GLC staff (2) from May to July 2017.

#### **Overview of the Sample**

Carers in the research sample tended to be older in age from 42 to 78 years old with a broad social spectrum represented. There was little internet usage amongst the group and the majority were full-time carers. They were looking after adults with dementia, cancer, autism, Downs Syndrome, learning difficulties or people unable to leave their house due to mobility issues.

#### **Awareness of Legal Needs**

Carers dealing with the day to day practical and emotional demands of their role can often be extremely stressed and anxious due to the mental exhaustion this can place on them. Consequently, there is little time to consider forward planning regarding legal and financial affairs and there was usually a specific catalyst that lead to legal advice being sought. Awareness of both legal issues that may need addressing, and solicitors, was low and subsequently carers mainly relied on their informal support systems to recommend a legal advisor – or use a solicitor they had used for a previous legal issue.

### Perception & Experiences of High Street Solicitors

The majority of carers in the research had previous experience of a High Street solicitor – and for some this was in relation to their caring role. Although carers were on the whole satisfied with the services they had received from solicitors utilised previously, there were a few issues which could affect their perception of this service. For example; fees they were charged, how legal issues were explained, difficulties with appointments and meeting locations and – for a minority – a perception that the solicitor lacked an understanding of carers issues.

#### **Carers & Govan Law Centre**

Amongst all carers interviewed as part of the research there was little or no awareness of GLC prior to engagement. All carer support organisations spoken to however had been aware of GLC services for a long time and spoke highly of them. They adopted a mix of in-house procedures and system formalities for referring carers to GLC. These appear to have been developed organically in response to the differing needs of that organisation.

In all cases, those that had engaged with GLC - both carer support organisations and carers themselves - were extremely positive about GLC and all were more than happy with the service they received. In particular, the home visits were highlighted as a major strength of the GLC's approach to meeting clients and making them feel at ease. These were appreciated as many had difficulty travelling to GLC offices due to transport complications and caring responsibilities. Therefore, a home visit reduced anxiety and stress, and carers were more likely to keep appointments in the home environment. Less formal home appointments were better for developing rapport and trust with their new client. GLC were also valued for their specialist knowledge and understanding; their non-judgmental attitude; and their patience and reassuring tone with carers.

## Demand for a Specialist Carers Legal Services Unit

All were extremely enthusiastic about the concept of a legal service that was exclusively for carers.

Somewhere that was regarded as the specialists about legal issues pertinent to carers, and all had quite definite ideas of how such a unit should be designed and delivered.

Carer organisations agreed that there was a need for a Glasgow-wide legal service for carers that had knowledge, expertise and skills to deal with carers legal issues and had excellent word of mouth recommendation – and GLC fulfilled these requirements. Amongst some carer organisations the way forward for this unit would be to work more closely with the Glasgow City Carers Partnership to ensure clear signposting through their multi-agency approach.

The most frequent request from carers was that the service be understanding of the demands and stresses carers had to deal with. They wanted home visits to be standard, that legal advisers be able to explain processes in layman's terms, that costs were transparent and discussed upfront, and that a 'package' of services be offered.

#### **Conclusions & Recommendations**

The findings from this qualitative research study illustrate that there is an unmet need for a specialist carers legal needs service. Carers were extremely positive about much of the GLC carer engagement process, finding it a beneficial and effective model for addressing their needs. Particularly, GLC appeared to understand carers, refrained from using technical language, explained processes clearly, had specialist knowledge, were patient, and kept the clients updated on progress.

There is a need for printed information for carers and their potential legal needs that can be made available through carer support organisations and various health settings that is simple, clear and jargon free. Thus when an issue occurs they are aware of their options and it may also prompt carers to act earlier. Key messages within the printed media must be tonally positive and non-judgmental and reassure carers of the expertise, trust and understanding of GLC.

A detailed marketing and communication plan should be developed with clear objectives and specific communication channels detailed to allow more formal structures around referrals to be put in place including how to increase representation within the Glasgow City Carers Partnership, raise GLC's profile and increase referrals overall.

It is also recommended that carer support organisations receive regular training or seminars to raise awareness of GLC and ensure they are up to date on any legal changes that may impact on carers. They would also be grateful for access to a support line to discuss cases prior to referral.

Within the delivery model developed, home visits should be offered as standard. Furthermore, consideration should be given to the ability of support workers to undertake part of this service – completing basic paperwork and updating and reassuring carers without always having to meet with their solicitor. Consequently, any project proposal should consider a mix of expert solicitors working collaboratively with support / advice staff.

Finally, it would advantageous to link the carers legal services unit to other in-house legal services such as education law services, housing rights, and welfare and financial advice to ensure a broad wraparound service can be delivered to carers, where necessary.

## Introduction

As of June 2017, there are an estimated 788,000 people in Scotland who are caring for a relative, friend or neighbour. This includes 44,000 who are under the age of 18.

In addition, the number of households headed by people aged 65 and over is projected to increase by almost 54% between 2012 and 2037. In contrast, households headed by someone aged under 65 are projected to increase by just 3%.

Furthermore, taking into account that the number of households headed by someone aged 85 and over is projected to more than double over the same period, from 77,400 to just over 200,000 it is clear that the number of carers can only rise over the next 20 years.

The Carers Act 2018 will also extend the rights of carers by placing additional requirements on the NHS and councils in Scotland to provide better and more consistent support for carers, which in turn should also lead to an increase in the number of carers being identified.

Carers however often do not identify themselves as such, confusing the term with 'paid' carers, leading in some cases to an invisibility in terms of support – especially in the early days of their caring role. Consequently, many organisations that support carers are adopting the term 'looking after someone' to distinguish between these groups.

Unpaid carers are defined as people who provide care and support to family members, other relatives, friends and neighbours. The people they care for may be affected by disability, physical or mental health issues (often long term), frailty, substance misuse or some other condition. Technically carers are not paid workers and they are not volunteers – although they may receive payment for part of their time caring through self-directed care.

#### **Support**

Supporting a cared-for person can be mentally and physically exhausting and carers may have

to provide a range of support including:

- giving emotional support
- helping someone seek help / cope with a mental health problem
- · cooking and cleaning
- personal care
- budgeting and looking after finances
- supporting them to live with others in the family (e.g. brothers and sisters)
- helping other family members understand the needs of the person being cared for
- · giving medicine or providing medical care
- going to appointments and advocating on their behalf
- · checking they are safe.

There are a number of organisations set up to help support carers and can provide help through support groups, respite care, assistance with financial issues and benefits, advocacy and peer support. At present within Glasgow however there is no specialist organisation dealing with the legal issues that carers may have to deal with. Carers can require legal advice around applying for Power of Attorney or Guardianship or may need assistance to challenge a self directed care decision. In addition, there may be welfare or housing issues associated with the cared-for person that needs legal guidance.

Govan Law Centre has observed a rise in the number of carers that are seeking their advice and services around such issues. There may be a number of reasons for this including the rise in the number of carers as detailed above; carers being identified earlier through carer support organisations; and / or the rules surrounding Self-Directed Care.

They believe there are large unmet legal needs amongst carers across Glasgow, and have consequently commissioned a small independent research project to further investigate whether there is a need for a specialist legal services unit within GLC specifically dealing with carers issues.

# Research Approach

#### **Aims & Objectives**

The overall aim of the research was to investigate the legal needs of carers and examine whether there is an unmet need for a carers legal services unit uniquely targeted at this group. The specific objectives of the research were to:

- Examine the nature of legal needs carers may have
- Explore awareness of future legal issues and process of engaging a solicitor when necessary
- Investigate satisfaction with legal services already utilised and identify any gaps in service
- Gather opinions around the need for a specific legal services unit for carers and models of delivery

#### Methodology

The research methodology chosen was qualitative in nature and comprised in-depth interviews.

In-depth interviews were the decided format as they allow for a greater depth and breadth of information and engagement. In addition, for carers themselves, it allowed a more confidential, relaxed environment within which they could be at ease, open up and discuss their caring responsibilities and legal issues.

In some cases this involved sensitive issues, and for care support organisations and GLC staff, was a more convenient way to participate.

The evaluation comprised of interviewing four main groups:

- Govan Law Centre solicitors
- Carer support organisations
- Carers who had not used legal services for carers issues
- Carers who had used legal services (GLC and / or others)

The recruitment approach for each of these groups is outlined below:

#### **Govan Law Centre Solicitors**

GLC solicitors with carers as clients were the first to be interviewed confidentially as part of the

research. They provided context and background for the researcher and such insight was invaluable in the development of the discussion guides for use with other research groups. They assisted in the recruitment of carers who had been GLC clients and they helped with logistics of contact, data protection, and meeting arrangements

#### **Carer Support Organisations**

It was agreed with GLC that a sample of carer support organisations who already referred carers to GLC should be included in the evaluation. The sample finally agreed upon was:

- Carers Scotland
- Glasgow Association of Mental Health, Carers Team
- Glasgow North-East Carers Centre
- Glasgow East End Carers Centre

As a national organisation our first discussion was with Carers Scotland. This discussion also helped frame the research and provided talking points for discussion guide development.

#### **Carers**

In addition to speaking to carer support organisations and GLC staff, a total of 11 in-depth interviews were conducted with a selection of carers, some who either had been, or were currently, clients of GLC, others had never been clients but had used other solicitors previously for issues relating to their care role, and carers who had yet to have the need for legal advice surrounding their caring responsibilities.

To achieve this, respondents were recruited using a three pronged approach:

- In the first instance GLC contacted a broad range and number of both current and previous clients who are carers and asked if they would be willing to participate in the research. The names and contact details of all those who consented were subsequently passed to the Researcher;
- Carer support organisations also asked their own service users if they would be willing to participate and again details of those who consented were passed to the Researcher;

 Finally, the researcher reached out to personal contacts to pick up carers who had no contact with carers groups to allow us to unpick where their recommendations around legal advisers originated.

A sampling frame of 15 individuals was developed from these sources to meet requirements and to build in flexibility to allow for drop out.

In total only 3 carers either failed to respond to phone calls / voicemails or texts to indicate their availability; and 1 indicated they there were no longer willing / able to participate.

Overall a total of 17 in-depth qualitative interviews across all three groups were conducted during May – July 2017 as follows:

Respondent Type	Interviews
GLC solicitors	2
Carer support organisations	4
Carers	11
Total Interviews	17

#### **Topic Guides**

A broad topic guide for each audience was discussed and developed in conjunction with GLC. The topic guide was structured to elicit open and honest responses, to understand issues and enable respondents to speak openly

#### Analysis

Interviews were audio-recorded with respondent permission from which the researcher compiled a detailed summary. A thematic analysis was conducted on these notes and compared across all interviews in order to identify recurrent themes and sorted by respondent type.

#### **Note on Findings**

This report is based on qualitative research. The nature of qualitative research means there can often be a wide range of differing views. Where a general consensus was reached across depth interviews this has been made clear – along with any caveats that should be taken into account. Similarly, it has been indicated that any other findings should be interpreted with contextual caveats in mind.

## **Overview of the Carers**

This section looks at the carers who were involved in the research before examining their attitudes and opinions towards their legal needs in more detail in the next section.

#### **Demographics**

Carers who agreed to be in the research tended to be older in age from 42yrs to 78 years old with a broad social spectrum represented. Four of the carers were home owners and a further seven lived in social housing. Only two of the carers were male and only two carers worked.

One carer was limited to part-time work due to her caring responsibilities, and the other carer worked in a school which allowed her the time off necessary to care for her child.

The remaining nine respondents were full time carers, with seven of them retired.

Internet usage amongst these carers was very limited with only 2 respondents regularly using the internet and only one carer had utilised the medium for advice around caring.

Carers were looking after adults with dementia, cancer, autism, Downs Syndrome, learning difficulties or people housebound due to mobility issues.

#### **Advice & Support**

Carers, quite apart from the people they care for, can sometimes pay their own price for their caring duties. as they tend to put others health before their own.

"I don't know what I would do without the wee group there every week. Gives me a break and a laugh..."

"I've been coming for over 6 years now. (They) have helped me sort out the rail for the house and got me my allowance..."

"If I need any advice about stuff this wee group on a Tuesday usually can help me out...we've all been through lots of the same stuff" All Carers, Glasgow East End Carers Centre They tend to be in a poorer financial situation due to their caring responsibilities and of course these also cause restrictions in their own everyday life. In particular, in dealing with matters that are not deemed 'urgent'. This was evident amongst the carers who participated in the research.

Consequently, although the amount and intensity of caring responsibilities may have differed, all carers faced a number of pressures. Dealing with the practical and emotional demands of looking after a loved one while doing their best to remain positive and hold things together leaves little time to focus on their own well-being. Their caring responsibilities may include helping the person with some or all activities of daily living, from intimate personal care to housework. Providing this level of constant support takes a great deal of time, hard work and compassion, and may often be emotionally and physically exhausting. And in addition to these roles they may also have to take on legal and financial matters for the cared-for person.

For the majority of respondents in the research, advice and support to manage all these demands came in many forms. For example, local carers support groups; GPs; social workers; other family members and friends. This support network helped in many practical and emotional ways and was an initial point of advice and information. Especially for those we spoke to from Glasgow East End Carers Centre – other carers in their support group and the staff at the centre were the first people to go to for advice about anything:

"Since I gave up work this place has been a godsend. I don't miss work but I miss the chat with everyone there... so this helps..." Carer, Glasgow East End Carers Centre

For some respondents however family and friends were their main source of support and these carers felt no necessity to become involved in more 'formal' support mechanisms such as that offered by carers groups.

Only one carer used the internet regularly and was a member of an online forum for parents of

children with Downs Syndrome. She found the help, advice and comfort she got from the forum to be invaluable and reduced the need for any face-to-face carers 'group' support:

"It can be late in the evening before I get a chance to breathe...that's when I need to speak to someone...but I can just get on the computer and chat to other parents in the same boat...so they are the first ones I go to for advice about anything to do with her..."

Carer, Adult with Learning Difficulties

"If I need advice I just ask our doctor... he's really helpful...and he's good to talk to." Carer, Spouse With Dementia

"I think our support worker would be the first person we go to with any problems...
he knows pretty much everything..."
Carer, Adult with Learning Difficulties

"I find those carer groups depressing...everyone just complains about how bad their life is..."

Carer, Adult with Learning Difficulties

#### **Awareness of Legal Needs**

Across the sample one thing was clear – no carer was aware of potential legal issues they may have to deal with concerning their loved one until faced with an immediate problem.

For example, when a child with a learning disability reaches the age of 16 they are classed as an adult and as such parental rights are extinguished. It is therefore necessary for parents to make a guardianship application, in order to have legal authority to make welfare decisions on behalf of their child. All parents we spoke to during the research were unaware of this until informed by either a peer, the school or a health professional.

For one respondent being unable to deposit a cheque in her housebound husband's bank account was when she realised she needed advice. For another respondent being technically unable to accompany her 16yr old child into the GP's surgery was the catalyst she faced to understand she needed information:

"It's really word of mouth...you learn things from other parents with kids a little older than yours..." Carer, Adult with Learning Difficulties

"You're left to flounder...there's no one place to go for advice"

Carer, Disabled Spouse

"When we were told [needed guardianship] we thought.... Oh here we go again...we have another hurdle to jump..."

Carer, Adult with Learning Difficulties

During the research there were four main legal issues that came up repeatedly. Carers had either dealt with these issues previously; were currently dealing with; or (the researcher identified) would have to deal with in the near future. Those were setting up a power of attorney, guardianship application, acting as an executor, or making a will.

However, we also identified some carers that had been dealing with issues that could have been resolved in a more positive manner had they understood that they needed legal advice. They either were unaware it would have made things easier, or such a move was dismissed due to cost assumptions. These included:

- House move application rejection due to inappropriate accommodation for disabled person
- · Lengthy wait for house adaption
- · Welfare benefit appeal
- · Challenging an educational decision

Carers in these cases had no awareness that they may have been able to obtain legal help with such issues and thus none had ever been sought.

# Perceptions and experiences of high street solicitors

This section details the respondent's experiences with solicitors other than GLC (which is dealt with in the next section). We look at both legal encounters relating to their caring responsibilities, and other legal issues and how this has impacted upon their perceptions.

#### **Previous Experiences**

The majority of carers in the research had previous experience of a high street solicitor – and for some this was in relation to their caring role.

"I think we only went down to see him twice...
I called him once when my son was wondering what was happening and he sent me a letter saying it should be through soon. Then I got the power of attorney thing through and then his bill. It was fine. Just expensive..."

Carer, Spouse with Dementia

For others the experience of obtaining guardianship was long and difficult. One carer's original solicitor passed her on to another firm with no explanation and she endured a number of visits to these 'new' solicitors who were located far from her home and necessitated a long bus journey:

"I'm sure it shouldn't have taken as long as it did...you could go months and not hear from them... I'd always have to call and ask how it was going..."

Carer, Adult with Learning Difficulties

Another carer did not feel reassured that everything that should be done was being done in a timely manner:

"I went to the local lawyer in the estate agents but he didn't really know family law. I just felt as though he didn't know much about it although they did get me the guardianship that the first time...just took forever – over a year..."

Carer, Adult with Learning Difficulties

'Linda' sought advice from the lawyer who had represented her when buying and selling property, She was advised by her GP to seek power of attorney due to her husband's dementia. Although the process was without issue she found it difficult to understand a lot of the procedural details.

Experiences differed however and consequently engagements were not always positive.

One respondent had engaged a solicitor in his local area to set up a Power of Attorney when his wife's dementia was beginning to cause problems. Although the process was smooth the respondent found the cost high for what was involved (£600). Another carer was told by her local solicitor that he was unable to set up a Power of Attorney and recommended another firm:

"He was a lovely man but I hadn't a clue what he was talking about half the time...you just have to trust them don't you...?"

Carer, Spouse with Dementia

For other respondents, previous legal experiences involved drawing up wills or dealing with the death of a spouse but no issues linked to their

that they would need legal advice regarding their caring responsibilities in the future, this had not yet been identified at the time of the interview.

caring role. For these carers although it was clear

Their assumption was they would use their previous solicitor:

"Only time I used a solicitor was for our wills... there was this lawyer's stand in Asda and they did it for £35 each. They sent me a letter after that saying I would need that Power of Attorney soon and they could do it for at a discount.... £250 I think they said...but I've never bothered...if I need it I've still got the letter..."

Carer, Disabled Spouse

#### **Perceptions**

Although carers were on the whole satisfied with the services they had received from solicitors utilised previously, the research identified four areas mentioned by a number of respondents regarding the experience:

- Costs
- Understanding of Legal Terms
- Appointment Setting & Location
- Specialist Knowledge of Legal Area

#### Costs

It was clear from interviewing respondents and

from discussions with carer support organisations that costs could be an issue for some carers when looking for legal advice. In some cases, this was more a perception of costs for legal advice that then became a barrier to seeking further help. For others – it was the actual fees invoiced for legal work conducted in the past that led to the assumption that further work linked to their caring responsibilities would be similarly expensive:

"I've avoided this for years [making a will & transferring POA to another family member].... when my husband died it was very sudden and it cost thousands of pounds for the lawyers to wind up his company. They charge plenty..."

Carer, Adult with Learning Difficulties

"I knew it would cost me money because my cousin had problems getting Guardianship. And they had to pay a lot of money for it..." Carer, Disabled Spouse

"Some of our carers do worry when Power of Attorney and lawyers are mentioned. Many of them have limited or no experience in this area so yes there can be an assumption that this is going to cost them a lot of money and they lack knowledge around legal aid..."

Carer Support Organisation

This perception of fees that may be charged may also be another reason for delaying engaging a solicitor.

#### **Understanding of Legal Terms**

A minority of carers felt slightly intimidated when meeting a solicitor and this, in part, appeared to be due to a lack of understanding of the legal process and / or the legal language sometimes employed - both in face-to-face meetings and sometimes also within written correspondence. This communication barrier could add to their anxiety when legal services were considered necessary:

"I got a letter telling me the Guardianship had to be done again... I didn't really understand everything that he did...he didn't really explain things that clearly... but it was done..."

Carer, Adult with Learning Difficulties

"The issue can become a problem because some carers can have problems reading... not serious but enough to make understanding of legal procedures difficult sometimes...and it can impact on how they understand paperwork definitely..."

Carer Support Organisation

"They all talk double dutch don't they? ..."

Carer, Spouse with Dementia

#### **Appointment Setting & Location**

Caring responsibilities can make it difficult to keep scheduled appointments sometimes. Although the appointment is made in good faith - in the knowledge that they were free at that specific time – the appointment may subsequently have to be cancelled due to respite difficulties, illness or time scheduling. Few things can be done spontaneously and carers may find themselves having to cancel appointments at short notice for issues they cannot control and which may not always be understood by their local solicitor. Furthermore, missed appointment letters can make the carer even more anxious about rescheduling:

"I just felt bad to be honest... I mean there was nothing I could do about it...I had to get the bus to get there and there was no way I was gonna make it...but he wasn't pleased and that made it worse."

Carer, Adult with Learning Difficulties

"We get it all the time... we make an appointment for them to see someone here [at carer support organisation] and then they don't turn up...it can be something as simple as their relief carer being late or a no-show, a transport failure, or the cared-for person being ill... you have to expect it sometimes really...these people are already stressed enough in most cases."

Carer Support Organisation

"There was no problems but we had to cancel quite a few appointments in the beginning...it was difficult because he gets a lot of chest infections and wee bugs and then we can't go out...I think he got annoyed in the end..."

Carer, Disabled Spouse

#### Specialist Knowledge

For a minority of carers who had previous experience using a local solicitor for guardianship powers it became evident that using their local solicitor did not automatically mean they were specialists in what can be a complicated area of law:

"I just felt as though he didn't know much about it... [guardianship] although he did get me it first time... it took a very long time though" Carer, Adult with Learning Difficulties

"Guardianship is one of those issues that can be complex dependent on the case...it does need someone with specialist knowledge of the area sometimes to unpick their way through all the documentation necessary...we have anecdotal evidence of some carers getting into a right pickle with the paperwork...and you need a good lawyer to walk you through it..."

Carer Support Organisation

## **Carers and Govan Law Centre**

This section sets out respondent's awareness of GLC; how referrals were made and appointments conducted; and satisfaction with the legal services that carers received.

#### **Awareness of GLC**

Amongst all carers interviewed as part of the research there was little or no awareness of GLC prior to engagement. One respondent however lived near GLC's Govanhill office and so was conscious that there was a "local legal aid lawyer" in her neighbourhood.

Furthermore, as discussed earlier, even amongst those who had never been clients of GLC, awareness of solicitors in general was limited, with carers tending to return to the law firm they engaged previously – for example – the firm that carried out conveyancing for their house purchase, assisted with their will, or had chosen the law firm due to its proximity to their home.

All carer support organisations spoken to however had been aware of GLC and its services for a long time:

"Do you know I'm not even sure when the relationship started...I have been aware of the work they do – especially around housing – for a number of years..."

Carer Support Organisation

"We have done a lot of work with them and they are always our agency of choice..."

Carer Support Organisation

"Well I first became aware of GLC when they helped a service user of ours in my last post... and that must be about 15 years ago now..." Carer Support Organisation

#### **Referral Process**

As discussed in Section 3 most carers were unaware of the need for legal advice regarding aspects of their caring responsibilities until there was a catalyst or it was mentioned by another carer, support worker or carer support organisation.

The research uncovered a mix of GLC referral

procedures. The majority tended to originate from carer support organisations, a few from Greater Easterhouse Money Advice Project (GEMAP) and only a small minority of self-referrals. Similarly, we found, for most respondents, it had been the carer support organisations who made the referral to GLC for them, one via GEMAP and one school head who had referred them to GLC.

The research also found that carer support organisations adopted a mix of in-house procedures and system formalities for referring carers to GLC. These appear to have been developed organically in response to the differing needs of that organisation. In general, an electronic template had been devised and this was sent to GLC who then contacted the carer directly – usually by telephone:

"We have a direct referral form which we pass on to them by email. It's been tweaked over the years... it works really well. We leave it to GLC to follow up...which is the best way for us really..." Carer Support Organisation

"All our staff refer direct to GLC. We ask a question on our self-assessment form around legal needs. I'm not sure how it started [the relationship] but we always refer to them..."

Carer Support Organisation

"We have a money and welfare advice worker here and he knows to refer to GLC if necessary... because we know they are the best at the job quite frankly..."

Carer Support Organisation

#### **Appointment Setting & Location**

Once the referral was made, carers within the research received a call from GLC to arrange an appointment.

In most cases the first meeting was held at the carers home. Home visits were appreciated by all and during the interviews, carers espoused this method of legal consultation. For many it was difficult to travel to GLC offices due to having no car and the long distance to travel on public transport. For others the cared-for person was housebound or had difficulty in strange environ-

ments and therefore a home visit reduced anxiety and stress and there was no need to arrange care while at the appointment. GLC also found that carers are more likely to keep appointments that are in the home environment where they are more relaxed and they found home visits were better for developing rapport and trust with their new client.

Not all respondents requested a home visit however. One respondent – although given the option – preferred meetings to be at Greater Easterhouse Money Advice Proect as the cared-for person could become stressed when strangers visited their house. For another carer visiting the office was not a problem as they lived nearby.

In most cases face-to-face in-home appointments were kept to a minimum and much of the work – unless complex – could be concluded via telephone calls and written communication. These letters and telephone calls were greatly welcomed as they were always reassuring and supportive:

"We tend to always do a home visit. We've done appointments at carer's centres before but some carers didn't turn up or re-arranged all the time. Could be any number of reasons... bus problems, care issues... just fear in some cases. We find that a better relationship is forged in a non-office environment anyway. Law offices can be intimidating..."

Solicitor, Govan law Centre

I got a phone call just to tell me not to worry... that [the Guardianship] can take a while to come through but there was no problems... she was so kind...always asking how things were and anything else she could do..."

Carer, Adult with Learning Difficulties

#### Satisfaction with GLC

In all cases, those that had engaged with GLC – both carer support organisations and carers themselves - were extremely positive about GLC and all were more than happy with the service they received. In particular, as mentioned before - the home visits were highlighted as a major strength of the GLC's approach to meeting clients

and making them feel at ease.

For carer support organisations GLC are recommended in particular because of their specialist knowledge and understanding:

"GLC just understand carers...they don't get fazed if the carer forgets the appointment or has to cancel or if they have to go back a few times and explain things again...this reduces the carers anxiety..."

#### Carer support organisation

"They are caring and take their time...It comes across when you speak to anyone from GLC. And they are not motivated by fees. And that's important... as some have had bad experiences being charged terrible amounts by lawyers in the past..."

#### Carer support organisation

"Working with people who are already physically and mentally stressed can be difficult so taking the time to listen to them and explain things again and again is important. GLC are happy to do this...it's one of their main strengths...they are just so human..."

#### Carer support organisation

"Some of our carers can have literacy issues so this can impact on how they understand paperwork... GLC try not to be jargonistic which is greatly appreciated..."

Carer support organisation

The terms 'kind', 'helpful' and 'understanding' were the words most often repeated during the research when asked to describe their GLC solicitor. In addition; many commented upon their GLC solicitor's patience in explaining a sometimes complex process without resorting to hard to understand legal terms. They also valued their non-judgmental attitude:

"She [the solicitor] has been amazing...she guided us every step of the way...it took a long time due to the different assessments and social work dragging their feet but Govan Law were so supportive..."

Carer, Adult with Learning Difficulties

"We didn't have to do much really. She did it all for us. It was such a relief. We just got the updates and the letters..."

Carer, Adult with Learning Difficulties

"There was never any letter or phone call that got us worried... in fact every letter just gave me peace of mind...it was something else ticked off the list...nothing was too much trouble..."

Carer, Spouse with Dementia

"If you're a carer that's the place to go to... lawyers can be quite stand-offish but they are nothing like that..."

Carer, Adult with Learning Difficulties

### **Demand for a Specialist Carers Legal Services Unit**

All respondents in the research were asked if they thought there was a need for a legal advice centre / unit particularly for carers in Glasgow. This section details their thoughts and attitudes towards the development of such a specialist service.

#### Carers

All carers were extremely enthusiastic about the concept of a service that was exclusively for their group. They were all keen for an organisation that could be perceived as the specialists regarding legal issues pertinent to carers, and all had quite definite ideas of how such a unit could be designed and delivered.

The most frequent request was that the service be understanding. This tended to be related to their experiences of missed appointments and the fear of being castigated for not cancelling within an appropriate time period, or having to re-schedule at short notice. In some cases, this request for understanding came from previous experiences with legal agencies they felt were not entirely empathetic of their issues as carers:

"Because of his condition [dementia] it can be difficult to always get to appointments so the place needs to understand that my plans can change..."

Carer, Spouse with Dementia

"I think they need to understand what I deal with in here on a daily basis so sometimes I forget arranged stuff because I'm dealing with other stuff that's more urgent..."

Carer, Adult with Learning Difficulties

"Just a place that understands that sometimes we need time to absorb what they are saying I think... and that has dealt with lots of carers of my type before so know the problems..."

Carer, Adult with Learning Difficulties

Of equal importance to carers was the ability for this service to arrange home visits – again due to their already stressful lives and in some cases transport and care arrangement complications.

Furthermore, they desired a specialist carer legal service that took the time to explain processes and procedures to them in 'layman's' terms. Of course there was an assumption that the solicitors were knowledgeable around their particular legal needs, but also aware of potential future issues they may need to deal with. One carer thought it was important that costs were clear and explained upfront.

Finally, they spoke about this unit being able to offer a 'package' of services that included commonplace carer legal needs such as Power of Attorney and Guardianship, but also Will writing and assistance challenging care, education or housing adaption decisions if necessary:

"I would've loved to have had somewhere to go when I first got told I had to get guardianship.

That knew what I needed and had done it hundreds of times before. It would have saved all the hassle I had with that lawyer before..."

Carer, Adult with Learning Difficulties

"It would be nice to have a lawyer that just dealt with everything really. The Power of Attorney thing getting changed, sorting out my will...that would really help me."

Carer, Spouse with Dementia

"A leaflet at the first meeting would've been helpful...or when I made the appointment...you know just something telling me everything that was going to happen...with contact details and stuff... what else they do...that sort of thing..." Carer, Disabled Spouse

"Costs...that would be important...it's all good having somewhere that knows what they're doing but how much is it going to cost me...I want to know that before I tell them to go ahead..." Carer, Adult with Learning Difficulties

#### **Carer Support Organisations**

Amongst carer support organisations there was a sense that there was still an unmet need for carers for such a service. Although positive about the concept of such a unit, all carer support organisations spoken to during this research believed that GLC was a specialist carers legal advice unit to them - in all but name - because they made use of a specific electronic template to a dedicated GLC email address; GLC were already specialists in the area; and these organisations have a close relationship with GLC already.

All agreed however that there was a need Glasgow-wide for a legal service for carers that had clear knowledge, expertise and a record in the area with excellent word of mouth recommendation. They felt its culture would reflect exactly what GLC also represent currently - understands the day-to-day stresses and anxieties of carers; perceives home visits to carers as the norm; did not view fee income as the main objective; and were happy to accept legal aid cases.

Carers Scotland were keen on a more specific 'hub' for carers which would support them around their legal requirements and acknowledged there was a need for such a service - not just in Glasgow – but Scotland-wide:

"Carers don't know where to go... nor what their rights are...we signpost when we can but with the new Carers Act coming into force next year there will probably be more demand for advice and support around legal needs."

Carer support organisation

Some carer support organisations also thought the best way forward for a such specialist unit

was to be developed around extending their reach via the Glasgow City Carers Partnership. Access to service and support for carers in Glasgow is now through a one stop shop approach known as the Glasgow Carers Pathway. The Carers Pathway gives carers from all care groups access to a range of services and supports Glasgow-wide including welfare benefits, emotional support, short breaks, advocacy, training, information and advice and peer support.

As this multi-agency unit was putting resources into identifying more carers earlier and that some in the Partnership already refer to GLC. It was felt that ensuring that every agency within the Partnership knew to direct their carers to GLC, this would lead to the GLC carers unit model running parallel to the Pathway but on a more structured footina:

"We tried weekly surgeries once, then monthly... they didn't work. People didn't turn up. So in order to be able to help more carers there needs to be a more targeted strategy looking to engage with many more carer support groups than at present..."

Carer support organisation

"There is a huge number of carer support organisations and support groups out there – all with different types of carers that they could be helping...so yes...the need is out there...they just don't know about GLC..."

Carer support organisation

"This idea of a specialist unit already exists for us with GLC. It's just a matter of rolling that out to all organisations within the Glasgow City Carers Partnership and for GLC to engage in a more formal way than at present..." Carer support organisation

# Conclusions and Recommendations

The findings from this qualitative research study illustrate that there is an unmet need for a specialist carers legal needs unit. Carers were extremely positive about much of the GLC carer engagement process finding it a beneficial and effective model for addressing their needs. Particularly, GLC appeared to understand carers, refrained from using technical language, explained processes clearly, had specialist knowledge, were patient, and kept the clients updated on progress.

However, there is little or no awareness amongst carers about their potential legal needs until it becomes urgent – mainly due to the daily stresses and strains they are dealing with and a lack of information to hand about what they may need to prepare for. Thus the issue becomes immediate fairly quickly after awareness.

Subsequently, for those with no experience of solicitors, advice and information around legal assistance tended to emanate from support groups, health professionals and other carers. Few used the internet to research the area. It is at these trigger points that carers can be signposted to GLC.

The task for GLC therefore is to ensure that amongst health professionals and carer groups that GLC and their expertise in this area is top of mind when the subject arises.

There was evidence that many carers had issues with their local solicitor around costs; lack of specialist knowledge; the length of time for the issue to be resolved; or confusion regarding the process. For others there was more a perception of high cost. Experiences of those using GLC though, clearly indicate that there were more than satisfied with the service they received. Their knowledge, experience in the area and different business objectives meant they could take more time through home visits, telephone calls and a lack of formality in communications to build trust and rapport.

#### Information for carers

There is a need for jargon-free printed information for carers which can be made available through carers organisations, GPs surgeries, health centres, and other agencies used by carers. Thus when problems occur they are aware of their options, and it may also prompt carers to act earlier.

For a variety of reasons many carers tend not to go online for information in the first instance for e.g. due to age; a lack of internet research skills; access to digital forms of communication. Carers do however read traditional brochures, particularly if they are simple, clear and jargon-free. So it would be effective to develop a selection of brochures / information sheets / leaflets for carers – outlining the legal needs they may have and detailing GLC's approach. It is recommended ensuring that the messages addresses the concerns of carers detailed within this report to allay inherent fears around engaging a solicitor.

Printed communications can be circulated to carers support groups and also be distributed via healthcare settings within communities allowing carers to self-refer to GLC. Both these awareness raising actions would assist greatly in reducing the unmet legal needs of carers in Glasgow.

#### **Key Messages for Printed Media**

Any brochure, leaflet or information sheet developed will have two main objectives: to raise awareness of their current / future legal needs surrounding their caring responsibilities and secondly to reassure carers of the specialist knowledge, trust and understanding of engaging with GLC. The key aim will be to ensure that carers take away valuable information about their legal issues in a positive, non-frightening tone.

Thus it is important to illustrate the brochure with examples that resonate with this audience (although not extreme) and have a clear, easy call to action for readers (e.g. carers 'helpline' or link to the already established Carers Information Line) in addition to including a clear link to a website for the minority who will go online (or other family members).

Communications developed for carers needs to emphasise the difference in GLC's approach. This will reduce any anxiety carers may have about engaging a solicitor and reassure them that GLC are specialists.

Rather than bombard the carer with detailed information contained in the printed media it is clear from the research that carers are looking for basic, easily-read information but with signposting to more detail. As such it is recommended that only short, concise information is given on each area but with clear messaging addressing the audience directly around help, understanding and reassurance. They should also - as much as possible - be encouraged to seek support around their legal issues as early as possible. Key legal areas to mention within the brochure would be those likely to be covered through legal advice:

- Guardianships
- Power of Attorney
- Self-Directed care
- Wills
- Welfare Benefits
- Housing adaptions
- Housing rights

This information can be supplemented by training carers organisations, support staff, providing materials online and engagement with carers meetings and support groups.

#### **Marketing, Communications & Partnerships**

Carers felt that having a one-stop shop would be less stressful and time-consuming for them. It is clear that as long as carers are aware of the service – they would use it.

Consequently, any specialist legal service developed that is targeted at carers directly will require a detailed marketing plan with clear objectives and multiple communication channels. As evidenced in the research many carers only seek legal help when a significant problem occurs. This means marketing plans must consider how to ensure that when that problem occurs, GLC legal service for carers is top of mind. This clearly calls for a written marketing and communication plan.

It would appear that as the Glasgow City Carers Partnership are engaging more and more carers earlier due to their multi-agency approach - and have a question around legal needs on their self-assessment form - that expanding relationships within the Partnership will greatly increase

the number of carers coming to GLC - filling this unmet need. In addition, there is a large network of carers centres and support groups across Glasgow – many of which are issue-specific – that have as yet not been tapped into. Part of the marketing and communication plan therefore must detail how work must be conducted around how to increase representation within the Partnership, raising GLC profile and increasing referrals.

#### **Second Tier Support**

There is a need for support organisations to – at the very least - be able to diagnose legal issues and know when to seek further advice and sign post / refer carers to more specialist help. This is already the procedure in many carers support organisations. However, where there are instances of a key worker or 'adviser' being unaware of GLC at this point, they may engage a local solicitor – chosen due to a referral, or having engaged them previously or because they were near their home.

Consequently, carers organisations need regular training and / or seminars both to raise awareness of GLC and ensure they are up to date on any legal changes that may impact on carers. They also may appreciate access to a support line to discuss cases prior to referral.

#### Referrals

The formal electronic referral system already in place in some carer organisations in Glasgow needs to be set in place for all other carer organisations that become part of the partnership with GLC. This will allow carers to be easily and efficiently referred to GLC ensuring a smooth and quick process for engaging with those with legal needs.

#### **Delivery model**

While GLC need to think through how they would deliver the model there were some key findings from the research which should be considered in this respect.

It is recommended that the project offer a home visit service as standard, although some clients may prefer to meet in the office, or within the premises of a trusted organisation (e.g. carers

support group). As the research detailed drop-in sessions and weekly in-house surgeries/ appointment systems have all been tried and have not been particularly effective with this group. In addition, respondents made clear during the research that appointment setting and travelling had been a barrier to obtaining legal advice in the past.

As was mentioned repeatedly during the research, with a home-visit carers are less likely to cancel, are more relaxed and able to absorb information, can more easily consider their options and – where necessary – can discuss with the cared-for person.

The model should also ensure that written communications with carers are jargon-free and frequent – to reassure even when there is little to report.

#### **Wraparound Service**

Given the varied spectrum of carers that will engage GLC – both demographically and in terms of looked-after person's carer needs - it would be advantageous to link the carers legal needs service to other in-house legal services such as Education law services, housing rights services, welfare rights and financial advice to ensure a broad wraparound service can be delivered – where this may be necessary.

#### **Resource Allocation**

In terms of resource allocation, it is suggested that consideration be given to utilising advisers were possible. For example, a great deal of the work required for carers legal issues such as completing legal forms and paperwork; collecting medical evidence; explaining processes; reassuring carers through process, explaining law could be carried out by advisers - not necessarily lawyers. Advisers / support staff may be able to meet with clients in their own homes and discuss issues and prepare paperwork enabling the solicitor to only be required to make one home visit to progress the case.





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