INSIGHT REPORT: THE EXPERIENCE OF IDENTIFYING AS A CARER WITHIN THE DERBY & DERBYSHIRE CARE & HEALTH SYSTEM

“One of the [paid] carers said to the other ‘don't listen to her. She's only the family’...And when you said respect, you know, that's it. I'm nobody. I'm nobody.”

“Every single time I ring up the doctors I have to explain. ‘Yes, I can talk about my wife because I'm a carer. It's on your file. Look at it’. And I've seen it. It's on there on the first page, but they don't read it, so it's just very tiresome having to keep going over things and getting pushed back.”

“A carer is something you become without being asked, it’s not a choice.”

1. Introduction

The 2021 Census data indicates there are 4.7 million unpaid carers (or 8.9% of the population) in England, providing almost £152 billion worth of equivalent care. The House of Lords Adult Social Care Committee (2022) and The Kings Fund (2023) have both warned that without unpaid carers, the social care system would collapse. Although councils have a duty to identify carers in their area and offer them a carer’s assessment on the appearance of need, a recent study (Alcock et al 2023) found that at most only 5.1% of carers were known to their council compared to the census. When records held by primary care and councils were combined, at most, 26% of unpaid carers were known to the local system compared to the census.

Information about unpaid carers is held in different parts of the local care and health system but there are no mechanisms for this data to be shared in any consistent or meaningful way so that carers can be identified early and offered seamless support which enables them to continue caring and look after their wellbeing. If we are to improve outcomes for unpaid carers, and intervene early to prevent carer breakdown, then we need to tackle the barriers to sharing this information.

Improving unpaid carer data sharing across local systems (councils, the NHS, carers support organisations, and by carers themselves) was a strategic objective for Partners in Care and Health (a partnership of the Local Government Association and the Association of Directors of Adult Social Services) for 2025-26. Partners in Care and Health (PCH) provided funding and resources to undertake some targeted work with two local care and health systems aimed at better understanding the barriers to sharing unpaid carer information; the Derby and Derbyshire Integrated Care system was one of two areas selected. An essential part of the project would be to ask carers how they felt about sharing their information with their local care and health system, what might be a barrier to this, and what they’d like to see happening to improve things for carers in their area.

As part of this project, twenty-four unpaid carers participated in three focus groups and three 1-1 interviews. This report summarises the key themes and messages emerging for these discussions about carers’ experiences, with recommendations from them for the local system which would increase their confidence in identifying themselves as a carer and getting the essential support they needed, at the right time for them and their loved ones.

Carers understand that health and care services are under pressure, and their asks of the system are modest. They put the needs of the person they support before their own, and many only get help when they are at crisis point, and their own health and wellbeing is affected. They are exhausted and suffering from stress. Despite this, far too many are having to repeat their stories to professionals over and over again, are being signposted to the same services multiple times, have regular battles to be recognised as their loved one's carer, and find clear, consistent information and the right support tailored to them difficult to come by.

My thanks to the carers who contributed their precious personal time to these focus groups, for their insights, stories, honesty and good humour in the face of daily battles to provide the best possible care for their loved ones. Thanks also to the local carers organisations who facilitated these discussions, providing a safe and trusted space in which to explore these experiences.

2. Project approach and methodology

The project's aim was to understand the barriers to sharing information about unpaid carers by the local care and health system, and to make improvements which would benefit everyone. Unpaid carers experiences were central to the design and delivery of this project and they have influenced and shaped the recommendations for action by the local system.

There were three elements to the collection of insights relevant to the project:
1. A series of 1-1 interviews with professionals identified by the project oversight group
2. Three focus groups with unpaid carers - online and face to face
3. An online insight survey aimed at professionals across the local care and health system.

Each focus group discussion was recorded and transcribed to ensure carers views were accurately captured. Confidentiality was assured, and each group received a summary of the key points made during the discussion. This was important as many carers experience professionals asking them for their views but never hear anything further.

For more information about the methodology used in the focus groups, feel free to contact [XX]

3. Focus groups

A semi-structured approach to focus group discussions was taken, designed around 5 barriers to people identifying as an unpaid carer drawn from previous research studies. The discussion aimed to test the accuracy of these barriers, as well as identify others not yet considered.

The five barriers:
1. People not recognising or identifying themselves as an unpaid carer; this is the most common barrier.
2. Carers tend to prioritise the needs of the person they care for over their own needs; they can often minimise the impact that caring has on their own lives which has negative implications for support seeking for themselves.
3. Stigma: research studies with carers described feelings of shame, failure or judgement associated with involving social services in their caring activity, both for the carer and the

person being cared for; some carers also dislike the ‘carer’ label, fearing it can stigmatise them or the person they supported.

4. Trust, Identity, Privacy and Security (TIPS) concerns over sharing personal information with professional or third parties; these include fears information might be used against them in some way (eg cuts to state benefits), worry about breaches of confidentiality and the security of the information they are sharing, and lack of trust in who is handling their information. Where people have had bad experiences of care after sharing their personal information (such as not getting help or their trust being breached by professionals) this can significantly affect their willingness to do so again.
5. Professional and system failure to proactively identify unpaid carers. Professionals in both the care and health system are not being proactive in identifying carers with a variety of reasons being offered for this including fear of raising carers’ expectations and then being unable to provide support, or not knowing what support was available.

4. What was discovered?

Through the focus group discussions, we heard many examples of all five barriers. One of the points made by a carer was that carers are not a homogenous group and should not be treated as such. This was seen by some carers as a downside of ‘generic’ carers support, and there were pleas for more specialist support for carers of people with mental health issues, younger age or working carers, and parent-carers for example.

Too many carers are simply being offered “signposting” to other services or websites (often getting the same information from multiple professionals) but experience this as being passed around the system with little practical help on offer. Registering as a carer with a GP was far from the ticket to additional support and consideration most in our focus groups hoped for, and the need to repeat their stories multiple times to professionals was probably the most frustrating thing of all. This experience significantly reduces confidence that the system values or respects carers, but despite this, in the main, and subject to the necessary safeguards, carers were willing to share their information, as long as it was of clear benefit to them and their loved ones. Several were keen that their experience, including participating in these focus groups, would benefit other carers in their area. They were also very clear however, that at present, they didn’t know how their information was being used by the local system, or who it was shared with, or how it was used to improve services for carers in their area. **This is a priority area for action by professionals in the local care and health system. You can see a full list of suggestions for action by the local system in section 7. at the end of this report.**

5. Headline findings from the focus group discussions

5.1. Carers are not clear what the benefits of registering as a carer are

Despite the emphasis on registering as a carer, carers said that in the main, there seemed to be little benefit to them of telling their GP they were a carer; for many, registration with their GP was simply a "tick-box exercise" which changed little in their lives "*The registration for me was, here's a box, tick this…it made absolutely no difference whatsoever.*" Some carers had received carers emergency cards, or access to peer support groups, but most had been frustrated by how little difference registration had made to them "*It really winds me up if it's just a tick-box exercise [by the GP]…I can feel really isolated and lonely; they [GPs] need to provide tailored information and do their own scoping and provide information which is up to date*"

One carer had considered encouraging other carers in their GP practice to register as a carer but had second thoughts *"We do have a newsletter, and I was tempted to put in it in… are you a carer? But then I thought what could I say were the benefits? … because I can't say things like, well, that would prioritise your appointment because I'm not sure they would, so I can't sell it if there's no benefit."*

Carers were also unsure about what 'evidence' they'd need to provide in order to register as a carer and found that GP reception staff were unaware of the registration process. Many were worried that registering might have an adverse impact on their state benefits, employment or those of their loved one. One carer said, *"I did go to my GP reception and say, 'I'm aware that I can register as a carer,' and they didn't know anything about it, and said that I probably needed to be registered somewhere [else]."*

Carers had similar worries about local authority carers assessments: that it might impact on state benefits, that their ability to provide care was being judged, or even that their loved one would be "taken away" *"I worry my ability to care is being judged and If I shared this, if they come and if they ask me if I'm having a bad day, does that mean Dad goes into a home?"*

The need to be much more explicit about the benefits of identifying as a carer with a GP or social care was a common theme throughout discussions. This should also include information about how their information would be used and shared, and clarity that eg benefits would not be affected.

5.2 People don't always identify or recognise themselves as a carer

Several carers described how caring 'crept up' on them gradually over time and they had only recently recognised themselves as a carer "*…I've been caring for my mum for about 13 years. It was gradual at first and it is very, very recently that I would say that I've identified myself as an unpaid carer.*"

"When you're working full time, [caring] it's just something you do when you get home. But the point of when I actually stopped work, I'd stopped for about two or three years before somebody said 'don't you get a carers allowance?' I said 'What's that? And that's the point… I'm just doing what I do."

Carers also prioritise the needs of the person they support over themselves, making identification as a carer less likely. This was very clear during the focus groups where carers struggled to talk about their own needs as opposed to the needs of those they support. *"I see everything I do as for my wife's benefit, not my own."* This is important in the context of professionals being able to spot the signs of stress or burnout in carers. It's also important not to label or stigmatise carers as "not coping" when in fact they need practical help with their caring role-more on this in the next paragraph.

5.3 Not everyone wants to be labelled as a carer

One person described the risks associated with being labelled as a carer and how that had impacted on her own health and wellbeing and sense of identity "*…there's also a risk that you just become defined as a carer, and actually I had a GP appointment where everything I said that I felt was medically wrong was put down to the fact that I was a carer and I was obviously stressed, and actually, it turned out that there was something medically going on… It's almost like we have these little boxes in which you're defined as a carer, that that's you. That's you, and you're not seen beyond that*." Another person said "*…we know the way social care and the health service can look at you, and once you're in that box, you're in that box*." This risk of being stereotyped as a carer cropped up several times "*The council have a stereotype of what a carer should be like, if you have an ill person in the household, you are automatically a carer and that you and the person you are caring for have no aspirations in life and that's it*."

Two different carers described how on breaking down in tears at their GP surgery because of the stress of caring, they were referred to the local mental health team and felt stigmatised by the label of "not coping" when actually what they needed was practical help and support. This had the effect of them being less likely to say they were finding things hard in the future. One carer felt very strongly that identifying oneself as a carer with the NHS or social care could "*lead to stereotyping, profiling and assumptions….I'm not a carer, I am a highly educated, accomplished woman with my own identity who has to [undertake] extra caring duties due to the caree needing extra support. It is done out of pure love and the pay truly sucks!*"

"*My doctor at the time wrote 'psychosomatic' [on notes about my symptoms]. He also advised me to go and see a life coach*."

5.4 Carers face constant battles with professionals over being recognised as a person's carer and think professionals use confidentiality as a way of avoiding consulting carers or sharing essential information with them about the person they support

Professionals refusing to talk to carers about their loved one, even if they were registered as a carer, was a constant and recurring theme throughout all discussions with carers as part of this project; listening to their stories, it's not surprising that there was a lot of scepticism about what the tangible benefits were of registering or identifying as a carer with the care and health system *"But we have tremendous problems communicating with the mental health teams [in] social services because confidentiality is used as a massive block and it's led to some very serious situations… We've sorted them out and then confidentiality is thrown at us again, and I think it's a huge problem* *that needs to be addressed really. Because if you're caring for somebody, you care, and that should be understood by people who are trying to turn you away..."*

"So, it's like confidentiality is a very useful method for the [NHS] Trust to hide poor care...They're generally concerned about protecting themselves [from] poor situations that have occurred."

It was common for GPs and reception staff to refuse to discuss the health of the person being cared-for with their carers "*When my mum didn't know if I was her carer, the doctor wouldn't talk to me. He just would not talk to me. I'm her carer, I need to know how she's doing, and he just would not talk*." Refusal was usually framed as being about consent or confidentiality but carers rarely received a full explanation of the circumstances in which professionals could and could not share information with them *"You try to look after somebody and they won't help you, and that's what they should be doing*."

"The biggest problem I've got is that even when I specifically speak to people and ask them to share the information that they just don't... I've had to battle with them at various times. I do wish [they'd] ...at least read the notes, when it's written on the file saying Mr. X is a carer; every single time I ring up the doctors I have to explain. 'Yes, I can talk about my wife because I'm a carer. It's on your file. Look at it'. And I've seen it. It's on there on the first page, but they don't read it, so it's just very tiresome having to keep going over things and getting pushed back."

"The GP knows I'm a carer...The GP practice knows that I'm a carer but... the battles and all of that, every single time...it makes me think, well, what's the point in them knowing that I'm a carer?"

There was a widely-held view that professionals often hid behind issues of consent, confidentiality and GDPR in particular, and were very risk averse about sharing potentially critical information with carers, both information pertinent to the person they supported, but also that which could benefit the carer themselves eg by referring them to another organisation for support. This lack of willingness to share information by professionals compounded the feeling that carers were not respected or valued as equal partners in caring for their loved one.

5.5 Carers know that their information isn't being shared or taken account of by the health and care system based on their experience of having to tell their stories repeatedly and constantly having to 'confirm' they are a carer

When carers were asked in focus groups if they thought their information *was* being shared with partners in their local system there was ironic laughter "*No, it's blatantly obvious that they're not*." "*Everything's fragmented. There's no joined-up-ness about it*."

"*There was a big issue made of joined up care [in Derbyshire]. So, you join up the care between social services, whatever that means? But the carer doesn't move, it's still with social services. So there's a lot of talk. But the reality isn't always followed through. It isn't rocket science."*

"*I also find with my GP surgery, which is the same one as my cared for, I never see the same person twice because they use locums, so they're only there for three months or something and then* *they're off...You have to regurgitate all the same stuff each time, if you can even get to see one which is almost impossible, but if you do, they know nothing about the history."*

Carers were also very frustrated when trying to get information about them or the person they supported changed or updated *"It seems once things are on the system they're there and it can't be changed, it can't be moved, it can't be flexible at all. If an error is made on an entry - I've got an error from years ago that's on the system, that has followed me through. Now, I've told about 20 million people that it's wrong, so it feels like it needs to be a live, reactive kind system that responds to changes for people."*

5.6 Professionals are not routinely and proactively identifying carers
Carers felt that there needed to be much better, consistent training for professionals in proactively identifying carers and knowing what was available locally to support them. There also needed to be a clear, common definition and understanding by professionals of what a carer was, particularly as we know from published research that many carers don't necessarily recognise themselves as such "*"And if you're not being given that opportunity to identify yourself as a carer, how much harder to recognise yourself as one and then to advocate for yourself as such?"*

"...other people would have recognised me as a carer, the GP, the consultants, the adult social care... even if we didn't recognise that ourselves, but nobody said 'you're an unpaid carer, there are these services there'."

"I think that goes back to that first point, doesn't it? I don't think of myself or describe myself as a carer...especially if things are going okay. If you're going okay, you're managing, you perhaps don't see yourself as a carer."

Carers described a very inconsistent approach to whether GPs identified them as a carer, one describing it as a "*postcode lottery*," very dependent on which surgery is attended; others described a situation where the surgery had initially been very good but had deteriorated "*Our practice at one time was probably the best in [place name]. Now, I wouldn't pay them in rusty washers to be honest, because ...nobody's getting any help."*

"That monthly meeting we had at our doctors when it started was brilliant, but then it just fizzled out and now it's nothing."

Another carer who visited his wife very regularly said that once she went into residential care, their role as a carer was of no further interest to their GP *"[my wife's] under the GP at the care home... As far as my GP [is concerned], I'm a carer for nobody. They're not interested now because she's not on their records any more."*

One carer said it was only by chance that they came to realise they were a carer *"I remember going to the community hospital. I think it might have been for an appointment for myself and I just aimlessly picked up a leaflet, something to do, and I was reading this thing about caring, and I* *thought, oh, hang on a minute, I think that might be me... I would've got there eventually but it was quite incidental at the time when I twigged and started looking into it."*

"*I personally just didn't know that there would be any help for carers. I didn't know that there was anywhere to go to get any help, so identifying as a carer, well, so what? [Laughs] It was only once I found out about [name of carers service] for carers I was, like, ting, I can get some help*."

Carers felt it was an important task for the local primary care network to ensure GPs are routinely identifying carers, able to identify stress and burnout. There was also strong support for GP practices having a carer support worker attached, in the same way as Allied Health Professionals or pharmacists *"Presumably people of all ages are living longer with more complex conditions, and a lot of them will have carers supporting them to be able to live longer and so on, so in terms of identifying a co-ordinator within a practice, it seems a no-brainer really, doesn't it?"*

5.7 Carers often don't feel respected as an equal partner and team member in caring for the person they support

One carer and a sibling caring for their mum who needed hoisted found the paid carers who came in didn't listen to them or respect their experience, even though they'd had training in using the hoist "*...and they said, no, no, they'll do it. And they didn't know which combination of the straps and everything. So, I said black on the bottom, yellow on the top. And I walked out of the room and one of the [paid] carers said to the other, 'don't listen to her. She's only the family'...And when you said respect, you know, that's it. I'm nobody. I'm nobody."*

"I get it. I know that the work is hard. I know people have serious caseloads... I'm very empathetic to those systems, [but] there's a lack of respect and when you don't think the person that you're speaking with respects you, then me identifying myself as an unpaid carer is not going to benefit me, is it?"

"One thing I think is massive, is how much money carers save the NHS and social services, massive amounts, you know. And that alone should give them some respect, you know. And that's not why carers do it, though. It's because they love whoever they're looking after."

5.8 Carers want more pro-active awareness raising about caring

There was consensus that the health and care system needed to be much more proactive and diverse in its communications and marketing, raising awareness among unpaid carers and clarifying what they meant by a 'carer' and helping them navigate the local system. Carers described considerable variation in the approach to carers by professionals "*Some of them [professionals] are very patronising and we have some tense conversations, some of them are great. Obviously, there's always different individuals, but the jargon they pour out is, it's very... Again, not all of them obviously, but... I think, God, if I'm struggling with this, and there's me putting notes in my spreadsheets and trying to keep all the services and work out what's going on, and which number and, oh, it's a Community Access Point. I don't know what a Community Access Point is, but there's all these different things, so I think that's why you then get lost in the wood*."

"Tell people...You might not call yourself an unpaid carer...have a publicity campaign on the TV, on YouTube or whatever. Twitter. Social media. Say 'there's a thing called an unpaid carer. You might be one, and if you're one then well done you."

"Start by telling people what an unpaid carer is, you know...someone you look after, might be your next door neighbour."

5.9 The importance of using the right language and avoiding jargon

One carer described the stigma which is still attached to asking 'social services' for help. Although others in the group pointed out that it's called 'social care' these days, for carers coming new to seeking help, this could still be a barrier *"I think it is because if I need help and I rang up the adult social services department, because of my age, and I think it is my age, my thoughts of social services are not good really, that it would be to do with abuse or something like that. So to think that there's friendly people there that would actually help me, I don't think so. I think they would interfere and then go, well, are you doing this right?"*

There was some interesting discussion about the term 'unpaid carer' and whether things like carers ID cards or recognisable badges or lanyards were a good thing. A lot of carers had initially associated the term carer with paid carers (eg home care workers) which is an important message for services when thinking about reaching out to people who may be caring. Some preferred the term informal carer *"People don't like the name unpaid carers, so we're using perhaps more informal carer. Just subtle differences in vocabulary can actually be really quite encompassing and inclusive."* Views on carer badges/ID and lanyards varied. Some were positive, as it meant they were instantly recognisable and didn't have to constantly establish their role as someone's carer, others felt it was potentially stigmatising. Either way, it's something worth discussing further with carers.

The issue of language and an awareness of stigma is very important in the context of supporting carers from black and minority ethnic communities *"It's really difficult for them [carers in some communities] to acknowledge that they are carers because of the cultural issues around caring duties as a family member...some of the communities are so close knit that they think that if they declare themselves as carers, they might be labelled by other community members or extended families that are around as not doing a good job."*

"One of the challenges that we can see from working with carers is that people from different cultural backgrounds, they often don't identify themselves as carers... I think it's the same caring for parents or siblings, husband or wife. It's simply seen as a family duty...and because they don't see themselves as carers, then they often don't know about the support and the services or any financial help that's available there. That means they could miss out lots of resources that could make their caring grow easier and maybe reduce some stress as well."

"...if you're looking at saving carers from telling their story, which might be really overwhelming for them, if we can save that, I think that would make their life much easier because it has already taken a lot for them [carers from black and minority ethnic communities] to come out from that

zone and acknowledge that they're an unpaid carer. They're coming out to seek some support in spite of everything else that is going on."

5.10 Be sure if you ask if I'm a carer, you know what to do next...

Carers made the point several times that if a professional asks if someone is a carer, then they know what to do next if the answer is "*yes I am*" or "maybe" or " *I'm not sure*." It was frustrating and disappointing that having taken the step of identifying themselves as a carer to professionals, that the next step didn't happen, and nothing changed for them *"My ideal answer...do you know there's local carer support if you want it... and being able to have that..."*

5.11 Most carers are happy for their GP, carers support organisation or the council to share information with each other as long as they can trust that its being safely and securely handled

Most carers in our focus groups discussions were supportive of sharing their information with others in the local system, but only if they were clear why the information was being shared, who with, how it was being safely and securely handled, and crucially, what the benefit to them would be, Carers felt that anything which reduced the number of times they had to tell their stories or 'prove' they were a carer had to be a good thing.

No-one however wanted a 'tick-box exercise' by professionals which left them no better off for having registered as a carer. There was some concern about the implications of this information were to be shared with the private sector (cold calling etc) , but overall, the feeling was it would significantly reduce the burden on them to repeat their stories multiple times to different professionals.

One suggestion welcomed, and strongly supported by carers in the group, was *"I wondered if there was a model of having a central register that carers could agree, right, it'd be useful for me to be in that system, and I know that my data will be shared with relevant bodies".*

Some carers did worry about how information about who is a carer would be used, and what asking for help might mean for the person they support *"Do you want your information shared? No. Why? Because there's a real, genuine lack of trust."* This issue of trust was a common theme throughout discussions and where carers had had a negative experience after sharing their personal information, they were much less likely to trust the system again *"It's hard to think positively- it's hard to seek help then the door is shut -hope is worse and then you don't get it [help]*." One person said that *I would return home despondent and then months would go by until I had the energy to repeat the process to see the doctor again, only with the same repeating result!*

Trust was certainly an issue for parent-carers *"[Trust] that is such a huge, huge issue and I'm just referring back to the notes that I made from [other carers] one person said, 'will the Council inform HMRC if that I'm a carer?...there's a real lack of trust."*

"I think... building some trust based on respect, mutual respect, would go some way towards people feeling more comfortable doing something that would be beneficial to them [and] would

improve the outcomes for the carer and the cared for. But I do think because of this lack of trust that it's a barrier."

Trust is also a consideration when trying to reach carers from black and minority ethnic communities *"[Using local] group representatives the carer usually knows and trusts...makes it easier for us to start the conversation. The group rep can also help with interpreting and ensuring the cultural sensitivity so the carer feels more comfortable and understood. We use that way and we found it just 100% helping."* Its important to be really clear what information is needed and why, and who it will be shared with "*We work with diverse communities, and each one of them would have a different concern about sharing their data ...a recent example was the alarms we distributed.. one of my colleagues was filling up the form with the unpaid carer with interpretation involved ... the unpaid carer didn't want to share their phone number because he wasn't sure about it... navigating through the support systems that are available around us can be a bit overwhelming for a carer to come out and seek that support. "*

"Refugees...are the hardest group to explain the role of a carer to...they don't call themselves carers so they will never consider that they [could] have that support. Refugees feel scared as well...They don't want to share their identity for legal reasons or for some, for safety, or for some experience that they had in in the past...there are concerns around their immigration status sometimes or if they're accessing certain benefits...if they're already struggling financially... then that's kind of an added barrier for them whether to come forward to look for any financial support as a carer."

5.12 'Signposting' carers to other support isn't always helpful, especially when multiple professionals signpost to the same support

Professionals frequently talk about signposting carers to sources of support, advice or information about caring however for some carers, what they want is practical help tailored to their particular needs and circumstances "*I've got booklets coming out of my ears! What I want is a solution or coping strategy."* For some, this signposting was synonymous with simply being passed around the system *"They're all very good at signposting you somewhere else, but it's getting somebody to actually do something. They're all good at saying 'What would you like me to do?' But you know, all it ends up being is 'I'll refer you somewhere else'...They don't actually do anything. So yeah, that's my particular grief."* For others, endless form filling in order to secure a small amount of help was daunting and off-putting *"We are on our knees; I can't face pages of silly questions to get a tiny bit of money."* This was also a challenge for carers from black and minority ethnic communities *"[One carer] was seeking some support for her child and at the end she was given a 30 page form to fill in and she just gave up at that moment... it was emotionally overwhelming for her."*

5.13 Not all carers feel they deserve help

Carers were acutely aware that resources in social care, general practice and the NHS generally were stretched and this impacted on whether they felt they were "worthy" of support when others may be struggling much more than them. One carer said they felt they had 'imposter syndrome' and that they weren't really a 'legitimate' carer *"I think for me at one point it was a bit of, there are other people that are in a lot more difficult situation than me, that I don't have the right to look for support* *or ask for support*." Many carers in our focus groups had only found help when at crisis point, when earlier support may have helped reduce the chances of a crisis occurring.

" ...if we're being told day in, day out that resources are stretched, stretching point, then you do think, oh, yes, like you say, maybe there are more deserving cases, and resources are so stretched that I shouldn't be taking up another person's spot."

"*When they're going into a care home or a nursing home, that's a very strong feeling that you get then, that even though you're still going and you're doing your bit and all that sort of stuff, you're a different sort of carer to ones that are keeping people at home*."

6.The experience of parent-carers

6.1 These experiences have been included as a separate section of the report as overall, parent-carers were much more likely to report consistently bad experiences of trying to get help from the care and health system over the lifetime of the young person they were supporting, in some cases over many decades. Parent-carers face particular challenges during the transition between children's and adult health and care services. As a result of these experiences, they were much less likely to trust professionals with their information and that of their loved one. They felt that in battling to get support they were often labelled as awkward and difficult and that they were not respected or valued.

Parent-carers said that generally they hadn't seen themselves as a carer, and it was often other people who had identified them as such *"I think for me it was more other people telling me, you know, when I've got other responsibilities and I'm saying, no, I don't know, I'm managing it all and it's, well, you are a full-time carer as well. So, it took a few people telling me that to actually think, Oh yes, I am, you know*."

"*I think when you're a parent it is difficult because when do you stop being a parent and start being a full-time carer?*"

6.2 Parent-carers can also often become what's known as "sandwich carers"-caring for both dependent children and young people and adult relatives "*Especially when you've got elderly parents and you're doing things for them... and then my daughter said, but you're a full-time caring mum already without those*."

6.3 Parent-carers were concerned about sharing personal information about the person they support with professionals, and this can limit them getting support themselves *"I think for me it was the worry of me sharing any information that could offend her [the cared-for person]. So, me asking for help through schools or whatever would highlight the issues that she was having and I felt like I had to protect her, so I didn't... I didn't ask for help or was worried about sort of sharing my concerns or going to children's services or wherever because of being sensitive to her needs and protecting her."*

6.4 Parent-carers were wary about sharing their personal information beyond their GP and had concerns about their privacy *"I mean sharing it with the GP was quite normal. I don't have any problems with the GP, but you have to share it with so many people anyway to get support. So, such as data centres and respite and everything else. Social services seem to want to know everything all about you."*

"Also, of course, we're getting all the benefits for [name of cared for person]. So, I think there's a lot of people out there who know an awful lot about us, and I don't know who to share it with. You know, I don't know how private it is."

"...if it's a need-to-know basis, then you know... when we go into hospital, obviously they need to know all the information. I just think sometimes it's out there and you don't know who else is reading it."

6.5 There was a strong consensus in this group that support from children's and adult social care, both for them, and their young person, had been lacking. Those with children who'd been in special schools felt they'd been supported, but children in mainstream schooling, and their families, had been offered no additional support "*I know a family as well whose son is not severely autistic, but he's probably having problems coping. But because he went to a mainstream school, he never had a named social worker. So I really feel that family doesn't [get any help].*" Most carers seem to have got their information, advice and support from other parent-carers but felt that many in similar circumstances to them are unknown to services "*I just don't think the support's there. They don't know who needs to know or why they need to know. Yeah, so I do think there's a quite a large population of people who are carers and aren't recognised.*"

6.6 Parent-carers didn't feel that their role as a carer was recognised or valued by the health and care system "*I think I was just seen more as a visitor [at the hospital].*"

"*Yeah, we are flagged at the GP surgery as carers, but I do have to still tell them that it's flagged. The only person really in medical that are really interested in our lives, as well as my daughter's, is her consultant ...He always asks about do we get respite breaks, etcetera, etcetera. And so that's good that the new consultant is interested and asks us, as well as my daughter.*"

"*My son's doctor, he's very much aware that, you know, as carers, you're the one who's going to have to put up his behaviour... So, he seems more aware of the impact it'll have on us. I mean, my GP just couldn't give a toss, but I just don't go and see him if I don't, unless I really, really have to...*"

Even where carers were identified in GP records, the feeling was that notes were not read in any case "*I don't think like with GPs and consultants, they don't actually read what's gone on before unless you tell them to read it and go through it and then they will look back at it. The same with social services really, unless you tell them they need to look back at.*"

6.7 Where social care did get involved, it was felt to be intrusive, judgemental, and even threatening "*We were told were told, when [child's name] got to 16, you're really going to need to* *get a social worker when she leaves school, you know you're going to need some help. And at that point, when we got in touch with social services, I found it very intrusive...they came to the house. They actually asked to look round the house. It was almost like they were checking. Yeah, they wanted to look in [child's name] bedroom. They looked round all of my house... I don't know what they were checking, but still. After they left, I literally burst out into tears. It was awful. It was a horrible experience... I didn't know what to expect, but I didn't realise that they would be that."*

"And there was one particular letter that he sent which actually said if you're not- because she was in adult services at that point- if you're not coping, then we'll look into supported living for you. And it was almost a threat of well...If you're not coping, we'll take her off you then. And then that instantly stopped us from asking for any further help at all because I was terrified that they were going to come and take her off me because I couldn't cope. You know, they were almost saying, well, if you can't cope. But I think the culture is changing. I mean, we've had some nicer social workers after that."

6.8 Parent-carers who wanted to combine work with caring found little support, with one person who had sought respite care being told that her job was her 'respite' break from caring
"*Yeah, working and my respite, I got told that... you go to work and that's your respite... well, I've got to work to support my family, but it was another cop out from social services.*"

6.9 Parent-carers of young people moving into adulthood frequently found their cases closed, with no social work support or account taken of their continuing rights to support as a carer of another adult "*If we need anything, even if it's something to do with, you know, respite or anything like that, we just have to go to the duty [officer]. And I said, but we'll have somebody who doesn't know [name of young person], you know, we'll have to go through all the history of it again.*"

6.10 Parent-carers had low levels of trust and confidence in how their information was handled by the council, and how it was used. Much of this arose from previous bad experiences, feeling they were not respected, and refusals to share information held on them and the person they supported by the council.
"*They [the council] probably talk amongst themselves [about us] ... And I think they do share between themselves....Oh, I bet they do.*"

"*You don't know where [your information] it's going or who it's going to and why.*"

"*Who are they sharing it with and what's the reasoning? You know, we've had so much, not lies... but you know, how do we know that they're not deceiving us again?"*

"Yeah, yeah. And I don't think they treated us with respect anyway, but no respect coming our way from [the council]...I just think there wasn't any respect."

"*I think if they were sharing my information, I'd be really dubious and I'm just not trusting them as to why they were doing it, because that's how they've made me feel the past few [years].*"

“Something else as well. I mean, I know all our information is on, is it Mosaic? It's called and I once asked if we could see what information they've got on us as a family of [name of young person] and me and [name of person] and it was like, no.”

“Why? Why can't we see what they've got about us? I don't know. I'd like to know.”

“It's how you access it. I'm sure it must have been [person’s name]. I'm going back a while and said can we access and see what they've got information wise? And it was almost like, no, probably not. So I don't know. I might try that again.”

“There is a system SARS [subject access request] request you can put in. I think I've forgotten what it stands for. I know is it subject access request where you can request your own information but it has to be redacted if you can identify another person in it. But you can ask for that from any services because we we've had them in the past.”

“I think with [the council] I'd be worried that the actual information that they held wasn't correct anyway, because let's face it, the information that they throw out is not real or correct. So why would it be correct for us?”

“There's many time I think, oh, I wonder if that's gone down on the records as something slightly different.”

“Yeah, I think the council have also shown as well that they twist the data as well. So you know, it might be accurate, but how do they use it? Do you know what I mean?”

7. Carers suggestions for action by the local system

Things which carers would like to see happening:

- More initiatives around a 'Think Carer' approach such as work with Fire and Rescue Service and Housing Associations who go into settings where there may be vulnerable adults with carers who might not be known to the care and health system.
- More creative approaches to reaching carers who wouldn't necessarily talk to their GP or social care through activities such as shopping, going to a pharmacy, or hospital.
- Be more joined-up-we don't want the same information/leaflets multiple times.
- Much more investment in preventative support for carers.
- A carers register shared between health, social care and the voluntary sector, with clear benefits for joining this register, and which reduces the need to repeat stories.
- A consistent, pro-active approach by professionals and front-line staff such as reception or call centre staff to identifying carers, and who have knowledge about what the next step is when they do identify a carer.
- Clarity and consistency about what the right language to use is, what being a carer means, and how and when to get help, without feeling judgements will be made .
- Widening communications and marketing to reach carers who won't see themselves as a carer but who could benefit from support.
- Avoiding jargon, explaining terminology, and not hiding risk aversion behind issues of consent, confidentiality and GDPR which makes carers lives more difficult.
- Professionals recognising that people are not "just a carer" and have other identities which are equally important such as partner, spouse, parent, child, employee.
- People with expertise in carers & caring in each GP surgery as standard – a more universal approach & better signposting to sources of support.
- Primary Care Networks need to take the lead on ensuring GPs are consistently identifying and registering carers, and can spot the signs of carer stress and burnout.
- Specialist expertise in supporting carers helping people living with specific conditions such as mental health problems and younger age or working carers; carers are not a homogenous group.
- If asked to share information, please be clear what is being shared and who with to protect individual privacy.
- The 'use cases' of carer information should be much more explicit-this needs set out when carers are asked to share their information. Understanding uses and benefits is key to consent.
- Please don't put on 'carer consultation' events in health and care but still don't listen…a year passes and then asking the same questions again…
- Think about support for carers whose loved one may be in care, but still needs support, or who lives in another area; carers said they were unable to register with their GP if their loved one lived elsewhere or access other forms of local support.

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