

The Invisibilities of Social Care: perspectives from unpaid carers

Episode transcript (automated)

This episode of the Care Matters podcast is dedicated to Katie Mountcastle 1967, 2002. A much loved and missed daughter, sister and friend.

The Care Matters podcast is brought to you by the ESRC Centre for Care and CIRCLE, the Centre for International Research on Care, Labour and Equalities. In this series, our researchers welcome experts in the field and those giving or receiving care to discuss crucial issues in social care, as we collectively attempt to make a positive difference to how care is experienced and provided.

Rachael Black

Hi and welcome to this episode of the Care Matters podcast. My name is Rachel Black and I am the impact specialist at the Centre for Care. And I'm joined today by Chris and Liz. We're going to be talking about this notion and idea that adult social care is hidden or invisible as a sector. And then within that the work and the role of unpaid carers is also visible and people are unaware of the work that happens. So as I say, I'm joined by Chris and Liz. Chris is an unpaid carer. He's also the trustee of Sheffield, Mencap and Gateway and Nomad opening doors and he sits on the expert panel of Sheffield Carers Centre. Liz is an unpaid carer and she sits on the Equality Objectives Panel and the Carers Expert Panel at Sheffield carers centre. Thank you both so much for joining me today.

This idea that adult social care is invisible has been explored in in lots of different ways and across lots of different kind of and means. But some recent examples are the House of Lords adult social care committee enquiry that they entitled Lifting the Veil, where they explored the impact of the invisibility of social care on people in receipt of care and support and the people who care for them. And this year's Carers Week theme was making caring, invisible, valued and supported. So again, exploring this idea that the and the efforts and the actions of unpaid carers are largely invisible and hidden.

So I'm going to turn to you now. And my first question is in two parts, really, it's do you do you agree this idea that adult social care and that the work and the efforts of unpaid carers are invisible and why you think that might be?

Chris

I certainly agree. There are a number of reasons. Social care doesn't have a good name in the population like the NHS. Everybody uses the NHS, but only people really need social care. Social care. So a large proportion of the population don't use social care. Some people can't even see why it's there in the first place. The government doesn't recognise social care because it's never been properly funded. And still isn't. And even with COVID, social care wasn't looked at, especially for people with learning disability, because they weren't on the priority list for vaccinations and neither were unpaid carers until they was brought to the Government's attention. But it should have been with the Government's attention because they get all the health and social care department does through the Leader programme that was run through Bristol University, which is looking at the low mortality of deaths with people with learning disability.

So the evidence is there. It's just that they're not bothering to look at it.

Liz

Yeah, I agree with Chris. Recently, Sheffield City Council produce a prototype of the carers delivery plan which says that each carer saves the economy 19,336 per annum. I think that that's an underestimate because if you think about how much it would cost a government or a local authority if there weren't unpaid carers I think were hidden because like Chris says, it would highlight the broken elements in society. We're not attractive, we don't make good looks, good news stories and it's not a good look for any government. Societies failing those people that are vital to shore up a system that can't fully deliver what is necessary because it would require being proactive instead of reactive, and that being proactive would again highlight something that is brushed under the carpet now. And the increase in delivery would be complicated to deliver and very expensive to do properly. So yeah, I think we all do. And I think we might. Yeah, we are ignored. Yes, I would say so.

Rachael Black

I think just a number of reasons why that might be in your absence. And I'm going to go pick some of those out and go back to what Chris said at the start, the idea of a bad press so that people don't really want to think about needing care and support. So and I look at what I do and the things with that is that and you both used to invest in press and good news stories is that there's a sort of stigma or a worry attached to it, because we hear we hear some of the negatives. And I just wondered what you thought about could that be changed or do we need to keep telling those kind of more negative stories to try and enact change?

Chris

And it depends on the negative stories are put forward is put forward in a way that is detrimental to the person or social care. Then no. If it's put forward as a way to improve social care, then yes. But it all depends what makes a good story and negativity makes a good story rather than positivity.

Rachael Black

Yeah. Yeah. And there's a genuine concern that people have about letting social care into their lives in some ways, and that they will then lose control of that situation and that they're part of a big machine.

Liz

Yeah, something just flashed in my mind as you were talking about being a carer and about news around being a carer. You could, you could very easily produce good little stories or interesting stories about being a carer. I think there's a problem about being a carer. I know that Sheffield Carers Centre have great difficulty getting people to identify themselves as carers, so that might be part of the issue and that it's something that people shy away from, people shy away from admitting or actually accepting that that's what they're doing. For me it's about. I'm sure. I'm sure with clever marketing this could be made into. Look at what's happening in our society rather like during COVID. The good neighbourliness that was identified. It could very easily be turned around to say, look at what the people of the UK are doing unbeknown to us.

Rachael Black

Yes. And actually so hailed as the kind of community and societal sort of spirits of look, look what we have the capacity to do as well. We're doing this on top of other commitments, working with other children or grandchildren.

Chris

Another area that could be looked at is the importance of social care to the NHS. Yes. Because lack of social care. Brings more questions to the NHS because if it's not looked at as a proactive situation, then it gets into a more serious situation. The NHS picks up the tab.

Liz

Absolutely. Absolutely

Chris

And know and also. Bed blocking: if there's no social care, You've got the ambulances waiting outside. You can't get in because there's no beds for them to go to. And that could well be because the patients that are ready for discharge can't be discharged to their own devices. They need help with social care and it's not there to be available for. So it's catch 22

Rachael Black

Yes. Yes, it is. So we sometimes think of these things as two different systems actually. So intertwined aren't they. That. So they need to be funding and supporting each other really

Chris

Integration of the both services should be a major priority.

Rachael Black

Yeah, absolutely. Thank you for that. And this sort of idea of people not recognising themselves as carers or not wanting to, because that sort of sets the wheels in motion that they may not feel that they want to do. There's been a lot of discussions about whose role is it to support people, to recognise that they are a carer is there and increasingly it's GP's. Well people would say that they would get to speak to a GP. So do you have any thoughts about where the support might be to enable somebody to recognise that they are carer or I suppose to reassure somebody who thinks they are but doesn't want to take that next step really.

Chris

I mean, they know they're caring but you're caring most likely for a relative. Well, it's saying that. Parents look after children and from the birth to the grave. And that's what a family does. It's not that it's looked at as something separate.

Liz

Yeah. I mean, it is interesting, isn't it? Because there are times when I'm talking to people about my caring role. And some people get it and say, You've got this forever. Whereas, you know, most people, by the time they're children are late teens, early twenties, are thinking, a lot of my duties are now over. A lot of my full time duties are definitely over, even if I have to start looking after grandchildren. But going back to the identification of carers, I've noticed in my own GP surgery, which is an excellent surgery, the notice about being a carer is very vague and the poster itself is very small.

Recently went up to another green surgery with Gabrielle for some physiotherapy and the carers notice that is the one from the Sheffield Carers Centre and is the first thing you see as you walk in

the door. So it's interesting how some practise will take it far more seriously than others and both of them are in an area where I'm sure there will be many carers, especially of older people.

Rachael Black

Yes, I mean that's the other thing I think where people get muddled by care or don't quite understand what it is because when you think of single, you maybe think of care homes or you think of older people and your experience is that you've cared for somebody throughout their whole adult life. So and if you have your social care feels very visible because you've been in it for a long time. Be about because there are people who will never have complexity until they're caring for an elderly relative maybe or somebody in later life. So I think there's also this maybe awareness of where social care comes into in somebody's life that may make something else think about until it happens. Yeah.

Chris

Yeah. I mean, with GP practises, this is part of health that virtually everybody comes into contact with at least once in their life. But there again, they're having a lot of pressure again on the funded really. Does the GP have the time to do that work? And most people possibly see a receptionist more than a GP or speak to a receptionist more than the GP. And there is some work in Sheffield which is a follow on project for some work that was done in Sunderland, I think, whereby some forms have been produced to make it clear to a receptionist what we need to be looking out for.

And some point is when they do find a carer, what to do, where to signpost, etc. There's a lot of in the out of St Luke's on the project to.

Rachael Black

Write about ID carers. But I think you right. I think probably the health sort of space of GP surgeries where I see somebody maybe for a few weeks will spot the signs and think, gosh, this person's progress in several point was not well, they are a carer and therefore can reserve signpost some support won't be that clear and this is quite a lot around signposting. Isn't that pointing people in the right direction? But some of the difficulties, that's the way it falls to the unpaid character card. Making all those different contacts as well is that it is not always or there's rarely, if ever I can take, would make someone

Liz

who's going to say just what I was going to say and what is he talking? Just said this so very well having the GP or the GP's receptionist being able to identify it. Many of those surgeries are overworked as is the NHS is overworked. What really needs to be, isn't there? Is that a sort of middle person who's an advocate or a broker who simply helps that person is who has been identified to know where to access. So it's all very well having the signposting on the website, but you have to know how to use whether that that signposting exists in the first instance. So it's, it's a role which would actually, as Chris said earlier, about being proactive, rather than reactive is a role that might actually save money in the long run because you're not going through the hoops that you would normally go through because you've got somebody who's not exactly fast tracking you but is certainly pointing you in the right direction and in much more efficient manner.

Rachael Black

Absolutely. Yeah. I think the idea of being proactive and reactive was really interesting. And I think you're right, it's not it's not a system with maybe some pockets of good practise overall is not

people's experiences. Is that suppose to them that they are the person to navigate what is a really complicated system.

Chris

which is really complicated because we're looking at the invisibility, we looking at generally the invisibility of adult carers, but we shouldn't forget that there's a fair proportion of young carers under the age of 16. They need to be concentrating on their education so that they can be a productive adult in later life. But in the family, they could be looking after vulnerable parents or vulnerable siblings. So therefore, it's not just GPs. It's the Education Department of Teachers that need to be on the lookout where a child doesn't seem to be doing as well as they expected. Is it that they doing care responsibilities? Because the first thing the family will look at is if we make this public, our children are going to be taken away from us. And so there's that there's a lot of fear bringing social care into any aspect of family life.

Rachael Black

Yes, I think that's a really important point, is this is that fear is at this point now lost control of this control going to somebody else's hands. And what could that mean for me and my family and the people I love?

Chris

Because it's placed on many occasions, it's been done by parents thinking that the best thing to bring social care and the next thing the children of God, awful, that's a thing of the past. But you can never be sure.

Rachael Black

That it's a definite fear in people's minds isn't it? Thank you that's been a really interesting it's not there's not just the one reasons there's not as much goes individual because of X it's multi-layered and there's lots of different reasons why opt for people's own reluctance to engage to then you know all the services themselves making people aware what they're entitled to what they're able to access, only making it easier straight for people in the same that a lot of time. No it's not you know are people are able to navigate all those different things to get where they need. And this idea of a kind of advocate. And I think there are you know, we talked about Sheffield Carers Centre and there are other charities or community organisations that do that don't they but I think often that very overwhelmed or not getting the funding they need to be able to make this.

Liz

They find it difficult to identify at GP level for example. So you know you're not I don't know, I'm sure it could, I'm sure it could be improved and I'm sure that the Carers Centre would want to know. But it's not very visible, it's not very, it's not very easy, it still seems a very ad hoc system. Yes. Yeah. I mean you're either lucky or you're unlucky in accessing it.

Rachael Black

Yeah, I think so. I think, Chris, you're saying that about integration of us. You know, it's not only integrating those to health and social care, but social care itself is an integration. It's lots of little bits of services.

Chris

It's also better integration within one organisation. These departments don't speak to each other.

Rachael Black

When we were collating evidence for that House of Lords inquiry we talked to other carers and there's this notion of being lucky, did you manage to speak to the right person and also the support would be temporary as well is that things can be in place and working for now. Could a change of government, could a change of system, could it not be civil again? And actually what you mean is working is changes. And so I think this idea of things being based on good luck rather than a and a widely accessible, equally available system, is it as well when.

Chris

There's a situation occurs where the police are brought in or safeguarding, brought in, it's normally a breakdown of social care and everybody saying, well, why didn't people recognise this? Why didn't they speak to each other? And they have these multi-agency reviews so they all get together and discuss it. Then you get the dreaded phrase at the end, lessons will be learnt. Well, it looks as though these lessons are being learnt. Is it because nobody wants to learn? Is there no money to learn? If they don't start learning, then it's going to continue.

Rachael Black

Absolutely. And the gap between those, there's a feeling that the lessons have been learnt, so they've been learnt often the hard way, but they've not been. But the learning from these has not been put into practice. And I think that sense of frustration is it feels like these conversations that we're having aren't new conversations, but we're not seeing the changes that.

Chris

We're coming up with much more regularity these days for a number of reasons, and if social care was more prominent, then possibly wouldn't be the case or that it was just more.

Rachael Black

Yes. So in terms of impact, I think we've touched on this in some ways in that there's the sort of role that you have of trying to pull together lots and lots of services. Which is an effort in itself. Isn't everything being spent? A lot of people in email and the kind of lack of responsiveness so that if you are going to approach service because somethings changing or a situation has arisen. Are you going to get the help you need or is this going to be a very long process? So just think about kind of what the impact on you as far as unpaid carers Is there anything that we've not covered that you would say is kind of it comes out of this invisibility or this lack of.

Chris

Just the general health of it an unpaid carer. Because it is stressful. It's stressful that you're looking after somebody for years on end. You really want to do it. And by doing so, your health suffers. And really that's even a bigger aspect to the to the NHS as well. If social care was is there and it wasn't as invisible as it is, people's health will improve.

Liz

I have a phrase that I use for my mood at times, and I don't know whether I would still have this syndrome that I get if I hadn't if I wasn't a carer. And it's called a state of suffering at the moment, some of the low level despair. And what it means is that it's there waiting all the time that I might get frustrated. I am getting increasingly weary about my role, and that is because I am getting older.

And but it always feels that there's something sitting on your shoulder waiting to happen or happening or that you're dealing with. And that's what I feel about, I suppose, the invisibility of a carer. I could be in a supermarket by myself and no one would know that I was an unpaid carer. But I know it.

I'd have to go back to 1976 and not have my child and then work out whether I was still the sort of person who would suffer from low level despair.

Rachael Black

Yes, but I think you could be in the supermarket when no one knows you're a carer. But you know that you've got that phone call to a particular service to make or you wait for an email from or you've got a review coming up in a couple of days. I think that's the thought that comes to constantly, always delivering your grade

Liz

and this idea of being in a meeting. I mean, I go to Zumba class on a Wednesday and I have to explain I it didn't more, but I had to explain in the beginning that my phone would be left on everybody else. It might not top everybody else.

I've got their phone on. I don't know that that carers, but my phone is on in case wherever Gabriel is somebody telephones to say she's just had a fit or she's had a fall or something like that, can you fetch her?

Chris

It's not going away either. It's generally being recognised for quite a number of years now. In Sheffield there are around 60,000 unpaid carers every year. About 20,000 disappear, another 20,000 come on. And since COVID is viewed that 60,000 is now increased to 90,000.

Rachael Black

And also, I think the amount of caring that people are doing, it's become much more intense where it may be a few hours in a week. It's now kind of more regular daily. Yes. Because other things haven't opened back up again. Some of the support that the groups that people have relied on a lot still not happening because of COVID.

Chris

Well, there's now Long COVID but people are living longer as well. So that means more complex health issues are come forward. People with learning disabilities, even though they are generally viewed as their early deaths of 20% below normal deaths, they are actually living longer as well. So the complexities with disabilities are going to be here much longer. And because of the nature of the disabilities, it means that the health and needs more care than it was previously under a longer period of time.

Rachael Black

Yet at the same time it's their carers that need some support Yeah. Yes. So we've talked about why social care is invisible, by the way, of the efforts in the what over years do is invisible. We talk about what that means to you. So what would we you know, if we could wave a magic wand, what would we like to see and doing differently? What do we think needs to change?

That is what I put right at the end of my. Yeah. So where would that money be kind of going? What would you like to see? Investment?

Chris

It's a number of there's a lack of social workers because of the burdens they've got, because there's a lack there's more pressure on the ones that's left a lot of councils are having to use agency social workers which are much more costly. So that's the professional area.

But in social care, when a family carer can't cope as long as it would like to. They've got to pay carers and this is a real deficit of paid carers as well. Yes, the money they get is round about the National Living Wage or they could be paid the real living wage. But currently it's not much difference in national, £9.50 in the real living wage as £9.90 So there's only about a 40p difference, which wasn't generally the case. It would be much, much lower what you get. But even that doesn't compare to what people could earn or the low generally low paid professions. Perhaps much less responsibility.

Rachael Black

Right. Is as well. Well, what people are doing compared to what they're being paid just doesn't add up

Liz

And I think what's interesting about this is, isn't it? It's just those figures that you've quoted and the fact that it is a low paid occupation and therefore it's a low status occupation, when in fact it ought to be a highly valued occupation and the recompense should equal that. But it won't. And I don't think it ever will. So what you've got to do is remarket it, if you like, keep using this idea of marketing. But my whole thing is when you said, What could we change? I think the first thing that has to be done is that we have to have a media campaign. There are lots of programmes out there about people with disabilities. I tend not to watch them because I find them deeply disturbing, but there's very little made in those programmes about the people who support the people with disabilities.

They are hidden people going back to the ethos of this of this podcast and it's what we value and what's out there and promoted as a service is not valued. The social workers are. Bombarded by people like us saying this is not good enough and they know it's not good enough.

So it's a broken system. It needs money, but it also needs awareness. It needs a media campaign with an explanation of what being a carer means to many different types of carers. And why aren't we identified, why aren't we recognised?

Why aren't we supported? And I think that's almost a philosophical question. But. Practically it is about money. And I don't know how this government or any subsequent government is going to find the will. To support us financially? Yes. Support the Support services financially. Yeah. I don't have great optimism because we go back to the original things. It's not very interesting. It's not very exciting. It's not like, giving you £400 off your energy bill.

Rachael Black

Yeah. It's not a quick win, is it? A lot of it needs to be unpicked and fixed and it's not going to be done. we don't have the magic wand, the way to do it overnight.

Chris

And it's not just a media campaign for the population. It should be a media campaign for government because sometime this year, one government minister said that to help social care,

families should do more. Quite frankly, that person is not living in the real world now because families are doing all they can and much more.

At the last count. In the U.K. unpaid carers saving the UK 139 billion a year. And when you have a needs assessment for a person unpaid care is not costed. I believe it's not costed because it would actually show that it is a much larger figure than social care can provide.

Liz

I was also wondering whether there could be some link to the Equality Act, the Equality Act that is now an umbrella term for all sorts of different inequalities. But this isn't an equality. Yes. And to make to put some sort of legality onto it.

Rachael Black

Yes, I think it's something that carers UK have discussed. I don't know. They do maybe a little bit here protected characteristics. And that means that you would be and you would have the right to certain protections through your employer through your health care things. But yeah, I think you're right. I think it's a notion that be sort of explore and again would increase that visibility because it would it would give people some legal protections that would recognise the role and the ways in which that impacts on people. And that will mean people have more health inequalities, less access to employment because people have to leave work. So yeah, I think there is discussions around that and it is one such way of, of raising the profile of protection. That is to.

Chris

Some extent this was done with the Care Act 2014 that within the act it was put down not as a must but as a recommendation. Yeah. The first thing the government did when COVID came was to dilute the Care Act so that the responsibilities of councils, if they so wished, they could apply for some of the responsibilities to be temporary alongside. Not many councils did. Sheffield certainly didn't. The. My guess was that it was the first thing the government did. We really the first thing the government should have been doing is provide more money.

Rachael Black

Yes. Yeah. And I think the Care Act does cover some of the things we've been talking about, as with the lessons learnt, we've not really seen interaction that way and I think that's the frustration.

Chris

To get councils to do to abide by the Care Act, you've got to take legal action. Another aspect is that legal aid is being drastically reduced in, you know, whether that was in. Implicitly to safeguard people, not to be legal. Action on the government is as I guess it's a costly process, it's a lengthy process. And really, unless a carer get another organisation to fund them, they're not going to tell people what to do. So it's as though everybody is against an unpaid carer and people with care needs

Rachael Black

So I think I mean, I think what we're saying is that there is a long way to go, but there's a lot to be done. And funding would be certainly vital in that process in terms of funding. People in various poses, social workers, care workers, and also not just funding more co-workers, but that that being your valued occupation, that is reflected in the salary that people get, but also the sort of public esteem we saw the clap for the NHS during COVID and it felt like carers was bought in at the last

minute but actually wasn't fully part of that discussion as well. So this invisibility impacts on not only the kind of support we get, but how as a sector, its values. And I think that.

Chris

What I'm talking about to finance also the carer's allowance is mentioned that the people really know what the carers allowances the it's not an it is not an allowance for caring it's an allowance to supplement people's income by not being able to work as much so.

Liz

And the minute you get the state pension, it's taken away. Again.

Chris

You still have to make a declaration that you have it, but in reality, you're won't because technically on a state pension. You lose an income. Yeah, but you're still caring It's not a payment for caring No, it's a payment for loss of income.

Liz

I'm just realising sitting here and it is an aside and it's very subjective. I worked here at this university for 28 years and to protect my health and sanity, I took retirement at the age of 58 and worked it out and there was an offer at the time. But that's seven years of pension contributions by me and the university that I lost out on, isn't it? Yes. In order to be a full time carer. Yeah. Because I could no longer hold down a very responsible job and juggle all the balls and that perhaps

Just like when you retire through ill health and you get your full pension. That's the sort of area that should be protected by law. Yes. Because you're leaving for a specific Purpose to do a specific task.

Rachael Black

Absolutely. And the impact of needing to leave work on pensions and then how well people's financial self stability in older age than it is I think is a huge factor as well. That means that people are making decisions during their working age. That has implications for their whole lives as well. And so, yes, that's I think something that and again probably isn't seen, you make that decision in the moment. Do you don't then think 20 years from now that's Less pension than I paid into.

Chris

Yeah, yeah. And if you're lucky to be able to get carer's allowance and do some work as well, it's not a non-taxable benefit. I'm not sure what the amount is, but I think it's less than 70.

Liz

Yeah, it's something like £68, something like that. Not that I've had it for years.

Chris

It's welcome if you can get it. But it's a certainly In the current climate, it doesn't really help that much.

Rachael Black

Yes. And also, like you says, it may not be maybe the awareness that they were talking through. If people aren't identifying as a carer or aren't seeking support still and then they would be missing out on a benefit. They even if it's not, it's not the way we'd like to see it. It could be helpful. They may not know.

Chris

I worked what the hourly rate was at one point was about five or six years ago and it worked out to be 1.92 an hour based on the minimum hours of 35 a week right.

Rachael Black

Now going to draw it to a close, I think because there's just so much that I think about has been so fascinating still through. But our discussions as we already kind of suspected that this is a huge, a multifaceted range of issues that that ultimately impact on carers and on the people that they care for.

So this is and unfortunately, there's not one, one feature that we can of see that there are a couple of key things that could happen in this funding act and an awareness and a see when the profile of adult social care isn't it but thank you so much Chris and there's still it goes it's been fascinating to hear your thoughts and experiences and certainly it was a lot to think about and maybe we didn't I maybe not much hope at the minute But if we were also saying similar things are pushing this forward, hopefully we'll start to see some changes.

But thank you so much for your time.

Chris

The good thing is that actions like this have taken place. Yes. Which is often beneficial.

Rachael Black

Yes. Hopefully in the end it was the same similar things to to make change. But thank you. Thank you for your time. Thank you.