HOUSE OF LORDS

Adult Social Care Committee

Corrected oral evidence: Adult social care

Thursday 7 April 2022

10.30 am

Watch the meeting

Members present: Baroness Andrews (The Chair); Baroness Barker; Lord Bradley; Baroness Campbell of Surbiton; The Lord Bishop of Carlisle; Lord Laming; Lord Polak; Baroness Shephard of Northwold; Baroness Warwick of Undercliffe.

Evidence Session No. 5 Virtual Proceeding Questions 46 - 54

Witnesses

I: Ian Loynes, CEO, SPECTRUM Centre for Independent Living; Kirsty Woodard, Founder and Director, Ageing Well Without Children.

Examination of witnesses

Ian Loynes and Kirsty Woodard.

Q46 **The Chair:** Good morning, colleagues, and welcome to the Adult Social Care Committee. This is our fifth oral evidence session and we have a few absences this morning. Lady Eaton, Lady Fraser, Lady Goudie and Lady Jolly sadly cannot be with us.

We were hoping to start this morning with a session with Sir Andrew Dilnot, but unfortunately that is not possible, so we go straight into our evidence session with two witnesses we are absolutely delighted to welcome. The first is Kirsty Woodard. Kirsty is the founder and director of Ageing Well Without Children. The second witness is Ian Loynes, who is the chief executive of SPECTRUM Centre for Independent Living. We know you are both extremely expert in your field, which is exactly why we want to hear what you have to say this morning.

As you know, this committee is exploring some of the ways in which adult social care, particularly compared with the familiarity we all have with the NHS, can be seen to be invisible, not just as a set of services or even a system, but particularly in terms of the people who are at the centre of it, either those who are drawing on the services or those who are providing unpaid care for those services.

We know that there is a lot of concern among both groups of people that they are often not listened to. We have heard already in our evidence that they are left out, and that the offers made to them through the services are not always appropriate or welcome. That is true if families are providing care, but of course they would rather stay as families than become, as it were, unpaid carers in the system. We have many different questions to ask you this morning about what people want and need, what they are ambitious for and on what assumptions we base our notion of adult social services for the future. That is where you come in, Kirsty, with the work you are doing, and Ian, with your ambitions for better models of providing care.

I start off this morning by asking both of you simply to tell us what you are aiming to do in your own work. In particular—this is particularly addressed to Kirsty, because we know so little about this—what do people who are ageing without children say to you about what they think their future is like or what, indeed, their present is like?

Kirsty Woodard: What people ageing without children mostly say to me is that they have a great fear for their future. That fear is rooted in a number of things. The first—this is a constant theme for people ageing without children—is their complete and utter invisibility. They are invisible in society, so they are invisible within adult social care, because adult social care is obviously part of society.

That came through particularly with Covid, with people saying that all the narrative about Covid and ageing has centred entirely on older people being separated from their grandchildren and families, with lots of things about people in care homes not being able to see their families or how to

get your granny on Zoom. They were like, "We were absolutely nowhere. We were not seen at all".

That leads to the biggest fear for people ageing without children. It is less about the provision of care, because the general perception among people ageing without children is that if it gets to the point where they are unable to manage personal care tasks, there is likely to be care available. The main thing they fear is a lack of advocacy, to have absolutely nobody to speak for them, particularly when they are unable to do so for themselves, and that they are unable to access all the low-level preventive support that prevents people falling into crisis in the first place.

For people ageing without children, if their care and support needs are quite low level, wider family networks might step in—cousins, neighbours, friends. But we know that the more people ageing without children see their care needs increase, the less likely they are to be able to access any kind of informal care. Therefore, they fall into the paid-for, formal care system much more quickly and are far more likely to end up in a care home. They are at least 25% more likely, but research from Australia suggests that it might be up to 50% more likely, to go into a care home, and at a younger age and a lower level of need, simply because there are no other options out there.

The Chair: That is a very graphic description. Can you give us some idea of the numbers?

Kirsty Woodard: One of the massive problems of ageing without children is a complete and utter lack of data. All that we record in this country is the numbers of women who do not give birth. We estimate that, of the numbers of women who have not given birth, there are around 1.2 million people aged over 65 at the moment. That will rise to 2 million by 2030. By 2040, I believe we are looking at a threefold rise in the numbers of people over 85 who do not have children. We are talking about an enormous number of people. Currently, around 4 million people aged over 50 do not have children.

The Chair: That is by 2050, you say.

Kirsty Woodard: No, currently there are.

The Chair: Yes, and they are living longer. That is very interesting. How do you collect data on men?

Kirsty Woodard: The data on men is not collected. We do not record if men do not become fathers. We only record if women do not become mothers. I should add that our definition of ageing without children does not just include people who have never become parents. When we talk about the numbers, we talk only about the numbers of people who have not become parents, because that is the only data we have.

The definition of ageing without children is wider than that. It also includes people who may have become estranged from their children. We

know that family estrangement is much more common nowadays, particularly in older men. We are talking about people whose children may have predeceased them. You may reach your 80s but your children have predeceased you. We are talking about people whose children may have care needs of their own. Therefore, not only may they not be able to support their parents, but their parents are also very concerned about what will happen to them. It is the whole range of people.

The Chair: What else do you know? Do you know anything about their housing patterns, for example? Do you know whether they are more likely to be owner occupiers and therefore to be able to stay in their own home, or do we have an increasing number of people in rented accommodation, for example?

Kirsty Woodard: We do not know. The lack of research is an ongoing problem. There is simply not the research in the UK. There is more research from the continent and in America, China and Japan. They have done a lot of work on this. It is primarily about looking at the reasons why we have more people ageing without children and the types of care they might need. When it comes to housing patterns, we do not know things like that.

In terms of some of the stereotypes about people ageing without children, we know that, generally speaking, women are more likely to be university educated, but the reverse is true for men. Men who are ageing without children, generally speaking, have a lower educational attainment and lower employment levels.

The Chair: That is fascinating. We may come back to you after this session with more questions as they occur to us about your own knowledge. My final question to you is a follow-up to what you said about invisibility. That, of course, is at the heart of what we are trying to get at. You said "invisible" in relation to advocacy, which I completely understand, as well as in the services.

Kirsty Woodard: When I go to talk to organisations about this, I find that there is always a penny-drop moment when people go, "But we work with loads of people like that. We work with loads of people in this situation, but we'd never joined the dots. We'd never envisaged them as a cohort of their own. We always see it as an individual thing". That is one of the real problems. It is not seen as a systemic issue, so every time it comes up in an organisation it is like it has come up for the first time, because there is no policy or process for dealing with it.

The Chair: We are in the same syndrome as a committee. Thanks to Lady Barker, this issue has been prompted, and thank goodness for it. It is an enormous implication for the service itself.

Baroness Barker: Kirsty, could you tell the committee the story of our colleague that made you start this work?

Kirsty Woodard: Of course, yes. It was Liz's and my colleague from Age UK. We were having a coffee and she was having a good old vent about the situation she was in, supporting her mother. Her mother had had a fall. Her mother was in her 90s and was in hospital. My colleague had been in hospital and had been doing the usual—up to the hospital two or three times a day to make sure that her mum was okay. She found that her mum was generally not okay. Lots of things were happening. She was not able to eat on her own, so food was being taken away uneaten. She was not able to get water. The call bell was not answered, so she could not get to the loo and all that sort of stuff. It was not because people were being deliberately neglectful, but because everybody is rushed off their feet. Diane was there to help take her mum to the loo, help her eat and all that sort of stuff.

Then when it came for her mother to be discharged, it was the usual thing of Diane phoning loads of people, talking to lots of people, filling out lots and lots of forms and all that sort of stuff. When her mother was discharged, the care package that was put in place was not adequate. A hoist was supposed to be supplied, but when it arrived it did not have all the component parts. When she phoned social care, they said, "We could get you the rest of it in about a week, or you can drive to the depot on the other side of the county and pick it up yourself". She dutifully drove and picked it up herself and brought it back.

Only one carer was in place, because that was meant to be enough to use the hoist. It was not, so Diane found that she was going there every morning to help get her mum out of bed. She was going there every night to make sure that her mum was okay. Inevitably, because the care package was not adequate and because Diane could not be there all the time, her mum fell again and so Diane was like, "This is a nightmare". At the end of it, she said, "God knows what she'd do if I wasn't here".

That was the massive lightbulb moment for me, as someone who cannot have children. It was like, "Exactly". What would have happened to her mum if she had not been there, and what will happen to people like me?

The Chair: Thank you very much, Kirsty. Thank you, Lady Barker, for prompting that story, which makes it absolutely true for us all. Ian, can you tell us about what you are trying to do maybe in the light of some of these assumptions and what you know to be the ambitions of people you work with?

Ian Loynes: We are helping disabled people of any age all the time. Some of them are older people, live a lifestyle of their choice, and have choice and control over how they choose to live their life, rather than how somebody else might choose their life to be led. That commonly gets associated with working-age disabled people. I do not think that is true. That is the case for anybody of any age.

At the moment, as Kirsty has said, people have very few rights in the sense of how their social care is provided. Very often, people find that their rights are denied them, or they do not have any rights at all. We are

helping to educate people about what rights they have, which are very few, what the provision is in their local area at the moment and how to make the best of how the system works.

The Chair: You have your own model for independent living. Could you say a bit more about what you think might be a way forward? It is the ideal way forward in a way, is it not?

Ian Loynes: Yes. People find it very useful to use a system that already exists called direct payments. That is supposed to be the default option in social care. In reality, it is not. That provides the individual with the money that their assessed care needs will cost to meet and then they can decide whether they employ their own personal assistants, use an agency or use some other provision.

Direct payments are a good way that many people of all ages choose in order to organise their own care needs to meet their complicated lives. I choose to work, so I organise my care needs around my work. That would not be possible if I was living in a care home or had home care. We use that a lot. More recently, there are various schemes, such as personal health budgets for people who have health needs. They are all around the notion that people receive the money and decide whom they will employ or what they will use to meet their particular needs, as they are on that day.

The Chair: Do you think that many people would choose to have a personal assistant, rather than a family carer, for example.

Ian Loynes: Yes, there is an education process involved. It is about helping people to understand that they have a choice. Some people choose to use family members or friends. That can be fine, but there is an old adage that you should not employ somebody you cannot sack, and you cannot sack your family, realistically. Clearly, not very many people growing up will have the same expectation of their lives that their parents have for them. If you want to live a life of your choice, rather than your parents' choice, the options come down to independent living and using direct payments or personal health budgets and those sorts of schemes to have the life that you want, rather than your parents' or your family's life.

The Chair: That is a very powerful way of putting it, actually. May I ask you the question I put to Kirsty about invisibility? Do you think we are on to something here: that people feel invisible, that it is a real issue?

Ian Loynes: I think so. Commonly, both government and the general public will see social services as something that deals with children and keeping children safe, or think of care homes or occasionally home care. They will not think about the vast majority of people who just want to live a lifestyle of their choice and need a little help to do that, and in some cases a lot of help.

There is a notion about younger people. More than half of social care expenditure is on young people of working age. Those people are normally completely invisible. Social care is normally seen as something that deals with children or older people, so there is a gap in the middle for people of my age, just about, who need help to live a life, gain employment, if that is what they wish to do, and enjoy the life they have.

The Chair: Thank you, Ian, for what you do for the people you work with and for giving us that information and expertise.

Q47 **Baroness Shephard of Northwold:** My question is for Kirsty. I obviously listened very closely to everything that you said. We had been prepared very well by Baroness Barker, who alerted the whole committee to the particular area that you had been working on. It seems to me that one of the main problems you have is the collection of data and how to categorise people who are alone but do not look alone on paper, as it were. You are always asked in the census if you have family.

In addition to the groups you have already defined, there are people who do have family, and they may be very caring, but they may also be in California, which is no help to anyone when there is the sort of crisis that you were describing earlier with your colleague. If, as a result of all this, we could come up with ways of improving your database, it might help. I would be delighted to hear if you have any more points to make about that in your answer now.

However, my real question is this. What are the options for people who are ageing without children? You said that a lot of them tend to end up in care homes, not old enough, not necessarily sick enough, because there are no other options. What options do you think could be developed?

We have been talking about personal assistants and care packages, so what do you think is the role of private agencies such as Country Cousins, Helping Hands and all the rest of it? It seems to me that they exist specifically to provide care packages for which the client pays, but they are designed to deal with people who are on their own. I have no idea how many such agencies exist—you may know—and how satisfactory they are. Nor do I know what regulations they operate under and whether they are inspected. That is a great kaleidoscope of questions and some requests for your views. Thank you for listening to this rambling question.

Kirsty Woodard: I hope I remember all of them, but prompt me if I forget one. I will pick up on the last one first about the role of agencies. Generally speaking, the paid-for care options available to people ageing without children are the options available to all older people. The issue is not so much that people ageing without children cannot necessarily pay for care. We find, for example, that care from agencies is arranged by their adult child. The arranging of the care, rather than the provision of it, is one of the real issues.

We know that the vast majority of information about care options is online. We also know that households headed by a single person over the

age of 65 are considerably less likely to be online. We know that four out of five people aged over 75 do not have a smartphone. There is a digital by default option. Everything is digital by default. If you are not able to look up that information yourself, if you do not even know where to start, generally speaking it is a younger family member, usually a child, who will go online, google the information, phone up the care agencies and ask, "Are you able to come and look after my mum or my dad?"

When we are thinking about services, we have to recognise the different routes for people, the diversity of the groups we are trying to work with, and that we do not create services, or pathways to services, that are reliant, either explicitly or implicitly, on having a younger family member to make it work. That is one of the key things. The services are there, but often the services "work", as far as they do work, because you have a younger family member, like the example I cited, running around sorting everything out and making it all work together. If you do not have that, that is much more difficult.

I know I keep harping on about the lack of research, but when we research services for older people, the case studies almost always say, "I'm going to talk about my mum" or "I'm talking about my dad". It is often the case stories of children talking about their parents and the terrible experiences their parents have. It is very rarely older people describing them for themselves.

Lots of people ageing without children would like there to be more co-housing—shared lives-type programmes. It comes up so much on the Facebook group: "What I really want to do is buy a house with some of my friends. I want to be able to employ carers to come in if we get to the point where that's what we need. We want to pool our resources and our knowledge". As Ian was saying, people want to live the lives they choose to live.

I know of hardly any people who have done it. Generally speaking, they have not done it because they do not actually know how. Buying a house with some of your friends and setting up care packages is quite a complex thing to do. What happens if somebody has particularly high care needs? What happens if someone has a crisis? What happens if somebody decides that they do not want to live there any more? It is quite a complicated thing to set up, even though it sounds quite straightforward when you are having a few glasses of wine down the pub and talking about it.

For data, we could interrogate ELSA—the English Longitudinal Study of Ageing—to find more data. That is a possibility. To be clear, AWwoC as an organisation is run entirely by volunteers and does not have any funding. AWwoC itself is limited in what it can actually do. We can work with organisations and universities, and say, "We think that you might want to research this", but we ourselves have no resources to do so.

Baroness Shephard of Northwold: I fully understand that particular point. I am also very interested in your co-housing point. I am struck by

the fact that, during the pandemic, in a lot of rural areas groups of volunteers, sometimes led by parish councils, were working very hard to think of anybody who might be alone and how to cope with that person's needs. Quite a lot of networks were formed. That was comforting and good altogether, but that was the pandemic, when people had the time. They might have been in lockdown themselves from work and wanted something useful and productive to do. There is good will at local level, but there is no mechanism, somehow, to make that kind of awareness more permanent.

That is all I would say, but what you have told us is most helpful and it has definitely taken us another step towards understanding the problems of this particular group. Thank you very much for that full answer.

Q48 **Baroness Barker:** Kirsty, I wanted to deviate from my set question a bit. First, I want to ask you to explain the sort of prejudice that people who are ageing without children face. That might help to explain the lack of systematic data.

Secondly, you said, quite rightly, that the issue was not about the provision of service but about access to it. You have highlighted to us that what people really miss out on is low-level and preventive care, and that is the stuff that is fast disappearing for everybody in social care. What do you think are the prospects for informal and mutual care models, because people have come to the realisation that there will not be suitable social care for them at all?

Kirsty Woodard: Dealing with the prejudice issue first, there is still a stigma in our society attached to people who do not have children. The stigma remains whether that was your choice or not. There is particular prejudice about people who choose not to have children.

We have certainly seen it in politics, for example. The fact that Theresa May or Nicola Sturgeon did not have children was commented on extensively, as if they were somehow lacking in an ability to understand society because they were not parents, so they played no part in it. I have certainly seen it suggested, for example, that people who do not have children should not be able to vote because they have no stake in the future. There is still considerable stigma and prejudice about being a person without children.

When we had a focus group to do a piece of research, somebody talked about how they went into their building society to change from one account to the other. They were chatting, as you do, and the woman said to her, "Do you have any children?" She said, "No, I don't", and the bank person said to her, "Oh, you selfish cow". There are quite astonishing things that people will say. All that contributes to the invisibility, because you are seen as a slightly lesser person because you do not have children. Even if that was not your choice, you are still seen as not quite part of society. You are not quite an adult.

Even when we talk about the Budget and things, there is always lots of rhetoric about hard-working families. There is very little comment on

people who live alone or who do not have children. You are simply not there. You are simply not seen as part of society. That invisibility plays into the narrative for older people in later life.

In terms of the prospects, the mutual aid things that came out of the pandemic could provide a model for a way forward. One thing that we looked at in AWwoC was something called "alter kin"—alternative kin—and whether people could create a circle of support. Circles of support are quite a well-known model of working, but could you put a circle of support around people before they hit crisis point?

People ageing without children have said to us, and this obviously applies to all older people, that people do not want someone parachuted into their lives at the last minute, in a crisis. They want people they know. If you do not have children, particularly if you are also single, you want to develop a relationship with people. People were saying, "I would really like to develop a circle of support and alternative kin that starts before I get to a crisis point, so that when or if I get to a crisis there's already a group of people I know and have a relationship with".

There is a complete understanding among people ageing without children that there is not likely to be social care provision from the state. It just will not be available to them. There is very much a want to create mutual support, and that is one reason why we have groups for people ageing without children in different parts of the country. A lot of that is about peer support and bringing experiences and knowledge together so that people can support each other. That is definitely something we could build on. The models are out there but, again, there need to be resources to create those models in the first place.

Q49 **Baroness Warwick of Undercliffe:** Thank you. The graphic descriptions from both of you have been illuminating. I want to pursue this problem of data. The sheer invisibility and knowing where to go to improve the data do not just affect the groups of people that you are talking about. It is affecting all the groups that we have been looking at. It has improved somewhat, but if you think about unpaid carers, for example, Carers UK and others have already told us just how difficult it is to get access to data that will then be reflected in the services that can be provided.

I wondered if you have thought through, and can help us with, the sorts of recommendations that we might make and practical suggestions that could improve the data, which we could challenge government with. You made the point that it is not about provision but about access to it. How true is that really, for everybody? One issue that has been raised with us is the whole question of supply. Even if you have the resource to purchase care, either you have to go out and hunt in order to find what you might purchase, or you do not know where to look, or it is not there.

I am reflecting through this my experience in the social housing sector, where I know that there is a real limit on the provision of supported housing. We know that there is a huge need out there for supported housing. I am particularly interested in the co-housing model. It is quite

difficult to find many examples of co-housing because of the difficulties that you have described. I wondered if both of you might say something about the practicalities of how we might improve data, but also about things such as the supply of housing, both for those who can and want to stay independent and for those who might need care anyway. How can we best find the ways for them to get what they want in the way they live and their ability to sustain themselves at home?

Ian Loynes: There is a role for data, and more data would certainly be useful. We already know how many people social care as a system looks after. We can extrapolate the unmet need in that. We can also see how few houses are being built that are accessible for everybody. If we changed the housing supply so that all houses were built to a lifetime homes standard, the provision of those accessible homes would be better.

That, in its turn, would deliver better outcomes for individuals, but also at a lower cost to the state than having to provide solutions to get round the various barriers that people might have in an inaccessible home. Simple things such as changing how we see housing and the design of housing can have a profound effect on the social care system, particularly the cost of meeting the various barriers that people commonly have in their inaccessible homes.

I certainly agree with Kirsty about the need for more data, but I also agree that we need to use the data we already have to see the bigger picture. Sometimes data on its own can hide or distract from that.

Kirsty Woodard: Picking up on the data thing, we do not systematically record whether people are ageing without children, so we cannot pull out how much of a factor it is in certain areas. I have a hypothesis about hospital discharge, for example, which is that people ageing without children are probably more likely to be discharged quickly, because they do not have someone saying, "You're not sending my mum home without this, without that". They are more likely to go back into hospital within the 28-day window because the support is not there. I cannot test that hypothesis unless somebody physically goes into somebody's hospital records. They could not go on to their database and just pull it out. We could have a category for recording AWwoC. I appreciate that it would be complex, but even if we literally recorded who had no children that might be a start. That would be a simple category.

Going back to co-housing, the model exists. There is limited co-housing in the UK, but we know that in Germany, for example, there are 900 co-houses. There are lots of models from the continent that we could look to. It would definitely be popular and we could do it. There is the UK Cohousing Network. It needs, again, more awareness and more resources.

Picking up on services, it is not just about access but about supply. I was trying to make the point that even finding out about services, just knowing that they are there, is really difficult. You are entirely right. We

do not have the supply of services that we need. For people ageing without children, that seems to translate into a very quick step into a care home. We know the pressures. Whatever you think of care homes and whether or not you think they are a good way to care for older people in later life, we know that care homes in the UK are going bust hand over fist at the moment. Even if that is the last port of call, we know that some will not be there and that what is left may not be what older people want at all.

Q50 **Lord Bradley:** Welcome, Ian, to the meeting. You lead an independent living centre to help support and advocate peer support and other mechanisms for people who may live alone and need that help. Some years ago, certainly in my own local authority area in Manchester, there was a development of what were then called elderly persons' resource centres, which were very much user-led and supported local communities, particularly those who are living alone, to have that peer support, advocacy and help in access to services. I wonder if you would support that sort of model of care being redeveloped, through local authorities and others, obviously subject to resource availability.

Ian Loynes: I would certainly agree that peer support is critical for helping anybody to be informed. Obviously we are talking about people who are users or potential users of the social care system today. Organisations such as ours, centres for independent living, are all peer-led, so they are run by disabled people. That is to pass on the knowledge and experience of how to live independently to others who can gain from the joys as well as some of the perils of employing your own staff and making decisions about whether your family helps you or you choose to do something different.

In some cases, it is to help families to understand their options so that they can make an informed choice. As Kirsty said, people who make an informed choice will have better outcomes and be less expensive for the state to look after when things go wrong. If we can prevent things going wrong simply by informing people about the options they have in order to make them more aware of which option is best for them, as well as having some resilience in the system that they build up around themselves, that will automatically be cheaper to the state to deliver. At the same time, it will deliver better outcomes to individuals.

There is an expectation or a presumption that family are there, or friends or volunteers may be there, to step in. The reality is that most people have their own lives. They are either busily employed or busy doing other things. The presumption that somehow they will just be there to support somebody who needs help in the social care setting may not always be correct. Certainly, I do not think that we want to create burdens or unnecessary responsibilities on people who have their own life to lead and might not see caring for their son or family member as part of what they want to be doing with their life.

We would not want effectively to force people into that arrangement. For some people, family is good, but for some people, it is not. Likewise,

some families want to look after their older relatives, some people do not and that is the way it is. Forcing the issue is always difficult, which is why we recommend an employment model. I employ my PAs and therefore I can dictate what they do. They get paid for what they do and there is a proper relationship there, not a kind of lopsided relationship.

Q51 **Baroness Campbell of Surbiton:** Hello, Ian. It is good to see you. I do not think we have touched base for about two years, so it is very good to have you online. You have talked to us a lot about issues with regard to personal assistance and independent living. Many people will see this as a new and innovative way to deliver support to disabled people. However, you and I know well that this model of care and support has been around for over 30 years. It would be really helpful for the committee to get more of a feel about this form of care, who uses it, who gains from it and some of the ways in which the infrastructure can be developed to support this direct payments model.

We talk about the invisibility of care, and you have talked about the fact that working-age adults are rarely discussed in that narrative. We normally talk about care homes, older people, relatives or unpaid care and care services provided by the local authority. There is still very little known about what it is to become a personal assistant user, yet there are 280,000 people around the UK using this model. It is not just a UK model, but an international model.

Could you tell us a bit more about this model of care and support? Does it have a national infrastructure? How many Centres for Independent Living (CILs) are there? What is the importance of information services, peer support and other training services that these organisations offer disabled people so that they can become confident employers and managers of their own personal assistants? Could you also please touch upon something that you raised earlier—that this is not just for young people? Older people can and do use this model of care.

Ian Loynes: On the last point, certainly I have seen no data that shows that younger people use direct payments more than older people or vice versa. It is a universal proposition that if you want to live your own lifestyle and make your own choices about what you do, one of the prime ways of doing that is to have control over who provides your assistance and, importantly, how they provide that. If it is in people's homes, people like their homes to be run their way, rather than somebody else's way.

That is a very different model from a home care arrangement, where you are effectively just a number and a carer will come, paid or unpaid, and meet your needs. It is in somebody else's control. A personal assistant is a very different person from a carer, paid or unpaid, simply because they are acting on the behest of the person they work for. That would be me. If I say, "I'm starting work early today", I will arrange for my PAs to do what I need to allow that to happen. I would not have that control in a care home or even with a care agency. I would simply have to take my place in the queue and be seen whenever that is convenient for the system.

There is an awful lot of history around various schemes. Direct payments are probably the most well-known of the unknowns, as well as the longest living. As you say, they have been around since the early 1980s. They grew up through one disabled person telling another disabled person just what the advantages were. There is that whole notion of peer support, peer information, and the huge issue we have raised this morning about people's lack of knowledge.

Baroness Campbell of Surbiton: How is that delivered, though? I want to get an idea, as does the committee, of how this structure is delivered. How many CILs are there? How many people are there? What are the training requirements? Some people will see this and think, "Gosh, I can't do that. I can barely manage myself. I can't manage to employ a personal assistant". Give me an idea of what needs to be put in place for this to be a successful model of care.

Ian Loynes: Centres for independent living are all around the country. It is fair to say that a lot of them struggle for funding. Quite a few have ceased to exist in the local authority arena, because in tendering and those sorts of systems no value is placed on peer support, so that very important aspect does not get counted when the funding is being dished out. That is something we might come to a little later. There has certainly been a struggle.

I run a CIL and it is a struggle every year to figure out how we can continue to exist. Maybe that is good. It keeps us on target, but people's lives should not depend on how good I might be at running this organisation. People should have a right to that sort of peer support, be able to gain that easily and be able to choose where that comes from, irrespective of where they are in the country. There are quite a few of us around, but there certainly should be more. There was a Prime Minister's paper in, I think, 2010 that said that there should be a centre for independent living in every local authority area. That is still an aspiration, rather than a met objective.

You said that some people do not like or do not want to take on the responsibilities of being an employer. Let us face it, most non-disabled people do not employ their own staff, so why would we necessarily expect disabled people or older people to take on those responsibilities? Various schemes have grown up around the country—we do some here at the centre—you can provide the service to certain people who might not want to run their payroll system, for instance. They will subcontract that out to somebody else.

Various pilot schemes have grown up—we do some of them here at the centre—to help people with the things they find particularly difficult. One of those will always be recruitment and what happens when your normal PA cannot turn up that morning, they have broken their leg or an emergency crops up. What happens in that situation?

There are various ways in which we help people to see what their options are. I think there are only one or two cases around the country that have

the notion of a personalised care agency. We do that here. We will handle all the recruitment aspects of the staff and deal with the HR side, but the service user, the individual older person or disabled person, will have control over who is employed. They will just be employed to meet the person's care needs, rather than just being a number in the queue.

That is one way in which we have worked with the Care Quality Commission (CQC) to figure out how its regulatory framework can work here to allow people to have the freedom of their own staff but not the burden of having to employ somebody, pay them and deal with all the HR stuff that crops up along the way.

Baroness Barker: Do you know the comparative cost of that model to other models of care?

Ian Loynes: Yes. Various documents have been produced over the years that show that a direct payment model intrinsically should be cheaper, simply because you are giving the money direct to the person, not paying the profits of an agency or anything like that. A direct payment model intrinsically should be cheaper. Certainly various research has been done that shows that it is at least no more expensive than dealing with a typical social care system.

Remember, people who live independently with their own resources are less burdensome on the social care system, so you would not expect social workers to be running round sorting out problems every five minutes. You do not have that institutional cost. That resource is available for other needs as well. There have been various documents. *Cashing In on Independence* by Gerry Zarb is the one that comes to mind, which shows the cost-effectiveness of a direct payment-style model.

Q52 **The Lord Bishop of Carlisle:** Ian, this is a sort of supplementary question to what you have just been saying. The personal assistant model sounds really good. We have heard others recommend it. It clearly works well and you have just told us that it should be cheaper. I think you, or somebody, mentioned earlier that about 280,000 people are currently using this model.

We also heard earlier today that, by 2030, there could be several million people ageing, disabled or without children who could be in need of such a model. That raises all sorts of questions about how this model could be scaled up, not least, presumably, the question of a potential shortage of PAs and of training for those who will undertake this kind of work. If we were to scale this up very considerably to meet the enormous need that is developing, what would we need to ask of government and local authorities? What is required if we are to expand this model very considerably?

Ian Loynes: Two things spring to mind. First, as we have explored this morning, 280,000-odd people are on the scheme. That is largely through word of mouth and background knowledge, rather than a system-wide, government-wide promotion campaign about what that system is and

what social care is in its full roundness, rather than the very narrow perception that there is out there, both in government and in the general public.

If we inform people before they need it about what social care is and the various ways in which they can meet future needs, people will have that knowledge when they need it at some stage, rather than scrambling around, when the emergency is there or when they are in hospital, to figure it out, and ending up, as Kirsty said, very often with poorly fitting solutions. People do that simply because they have a lack of knowledge and it is left until the last minute when that emergency arises. That is not a good time to start evaluating the pros and cons of different models that may or may not be appropriate for you.

If were to do that and if we were to work on the notion of peer support organisations, make them far more numerous in all areas and actually value what peer support provides to a society in an economic sense in the way contracts are tendered nowadays, we would see more of those organisations develop. We do peer support, but it has never been valued in any tender I have seen.

If we placed a value on locally based peer support services, they would grow in numbers and would be able to tell more people about it. Then, if we have government also making people more informed about what social care is and the various ways in which people can have their needs met, we will end up with far more people knowing, and the number that you mentioned will grow to meet the expected need that we have. It is that simple.

The Lord Bishop of Carlisle: That is really helpful when it comes to people knowing about what might be available. What is required with regard to the actual availability of PAs, how they know what to do and how they are properly trained? What happens at the moment with regard to people becoming PAs? How are they trained to do the work that they need to do?

Ian Loynes: On a shoestring and via pilot scheme is how it has grown to date. As I say, if people are helped to see that they can form a career out of being a PA and gain far more job satisfaction working for an individual by helping them to meet their particular aspirations in life rather than just going house to house to meet people's essential needs, I believe that they will intuitively see that as a vocation, as a career. Therefore, we create a whole new economy, quite quickly, of people seeing that as a better or different choice, rather than just seeing PAs under the same criteria that we see paid carers under at the moment.

They are different jobs and they need a different approach in how they are marketed, I believe. There are already various websites where you can advertise your wares, so to speak, both wanting a PA as well as being a PA wanting employment. If they were scaled up and national attention was paid to them rather than just a bit of voluntary sticky tape here and there, that would become far more successful and become part of a

strategy, rather than just the best efforts of people who have a mind to make that work.

The Lord Bishop of Carlisle: That is very helpful. Thank you.

The Chair: That is very interesting to us indeed. Thank you very much.

Q53 **Lord Laming:** Ian, the evidence we have heard from both you and Kirsty is extremely valuable. Should we draw the conclusion from it that society currently operates on the basis that if someone is not entirely independent it means that they have become dependent, and that once they are dependent other people can make decisions about their lives?

Ian Loynes: To a degree, that viewpoint can be taken. It is important to point out what we mean by "independent". Independence is about having choice and control over how you live your life. It is not necessarily the mechanical thing of whether I can wash myself or drive myself to work. As long as I have control and choice over how those functions are met, that is what independence is, rather than being able to physically do everything oneself. I make the parallel that very wealthy people normally have various staff doing almost everything in their lives, but nobody would deny that they were independent. They just have the resources to employ people to do the jobs that they really would rather not be doing themselves.

If we see independence in a choice and control arena, it becomes a valuable thing in making sure that people have choice and control over how they live their life, and their knowledge of resources, PAs, various other services and schemes. They can then pick from that menu of options what would best allow them to live a life of their choice and not to feel that they are a burden, as well as in some cases actually being a burden to their family, who would rather be getting on with their lives. It might be quite different from caring for their family member.

Lord Laming: That is extremely helpful and well put, if I may say so. What I want to get at is whether, underlying this, there has to be a change of attitude in society about how we help people to preserve choice in their lives, irrespective of how dependent they are?

Ian Loynes: There definitely needs to be a change of perception and a change of understanding about disabled people and older people. There is a notion that, once you become disabled, you are automatically dependent and you need somebody else; you are just looked after and you are wasting your life until you die. That is not the reality for any age or for any disabled people. We all want to make the most of our lives. We get to live only once. Disabled people should have that right to live a decent life, a life of their choice, and for their ambitions to be met.

Just because I have become disabled does not mean that I am more dependent than anybody else. I will be dependent in some aspects of my life, like we all will be. I can drive my car, which makes me more independent than somebody who cannot drive their own car, maybe. We all have different aspects that we need help with during our lives,

whether we are disabled or non-disabled people. If we can change the mindset about disabled people's independence, that will, over a generation, change the way we provide social care in this country, to make it clear that the ambition is to promote independence and to minimise dependency.

It is my intuition that, if you live a dependent life, you are more expensive to the state to look after than if you lead an independent life. I have chosen to live independently. I employ my own staff. I have a job. I pay my taxes. I have a decent level of income. I can go around doing things that other people just would not be able to dream of.

Lord Laming: It is in society's interest for this big mindset to change from creating dependency to preserving independency.

Ian Loynes: I absolutely agree with you. The one thing we should not do is take people's independence away from them and deny them the chance. They may become disabled with various impairments through age or just through illness, but that should not mean that their ambitions or their independence is threatened and automatically taken away from them.

Lord Laming: This would require a number of changes, one of which is the language that is used.

Ian Loynes: Yes, I agree. There is a perception out there that, if you are a disabled person, you really do not want to be disabled. "None of us would want to be disabled, would we?" We are trying to say it should be seen in the same light as being a woman, a black person or any other equality group. Disabled people should have the same ambitions. Indeed, there is no "I've seen the light" to independence. They can be an economic advantage to any economy. We as a nation would do best to unlock that economic potential rather than lock it up in a dependency-based model.

Lord Laming: Have you seen examples of commissioning of services that promote that attitude or are commissioners of services still pursuing what I would call a dependency model?

Ian Loynes: We have talked about direct payments a fair bit today. The commissioning of that talks about choice and control, and all of that. Those things do get talked about, but the vast majority of social care is seen in that negative aspect—that it is about looking after people rather than allowing people to live a lifestyle of their choice. I have never seen a commissioning document that places some value on the principle of informing, peer support and making sure that people have informed choice about how they choose to live their life and get the help they need in a social care setting.

Lord Laming: You mentioned in passing that the model you have very helpfully set out this morning should be available to all people. Did you mean all people, or did you mean younger disabled people? What I am

really getting at is whether we need to have a fundamental shift and see this as a possibility for everyone.

Ian Loynes: Yes, it should be for everybody. I am transitioning between being a "younger person" and an "old person" myself. I certainly do not want to live a different lifestyle from the one I have now just because I have tipped to being over 65 or any other age. It is just a number. People should have the choice. Some younger people will choose to live in a care home, and that is fine if they make an informed choice about that. Some older people will want to have a very active lifestyle into their 80s and 90s. Thankfully, they are able to do so with the health advantages these days. People should have choice, and age is just a number. It should not dictate people's aspirations in life at all.

Lord Laming: Thank you very much indeed for all your help. This is my final question. People may be willing to accept this model that you have very helpfully described for younger people. Have you come across examples of it being applied successfully for older people so that we could actually learn from those examples? You do not have to give them today, but if you have some examples, if you could let us know, that would be wonderful.

Ian Loynes: There is a general acceptance by people outside the system that options such as direct payments and independent living are more appropriate for younger people than older. That is a falsehood. There is no evidence to back that up. Older people use direct payments just as often as younger people. Let us remember that many people are transitioning those artificial age barriers all the time. We need to change the music on social care options for people of any age and then allow people to make their choices.

You asked whether there were examples. It is always very difficult with examples, but you could use me as a person who is 59 now. I have chosen to live my life as I have. I do not have children, which does scare me for older age, as Kirsty outlined earlier on. I choose to do a job, but I have been self-employed in my life. I have all sorts of opportunities out there.

Some older people will like going abseiling and will just need a little help to be physically able to do that. You simply could not do that through a home care or a care home model. It would not be realistic, whereas if you are employing your own staff it is very easy to do the things that other people take for granted: go surfing, go abseiling, learn a new skill that requires going to university. It just needs a PA to help you to manage while you are in university. All those options become available through an independent living model.

Lord Laming: Sorry, let me have just one final question, which is this. That model sounds wonderful for younger people. Have you come across examples of someone in their 80s being able to use this model?

Ian Loynes: Yes, in a previous life I was a direct payment support worker and I was supporting older people of that age all the time to use direct payments. In fact, probably the majority of work that I did was to help both the individual and their family to understand the opportunities of having a PA-type arrangement. Thankfully, nowadays there are many more support schemes available to help people with more difficult things such as recruitment and payroll. The vast majority of the people I used to support were above 60. In those days, 60 was retirement age for women. The majority of the work that I did on individuals was people who were deemed older people.

Lord Laming: That has been most helpful. I am grateful.

Q54 **Lord Polak:** This has been a fascinating and very informative conversation this morning. I have one aim in all this. How can we help people who will need help? My point is this. We around this committee and both of you are expert at dealing with this. I can actually use a very practical story of my mother.

Often this all happens when you least expect it, when somebody is on their own, needs help and does not know where to turn. They do not know whom to talk to, and that is even more so for the people who do not have children and so on. I wonder whether eventually we can help by just having some hymn sheet somewhere. If somebody, God forbid, has a heart problem, we know where the defibrillator is and we can do something. What recommendation can we make as a committee to give a menu: "What happens if … ?" Here are some numbers. Here is what happens.

Often, people are on their own and suddenly find that they cannot use their right hand. They have been perfectly able-bodied for all their life and find this very difficult. It is that shock moment of panic. Is there a way we can create some menu of what to do and where to go?

Ian Loynes: I will defer to Kirsty in a moment, but, simply, we can inform the general population about what social care is—that it should be about independent living and allowing people to live a lifestyle of their choice. I agree: if people are getting their various impairments in a crisis, which they normally do, that is the poorest time to start trying to decide what the best solution is in their lives. If there are various opportunities and the Government have spent time informing the population about social care, what it is and what the options are, they will be less scared, better prepared to examine those options before they come to a crisis, and so better able to meet those needs when that crisis does happen.

The Chair: Kirsty, would you like to have a final brief word?

Kirsty Woodard: We need to do two things for older people. First, we need to normalise planning for later life. Everybody should be encouraged to plan for their later life, and not just from a financial perspective. Often, when we talk about planning for later life, we generally mean, "Do you have your pension sorted?" as opposed to "What are your aspirations for later life?" We are all living longer, and that is a brilliant thing, but that

means that we will spend 30 years past the age of 60. What kind of later life do people want to have? We need to normalise planning for that later life and all the different stages of it.

Secondly, linked to that, we as a society desperately need to become far less ageist. We do not talk about a lot of this stuff because none of us are going to get old, are we? Generally speaking, that is what we all think. None of us are getting old. I think of the number of older people I have spoken to who are like, "Well, I don't want to go there and do that because it's full of old people", and the people are younger than they are. We have to remove that stigma around ageing and we have to encourage people to plan.

The Chair: You could not be talking to a more sympathetic audience than in the House of Lords. We defy ageing in every way you could imagine. We are very privileged to be able to do so. We have been very privileged indeed to hear you today and to share your expertise and your unique information. I apologise to colleagues I could not call at the end.

It struck me, as I was listening to you, that you both identified some of the massive missed opportunities, such as the lifetime homes problem, which I was involved with and was very sad did not materialise. With so many other things, the landscape is littered with missed and failed opportunities. Part of what you are doing now in your advocacy work is trying to make up for a lot of the things that we should have had in place. You have also alerted us this morning to some of the enormous issues that we are facing, which we did not even know or acknowledge.

From that forensic questioning at the very end of the session, we have real issues of perception, language and approach, and therefore of creating models that will work for the future, because they are based in the reality of people's lives and aspirations. You could not have been better advocates or provided better evidence for our general thesis that things need to change. We are beginning to visualise some of the things that are needed urgently.

We will look forward to coming back and talking to you. I suspect we might send you some homework questions, which I apologise for in advance, but you have primed our appetite for more, so we may take advantage of that. Can I just thank you very much indeed on behalf of all my colleagues for your brilliant evidence this morning and for the way you have responded, opening our eyes and indeed our hearts to so much? Thank you very much indeed.