

Levelling Up, Housing and Communities Committee

Oral evidence: Long-term funding of adult social care, HC 35

Monday 29 November 2021

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Members present: Mr Clive Betts (Chair); Bob Blackman; Ian Byrne; Brendan Clarke-Smith; Florence Eshalomi; Ben Everitt; Rachel Hopkins; Mary Robinson; Matt Vickers; Mohammad Yasin.

Questions 51 - 103

Witnesses

I: Brian Dow, Deputy CEO, Rethink Mental Illness; Emily Holzhausen, Director of Policy and Public Affairs, Carers UK; Jackie O'Sullivan, Director of Communication, Advocacy and Activism, Mencap and Co-Chair, Care and Support Alliance.

II: Fazilet Hadi, Head of Policy, Disability Rights UK; Ruthe Isden, Head of Health and Care, Age UK; James White, Head of Public Affairs and Campaigns, Alzheimer's Society.

Examination of witnesses

Witnesses: Brian Dow, Emily Holzhausen and Jackie O'Sullivan.

Chair: Welcome to this afternoon's session of the Levelling Up, Housing and Communities Committee. This is our first time meeting under our new name, which reflects the name of the Department we scrutinise. This afternoon's session will look at the long-term funding of adult social care, which is clearly a really important issue that has been much in the news of late.

I will first ask members of the Committee to put on record any particular interests they may have that may be relevant to this inquiry. I am a vice-president of the Local Government Association.

Mohammad Yasin: I am a member of Bedford Town Deal Board.

Rachel Hopkins: I am vice-president of the Local Government



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Association and I employ a councillor in my office.

Ian Byrne: I am still a sitting councillor in Liverpool, and I employ a councillor in my office.

Florence Eshalomi: I am also a vice-president of the LGA.

Bob Blackman: I am vice-president of the Local Government Association. I employ a councillor in my office. My sister works in the care sector.

Matt Vickers: I am a councillor, I have family members who are councillors, and I employ councillors.

Mary Robinson: I employ a councillor in my staff team.

Brendan Clarke-Smith: I employ councillors in my office.

Q51 **Chair:** We will now come to our witnesses. Please say who you are and what organisations you are representing.

Brian Dow: My name is Brian Dow. I am deputy chief executive of Rethink Mental Illness. I am delighted to be here.

Emily Holzhausen: I am Emily Holzhausen. I am director of policy and public affairs at Carers UK.

Jackie O'Sullivan: I am Jackie O'Sullivan. I am the director of communication, advocacy and activism at Mencap, but I am here today in my capacity as one of the co-chairs of the Care and Support Alliance, which is 70 charities that campaign for a well-funded care system.

Q52 **Chair:** Let us begin with the important subject of funding. This is a difficult question. We will begin by pointing out that the Government are making £5.4 billion available over three years from the new levy—the increase in national insurance payments. Some £3.6 billion is effectively to fund the changes in the cap and means test, which we will come on to explore in more detail later. There is an extra £1.6 billion over three years for local government services, but not just for social care. The difficult question is whether that is enough. Is the funding that has been announced sufficient?

Brian Dow: I want to set out first why the funding is not enough. That is primarily because we do not know or properly understand what mental health social care actually is. One pound in £12 that is spent in social care is spent on mental health. Local authorities have a range of legal responsibilities that they have to cover, which includes things like personalised support under the Care Act, mental health social workers who can help to navigate people around the system, and specialist employment services that enable people who have a mental illness to get in and stay in work. They have to provide advice and information for people. Supported housing is incredibly important, and I am sure we will touch on it later. It makes a huge difference, not just to people's lives and their ability to recover from mental health problems, but it is a saver



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for the system as a whole. Then there are a range of crisis services that step in when people are having a really difficult time.

That is a bit of a fly-through. It is fair to say that, prior to the pandemic occurring, there was already a crisis in mental health social care. It is pretty much every supplier that you speak to, and Rethink Mental Illness is a supplier of a large number of services across England. There is a picture of instability in terms of service provision. There are huge challenges in terms of recruiting a workforce and retaining that workforce. Then there is the impact on wellbeing, not just for our staff members but also for the people whom we are trying to support.

In one sense, some of the funding is very welcome. I was about to say to the Committee that ADASS's recent survey showed that 40% of directors of adult social care services were concerned about funding for people working with disabled people compared to 3% who were facing financial pressures for older people. That was the case, but I am sure we have many avid *Guardian* readers around the Committee who will have seen that the sense of pressure amongst social care leaders is very profound. That is increasing in terms of adult social care. What does that tell us about people who are receiving support for mental health problems?

Some of the recent funding is very helpful. The Covid-19 emergency funding is very helpful. If you look at that in the context of increased need for mental health support since the pandemic, it is fairly clear that, although that money is welcome, the health and social care levy, for example, will not really go the distance that we need it to go to meet the need that is out there and increasing.

Emily Holzhausen: From the perspective of carers, I am afraid it is not enough. Jackie might go through some of the bigger figures that we might need to look at, but I can come to what families are experiencing as unpaid carers. As Brian set out, we already had a shortage before the pandemic. Since the pandemic, we have seen the number of families providing unpaid care shoot up from about 9 million, we estimate, to about 13.6 million. That is about 4.5 million people becoming carers overnight. We know that 81% are providing more care, and the vast majority are on the brink of crisis. About three quarters have not had a break since the start of the pandemic.

When I am talking about unpaid care, and where these figures are coming from, I am talking about people who are providing 24-hour care, seven days a week, so their service has shut. Some 55% of those services have not returned, if we are looking at day services. We have people who are caring in a very isolated way, short of services. Prior to the pandemic, 600 people a day were giving up work in order to care, many of them because there is a shortage of care services.

This is where we are now, where we are seeing an increasingly worrying pressure on families who are unable to cope and unable to get good care workers in to support them so that they can take the breaks that they



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need and to prevent the risk of them falling out of their own employment from their own job, because they cannot get care.

Although the health and care levy, and elements of it, are welcome, as is the local government settlement, we have this shortage here and now it is really urgent, and we need to tackle it. We also need surety for the future.

Jackie O'Sullivan: I agree with Brian and Emily that it is not enough. Looking at the figures that came from ADASS this morning, we have 400,000 people waiting for care assessments; 1.5 million hours of care has not been delivered; and 50% of local authorities are reporting that a care home or provider has gone bankrupt or failed in their areas. Behind those figures are real people. Where have those 1.5 million hours gone? There are people who did not get out of bed in the morning, skipped a meal or who have not left the house in over a week. As Emily has highlighted, the consequences are real and are impacting on the people in receipt of care and their families in a very profound way.

Pre-Covid, the Health and Social Care Committee called for a minimum of £7 billion a year for the next four or five years. The Health Foundation thought that £12 billion was required to do the reforms themselves. The figures from the Local Government Association, which I am sure you will be familiar with, show that an additional £6.6 billion in costs have accrued over Covid, and that is rising all the time. The levy is welcome, and the money that comes from it is much needed, but it is not enough.

Q53 **Chair:** I am going to go around and ask one simple question, and probably one slightly more difficult one. How much is needed now to deliver the system that you are asking for to meet needs? When we get to the point in three years' time when the Government said there might be a switchover of more levy money into social care, how big should that switch be?

Jackie O'Sullivan: The figures that I just quoted give you an indication of the scale of need. Further to that, the Health Foundation has said that, in addition to the money that is in the levy and the spending review, £7.6 billion should be required in 2023, and £9 billion in 2024-25. That is over and above what has already been allocated.

Emily Holzhausen: I would go so far as to say that we need a specific dedicated fund, in addition to what Jackie is talking about, of around £1.5 billion, just to focus on carers' breaks. We are extremely worried about carers, and their ability to take breaks is absolutely paramount and central to their health and wellbeing. That is something we would very much like to see on top of some of the figures that Jackie has been talking about.

Q54 **Chair:** When we did our previous report in 2018, jointly with the Health and Social Care Committee, we looked at the German system where their family members can be paid, at a slightly reduced level, the amount that it would have cost to pay carers to help people. Do you have any views



about that system? It saves a bit of money at one level, but it also means that family members who care can get a proper return.

Emily Holzhausen: It is a different system. It is always difficult to compare different systems. We have a carer's allowance. They do not have a similar benefit there. That is an income replacement benefit, but it is way lower than what is paid in Germany on the three different levels. I think that a lot of carers would welcome something similar to be able to have a higher income, however that is paid. At the moment, you can pay family members through direct payments but only in exceptional circumstances.

We absolutely have an issue about carers' incomes, and that needs to be tackled, but what we really have at the moment is a shortage of hands-on care. That is where people need a break. They need time off. We have one carer who has not been out of the house since June, for example, since her husband was discharged from hospital. She has not even been out for a walk. They cannot get care workers in with the specialist care services to give her that break. She is absolutely at the end of her tether. Local carers' organisations are taking increasing numbers of calls from people who are at the end of their tether. That is why we are saying we need that kind of investment. It is a separate issue about carers' incomes but a very valid one.

Brian Dow: Three years ago, we did some research with the IPPR, and we assessed that there was an additional £1.1 billion of funding to go into mental health social care up until 2030. That was only to take us back, to be frank, to the fairly sub-optimal 2010 figure, which was never good enough in itself. If you accept that that was never good enough, there was always therefore a gap for the demand that needed to be filled, and then we have had the pandemic. For example, the Centre for Mental Health estimates that an extra 10 million people will require mental health services, and a large proportion of those will require that support through social care. You begin to see that the figure can be a multiple of three or four.

It is not just a question of a figure; it is a question of principles. At the minute, we have a system that really does not work together. The health system and the social care system often work against each other. I can give a very quick example.

Chair: We will come on to the issue of integration in due course.

Q55 **Ben Everitt:** The Government have made a series of commitments about how individuals are expected to pay for their care. There is the cap on the costs at £86,000. There is the new upper capital limit of £100,000, and then the lower capital limit of £20,000. Last week, we had the amendment to the legislation so that the cap covers only the costs that individuals pay themselves and not those costs that are covered by local authority, and so that does not count to that £86,000 cap. What does the panel of witnesses make of these changes? How would they affect the



groups that you represent?

Emily Holzhausen: It is always very complicated to describe this. We are very disappointed to see the changes. It affects unpaid carers in that, primarily, a certain group of those with more modest assets in terms of families are much less likely to benefit as they would have done from what we thought was the system beforehand. Some of us are very knowledgeable about the Dilnot system beforehand, so we thought this was included originally and were very surprised and disappointed to find out that it was not. It means that people with more modest means will run savings and assets down slower.

For example, a young man with learning disabilities might contribute £20 from his income towards his care. Without including the local authority amount, it would take him a very long time to get up to the cap. If you included a local authority amount, he would then have that £20 in his pocket. He may have very low assets and very low means but that would be important for him.

It is also very difficult for older parents trying to make provisions for somebody, or for somebody having a pension drawdown, for example, and putting that money that they thought they were going to live on into savings and then being taken over that level.

I have to say that the changes do mean that people would be better off than now. It is just that the changes would mean that this particular group of people with more modest assets would not benefit as quickly or as much. That would affect people in different parts of the country differently, where people have fewer assets.

I just want to end by saying that raising the lower capital limit is also important for people on the most modest means. We welcome that raising to £20,000.

Q56 **Ben Everitt:** Indeed. That is the critical point. The Government would argue that what they have put forward is better than the system that is there now, although, comparing it to the Dilnot suggestions, it does not quite match up. It is comparing it to a system that was never implemented. Jackie, do you have any thoughts on that?

Jackie O'Sullivan: Emily has put that very well. There are some elements that we support, including the raising of the minimum income guarantee and the bottom threshold. It is a question of fairness, is it not? In some ways, the original proposal was fairer to people and did not disproportionately impact on people with the least means and less means. There is a point where, if we are going to do this once-in-a-generation change to the system, it is really important that we get it right and that it is fair for everybody.

Ben Everitt: It is difficult to argue with that, Jackie.



Brian Dow: I would strongly agree with the points that both Emily and Jackie have made. I would make the perhaps fairly obvious assertion that, for many people who have severe mental illness, it is difficult to get in and to stay in work. Therefore, people's levels of savings are obviously very low, and lots of people who have severe mental illness are surviving on a benefits system that I have to say has not served them very well. It would be very unfortunate indeed if the effect of this process is to give people that choice of either paying for the care that they require or paying for the cost of living through their benefits.

Q57 **Ben Everitt:** These reforms apply only for people entering the care system from October 2023. Do you think it might be possible to introduce them sooner?

Brian Dow: I would hope so. The bigger problem here is that you have a very uneven system where people are receiving some care through the health system, but are highly dependent on the social care system for support. I am not quite sure why we need to wait for that length of time, particularly when, since the pandemic, more people are more dependent on social care for the support that they need.

Q58 **Ben Everitt:** I suspect the complexity is why we are waiting. Emily, do you have any thoughts?

Emily Holzhausen: I agree about the complexity of this. It is a highly complex system, and lots of systems and processes need to be put in place—not least really good information and advice to the people who are planning their care, wondering what they buy, how much they will get back, and the tracking and metering systems. Let us not forget that we are in a pandemic. We would not want that deadline to slip. This is a system that was going to be implemented a few years ago but that has been delayed. We were involved a lot with those discussions. The timescale is probably about right for the situation we are in now.

Q59 **Ben Everitt:** Yes, there is a big systems change behind this. Jackie, do you have any thoughts on that?

Jackie O'Sullivan: I totally agree with Emily. It is important that we do not get it wrong by rushing. It is better to get it right and take the required amount of time than rush and have some unforeseen consequences.

Q60 **Ben Everitt:** The final line of inquiry on this is in relation to the top-up funds. The Government have announced that they will change the regulations so that people receiving local authority support can fund top-ups to their own care or have family members fund those top-ups. This would basically end up being some kind of "premium room" where it could be financed either by the person themselves or a third party, a charity or a relative. Does that seem right? Is that sitting well?

Emily Holzhausen: People have quite often topped up different sorts of care. If I think about care in the community, there are a lot of people



who sometimes go out and buy better care. On the one hand, it is practical but it also makes me very nervous and anxious if local authority rates are depressed, either from the enormous buying power that local authorities have as a monopsony or if the definition of it is low. It just means that there is almost a default position of relying on family or the person to top up. That is what worries me, because that passes cost down the generations.

We know, for example, from carers, that a large proportion—because they have given up work to care or have reduced their working hours, and because they are contributing to the care of other people, as well as the care that they are providing, which has been worth £193 billion during the pandemic—are far less able to contribute to their own care. About two thirds are very worried about how they will fund their own care in the future.

It is a long answer to a short question about top-ups, partially about practicality and partially about worry.

Q61 Ben Everitt: Yes, indeed. I totally accept that. In principle, people paying a little extra to have a little more is not a problem. It is about how that interrelates to means testing and what that means for the wider calculations and assumption in the legislation as well. Jackie, do you have any points to make on that?

Jackie O'Sullivan: No. Again, Emily has articulated that really well. I would just point out that this is currently the situation. That system currently exists at the moment, so it is not a real change going forward.

Q62 Ben Everitt: That is useful to point out. Brian, you mentioned that £1 in £12 went towards mental health care. How would this situation interact with that split in financing mental health care?

Brian Dow: My two colleagues are probably slightly more expert on the matter than I am. The point I would encourage the Committee to consider is that someone with a severe mental illness who is left with a legacy debt will often have cognitive challenges that means they may not be able to handle their own finances. Having some sort of provision there to support people in that situation would be very important.

Q63 Rachel Hopkins: Emily, we have heard a lot during our inquiry about issues facing the social care workforce, including issues around low pay, lack of progression and high vacancy rates. How do these issues interact with and affect unpaid carers?

Emily Holzhausen: That is a very good question. We have looked at this. Pre-pandemic, that was already a feature of the system. What happens is that you might get the workers coming in so you have to re-teach how to move your husband, what he might like and what he does not like. That is exhausting. It means that the help that comes into the house is not the help that you need. If there is then a gap in care, you have to step in. When care becomes very unreliable, it becomes more



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stressful than not having the support, and that is when carers start to stop having it altogether. That puts enormous pressure on their health and wellbeing. We know that, if the health of the carer breaks down, the costs to the state and to the family can be very considerable. Instead of one person, you end up paying for two.

We are starting to see different things come through. As I said, a lot of people are finding that services have not returned. Home care services have sustained better than some others. Fifty-five per cent. of day services are not back fully; 20% of those have closed in their entirety. We are seeing working people being asked to give up their work in order to care for people, both at hospital discharge and just generally, when a mum, dad, brother or sister cannot cope anymore.

We are seeing parents of people with learning disabilities being asked to take their son or daughter home. Some people chose to do that in the pandemic to keep them safe, but now people are being asked to do that because of a shortage of care workers. We are seeing the workforce being redeployed, in some situations, where there is a carer and they are being redeployed to people who are living on their own, because they are more at risk, again leaving carers without the vital support that they need.

This is having a devastating impact on people's health and wellbeing and their ability to manage, because they simply do not know how long this is going to last. They have had to cope. Pre-pandemic, about 25% had not had a break in a year, and 72%, as I said, have not had a break since the start of the pandemic. We are building up a crisis. I know that the Association of Directors of Adult Social Services talked about a rise in safeguarding concerns. A lot of local carers' organisations, as I said before, are receiving cases where people are caring with much more complex situations and are at the point of breakdown or crisis. It is very difficult to see where they can offer support because of the shortage in the workforce. When people talk about crisis, that is what it feels like in a family.

Jackie O'Sullivan: As Emily said, what became really clear during Covid was just the very fragile and complex nature of the way that people arrange their care, particularly when they are getting some family support. What we might not see as formal care, because it is not in a care home or a supported living setting, could comprise things like a bit of respite. It could be a couple of afternoon day clubs that would not even be called day services but really are. It might be more informal care and support like a Friday evening disco or something like that, which is actually organised by a local group or charity. Lives are structured to require all of that support to get through. If you take a bit of that away, it is like a big Jenga tower—the whole thing becomes very fragile and risks collapse.



The other thing we are seeing is that families where somebody might be a personal budget holder are starting to find it quite hard to find paid care. Large care providers are struggling to find the workforce. If you employ one or two personal assistants, that can get very complicated and very difficult.

Q64 **Rachel Hopkins:** Do you want to add anything, Brian?

Brian Dow: In a sense, both my colleagues have almost made my point for me. The effect on somebody's mental health of being a carer is very profound. One in five people who are carers are caring for somebody who has a mental health problem. In a sense, if we are not taking account of that, we end up with a bigger problem further down the line.

Q65 **Rachel Hopkins:** Jackie, in the written evidence from the Care and Support Alliance, you said that unpaid carers need "increased support". What form should that take?

Jackie O'Sullivan: Emily, if you do not mind, would you be able to pick this up? Emily is also one of the co-chairs of the Care and Support Alliance, and I think she will answer this question much better than I would.

Emily Holzhausen: We asked this just very recently: 8,500 people responded that their No. 1 need, personally, is better support to improve their health and wellbeing. That is the first time we have seen carers really putting their own health and wellbeing first. When we asked them, in terms of social care reform, what their top priority is, it is better and more personalised support for the person who they care for. Those are their top two priorities. Then comes better recognition in society, so that they are visible and valued for what they do. They often feel invisible. They often put their own needs at the back of the queue. Breaks also comes very high. For the people on low incomes, I cannot go without mentioning the low level of carers' allowance, at only £67.60 per week for providing a minimum of 35 hours' care. Those are their priorities at the moment.

Q66 **Rachel Hopkins:** The written evidence from the Alzheimer's Society stated that 53% of carers have not had a carers assessment. Do you recognise that figure? Secondly, what can be done to drive up the number of carers assessments?

Emily Holzhausen: I do recognise that figure from the Alzheimer's Society. When we talked to carers across all different conditions, disabilities and ages, I am afraid it is an even worse picture than that. Only 24% of our respondents had had a carers assessment, and that has fallen from 31% in 2016. That was a carers assessment or reassessment as well. Some people were even less likely to get them. Again, given that you are the Levelling Up Committee, we were very worried to see that carers who were struggling to make ends meet were less likely to get them. It is very important that we get the first information and advice. When asking those carers, quite a few of them did not know what a



carers assessment was. It is very important that we help people with that.

We have seen a backlog. ADASS, through local authorities, have done 20% more assessments, and yet we still have this big backlog of carers assessments. There are definitely ways that we can use more online and preventive services in helping people to have guided conversations and use different digital methods. There is a point at which you need that proper conversation with a lot of people about their needs. Perhaps we could be looking at more pre-assessment stages for people. It is very possible. We have built several different tools over the years to be able to do that, but we still need to lever in enough support. This goes to some of the figures that Jackie was talking about. It would go towards helping not just those assessment but what happens at the end of it as well. It is really important.

Brian Dow: The situation, again, is very similar for people who are carers for those who are affected by mental illness. That emotional support and peer support, reaching out to somebody who has been through the same thing, is very important. Perhaps one of the differences is the knowledge and skills, because the truth is that mental illness remains relatively misunderstood at population level, so people are not necessarily sure where to turn to for the support. That slightly more specialist support is also helpful.

I also recognise that figure around the lack of assessments. The corollary of that is the question of why that is happening when local authorities have a statutory duty to make those assessments. It says something about their confidence and their ability to meet the needs of the person that is coming forward to request. That presents us with a very significant challenge.

Q67 **Rachel Hopkins:** Do you have a final comment, Jackie, or are you in agreement with the others?

Jackie O'Sullivan: I agree with the others. I have nothing to add.

Q68 **Matt Vickers:** The Government intend to publish a White Paper to address issues of choice, quality and accessibility of social care, and the social care workforce. What are the top three policies that you would like to see feature in that White Paper?

Brian Dow: We need a long-term vision for social care in relation to mental illness. It just is not there at the moment. It would be silly of me to pretend otherwise. We first need to invest in new models of care. I know that the Committee will come on to this in a second, but some of the integration that we are starting to see through the new architecture that has emerged through the integrated care systems is very positive and is building a much more collaborative relationship. That also includes the voluntary sector, and we have representatives here who are able to tell a story about how the voluntary sector can come in and help deliver



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different kinds of services. We are doing that in particular down in Somerset, where we are seeing some fantastic results.

The second thing is to try to co-produce more of what is available for people with people. Too often the system does to people, and it does it in a somewhat suboptimal fashion, as I said earlier on.

We should really be looking to commission for quality of outcomes, not for price. The last 10 years for any provider have been very difficult because, increasingly, we are being asked to do more for less. There is a point at which that becomes dangerous and unsafe. Those three things are probably paramount at the moment.

Emily Holzhausen: On the White Paper, I agree with Brian that it is about a good vision that we can all sign up to. Carers would want to see themselves threaded throughout the paper, as well as specific measures to support them as well. That is incredibly important to see for them to feel that they are valued and recognised.

The second thing is that I agree with Brian as well about new models of care and investing still in innovation so that we continue to learn as we go along. We also need to make the most of data opportunities, not just to recognise carers, but to make sure that we understand more about populations that might find things harder or more excluded.

The third thing is to look at breaks and sufficient funding behind the White Paper to make the vision a reality. In terms of engagement, that is also what people have been saying to us and where that would make a difference. If we had a carer in front of us, what would they say would make a difference to them? How would they say that it has changed their lives?

Jackie O'Sullivan: Like the others, we need a vision that puts the recipient of care at the heart of everything. We need a good plan for the workforce—show them that they are valued and properly rewarded. We also need a plan for sustainable funding that can bring stability to the sector for the long term. I also agree with Brian about outcomes. If you focus on outcomes and ban commissioning by hours, that would be a big step forward.

Q69 **Matt Vickers:** The Government have indicated that they intend to consult the adult social care sector on this White Paper. What has been your experience of this consultation so far?

Emily Holzhausen: We have been engaged with it. I just want to say as well that we have ongoing engagement with the Department. We bring carers to policy makers and decision makers, including into Parliament. We make sure that they have first-hand experiences, and that includes Ministers as well. It has been very fast, but there has been engagement across lots of different areas.



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Once it is published, it is really important that we look at that engagement and how things are going to be delivered. That is something that carers absolutely want. Brian was talking about co-production. Because it affects their lives, they want to be involved.

Jackie O'Sullivan: The engagement has been good with Ministers and officials. They have been really willing to listen, and they have been open to conversations. The timeframe is really tight, and so there has not been as much opportunity to do the real co-production with people with lived experience and care users as much as anyone would have really wanted.

I should also say, though, that there was no consultation or early sight on the changes to the cap that came out the other week. That felt a little disappointing, because it went against the grain of the real co-operation and openness that we had experienced before then.

Brian Dow: I would want to, in general terms, pay tribute to the Department and the civil servants in it over the course of the pandemic. They have been heroic in the way they have worked and engaged with people across the sector. I really want to say that.

In this case, the level of engagement around mental health social care has not been great. That reflects what I have been saying throughout: there is not really a good understanding that the social care sector is absolutely critical for people with mental health problems. I would hope that the remedy to all that is that we come out of this at the end of the process with a better vision and a better model that understands all of the other things that affect someone's mental illness such as their physical health, their housing situation, their financial health, how connected they are in their community and so on.

Q70 **Matt Vickers:** Jackie, the Care and Support Alliance has said that, as part of reforms, adult social care should be free at the point of use like the NHS. Do you have a figure for how much additional funding would be required to deliver that?

Jackie O'Sullivan: The Health Foundation has estimated that £12 billion of investment would be needed for that. I would also point out that some savings could go along with encouraging people to get help earlier. If we look at prevention, and early intervention as a form of prevention, that would be very beneficial.

Emily Holzhausen: I mentioned the £1.5 billion for carers' breaks. The point about carers' breaks is keeping those free at the point of delivery. That is hugely important so that people take the break to get the benefit for their health and wellbeing. As soon as we ask people to not only contribute their time for free plus make them pay for any time off they might have—simply to have an hour off or to get a night's sleep—we start building up problems for the future. There are some services like that where you could instantly see how important it is to have things free at the point of delivery.



Q71 **Mary Robinson:** Earlier this year, we had a White Paper on the integration of health and social care. During our previous sessions, we have heard from witnesses who have said there was no clarity on what “integration” means. In your view, what should “integration” mean and how should it work?

Brian Dow: To some extent, the Bill really codified what has been happening in some—I will use the word in inverted commas here, and I am sure you are familiar with it—“places” across England. Somerset is a very good example where we are working very closely with the local health provider and the local authority to try to develop an open mental health service, which means that, regardless of how unwell you are and where you are coming into the system, you can access the care that you need, depending on your situation. As I say, it is fairly early in that process but both the spirit and the outcomes of it are looking incredibly positive.

The limiting factor though, if we are realistic, is the fact that you have a huge imbalance in terms of both the legal responsibilities and the funding across those two different partners. Ultimately, integration means, yes, the health system and the local authority, but also the voluntary sector and businesses working in a genuine partnership with people, co-producing what it is they need in their area so that, whatever their circumstances are, they are able to access that support seamlessly.

Q72 **Mary Robinson:** Do you see challenges there? Funding pools are different between the NHS and local authorities. How would that work?

Brian Dow: People have talked about pooled budgets but, to some extent, that is a bit of a red herring. If you have a huge imbalance in terms of where the need is coming from, by definition you are going to find it very difficult to meet that need. It is much more about the spirit of recognising that all people in a local landscape can provide the support that people with severe mental illness actually need, and building that in in a way that is not about people jumping through referral hoops. Part of the problem, if you have a severe mental illness, is that you may not have the confidence, the capacity or the capability to navigate your way around the system. One of the things we are trying to pilot is a navigator system that supports people to get to where they need to go seamlessly rather than asking them to keep finding their way round.

Q73 **Mary Robinson:** Emily, what would an integrated system look like from your point of view?

Emily Holzhausen: If we ask carers, they know exactly what it looks like. They are quite often the connectors between all the different services. I spoke to one man who was caring for his wife with MS. He did a spider diagram of 32 different professionals across health, social care and housing. It was an enormous number of people that he needed to knit up and co-ordinate while also trying to juggle work and care, and having school-age children. It was an enormous struggle.



From the point of view of integration, for the carers, it is the way that health services work with each other as much as it is with how they work and communicate with local authorities. We need smoother journeys across all of these interactions. That is where it is absolutely critical to identify carers. On the social services side, we have legislation that recognises carers equally as partners in care, who have equal rights, whereas, in health, they are not systematically identified or recognised, and there are no duties towards carers in relation to their own health and wellbeing apart from being an ordinary human being. This is a problem when we come to integration. The White Paper that you mentioned earlier did not mention unpaid carers at all, even though it was across health and social care.

One of the things that we are recommending and that we would like to see is the Health and Care Bill include a duty to have regard to carers and to promote their health and wellbeing, as well as to establish some sort of common baseline—not exactly the same because local authorities have much more beefed-up responsibilities for carers, as you know—and common understanding that would thread through everything, top to bottom, in the NHS.

Q74 **Mary Robinson:** Jackie, from your point of view, with the Bill and integration, how would it look? In particular, you have 70 members in your alliance. What is their feeling?

Jackie O'Sullivan: We would really welcome a focus on outcomes for individuals, and set that very much in the context of wellbeing. There is a huge risk, which Brian mentioned, about parity of esteem between health and social care. It needs to be equal. We cannot refer to people as patients. It would be awful if this led to the medicalisation of social care.

In terms of the budget question, some sort of shared budget could be a very good idea, partly because sometimes that brings parity. Money is often power in these sorts of relationship. It could also lead to solving some of the issues we have around people with learning disabilities and autism who end up in assessment and treatment units, where we end up with this perverse financial incentive to keep them there. They would be much better served having community care in communities but that would come from a local authority budget, whereas they then end up in a much more expensive assessment and treatment unit but that comes from health funding. That is part of the challenge: trying to find solutions for them. It is definitely worth exploring the shared budget ideas but the main thing is a shared framework of outcomes for individuals.

Q75 **Mary Robinson:** Brian, in written evidence, Rethink Mental Illness said, "The NHS funding taps are on but the plug is missing". What did you mean by that?

Brian Dow: There is a huge disconnect there. At the beginning of the year, the additional money, £1 billion a year, started flowing into the community mental health transformation programme. That is incredibly



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welcome because that is trying to deliver the kind of care that I set out a moment ago. Back in March, the National Audit Office found that 94% of local authorities were planning some cutbacks to services. Given everything that we have talked about, it demonstrates that there is additional money going into one part of the system whereas the spend is required somewhere else.

I can give a very live example of that to the Committee. The Crisp commission recently assessed that 39% of delayed discharges from secure care were due to a lack of appropriate housing in social care. Why is that a problem? The cost is about £130,000 a year for somebody to be in secure care. We did some analysis; it is not perfect, so I would not want to over-egg this particular pudding, but just four of our accommodation services provide that sort of step-down support to people, funded by social care, and we reckon that we have saved the NHS hundreds of thousands—possibly as much as £750,000. That is a really good example of the fact that money is being spent in one place but, unless there are the funds to meet the need somewhere else, people get stuck in expensive care. That is not good for them, the system or the families. We need to get that balance right. Put the plug in and fill the bath up so that people get a nice, warm bath.

Q76 **Mary Robison:** Is that a conversation that you foresee would be had under a properly integrated system?

Brian Dow: Yes. In those place that we work in very closely, that is beginning to happen. You are getting all the players together who have a genuine voice at the table, able to identify what is going wrong across those different areas of health and social care.

Q77 **Mary Robison:** Just more widely with regard to where a person may have two or more conditions, the Papworth Trust suggested that problems arise in those cases “when health and social care are funded from different budgets and are not strategically linked”. Should there be one joint budget for health and social care at a national or local level? Is it national, local or both?

Brian Dow: In a different ICS or local authority, the need is greatly differently. So long as the total pot is there to meet the need, then that is absolutely fine. As both Jackie and Emily said, it is certainly an aspiration to work towards. To some extent, the issue has been that the two different parts of the system have totally different responsibilities and work in very different fashions. Again, in the case of mental illness, it is only relatively recently that we have started getting even the prevalence data in a local area that would be able to provide the benchmark for any kind of social care or health provider to meet the need that exists. It depends on having a good understanding of your local community. That is certainly an aspiration to work to, as long as that total pot meets that need.

Q78 **Mary Robison:** Steve Scown, CEO of Dimensions UK, which supports



people with learning disabilities, told us, "Services for working-age adults, people with learning disabilities, are not on that integration agenda at all". Do you agree and, if so, what can be done to change that?

Jackie O'Sullivan: I would not say they are entirely missing but they could be a lot stronger. The starting point would be a greater engagement with people with lived experience. Working-age disabled adults should explicitly be part of the integrated care system's priorities. The NHS long-term plan said that we should have a named individual for learning disabilities and autism, and that they should be part of the system. We would actually like to see them as part of the board to give that greater emphasis and priority, putting them at the heart of decision-making.

Emily Holzhausen: I agree with my colleagues, particularly Jackie, about getting that voice integrated. I am sure Brian would agree too. I am very pleased to see that some integrated care systems are starting to have a senior officer who champions carers. We have seen that in one or two areas where we have somebody with a specific responsibility for carers. That is not, by any means, in every single area. For us, that approach really helps across the system.

There are certainly some challenges around pooled budgets because the local authorities are not necessarily coterminous with ICSs. Where pooled budgets are possible and we have, as Jackie said, aligned outcomes and aligned assurance frameworks, we hopefully get closer to the same shared or understood strategic goals as well. That should come back to improving the health and wellbeing and the lives of all the people that we represent and who need care and support of all kinds, including healthcare.

Brian Dow: I absolutely agree. Fundamentally, we can talk about reform, integration, pooled budgets and so on but, unless we start with the basics and recognise that the people with a long-term mental illness have a disability—this does tend to get dominated, for obvious reasons, by people who are older—and recognise that need that exists in the system, we will not genuinely have social care reform.

Q79 **Chair:** None of you argue that the NHS should take over social care and run it as one system. You were all talking about sharing, collaboration and working together. Is that essentially the way that things should progress?

Brian Dow: I am not sure there is any appetite for any restructure there. Gradual collaboration, as Emily said, based on a shared understanding of what we are trying to achieve, driven by people who are experiencing, in the case of people I represent, mental ill health, is the solution, rather than doing a big structural reform.

Emily Holzhausen: No, because there is no requirement to identify carers in the NHS. They have very few rights and entitlements to their



own support, so I would worry that the legislative structure is not there to then deliver the support that carers need.

Jackie O'Sullivan: No. We have talked a lot about how good social care can relieve some of the pressure on the NHS, but it is really important that social care exists. It is there for the quality of life for individuals, giving them the maximum comfort and independence at whatever stage of life they are at. It would be awful if this led to care being medicalised and people being treated rather than people being in control of their own lives and in control of their own care.

Chair: Thank you all very much indeed. Those were really clear answers right the way through indeed. That is very helpful to the Committee. Thank you all very much.

Examination of witnesses

Witnesses: Fazilet Hadi, Ruthe Isden and James White.

Q80 **Chair:** We have three witnesses joining us now for our second panel. I will ask each of you to introduce yourselves.

Fazilet Hadi: Good afternoon, everyone. I am Fazilet Hadi. I am head of policy at Disability Rights UK.

Ruthe Isden: My name is Ruthe Isden. I am the head of health and social care at the charity Age UK.

James White: I am James White, head of public affairs and campaigns at the Alzheimer's Society.

Chair: Thank you all very much for joining us this afternoon. First of all, we will look at the recent Government announcements.

Q81 **Florence Eshalomi:** Good afternoon to you all. You will have heard some of the issues that we raised with the first panel, coming back to the big question about funding, and you will know about the recent announcement on social care funding with the £5.4 billion over three years. Of that, £3.6 billion will be for the new funding cap, which would be means-tested. We also have the additional £1.6 million for local government each year over the next few years in the spending review. Do you think this is going to cover all the services and, in particular, adult social care?

James White: The Alzheimer's Society welcomed the announcement of the health and social care levy. It is an important first step in the reform process, because there has been inaction for a very long time. However, we have some concerns about the inequitable allocation of the funding to social care, as well as the amount of funding that has been set aside in terms of workforce and the level at which the cap has been set. We are disappointed that there was not a specific announcement on social care funding in the spending review. As you said, in terms of the announced funding, some of it is ringfenced for areas outside in terms of the local



government settlement. In practical terms, there is about £1.5 billion per year left over to cover social care and the additional demand on all other council services. Effectively, we feel that there has been a real-terms cut in light of recent announcements. It was a guarded welcome back in September but we have concerns.

Ruthe Isden: We would agree. In terms of the additional money that has been announced, there has been analysis from the King's Fund suggesting that, once you have added it all together, you are looking at about a 1.8% increase in spending power on the part of local authorities, once you have taken into account some of the other responsibilities that they will be asked to take on as part of those reforms. In the face of the challenges of the social care system as it stands, that is really not going to be adequate to the task.

Looking at other estimates, the Health and Social Care Committee estimated last year that we really needed a £3.9 billion investment in social care, effectively to stand still. That is a broadly accepted figure amongst other commentators. The Health Foundation more recently suggested £3 billion this year, rising to about £4.8 billion by 2024-25. Again, that is to stand still, effectively, where we are.

If we want to look at improving the system and making some of the changes that we would all really love to see come through, to support the changes in the cap and the means test, and to support the ambitions of the White Paper, we are realistically looking at a £7 billion investment, rising to about £9 billion over that timeframe. Set in that context, we can see that what we are working with is really quite a small down payment on that.

Fazilet Hadi: The Government announcement was totally inadequate. Funding needs to be based on really clear values and a really clear strategy. Funding does not come first; funding follows your strategy. Social care is in utter crisis. The Association of Directors of Adult Social Services' latest survey report shows that, as Stephen Chandler said, everything on the dashboard is red. Those are real people's lives. This is disabled people, old and young, experiencing really unacceptable levels of service or no service.

We saw in the pandemic that services for disabled people and social care were initially treated as poor relatives of the NHS. As the months went by, some of us thought there was a glimmer of hope that the Government did believe in parity between the two services, with the NHS helping to fix people and manage conditions, and with social care helping us to lead our lives. If we start from the premise that they are different but equal services, we might go to a very different place in terms of funding.

Q82 **Florence Eshalomi:** Yes, I agree with you in terms of disabled people during the pandemic. I spoke in a Westminster Hall debate organised by Elliot Colburn MP on the impact of Covid-19 on disabled people. In terms



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of funding, after three years we are going to see money from the health and social care levy being shared between the NHS and social care in a proportion that is going to be outlined and determined by the Treasury. Coming back to how that split will be, what should the Treasury take into account when making that decision?

James White: It is really important that they take into account the fact there are 770,000 people with dementia in England. That is a figure that is going to rise to about 1.4 million by 2040. We are going to have to contend with a really sharp rise. There is a lot of pressure on our social care system at the moment. That is only going to increase, as things stand. As Ruthe was saying, the £3.9 billion that we talked about is just to stand still and maintain current standards. If you take that logic and follow it through, that would suggest that you really do need look at how that levy funding is going to be allocated to give social care the reform that it needs.

It is also really important that there is certainty. For too long, there has been a lack of clarity about what funding is coming through. In order to enable providers to plan effectively, there needs to be certainty about that settlement. Overall, if we are serious about social care reform in this country, we have to fund it appropriately.

Ruthe Isden: I would certainly agree with a lot of that. In the NHS, we are seeing this tremendous backlog emerging, and we all acknowledge that it is very important to deal with that. Going forward, we have to be incredibly mindful of the fact—it may be that we have to go back and look again at the levy itself and the total quantum of funding that it raises—that there is also an incredibly large backlog developing in social care.

I have seen this myself. We have been tracking the impact of the pandemic on older people. It is coming up on two years now. It is fair to say that carers, older people and many other people are in a profoundly worse position than they would have been without the impact of the pandemic. We have seen people losing mobility, strength and balance. They are living in more pain, and more conditions have gone unaddressed. We have to be really realistic about where we are and what demand looks like as we come out of the pandemic compared with where we thought we might be at this stage.

As part of that context, we need to understand that and we need to have a very realistic picture of that. We need to set that against a very realistic picture of costs to the NHS. That is why I am not sure the right way to come at this conversation is to ask, “How much of the levy should go to social care and how much should go to the NHS?” We need to be looking at both of the services and what they need in order to address the demand as it emerges. We do not do ourselves any favour by robbing Peter to pay Paul.

We know the NHS has a tremendous challenge to deal with. These things are interdependent. It does not do social care any favours if the NHS is



not able to work through the backlog. People are in pain; people's conditions are going untreated; and they are deteriorating while languishing on waiting lists. That drives social care demand. Equally, if there is a lack of social care—for example, if people cannot be discharged safely in the community or if they cannot stay well at home—that is going to drive NHS demand. We need to look at the quantum that is required across both services and think about how we fund that. If that means we need to look again at the quantum of funding required, that is what we need to do.

Fazilet Hadi: The Government need to make an announcement that social care will get the money it needs. If that is £12 billion, so be it. I do not know whether it should come from the levy, because that does seem to disproportionately affect people on low incomes, but that is another discussion point. Social care and health must have parity. Even in this Government announcement we see health getting the money straightaway and social care having it deferred until October 2023; we have social care being told what they will use it for, which is capping care costs. That takes up most of the money.

It does not feel completely honest and transparent. There must be parity. It is foolish for there not to be parity. As we starve social care, we are creating expense in health that does not need to be there. We are creating more acute need rather than coming in early to prevent need.

Florence Eshalomi: I agree with all of you, and I am really acutely aware of the NHS backlog. I have St Thomas' in my constituency, and I met with the chief exec on Thursday last week to talk about the backlog. Equally, I know the issues around social care.

Q83 **Ben Everitt:** Fazilet, this really follows on from the thread of your answer to Flo. The Government have made a series of commitments about how individuals will pay for their care. There is the cap on costs at £86,000; there is the upper capital limit of £100,000 and the lower capital limit of £20,000. Last week, we had the amendment to the legislation that said the cap only covers the costs that individuals pay themselves and not the costs that local authorities would pay towards that £86,000. What do you make of these reforms in terms of what is passed on to individuals?

Fazilet Hadi: The first thing I would ask is why I can go into hospital and get a hip replacement free at the point that I need it, but it is different if I need some support in my home to live with dementia or other conditions, learning disabilities, or because I have physical difficulties, whether I am young or old. Why are we a society that treats that differently?

Coming back to your question, both services should be free at the point of use. We should fund that through taxation. I cannot believe that we are a society that does not think that is the appropriate thing to do. I find that quite upsetting. If we look at the announcement, there is this £86,000 cap. Say I am a 30-year old needing support in my home



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because of my disabilities. I am trying to live a life, perhaps mainly on benefits because of my conditions or perhaps with a little earned income. I am having to pay for my care costs up to £86,000. A colleague of mine tells me that that could take me 10 to 15 years to pay that £86,000. I have no chance of building up savings. I have no chance of leading a life—I have to pay these charges.

If I am older, there are well-rehearsed arguments in the press that the poorer I am, the more disadvantaged I am. I find the proposals completely unacceptable and inappropriate. If we are going to spend £5 billion on social care, surely we could come up with a better solution than that.

Q84 Ben Everitt: James, in written evidence, the Alzheimer's Society has suggested that it would endorse a cap and a floor, but it depends on where they are set. Are those settings of £100,000 and £20,000 something the Alzheimer's Society would endorse?

James White: That is right. Since submitting our written evidence, there has been something more substantive to talk about. To take your question in its entirety, there are elements to be welcomed. Broadly, we welcome the changes to the upper and lower capital limits. However, we do have concerns around the £86,000 cap. As was heavily publicised last week, not all of the costs that people incur will count towards that cap. On average, a person with dementia paid just under £100,000 for care over their lifetime. If not even all of that counts towards the £86,000, you can see why we have concerns around it.

In our view, there are other ways to do it. For example, if you were to take the original Dilnot proposals and adjust them for inflation, you could perhaps reduce the cap to something like £43,000. That would cost more. It would cost £4.5 billion more than the current system or about £3.6 billion more than the latest proposal, but you would also be protecting about twice as many people for that investment. As I say, there are some things to welcome, but we do have some serious concerns around £86,000.

Ruthe Isden: Like the Alzheimer's Society, we have welcomed the principle of implementing a cap and a fully means-tested system. It is not by any means a panacea. It will not deal with all of the problems and challenges that we have discussed in the social care system, but it starts to go towards dealing with one that we know is very real for people, which is the threat of catastrophic costs.

As it was originally proposed, there was a lower level set on the cap, which is certainly to be welcomed. There was also greater fairness in the way in which it was foreseen that the cap would be distributed across your life. For people who were in the current health and social care system, some of the historic contributions of people who have already been living in a care home for a significant period would be taken into account at the point at which it was implemented.



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I would have to agree with colleagues that the changes that were proposed last week significantly watered down the benefits of the proposed system, and in fact hugely so for people with more modest incomes and assets. That is particularly for people of working age and for people in receipt of domiciliary care services or home care services. Very few people have an income that is high enough that they are paying the full cost of those services out of their pocket. To not recognise the full cost of that package is significant disadvantaging anybody who is receiving care in their own home.

As we have talked about and as has been widely discussed over the last week, this really hits anybody with assets, but, generally, when we are talking about the social care system and leveraging assets, we are talking about older people going into residential care. Most older people do not have a lot of money in the bank. Overwhelmingly, what they have is a house. As we know, house prices are wildly different across the country. It really does hit older people of more modest means who have properties in cheaper parts of the country: the north-east, the north-west or Yorkshire and the Humber for example.

We are now almost regressing to the position that we were in under the current system, which is that they are going to lose a lot of everything compared to people for whom this change will not make a lot of difference, because they are probably never going to exhaust their assets down to the level of the means test anyway. It introduces a very significant level of unfairness into the system, which was not the original intention or design.

Q85 Ben Everitt: Indeed, and the more complex we make it, the more risk there is.

Ruthe Isden: I would certainly agree with that. The cap already is rather fiendishly complicated. I do a good round in a PowerPoint presentation that takes people through it in some excruciating detail. It is complicated when you look at it from an individual level. We are introducing more complexity into that, which will make it much harder for people to understand where they stand. We are talking about extending the periods of time that people may be required to pay. Two people with similar care needs at a similar price point in the system but with very different assets could now expect to reach the cap at a very similar point in time, and they can see that. That is going to start varying quite significantly.

Q86 Ben Everitt: The Government would argue that some of the complications are there to make it fairer, such as the housing disregard, or the element in the calculation about whether there is a spouse in the house and whether that spouse or the care receiver is receiving domiciliary care. As we have just said, this does just add more complexity to it.

Ruthe Isden: It does.



Q87 Ben Everitt: Might that ultimately impact on our ability to deliver this and the timescale on which we can deliver it? We are trying to deliver this in October 2023. Can we do it sooner? Is October 2023 unrealistic in and of itself?

Ruthe Isden: That is a difficult question. For some of this, we are not moving that far away. Properties are already disregarded for the most part, if the property asset is still in use by the individual or a spouse, partner, dependent child or relative, who has every right to be there. In that sense, to suggest that we are doing something that changes the way in which we protect that asset for people is a little bit disingenuous in that context.

In terms of the complexity of implementation, it is going to be a challenge for local authorities to get this up and running. The systems are quite challenging. Therefore, 2023 is probably the most realistic date. You could not pull that forward. In terms of the implementation of the cap, there are things that you could do sooner than that in order to try to create some benefit for people who are currently in the system. If we are honest, a lot of the people who are in the system today, particularly older people, are not going to be with us in 2023; they are not going to see the benefit of this.

We could look at pulling forward changes to the means test, improvements in income disregards or minimum income guarantees. We could certainly look at what we are doing to improve quality and access to the current system for people who are already in it. There is a lot that we could do to move things forward, as well as perhaps going back to look at that critical point about people who have already spent a substantial amount of money on their care by 2023. We know there will be older people living with dementia, for example, who will have already spent hundreds of thousands of pounds. What can we offer them at that point?

Q88 Ben Everitt: James, is there anything else to add from the perspective of people living with dementia?

James White: Just to build on the final point that Ruthe made, it is about 15% more expensive to deliver dementia care than standard care for older people. When you have that fact, it does seem strange to us. We flagged this at the time the levy was announced. What is happening for what people are paying between now and 2023? It does seem unfair that that is not being brought forward sooner.

Fazilet Hadi: Care charges for disabled people of working age have gone up hugely over the last two years as local authorities try to bridge the funding gap. There is a certain irony that the disabled people who need the support are now having to hand over their personal independence payment, their care component and some of their benefits to pay for that support. The thought of just waiting until 2023 to make the care system better does not seem to recognise the crisis that people are in.



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Q89 **Ben Everitt:** Of course, the Dilnot commission recommended that the cap should be set at zero for disabled working-age adults until the age of 45. Is that something you would be keen to see? I recognise that in your earlier answer you did say that it should be free at the point of delivery for everybody.

Fazilet Hadi: Free at the point of delivery is my gold standard, but, yes, I would like to see the Dilnot recommendations implemented.

Q90 **Ian Byrne:** As of 2020, Carers UK estimates that 13.6 million people were providing unpaid care during the pandemic. It is estimated that this unpaid care has saved the economy £132 billion a year. Many of these carers are older themselves. There are an estimated 2 million carers over the age of 65, of whom 417,000 are aged over 80. In 2018, a survey from Care UK said that 72% of carers experienced mental ill health as a result of their caring responsibilities. The figures now, amidst a pandemic, must be even more terrifying.

The Joseph Rowntree Foundation reports that poverty captures a quarter of carers, with women carers experiencing higher poverty rates than men. Do the Government recognise these numbers and the importance of unpaid care?

Ruthe Isden: We have a tremendously long way to go. That is partly for the reasons that were outlined in the previous session. As our colleague Emily from Carers UK said, one of the single most important things that we could do for informal carers is resolve the challenges in the formal care system.

Over the last decade or more, informal carers have been at the sharp end of three trends. The first is rising acuity. That is great news in lots of ways, because people can live a lot longer with much more complex conditions than they could ever have done in the past, but the social care system has not moved to recognise those facts. We are still operating a social care system that is centred on a much more historic understanding of the level of acuity that a person with social care needs might experience.

At the same time, we have seen a rapid reduction or a shrinking of the formal offer from the state. Eligibility thresholds have gone up. The amount of care that people do receive when they are in the care system is smaller; the budgets are smaller. Everything about that offer has shrunk.

As a result of some of those things, particularly that withdrawing of the state, we have seen major disruption in the wider social care market. Even people who are choosing to or required to purchase their own care or organise their own care in that market are now trying to do that in a much more disrupted and much less stable environment. You can see that in all sorts of contexts, not just domiciliary care and care home services, as we typically talk about, but also day centres and lunch clubs. There was a whole wraparound piece being sustained by that ecosystem,



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which was so important to people. A lot of that has disappeared. The pandemic has really accelerated these trends. The problem is that informal carers get stuck on the front line of that, because in a lot of these contexts they are the one person who has to continue absorbing more and more of the burden of the support requirements that somebody has. It is a really negative position for carers to be in.

It is also incredibly difficult for people receiving care. At Age UK, we estimate that there are about 1.6 million older people who have unmet social care needs. In most of those circumstances, they do get support, primarily from family and friends, but what family and friends can do is not simply enough. There are not enough hours in the day. People only have one pair of hands. As you alluded to, a lot of carers are often older people themselves, especially spousal carers. They have their own health conditions going on.

First and foremost, we need to get the balance right and shift the balance back so that what we are asking of informal carers is appropriate and sustainable, and ensures that they can continue meeting their own needs within that context. There is a whole other set of things that we could look at doing to support carers more directly. I agree with colleagues who have talked about the level of carer's allowance, for example, and the financial support to carers. Often people are giving up work. The amount of money that they are able to claim for that is incredibly small. It is a very, very low level.

We do not invest a lot in supporting carers directly. There are some things around respite. As I said, a lot of those more day-to-day respite services like lunch clubs and day centres have disappeared in lots of parts of the country. That does not help.

Coming off the back of the pandemic—this is an area we have done research on again and again; we are on the third wave of research now—it is notable that the two areas where you see the greatest inequalities emerging in older age groups are people in lower socioeconomic groups, which is what we would expect to some extent, and carers. Carers talk about how they are living in more pain; they are more anxious, more depressed and more likely to report a breakdown in their own health and wellbeing.

To reflect on some of the comments from our most recent round, if I may, people are saying things like, "I have begged for help, but I cannot get it"; "Support locally is almost non-existent"; "Total failure"; "The system has died"; "There is nothing for me anymore". Those are the kinds of verbatim quotes that we are getting back, because people are knocking on doors for support, but it just is not there for them at the moment.

Fazilet Hadi: Why would we not, as a society, want to help people support their loved ones? As Ruthe said, we are not doing enough. Instead of thinking about rolling forward the models of care that we have,



we should be thinking imaginatively about how we could help more people to become carers by providing the right respite, the right income support and the right flexible working. That should be a really creative way of helping people live in their own homes and with their own families as long as humanly possible. We need to think about different service models, whether that is about how we support the carers that we have, have the right incentives to encourage more people to support their loved ones, support people to live in their community for as long as they can in their own homes and support people to live in community settings where they need a bit of extra care support.

I do not know why there is a lack of imagination from Government in terms of how the money can be used differently. When we talk about injecting money into the system, we should not just say, "Let us inject it to do what we are doing now." We need to inject money in to do what disabled people and people who are supporting us want to be done. We could do with a bit more consulting with us about what is needed as opposed to consulting with service providers.

James White: The Alzheimer's Society is here for people affected by dementia. In the context of this question, there are around 700,000 informal carers working with people and helping people with dementia. They do an absolutely incredible job, but the pandemic, as in so many cases, has left people completely worn out. We hear stories about people feeling isolated and struggling to cope.

There are a couple of tangible things that we think would improve the situation. I would echo a lot of what has been said in this session and in the previous one, but we would like to see, for example, the Government requiring public health bodies to collect local health authority-level data on the number of assessments that are taking place. In terms of the language that is used around assessments, quite often we hear that people feel a sense of guilt about looking to access support. The terminology of assessment is quite disempowering. We could look at something there.

All reform simply has to recognise the absolutely incredible and vital role that informal carers play. That should be a cornerstone of any reform.

Q91 **Ian Byrne:** I will go to you now, Ruthe. In written evidence, Age UK called for a new deal for informal carers. You might have touched on a bit of it in your first answer, but what would Age UK want in that deal specifically?

Ruthe Isden: Over and above that question about sorting out the system more generally, we certainly support the work that Carers UK is doing in thinking about a new deal for carers. One of the first planks of that is thinking about better financial support for carers. As I touched on, carer's allowance is incredibly low. We are often talking about people who have given up their place in the workforce. It can be very difficult for them to go in; they have to reduce their hours. People are taking a very



significant financial hit. That follows people long term as well. Mid-life carers are people who are coming into later life with lower pensions and all sorts of things on their own part. We need to recognise that.

We certainly need a significant investment in breaks and respite. Services that support carers to have some time back for themselves are incredibly important. As I mentioned, respite care has all but disappeared, as have a lot of those day services that provided some of that support as well.

Q92 Ian Byrne: That would be free at the point of use.

Ruthe Isden: In an ideal world, yes. We would certainly echo the sentiments that you have heard from others today in your evidence session. In an ideal world, the whole system would be free at the point of use, and we would deal with who pays what and the fair distribution of that at the front end through the taxation system.

That is not quite the world that we live in, as things stand, although it is where we would ideally like to be. The more you can do to encourage people to take up these services and not penalise them for using them, so much the better for supporting unpaid carers. You have to think about it as an investment in unpaid carers to carry on doing what they are doing.

The third area is in addition to work that Carers UK did last year. Coming back to those sentiments and the issues that I have seen through our own research about what has happened to people over the course of the pandemic, we need to ensure that carers and the people they care for are in no way disadvantaged in terms of Covid recovery. We need to think about them as part of that recovery piece. We need to think about ensuring that they do get access to health services. As I have said, we have seen a lot more carers reporting that they are in pain and that they are going untreated for particular medical conditions. When we are looking at ways of tackling the NHS backlog, for example through hub centres in urban localities, we need to be making sure that carers can get to those. Can they avail themselves of them or will they just get left behind at the bottom of the list, because they cannot travel or be flexible about how they use their time?

We need to think about how we prioritise the things that we might want to do across our communities in order to help people recover and the types of support services we might put back in place. For a lot of people, this is about getting leisure centres reopened again. Many people say, "One of the single best things you can do to help me recover and regain some of my health is to get swimming back on the agenda." People really value it. It is one of the ones that comes out top. How do we make things like that inclusive and accessible for carers? That is partly about thinking about them and their needs, but it is also about asking whether they can take the person for whom they care swimming, to an event or to a service. If it is not inclusive for the person for whom they care, it is not inclusive for them.



Fazilet Hadi: I agree with all of that. When we are thinking about carers, we also need to think about the disabled person they are caring for and whether they are getting the best support. It is not an either/or. You need happy and supported carers, but you also need stimulated disabled people who are connected with the community and with the activities they can still enjoy. We need to look at both. The state needs a role in making sure that—I do not even like to call it “informal caring”—care arrangement is the best it can be for both parties.

James White: From a dementia perspective, we hear that there is a lack of dementia-specific support services. That relates not just to people with dementia but to carers as well. That would be one tangible thing that we think would make a big difference. Again, we would echo an awful lot of what has been said.

Q93 **Ian Byrne:** I will stay with you now. In written evidence, the Alzheimer’s Society stated that 53% of carers have had not a carers assessment. What are the consequences of this? Do local authorities have the funding resources to undertake the assessments?

James White: Yes, we did. It was interesting to hear in the previous session that people agree with those figures and that their own findings are even worse. For us, we think there are solutions. The Government should require public health bodies to collect local authority-level and health authority-level data on the number of carers assessments that are offered but also the numbers that are actually taken up. Within that, the actual nature of the caring responsibility should be recorded.

There is also something here about dementia being a progressive condition. That means those assessments need to take place on a regular basis. We would say at least annually. The condition that people’s loved ones have can alter, as indeed can the ability of the care provider to provide that care. To what I was saying earlier: we need to make the language around assessments less intimidating.

We also hear of gaps between diagnosis and people being contacted. It is not unreasonable for councils to make contact within four weeks of somebody being diagnosed to start to begin that process. We feel that clear and ambitious targets would really start to move the dial.

Q94 **Ian Byrne:** I fully agree about the assessments and the terror they can bring. What would the Alzheimer’s Society rather call them?

James White: That is a great question. We should ask carers themselves about the language that would work for them. I would not want to presume that. We do hear about the stigma around labelling yourself a carer. That would be one. Again, the Alzheimer’s Society has a great panel of people who could play a role in starting to discuss potential ideas.

Ruthe Isden: I agree. I certainly agree that a lot of people do not recognise themselves as carers. A lot of people would say, “I am helping



my husband"; "I help my wife. I am here; of course I am going to do it." We need to find more inclusive ways to bring them forward, to offer support and to make it not necessarily sound so formal. Particularly for people who have been or are going through the local authority assessment process on behalf of the person they care for, that can be quite a challenging experience. When you suggest that they should go through that all over again for themselves, people think, "No, I just do not have the energy for that". Making it more of a supportive and inclusive experience rather than a battle would help.

Ian Byrne: Yes, absolutely. We have heard figures about mental health. That is a good point.

Fazilet Hadi: I completely agree with that. Sometimes disabled people do not define themselves as disabled and sometimes carers do not define themselves as carers. We need to find a way of providing people with the right support to help them through the trickier times, not to institutionalise it, bureaucratised it or medicalise it. Yes, I quite like James's idea of asking the people affected.

Q95 **Florence Eshalomi:** I have a really quick question, being mindful of time. You have all touched on the fact that a number of people care and do not realise they are carers. I was a carer for my mum when I was younger. One thing we did not talk about was young carers who are caring for elderly residents—adults in the social care system. I spoke to a lot of young people during the lockdown who became carers overnight, having to administer complex medication or care for an elderly family member. What more needs to be done to help those carers and make sure they are part of this conversation in the adult social care world?

Fazilet Hadi: I cannot believe that any disabled adult wants to turn their child into a young carer. It points to inadequacies in the care system that they are essentially forced to. I do not believe it is a choice for everyone. Maybe it is for some people, but that choice should not have to be made. Children are children.

If we have come to the point, in a developed country—one of the richest in the world—where we expect children to care for adults, I do not find that acceptable. As a disabled person, that is not what most people want. Do not get me wrong. If I am in a family, I might need assistance; I might need an arm down the road; I might need some help with various things. That should be in addition to me receiving state support, not instead of.

Ruthe Isden: One of the things about the pandemic is that we need to accept that we are not where we were two years ago, and we are probably not where we thought we would be heading into 2022. One of the ways in which we are not is that an awful lot of people have found themselves carers overnight. That was in part because of the nature of the lockdown itself. People did not feel able, or were too afraid in lots of cases, to have people coming into the house. Lots of people stopped



domiciliary care services. That was a decision taken by the families, because they felt the risks of having domiciliary care workers coming in and out were too great.

A lot of the more periphery support was stepped down as well. If the early weeks and months of the pandemic taught us anything, it is how incredibly important people's cleaners are as a source of support. It is essential for a lot of people. People felt unable to have cleaners coming into their house. We would not recognise it as formal care support, but it was a very, very important source of that support for a lot of people. Family support networks also really shrank down to the household. Previously, neighbours or family members who lived further away were able to come in and out, do things and support people. All of that disappeared as well. It fell away, because people were not clear on what they were allowed to do or what was safe to do. We need to recognise the impact for people of all ages, but particularly young people, where that has shrunk down to the household. We need to think about how we rebuild in order to make sure those support networks come back.

One of the things we are seeing is that we cannot assume that will happen. People are not just going to bounce back for all sorts of reasons. Being told that you are that vulnerable has had a profound effect on a lot of people's identities. They did not think of themselves as a vulnerable person, but they do now after we essentially told them to lock themselves in a cupboard for three months.

A lot of those informal support networks, the community-based support and all that informal stuff, has fallen away. The clubs are not restarting; the venues are not reopening. People have lost contact with neighbours, church groups or whatever it was that was sustaining them. The more that happens and the more we allow that to be eroded, the more pressure that puts on those very immediate household members of the family.

Q96 **Mohammad Yasin:** The Government intend to publish a White Paper to address the issues of choice, quality and accessibility in social care and the social care workforce. What are the top three policies that you would want to be included in this White Paper?

Fazilet Hadi: I would like the service models for social care and a long-term plan for social care to be co-produced with disabled people, both older disabled people and younger disabled people. We cannot carry on with people who do not have lived experience telling other people how to develop a care system. I would like to see that co-production.

I would like to see personalisation, which has not really been delivered. When I need a care plan, I want to have more determination over what is in that plan and for the plan to be not just about washing, dressing and bathing but about me living a life, connecting with my community, working or going swimming, if that is what I fancy. I would like to see the



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notion of social care be much more about supporting people to live a life, not about just keeping them fed and watered.

Thirdly, I would like to make sure that disabled people can play a full part in working across integrated care and have a role in the wider system so that we begin to sit at the table when decisions are made about priorities and tackling health inequalities.

Q97 **Mohammad Yasin:** You mentioned social care. The Government have indicated that they intend to consult the adult social care sector in this White Paper. What is your experience of the consultation so far?

Fazilet Hadi: My experience is that the Government do not start with disabled people. As the head of policy for Disability Rights UK, I have not had any meetings with any Ministers or any civil servants. I have been invited to some; do not get me wrong. They were very big meetings with lots of providers sitting round the table.

We have asked the Department to listen to the voice of disabled people. They do not have to do everything we say, although that would be lovely, but should just have the decency and the courtesy to listen to disabled people who are affected by social care up and down the country. As far as I know and as far as the disabled organisations that I talk to are concerned, that has not happened in any systemic way. Do not get me wrong; I am sure the odd Minister has talked to the odd disabled person, but we are not at the heart of social care reform.

Q98 **Mohammad Yasin:** Ruthe, what are the top three policies that you would like to see added to this White Paper?

Ruthe Isden: We will probably see a great deal of agreement breaking out between us and with the last session as well. There is this question about what we are providing as part of the social care service and what support looks like. We have a very unstable market position at the moment. That stretches across the piece. We have talked about how a lot of services have disappeared and have not re-emerged post-pandemic. We really need to think quite carefully about the shape of the services that we want in the future.

In order to do that, we have to think quite carefully and understand that social care is not one thing. It represents a lot of different things to different people, and that depends on your reasons for drawing on social care, where you are in your care journey—things change over time—and partly what stage of the life course you might be at. We need to look across the piece and think that this is a series of services, which are there to do quite different things.

We would not want to throw the baby out with the bathwater. I know we often talk about how it is not just about discharging people from hospital, but support to people discharged from hospital will always be incredibly important. It is both/and when we are thinking about how we develop these services. That needs to begin with a really clear understanding of



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what people need from the system at any particular point in their care journey. We need to think about it in that context.

The workforce would be one of the other major priorities that we have not touched on yet. We need a proper workforce strategy that looks at the challenges we are facing. It should be aligned to but not subsumed into an NHS workforce strategy. They need to be completely aligned. We do not want to continue in the ridiculous position we have at the moment where care homes are relying on agencies to bring in enough nurses to cover shifts in nursing homes, but they are being gazumped by the NHS because there are not enough to go around. Care homes are deregistering their nursing services, because they cannot bring people in. There are areas of alignment that we need to get right.

In order to do that, one of the things we have called for through the Health and Social Care Bill and the White Paper is thinking about the role of registration in that. Again, it is not the be-all and end-all. You cannot just register the workforce and say, "Job done." We do think it is an important building block. It starts to give the workforce shape and form so we can start to have some proper conversations about what a strategy looks like, what training and development look like and what career structure and pay structure look like. At the moment all of those things are very difficult, in the absence of a defined understanding of who we are talking about when we say "the social care workforce".

The last thing that I would add is how we widen access and eligibility. We know that eligibility criteria have edged up and up and up over recent years. We know the quantum of care that people do receive when they are eligible within the system has shrunk. We need to reverse those trends and have another look. Although the Care Act sets out the wellbeing outcomes that people are expected to obtain from accessing care services, it is quite difficult to hold people to account for not delivering on those. We need to think about how we give older and disabled people much clearer rights and a much clearer structure to challenge where they do not think the sums of money that are being provided to them to meet their care plans are acceptable or suitable under the circumstances.

James White: As a quick plug, in September, the Alzheimer's Society published a report called *Stabilise, Energise, Realise*, which is our attempt at a 10-year vision. It has 30 recommendations. I will not go into all of them right now, but I would commend that to the Committee as well.

In a breakout of mass agreement, I would make a real plea for personalised care and the importance of personalisation. Fazilet was talking about how social care is more than just being helped to have a wash in the morning. If people with dementia are going to live their lives to the fullest, we need to think about what is right for each individual. When I started working at the Alzheimer's Society, I was told very early on, "If you have met one person with dementia, you have met one



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person with dementia". That is a really good approach to have. Specifically, we would like to see the Government set out a clear timetable for introducing personalised care over the course of this Parliament.

Secondly, as Ruthe was saying, is the workforce. You cannot do anything without having trained, motivated and well-rewarded staff. They do an incredible job; they have done an incredible job. We need to make sure we retain the very best and encourage more people to see it as a career for them.

The third point, just briefly, is about funding. I really hope the White Paper delivers the ambitious vision, but I also hope it is backed up with the funding that is needed. The 200,000 people with dementia who have moderate care needs at the moment do not get any support. We would like to see that addressed as well. Those would be my three.

Q99 **Mohammad Yasin:** If I stay with you, both the Alzheimer's Society and Age UK said in their written evidence that as part of the reforms adult social care should be free at the point of use, like the NHS. I would love it if that happened. It needs extra money. Do you have any figures in your mind as to how much extra money we would need to do that?

James White: I defer to Ruthe. If we were talking about £3.9 billion just to stand still, you can get the sense that it would have to be significantly higher than that.

Ruthe Isden: It is not something that has been analysed in great depth over a period of time. In 2018, the King's Fund and Health Foundation estimated that implementation of free personal care—that is a little bit of a caveat—not free care in total, would cost around £6 billion in 2020, rising to around £8 billion by 2030.

More recently, the Health Foundation's REAL Centre has estimated that the cost of a zero cap—again, pretty much care free at the point of need, although with some caveats around it—as around £8 billion. Those would be figures over and above the sums we are talking about in terms of sustaining the existing social care infrastructure in the face of growing demand.

Fazilet Hadi: One point that I would make is that we must not just spend on rolling forward what we have now. People do not want what we have now, and it is ridiculously expensive. We need more imagination about supporting people to live in their own homes, supporting carers and taking disabled people out of long-term institutions if they do not want to be there.

If you look at the Association of Directors of Adult Social Services report, they are literally placing people in care homes, or trying to, because they do not have the staff to support them in their own homes. To roll forward that system is just crazy. If we can get in earlier—Ruthe and James have



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made this point—and provide services to people with moderate needs, we may save ourselves an awful lot of money. Whether it is £8 billion or £12 billion, we need to be sure that we are funding what people want, which is not often the expensive solutions.

Mohammad Yasin: I absolutely agree with you. Thank you all.

Q100 **Brendan Clarke-Smith:** Good afternoon, everybody. Earlier this year, we had a White Paper and a Bill on the integration of health and social care. In our last evidence session, our witnesses said that there was not really that clarity on what “integration” actually means. What should integration mean? How should that work?

I will give an example. The Papworth Trust suggested that problems arise for individuals, particularly those with two or more conditions, when health and social care are funded from different budgets and are not strategically linked. They question whether there should be one joint budget for health and social care at a national or local level, for example. **Fazilet**, what does integration mean to you?

Fazilet Hadi: To me, integration means acknowledging that 80% of the determinants of health are not anything to do with our health service; bringing people together and getting out of the silos of social care, health, housing and public health; bringing in the voluntary sector; and looking at the population’s needs.

The thing that excites me most is looking at the population health of an area and tackling health inequalities. The danger is that we could be moving around a lot of deckchairs and setting up a lot of new boards with a lot of well-meaning people sitting on them. If it is done right, if the culture change happens and if people do collaborate genuinely, it could mean that people start with the person, the disabled person, the carer, the person who needs a health intervention, and work out the best thing to do for them as opposed to thinking in their little boxes.

There is a lot of work to do. The comment was made earlier about how disabled people, carers and others have to be part of the top-level conversations at the integrated care partnership and the integrated care board. Otherwise, it is just these leaders talking to each other. We may not end up much further on.

Ruthe Isden: This comes full circle to something that I said earlier, which is that social care is a lot of different things to different people at different points in their lives. Our starting point around integration is that we need to take a population view. We need to think about which groups of people are drawing on social care for different reasons at different points in their lives and what integration means in those contexts.

An example would be about the level and nature of integration that you would be looking for around, for example, routine social care in the NHS, when you are talking about ensuring you can safely discharge somebody



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who is profoundly unwell back to their own home or when you are looking at supporting somebody towards the end of their life.

Particularly for care homes, for example, we are talking for the most part about profoundly unwell and frail people, who are coming to the last years of their life. That is very different to the type and nature of integration that you might want to look at, for example, for a young person coming into adulthood with learning disabilities who has stable needs. For them, it is about independent living, accessing education and employment, and getting themselves set up and moving in their life. Those are quite different things, and you would want to look at them through quite different lenses. That would be my starting point.

The idea that some of our problems would be solved if we just took structures and integrated them by smushing social care wholesale with the NHS does not work for everybody. It might suit some groups of people and might be exactly the sort and level of integration that they are looking for. It would not be a good policy position for others. I am sure Fazilet and other people could say more about that.

That is the starting point. Who are we integrating for and why? What are their needs? Therefore, which services need to come together, collaborate and integrate? Therefore, how might we integrate the funding around some of those? There are cases where you might say, "Well, perhaps the NHS should be the lead commissioner for services for some people, but not for social care as a whole". That might be a position we move to, where budgets are more integrated.

I would just finish by saying that one of the really good examples I always come back to is the enhanced health in care homes programme, which has taken us forward a tremendous way. It is a really good example. There is a lot further to go and much more that we could do around that programme, but we are thinking very specifically about the needs of care home residents, what social care can be providing within that context and the input that the NHS needs to be bringing, and how we make that work around the lives of the residents in the most seamless way possible for them and their families. That is the model we should be looking at for other groups of people as well.

James White: However you define integration, one way you can judge whether it is a success is whether it works for people with dementia. That is one condition that clearly cuts across both health and social care. However you are going to assess the success of integration, if it works for people with dementia and they are reporting improved outcomes, that is a good thing. It would be a little more preferable to have this conversation in a week or so when we have had a chance to digest what has been said in more detail around social care. Without that social care plan, you cannot really have a full discussion about integration as well. I would agree with a lot of what Ruthe has said in terms of the specifics and the complexity.



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Q101 **Brendan Clarke-Smith:** Fazilet, if I can just come back to you, Steve Scown, the chief executive of Dimensions UK, supporting people with learning disabilities, told us, "Services for working-age adults, people with learning disabilities, are not on that integration agenda at all". Do you agree? If so, what can we do to change that?

Fazilet Hadi: I do not know what issues are on that agenda yet, because so far the agenda has just been around structural change. "Who should sit on this board? Who should sit on this other board?" It will be played out in the 42 different integrated care partnerships. The ones that do begin to talk to the voluntary sector and to disabled people's groups will be the ones that populate their agendas with the right kinds of things. The ones that just talk to each other and exclude the community from their dialogue will, unfortunately, not have the right things on their agendas.

The jury is out, but everyone should be working to make sure the 42 ICSs talk to their communities and disabled young people with learning disabilities and others are on that agenda. This is all going to play out not because of legislation but because of work on the ground and how the leaders behave in each of those individual partnerships.

Q102 **Brendan Clarke-Smith:** James, if I could just come to you, in written evidence the Alzheimer's Society pointed to gaps in the data we have for social care at the moment. The Government's integration White Paper has promised that that is going to improve, that the sharing is going to improve and so on. What is your assessment on how this is progressing at the moment?

James White: It is a work in progress. The pandemic has had a significant impact, because certain requirements for data collection understandably were dropped. We need to make sure that data comes back as soon as possible. In a number of answers today, I have spoken about the need to strengthen that data collection, because it will help inform the quality of services that people go on to receive. We do hear from carers particularly that there is a consequence of that discrepancy. It is improving, but it would be interesting to come back in a future session and give a more fulsome answer there.

Ruthe Isden: This is one area where some of the reforms will be helpful simply because there is so little that we know about social care. As became very apparent to Government and a lot of national bodies at the beginning of the pandemic, there was very little known and very little understood even to the extent of how many people received it and where they were, or who the providers of social care were up and down the country.

As part of the pandemic, we have gone some way towards accelerating our understanding of that nationally in collecting information through the capacity tracker and others. The thing that concerns me is that we still have a huge blind spot about both people who are receiving social care



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informally from family and friends—we just do not know that they are there—and people who are receiving it formally but are self-funding their own services. Very little is known about them. We certainly do not know much about people who are outside of the system who have care needs that currently cannot be met in one way or another.

All of that curtails our ability to have a very robust conversation, particularly when we come back to these questions about what kind of services we want and need. At the moment, we cannot even give a very accurate assessment of how many people need them and where they are. If so, that is probably a starting point. We need to start thinking about how to collect that data, including self-funders and people in informal care within that.

Q103 **Brendan Clarke-Smith:** Fazilet, do you have anything else you would like to add on that?

Fazilet Hadi: On integrated care partnerships, my colleagues are right that we need to understand how social care and health come together. It may not be called “budgets”. I very much doubt it will be, because local authorities and the NHS are funded very differently. If there can at least be good dialogue at the integrated care boards about how that money is being spent in the most sensible way to benefit populations, that would be a huge step forward. It is a positive move, if disabled people, people with health conditions and carers are involved. It is not a positive move if it is just, as I say, moving the deckchairs.

Chair: Thank you to all three of our witnesses today. That has been very helpful for the Committee. We have gone into lots of detail on some really challenging subjects. Hopefully that is going to inform the Committee when we come to do our report, which looks at the challenges and the opportunities that exist in this very important area. Thank you all very much indeed for coming to give evidence this afternoon. That brings us to the end of our public proceedings for today.