Reflections on 'A gloriously ordinary life': In conversation with Baroness Andrews

Episode transcript (automated)

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

Kate Hamblin:

Hello and welcome to another edition of the Care Matters podcast. I'm Kate Hamblin, the lead for the Digital Care theme in the Centre for Care and a member of the IMPACT Implementation Centre's leadership and delivery teams. This episode focuses on a recent House of Lords Committee and report.

The House of Lords Adult Social Care Committee has been looking into what needs to change to create a fair, resilient and sustainable care system that enables everyone to live an ordinary life and in doing so, have greater choice and control of their lives.

In December, the committee published its report "A Gloriously Ordinary Life': Spotlight on Adult Social Care', and today I'm joined by the chair of that committee. Baroness Andrews. Baroness Andrews was the government whip and spokesperson for the House of Lords for Health, Work and Pensions and Education and Skills from 2003 to 2005, before becoming the Parliamentary Under-Secretary of State at the Department of Communities and Local Government from 2005 to 2009. She then moved from 2009 to 2013 to be the chair of English Heritage. Welcome, Baroness Andrews.

Baroness Andrews:

Thank you so much. It's very good to be here. I'm very happy to take part in such a useful podcast.

Kate Hamblin:

Thank you. I found the report really fascinating and I was, full disclosure, asked to give evidence at the enquiry, but would you mind maybe telling the listeners first a bit more about the inquiry and its origins?

Baroness Andrews:

Certainly. I'm so glad you gave its full title because 'A Gloriously Ordinary Life' was the title suggested to us by one of the people that we took evidence from, and it sort of sums up actually what it was that we eventually wanted to say in very succinct language.

It was a short select committee inquiry and we have two types, one set of select committees run for three years, a more or less permanent. And then there are a series of ad hoc committees which we volunteer and offer up as subjects which are very appropriate for a shorter inquiry, which across different areas of policy.

And because adult social care is such a key issue at the moment, is such a contentious issue, such an important area of policy, one of the members of the House of Lords, Lord Laming, suggested that we looked at adult social care, but we all agreed once the committee had been appointed and I should say we came from all parts of the House, every policy. We had a bishop, Bishop James of Carlisle, and of course as well. We all agreed that it was an enormous topic, a very, very well trampled over topic. And we should find something which nobody had really focussed on. And so the original focus of our inquiry was to be on unpaid care, because the whole set of issues around unpaid care care in the home, a relatively invisible and very, very hard to grasp because the data isn't there and these millions of people and the number does vary between five million and above.

These are the people who really are the backbone of the system, without which the whole adult care set of provisions simply wouldn't work. And in deciding to do that, because what we realised it very quickly was you couldn't talk about unpaid carers without talking about the whole set of issues around disability and and growing older and dementia and all these issues which are associated with care. The people who receive care and the people who provide care in the home are two sides of the same coin. And so the to my great joy, to be honest, actually, we found ourselves in the middle of an inquiry where we were looking at both the whole range of issues around chronic disabilities, adults, current disability and so and young adults, working adults, older people. All these issues which raise the crucial question you've already raised is how do people get to choose what's on offer and how did they get to choose what is best for themselves?

And so it was a very satisfying, coherent committee. And we finished- We had a year, we took advice from Andrew Dilnot as well. And he said to us and it was very striking. And we followed his advice that one of the problems about adult social care in its whole is it's invisible.

I mean, we all know now about care homes, COVID made that such an incredibly important and dramatic and awful issue, but the rest of adult social care is relatively invisible unless you're in it, unless you've come up against it.

And that is what makes it so difficult to create a visible policy for it. So those are all some of the issues which we wrestled with. And when we published our report in December on time, of course we had to wait for people's judgement.

I'm very pleased to say that the report has been well received. It's seen as optimistic positive, a new positive approach to adult social care, seeing it for the huge, huge benefit it is to us all, and with some good press for recommendations.

Kate Hamblin:

Oh, absolutely. And I think the thing that really struck me that, you know, you did it in a year, but the sheer range of people you spoke to, you know, so much lived experience in there, so much people with practice experience, academics, just a huge number of voices in there.

And it seems like there was a very reflexive process of expanding that focus away from, okay, we can't look at unpaid carers. We need to take a whole systems approach to this. Really interesting. And I think another thing that struck me was the sort of the foregrounding of care will affect us all.

This isn't a peripheral issue if this is, you know, it's invisible, but it's so common in all. It will be increasingly common as we age. So we can't keep ignoring it. And it was really things that struck me.

Baroness Andrews:

Well, thank you for saying that, because you're absolutely right. I mean, just on the invisibility point because, you know, we explore the reasons why it is invisible, because its historically invisible, it was never in the heroic settlement of the welfare state in 1945 because the demography was so different.

Expectations around what women did was so different people didn't live as long, especially people with disabilities. We weren't planning for an ageing society in 1945 and consequently nobody actually

caught up with the issue and we've known about ageing is hardly a surprise, but we've still not actually thought about the implications.

And this is one of the implications of course, and one of the issues that we addressed, you know, we couldn't address it thoroughly, but we raised it was that we have a million people already ageing children and it would be 2 million in ten years.

But in terms of the range of voices, so what we wanted to do, we wanted this to be a different experience and we decided that we would co-produce it with as many people as possible. And it really was, course, because it's such an interactive issue.

And if you don't listen, if you don't take account, then there's no point in you doing this sort of inquiry frankly. So we had two experts advising us one expert by experience, Anna Severwight and another one Jon Glasby who is a well-known academic, so between them they kept us completely on the right track.

And of course, they brought their contacts and their knowledge and their perspectives. And what we tried to do was to get as many people as possible in conversation. And these include and a lot of people who are receiving care.

We have some fantastic witnesses who told us about how fearful they were every time they had to go back to social services and say, you know, is this something I could get? Or I do I need a review and thinking you might end up getting less.

And then of course we talked to carers and it was, it was quite difficult sometimes it was, these were public sessions. I found myself listening to carers who would be caring for elderly parents with chronic conditions, sometimes dementia, disabled young adults, children who were really, really well loved and well respected but still really challenging in the home Some people caring for two generations at the same time. And I said, listen, we're going to listen to these extraordinary women and men. And at the end of whatever question we'd ask, I would find myself thinking, I don't think I go on with these questions, it's is not intrusive, is just what we're hearing is so powerful, it's so intimate and it's so revealing of the day to day stress, I wouldn't be able to do this. And so that sense of co-production of listening. Respectfully and closely to so many different voices. And then, of course, we heard all these brilliant people from the agencies, many of whom themselves are expert by experience.

They've been carers or they are disabled in different ways. We took evidence from senior officials of the Department of Health each of which were very good, doing their very best we took advice from the ageing SS. We took a lot of advice from local authorities who were doing brilliant things like Somerset Wigan and that's in the report because there

is some brilliant practice which frankly could be shared much, much more widely we took evidence from other countries, not enough because we didn't have time. I would love to talk to people in Australia, in Holland and so on, but we had this great expert from Sweden being very important in the independent living movement and we crammed in as many people as possible into these two-hour sessions over the year.

Kate Hamblin:

The report really speaks to that and some of the key words that were coming as I was reading it were fight and the fear around reassessment, but also the thing that I found. Really valuable was the sort of push back on the family first.

And families should do more, partly because, as you say, there is this growing number of people who are growing up, who are growing older without children, but also pushing back on those sort of funny, old fashioned archaic values, which I think also contribute to the invisibility of care, that it's a private matter for families to deal with women. And it's tough stuff. I would think.

Baroness Andrews:

They weren't complaining, you know, that they really weren't. These are these are people of enormous dignity to who said things like, you know, I've learnt so long I wouldn't be without my disabled child. I know I love my parents.

I'm proud to do this. There was there was no complaint about the relationship. They complained about having been called carers many times and they're right to, it's such, in a way such an exclusive role. And people are not just carers, mothers of carers of children, you know, and it's a really clunky thing, but it's not what gets you into

the benefits system as it was. So that's something we should really try to change. But the families by and large actually, saw it, of course it is a duty and there's nobody else. But there is huge joy in it as well

And I mean to complain such as they were, were with the system.

Kate Hamblin:

I think there was a really interesting bit where you where the report sort of lays out like we're using the language of carers, but we acknowledge that it is a problematic and difficult term and often people don't identify with it and that leads to a sort of measurement problem that we have.

Baroness Andrews:

I mean, one of the things going back to the issue of who we asked to give evidence, you know, there are many people who would love to have spoken to GP's who are doing really important work in referrals and creating simple pathways, you know, into the care arrangements and so on. People who know in the private sector were doing really interesting things and many people have been in touch with me since and that's been a real revelation because there is an awful lot of good practice out there and people who are really trying to improve on and make some universal differences.

You know, it's a question of finding a way into it because the system is so fragmented, because it's a local delivery system. All the best practice is fairly local and that's what the challenge is. How do you actually make the best universal?

Kate Hamblin:

I think yeah, that's certainly something we're wrestling with in the IMPACT implementation centre into how you scale and spread practise that might be quite bound within a specific local context.

And capture what makes it work to another completely different local authority or local area is that challenge, I think. And I just wanted to ask you about the title, because I think one of the things the report really does and the enquiry has clearly done is to.

To sort of go back to first principles and think what is adult social care for? And the idea that it's about decline and crisis and then managing people when they're very, you know, most desperate and it's pushing back on that. I just wanted you to maybe explain where that title came from.

Baroness Andrews:

Well, as I said, I think it came from Social Care Futures, because what we were impressed by, I mean, it is so depressing to be faced with the litany of failure and, you know, not least because you're trying to recruit good people into this workforce.

Why would they want to join a failing institution? And part of the problem of invisibility is you can't easily construct a narrative because it's not graspable as it were But it was so obvious to us, so

much of what we have, especially from, you know, people like Social Care Futures and many others, the centres for excellence and so on and individuals

Because it's instinctive to us. We want to be optimistic. We've got our health services visible. Despite all its challenges, we're very proud of. And the pandemic reveals the fundamental importance of social care, residential care, if you didn't understand that already.

But what adult social care offers and what this report is about is not a service which is set to prop up the health service. It's a service which we should be able to rely on to be confident, but to have a sense of entitlement about it, because when we needed it will listen to us and it will try to offer us what we want to continue the lives that give us the greatest pleasure and effect on the title. 'A Gloriously Ordinary Life' says it all for me. And when I was on Tuesday, when I was at the launch of the Archbishop's Commission on Reimagining Social Care, the term they used is the

full life, the fullness of life. And they had a video which included two phenomenal ladies, both severely disabled, who described in their terms what it meant to have a gloriously ordinary life ,like birthday parties, like going shopping, you know, like feeling that there was things in the course of their day, it didn't matter at all that they

were as they were. They were doing things they wanted to do. People wanted them to be able to do. And so it comes into the coproduction argument, of course. And at the moment, you know, the adult social care service is so strapped in what it can offer. Is minimum quite often to keep people safe in their homes, to keep them stabilised, in terms of their health conditions and so on and so forth. It can't help them to reach the ambition of being as.

Their best selves as they remember themselves, as they want to continue to be.

Kate Hamblin:

I think one of the recommendations is around sort of returning to the Care Act where wellbeing is at its core and that speaks to this sense of the person and what they think would enable them to have that wellbeing, which you know is about having an ordinary life.

And it's not about just managing risk and managing conditions and getting people out of hospital as quickly as possible. It's there legislation. It's just they.

Baroness Andrews:

See that is what is so frustrating about all of this because, you know, there's a litany of failed promises. And, you know, I'm arguing constantly outside this report that this report makes a case for a positive, creative, ambitious vision for social care, which is what it should be.

It shouldn't be something that we're fearful to engage with or despair about having to because it's a last resort. It should be a welcome first resort because we know is there to help and it will help us as best it's and we come together.

The CARE Act more or less says that. It doesn't use the term coproduction and it doesn't use the term invisible or anything like that, but it is about wellbeing, it's about autonomy, independent living and all these things. But because not entirely because of funding, a failure of will and a lot of the act has been swallowed by the urgency of other things. You know, we can mention a lot of the things that have gone on since 2014, but the point is that it hasn't been implemented and it needs to be and we don't need lots of new legislation.

We really don't, I think we need to revisit the act and probably the guidance so critically now because we know more now we're a bit more aware of the frailty of the system. But my goodness, it's a good it's a good piece of legislation.

Kate Hamblin:

Yes. Thank you. And I think that that's the kind of key recommendations are the other recommendations you'd want to highlight as being what's the key things that we need to do next, really?

Baroness Andrews:

Well, there are a lot of recommendations. And I have to say, we thought hard about how many recommendations we all should put. In the end, we just said what we thought needed to be done. One recommendation which addresses the invisibility point, and it may sound like an easy recommendation, but it's not, is actually having someone to act as an advocate and an agent of change for the whole sector, we recommended a commissioner for care and support. Now this would be someone model a combination like on the children's commissioner, the old persons commissioner in Wales, who has got some teeth, you know, who can actually challenge and point to and rage about awful practise, who can act as the voice of the people who work in the system and the people who receive it. Now it will be an enormous job if you tried to do everything. You just actually need to have somebody to underwrite a job description, which is practicable and which fills the really big gap, which is there

is nobody there and nothing there at the moment. So that's one recommendation. And I actually think that it should be one of the first things to be done. The second thing is very obvious actually. We do need a workforce plan and there are lots of groups working on the possibilities of workforce plans, frankly, and they really are

We need to audit, respect and enhance the skills of the care workforce. As long as they considered unskilled, as long as they're considered to be, we can pay them less than the minimum wage. We're never going to have that sustainable, resilient workforce that we need. So we really need to rethink how we employ and train and sustain and retain people. Another thing actually that is urgent, I think, is to tackle what we do not know. And one of the things and again, this is about invisibility, is the absence of data when so many things actually we simply did not we couldn't answer because the data wasn't there. And we don't really know. I mean, we've had new, you know, new numbers recently, the number of carers and so on.

So we need a centralised- I hate the term- We need some we need somebody like maybe the Centre for Care, to bring together what we do know, to identify the gaps in our knowledge and our research base, to actually work out who's doing what, where and what needs to be filled in.

For example. I said that there are about another million people ageing without children by ten years, but we don't know. We only collect data on women. We don't know how many of those will be men. We don't know, for example, what the typical care package costs.

Let me read you something. Andrew Dilnot, if I can find it quickly describes the problem very well, he said basically it was like being in a shop 'needing social care at the moment is a bit like being in a shop with no prices, you know, how much to care for your partner or parent with cost per week or month, but you have no idea how many weeks or months that need will go on. So you simply do not know what the bill is.' There's one form of lack of data and that's very, very important, that's personal and that's about how much it costs us.

But, you know, all across there are gaps. So that's another thing. But, you know, when we were talking about sorry, I mean, I'm going through all the recommendations now when we were talking about unpaid carers and the things that need to be done urgently, we need to honour the promises that were made by successive governments to unpaid carers. Carers leave where was that for goodness sake, where are those five days? And where's the plan for respite? How do we work more closely with employers and require them to provide carers?

So that's the and then the carer's benefit. Carers benefit is the lowest of all benefits with high barriers in terms of working hours to claim it. We need to revisit our address because if you can pay carers a little more.

Not only do you keep them in better health, they get some decent food and some rest, and that helps everybody and helps the whole service, but it's their rights and dignity to that and it puts a value on these invaluable services.

So that's another another set of recommendations around that. And then when we come on to the the narrative, the bigger picture. I just want our politicians and in fact I would like the national convention the bishops would come up with.

And everybody in the field just start talking about the gloriously obvious possibilities of adult social care and what it does. One of the people that we didn't take evidence from so we couldn't quote him officially said the difference between the health service and adult social care is that the health service saved my life and adult social care has enabled me to live it. And I think that is a fabulous description. I think, you know, I'm not saying we don't acknowledge the impossibilities, the difficult situations we face day in, day out in East Sussex, for example.

Some friends of mine have just been told they need to then have to wait 19 weeks to get support. And this is somebody in pain. Real pain needs real help. But what we can say is that above and beyond this, there is a goal that we should be reaching for. And that I think that is about telling this bigger story and raising our spirits and making it a national imperative. And finally, I want to address I mean, there's housing, we've got we need to do something urgent about ageing in place so people can go back to their homes.

They don't linger in hospital. Their homes are safe, they're warm. They're not going to fall down the steps. You know, they're not going to electrocute themselves with faulty wiring. They need we need a housing policy which is geared to an ageing society, and that's market financing, extra care, housing.

It's the whole range of housing options that all within reach. I mean, the developers could do it tomorrow. They really could. All that new housing could be done through lifetime home standards without any difficulty and they should be mandatory.

And we've always said this. So there's a lot of issues around housing and inescapably there's the issue around funding because frankly, you know, when health service costs 156 billion a year and adult social care 17 billion, and if we only had what has been asked and estimates vary between about 6 billion a year, the cost of the health service would come down. So, I mean, those are the other recommendations. I think those are some of the key ones.

Kate Hamblin:

And I think there's a lot of them underpinned by the commitment to co-production as well.

Baroness Andrews:

So yeah, I mean, that is at the heart of the design because coproduction is, you know, it goes from. Me as a disabled person, say, working with my care provider, Just say 'I would like to be able to

Go here on a Wednesday. Can you arrange for me to do some, you know, some open university programmes or something?' You know, because it's not just a question of when will a carer come in and then

it goes from that to the systemic implementation of policy which is geared around that conversation around joint goals and places like Wigan and

Somerset have done this and they've done it because they could see that it was the best way of maximising, of optimising their resources not least and ensuring that people actually were satisfied with the service and then actually you know, frankly some prevention mechanisms are really good, Wigan is a good example so obviously this is about Wigan but there's no reason why it shouldn't be about other places if you make those adjustments. Somerset has got microcommunity development, a huge amount of community development in our report, of course, your community assets, community strengths on capacity which can be built up not that expensively, let the local authorities do what they do best, which is to create this agency within the community. And the voluntary sectors are absolutely essential. And they are so creative, so nimble. And I speak as someone who has spent a lot of time in the voluntary sector So there's a lot about that and about co-production in that sense.

And of course, then you come on to another form of co-production in terms of independent living and the ability to choose who does your care. Now, you may choose family and many people would. You may choose some friends or neighbours, but you might choose a personal assistant.

And increasingly, actually, I think we need to make that choice more realistic and at the moment it is beyond the reach of so many people because there are so few that they are, you know, they can't afford to stay.

As a personal assistant, we talked to one lady who had employed over the course of a year, 27 different personal assistants, all of whom in the end found they couldn't survive on the money. And of course, if you're dealing with a personal assistant, you become a small business, you have to know about health and safety, national insurance and everything else is too much. Too much for people.

Kate Hamblin:

Yeah, that that that's really interesting. And we've been in as part of IMPACT we've been doing stuff around choice and control for people. And you know, there are the policy mechanisms that sit in between direct payments and commission services, but the take up is so low because again, the sort of acknowledgement that there will be an administrative

burden placed on someone to manage an individual service phone, for example, isn't factored in to any of the costs.

Baroness Andrews:

Well, that's right. And it costs, it costs emotionally. It is very taxing.

Kate Hamblin:

Yeah. There isn't that sort of acknowledgement that there is an additional you know, there's a benefit, but there's also a cost there. Someone has to weigh up whether they can take that on. And if if, if ultimately the churn of PAs they're having is not sustainable, then.

Baroness Andrews:

But it goes back to the earlier question you asked me about, you know, well 'family first'. Well, yeah, I mean, you we take it as read, the family will be first. But, you know, just these people actually, who don't have children with children like mine live the other side of the world.

But people who don't want to ask that of their family, who don't feel they should be required to, who don't feel they should put the pressure on them to step in because there's no other choice. And families who do that willingly, but not knowing how long it's going to last.

some of the witnesses told us they gave up academic jobs, very high level professional jobs. Years later, they were caring for more than one of their family and they didn't say it with bitterness. Because that was a choice they made, but it was not a choice

They should have had to make. You know, when we talked to carers I think one of the things that struck me, as always, struck me actually, is how modest carers expectations are, how modestly what they ask for is so modest, and yet we ask so much of them.

Kate Hamblin:

Absolutely. And it's is sort of short termism I think in the way that a family first but. That will have a knock on effect to pensions and.

That's creating other dependencies within that system that we've done within the Centre for Care and Sustainable Care work around the financial implications for carers, the health and wellbeing implications for carers. So yes, they're taking on care that could be or might have been taken on by the out of social care system otherwise.

But they themselves are more likely to then drawn other forms of support because caring is is hard and if you have to give up work then yes, you financially are going to struggle and the sort of very small and short term approach to it almost by by policy.

Thank you. What I want to know understand is what happens next. Obviously, this is the start of something, not the end of something.

Baroness Andrews:

Well, indeed, indeed it is. I mean, I think we've all been I mean, I've been talking on behalf of the committee and this was not a solo effort. There were 12 of us involved. And we've all been very pleased at the response and the fact that we seem to have struck a chord and we seem to have been saying something new in a field where there is an awful lot of voices. So what we do now, Is frankly campaign on the basis of what we discovered. You can't leave this. This is far too important. So, for example, we are waiting for a government response to our report.

We have a debate in this House. We asked questions, asked a question yesterday about the budget and where adult social care would fit. I've been engaged in correspondence with the Chancellor who chaired the health and social care select committee in which he was a passionate advocate for adult social care.

We're trying to sort of understand where the money and the new money he promised in the autumn is actually going to go. Where we will see it. We will try obviously, to influence the political parties in the run up to the election.

I hope we'll be here for people who want to give us more information. I'm you know, I'm in the business of listening to any good ideas now. I'm trying to do what I can to join people up and so on and so forth.

It's unusual, in a way, for a committee to have a sort of shadow life after it's finished its work officially. But I think all of us feel actually that this is one of the great issues of all time.

I think ageing, demographic change, ageing and climate change are the great issues of our time and this belongs in that whole set of issues. Of course, it impacts from climate change as well. So that's basically it's a personal ambition, but it is shared with a lot of people.

Kate Hamblin:

Absolutely. And certainly one that the Centre for Care and IMPACT also share with you as well. Thank you so much for your time, Baroness Andrews. Thank you for speaking to us. And I would urge any listeners who have maybe got a flavour of the report to actually go and read it. Cover to cover. It's just the wealth of experience in there. The wealth of interesting practice is really fascinating and all builds to those really concrete recommendations. Thank you.

Baroness Andrews:

Thank you very much. It's been a huge privilege and I really it's been an opportunity for me to think aloud again about what we did. And that in itself is really refreshing and energising. Thank you.