

Public Accounts Committee

Oral evidence: Care for People with Learning Disabilities, HC 1038

Wednesday 29 March 2017

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[Watch the meeting](#)

Members present: Meg Hillier (Chair); Philip Boswell; Chris Evans; Kwasi Kwarteng; Nigel Mills; Karin Smyth; and Mrs Anne-Marie Trevelyan.

Sir Amyas Morse, Comptroller and Auditor General, Adrian Jenner, Director of Parliamentary Relations, National Audit Office, Ashley McDougall, Director, NAO, and Richard Brown, Alternate Treasury Officer of Accounts, HM Treasury, were in attendance.

Questions 1-129

Witnesses

[I](#): Sarah Battershall, Operations Director responsible for Transforming Care, United Response; Viv Cooper OBE, Chief Executive, Challenging Behaviour Foundation, and Dan Scorer, Head of Policy, Research and Public Affairs, Mencap.

[II](#): Chris Wormald, Permanent Secretary, Department of Health; Ray James, Immediate Past President of the Association of Directors of Adult Social Services; Simon Stevens, Chief Executive, NHS England; and Professor Jane Cummings, Chief Nursing Officer for England, NHS England.

Written evidence from witnesses:

- [Submission from Mencap and the Challenging Behaviour Foundation](#)

Report by the Comptroller and Auditor General
Local support for people with a learning disability (HC 1053)

Examination of witnesses

Witnesses: Sarah Battershall, Viv Cooper and Dan Scorer.

Q1 Chair: Good morning and welcome to the Public Accounts Committee on Wednesday 29 March 2017. We are here to discuss with witnesses the National Audit Office Report on learning disability services. There are two parts, one of which is the commitment made by NHS England to move people who have learning disabilities out of long-stay mental institutions and into the community. That applies to about 2,500 people, so it is a strong commitment for the Government and NHS England to deliver on. That is a big part of the work, but we must not forget that 1 million people with learning disabilities receive support from local authorities one way or another, and we are very keen to cover that element of the Report in detail.

I welcome our first witnesses. Thank you for rearranging your diaries to fit in with our schedule change. As you will appreciate, it is a big day in Parliament; we don't usually make such a change, but thank you very much. Sadly, Rosa Monckton, who is the founder and trustee of Team Domenica, is unable to be with us because of the change of schedule—not for any other reason.

From my left to right, we have Dan Scorer, the head of policy research and public affairs at Mencap—welcome back, Mr Scorer, I think you have been here before. We also have Viv Cooper, who is the chief executive of the Challenging Behaviour Foundation, and Sarah Battershall of United Response—I think you have a link to Learning Disability Voices as well through your organisation.

I have highlighted those two issues, but before we go into the Transforming Care programme, let me focus on the support that people with learning disabilities need in the community. I want to ask you each in turn what you think the main barriers are to progress on improving the services delivered to people with a learning disability. We will start with Mr Scorer and work across.

Dan Scorer: We know from the NAO Report that 120,000 people with a learning disability are getting access to social care support through local authority statutory services. That compares with 1.4 million people with a learning disability across the UK, so there is a very significant level of unmet need in the community. In recent years, there have been very significant pressures on local authority finances. That has seen significant changes to the way that people with learning disability are supported.



The NAO Report makes it clear that learning disability services have fared better than social care services in general, and particularly those for older people. None the less, from the work that we do with families and from what families are reporting to us, we are seeing very significant stress on key services that families rely on, such as respite services. There have been very significant changes to services that offer meaningful daytime activities that people with a learning disability rely on—such as the changes to day centres—and they are often not being replaced with the quality of service or degree of choice and control that we would want to see around people with a learning disability getting out in the community and being active.

Q2 Chair: In simple terms, do you think the barriers are partly because of money in local government?

Dan Scorer: Partly financial, but also structural as well, in terms of actually putting in place the arrangements that will give people genuine choice and control about what they want to do with their lives.

Chair: Okay. We might have to come on to personalised budgets in that respect.

Viv Cooper: My experience is as a mother of a young man with severe learning disabilities and complex needs. Our organisation supports that group of families. The issue, in terms of access to support for people, is that we continue to have a crisis management approach—we don't start early enough. We know the children with learning disabilities, we can identify them very early on and we know how to support them, but usually what happens is that we channel them into a system that perhaps does not particularly meet their needs.

The systems that are meant to be there to support people and which should be working often do not work. Because there is that crisis management approach, once people get to crisis there are fewer opportunities for meeting people's needs appropriately and in a timely way. There needs to be a real investment in families, because families are the main providers of love, care and support, and usually continue to provide that throughout the person's life; whether or not they leave home, they do not leave the family. There needs to be real investment in supporting families and also supporting advocacy organisations.

Chair: We definitely want to come back to the family point, because the figures speak for themselves about how many people are really looking after people with learning disabilities.

Sarah Battershall: This is much more from a social care provider perspective. I support the things that Dan and Viv were saying. We have received funding cuts and our income has reduced in real terms by 23% since 2010, although I understand from the NAO Report that spending on learning disability has increased over the past few years. That leads to bigger management stretch, so the leadership of teams supporting people,



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who often have very complex needs, is maybe not always what it needs to be for people to achieve the outcomes that they need to achieve.

The other gaps are particularly around improving services for people with learning disabilities and improving outcomes around lack of opportunities in employment for people—the numbers of people with a learning disability in employment is reducing—and support and training for the workforce. We have increasing recruitment problems to get good quality staff to support people. I also think advocacy is definitely an issue for both families and the people who we support.

- Q3 **Chair:** One of the things we were looking at is something you have mentioned, which is employment, and things like health checks with GPs. Those are indicators that the Department uses to measure the success of some of the work that it is doing in supporting people with learning disabilities. However, there has been little movement on things like life expectancy, which is still far lower—about 20 years—for someone with a learning disability. Do you think that the Department has the right indicators? I will start with Viv, who lives this every day. You know best what your son's improvements are. Is it possible to codify that in a central way? There must be a better way of doing it than these minimum indicators that exist?

Viv Cooper: Yes, health is a big issue for people, because there is often diagnostic overshadowing. My son recently had to go into hospital, and they tried to send him away because they were saying he was fine. So, health is a big issue, and I said that health checks are really helpful, but it is what outcomes come out of the health check.

You have health check, and then it needs to have an action plan, in terms of moving it forward. Generally, the approach of most families is that they want their relative to have the same life opportunities as everyone else—that is, a family life, leisure activities and a social life. All those things are quite hard to quantify and measure, but the system that we have—for example, my son had to go to a 52-week residential school when he was nine; how can he have a family life if that happens?—channels you into a situation that you don't want to be in.

The ordinary life indicators for friendships, social activities, being part of the community, going out and employment—my son has very complex needs, but he has two members of staff supporting him at all times, day and night, so they can support him into employment just as well as the can support him to sit and watch television. Daniel has support workers, not employment support workers. It is about trying to change the mindset to say, "He does not need to be cared for in that way; he needs to be empowered to do these things."

- Q4 **Mrs Trevelyan:** On that point, some employers say—correct me if I am wrong—that, if those with learning disabilities are capable of work at whatever level, the support from support workers, such as those that your son have, would disappear and the employer would find themselves responsible for that support during that working period.

Viv Cooper: No, there are different issues, because we are talking about a big spectrum of ability.

Q5 **Mrs Trevelyan:** But that seems to be a barrier to employers.

Viv Cooper: For some, that is, but my son needs two members of staff—that is his assessed need—so they can support him into employment.

Dan Scorer: We should also mention the Government's Access to Work scheme, which is very important in providing exactly that kind of support. If a disabled person is entering work and needs a personal assistant to support them with those work-related tasks, the Access to Work scheme can pay for that.

Q6 **Mrs Trevelyan:** So the employer does not have to carry that burden or the extra responsibility of having to learn a whole skillset, which they may not have had before.

Dan Scorer: No, but the problem is that there is very low awareness among employers of the Access to Work scheme, which the Government have put welcome additional investment into. But undoubtedly, a key barrier is employers' awareness of the support that is available and the perception that they would have to shoulder extra costs, when in fact, they won't.

Q7 **Chair:** I will come back to you on the wider point, Mr Scorer, but on employment, there is a variation among local authorities regarding which local authorities have done a better job than others of helping people. Whether that is about local authorities or not, we can't be absolutely sure, but in certain local authority areas, employment rates for learning-disabled adults are higher. Can you think of any examples of really good practice that is worth highlighting?

Dan Scorer: I would be very happy to talk to my colleagues in our employment services and write to the Committee with specific examples.

Chair: Okay, do that.

Dan Scorer: But you are absolutely right. We are seeing a huge variation, with over 20% employment in some areas down to literally a couple of percent in others. Some of that will be other factors, such as geography and the labour market, but it shows that although the headline figure of 5.8% is people with a learning disability who are known to social services—we should say, that small group—the actual employment rate of people with a learning disability is higher. We are seeing in some areas what is possible with good-quality support so people with a learning disability can be supported into long-term, sustainable mainstream jobs.

Q8 **Chair:** That goes to the wider point about these indicators. As you say, you are probably in touch with a bulk of people, and not just the people who are in touch with local social services. What indicators would be good, or do you think that the indicators the Government have are good enough to measure whether learning-disabled adults are progressing and getting the outcomes that parents, families and they themselves would



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desire?

Dan Scorer: There are some quite major issues with the data that the DWP have. For example, recently we have had the health and work Green Paper. Consultation on that closed in February. As part of the work we were doing, we tried to work out in detail where people with a learning disability sit in the benefits system. How many are on jobseeker's allowance? Where do they sit in relation to employment and support allowance, either in the work-related group or the support group? The Department does not hold those data, so trying to work out in detail who is in that very large group—around 1 million are in the employment and support allowance work-related activity group—

Q9 **Chair:** How would they get the data? As a Committee we can make recommendations to the Government. Mr Wormald is grinning—perhaps grimacing is the word—at the idea of us setting another data demand. We know that there is a big issue—we see it all the time in the Committee—so what is an easy way of collecting that sort of information? People have said in evidence, “We are asked to give data”—this is particularly about the Transforming Care partnerships—“by different bodies in different formats all the time, and it gets very cumbersome.” That is not what we want to achieve.

From your perspective, what would work? How could someone who has a learning disability tick the right box or get the right information through so that the data could be collected? The Government, NHS England, local government, and you and others, could then determine where the weak spots are and how we move on and progress.

Dan Scorer: That is when people are applying for benefit and going through the employment and support allowance process. They fill out an application form. Many of them go to a face-to-face assessment, so there are plenty of opportunities to gather this information and put it in the system. We are talking to the Department at the moment. I think they agree that we need to get much greater insight into—

Q10 **Chair:** Forgive me; I have not filled in a work-related form at a jobcentre in a long while. Is there a proper opportunity on that to say, “Do you have health needs?” and to describe those in any particular way? As Ms Cooper highlighted, there is a wide range of people with learning disabilities, from people with mild learning disabilities to people with very severe learning disabilities and challenging behaviour. There is quite a range.

Dan Scorer: Yes, there is. And people will also submit additional medical evidence as well from health professionals and other professionals that they are involved with, which will give extensive insight into any diagnosis that they have around a primary condition, or secondary conditions as well.

Q11 **Chair:** What you are really saying is that health is pretty critical in getting the data. If you have not got the health assessment, that does not feed through to the DWP and benefits.

Dan Scorer: The information is being gathered. People are answering very detailed questions about the functional impact of their disability on their ability to work and to perform a range of tasks across different areas. So the information is being explored in detail through the assessment.

- Q12 **Chair:** But the Report tells us that only 23% of people with learning disabilities are registered with a GP, which seems very low, although it has gone up considerably. What about the 77% of people who are not registered with a GP? Perhaps Mr McDougall will check whether I have got that figure wrong, but the people who are perhaps not very connected to the health services—maybe they have a mild learning disability and no other particular health problems—might not be in the health system to get a tick in the right box.

Dan Scorer: That is a significant issue that comes across when people are applying for benefits. They do not have access to the medical correspondence and history that they need to be able to demonstrate the issues that they face. That can be a real barrier. We are working with NHS England at the moment to promote people with a learning disability to be on the GP learning disability register and to engage with services. As you say, it is vital that we increase that number to tackle health inequalities and to make sure that people have the contact and the evidence that they need to apply for the benefits they are entitled to.

- Q13 **Chair:** How many people are on the learning disabilities register at the moment?

Dan Scorer: In terms of GP registers, it is very low. I think it is around 15%. I will clarify that for you.

Ashley McDougall: It was 23%.

- Q14 **Chair:** It was 23%. Okay. Are any of your organisations doing anything to encourage people to register? It seems the GP registration is a gateway to lots of other services, so it is pretty critical.

Dan Scorer: Yes, we are. This is an objective in NHS England's current business plan. We are doing a project that it funds with us specifically to promote to people with a learning disability the benefits of GP registration in terms of reasonable adjustments, getting access to annual health checks and of course the benefits of having the additional summary care record—

- Q15 **Chair:** We have got the benefits; it is just how we do it. I suppose people from the Challenging Behaviour Foundation, like your son, will be registered.

Viv Cooper: Yes, because of the level of need.

Chair: Sarah Battershall, is there anything you want to add?

Sarah Battershall: Yes. I think it is a critical part of everybody's care, and healthcare generally. People with learning disabilities do not receive the same level of healthcare as the general population. As a social care provider, it is incumbent upon us to ensure people do. For the wider



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population of people with learning disabilities who do not access social care, that knowledge and support to access and register with a GP is perhaps not where it needs to be.

- Q16 **Mrs Trevelyan:** What do you think stops families from encouraging members of their family with learning disabilities to register? Presumably at some point as a child they were registered wherever they lived then, but they have moved. Is this adult not supported by a family and therefore not registering? What are the reasons around this huge differential with the rest of the population?

Sarah Battershall: I don't have the data in front of me, but we can look at the numbers of people who used to get low-level SEN support, often funded by the local authorities, who perhaps live on their own and do not have family contact. There is still a lot of family breakdown and we have a mobile society. There are a lot of people who have had very low-level support—with tenancy support and general support to live their life—who would have been supported to register with a GP, but they were absolutely the people who, after the funding reductions, lost that level of funding. A lot of the low-level support for people to maintain their independence, and to live independently but well, is not there anymore.

- Q17 **Mrs Trevelyan:** But do those people not need to access healthcare? Or are they just choosing not to?

Sarah Battershall: It is about knowing what to do and how to do it, and that you need to go and register with a GP. A lot of people with a learning disability can function well in society with minimal levels of support to use the systems and use what is available to them. It is that level of support that has probably reduced significantly over the last five years or so.

- Q18 **Mrs Trevelyan:** How are you targeting that 75% in practical terms? Do you know where they are? Does the system know where they are, with PIP assessments and all those sorts of things? Are they hiding? What could the Government be doing better to push that number rapidly up and to give confidence to those people who are not registering?

Sarah Battershall: There needs to be a more significant, joined-up campaign around good health for people that feeds into those places where people would naturally go, like the DWP and local shops. If you think about what people usually do, it is using the facilities in their communities and it is getting people who know them and live around them to help point those things out, because they don't feed into systems naturally.

- Q19 **Mrs Trevelyan:** So a general awareness of the value of it would be a useful way to do it?

Sarah Battershall: Yes.

- Q20 **Chris Evans:** I know that social care is devolved in Wales, and I was quite interested reading the Care and Social Services Inspectorate Wales report that found that "funding disputes caused delays for people" with learning disabilities "and frustration for the front line staff". In other



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words, frontline staff were spending more time filling forms in and trying to sort out funding applications, which was cutting into their clinical time. I was wondering whether that is the same as you have found in your experience? Mrs Cooper will probably be the best person to answer this.

Viv Cooper: There is some evidence that care staff are sometimes spending more time with the bureaucracies of care than actually interacting with individuals. There are some good support providers who really focus on good, active support for people, so that the staff engage positively with individuals to support them to participate in activities that they enjoy and that are meaningful to them. I am not really overly sure of what you were wanting?

Q21 **Chris Evans:** Basically, I was just trying to discover if, in your experience or your son's experience, you have found that clinicians were basically spending a lot of time filling unnecessary forms in, rather than actually trying to solve the social care needs of the person in their care?

Viv Cooper: That hasn't been my direct experience. It is often hard to get access to the clinicians and support that you need. As I said, there is this sort of crisis management approach—you often only get access to clinicians who can provide really good support if things have gone wrong or deteriorated—as opposed to a proactive approach. Thinking about my son and his needs, he has a range of needs, such as communication needs, occupational therapy needs and physiotherapy needs, as well as support around his behaviour. Accessing that team of expertise on a routine basis can be difficult, as opposed to when his behaviour escalates and then he gets a referral.

Q22 **Chris Evans:** I have a second question for the two other members of the panel. Do you find that people with an active, strong family support network have better outcomes than those who don't? In other words, they have family members who are stronger advocates for them than people who don't? Is that a concern of yours?

Sarah Battershall: I think that is absolutely true. Where people have got families or people who care about them who speak up and who support them to speak up, they generally get a better level of service across the board. I think that is where good advocacy makes a difference for those people who don't have those family networks to speak up for them. It makes a significant difference in both healthcare and social care.

Dan Scorer: Yes, I agree. In terms of the work we do around avoidable deaths of people with a learning disability, families work incredibly hard when their loved ones are in hospital to make sure they get good-quality healthcare, their needs are understood and they get reasonable adjustments. That does not always happen.

I would also say that paid care staff work incredibly hard to make sure that the people they are working with get that support, but we have to recognise that families' lived experience and insight into their loved one is incredibly valuable and in many cases is not respected and listened to by professionals enough.



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Q23 Chris Evans: How about you, from personal experience and from a professional point of view? Do you agree with those views?

Viv Cooper: Yes. At the Challenging Behaviour Foundation we are really concerned about people who do not have families. The group of people we are involved with are very vulnerable, and that vulnerability is increased if the person does not have a family or a strong advocate acting on their behalf. We really should be investing in families. We should be providing information that is timely, useful and accessible and supporting families, because we are, or should be, seen as really valued partners. We are lifelong, and we have a whole range of knowledge and experience.

My experience is that you get better outcomes for individuals if families and a whole range of people work in partnership around that person to deliver good outcomes for them. I cannot provide Daniel with a good life on my own as his mum, and yet with a team and a whole range of people working together, we can do that. In the Transforming Care programme, which I know we are going to get on to, families' relatives are often channelled by the system into terrible circumstances, and the families are often the ones who are able to retrieve them from those circumstances and get them better outcomes; it is not the system.

Q24 Mrs Trevelyan: Are there any councils or areas that do a better job by effectively acting as advocates for those who do not have families, or are they really a lost group, in terms of having people who go looking for them and support them in the way that a family would if they had one? Have you come across anywhere that does it well?

Sarah Battershall: Some local authorities do it well around best interests and the Mental Capacity Act. There are some very good examples of that, but that tends to be the extent of it.

Q25 Mrs Trevelyan: Does anywhere spring to mind that you have experienced anywhere in the country?

Sarah Battershall: York do it particularly well.

Q26 Mrs Trevelyan: But they stand out as unlike most.

Sarah Battershall: There are some that stand out.

Q27 Philip Boswell: The National Audit Office Report, in paragraph 9 on page 7, states: "The Department, NHS England and local authorities have limited measures to assess the quality and impact of health and social care support." Do your organisations have better metrics, measurements or information that could supplement the Government's lack?

Dan Scorer: Yes, we do. We provide care services to around 8,000 people with a learning disability—mainly in their own homes, but with some in residential establishments. We have a detailed planning framework and evaluation framework around the outcomes that individuals want and whether their care is person-centred around them and meeting their needs and stated objectives. Certainly there are things that we could share



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around measuring the outcomes that matter for individuals and the way we have done that.

Q28 Philip Boswell: Given the average real-terms cuts, do you think you are being listened to?

Dan Scorer: Do you mean cuts to social care budgets?

Philip Boswell: Yes, in the community.

Dan Scorer: Well, providers up and down the country are facing huge challenges in terms of maintaining high-quality care for people in the face of what has been in some cases year-on-year reductions. We know that providers have been walking away and handing back contracts because they believe in some cases that the amount of money that local authorities are offering on an hourly basis is just not enough to offer a safe and high-quality service.

It is obviously very welcome that we had the announcement in the Budget of £2 billion in extra funding for social care. We will wait and see the guidance on how that will be distributed, but I think the crisis in funding in social care has not gone away. It is still with us, and we need to see what the Government comes out with later this year, in terms of the Green Paper, about long-term, sustainable funding.

Q29 Chair: I am just going to hurry you on, because I am aware of time and I want to cover the issue of supported housing before we move on to the transferring care partnership, which we are going to have to do fairly quickly. Supported housing is obviously very critical for the people you represent, who we are talking about today. Have any of you got any observations about what is not working there? Clearly, there have been some big challenges. That is probably for you, Sarah Battershall, isn't it?

Sarah Battershall: There are a couple of things, particularly around housing, that would make a huge difference to the barriers we face in moving people out of institutions and ATUs. There are two things that I really hope would deliver good housing. We welcome the capital investment that is there, but it finishes at year end, whereas the planning and delivery of services and getting the right housing often takes longer than a year, so there is a real barrier there that we feel we could shift fairly well. Changes to local housing allowance are planned in 2019, and we know that 80% of the planned supported housing for this year has been put on hold while people assess what the impact of that is. That is quite significant.

Q30 Chair: What is the threat to your current provision? There have been a lot of changes to supported housing over the last few years. There are real threats, and then there is a temporary reprieve sometimes. Where are you at now? What is your fear now?

Sarah Battershall: Over 50% of the people we currently support live in houses where the local housing allowance may not deliver what we need to deliver to support them there. We have got no guarantee of the top-up funding from the local authorities, so over 50% of the people we currently



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support are doing that. To some extent, although this may seem like a side issue, I think the issues we are facing with sleep-ins, the HMRC, the back pay and the threats to organisations—

- Q31 **Chair:** Which was in your evidence. Will those people be trying to apply to social services for some sort of floating support?

Sarah Battershall: A lot of the people we support have got really complex needs, and the low-level support would not meet their needs.

- Q32 **Chair:** So what you are saying is that they could lose their support through supported housing and there would be nothing suitable to replace it?

Sarah Battershall: Yes. For a lot of those people, their rent would not be covered.

- Q33 **Chair:** I want to move on to the Transforming Care part of the programme, because obviously that is key. There is a big commitment to move people out of these mental health beds, and some interesting challenges there. Viv Cooper, do you think that is making a difference yet? Have you seen any signs of great success? It is relatively early days yet.

Viv Cooper: The first thing to say is that everyone wants Transforming Care to work. There is a united desire to move away from in-patient provision and to get people out and supported properly in the community, because hospitals are not homes. We have known that for a long time. Although we are saying it is early days, it is in fact six years since the Winterbourne View programme was screened. There have been a number of false starts.

- Q34 **Chair:** I was thinking of the two years since the last commitment.

Viv Cooper: Yes. In terms of the National Audit Office Report, we welcome the structures that have been put in place. The Transforming Care partnerships have got the potential to help move things forward. We have not seen evidence yet that that is going to smooth the lead-in or the outcomes that we want to see. The Report reflected the experiences of the families we support.

As I already said, the system still channels people into inappropriate provision, and then it is very hard to get them out. As yet, the Transforming Care programme hasn't been able to demonstrate that it can swiftly move in and change things when they are starting to go wrong. We saw the "Dispatches" programme. NHS England are still buying places in old-fashioned institutional provision, and then once relatives are in there—it is children we are talking about, we are putting children in institutional provision—it usually takes families with the support of their MPs and organisations to get them out. The system does not support them to come out; the system is still channelling people in.

- Q35 **Chair:** Are you seeing any evidence, where beds are being closed that the money is following the individual to the community?



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Viv Cooper: That is a big issue as well. We see that families are saying, "My relative is in this institutional provision. It's costing £10,000 a week and it's not delivering good outcomes. My relative is over-medicated, and I'm trying to get them out, but I can't get a house; I can't get the support." So I don't see that there is a mechanism for freeing up the funding. Vast amounts of funding are being spent on inappropriate provision.

To swiftly move on, I am a member of the assurance board and we have been constantly asking, "Have you sorted out the money flows? Have you made sure that there is a process that is really clear, so that if you're in a service, the money comes down here? Has that been sorted out?" We have not received an answer on that.

- Q36 **Chair:** There was an announcement in January of this year about trying to get to grips with this money-flow issue so that the money does follow in a timely fashion and stays with the patient. It's early days; that was only a couple of months ago. Are you confident that it is pushing things in the right direction? Is it better?

Viv Cooper: Moving in the right direction is a good thing, but the question is how swiftly that is moving forward. If you asked a family whose relative is in institutional provision today—this minute—"Do you know how the funding will work to get your relative out?", the answer would be no.

- Q37 **Mrs Trevelyan:** You have mentioned that councils are still buying into the areas of provision that we are trying to close down where they are inappropriate. What is the reason for that? Is it because it's too difficult for them to set up the right care package, or because there is a genuine clinical need that they cannot address at community level?

Viv Cooper: It is the system that is not working still. It is not councils that are buying the places; it's NHS England. NHS England have produced a model that says, "This is the service model. It is not institutional provision; it is individual provision," yet they have a specialist commissioning team. If things break down locally or things are not working, there is a perverse incentive whereby suddenly people get shifted over to specialist commissioning, which is NHS England-funded, and specialist commissioning purchase places. They do not act in line with their own model, but buy places in places like the places in "Dispatches".

- Q38 **Mrs Trevelyan:** So the two have not been joined up? Is it as if they have forgotten to say, "Actually, we're not doing that policy any more"? That's what it sounds like.

Viv Cooper: I can't understand how that happens. I would hope that NHS England would say that they can make a commitment not to buy places at high cost—these are £10,000-a-week places—and they will not buy any more places in institutional provision because it goes against their model. That would send a really important message to everybody else, as well as, hopefully, freeing up some funding. We can't have NHS England saying, "This is our model. We want everyone else to work to it, but we're not going to do so."



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Q39 Chair: Presumably you need some transitional funding, because obviously to provide the new facilities, you are going to have to build them before you have got the money from the closure of the old service.

Viv Cooper: Yes, all of that. There needs to be some double-funding. You can't say, "I'm paying £10,000 a week till Friday and then on Monday something else is going to be in place."

Chair: I'm now going to bring in the Comptroller and Auditor General, Sir Amyas Morse.

Sir Amyas Morse: I only wanted to ask for your reaction to this. If they are doing that, is it because they have found themselves under pressure to find a placement at very short notice and the only ones that are available at very short notice are the ones you are describing? What do you say on that? I just wondered about your reaction to that.

Viv Cooper: That is the big issue for this programme. We want to move people out of inappropriate in-patient provision and into the community, but we also need to stop people going in in the first place, so there has to be a co-ordinated approach: develop good local community facilities. That is to stop the next population coming in, but it is also to enable the population that are in to come out.

All that is tied up with the need to sort out the funding. The thing that we struggle with is this: if you get shifted up to specialist commissioning, you expect that to be both commissioning and specialist —it is not just purchasing what is available. I think NHS England could take a lead in terms of moving that forward.

Q40 Chair: Sarah Battershall, from your point of view, as a provider, do you deal with any people coming out of institutions under this programme?

Sarah Battershall: We have quite a long history of supporting people coming out of institutions. My summary is that it can happen, and it can happen really well. Not living in an institution makes a huge difference to people and their families. As a health and social care sector, we have over 30 or 40 years' experience of getting people out of hospitals. It takes strong leadership, funding agreements and housing, but we have done it before several times. It is about sorting out who is going to pay for which bit, agreeing the pooled budgets and agreeing capital investment or transitional funding that does not finish at the year end. It is about working together.

Where we see it not working is when the commissioning of services for people coming out is not planned and not done collaboratively with providers and family members. It is when you get a phone call from someone who says, "We need a place for someone tomorrow." We have to build a skilled workforce around those people, so what we need is some sort of overall commissioning plan for a local area that says, "This is what we need to commission, and these are the people who need to come back."

Q41 **Chair:** But these 48 footprint areas are supposed to be doing that.

Sarah Battershall: They do, but I am not sure that they are all that robust, and they are not collaborative. But we have seen some very good examples where we have got quite a number of people out of institutions in the last two years. We have worked closely with local authorities and health partners and it has been planned. We have sourced the housing, moved people out and worked with the families, and that is really working for people. So yes, we have some very good examples of where it can work.

Q42 **Chair:** Finally, what are your top three asks of Government, or what are your top three concerns about things that aren't quite there yet?

Sarah Battershall: My top ask, which I mentioned earlier, has to be the HMRC position on potentially claiming six years' worth of back-pay for sleep-ins, because that is the biggest threat for the LD sector and social care across the board. That is absolutely my No. 1 ask. Then there is getting good funding agreements so that we are not battling that all the time, and then planned geographical commissioning.

Viv Cooper: Sort out the money, as I have said already. Have local people with the right experience. There are a lot of processes going on at the moment, and actually what we need is people locally who can deliver this stuff. We need to sort out the workforce and how we access housing, and we need to invest in families. We need to do all that stuff, but actually people are really busy and it is another thing to do and another programme, so we need to do that. We need to make sure that that is lifelong, so that we get it right for children and people moving through. We need NHS England to stop commissioning places in institutions.

Dan Scorer: I think we need long-term, sustainable funding of social care so that people with a learning disability and other disabled people can live their lives in the way they choose with the right support. Immediately, we need the Government to listen to the major concerns about supported housing funding and the local housing allowance cap, because that has the potential to really damage people's ability to live with support in the community, and damage the Transforming Care programme. I would echo what Sarah said about sleep-ins, which is a huge threat looming over all providers, and we hope to get a positive and constructive way forward in a ministerial meeting this week.

Chair: Thank you very much indeed for your time and evidence, which has been really good and clear. We will now move on to our second panel of witnesses. You are very welcome to stay and listen, although you don't have to—it is all on TV if you want to catch up later.

Our transcript will be up on the website in the next couple of days. You will be sent a copy, but it is put up uncorrected. You can't rewrite it, but let us know if you have a major change to make. Our Report will be published at some point after the Easter break, but I can't give an exact date at this point. Thank you very much indeed.

Examination of witnesses

Witnesses: Chris Wormald, Ray James, Simon Stevens and Professor Jane Cummings.

- Q43 **Chair:** Good morning. Welcome to our second panel on this important subject of support for people with learning disabilities. I will move quickly on to introducing the witnesses, who are Professor Jane Cummings, chief nursing officer at NHS England, Simon Stevens, a regular visitor, the chief executive of NHS England, Chris Wormald, the permanent secretary at the Department of Health, and Ray James, who is the immediate past president of the Association of Directors of Adult Social Services and director of health, housing and adult social care at the London Borough of Enfield. Welcome to you as well, Mr James.

I want to kick off with Simon Stevens. Mr Stevens, you were in front of this Committee in 2015 and you made then a bold and strongly personal commitment in this area, following on from the commitments of your predecessors. You were very personally committed and you got a lot of credit for that. We have heard from our previous witnesses that the movement is in the right direction. Knowing what you know now about the challenges of getting from where we were then to now, have you learned anything? Is there anything you would do differently or that you are now having to think about doing differently as a result of your experience over the last couple of years?

Simon Stevens: That discussion we had back in 2015 was a wake-up call for the NHS in terms of the contribution it needs to make to these profound service changes. I think the NAO Report before us today very fairly sets out the fact that there had been, frankly, slow progress, if any, between 2012 and 2015, and I think we have had a significant pivot in momentum since then. For the reasons that the NAO set out, I don't think that this is in any sense a mission accomplished, but I do think that, over the course of the last 18 months or so, there has been demonstrable progress in reducing the number of people using in-patient services. But there are some big things that we have still got to get right. Yesterday we announced the results of the public consultation and our in-principle decision on the full closure of Calderstones hospital, as we discussed at the PAC. But on that and a number of other areas, there is a lot of work in front of us.

- Q44 **Chair:** Absolutely. We will come on to Calderstones later. One of the things that struck me is that the cohort data you have now got, which you didn't have even two years or 18 months ago when you came in front of the Committee, demonstrate that there is quite a complexity. I think everyone knew that in theory, but we have now got more information. There are still gaps in that. You have got quite a range. Is there anything that is making you change the way you are thinking about doing these things? You are looking at people with autism, which is not always very well recorded. You have mental health, learning disabilities, sometimes criminal records or challenging behaviour, which all combines sometimes in the same people with multiple problems. Is that affecting the way you



are looking at the programme going forward?

Simon Stevens: Yes, and as you say, that complexity is laid out in figure 12 on page 32. It shows the combination of people currently using services. However, we shouldn't jump to the conclusion that just because we've got a proportion of people who are under current Ministry of Justice restrictions or who are in secure settings that that is a God-given fact of life. We have seen significant opportunities where people have been provided with more supportive care in less restricted environments. There are a lot of conditions that gave rise to them being in a secure environment in the first place that dissipate. So this is a big change programme, but as you say it has got many different dimensions to it.

Q45 **Chair:** One of the challenges is the money flows, which we were all discussing earlier. You were not in for the previous session, but we heard some clear evidence from Viv Cooper of the Challenging Behaviour Foundation. In the Report, the challenges of closing a bed were quite apparent: money is supposed to follow the individual, but the institution still has the same costs.

Can you explain the changes announced in January this year and how you see those making a difference? We are in a very challenging financial situation, which we repeatedly cover in this Committee—I do not need to lay that out—but in this area, without twin tracking, it will be quite difficult to get that money to follow the individual who needs it badly and cannot live without it.

Simon Stevens: On bed closures, rather than the reduced usage of in-patients, I am pleased to be able to confirm to the Committee that we have indeed met the bed closure goal that we set for the year. By the time the NAO were finalising their Report we did not have those data; we now do. Rather than the 60 beds that the Report refers to, we have closed more than 136, as intended. We are at the beginning of a process, we are on track with that process—

Q46 **Chair:** It is the money from those beds that is the key thing, isn't it? How is the January announcement going to make a difference?

Simon Stevens: There are two pieces to this. Where we are buying beds from NHS providers we have to work with them to free up discrete blocks of cost that they are incurring. Where we are buying services from third-party providers, then, in a sense, as the person moves, we are not paying for the service that remains. That is the distinction.

For some of the larger NHS-provided services, we need the equivalent of the type of programmes that we ran in mental health hospital re-provision in the '80s and '90s—often the so-called retraction programmes—where there was an agreed profile of service transfer. That is the process that the local partnerships have agreed now with a number of those providers. I should bring in Jane Cummings, the chief nursing officer, who is our lead director on this programme.

Professor Jane Cummings: What was really important—this was done slightly before January—is that for the first time we were able to put an



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indicative allocation of specialised commissioning funding to each of the Transforming Care partnerships. That took a while because we had to disaggregate the spend on complex mental health patients for those with a learning disability. That meant that each of the TCPs had an indicative amount of money that they were spending across the system for specialised patients.

In January, we agreed how that money could flow from specialised commissioning, as Simon has referred to, after we had been able to close the beds and extricate the money from the providers, and be moved to CCGs. CCGs can then use a variety of mechanisms to move the money across the system or into local authorities. Using the Better Care Fund or two different sections—256 and 117—they have been able to start to do that.

Q47 Chair: Can you explain the sections you have just described?

Professor Jane Cummings: I might look to Ray to do the detail, but one is about transferring money and one is about enabling the purchasing of joint commissioning of services. We also spend money, through the NHS, on continuing health care. Quite a lot of the patients and the people we are referring to are eligible for continuing health care, so some of that NHS money will fund that in the future.

At the end of '16-'17, we believe that about 110 people whom we have discharged will be eligible for the dowries that Simon referred to back in 2015. Of those, 75 are funded through CCGs and we have been able to cover the costs of 75% of those patients through moving money already. About £1 million that was provided by specialised commissioning is being released back into the system to support the other patients. We are moving money, it is beginning to move, and that is a positive step.

Q48 Chair: The line of sight on the dowry is something we are quite interested in. Let's face it, in the past, with the closure of institutions, the money sometimes just silted away. How is NHS England watching to see that that money, when it goes down to the CCG towards the individual, stays with that individual? There may be times when there is a reassessment of that person's needs and they do not need all of that money all the time, but it is their right to have that support.

Professor Jane Cummings: We have agreed which of the patients are eligible for the dowry: those who were in an in-patient setting for more than five years as of 1 April 2016. You referred to the complexity of the patients in your opening remarks. Some of these individuals will require ongoing NHS support. I know you talked in the pre-panel about the complexity of how we commission those services, but that will also have an impact. This is about geographical commissioning, looking at people's needs in a wider context, but it is also about the individual.

You will know—the NAO has referred to it—the complexities and the differences between individual people. The trick, which we are doing, is to follow each of those individual patients. The local commissioners know them by name, and they understand what they need. That money is then



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allocated through them to NHS services and to support in the system. We are doing that, considering it patient by patient across each of the TCPs.

- Q49 **Chair:** If someone left an institution today, are you confident that in five years' time you would be able to tell whether the money had followed the individual?

Professor Jane Cummings: What we are saying is that the money that we release will go to support people in different circumstances, whether that is in community settings or in residential care. At the moment, about 26% of people discharged go into residential care. The money can follow, but we have also been very clear that the money that will go to support dowries is as much as the NHS can afford to move. We will also use it to commission and fund community services to support people in those circumstances, and we have evidence of doing that already this year.

- Q50 **Chair:** The danger is that some people may end up in positions—it has certainly happened in the past—where they are supported by a family member and that breaks down, perhaps because the family member is a parent who is older. I do not need to replay it to you; you know the landscape. There is a danger that people will not all be demanding in terms of getting the right support first off, but that their needs might become more apparent down the line. If the community placement is done very well, they might be less demanding on the system financially for a period of time, but then it might kick in down the line. Where will the money have gone then? That is the question.

Professor Jane Cummings: We were very clear when we published "Building the right support" that this is not about saving money. Any reduction in inpatient expenditure will be reinvested in services. We were also clear that we want better commissioning and better provision of support further up the system, if you like. That is something that we need to do in combination with local authorities. This is a combination of NHS and local authorities working together to deliver services up front as far as we can.

- Q51 **Chair:** It is great that you are sitting here today making that commitment not to reduce. Of course, future Governments—we politicians get in the way of these things—could decide to make cuts in the system. Is there a guarantee of how long that money will be in the system without being cut?

Professor Jane Cummings: My colleagues might want to comment on this, but I assume it is guaranteed as long as we are running the programme and nobody decides for us that it should not happen.

- Q52 **Chair:** So as long as you are running the programme, that is the transforming—

Simon Stevens: The point is that it is supposed to be in perpetuity, so there is no—

- Q53 **Chair:** Yes, it is, but just to be absolutely clear. It is supposed to be in perpetuity, but is there any—



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Simon Stevens: Well, you just posed a scenario in which Parliament legislates for something different. In that situation, that is up to you.

Chris Wormald: There aren't any statutory guarantees. I don't think there are any political parties that are challenging that concept.

Q54 **Chair:** Maybe I am a cynic. I will bring in the Comptroller and Auditor General, and then Anne-Marie Trevelyan.

Sir Amyas Morse: I have a specific question. I am looking at paragraph 3.19 of our Report, which states that you have saved £10.8 million from bed closures, and so far you have transferred £1 million. That is great, but what is the hold-up with transferring the rest of the money? I do not quite understand.

Professor Jane Cummings: As Simon said, at the moment, patients may be treated in hospitals that have overheads—wards, staff—and you can only take the money out once you have changed the contract you have got with that organisation and they have been able to reduce the overheads, staff and facilities with it. We have talked already about the difference between people who are commissioned on an individual or cost per case basis, because that money can immediately follow the patient, and the NHS ones, which are slightly more complex. It will happen; there is just a slight lag time.

One of the reasons we set up, through “Building the right support”, some transformational funding is that there was money available each year—the year that has just finished and for the next two years—for us to use to help support that transition while we waited for money to be released from in-patient services.

Q55 **Mrs Trevelyan:** That is helpful. In terms of those you have talked about who you have been able take out of institutions, where is the lead advocacy for them? They may have family members who make sure that they keep all of you and the various parties on their mettle to make it happen, but there will be many who you and the clinical commissioners have agreed should not be in those institutions anymore but do not have a family advocate. How will you ensure that they get someone who fights for them? This is a very complex set of organisations to pull together, so how is that working in practice?

Professor Jane Cummings: There are several mechanisms for that. Probably the most obvious is our implementation of care and treatment reviews. We have a combination of commissioners and experts by experience—people with a learning disability or carers for someone with a learning disability—who do care and treatment reviews. We have done 5,000-odd of those since we started that in October 2014. As part of that, there is follow-up. We need to be slightly better at doing some of that follow-up, and we are working on that at the moment. So that is one way, and the experts by experience often act as advocates to support individuals who are in in-patient—

Q56 **Mrs Trevelyan:** But they will not stay with them?



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Professor Jane Cummings: They will not stay with them, but we also have case managers. Specifically, many specialised commissioning patients have a case manager who supports them and oversees both their support in hospital and their transfer out.

The third thing we have done in some areas, using some of the transitional funding, is actually bought in advocacy services in order to support individuals. The couple of examples of that are in the north-east of England and Nottinghamshire. They have actually purchased additional advocacy support to help those people.

- Q57 **Mrs Trevelyan:** Of the 137 so far who Mr Stevens identifies as having had their beds closed and are therefore now back in the community, how many were advocated for by their families and had the advantage of that family support, and how many would you say have what I would call an independent advocate because they have none of their own? If you don't know, could you find out and tell us?

Professor Jane Cummings: I don't know, because we don't hold that level of personal data at a national level, but I can certainly look into that.

- Q58 **Mrs Trevelyan:** Yet the cost of having to provide advocacy compared with the free investment that families provide is going to be critical to those who don't have family advocacy.

Professor Jane Cummings: We completely agree with that. Having advocacy through families and carers is one way, but it is absolutely vital that individuals who do not have advocacy through families and carers have advocates speaking on their behalf. It may be worth saying that, although we have closed over 136 beds, we have discharged a lot more people than that over the last 12 months.

- Q59 **Mrs Trevelyan:** So that means you are putting new people into those beds even though the Transforming Care programme is to reduce by half.

Professor Jane Cummings: There is a difference between the number of beds closed and the number of patients who have been and are being discharged. Yes, of course, there will always be some who go back in, but we have discharged a lot more people from hospital than the 136-plus beds that we have closed.

Simon Stevens: Twice as many, in fact.

- Q60 **Mrs Trevelyan:** Who are now in the community environment?

Simon Stevens: Yes. The 12% reduction in in-patient bed usage is 330 places, compared with the over 136 beds.

Mrs Trevelyan: It would be helpful if you identified for us—if you can—how many of those have family advocacy support and how many do not. It is going to be an impossible challenge to bring these down if we rely on non-family advocacy. From my north-east experience, my instinct is that families fight harder and push all of you, which is great for individuals who have that support, but those who also need to come out—



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Ashley McDougall: I have a couple of points on the care and treatment reviews, which are working. NHS England thought perhaps care and treatment reviews were not working the way they needed to and was looking to review the policy by March to make sure that they were actually working. They are perhaps not actually reaching all the people, because, as Anne-Marie Trevelyan mentions, paragraph 3.12 says that patients and families do not really understand the process, which is one of the reasons for the review.

- Q61 **Chair:** We are going to come on to that, but I want to come to Ray James first and ask how engaged local authorities are in this. We had quite a good picture painted by Professor Cummings. There is obviously a will to do this. How is it working from your perspective?

Ray James: At national level, ADASS is represented on the Transforming Care delivery board. I am formally vice-chair, but it feels more like I am co-chair with Jane on that, in the approach that we take. The LGA is also represented on that board. You will see local authorities represented on each of the Transforming Care partnerships locally as well. Indeed, some are led by local authority SROs.

Inevitably, there is a degree of variability in the strength of local authority engagement. Some of that is back to the line of inquiry you were just having, which is essentially about how much clarity and confidence there is in the pace of the financial flows. I think we can point to pretty strong local government engagement and a very clear desire to do all that we can. As was mentioned in your first panel, despite the scale of funding reductions that local government has faced in recent years, the actual spend on people with learning disabilities increased slightly during that time.

- Q62 **Chair:** Is that under threat in future, with more cuts coming down the line?

Ray James: Inevitably there is a risk between the longer-term sustainability of the whole system and what we are able to do for the group of people who are covered by the Transforming Care programme.

- Q63 **Chair:** The NAO reminds us about the care and treatment reviews process, the 48 areas where all of this is being worked through. We have heard from various witnesses about a lack of specialist learning disability commissioning in those areas. Would you acknowledge that is a problem? If so, what are you planning to do about it?

Ray James: As I said earlier, I think there is more variability than we would want. Part of what we often do in local government is a kind of sector-led offer, where we will try to pair some of the strongest and best so that they can share their experience with other areas that are struggling.

The delivery phase of this programme will not be effective if it is done centrally. It needs to understand closely what is happening in each region and each Transforming Care partnership. It is there that the local



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expertise that Viv Cooper talked about needs to get alongside and provide support, and it also needs to ensure that the voice of people with lived experience and their families are central both to the planning and to the checks and balances in the assurance that happens in each locality.

- Q64 **Chair:** Are you confident that families have a strong enough voice? You say there is variability. Are there good examples where families are really at the table helping to plan? It is often families who can be most experienced, notwithstanding your professional experience. Most have experience with their own family member and the general situation.

Ray James: I am very fortunate in Enfield to have some very strong connections with parent carers and families who both have advocated and continue to show an interest, not just in the lives of their own family member but collectively, in others. It is probably true to say that very often, people in positions of authority will not make profound change unless they are made to feel a little uncomfortable en route. There are very few people who can do that as effectively as people with lived experience or their family members, parents and carers.

- Q65 **Chair:** Perhaps you, Simon Stevens or Jane Cummings could say whether you think the system is designed to support and encourage families. You say there is variability, and everybody acknowledges that there is still a challenge getting everyone up to the same level. How do you ensure that areas where they are not including families as much are getting on top of that?

Ray James: One thing we have looked for from each of the Transforming Care partnerships is clear evidence of the strength of their engagement with local families. We have heard at the assurance board that that has not been the case everywhere, and we are always reflecting that. It needs to be in each of those 48 local areas and, below that, very often at individual local authority level as well.

- Q66 **Chair:** Of course, these plans do not fit with the sustainability and transformation plan areas. Is that causing any difficulties for you at local level?

Ray James: There are probably a few places where they might perceive this as a degree of inconvenience, but ultimately a place-based approach, with health and social care working together, focused around the experience of people who really understand—as we have been talking about—is the best way to try to ensure that we make a real and lasting difference.

- Q67 **Mrs Trevelyan:** The reality of getting out of this cycle and moving on is having the skilled workforce in the community who can pick up and support. How is that going? Across the NHS, the workforce challenge is very real. Within this particular sector at a council-supported level and right through, how do you see that progressing so far?

Ray James: This is a key challenge. One thing we can take some encouragement from has been the growth in positive behavioural support and similar approaches—that is, where the approach taken with an



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individual is centred on their needs, and focused on the recognition and encouragement of positive behaviours, rather than always waiting for something to go wrong and then responding. We have seen a significant increase in the amount of people who are trained and accredited in that and similar approaches.

In my local authority, as in many others, the integrated health and social care learning disability team routinely trains staff with local providers in that and similar areas of work. That said, there is more variability up and down the country than we would like. If we are going to make a success of so many people moving from hospital and long-stay settings into community settings, then a sustained investment in the skill, remuneration and support of that frontline workforce will be crucial.

Q68 Mrs Trevelyan: That should start now, logically. That investment seems to be slightly back-loaded towards the end of the programme, yet we should be getting those teams of people now. We are closing Calderstones. That is 223 people who will presumably be spread across the UK. They are not all going to be moving out to Lancashire. In practical terms, the reality of finding the right place with the right support involves that workforce challenge across the country, does it not?

Ray James: Yes. The partnerships involve both Health Education England and Skills for Care—health and social care—and representatives of a large number of providers. There is good work starting to happen in relation to that, but I agree strongly that it has to be sustained if we are to see the success we need in coming years.

Q69 Mrs Trevelyan: Mr Stevens, do you think we are doing it the right way round, in terms of the workforce challenge and investing in that community network? The Report indicates that it is very heavily weighted to the back end of the programme.

Simon Stevens: As Jane said, 21 new community teams have come online during the past year, and another 11 will come online over the next three or four months. A lot of this will be about local employment training and development, but there is a national angle to this, and I agree with what Ray just said on the importance of the HEE and Skills for Care development that we are going to need to see on the workforce.

Around learning disability nursing, we have about 7,000 learning disability registered nurses in England, of whom 3,200 are working in the NHS and 4,000 are in social care services or settings, and that balance may flex. We have a particular set of issues, which I am sure Jane will talk to, about recruitment to learning disability nursing. Later this week, we are going to be setting out plans for various aspects of how the NHS needs to evolve, and one of them will be an initiative around attracting people into learning disability nursing.

Chris Wormald: I would add one thing on the specific question of whether this was done the right way round. As a newbie who was not here in 2015, if there had not been the galvanising pledge that was made in 2015—



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Q70 **Chair:** I think we acknowledged that right at the top.

Chris Wormald: No, but I think it was required to do it this way round in order to galvanise the system—

Chair: I see what you mean. It was leadership, rather than waiting for it to emerge from the bottom.

Chris Wormald: Exactly.

Q71 **Chair:** Point made. How much do care and treatment reviews have an impact on the staffing that is needed? Only 39% of people had a care and treatment review in the past six months. First, why is that quite so low? Secondly, as that goes up, will that determine what people and skills you need in the community?

Simon Stevens: I will start, and then I am sure Jane will want to come in. The first thing to say is that there has been a very substantial increase in the number of care and treatment reviews. There has been a 50% increase over the course of the past year, with more than 5,000 done—

Chair: The galvanising approach that Mr Wormald gave you credit for.

Simon Stevens: Indeed. There has been a huge increase. The second thing to say is that care and treatment reviews are not just about helping review the support that people who are already in-patients are getting; they are an admissions avoidance tool. They are a way of saying, "For this individual, are we really sure that heading in this direction is the right alternative."

Q72 **Chair:** To be clear, if someone is being assessed, they will be under a care and treatment review now. That will be the new approach.

Simon Stevens: Yes, so 71% of the care and treatment reviews that were done pre-admission resulted in a decision not to admit. That is a pretty substantial way of providing alternatives upstream, as it were. The proportion of people who are in-patients who have not had a care and treatment review has gone down from 47% last January. I think the NAO recorded it as 27%, and it has come down even more since then: in February only 20.5% of people had not had a care and treatment review. I think that is really substantial progress.

Chair: The trajectory is going down.

Simon Stevens: Yes, it is.

Q73 **Chair:** Does it make a difference to the people who will be needed on the workforce skilling? Does it feed into that?

Professor Jane Cummings: When we do care and treatment reviews, we use commissioners, but also expert clinicians who are able to challenge and question. They can ask the questions that people who may have been looking after somebody for some considerable time may not always think about. Yes, it does take—



Q74 **Chair:** Sorry to interrupt you, but it is interesting that you say that, because the Royal College of Psychiatrists said to us in evidence that most of them do not currently include an independent clinician who is senior or experienced enough and who has the power to properly challenge the care package that a patient is currently receiving. Do you disagree with that?

Professor Jane Cummings: We have a combination of medical clinical professionals and nursing professionals. When I first set this up some time ago, I brought in a consultant nurse with learning disabilities specifically to go in and look at one particular case where there was a really horrible story about the way in which that individual had been treated. The care and treatment reviews built from them. The overall feedback we have had is very positive, both from the experts by experience who have been involved in them and from the clinicians, the nurses and the people who have been there doing it.

Simon has already referred to the reduction in the number of people without a care and treatment review to 20% of the total. I think it is also worth saying that of those 20%, about 70% are in secure settings and/or have a Ministry of Justice restriction. What we have just done over the last few months, as Ashley referred to, is a review of care and treatment reviews. We have had over 700 responses from families and patients about those CTRs, so the new policy that we have just published, or are just about to publish—

Simon Stevens: We published it this morning.

Chair: An amazing coincidence.

Simon Stevens: Well, we said we'd do it by the end of March, so it was today, tomorrow or the day after. We stick to our deadlines here at NHS England.

Professor Jane Cummings: Based on the feedback we have had, we have said that for children—we have about 185 children who are in-patients at the moment—we should do them more frequently, but for those patients who are under MOJ restrictions or in secure settings, we may want to do them less often, perhaps every 12 months rather than every six months. That is based on feedback that we have had from the clinicians who have been doing them, and also from the families, the carers and the people who have responded. What I think that will do, and we are hoping it will do, is increase the proportion—I don't really like the term "conversion rate"—of people we do a CTR on who we think are then ready for discharge.

The work that we have done so far over the last 12 months has shown, I think, that the proportion of people who have a CTR who are thought to be ready for discharge ranges between 26% and 39%. The idea is that hopefully we will start to increase that percentage by doing the CTRs more appropriately, rather than having a blanket approach of doing them every



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six months. We said we would do a review; we have done it, and I think we will be in a better position moving forward.

- Q75 **Mrs Trevelyan:** Your task at the moment is to review everyone every six months. As you say, maybe that is not the way forward, but what is your latest figure? According to paragraph 15 of the Report, “only 39%... had had a review within the last six months”. That is a big cohort. Whilst 75% or 80% have now had a review in this new framework, which is good news, more than 50% still are not in your at least six-monthly cycle to a point where you can assess them.

Just to throw something else in, there was a ripple of disbelief behind you when you said you had specialist clinicians doing these assessments—it was palpable.

Professor Jane Cummings: I have clinicians behind me who have been part of them.

- Q76 **Mrs Trevelyan:** I want to challenge you on how you can be sure that you have the right people and the best people, because this is across the country; this is social services from Dorset having to go to Lancashire. How can you make that work in practice?

Professor Jane Cummings: The CTRs are commissioned locally. The policy explains how they should be carried out and who should be part of them. They are monitored and reviewed locally and then reported up. Part of the policy work was looking at how we could improve our ongoing evaluation of those CTRs.

What the figures in the NAO Report show—as we acknowledged they would, and the NAO accepted that—is that we said we would increase the number who would have been assessed by the end of the year, and we have done that, so we have got a lot less now that have not. Of those who have not, about 10% of people have been in for less than three months anyway, so they would not even be in the position where they would be eligible. I think we are moving in the right direction and—I really do believe this—nobody here is complacent. We are making substantial moves in the right direction, but we know we have still got further to go.

- Q77 **Chair:** One of the things we heard from our previous panel was about the fact that people are being admitted. Mr Stevens, you just talked about preventing admissions, but you are still admitting people. Have you got an analysis of how many mental health beds you will need in the future and what the provision will look like, given that you are closing some institutions? Are you planning to keep some open? What is the plan?

Simon Stevens: Yes. I am sure Jane will supplement this, but the plan that the local partnerships have produced and that Jane and her team have reviewed with Ray and the broader stakeholder panel is for a 35% to 50% reduction in beds as a result of this programme.

- Q78 **Chair:** Okay, and what about the pattern? What will the beds look like? Will they be in the existing institutions or do you plan to close—



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Simon Stevens: Well, we have talked about some of the larger institutions. One of the things we talked about back in 2015 was the stark geographical differences across the country, which I think tell us that this is not as a result of differences in individual need or preference but is legacy modes of provision that have been reinforced down the years and decades. Frankly, there is going to be a bigger shift of services in the north-east and in parts of the north-west than in parts of the country that have already successfully undergone that transition. That is why we need these localised planning processes through the 48 Transforming Care partnerships.

Chair: I will bring in Mr Boswell.

- Q79 **Philip Boswell:** Thank you, Chair. This question is for all of you. It follows on from Mrs Trevelyan's question and it is in relation to Calderstones closing. With reference to figure 11 on page 29—the Transforming Care partnership map and locations—I see six are fast-tracked. Is the closure of 223 beds at Calderstones in Lancashire in 2019 the reason, or one of the reasons, why TCP No. 35 is fast-tracked? Mr James mentioned the requirement for sustained support. I understand that the budget for new buildings is over five years, but I presume it takes time to set up local support properly and move beds that are closing. Is rushing into the statistics and closing so many beds in one place before appropriate support services are in place putting patients at risk?

Simon Stevens: First of all, I do not think we are usually accused of going too fast in this area. There has been a consultation, and I think it is fair to say there are split opinions about the future of services at Calderstones—inevitably there are. That has been the history of these kinds of service changes. There is still a process to be gone through, through the outline business case and full business case; the trust will need to secure capital approvals from NHS Improvement, DH and the Treasury for those transitions. All these questions will be thoroughly vetted as part of that process.

- Q80 **Philip Boswell:** On page 7, paragraph 9 says: "The Department, NHS England and local authorities have limited measures to assess the quality and impact of health and social care support." How do you know you are not damaging the services by closing Calderstones in 2019 and cutting these beds without getting the support in place? How do you know adequate support is in place?

Simon Stevens: There are two separate questions there. One is: is the service model currently in place an acceptable service model for the future? The answer to that is no. Once you have answered that, the question then is all about effectively managing the transition.

- Q81 **Chair:** To back up Mr Boswell's point, one of the concerns is the unfunded costs for local authorities. We talked about health funding going down the line, but there are other costs associated with someone living in the community. How much do you at NHS England interact with the DWP



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elements on housing benefit support and all the things that might go as part of a package for somebody who is living in the community that they would not need in an institution? I will bring in Mr James after Professor Cummings.

Professor Jane Cummings: I think it is fair to say right up front that clearly, in order to close the beds—we are closing the beds on that site—we are reproviding some beds in other places. So, medium-secure beds will be moved and reopened, and some of the low-secure beds will be provided in different settings across the north-west, so that people can get care closer to home. Clearly, we would need to make sure those are open, available, staffed and all the rest of it before we move.

The really important thing about this is local support for those individuals and patients. The point that the Chair has made about housing and working across system is really important. NHS England has funded and employed people, both nationally and in regions, to support housing, because this is an important factor; it is critical. We are providing some capital money, as is the Department, in order to provide housing, but also we have to work with people within the NHS who currently are not as used to sorting or managing housing as other people, but local government DWP colleagues are supporting them, and we are helping to fund that. That is a really important point.

We have also commissioned a partnership to evaluate the Transforming Care programme, which is really important. So we have a combination of people, including a Commissioning Support Unit, Birmingham University and a couple of other organisations that have already started an evaluation of the Transforming Care partnership. As part of that, they are looking at quality of care, quality of life and the services that are being reprovided in the community. They will report to us on a quarterly basis, so that is a really important factor that we have built in.

Then, subsequently, as part of the response to the consultation on the future of services across the north-west of England, we have reinforced the oversight and assurance around the development of community services across the north-west, to ensure that the comments that have been made by Mr Boswell will actually be addressed. So, we have plans—

Q82 **Chair:** Mr Wormald wants to come in. I always want to ask you, Mr Wormald, about this capital funding. Mr Stevens and others have talked about the in-perpetuity promise of funding following the patient, but the capital funding is additional from the Department and NHS England. Is that also guaranteed, given the pressure on your budget? Of course, you are bringing your accounts to an end at the moment.

Chris Wormald: It is part of the wider capital budget for the—

Q83 **Chair:** So it is as at risk as any other part of your budget?

Chris Wormald: Yes. It takes its place in the priorities of the NHS, which does require—

Q84 **Chair:** So, as you are balancing your books every year, you will be



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looking at this as part of that pot?

Chris Wormald: Yes. Can I just say something on Mr Boswell's questions very specifically, because I think there are two parts to consider? On the Transforming Care programme, I think I am right in saying that there is a very strong professional consensus that the model of care that NHS England and local government are working to—of moving people out of big institutions and into community care—is right. That is very well evidenced, academically and in practice.

There is then a wider question that I think the NAO was getting to, which I suspect we will come back to later in the hearing, about how we judge the overall quality of all our interventions with learning disabilities. There is a lot of work to be done, but I think on this specific point there is a very strong evidence base that the model of care is correct.

- Q85 **Philip Boswell:** That's fine. A lot of what you are saying again backs up page 7, point 9, where it says under the heading, "Most of the national measures focus on activity, rather than outcomes (paragraphs 1.13 to 1.19)". Specifically, in paragraphs 1.14 and 1.15 on page 21, which are on Healthcare outcomes, the second sentence of paragraph 1.14 says, "Even so, there are few indicators that show whether the health of people with a learning disability is improving." So, how do you know—

Chris Wormald: We are now moving away from the Transforming Care programme and talking about—

- Q86 **Chair:** We will talk about that in a moment; we will go back to that. Hold that thought. I just want to ask Ray James something. You have heard about the capital money coming through. Are you confident that it is coming through in the right timeframe and are you worried about its long-term sustainability, given the funding challenges of the NHS, because it is pretty critical for your members?

Ray James: I think the Report clearly evidences how oversubscribed the capital allocations were. So, while what we have done has been helpful today, any greater certainty about the adequacy and sustainability of both capital and revenue funding going forward has to help local areas to plan. Particularly when you are bringing forward housing solutions, you need a lead-in time, given how bespoke some of those solutions may need to be for individuals.

If we could combine greater capital certainty with a joined-up approach across Government—a comment was made in the first panel about this—in terms of the risks that changes to local housing allowance might bring and how many supported housing providers have stalled their plans and are still a little hesitant in terms of what we are doing for the future, that would definitely help with the housing part of this programme.

- Q87 **Chair:** That is a really important wider policy issue, in terms of the interaction. Mr Wormald, you are responsible for this overall. If the provision of supported housing collapses, it will be catastrophic for this cohort, as well as many others. It is not the Department of Health's



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responsibility, but you have overall responsibility for learning disabled adults and the support for them. What are you doing in Whitehall to make sure this is really joined up?

Chris Wormald: We discuss these issues with our colleagues at DCLG all the time, as part of our wider discussions with them about adult social care that we described before.

Q88 **Chair:** Do they listen?

Chris Wormald: We have very productive conversations, and as you know—

Q89 **Chair:** You have got your standard phrase here. I am sure they are productive, but what are the outcomes? We are hearing that there is a crisis here and now. It is your area of responsibility, even though it is another Department delivering it—for learning disabled adults, in any case. We all have constituents who are losing their support, some of whom have managed very well for many years but are suddenly going to be in crisis if they lose that support. What are you doing about it? Does the buck stop with you?

Chris Wormald: You described the current situation earlier. As you know, the Government is going to be coming forward with consultation proposals on this later this year, and we will be involved in that.

Chair: You will be involved. I hope you will be a bit more than just involved—driving through and being passionate—with the people you are responsible for.

Chris Wormald: This, as you know, is a DCLG lead, and we will be in discussion with them. A whole-Government agreed approach will be brought forward in the usual way.

Q90 **Chair:** What do you think will be the outcomes if supported housing does not get resolved and the supported housing providers can no longer provide that support?

Chris Wormald: We will have to ensure that it does get resolved. As everyone has made clear, this is an important part of the package, and it is very important that the whole of Government works together on these issues.

Q91 **Chair:** You just said, “We will have to ensure it does get resolved.” That sounds quite positive, in mandarin talk. We will hold you to that in future, because it is pretty critical for this whole programme, in terms of getting people out of hospitals and the area we are going to move on to—the many thousands of people who receive care through local councils already.

Chris Wormald: I do not think there is any disagreement across Government about the importance of this group of people or that because the responsibilities are split across Government; we have to work very closely to ensure that we get the right package.



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Q92 **Chair:** Do you feel a passion, as the main advocate in Whitehall?

Chris Wormald: Oh yes.

Q93 **Chair:** Obviously there is NHS England, but in terms of the Whitehall permanent secretaries, you have the policy lead for people with learning disabilities. I am giving you the opportunity to put on record your commitment to those people.

Chris Wormald: We are completely committed to that. In fact, we have made some considerable elements of progress in the last couple of years, particularly on employment. The fact that we have a joint Green Paper with the Department for Work and Pensions and a joint unit between the Department of Health and the Department for Work and Pensions—

Chair: We are going to come on to employment in a minute.

Chris Wormald: That is Whitehall co-operation of a type we have not seen before, and we are seeing that with other Departments.

Q94 **Chair:** People who have a relative with a learning disability or who themselves have a learning disability want to know that they have a champion in Whitehall. Is that you, Mr Wormald?

Chris Wormald: It is certainly the Department of Health.

Chair: And you personally.

Chris Wormald: And me personally.

Q95 **Chair:** Thank you. Mr Stevens has made his commitment, so we are getting you to make the same commitment. Can I ask a couple of last questions on this area before we go on to the wider support that people with learning disabilities need and get in the community? There is a readmission rate currently of one in four, according to paragraph 3.28. What are you doing to reduce that? Does it concern you that the readmission rate is 25%?

Professor Jane Cummings: We have looked at individual cases for that. We know that the complex needs of some of the people we are supporting means that some will need readmission, and that is the right thing to do for them. We also have to make sure that the services that are provided, and the support that is provided in the community, are sufficient to ensure that they are supported to stay in the community where that is possible. We have done multiple case studies of individuals who have been readmitted—sometimes for a short time, sometimes for longer—and that has been the right thing to do for them in their circumstances.

Q96 **Chair:** So some of those readmissions will be short-time crisis readmissions; is that what you are saying?

Professor Jane Cummings: Yes.

Q97 **Chair:** They are not all long stay.

Professor Jane Cummings: They are not all long stay.



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Q98 **Chair:** Do you have a measure, so that you could send us some information about how many—I think there may be some metrics, actually, in the NAO Report.

Professor Jane Cummings: What we can look at, and we have got some information on, is the people who were admitted—just general admissions; we can have a look and see whether there is anything more detailed we can do about readmissions. The people who have been readmitted or admitted to hospital in Q1 of last year, versus Q1 of the year before, are admitted for less time.

So there is a significant reduction in the number who are still in-patients after six months, as compared to the previous year. That is particularly stark for NHS England commissioning people, which was quite surprising when we looked at it. We have seen that for specialised commissioning; two years ago 90% were still in after six months, and this year just gone 72% were. That is quite a big reduction, so I think we are seeing more and more people being discharged; we are seeing fewer people being admitted, and for less time, which is what we wanted to see. Clearly, readmission, on a case-by-case basis, is something that the local teams need to look at very carefully.

Q99 **Chair:** My final question on this section is for Simon Stevens, I suppose, but maybe for Professor Cummings, too. How confident are you, Simon Stevens, that the partnerships will close all the planned beds by 2019?

Simon Stevens: I think I agree with the assessment in the NAO Report, which is that there is a solid basis for the programme. We have made good progress over the last year, but there is a lot of work to be done to put us on that track in a confident fashion—work that we are committed to doing.

Q100 **Chair:** Thank you. We are going to move on to the next issue. There are 100,000 people who receive care packages through local government, but of course there are different figures. Mencap told us earlier that there are 1.4 million people with a learning disability, some of whom will receive more support, and some less. We were struck by the issues that you may have heard about from the first panel, if you were in the room—the number of people in work and the number registered with a GP. Perhaps I will go to the matter of registration with GPs first. I guess that that is for Simon Stevens, but Chris Wormald, as you have the overarching responsibility across Government, this is also important for you. The variation—we got some breakdown of comparative performance for GP health checks for people with a learning disability. The figure, of course, as we heard earlier, is 23% of people with a learning disability registered with a GP.

Chris Wormald: No.

Simon Stevens: No, I think there is a big conceptual confusion there—

Chair: I asked Ashley McDougall to check the figure.



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Simon Stevens: No, I think we are talking about two separate things. One is the proportion of people registered with a GP. The other is the proportion of people with a learning disability registered with a GP who are flagged as having a learning disability on the GP register. I think it is the latter that is the point. So it is not the proportion of people who do not have a GP; it is just that they may not be flagged as having a learning disability on their GP practice register.

Chair: Which is the gateway to opening other support services up.

Chris Wormald: Yes. It is still a very important number. It is just not as—

Q101 **Chair:** Thank you for clarifying. And the GP is the gateway, as we said earlier, to other services. In my area, the percentage of eligible adults with a learning disability who had a GP health check—this is in the London Borough of Hackney—was 59%; but if you go to Brighton, or the Brighton and Hove council area, 9.4% had had a health check; and in East Sussex County Council 6.3% had. Those are just two variations.

I should give Anne-Marie Trevelyan's area a big-up, because once again Northumberland seems to be at the top, with 76% of people having had a health check. Presumably, sometimes people with learning disabilities will have had health checks but may not have been logged as having a learning disability; but that comparative performance is poor—the fact that there is some very good practice and some very poor practice. Why is that? And what are you doing to make it better?

Professor Jane Cummings: First of all, we completely agree that annual health checks are critical. A lot of evidence and research was published last year showing that people with a learning disability who have an annual health check have much better health outcomes, so we know that it is really important. Annual health checks are an enhanced service for GPs—so they are not mandated, but we are funding them. The numbers have gone up quite a lot. About 90% of GP practices have signed up to doing annual health checks.

What we have done to increase the number: first, we have increased the amount of money that we have allocated. So from April '17, it will go up from £116 per health check to £140, which is an increase of about £9 million a year going to GPs to do that. We have worked with the Royal College of GPs to create a new template to make it easier for them to do—it is simpler, it has more drop-down, it is easier to get it done—and that was based on feedback we had had from GPs. We have also included it in the CCG assessment framework, so it is part of the way in which we assess how CCGs are delivering against the key priorities. For learning disability, this is one of the things that we have done.

We are expecting to get something like a 10% increase every year. Our aim is to get to at least 75% by 2020. We know that where there has been targeted action, like in the north-east where we had some specific support going in to look at that, it has been beneficial and that has increased. We have put in a range of measures—some are financial, but some are in



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terms of our performance management and our monitoring—and we are reporting annual health checks much more frequently from '17 onwards, as opposed to annually as it was in the past. Those things combined will help.

Chair: I am sorry, can I ask you to be a bit quicker on questions, because—

Professor Jane Cummings: There is a lot to tell you.

Chair: I know! I am passionate about this subject, but we also need to get through our points.

Professor Jane Cummings: Okay. I'll be quicker.

Q102 **Chair:** May I ask Ray James a question? Presumably it is very crucial for your members, the social services providers, to make sure that the health checks and the logging with the GP is done, because that is a gateway and a provider of information to the people who are actually providing the care day to day on the ground. Do those figures worry you?

Ray James: Nationally they do. If you were to dig deeper, what you would probably reveal is that most of those people known to social care, with active ongoing support, are those more likely to be on the register. It is potentially those with lower-level needs, not getting that kind of support, that are on the register.

Q103 **Chair:** Do you think that there are people that local government is missing support for because they are not registered at the GP as having a learning disability? Therefore there is no flag in the system to push them through to the relevant support.

Ray James: This is my 11th year as a director. In that time there have been a couple of occasions on which we have been surprised to find people with a learning disability not previously known to us managing to live independently without much support. That is relatively uncommon, but it still happens.

Q104 **Chair:** Do you think that if more were registered with GPs it would make a difference?

Ray James: Yes.

Q105 **Chair:** I want to move on to the issue around work. We had good, clear evidence with a report that highlights the average level of the percentage of people in work, which ranges from 3% to 20% in different parts of the country. It seems quite shocking that people can be written off. This obviously links in, Mr Wormald, to relations with the DWP, to how employment support allowance is calculated and to all sorts of other elements of the system. In your role as someone responsible for this area across Whitehall, what are you doing to help improve the figure for the number of people with a learning disability getting into work?

Chris Wormald: I have already mentioned the biggest thing, which is the Green Paper that we published jointly with the DWP about work, health



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and disability in general. As I said before, it is a very big step forward that there is a Green Paper on that subject, even before we get to the important policies contained in it. We work more closely with DWP than we ever have before.

When I have discussed this with the DWP—I think this comes out of the National Audit Office Report as well—the actual explanation both for the level of employment and for the variability that we see is not a well understood or researched area. As I think you said earlier, Chair, it is linked to socioeconomics, but that clearly does not explain the entire gap.

The approach that my colleagues at DWP, with us, are taking through the Green Paper is basically to pilot a whole series of different approaches in local authorities, particularly around improving employment support. They are working with local government and seeking pilots around support for employment.

Q106 Nigel Mills: Given that Derbyshire is very low—I think we have got 1.7%; 136th out of the 150—is one of those pilots in Derbyshire, by any chance?

Chris Wormald: The DWP has sought proposals, but I don't know whether Derbyshire is one of the places that has put forward a proposal. They say they are very encouraged by the level of interest from local authorities and they will announce the successful areas shortly.

We are also doing a considerable amount for the younger age range, some of it in my former Department. Supported internships are important in this area. We are also doing supported work experience for young people. The overall approach, because the phenomenon we are dealing with is not well understood, will be to try out a lot of different things, see what works, build on that, and then build that into a more general policy. So I cannot give you a specific answer.

Anecdotally—I will ask Ray to come in as well—DWP and we see that some of the high performers are in places where the local authority has put an enormous amount of passion and effort in, but that does not seem to explain the entire thing. As came out in the pre-panel, the mindset of employers in an area is very important as well.

Q107 Chair: What strikes me about this is that if someone has got a learning disability, it is a lifelong condition—it will not get better—and people have different levels of need. You have to go through many bureaucratic hoops to go to the local college, to get DWP support, to qualify for supported housing, and to be assessed by social services.

Have you as the person with overall responsibility given any thought to some sort of passport so that someone with lifelong issues does not have to be constantly reassessed, but gets passported through? It seems the GP is a gateway. Have you considered an approach that would save a lot of money, time and effort in the system? That is our focus, rather than policy. Is that something you have looked at, rather than having to apply endlessly and be reassessed all the time?



Chris Wormald: Yes, that is of course pretty much exactly what we have done for young people in the integrated system. That is in its early stages. It has huge potential. What is happening is encouraging, but it has a long way to go before it fulfils its potential. I don't think we have looked at the same approach in adults, although I think that is an interesting idea. The complications are obvious, but, as we have taken that approach—

Q108 **Chair:** It is not that difficult for government. When you service lots of benefits, for instance, it unlocks other things such as a disabled parking permit or whatever. There are certain things you have to do that trigger other events.

It would save a lot of money if you could have an agreed trigger. Once that is agreed, the GP or social services assessment or whatever then triggers a level of access to support. It might change over time because people's needs may change over time, notwithstanding that they have a lifelong condition—they are not going to suddenly not have a learning disability. They will have that for life.

Chris Wormald: This is not something we have looked at. I think it is an interesting idea.

Chair: Okay. Do you want to come in, Anne-Marie?

Q109 **Mrs Trevelyan:** Can I come back briefly on the GP registration and the numbers being so low? Why is that? We hope that children with learning disabilities are being identified now while they are in the school framework in whichever part of it they sit—as the Chair has said, having identified that, it stays with you as an individual—and are therefore likely to be attached to a GP surgery through that part of their lives. Why is there such a fall-off when they become adults? Why are we not trying to find a system that automatically helps them stay within the GP-registered framework?

Chris Wormald: Shall I say something first on that? The integrated health and care plans in place for special educational needs assessments are very new. They are coming in right now. I suspect it may have an effect, but of course that would not affect the stock of people at all. The idea of the whole reform was to bring together health and education assessments, but, at the moment, if you are over the age of 19 it would not have affected you, so it would not affect Jane's stock figures.

Q110 **Mrs Trevelyan:** So it is the older cohort of those with a learning disability whom we seek to identify and give support with that trigger, as the Chair refers to it.

Professor Jane Cummings: Yes. The annual health checks are for 14 years and older, but I think the reforms that Chris has referred to will make a difference. We have commissioned some support from the local voluntary sector, such as Mencap and NDTI, to help us campaign with families and people with a learning disability, so that there is a bit of a push-pull and people are actually asking and knowing that they should be on a register. It works both ways, and that is really important, too.



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Chris Wormald: I suspect, in the long term, the bigger challenge, which Ray referred to earlier, as you flow through from the younger ages, will be the people who have identified special needs but who do not have an integrated care and health plan, which is, of course, a very small proportion of those with special needs. I expect they are the same people who are not normally on the local authority radar and are in danger of being missed. I think there is quite a specific challenge that we will have to take on going forward on how we get to those people.

Q111 **Chair:** And, Mr James, there are a lot of people with learning disabilities who do not get any support from social services and who are supported by their family or live independently. Are you worried that there is unmet need out there? I guess for local authorities to seek it out is a big potential cost at a time when you have big stresses on the adult social care budget.

Ray James: The reduction in the number of people getting support in recent years that the NAO Report highlights reflects a combination of, first, the tightening of eligibility criteria in local authorities pre the Care Act. Those authorities might previously have funded moderate needs, rather than critical and substantial, and would have been providing a relatively small but important level of support to individuals. The consequences of changes in the Care Act and are that eligibility is now set for local authorities consistently.

Secondly, it reflects the overall funding situation. Local authorities are inevitably facing a difficult choice around ensuring that they meet their statutory duties to those with the most complex needs. When we surveyed ADASS members, one of the two things people most wanted to do more on was prevention, yet in the same survey many recognised that they were spending less on prevention as a result of the overall funding situation.

Q112 **Chair:** How does respite fit into that?

Ray James: Respite is one of the things we hear most frequently from parent carers about its value and the risk in relation to that. We tend to have conversations about overall personal budgets with individuals and their families, and we try to make sure that respite needs are a part of that.

It is also difficult to get specialist respite provision. For some providers, an operating model sensitive enough to provide specialist respite to people with complex needs, and where those providers won't be there full time but may be there on a number of occasions, is just a more difficult business model for some providers to operate. Very often, we talk about whether there are different forms of respite that we can provide in the family home or other options around breaks and people taking breaks together and so on. It is consistently one of the most referenced issues by family carers.

Q113 **Chair:** Okay. You talk about the family home. Has actual respite provision gone down across local authorities, in your experience, because of the



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funding challenges?

Ray James: I think we've seen a number of local authorities try to arrive at a fairer distribution of the resources that they spend. On some occasions, that has led to discussions about limiting the amount of respite that individual families may get. I don't have definitive data about that service specifically, and sometimes it will be obscured within the overall personal budget, in terms of the choice that a family will make. However, I hear it said enough to believe that it is an issue for many families.

Q114 **Chair:** Are personal budgets working for this group of people, in your experience?

Ray James: I am a strong advocate. I think personal budgets—particularly personal health and social care budgets—give really meaningful choice to individuals and their families, and they very often know what works best. I would be a strong advocate of trying to encourage that. In terms of combining programmes, the Transforming Care programme has been talking to a lot with the integrated personal commissioning programme in order to ensure that this very cohort of people are at the forefront of those considered for personal health and social care budgets.

Q115 **Chair:** How well is it going? We have looked at this before, and it is rolling out, but it is not all there yet. What do you think the penetration level is? Do you think it is working, in terms of getting to the right people and getting those families and people with learning disabilities to be able to really control their own budget? Is the money following through?

Ray James: In local government, broadly, the penetration rates around personal budgets and direct payments are strong and sustained. They are beginning to increase, in terms of the NHS and both health and social care budgets, but they are still at relatively low levels compared with the overall number of people we are talking about. The direction is right.

Q116 **Chair:** The direction is right. Mr Wormald, on that, the direction is right but the area you are responsible for across Government spends £8 billion—if you take local government and central Government together across all Departments—on improving the lives of people with a learning disability. You have indicators around registration with GPs and placing people into work. Do you think you have the right indicators to measure real life outcomes for people? While it may be complex, is there a better way you could be doing that?

Chris Wormald: We hope so, yes, but I can't tell you what it is. I will say three things in relation to that. The point was made in the pre-panel: what the vast majority of people with learning disabilities want is exactly the same as what other citizens want—a home, a family and a job. A number of those things are just very difficult to measure and of course we don't measure them for the general population. Secondly, the process measures that we have right now are important. We have discussed a number of them today. It is important—

Q117 **Chair:** I am certainly not suggesting that you abandon them.



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Chris Wormald: No, exactly, so we would keep those. We are doing some work with Kent University—the first stage of which will be published early next year—on whether there are better quality of life and quality of care indicators that we could use, but at this moment there are not any out there that fulfil the requirements that we have.

Q118 **Chair:** When is that work from Kent going to come through? It is early policy development from the sounds of it.

Chris Wormald: Yes, this is quite early. The first stage of it is due to be published early next year and then there will further work after that.

Q119 **Chair:** Presumably you will put that out to networks of parents and people with learning disabilities themselves and the charitable organisations.

Chris Wormald: Yes, and this issue is discussed quite often. Jane described what was happening in the Transforming Care programme around this. There is a lot of work going on. What there isn't is an obvious answer. We recognise exactly what the National Audit Office said—that it would be better; but there aren't—

Q120 **Chair:** We recognise it is difficult; we just want to know, and you have said, that you are looking at it. Kent is looking at it, and then you are going to talk to parents and people with learning disabilities about it. As you say, it is not rocket science. People want a home and a job and good health and the rest of it.

Chris Wormald: Yes, and what are the appropriate measures to do so? That is with the caveat—I know you love my caveats—that this is an area, as I was discussing with Mr Bacon last week on ambulances, where the targets and measures you set can do harm as well as good. So we will do this very cautiously and carefully, but the challenge that the National Audit Office set us is I think the right one.

Q121 **Chair:** I don't think we are saying have a complete, ultimate checklist at the centre of Government, but it does go back down to local authorities. Mr James just talked about personalised budgets, for instance. Is that something you are watching from the centre—how many local authorities have personalised budgets for people with learning disabilities?

Chris Wormald: I don't think that is one of the measures we currently check.

Q122 **Chair:** I don't remember it from the last time we discussed it.

Chris Wormald: No, I don't think that is—

Q123 **Chair:** Would that not be something that as the person responsible in Whitehall for this area you should be looking at—to see, just as with GP registration, the numbers of people on personalised budgets or who have been offered them?

Chris Wormald: There are any number of things that we could track. Our choice is, as I say, to look at this carefully.



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Q124 **Chair:** But you just said, as I think most people would agree, that it is very hard to establish a set of rules about what would be absolutely finally a good outcome for every individual, because people are individuals. A learning disabled adult is no different from anyone else. But if people have a personalised budget, they are in personal control of their outcomes. Surely it would be one of the options that you should be thinking about looking at as a good indicator.

Chris Wormald: Yes. It is not one of the things we track at the moment, but I will go away and look at that specific question. The danger is, of course, that that is another process target without a "And is it working?" part to it. We are not at the moment proposing to change the set of things that we are measuring.

Q125 **Chair:** Okay. I am going to bring in Simon Stevens and then Ray James.

Simon Stevens: Agreeing with what Chris has said, but just supplementing it: on the personal health budget side, we do have a set of expansion targets. Ray referred earlier to what we have called integrated personal commissioning, which is bringing together health and social care budgets for individual people, who then get to exercise choice over how those services are configured around what they want and need, rather than what the system is telling them they should have. We have gone from zero to about 13,000 people with those integrated personal health budgets.

Q126 **Chair:** Do you measure how many of those people have learning disabilities?

Simon Stevens: We do, through the pilot sites. We have particular geographies that are working with particular groups of individuals. Our goal is to get that to between 50,000 and 100,000 by 2020-21. So that is a pretty big ramp up.

Q127 **Chair:** Jane Cummings, you were nodding there. Are you able to give us some figures?

Professor Jane Cummings: Yes. As Simon was referring to, at the moment we are measuring that in pilot sites. Out of the 13,000 that Simon has just mentioned, there are about 4,500 that have. But that is only within the pilot sites.

Q128 **Chair:** But you don't know what percentage that is of people in that area who have a learning disability?

Professor Jane Cummings: No, but there is a very clear sense of direction within NHS England that we want to roll out both the personal health budgets and the integrated budgets. We have a programme in place to do that across the board, and learning disability is an important part of it.

Q129 **Chair:** A final word from Ray James.

Ray James: I would be disappointed if local areas were only using those metrics. I would expect everywhere to be combining something that tells



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them about the quality of local services and how they are experienced by people with learning disabilities—and, in many cases, that people with learning disabilities are employed or act as quality checkers, to give that perspective directly.

There has been some national work around statements with National Voices, and other kinds of outcome-based approaches, which give a framework within which people can have a look at a more outcome-based approach. I think the line of inquiry on what we should concentrate on nationally is right, but that doesn't stop localities having much richer datasets that actively involve people with lived experience, in both the collection and consideration.

Chair: Thank you very much for your time. I forgot to thank you at the beginning for rearranging your diaries to fit in with our complex diaries; we all had to do that today for various reasons. Thank you very much. As ever, the transcript will be up on the website in the next couple of days. The report will be out after Easter.