



# Autism Act 2009 Committee

## Corrected oral evidence

Monday 24 March 2025

4 pm

Watch the meeting

Members present: Baroness Rock (The Chair); Lord Addington; Baroness Browning; Lord Crisp; Lord Elliott of Mickle Fell; Baroness Goudie; Baroness Hodgson of Abinger; Lord Hope of Craighead; Baroness Pitkeathley; Baroness Ritchie of Downpatrick.

Evidence Session No. 5

Heard in Public

Questions 30 - 35

### Witnesses

I: Dr Conor Davidson, Autism Champion, Royal College of Psychiatrists;  
Professor Mark Mon-Williams, Chair in Cognitive Psychology, University of Leeds.



## Examination of witnesses

Dr Conor Davidson and Professor Mark Mon-Williams.

Q30 **The Chair:** Good afternoon, and welcome back to this meeting of the House of Lords Committee on the Autism Act 2009. We are now commencing our second evidence session of the afternoon. Once again, I draw attention to members' interests as published on the committee website.

I am delighted to introduce our second panel of witnesses. We are delighted to be joined by Dr Conor Davidson, autism champion of the Royal College of Psychiatrists, who is joining us remotely; and Professor Mark Mon-Williams, chair in cognitive psychology at the University of Leeds, who is joining us in person. You are both very welcome indeed.

This is a public evidence session and a written transcript will be taken. I will now ask the first question and invite you to answer it in turn, starting with Mark, please. Please give a brief introduction before you answer the question. Since the Autism Act 2009 was passed, how have the Government, the NHS and public services responded to changes in demand for autism assessment and support? Within your answers, could you add what role the Autism Act statutory guidance and the successive autism strategies have played in this?

**Professor Mark Mon-Williams:** Thank you very much. It is a great privilege to be here and hopefully represent a lot of the evidence that has been gathered by so many people with lived experience throughout the UK.

I will be relying quite a lot on the evidence that was accumulated through the Child of the North Report. I could not carry down too many—I am getting old and cannot carry that much weight—but I brought down a number of copies and I will send down some more.

This is a report that was brought together by the research-intensive universities across the north of England, together with their partner universities and colleagues throughout the UK, really trying to understand the barriers and enablers that are faced by autistic people within the system. I play a role within the original universities in trying to see how we as universities can play a role in bringing evidence to the table in considering the various issues related to the Autism Act.

Our perspective of this is that the Autism Act was very welcome—it was a great catalyst for a debate and discussion. However, we also recognise that we are in a very bad place in supporting autistic people throughout the UK. We have accumulated a lot of statistics from throughout the UK, and it is fair to say that the provision is not what was ever envisaged within the original Act. It is very patchy and frankly diabolical in many areas.



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I have the privilege of working within the Bradford Royal Infirmary, where we have horrendous waiting lists for autistic children and young people to receive a diagnosis, within a very diagnostic-led system. That means that a number of children and young people who have needs that we need to be supporting right now are just sat on a waiting list, year after year, and are not getting the help and support that they need.

We have large, connected datasets, so we can see how that plays out across the wider system. We can see the pressure that this places on families, which then creates this huge burden of mental health problems that we see playing out across our district.

When we really drilled into the evidence, our evaluation of the problem was that there are so many individuals and organisations doing such well-meaning work, but it is all completely disjointed. We have fantastic colleagues in education doing great work, but they are completely disconnected from our fantastic colleagues in health who are also doing great work. We start seeing problems with children and families falling through the gaps between health and education playing out in our social care system. We suddenly see all of these issues reflected in our care systems, and then we see them playing out in our criminal justice system.

In summary, we welcome the Autism Act 2009. It was a great starting point, but the harsh reality is that we are not where we need to be as a country in supporting autistic individuals at this moment in time.

**Dr Conor Davidson:** I am a general adult psychiatrist and clinical lead for an NHS adult autism service in Leeds. I was also trust-wide autism lead for Tees, Esk & Wear Valleys mental health trust up in the north-east until 2020. Since 2021, I have been the autism champion for the Royal College of Psychiatrists. That role involves promoting the importance of autism to psychiatrists. I have been closely involved with launching and running a national autism training programme for psychiatrists, in collaboration with NHS England.

I am going to speak mainly about autism and adults, which dovetails quite well with Mark, who will probably focus on children. I am drawing on my personal experience. In many ways, the Autism Act has helped to shape my career, because 20 years ago, I was training to be a general adult psychiatrist, and we deal with working-age adults from the age of about 18 to retirement.

Some 20 years ago, autism was not particularly seen as the business of working-age adult mental health services; it was seen as something for child and adolescent services and for learning disability services. I was regarded as quite eccentric for taking an interest in autism. One of the things that the Autism Act has done very successfully is catalyse that interest in adult mental health services, and there has been a real culture shift in that. Now, not only psychiatrist colleagues but clinicians working



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across adult mental health are taking a much more active interest in autism and other neurodevelopmental conditions.

The practical impact of the Act and particularly the Think Autism statutory guidance that accompanied it a few years later was the proliferation of adult autism assessment services across the country. The Act, of course, is aimed at autistic adults. Take my region as an example: I work in Yorkshire and, prior to the Autism Act, all adult autism referrals across the whole of Yorkshire were channelled to a single assessment service in Sheffield. Since the Act, we now have a service in Leeds, Bradford and York, and that has been replicated across the whole country, so there is much greater accessibility to autism assessment now.

We did not anticipate the scale of demand that we have seen since then. When the referrals in Leeds used to go to Sheffield prior to the Act, there were about 12 a year. After we set up the Leeds service in 2011, pretty soon, we were getting 12 a month. Now, particularly since the Covid pandemic, it is not unusual to get 12 referrals a day, and that is the kind of pattern we have seen across the country—this exponential increase in demand for assessment.

That means that there has been some investment in increasing resource for assessment, but that has not really kept pace with the increase in demand. The situation now is of a real capacity-demand mismatch. We now have over 200,000 people across England waiting for an autism assessment, which is obviously not good for patients or families. It is actually not good for clinicians either, because there is a sense when you are working in one of these services of how you are ever going to meet the demand. We are putting patients onto waiting lists that are two, three or even four years long in some cases.

In terms of my perception of the government strategies, the one that has made the biggest impact is the Think Autism statutory guidance. The reason for that, in my view, is that it carried some legal weight behind it. It was very clearly written. It was quite prescriptive, which is actually no bad thing in this field. It literally said to NHS trusts: you must do this. It said to local authorities that they should do that; they must do this. That was a great lever when it came to people like me who have a passion for improving the lives of autistic people. We could use that to say that we need to do autism training, we need to set up a pathway to autism diagnosis for adults and we need to have an autism partnership board in each area. There were real material changes that came from that. There has been a bit of a law of diminishing returns from subsequent strategy documents that have not had that same impact.

**Q31 Lord Addington:** I am president of the British Dyslexia Association, I have a special educational needs brief and I work for a disability support firm called Microlink PC. That is my declaration of interests out the way.

Could you go on to the main barriers to effective and timely autism assessment and support? How are those barriers to be addressed, in your



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opinion? Is there a consistent approach to autism assessment support in services? How could this be improved? What really catches my attention on this is the question of whether there can be a pathway developed for some people, who do not get the clinical assessment, to receive autistic support? When you are looking at that, what are the major pitfalls and advantages once you get out of that nice, safe medical block? Shall we start with the kids first?

**Professor Mark Mon-Williams:** I will deal with the paediatrics, which is suitable—I am a fellow of the Royal College of Paediatrics and Child Health—and Conor can do the adults, so this has worked out very well.

For me, one of the biggest barriers is that disconnect between health and education. That is made manifest in the very poor information sharing we have between those two different organisations. That has allowed a lot of cultural differences to accumulate. We now have this perception—and sometimes the reality—that children will not get support until they have had an assessment and a diagnosis. That is where we then end up just having a child on a waiting list, with no help or support, waiting for years. By the time they are hitting the system, what could have been a relatively straightforward intervention is now a complex intervention. For me, this is a big barrier.

How do we overcome that barrier? It is through better information sharing. This is something that we have been trialling in Bradford—how do we share information across health and education? It seems such a simple step—and it is relatively simple—but it is absolutely transformative. Then, we start moving towards a system where we have integration across different public services, with everybody working together to have a system that works for all children and young people.

**Dr Conor Davidson:** For me, the main barrier is this capacity demand mismatch that I spoke about. The NICE guidelines were published in 2012—they are rather out of date now and are being revised—and there was a target in those to commence autism assessments within 13 weeks. The thrust of many of the strategy documents has been around minimising wait times.

Not surprisingly, adult autism services put the bulk of their resources into the assessment bit, at the expense of any pre-diagnostic support—support for those who are actually waiting—and particularly post-diagnostic support. For example, in my service we have a very good assessment pathway but, after that, we have the resources to offer only a single follow-up after 12 weeks and then we mostly discharge patients. So it is not the ideal model.

You had Bryony Beresford giving evidence earlier and she would have talked about specialist autism teams being about not just assessment but support and post-diagnostic work as well. But in most parts of the country, we do not have that model in operation. A colleague of mine in



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the Royal College of Psychiatrists described it as a kind of Rolls-Royce assessment service, sitting in a desert with nothing before or after.

How do we improve that? Across the whole sector, we would love to see more funding. We need more funding, staff and resources to meet this demand and to start making inroads into the waiting list. Everybody would accept that, given the financial position of the NHS now, as well as increasing funding, we need to think of other strategies.

There are three main reasons to try and tackle these waiting lists. One is more efficient assessment pathways. To take my service as an example, we have collected more information using pre-assessment questionnaires. We are just piloting an AI-assisted voice recognition note-keeping tool, using technology to reduce clinical admin.

The other approach is to try and manage the demand. There are two ways to do that. You can have very strict triage procedures at the front door, so you are only letting in people with the highest need and risk—that is an approach they have taken in North Yorkshire, for example—or you can have a clinical prioritisation system, which is the approach we have taken in our team, where you still accept people for assessment but prioritise them according to the level of need and risk. The ones that have the highest need are seen quicker.

In the third approach, which we have seen in bits and pieces across the country, the model at the moment, certainly in adult autism services, tends to be that the assessments are done by a super-specialist autism team. One approach is to mainstream more of the assessment process, either into more general mental health services and perhaps even into primary care. There is a pilot going on in Cambridge at the moment looking at whether it is feasible for autism assessments to be done in primary care—or indeed, in the third sector—so that non-clinical and non-qualified clinical staff might do some of the assessment process. There are those types of innovations are going on across the country. At the moment, it is not particularly joined up.

On the second part of your question, about support for people without the need for clinical assessment, strictly speaking a lot of the support is not supposed to be dependent on diagnosis. Things such as special educational needs, reasonable adjustments in the workplace and even social care support are supposed to be needs-led rather than diagnosis-led. We are told by patients, carers and families that the reality is that you need a diagnosis to access most of that type of support. Given the pressures on the SEN system and social care, I cannot see that particularly changing very much in the future. There might be a place for lower-level types of interventions—particularly reasonable adjustments in schools or in places of education—that might be accessible without a formal diagnostic label. But for people with higher needs, it is difficult to see the centrality of the diagnostic assessment changing anytime soon.

**Lord Addington:** Just to come back very briefly on that point, we know



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that people with high needs and who present classically in all these fields get diagnosed, particularly if they come from middle-class backgrounds. That is unanswerable. Would there be a quicker thing that says, in some form—particularly when they are younger, that they could stick with—“Here is somebody we are pretty sure is on the spectrum”? Would there be room for bringing something such as that, that might be a tool for accessing support in? Is it technically possible?

**Professor Mark Mon-Williams:** Absolutely—the evidence absolutely supports that this is what we could and should be doing. Your caveats on middle-class backgrounds are extremely important. All our research shows this big intersectionality, where children born to mothers of south Asian heritage are getting into the system two years behind their white British peers. Children born to mothers without educational qualification are likewise coming into the system years behind their peers. There is also a massive lag before girls get into the system. You start seeing all these different factors intersecting. While some children with quite complex and obvious needs are getting into the system, when you start going to particularly disadvantaged areas, that is no longer the case.

**Lord Addington:** Just to be clear about that, in your opinion, even that stereotype has got a sectionality to it that you have to put in.

**Professor Mark Mon-Williams:** Exactly, but the evidence is unequivocal that there are signals right across all our administrative routines that are in datasets. We have done a lot of science using our Born in Bradford longitudinal birth cohort study and our Connected Bradford datasets, which bring together all the health, education, social care and policing data into one place. There are signals right across those datasets that tell you at the very earliest stage that, “Here is a child who is massively likely to end up, many years downstream, with a diagnosis for autism or other special educational needs”. We can see it in our datasets. Right now, a child is waiting five, seven or 10 years until they make it through these very complex pathways into the system, so we could and should be changing that with immediate effect.

Picking up on Conor’s point about new, innovative ways, one of the things that we are looking at is that much better connection between primary and secondary care health services. That has got to change. Within Bradford, rather than waiting for children to try to make their way into our services in the hospital, we trialled taking our multidisciplinary teams and putting them in the school. We found that a process that would take us a couple of weeks in the hospital we could suddenly do in a day in the school, and everybody found it much easier.

The children were being observed in their normal settings. The families from very disadvantaged backgrounds did not have to catch two buses and take a day off work—which often means they do not eat that day—to get into our hospital. The multidisciplinary team could immediately draw on the insights of the teachers, the school leaders and the SENCOs within those schools.



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It proved to be particularly advantageous in some of our communities where there is a lot of stigma attached to mental health disorders, where actually turning up in some of our clinical services could result in that family being ostracised from their communities, but engaging with the school and educational settings is far more acceptable. So, the evidence is quite clear that there are things that we really should be doing differently, exactly as you proposed.

**Lord Addington:** But it is the case that you still need some of these services, and you still need an assessment, so it has to be something that has some bite officially but which might not be the full assessment.

**Professor Mark Mon-Williams:** That is true; we must always have these pathways. There are many very good reasons why we need a diagnostic system. However, if you are picking up children who immediately appear as if they need support, why not start providing that support and start wrapping around evidence-based approaches—those reasonable accommodations that Conor talked about—from the outset? They will do no harm and will likely do a lot of good.

That immediately takes some of the pressure off. The family are no longer saying, “Somebody needs to do something with my child”, because something is happening with their child while we start trying to improve these pathways into that assessment process.

Q32 **Baroness Hodgson of Abinger:** My questions are around the main inequalities in access. You may feel you have touched on some of this already, but what are the main inequalities in access to identification, diagnosis and support for autistic people, and how should these inequalities be addressed?

**Professor Mark Mon-Williams:** As I say, in our datasets we can very clearly see ethnic inequalities, structural inequalities, inequalities related to socioeconomic position and inequalities related to gender. Those inequalities intersect. That is unequivocal; we can see these structural inequalities playing out across our systems.

When you actually start looking at the systems, you can see why. I will often sit in a room with colleagues trying to map out each system. We have A4 pieces of paper where the system looks quite straightforward for that particular service, but of course we are talking about multiple different services across a large geographical area. You suddenly realise that we do not actually understand how these services connect and interact. There is no way that a family who do not have a large amount of social capital can try and navigate their way through this spaghetti junction of service provision, so we see all these structural inequalities playing out.

What can we do about it? One observation that we have made is that we can do geospatial mapping, so we can see there is a real hotspot, where there are really high concentrations of individuals from those most





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disadvantaged communities sat on waiting lists. One way is to take a more proportionate, universalist approach where, rather than trying to solve this problem nationally, in the first instance we target some of our most disadvantaged areas where we have the greatest number of individuals sitting on waiting lists. There is the 20:80 rule that about 80% of some of those waiting lists are coming from 20% of our areas. Scientifically, there is a very strong rationale for going into those most disadvantaged areas and really trying to get that whole system working within those localities. Then, hopefully you start to address some of those regional inequalities.

These regional equalities feel very true to us within the north of England, because there is a clear statistical divide between the services that children in the north and south of England are obtaining. You can really see these inequalities writ large across the country.

**Baroness Hodgson of Abinger:** Would you ever see schools playing a part in that?

**Professor Mark Mon-Williams:** Schools have got to be at the heart of this. We often joke—and this is why we start putting multidisciplinary teams in—but, if we want to carry out assessments on children, where better than where the child is spending five days a week during most of the day? Often those schools have very strong relationships with the families and can do a lot of the onboarding. Conor talked about those preassessments and questionnaires—all of that can be done really effectively by schools; we demonstrated that.

Suddenly, we move towards an integrated system where families do not feel that they are fighting with each and every service but rather that the services are meeting the needs of those families within these community settings. For us, schools absolutely have to be at the heart of solutions as we move forward.

**Dr Conor Davidson:** I agree with everything that Mark said: there are clearly issues with ethnic and socioeconomic disparities. I would also highlight three others; one is around the older age group. There was a very interesting research paper published by Elizabeth O’Nions and colleagues about two years ago, looking at the age differential in terms of autism diagnosis. We have much better recognition of autism now in young people, particularly in high school-age children and the student-age population, but, as soon as you get over age 40, the rates of autism recognition and diagnosis drop off very substantially. It is estimated that for over 90% of autistic people who are over the age of 50, the diagnosis has not been picked up or recognised.

That can be a problem, because we live in an ageing population. I think that autistic people struggle more than the general population with some of the challenges of ageing, for example around the death of a spouse, increased physical frailty, if they have to have a home care package or even move into a residential nursing home. All those challenges can be



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magnified for autistic people, and all older people's services are probably now where working-age people's services were 20 years ago. There is still not a great level of autism awareness or expertise within those services, so that is one area that could be tackled in future autism strategies.

The other group I would like to highlight is autistic people with major mental illness. It is crystal clear from all the research that autism unfortunately predisposes one to all kinds of mental health problems, not just anxiety and depression but also severe mental illness like bipolar, schizophrenia et cetera. We are not particularly good at picking up underlying autism in secondary care mental health settings. For about half of autistic adults who are in psychiatric in-patient units, autism has not been picked up. I think that this is because the mental health problems overshadow the autism. That can be a problem because, if we do not recognise the autism, we are not able to make appropriate reasonable adjustments or to adapt mental health treatments to take account of the autism, and patient outcomes are poor.

**The Chair:** I apologise for interrupting you, Conor, but I am afraid we have a Division. We will pause this session for as short a time as we possibly can while Members go and vote, so this session is now paused.

*Sitting suspended.*

Q33 **The Chair:** Welcome back to the second session of this afternoon. We come on to question 4, which is: how effectively do the NHS and public services support people with an autism diagnosis throughout their lifetimes, including at key milestones and transitions between life stages, and how could this be improved? Conor, perhaps I could come to you first.

**Dr Conor Davidson:** The short answer is that, unfortunately, in too many cases we do not support autistic people very well. There are various transitions in life stages that services could do better, frankly. I am sure Mark will talk about the situation in children and young people's services, but often I hear from families that there is a kind of cliff-edge effect when you hit 18, and that the provision for over-18s is very different to that for under-18s.

Often, mental health services are not particularly well set up to meet the autistic needs of autistic adults who have high mental health needs, so I do not think we are good enough at consistently implementing reasonable adjustments in mental health services. I think there has been a move over the last five or 10 years to a much more episodic model of care in mental health. Typically, patients are in services for, say, three months, six months or 12 months and are then discharged again. That model does not work particularly well for autistic people, who need that continuity of care and need somebody there in the background, almost, who can step back and then step up according to what is going on in the autistic person's life.



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For autistic people who have high levels of social care needs, because of the financial pressures we have seen local authorities and social services under in recent years, in most places the eligibility thresholds have been raised for accessing social care support. That means, again, that many autistic people miss out on that. So we still have this same problem with autistic people falling through the gaps of services: they are not mentally ill enough for mental health services or do not have high enough social needs for social care services. That can then mean that needs go unmet and they end up presenting to services in crisis. That is one of the drivers of the increasing rates of autistic people in in-patient settings that we are seeing.

To improve that situation, we have to aim to improve autism awareness and expertise across the whole of the health and social care system. One model for doing that is to pivot the function of specialist autism services, not just from doing all the assessments, which is kind of what happens now, but into more mainstreaming of some of that assessment work into, as I say, mental health services—perhaps even primary care or third sector. The specialist teams then become a resource of training, consultancy and advice to disseminate that expertise across the wider system.

**Professor Mark Mon-Williams:** I can be relatively brief because I am just going to echo everything that Conor said. I could not agree more: we are not doing a great job. I think the evidence is absolutely clear. We need new systems that are fit for purpose. We cannot just put this on the NHS. It is about all the services working together effectively to address these sorts of issues. Just to really emphasise everything that Conor said, again, all the evidence is clear that the transitions are points where the gaps open up. We see far too many families or individuals falling through those sort of gaps—particularly between child and adult services, as Conor has already said; between education and employment, another big transition point where we see the gaps opening up; and again, from supported living to independent living.

Again, I want to emphasise what Conor said about us having far too much of a crisis-led approach right now, as opposed to taking that step back and thinking, “How can we prevent these gaps opening up? How can we support people to survive and thrive across all our different services?”

Could I share one piece of evidence? I am part of the Link consortium, which takes five very large datasets, and what we have been looking at is actually mid-life multimorbidity. The very large number of individuals within the NHS at middle age who have a really horrible combination of what we call internalising disorders—anxiety and depression plus cardiometabolic disease—cost us an absolute fortune in the NHS. Because we have these large datasets, we can go back a certain amount of time and what we find—again, I think this is just reflecting what Conor said—is that the proportion of autistic individuals within that population is far more than it should be. There is clear evidence that our failure to support



these needs earlier on in somebody's life is just playing out, and it is costing us billions of pounds downstream. Again, we have really got to get away from this crisis-led system and start thinking about how we can put support in place, especially around these transition points, to make sure that we actually help the NHS flourish because it is not dealing with all these highly preventable diseases that are occurring in mid-life because we did not have that support in place in those early years.

**Q34 Lord Hope of Craighead:** My question is about the other group. It is asking exactly the same questions, but this time asking whether the support is available for people who do not have a formal diagnosis. Conor, I will come back to you and ask you not to repeat what you said in response to the previous question, but to try to concentrate on this particular group—people without a formal diagnosis who are nevertheless in need of assistance.

**Dr Conor Davidson:** I may end up repeating myself slightly here, because I think that the two biggest demographic groups that fall into that category are, as I have said, first, older people, particularly people over the age of 50, very few of whom have their autism recognised. Some thought needs to be given to how we meet the needs of those older autistic adults, particularly when they are entering some of the challenges of later life, such as getting care. It seems to be particularly difficult if somebody needs a care package coming into their homes and they are autistic—you have people coming at perhaps unusual times or there are different staff members each time. That can be a very difficult thing to deal with.

The other group that is systematically underrecognised are people with significant mental health problems. We know that autism does predispose to all kinds of mental health problems, yet we are not particularly good in mental health services at picking out the patients who have an underlying autism that might be contributing to their mental health difficulties, and therefore making the correct reasonable adjustments and treatment adaptations for them.

Those are the two groups where I think we need to do better at recognising their autistic needs. It does not necessarily even need to be a formal diagnosis. If somebody is admitted to a mental health ward and the staff have adequate training in recognising the signs of possible autism, at the moment, often what they will do is refer them to the local specialist autism team, and they will get put on a two-year waiting time and nothing will then happen for two years. But if we had mental health staff that were really clued up on the possibility of underlying autism, they could start making those reasonable adjustments and sort of adapt to the patient's sensory needs on the ward, for example, without having to wait for that official diagnosis necessarily.

**Lord Hope of Craighead:** Thank you very much for that. That is a very positive indication of the way we should be going. Waiting for a formal assessment is a long, long wait, and I can see that it would be good if



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you could do something before that. Is there a difference between the way the NHS is dealing with this problem and other public services?

**Dr Conor Davidson:** My expertise is really within the NHS, so Mark might be better placed to answer that in terms of what happens in schools, for example.

**Professor Mark Mon-Williams:** I just echo everything that Conor is saying. People who do not have a sort of diagnosis and could do with support—well, there are all the children sitting on a waiting list, and that is a huge number of individuals sitting there for years. The other point about those waiting lists is the conversion rates: in other words, how many people on that list who will ultimately end up with a diagnosis is ridiculously high—80% or 90% in most areas. So they are waiting years to be told what we already sort of know to be the case, and the small number who do not end up with the autistic diagnosis end up with a very similar diagnosis, which means that actually we knew years ago what accommodations needed to be made to support that sort of a child. So it is absolutely the case that we should be putting support in place in the first instance.

One of the other real problems that we have right now is the number of children and young people who, with a few reasonable accommodations, could have their needs met and will start surviving and thriving in a school. All our child psychiatry colleagues will tell you that you can walk into some schools and they are autism-friendly schools; you could have the same individual in that school, and they would thrive and not need a diagnosis. If they want one, great, but often they do not need one because all the needs are met—whereas for the same child in another school, the wheels come off. Then, by the time they eventually get into the system, they have so many other issues, because children are developing and, if they are not getting this sort of support and the wheels are coming off, it gets worse and worse. Suddenly they are putting massive pressure on the system. Again, if we just move from this diagnostic-led system—protecting and valuing that diagnostic pathway but starting from the premise that, if a child has needs, let us just start supporting those needs with immediate effect—it would transform everything.

That really takes us to the space where we ask, “How do we start supporting schools?” Your question was, “Is this happening?” Some schools, as we were discussing, do a great job. Other schools are in denial. So how do we start getting every school being an inclusive environment where every child can survive and thrive? If we start getting that right, I think you will start finding a lot of the other pressures decreasing.

One of the questions that we should be asking ourselves is: why is it such a crisis now? I am old enough to remember when it was not such a crisis but, actually, if I cast my mind back, we used to have lots of educational psychologists, school nurses and broader support structures within our



education system. As they have been stripped out, I do not think it is particularly surprising that we are starting to see more and more of these sort of problems cropping up, where children do not feel included, they do not feel they belong, their needs are not being met and eventually they find themselves in the NHS—by which time they have a whole bunch of other problems, which then are bringing the NHS to its knees. We have just got to start having a needs-led system, putting support in place at the earliest possible time, and start to save the billions of pounds that we are currently spending on sorting out all these issues way downstream.

**Lord Hope of Craighead:** Thank you both for the very interesting and helpful answers.

Q35 **Lord Elliott of Mickle Fell:** This question brings together some of the threads of the conversation so far and will help us with our conclusions. How, if at all, should the aims of systems for identifying, assessing and supporting autistic people change in the coming years and how should services change to achieve this?

**Dr Conor Davidson:** We have touched on some of this already. I am speaking more here about mental health services for adults. The latest NHS England figures are that 5%—one in 20—of all people accessing secondary mental health services are autistic, so it is a huge patient population. This current model that we have spoken about, where the autism teams almost sit in a silo, in some cases isolated from the rest of the wider health and social care system, has to change going forward. We really need to mainstream autism and, indeed, neurodevelopmental expertise throughout all of health and social care.

As Mark was saying in the previous answer, not everybody needs a 13-hour, all-singing and all-dancing autism assessment to have their autistic needs recognised. If we have staff who can do that early and implement those reasonable adjustments where needed, we will see improved outcomes in future.

I see the role of specialist services moving more towards dealing with the most complex cases. For the more straightforward cases, they are offering support and guidance to the wider system. For that type of approach to work, we will need more robust and consistent ways of measuring needs. We hear a lot at the moment about moving from a diagnosis-led approach to a needs-led approach and, by and large, I support that. Some autistic people will need greater self-understanding and perhaps some relatively straightforward reasonable adjustments at work; that is their level of need. Some will need, 24-hour social care packages and there is a spectrum of need in between.

At the moment we are at the stage where we are talking about introducing needs-led services, but we have not quite cracked how to do that in a fair and consistent way, so that is the next challenge for the field.



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**Professor Mark Mon-Williams:** I feel this is not a very interesting session because we just keep agreeing with each other. I am going to really reiterate some of the points that Conor made.

We need to work out how better to identify those needs. I say this from a children and young people perspective. There is a lot of really exciting work that is happening now: Professor Laura Crane and her colleagues at the University of Birmingham are leading a group within the Department for Education around neurodiversity and looking at how we can empower schoolteachers to identify need early.

The evidence is clear. We have shown that the early years foundation profile score that schools conduct when a child enters school is really good at identifying needs associated with autistic children. We already have a measure that can tell us, with really very good specificity and sensitivity, which children are likely to need that extra support. We can really lean into that science and start saying, “Teachers are incredibly well positioned”. They have years of experience, and they typically know that a child at this age should have this particular skill. If they do not have that skill, then we need to support that child in that space—of course, they do it the whole time, so every teacher is very adept at measuring a child’s reading age. They can then tailor their teaching accordingly.

Our science shows that they are really good at identifying children’s communication needs and how their skill levels compare to the other children in the class, but also to other children they taught. It is a statement that seems obvious when you say it, but schoolteachers, educationalists generally and nursery leaders are really well positioned to start identifying those needs. We can help them to do that in structured ways, using some scientific methodology. That then starts allowing us not to wait for that diagnosis by saying, “Here are the needs”, and then we can start signposting where the evidence-based accommodations and interventions can be pulled in. It allows a very rich conversation to happen across family and school, which suddenly starts making families feel that they are listened to—one of the biggest problems right now—and can immediately allow schools to start understanding the needs of the child and start adopting their practice accordingly.

All this is very achievable. We need real political will right now. We need, really, a degree of bravery. The reason we need bravery is because we have got to accept that this cannot just be done by our health leaders, it cannot just be done by our educational leaders and it cannot be done by social care. Everybody really needs to come together and to be working together effectively in the best interest of children and young people, in my world, and of adults, in Conor’s world.

I have already mentioned this on several occasions: we have really got to have those services much better joined-up—that means much better information sharing. We are privileged within Bradford to have these large, connected datasets, which suddenly mean that we can see these



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problems, we can see all those structural inequalities and we can see the gaps that everybody's falling behind.

We see them in technicolour and in three dimensions. Normally, the educationalists just see the education bit of the picture, health just sees the health bit of the picture and social care just sees its bit of the picture. That makes no sense. These are individuals' lives—they do not fit into nice, neat component parts. Yet, currently, all our systems are organised as if you can divide a child or family up into the health bit over there, the education bit somewhere else and social care somewhere else again. We have got to put that to bed once and for all, and have proper, joined-up services and effective information sharing across those services. If we start doing that, we can start to identify need in a scientifically robust way and start putting that support in place; suddenly, we are in a very different situation than we currently are.

**The Chair:** Thank you. Lord Addington, you had a short supplementary.

**Lord Addington:** Just really that nothing that you have said is actually unique to the autism field. Do you have any examples—just a yes/no, and sending us the answer in—of anybody who has been doing this better or is this a universal problem with neurodiversity or things like hearing impairment across the field? Do they all have the same problems?

**Professor Mark Mon-Williams:** They all have the same problems, because these are actually system-level problems. We could cut and replace autism with ADHD. We could cut and replace ADHD with Professor Laura Crane's area of speciality of children with motor problems. These are system-level problems that we see playing out very acutely in autistic people's lives, but actually we see them playing out across a whole range of different individuals with different needs that are currently not being met because we have these completely siloed approaches. So yes is the answer.

**Lord Addington:** That is depressing.

**Professor Mark Mon-Williams:** But there is hope that we can change.

**The Chair:** Conor, if you have anything further to add, perhaps you could be very kind and write to the committee.

**Dr Conor Davidson:** I will do that. I was going to say that I chair a cross-faculty autism group in the Royal College of Psychiatrists, so I will ask our group if there are any examples of best practice that I can share with the committee.

**The Chair:** That would be extremely helpful from both of you. We would be very interested in that evidence. It is beholden on me to say thank you to both Conor and Mark for a really fantastic session. We are really grateful for your insights. The next evidence session will be on Monday 31 March. In the meantime, the evidence sessions are now concluded.