



Autism Act 2009 Committee

Corrected oral evidence

Monday 24 March 2025

3 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. 4

Heard in Public

Questions 23 - 29

Witnesses

[I](#): Professor Bryony Beresford, Co-Director of the Social Policy Research Unit (SPRU), University of York; Professor Jonathan Green, Professor of Child and Adolescent Psychiatry, University of Manchester; Professor Will Mandy, Professor of Neurological Conditions, University College London.



Examination of witnesses

Professor Bryony Beresford, Professor Jonathan Green and Professor Will Mandy.

Q23 **The Chair:** Good afternoon, and welcome to this meeting of the House of Lords Committee on the Autism Act 2009. The committee has been appointed to examine how well the Autism Act and the Government's autism strategy are working and to make recommendations about what the Government should do next. Today, we are focusing on key issues in the identification, diagnosis and support of autistic people, and we are delighted to be joined by witnesses Professor Jonathan Green, professor of child and adolescent psychiatry at Manchester University, and Professor Bryony Beresford, professor of social policy at the University of York, both of whom are appearing in person; and Professor Will Mandy, professor of neurodevelopmental conditions at UCL, who is joining us remotely. You are all very welcome and thank you very much for coming.

We will continue hearing oral evidence on Monday afternoons most weeks when Parliament is sitting until the summer. We are also publishing a call for evidence, which is open to anyone to respond to before the Easter Recess in April. The committee's job is to scrutinise the Government and their policies. We are not able to help with individual problems or complaints. We do not permit personal criticism of individuals as they do not have the right to reply. Members of the public can watch our proceedings either online or in person but are not allowed to speak during a public session.

Our evidence sessions are on the record, which means that they are broadcast, and a written transcript is taken for subsequent publication. The list of members' declared interests has been published on the committee's website. Having made that introduction, I will now ask the first question. When you answer, I would be most grateful if you could introduce yourself briefly.

What are the main purposes of autism assessment and diagnosis for both adults and children? When answering, can you cover what the main benefits of autism assessment and diagnosis are, whether there are any associated harms or disadvantages, and how benefits can be realised and harms minimised? Jonathan, perhaps I could come to you first.

Professor Jonathan Green: Thank you. I speak as a clinical academic; thus I am a clinician, child psychiatrist and a researcher in autism, particularly into the early years and early years care.

The main purpose of a diagnosis within a health context is to identify the form of a presenting problem and need, and therefore provide a framework for care which is appropriate to that need. From a clinical perspective, diagnosis made well, and in that way, is pretty much always



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positive for children and their families because it helps families understand their child and their child's needs and development; and when the child is older into adolescence, it is an important way of them understanding themselves and helping the formation of their identity.

Of course, diagnosis in the real world has broader implications, and this is one of the areas of difficulty at the moment. Diagnosis has a meaning and an import beyond just that health context. It provides a gateway into service support, into special educational needs assessment and benefit, and also into social care, associated benefits and disability benefits. So, the diagnosis, although it is a medical term in a medical context, actually has a broader implication. In that broader sense, the diagnosis—arguably, at times—has perverse consequences. This is because there can be a series of perverse, as it were, incentives for diagnosis in relation to the benefits accruing. There are some complicated issues for public policy around this, that I am sure we will talk more about. That is my sense of the positives and the potential complications of diagnosis in the current state.

Professor Bryony Beresford: I am not a clinician. One of my main studies in this topic area is looking at people diagnosed with autism as adults, looking at access to and outcomes following diagnosis, the services that are available and how that differs across the country. I have also done research with young autistic adults and young people, which I will draw on as well.

I draw particularly on the research we did, which was a national study looking at the experiences of adults who are diagnosed with autism as adults. Because the context of adult services is quite different to children's services, a lot of adults are diagnosed and that is all that happens. They have nothing beyond that. Evidence from our study suggests that for at least some, that can lead to a deterioration in outcomes for them, because it leaves them in a position of having to make sense of themselves and their lives to date, which for some was at 60 years old. There are lots of questions around that. It also often leaves the reason they sought or were referred for a diagnosis unresolved, because there is no ongoing specialist support for them. So, there are risks, potentially, if the care going forward from diagnosis is inadequate.

In terms of the benefits, I absolutely agree with everything you said, Jonathan. It is not unique to autism, but there is something about not only interventions and support for the person diagnosed, but also recognising that people live in families, and for some conditions, that support, advice and information to those around them is important in securing the best outcomes. A diagnosis can be the way in which those people make sense of what is happening and can access information and support for their family member.

Professor Will Mandy: I am a clinical psychologist by background, although I do not work clinically at the moment. I spend most of my time doing autism research with young people and with adults, with a focus on



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quite practical, service-related questions, in particular around the mental health of autistic people.

I agree with Jonathan and Bryony's ideas about the function of a diagnosis, around helping people understand themselves better, helping other people understand them better, and really enabling the person to be, under ideal conditions, linked to a set of interventions or types of support clinically, but also in a number of other contexts, such as in education or employment.

On the question of some of the potential harms of diagnosis, there is a point that I thought I might amplify in the context of seeing diagnosis as generally a positive and constructive thing. It is the question of stigma. Having an autism diagnosis can bring with it stigma and misunderstanding from other people. For example, it might cause people to underestimate the capacities of a certain person, or to make certain assumptions about roles that they can and cannot fulfil.

There is another issue to do with what might be called self-stigma. There is always some risk that, in diagnosis, people might develop negative ideas about themselves, their potential and their capacities due to their beliefs about autism. To me, that highlights an important point about one of the functions that services need to fulfil. When a diagnosis is given to a person, there is a piece of work to be done there, which is, to put it crudely, to maximise the potential benefits of that diagnosis and to minimise its potential harms.

When we are thinking about things like self-stigma or misunderstanding around autism, there is an important piece of work to be done there to do with psychoeducation, in helping people understand what autism is, to understand what their autism is, and to make use of it in a way that is constructive for them. That is particularly important given the point that Bryony has just made about the lack of post-diagnostic care that is on offer to many people after diagnosis, particularly in adult services but right across the lifespan.

Q24 **Baroness Pitkeathley:** Good afternoon, it is very nice to see you. As you know, this committee is focused on the working of the Autism Act 2009. We will take a different order this time, if we could perhaps start with you, Bryony. What are the main trends in the identification, support and diagnosis of autistic people since 2009 and why? What are the main reasons for those trends?

Professor Bryony Beresford: The biggest trend is probably the number of people being referred for diagnosis. In a sense, the Act was successful in that way because that was one of its big emphases. However, we are now at a stage where some services have waiting lists of years. That then starts to become incredibly counterproductive for the people on those wait lists.



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The profile of people being referred for a diagnosis in terms of age and gender has also changed. That is a real shift from when the Act first came into play. That has meant that services have had to learn and develop practice around diagnosis and ongoing support of a population that was quite a minority group in 2009.

In the wider context, the trends are that constraints on resources mean that there has been a shrinking of services and support post diagnosis. There has not particularly been a trend around an aligning of how we diagnose across services, so that and the rates of diagnosis vary between services. There is an interesting disparity and diversity there.

I certainly know that there are services that used to be able to offer post-diagnostic support for adults and now can no longer because of the pressure to diagnose. That has meant that they have been able to do something around keeping up with that, but potentially leading to the consequences that we have talked about just now.

Baroness Pitkeathley: Is that because of the shortage of resources, or simply because diagnosis takes up more time?

Professor Bryony Beresford: Yes, it is because of the numbers coming through of those being referred for diagnosis. I think there was a BBC news story this week that somebody has been told there is a wait of 18 years. That is nonsense, really.

Professor Will Mandy: I obviously agree with everything that Bryony said. The ongoing rise in the diagnosed prevalence of autism—which has been happening ever since the 1990s, really—has very much continued since the Autism Act 2009. Increasingly, the envelope of autistic people or people with diagnoses includes groups who are historically underdiagnosed, including girls and women, and adults.

One of the effects of this in terms of changing the profile of the group of people who have an autism diagnosis is that we find an ever-greater proportion of autistic people are those without an intellectual disability, which has been a change since a decade or two ago.

I would like to mention in passing that, certainly in the research literature, there has been an arguably increasing neglect of those who are autistic and who also have an intellectual disability. It is important to highlight the need to continue to develop better understandings of their needs and how to support them.

Another important change in autism practice since 2009 has been a growing awareness of the physical health needs of autistic people. Work has come out in that time showing a quite significantly reduced life expectancy for autistic people compared to non-autistic people, an awareness of the difficulties that autistic people have in accessing physical healthcare and the range of physical health conditions that they



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are more likely to experience compared to non-autistic people. That is a really important area that services are trying to change and evolve.

That is linked to a broader point—that people are ever more aware that it is not just autism-specific services that need to be there to support autistic people, but that autistic people need support in a very broad range of contexts and public services, be that in employment, education, physical healthcare, homelessness services and so on. So, there is an awareness of a need to spread good practice and support right across the system that was perhaps a view less widely held at the time of the Autism Act.

Baroness Pitkeathley: Thank you. And your thoughts, Jonathan, on the trends?

Professor Jonathan Green: As my colleagues have said, the trends are certainly of a massive increase in the referrals for diagnosis. This is well documented. Going along with that are huge changes in cultural awareness and the way people think and talk about autism. The neurodiversity movement, the rise of the much greater prominence of the voices of autistic people talking about their own needs and their own lives, has been a great change in the landscape since 2009. It was not the result of the Act, but it is coincident with it.

That awareness has led to a lot of positive things. Will was talking about stigma associated with autism. It is hard to generalise, but at least one could make the argument that the cultural stigma is rather less now, and that there is more cultural awareness, acceptance and valuing of autistic individuals. I certainly agree with Will that if you look at the distribution of the kind of referrals that come, there is a very wide spectrum of individuals, including many more females. When I first started in the field, autism as a diagnosed entity was very largely in boys. It was not a very common thing, and it was often most commonly associated with intellectual disability, as Will says. That has really changed. Now, we get much more of a balance in the gender of people coming to us. As Will says, we also get a greater balance of children and young people who do not have intellectual disability but have autistic traits.

This increase, as is well known, has led to a real crisis in services. You will be aware of this, but it is absolutely there in the services. The estimated prevalence rates have increased multifold across the world. This is partly because of awareness and identification. It is also partly a relabelling. For instance, lot of children who were thought to have intellectual handicap and disability are now thought of as autistic, so there is a certain amount of relabelling that has gone on.

The awareness has been a massive change, and it has led to a real issue for service response. There are around 200,000 children and families waiting for a diagnosis in the NHS system at moment. I am talking not just about CAMHS but child health generally. Some wait times for young people and children are several years or more, which in a child's life, as



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Bryony said, is crazy. In some areas of CAMHS through the country, up to 80% of referrals now come with questions about neurodiversity—that includes autism. This is a huge change from where we were. It gives us a real challenge as clinicians and policymakers, and I am sure it is something that you will want to think about as a committee.

For clinicians, it is a massive pressure. It has meant, which I think has been detrimental, that so much focused attention and personnel power is going into the diagnostic process, not the care process. One therefore sees a perverse situation where there are big waiting lists for diagnosis as a gateway to care, a majority of specialist personnel sucked into meeting this need, with relatively less personnel to provide the care after it. We have not cracked that, but maybe we will come on to some ideas later about how we can. To me, that is a big issue at the moment in the services.

Q25 **Baroness Goudie:** Good afternoon, and thank you very much for coming. Could I ask my first question to Professor Mandy? How effective are autism assessments and support pathways, and how could they be improved? How effective are autism assessments and the support pathways for people with co-occurring conditions? How could they be improved? I know that you have covered a little of that, but perhaps we could continue that discussion a bit more.

Professor Will Mandy: They are themes that we have already talked about. Obviously, there is a struggle to meet demand for assessment. As Jonathan just said, the assessment task is draining resources away, which leaves less for supporting people post assessment. There is also emerging evidence nationally that there is quite a lot of inconsistency in how diagnosis is applied, with different centres appearing to have quite different rates of people they are diagnosing. I know some of Bryony's work has found that. A recent report by the charity Autistica called *Not a Priority* showed that there are quite different rates at different centres. It is not fully conclusive—it could be that they just see different populations—but it raises quite a significant possibility that there is inconsistency in diagnostic practice and that a lack of post-diagnostic support is offered. Another challenge we still have, although it is getting better, is a lack of a really strong evidence base for people to draw on, especially when supporting autistic people with and without co-occurring conditions.

As for some thoughts on how this might be addressed, my instinct is that we need to do something different from just trying to scale up the operation. Things will have to be done differently. A big part of that will be trying to make assessment more efficient to get through waiting lists so that people can be assessed in time and to leave more resources for support. Certain ideas need to be tried and trialled, such as a more tiered, stepped approach, where assessment resources are allocated more accurately depending on how complex the assessment is.



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When we look to transform our assessment models, there has to be a role for AI. I know people talk about AI as a bit of a magic wand, but there are concrete ways it can be used. For example, clinicians often spend a lot of time writing long reports after assessment. That drains a lot of time out. AI could have a huge role there, for example, as well as around pulling together information to support diagnostic decision-making.

My opinion is that there is work to be done in developing a workforce of neurodevelopmental practitioners. Again, this could be linked to more consistent training and accreditation nationally, with more transparent, clear standards for the levels of training and practice that you would need, potentially with different levels of practitioner depending on training and experience, with these different levels performing clearly delineated roles within assessment services. Something like that could support a scaling-up of services, as well as new assessment models.

There also needs to be ongoing research, with a focus on service improvement. This is happening already in the NIHR—the funding part of the NHS. It is investing in clinical trials, but we need practically focused work. What is already happening, and it is a trend that needs to grow, is that that research is shaped by autistic people and their families to make sure that autism researchers are doing the work that they need. I will leave it there, but those are my initial thoughts.

Baroness Goudie: Professor Green, would you like to continue on that, following your discussion earlier?

Professor Jonathan Green: Yes. I will build on what Will said. I completely concur that business as usual with increased capacity does not do it. We need system redesign, and some really flexible thinking about how we think about the issues here and manage them so that the people involved—the families, the young people, the children—really get the best deal.

That has been the focus of a lot of my work, as a clinician and in clinical science: to try to think about new pathways of early care. To speak a bit about what I have done from my experience, we have done about 25 years of treatment development work from the ground up, thinking about how to design early support interventions focused with families that will best build on the developmental science we have and be most efficient and effective.

We built those models and tested them in a number of clinical trials, so we have good evidence that working in the way we have done—which basically is working with parents rather than directly with children themselves—to build an adaptive communication and understanding environment around the growing neurodiverse child, is really effective. Basically, we are putting the family where they need to be, which is in the prime focus in terms of support of their child, because of course they want to be the best parents they can be. That is what we do in this



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model: we support parents to be the best parents they can be for their neurodiverse child. This is a relatively low-intensity but technical form of work. It uses video feedback with parents to help them attend to their ND child, so as to understand and 'read' their child's behaviour and communication most effectively. If we do this pre school we get long-term positive effects on the child's development that we have shown are sustained into middle childhood (six years after the therapy ending). These are effects that have been modelled by health economists to be cost-effective. In other words, the investment in this early intervention gives back cost-effective returns on positive outcomes.

This model of early care is therefore developed and evidenced. One of the things I would say about our current system, really echoing what Will said, and with all respect to wonderful colleagues around the country, is that the health care response to autism has grown like Topsy, is patchy and duplicative and most of it without good evidence of effectiveness. We have a health response currently where people are doing their best, but not doing evidence care. We know that evidence care is the most efficient and effective thing—we know this from work throughout medicine.

I think the system redesign has to be more developmentally focused. It has got to use the foundational elements to support families rather than wait to firefight problems as they arise later. This is what we call a pre-emptive approach. We have shown that investing in that will pay dividends. In a way, it is common sense, but the system as it is does not work like that. It works to firefight the problems as they arise. Getting that system redesign is quite a challenge. A lot of what happens currently in practice every day is very well-meaning and skilled professionals really not employing what we can think of as the best-evidence practice. Getting that evidence into practice is going to be a real issue.

The final thing I would say is, to echo Will again, that this idea of stepped assessments—stepped care, not the one gateway model. This is what I was saying in my first answer: the diagnosis process as a gateway to care, SEND and other support is now a constraining bottleneck. We have got to somehow rethink how we do this to be much more agile to meet people's needs early on and not do one size fits all. We need to adapt according to what we need. We have shown in our implementation studies, in Manchester particularly where I have been doing this for a few years, that we can achieve this pre-emptive system redesign, and we have demonstrated good results from that. I can go into more detail if you would like.

Baroness Goudie: Thank you, that was so helpful.

Professor Bryony Beresford: I would just reiterate the points that have been made. On that notion that we talk about specialist autism services, given the prevalence, what does "specialism" mean now? Will said much earlier on that that is not sustainable, and we need to change in terms of looking at more mainstream services and the skills they have. It is not just about making adjustments to interventions. It is finding effective



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ways to work with autistic people. That is not about just marginal adjustments in terms of autism, it is learning clinically how best to work with autistic people. There are some specialist services which are moving towards that model of acting as consultants to mainstream services and mentoring and training them to be the ones who are delivering the care. One service has certainly done that from the outset—I think they were established 20 years ago. They always felt that this was what was going to be sustainable, that they could never work individually with everybody in that area, so they would have to do that. That has worked, in a sense, from diagnosis through to ongoing mental health care.

I totally agree that episodic care leads to crisis. “Treat, discharge” does not work with a condition like this, so we need to look at that.

It is very hard because, when services are under such pressure, who has the headspace to redesign? That is very challenging, and I am not sure what the answer to that is, but it could be bringing to services evidence of what another service has managed to turn around, to some extent to show that it is possible. It is about how we get that evidence out on the capacity of services, just to take that breath and look at what they are doing.

Will spoke earlier about the involvement of autistic people and their families in this redesign process, which is absolutely central. A trend since the Autism Act first came in is that services would say that they had moved increasingly to co-producing service models, involving autistic adults in some intervention and delivery. That is all very good—you want to hold on to the good things that have been learned if you redesign.

Baroness Goudie: Thank you all very much. The idea of better services and changing is coming through quite a lot.

Q26 **Baroness Ritchie of Downpatrick:** You are all very welcome. Building on the pathways theme, do you think they can be developed for some people who may be autistic to receive support without clinical assessment, and what are the opportunities and risks of this approach? Could I start with Professor Green?

Professor Jonathan Green: We have done very specific work in this area, so I can speak to that because I know the most about it. The logic behind this is the fact that autism is a developmental condition. We know that the earliest signs of an autistic trajectory emerge very soon after birth, in the first year of life. One can then track that through to autism emergence later. I have been involved in a lot of this work, and we know what those trajectories look like.

That led us to think: could we do supports earlier to help at the time of that early identification? That is what we have done. We have got a therapeutic support model with parents—the same kind of thing as I was describing. Essentially, we have a kind of surveillance or screening exercise, which health visitors can do in their regular child development



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screening in the first few years of life. The modern version of this proves to be specific and effective, and we have demonstrated its practicality.

It is a light-touch identification. It is not a diagnosis, but a probabilistic identification. We take those children and then put a support model in immediately. It is a linked detection care model. The rationale is that it means families are not waiting on a list to get care. Of course, they really like that, because they are not waiting in anxiety to know what is going on. It also means that the therapeutic system gets to know these families early. Some of them do not turn out to have an autistic trajectory; they will have other neurodiverse or developmental needs, and those can be looked after. But it is a more seamless, efficient, pre-emptive approach prior to diagnosis.

We have implemented this in Manchester over the last few years, so I have got good evidence in practice as well as through clinical trials. The upside is that parents love it, and we see good clinical outcomes and trajectories so that the associated needs are reduced as we do that early care. In this cascade model, things amplify over time if you do not put in place the right things, so we need to help that from early on.

The downsides would be if you flooded the system by having early identification. However, using this instrument we have shown so far that you do not get that, which is really encouraging. Other downsides include that you might be raising anxieties instead of dispelling them. On the whole, that is not the case. The parents are concerned enough about their children as it is. If anything, they are relieved and understand more about their child's needs and how to help them themselves, and that reduces their anxiety.

I do not think there are many downsides to this. There are in theory—with any process like this, there are theoretical downsides. In practice, we have not seen those particularly, and we have got that documented, so I am fairly positive about this kind of approach. The key thing is: can you redeploy the workforce to act in this more pre-emptive way, away from doing things that maybe have not got evidence of effect? That is a system change. It is a hearts and minds thing with managers and clinicians, to ask if we can redeploy our efforts into something that we know has evidence of working.

Baroness Ritchie of Downpatrick: Professor Bryony Beresford, what is your view?

Professor Bryony Beresford: With respect to adults who are wondering whether they are autistic, I do not think there is a lot of evidence about what might be helpful. Self-identifying as autistic can be very helpful. People say it is helpful and it connects them into communities, but we do not really know about the potential risks of supporting and enabling that, so I would not want to say more than that, really.

Baroness Ritchie of Downpatrick: And Professor Mandy?



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Professor Will Mandy: I thought that I would share an example of practice from a different area to the one that Jonathan outlined, from adult eating disorder services. We know that quite large numbers of autistic people, particularly autistic women, with significant eating disorders in their late teens and early 20s present to eating disorder services. For example, there is quite consistent evidence that of those experiencing anorexia nervosa, among the women receiving in-patient and out-patient treatment, you often find rates of 20% to 30% of autism. Under current systems, they usually present undiagnosed, without an autism diagnosis.

When clinicians are working with undiagnosed autistic women with an eating disorder, it matters to know that they are autistic. It matters in terms of how you engage them with the service—whether you need to make adaptations just to make that service accessible to them, so they can get through the door and make use of the treatment. It can also have a big effect on how you understand and treat their eating disorder. Sometimes, the eating disorders of autistic people have different drivers to the eating disorders of non-autistic people and so require different treatments.

Services are facing this problem. They have people presenting with eating disorders who are often acutely ill with their eating disorder. They suspect that person might be autistic, but they cannot have them assessed because it is a two or three-year waiting list. One of the ways that services are commonly dealing with that is not getting so interested in the question of whether they meet the diagnostic criteria for autism but assessing their autistic characteristics and traits, using that information so that they can understand the person better and change the service, their formulation of their eating problems and their treatments.

This also helps them to understand themselves better. It is almost sidestepping the issue of the yes/no question of whether they are autistic, to think about their autistic traits and characteristics and incorporating them into the way they work with these people, how they adapt services and how they aim to target their eating disorder.

I have spoken to quite a few clinicians in a range of services that are doing this, but there is not—it is important to say—a randomised control trial or anything such as that that shows this is an effective approach. But I think it is promising, and it is an approach that could potentially be generalised.

In terms of advantages, it allows clinicians to engage with autistic characteristics, thereby improving their clinical work, even when it is not possible to secure a timely diagnosis. It can also be helpful for people with autistic traits, which might not reach the level for a clinical diagnosis, but who, nevertheless, are impacted by these traits on their eating and well-being.



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In terms of disadvantages, if you transitioned to a system where you really were sidestepping that question of whether somebody met the diagnostic criteria, and you were just thinking dimensionally, if you like, about autistic traits, you can lose some of the real benefits we have already spoken about of diagnosis—such as the identity benefits that many people really do benefit from, especially in adulthood, taking on this autistic identity. It changes their story about themselves and helps other people understand them better.

There is this dilemma that both Jonathan and Bryony referred to, which is that one of the diagnostic assessment's functions is to direct resource allocation—who gets into this service or who receives this particular adaptation. How that works would still need to be worked out if you are doing more needs-based or trait-based assessments. This is an approach that people are using clinically at the moment. It definitely has some real benefits.

The Chair: Thank you. We have a couple of supplementaries before we move on to the next question, from Lord Addington and then Baroness Hodgson. Lord Addington, could you go first and do you have any interest to declare?

Q27 **Lord Addington:** I am the president of the British Dyslexia Association and I am dyslexic. I cover special educational needs. I work for an assistive tech company, so I have interests.

Really, my question is about the co-occurring conditions. Now, autism is diagnosed quite early. For instance, it is diagnosed several years earlier than dyslexia, which hangs on to mother's hand for a minute. What is the problem with a condition that is swamped by this early diagnosis? Do people simply not have the energy to go into it? What are the pitfalls there and how would you correct that? If "Oh, you have got ADHD, you are autistic and you have a bit of dyslexia in there as well", which is not that uncommon, was said to somebody, how would you try and fit that together and make sense of it, to give that support pathway early and support what you are doing? Is there a way around that, or is the response to just run out of the room screaming?

Professor Jonathan Green: Definitely do not run out of the room screaming!—we need to face this. In the trade, we call this diagnostic overshadowing, where you get so focused on one aspect, one diagnosis, that everything else is explained by the autism and you lose the nuance about other aspects and conditions. This can happen across medicine; it is not just in this condition.

The route out of this is through good clinical training for clinicians—this is fundamental to medicine, clinical care psychology and clinical care generally—so that they assess the different needs of the individual, not getting blinded by one aspect, but making sure you are picking up other things that may be the most functionally disabling area of their lives and dealing with it. Where you focus your energy in a complex presentation is



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a big clinical skill, and it is about your awareness and making sure that you are covering all the different aspects. Good clinical training is the main thing.

Within this we do need to train our clinicians and our services up to be aware of the different co-occurring challenges that autistic people face as they grow. Dyslexia certainly is one co-occurring thing, as well as a lot of mental health conditions. Dealing with those on their own merits is important, as is working with families, because they often know the children really well—to really listen to them is basic clinical practice. Then you do not miss things so much.

Baroness Hodgson of Abinger: I wanted to ask Professor Beresford: for adults who may think they are autistic, is there enough information about where to go? I imagine a lot of them are having trouble with their life in some way, and may go to a counsellor, who may or may not be clued up about all this. Should there be more information out there, both for the person concerned and to ensure that the average therapist is very aware of these types of conditions?

Professor Bryony Beresford: The danger now is that autistic adults—or people who suspect they may be autistic—as well as anyone else, look to themselves, and there is a lot of information out there that is not helpful and is incorrect.

What newly diagnosed autistic adults say is, “I wanted somebody to help me navigate and find the right information that is helpful”. What autistic adults say they find most helpful is, “This is how I manage, these are the things I have learned about how to live life and the strategies that I find helpful”. That first-hand experience is very valuable. They equally tell stories of coming across some very unhelpful things on the internet, which have had some quite devastating effects on them. There is a desire for some sort of curated set of trustworthy information. That would be helpful for them. That is a real issue.

Q28 **Baroness Browning:** Good afternoon and thank you for some of this information you have been giving us already. You have covered—particularly Jonathan—a lot of my question with reference to younger children post autism assessment. How effectively do you think the NHS and public services support people who have received an autism diagnosis and people who have not? How could this be improved? You have mentioned quite a bit about children and the 2009 Act, although in the strategy we are looking at at the moment, children and early diagnosis are included. When the Act came out in 2009, it was specifically to deal with that section, as you get into adolescence and then adulthood. What happens for that age group as they get into adolescence—or as adults—when they get a diagnosis?

Professor Jonathan Green: Are you focused on adolescents and adults?

Baroness Browning: Yes, because you have already given us some very



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helpful information about children and other strategies that you have incorporated into your own practice.

Professor Jonathan Green: I do not know if Will is better placed than me to talk for the young adult population. I am happy to talk about it, but I do not know if Will wants to comment.

Professor Will Mandy: I could say a few words about transition to adulthood. It is an absolutely key moment in many autistic people's lives and can be a moment where things really go wrong. The broad picture—just generally developmentally—is that increasingly, in one's late teens and early 20s, the scaffolding and support that people have around them, whether that be from education or from family, tends to fall away. You are right—many autistic people are left floundering in that situation. Often, that can coincide with a transition from young person services to adult services.

If we are going to address some of the challenges that autistic adults face—such as high levels of mental health problems and physical health problems and high unemployment and underemployment—that transition period to adulthood is a key focus and a key target. It is a service issue as well, in that people can experience a bit of a service cliff. There are models in other areas where people think a bit more flexibly than, "There are child and adolescent services that go up to 18, and then there are adult services afterwards". If we can think more about transition-age services—young adult services—that might be an initial step towards addressing that absolutely critical moment in many autistic people's lives: the transition to adulthood.

Baroness Browning: That was exactly why the Autism Act was introduced—to create that transition through adolescence into adulthood. Are you saying that that is what should happen, but that is not what is happening at the moment?

Professor Will Mandy: Yes. I would put that in the broader context that we have been saying that there is just very little support—certainly a lack of consistent and evidenced support—in that area. So, yes, I think there is a lack of support through transition.

Baroness Browning: I dread to use the word, but do we need a proper "pathway"?

Professor Jonathan Green: To be positive, one of the things I think we really have gained, as I was saying earlier, is this sort of social awareness. This builds on something Will was saying earlier, actually. There is a sense that there are quite generic things here, and we do not have to have specific person-centred pathways. We need a social revolution around all this, and that has happened in lots of ways, such as social and work policy. The charity Autistica, for instance, which I have been associated with, has a tremendous programme of supporting



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workplaces to become autism-adapted. That can be true throughout public policy.

There are things we have learned in general terms. We know how we need to and can adapt the environment to autistic people's needs, and that they really benefit from that. That quality of adaptation produces optimal outcomes. In a sense, what we do very early in life is exactly the same; it is in there the context of early relationships and communication. But later on, in the workplace, we can help autistic people thrive by those kind of appropriate and reasonable adaptations. It does not mean that all the problems go away, but it makes a substantive difference.

In this transition period, certainly in my work clinically with autistic adolescents, you are preparing them—just like any adolescents—for and helping support them into adulthood. They have particular challenges too. Often the autistic identity helps, but not always; sometimes autistic adolescents want to forget about it: "I just want to be me as a person"—you know what I mean? That is fine. Each individual handles this their way, but they need good support to do that. It is not a simple answer. I think there should be general adaptation, but of course individuals need specific support as well.

Baroness Browning: Thank you. Could I just ask Bryony something from the research that she has been doing? You have clearly had a lot of contact with, for example, local authority services in the community. In the 2009 Act, there is a very small section which actually gives the Secretary of State for Health the power to call in local authorities that are not providing these services. I am not aware from any questions I have asked in the past that that has ever been enacted, and I wonder whether you in your work would identify—I am not asking you to name them now, of course—geographic areas or local authorities where perhaps, if the Secretary of State had called them in, the areas might be better provided than they are at the moment. What I am really saying is: is it a postcode lottery out there?

Professor Bryony Beresford: In terms of diagnostic services and post-diagnostic support for people in adulthood? Yes. There are localities where a specialist autism team is jointly staffed and jointly funded by local authorities and the NHS, but that is incredibly unusual. That is the model of care that is set out in the NICE guidance: a multidisciplinary team in a locality. When we did our research, I think there were 13 localities out of 130 or something. Within social care, the threshold of eligibility for support is too high, often.

Could I just come back to the adolescents? This is some research I did with King's College in London. We have a scenario where children are diagnosed when they are five or six, and then they hit adolescence and there is work they have to do around, "How do I feel about this?", and this whole thing that goes on with our identities during adolescence. It can lead to a very explicit rejection of that autism identity, which perhaps previously they were quite proud of or had no issue with, and that can be



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very distressing for them. The key thing is that typically they are not in contact with services any more. You get the diagnosis and you get post-diagnostic support through the parents but, in a lot of localities, when you get to late childhood, you are not being seen unless there are concerns about mental health.

They hit this crisis and there is no one there for them, and crucially, parents have not been advised about “How do I talk to my child—my growing child and my teenager—about their autism?” Alongside this, we know more generally that mental health problems are most likely emerging for anyone during this period. So you are stacking up the risks, which is when, as Will was saying, you hit young adulthood and you are highly vulnerable if not have already developed a mental health problem.

I am just reflecting on the conversation, and we have not really mentioned schools, which is quite interesting. In our discussions about professionals needing to be better trained up—clinically; that is what we have talked about—I am just wondering about this. Schools can have a vital role to play. They can be make or break really, in how a young person comes out of their teenage years. I have not done a lot of work on schools, but I think that is something missing. All I know is that parents say they can either be incredibly helpful or another risk factor for a young person, particularly secondary schools—you know, increased risk for mental health difficulties. Sorry, I have gone slightly off tangent there, but I wanted to because I just noticed that absence in the conversation.

Q29 Lord Elliott of Mickle Fell: We have covered some of this ground already, but I think it is a useful question to bring the conversation to a conclusion. How, if at all, should the aims of systems for identifying, assessing and supporting autistic people change in the coming years? How should services change to reflect this? Perhaps we can start with Professor Mandy, then move to Professor Beresford and then Professor Green. Thank you.

Professor Will Mandy: As has been a theme of our conversation, I think services should be aiming to spend proportionately less time on assessment and more on what happens after assessment. That is not a trivial task. It is a challenging thing to do. We need to generate new assessment models that are more efficient in how they give resources to people, that draw on things like AI, but also on training up other neurodevelopmental practitioners who are perhaps less highly trained than psychiatrists or clinical psychologists and so on, but who can perform certain delineated functions within these new assessment models which will hopefully increase efficiency, and allow for a bit of scaling-up as well. Then those models need to be evaluated. Rather than have a system where it is a bit of “Let a thousand flowers bloom”—you know, lots of people doing lots of different things—there needs to be more of a centralised, concerted effort to co-produce reasonable and viable models, and then to put them to the test to see if they really do improve service experience and efficiency. I hope that this will give way to a growing emphasis on support.



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The other theme I would really like to emphasise is that autism services should—again, Bryony and Jonathan have both talked about this—see themselves as disseminators of knowledge across much wider systems. There should be more consultancy training functions with a really clear aim to make sure that GPs, teachers and people working in employment services are really getting the benefit of their knowledge and of their ways of working, to recognise the fact that autistic people are just using public services right across the piece.

I suppose one other point is that I think there is a training and standards task. There is a huge amount of variability across the system that can give rise to unfairness—you know, one person coming to a service and getting one thing, and someone going to another and getting something else. We need some form of agreed accreditation of those standards and training. We have seen things like that, for example, in CBT, where the BABCP—the British Association for Behavioural and Cognitive Psychotherapies—has created very highly respected tiered standards for competence in CBT, and that is often linked now to posts in the NHS. You have to have reached a certain standard, and that gives a certain guarantee that you are practising at a certain level. I see that as potentially a really attractive model to drive up standards, and to do so equally across the country. There is so much great practice out there and so many people working very passionately and very hard. This could just add to that and potentially make a difference.

Professor Bryony Beresford: I reiterate everything Will has said there. That has to be the direction of travel—the specialist experts training other professionals and acting as consultants, and for there to be an expertise group that these professionals can come back to for particular supervision and support.

That whole ethos of services involved in the lives of autistic adults, children and young people is that they address the priorities of the children, young people and adults themselves. There is not a standard approach. Their families—be that partners, parents or others close to and around autistic people—are supported to support as well. In children's services, that is the model—it is a family-centred model of care. When you move to adult services, it is individualistic and that is problematic.

Professor Jonathan Green: I will just add a few points—I do not to want duplicate what has been said, which I agree with. One of the challenges we have at the moment with the health system is a fragmentation, and the devolved commissioning structure within the NHS. For all the positives that are seen of that devolution, it has lost something that we valued and treasured in the NHS, which is a capacity to have system redesign at scale. If you have someone in my position, who would like to advocate for a particular kind of model with evidence behind it, you have to speak to 70-plus commissioners in ICBs around the country. It just does not make sense.



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The devolution—the devolved commissioning—has got so far now, that it is hard to see how that could be, as it were, reversed. I am not even suggesting it should be, but some kind of central commissioning or central organising function is really important. I have been talking about this with NHS England for a few years.

The Autism Act has had real benefits. It has been of material benefit on the ground to have this legal structure. Obviously, its implementation is patchy, but to have that there at all is a huge achievement. In my personal view, I would like it to be extended downwards to a younger age because this is a developmental condition and, if we start right, things will keep going much better. I would love the Autism Act to be extended downwards.

It has been mentioned before that, throughout healthcare, there is a vision of an adapted pathway approach to developmental care which uses modern technology. That is another huge, important thing for the NHS to develop. I am involved in that, with others—to try and do that, but that is another challenge. We can harness technology to help us with this. This system redesign that we have all talked about needs a coherent shaping. You cannot just leave it to individual commissioners, even though they are trying to do their best in a locality. We have lost something around that coherent organising capacity from the centre. If the committee was able to do something about that, I, for one, would be very happy. I will leave it at that.

The Chair: I just want to say thank you, hugely, to our witnesses—Bryony, Jonathan and Will—for an extremely interesting and very informative session. There will be a transcript, which will be sent to you for checking for accuracy. If there is anything that you feel that we have not talked about in the session that you particularly wanted the committee to look at, please could you write to us and we will make sure that that is covered?

We will continue in a moment with our second evidence session. In the meantime, this first session is concluded and the meeting is suspended briefly.