

## **Supporting autistic adults: an interview with Prof Bryony Beresford**

### **1. Can you tell us how you first became interested in autism?**

I think it was a project in 2005 with the first piece of research I did looking at autism, and it was looking particularly at what outcomes children and young people want from using services, and that was healthcare, social care and education, and we looked at what they wanted in terms of those outcomes and we compared those, their aspirations and priorities and compared those to children with complex medical needs and children with life-limiting conditions.

### **2. Can you tell us about your current work?**

I'm doing two projects on autism at the moment. My first project is in partnership with Institute of Psychiatry, and they have a programme grant looking at improving mental health outcomes for adults with autism. And the project I'm doing within that programme of work is looking at how young adults with Asperger's syndrome understand their mental health experiences and difficulties within the context of having a diagnosis of autism. And then the second piece of work I'm doing which I'm speaking about at the conference today is we are doing a national evaluation of something called specialist autism teams, and they are a model of service provision, that NICE, the National Institute for clinical and care excellence, recommended every locality have. Which is a kind of holistic multi-disciplinary service for adults with autism.

### **3. When evaluating specialist autism teams, what are the biggest areas for development?**

So, we're not finished, I'm gonna have to be a bit limited in what I can tell you at this stage, findings will come out in the summer. We have completed a piece of mapping work where we tried to identify, across England, what localities, that's local authorities in partnership with CCGs, what localities are actually providing this specialist autism team service. And that means a single service that is doing diagnostic assessment, needs assessment, providing specialist interventions, and also ensuring and supporting people to access other services, so it's a very, kind of comprehensive provision. So we just found 16 localities across England who are doing that at the moment, and most of those have been set up in response to both the NICE guidance and The Autism Act. So there's evidence, I suppose, you can say

it's doable, there's evidence you can get the NHS and local authorities working in partnership and jointly commissioning provision. However, these are services which are small, and so the extent to which they are, in their current model, able to cope with increasing numbers of referrals, and building numbers of referrals is questionable. So there's certainly a concern about, unless these services access more resources, and receive more funding, the extent to which they can scale up in terms of demand. Now, one way these services are currently kind of rationing access is by only, for some services, you can only get access to this service through the diagnostic pathway. So that's good, that's good if you're, as an adult, seeking a diagnosis for the first time, and there's some very good practise within that. If you've been diagnosed with autism already, perhaps in childhood, or perhaps 20 years ago as an adult, in some localities you still cannot get access to that specialist support as an adult living with autism. And so that's a concern. All these services want to be doing more, it's around the resources they're being given. And that's why our evaluation is so important, 'cause if we can show evidence of their benefit, then that's something that commissioners will be interested to read about.

#### 4. What does the research tell us about post-diagnostic support for autistic adults?

Within the study, we are comparing the experiences and outcomes of individuals who receive help through a specialist autism team and individuals who only attend a diagnostic and assessment service which is what around 50% of localities now are able to offer people. And we're interested to know about their outcomes, does it make a difference having the kind of more comprehensive support, and we're still doing the analysis on that data, but I can share with you findings from our interviews with people who've either gone down either of those pathways, and what seems to be different about specialist autism teams is the depth and duration of what we call psycho-education and support. Learning about what is autism, what it means for me, and how I'm going to live with it. Now those teams have a capacity to do that over a number of sessions, offer opportunities for group sessions, whereas the diagnostic services, by their nature, only can give that in a very limited way. Now what we've found in our interview sample, we need to confirm this with a wider, quantitative data, is that, for those who got the brief psycho-education from the diagnostic service, 12 months later on, some of them were still very unresolved about the diagnosis they'd received. I'm not placing blame on those diagnostic assessment services, 'cause that's all they're commissioned to do. And I think they would want to do more, but it does high-light that issue. And that's important in itself, but what I think we're also seeing on our interview data is, if that isn't dealt with, and people are resolved, and start making adjustments, other needs, in a sense, will remain unmet. If people haven't reconciled

or accepted the diagnosis or it is troubling them a lot, other mental health issues, for example, will remain under-addressed. So there's a concern there. So that's one finding I think that's important, that we feel, certainly, is something that has real implications in terms of future practise. The other thing, I'll just pick a second one just for now, is what we've learned about how people who've been diagnosed with autism, what they do when they're given information, so it's that sort of thing about sign-posting. And a lot of them don't do anything with it. So just providing a leaflet is unlikely, actually, to do anything or be of any help to people. And in fact, if that's all you get, it actually has a negative impact, an additional negative impact on people, a sense of abandonment, which adds to everything else they're having to process at the time. So I think there's real questions about just handing out leaflets, just sign-posting, some individuals are gonna need support to help them access whatever services they're being sign-posted to, in a more active way. Again, services work under constraints, resources. So I think that's something else that certainly we need to look at in the future.

5. How will the findings be used to improve current services within autism teams?

So one of our partners, on the members of the research team, is the National Autistic Society, we're very keen to have them as partners in the research from the beginning. And they've been really good about helping us be aware of opportunities, along the way of the project, but also planning what we can do to maximise the impact of this research. Now the fact that research is coming to an end in the ten year anniversary of The Autism Act and all the activity that's going on around that means there's going to be lots of platforms and forums for us to share our findings, which is very exciting. We're also going to be working hard to make sure that the findings, our findings are produced and shared in ways that are meaningful to the people we're speaking to. So what commissioners want to hear is gonna be different to what a service manager is going to want to hear. And what people in the autism community themselves want to hear, they might want it differently again, or what's important to them, or the implications for them will be different. So we'll be doing work on tailoring our findings and sharing them in ways that are meaningful and I hope helpful. And then we'll also be submitting evidence from the study to NICE, who will be reviewing the NICE guidance in 2020, and we have already alerted them that the study's going on, so we expect that that will be evidence they'll take on board when they revise the guidance.

6. How can the findings also be used to improve mainstream services?

I think the issue for mainstream services is that a specialised service, is that. It is a specialised service. And specialised services shouldn't be delivering services to lots of people, and so one of the roles of specialised services is that part of their role and part of their job is, and this is what these teams are doing, is what we call up-skilling mainstream services so that they can better deliver interventions and support themselves. And, in a sense there is a need for mainstream services to take that on board, be that IAPT within NHS mental health provision or local authorities' social care. So, a willingness really to be up-skilled, a willingness to take referrals with people with autism rather than always pushing them to the specialist service, which, given their size and the nature of them, that's not a sustainable model.

7. How can we ensure the views and experiences of autistic people are used to develop best practice?

As a researcher, I have a responsibility to make sure I share my findings in a way that the autistic community can use them. Because they are the best lobbyists, the best advocates, but they need support and resources to make their arguments, to shift the minds of policy makers or local commissioners. And I think that's, in a sense, that's the role of research is to provide those resources and information, evidence, that then the community, with our support if they want it, can have those cases made. And I've certainly had experiences of that with other projects, where evidence that we've produced as a research team has been taken and has resulted in significant changes, because it was actually parents in that project who took it to their governments around the UK, which generated changes in policy.