Funding the Future

Why we have constructed a society so prejudiced against...

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The background

The Times **published an interview this week with Dame Uta Frith, one of the UK's best-known researchers on autism, in which she made an extraordinary claim about Chris Packham. Packham has publicly discussed his autism for many years, but Frith questioned his diagnosis. Referring to his abilities as a communicator, she said he cannot be autistic. She went further, describing the suggestion that he is autistic as absurd, while apparently regarding his exceptional ability to communicate as a contraindication of autism.**

Saying this, she builds on arguments she previously made on the University College London website.

I am staggered by Frith's claim, but I think there are two quite separate issues here. On one of them, Frith may have a point. On the other, I think she is profoundly mistaken.

Types of autism

Let me start with the point on which I think she might be right. I strongly suspect I am autistic. It is clear to me, and others, that I meet the three social communication criteria in what is called the DSM-5, which determines the diagnostic standards for autism. These are described as A1, A2 and A3. I also think that few people would challenge the idea that I am an effective communicator whether in person or in a variety of broadcast media. I see no contradiction between those statements.

I do, however, accept that describing what is currently described as level 1 autism and what is described as level 3 autism as the same condition might be confusing and even misleading. There are clearly things in common, which is why they have come to share a diagnostic category, but the differences in lived experience, communication, independence and support needs can be enormous. I think it is fair to ask whether putting them within a single spectrum now obscures as much as it explains.

Saying so, I stress that medicine already accommodates this sort of distinction. Type 1 and type 2 diabetes share a name because both involve problems with the regulation of blood glucose, but no competent clinician would suggest that they are therefore the same disease. Their causes and treatments can be very different. I wonder whether autism requires an equivalent conceptual separation. Perhaps what we now call level 1 and level 3 autism deserve different names, while recognising that they have characteristics in common.

If this is what Frith is really arguing, although she does not quite say so, then I think she has a valid point. A diagnostic spectrum can become so broad that putting everyone within it ceases to help either scientific understanding or the people being diagnosed. But that does not, in my opinion, justify what she says about Chris Packham.

Who decided that neurotypical communication is the standard?

Frith's argument appears to be that Packham communicates so well that this provides evidence against his being autistic. The problem with that claim is that it immediately raises another question: what does communicating well actually mean?

The conventional assumption is that autistic people have deficits in communication because they do not always communicate in the way that neurotypical people expect. But my question is, why is neurotypical communication presumed to provide the standard against which everyone else must be judged? Why must the autistic person learn the language of the neurotypical person when there appears to be almost no expectation that the neurotypical person should learn the language of the autistic person? Most importantly, why is the resulting failure of communication then described as a deficit belonging to the autistic person?

There is an extraordinary assumption of superiority implicit in this that I can only describe as repugnant. The assumption is that the neurotypical person effectively communicates normally, while the autistic person communicates abnormally, and as a result any failure of understanding between them must necessarily be the fault of the autistic person. I cannot see any way in which that conclusion can be justified. Communication is necessarily an interaction between people. If two people fail to understand one another, it does not follow that one of them has a communication deficit and the other does not.

I would stress what Frith does not understand. The autistic person needs to be bilingual and spends a great deal of their time communicating in their second language. The neurotypical person rarely, if ever, realises this issue exists, or the effort and cost it imposes on the neurotypical person.

The double empathy issue

Implicit in this observation is the importance of what has become known as the **double empathy problem**

. This recognises that autistic people can have difficulty understanding the assumptions, signals and social expectations of neurotypical people, but neurotypical people can also have difficulty understanding autistic people. The failure of understanding can run in both directions.

This matters because there is evidence that autistic people can quite often communicate very effectively with other autistic people, while communication can become more difficult when autistic and non-autistic people interact. If that is true, the problem cannot simply be that autistic people do not know how to communicate. It may instead be that people with substantially different ways of experiencing and interpreting the world do not automatically understand each other.

There is, however, an enormous asymmetry in the way society responds to that problem. Autistic people are routinely expected to learn neurotypical communication. They have little choice but learn when eye contact is expected, when they should speak and when they should stop, what subjects they are permitted to discuss at length, how much information another person wants, and the many occasions on which a question that appears to ask for information actually means something quite different. They have to learn that implication is frequently preferred to saying what is actually meant. They learn scripts, expressions and social rules because the world overwhelmingly operates according to neurotypical expectations.

In other words, they learn to mask.

In the briefest possible way I can summarise it, masking can be defined as hiding or compensating for autistic traits to meet non-autistic social expectations. It can make someone appear socially fluent while requiring substantial conscious effort.

It would appear that Uta Frith denies that an autistic person can or does mask. Her claim appears to be that what you see is what you get with an autistic person. In that case, I can only suggest she does not understand level 1 autism at all, and I know her supposed status in the field of study of this issue, but she comes across as a neurotypical person who is completely out of her depth. Incomprehension at this level from someone who claims to be an expert is, in my opinion, quite baffling.

What I would ask is where is the reciprocal education?

How many neurotypical people are taught how autistic people communicate? It would seem that Uta Frith has not been.

How many are taught that avoiding eye contact need not indicate inattention, that directness need not indicate hostility, or that an intense discussion of a subject can represent engagement rather than social incompetence?

How many consider the possibility that the autistic person whom they find difficult to understand may find their behaviour equally baffling?

The burden of translation is overwhelmingly placed on the autistic person. That is not reciprocity. It looks much more like an expectation of assimilation into neurotypical norms.

The problem with Frith on Packham

This is why masking matters so much to Frith's argument about Chris Packham. An autistic person can spend decades learning how neurotypical people communicate, and some become extremely accomplished at doing so. I think I have.

Autistic people can speak in public, lecture, broadcast, conduct interviews, entertain audiences and learn to read a room. By any ordinary standard, they can become excellent communicators, but the processes by which they achieve that result may be quite different from those used by a neurotypical person. What is little understood is that the cost of achieving that may impose a heavy burden on an autistic person. In my experience, very few neurotypical people are aware of that.

In addition, having demanded that autistic people learn neurotypical communication, society can then do something quite extraordinary. It can use their success in doing so as evidence that they cannot really be autistic. If they cannot communicate according to neurotypical expectations, their inability is taken as evidence of autism, but if they successfully learn to communicate according to those expectations, their ability is taken as evidence that they are not autistic.

That is a Catch-22.

It is also why recognising masking within the diagnostic framework matters. Outward competence cannot, by itself, tell us how that competence is being achieved, how much conscious effort it requires, or what happens when the person no longer has the capacity to maintain it. Looking at an accomplished television presenter and concluding from that performance that they cannot be autistic therefore seems to me to miss something fundamental. I cannot believe that anyone could do that, except that people have made similar claims about me.

The inherent exceptionalism

There is also a harder question here. Why is neurotypical behaviour assumed to be intrinsically superior? There is an uncomfortable possibility that what is presented as a neutral clinical standard sometimes incorporates what might better be called

neurotypical exceptionalism. The neurotypical way of communicating is treated as normal, while the autistic way is measured according to its deviation from that norm. The autistic person is expected to adapt, while the neurotypical person is not, and when communication fails the deficit is located in the autistic person. I think it is reasonable to ask whether that can in any way be scientifically justified, or whether some of it is just prejudice based upon an assumption of neurotypical superiority.

There are, of course, real disabilities associated with autism, and there are autistic people with very substantial support needs. Pretending otherwise would help no one. Recognising disability does not, however, require us to assume that every difference between autistic and neurotypical communication represents a failure on the part of the autistic person.

To conclude

That brings me back to Frith. If she is arguing that the category called autism has become too broad, I think there is an important discussion to be had.

I am not convinced that level 1 and level 3 autism should continue indefinitely to be described as different degrees of precisely the same condition. They might eventually prove to be related conditions requiring different names, just as type 1 and type 2 diabetes share important characteristics without being the same disease. If that is Frith’s underlying concern, she may be pointing towards something important.

But if she is saying that Chris Packham cannot be autistic because he communicates too well with neurotypical people, I think her arguments do not just fail but are insulting, and reveal a staggering level of both ignorance and prejudice on her part.

More than that, she may be demonstrating the double empathy problem, which her apparent denial of masking's existence overlooks. An autistic person can learn the language of the neurotypical world so successfully that a distinguished autism researcher concludes that this very success proves that he cannot be autistic, while almost nobody asks why the neurotypical world has made so little effort to learn the language of autistic people.

Perhaps, then, the question is not simply whether autistic people can learn to communicate with neurotypical people. We should also ask why we have constructed a society in which they are expected to do almost all the learning, and whether assuming that one way of communicating is inherently normal while another is inherently deficient is really science.

If the obligation to understand always runs in one direction, that is not double empathy. It is neurotypical exceptionalism, and I can see no reason why that should be considered acceptable.