

Interview |

## **Simon Baron-Cohen: 'Neurodiversity is the next frontier. But we're failing autistic people'**

*Saba Salman* |

**All different types of brains are normal, but greater understanding has not led to more money for autism, says world-leading expert**



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As a graduate in the 1980s, Simon Baron-Cohen taught autistic children at a special school in London. Little was known about autism then, and people often misheard him, assuming he taught “artistic children”.

“People would be ashamed if they had an autistic child, or ashamed of saying, ‘I am autistic’, whereas now it’s treated as more ordinary and there’s less judgment,” he says. “In the 1980s, autism was seen as categorical, so ‘you either have it or you don’t’ ... nowadays, we talk about a spectrum.”

Today, Baron-Cohen, 61, is a world expert on autism, a Cambridge professor and director of the university’s influential Autism Research Centre. There is also greater awareness of autism, a lifelong condition affecting how people interact or process information.

Estimates suggest one in every 100 people is on the autism spectrum (700,000 adults and children), from those with severe developmental disabilities needing intense support, to those with milder traits. Well-known autistic people include campaigner Greta Thunberg (who calls her “difference” a superpower). As a cognitive neuroscientist, Baron-Cohen has helped focus attention, from his pioneering psychological studies (autism was first diagnosed in the 1960s in the UK) to founding the UK’s first diagnosis clinic for people with Asperger syndrome in Cambridge 20 years ago with charitable funding (today the centre is NHS-run).

Yet his latest research reflects how improved awareness and understanding of autism have not led to improvements in the lives of people with autism. In the study exploring how autistic adults experience disproportionately more “negative life events”, 45% of the 426 participants say they often lack money to meet basic needs (compared with 25% of non-autistic people) and 20% have been sexually abused by a partner (compared with 9%). The research, involving questionnaires created with autistic people, suggests why those with autism may experience more depression.

These findings add more weight to existing evidence about the significant challenges facing autistic people. Diagnosis can take years; children face cuts to special educational needs provision; just 16% of autistic people had jobs in 2016 (compared with 80% of non-autistic people); and they are among those locked up in secure hospital-style units instead of living in communities. The Autism Act a decade ago obliged the government to create a strategy to improve support, but legislation has fallen short of promises.

“Many autistic people and their families will tell you that while the [government’s] autism strategy has raised awareness, nothing much has changed on the ground in the last 10 years. And, despite our research flagging up suicide risk and other kinds of vulnerability, too many autistic people are languishing unsupported because there’s no new money in social care for autism. This is unacceptable,” says Baron-Cohen.

He hopes his centre’s recent findings will encourage better practical help, such as a lifelong support worker, “so there’s a pathway from discovery in the lab through to changing people’s lives”. He says: “The old style of doing research was, without [us] realising it, arrogant, in

that the scientists thought up the questions and then did it. The new way is to involve people from the outset ... to codesign the studies, and check the relevance and wording.” Gaps between research and practice influenced plans for a £35m Autism Centre of Excellence by 2025. Aiming to be the UK’s first national clinical and research centre for autistic people, it will combine academic expertise with practical help. In theory, children or adults referred by a GP would get a diagnosis, then immediate support from specialists like psychiatrists, employment or benefits advisers. “Locally, we’ve got this research centre and world-famous university, and all around it people are sitting on waiting lists, unable to be seen, and they’re struggling, so it’s about closing that gap,” he explains.

Baron-Cohen’s late sister, Suzie, had severe learning disabilities. She was sent to an institution aged two (common advice from doctors at the time). Later in life, he moved her to supported housing near his own home. She died in 2014. In an emotive eulogy, he recalled of his sister: “Our lives were richer for having shared the journey with her.” He talks movingly of her and how she influenced his work. “Maybe because I had a sister with a disability I was already sensitised to and fascinated by people who think or develop differently,” he says.

He has won national and international awards for researching the biological, hormonal and genetic factors in autism. Yet Baron-Cohen’s theories remain controversial. The extreme male brain concept, outlined in his provocative book, *The Essential Difference*, describes men’s brains being wired for systemising and women’s for empathising. This led to criticisms of “neurosexism” and gender stereotyping, which could risk misdiagnosing or underdiagnosing autistic women, and also of fuelling the idea that people with autism have no cognitive empathy. In his defence, he stresses that “equality between the sexes is very important”, adding that his research explores groups of males and females “on average”, adding “this is not about individuals”. With empathy, he argues that while autistic people may struggle to imagine others’ emotions, they feel emotion if others are upset (the distinction between cognitive and affective empathy).

In future, he hopes the idea of neurodiversity becomes more mainstream. “Brains come in different types and they’re all normal,” he says. “What we want is that one day every workplace will be diverse - we already encourage that with gender and ethnicity, but the next frontier is neurodiversity and it will become ordinary. People won’t think twice about it.”

## **Curriculum vitae**

**Age:** 61.

**Lives:** Cambridge.

**Family:** Widowed, three adult children.

**Education:** Haberdashers’ Aske’s school, Hertfordshire; New College, University of Oxford (BA human sciences); University College London (PhD in psychology); Institute of Psychiatry, London (MPhil, clinical psychology).

**Career:** 1995-present: director, Autism Research Centre, University of Cambridge; 1994-present: teaching fellow then professorial fellow in experimental psychology, Trinity College, Cambridge; 1994-present: lecturer then reader then professor in developmental cognitive

neuroscience, departments of psychiatry and psychology, Cambridge; 1988-93: lecturer then senior lecturer in developmental psychology, Institute of Psychiatry, London; 1987-88: lecturer, department of psychology, University College London.

**Public life:** Vice-president, National Autistic Society; trustee, Autism Research Trust; trustee, Empathy for Peace; president, International Society for Autism Research (2017-19); chair of psychology section, British Academy (2016-19).

**Awards and honours:** Fellow, Academy of Medical Sciences; fellow, British Academy; Distinguished Contributions award, developmental psychology section, British Psychology Society.

**Interests:** Plays bass guitar in Deep Blue, a Cambridge soul and blues band.

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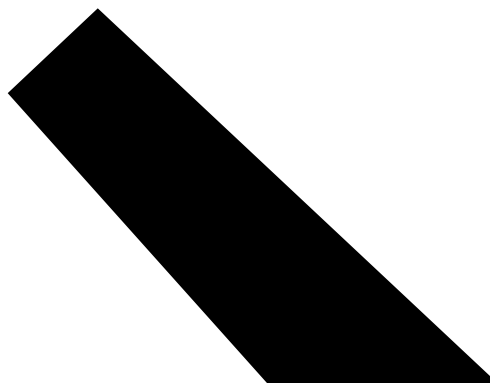
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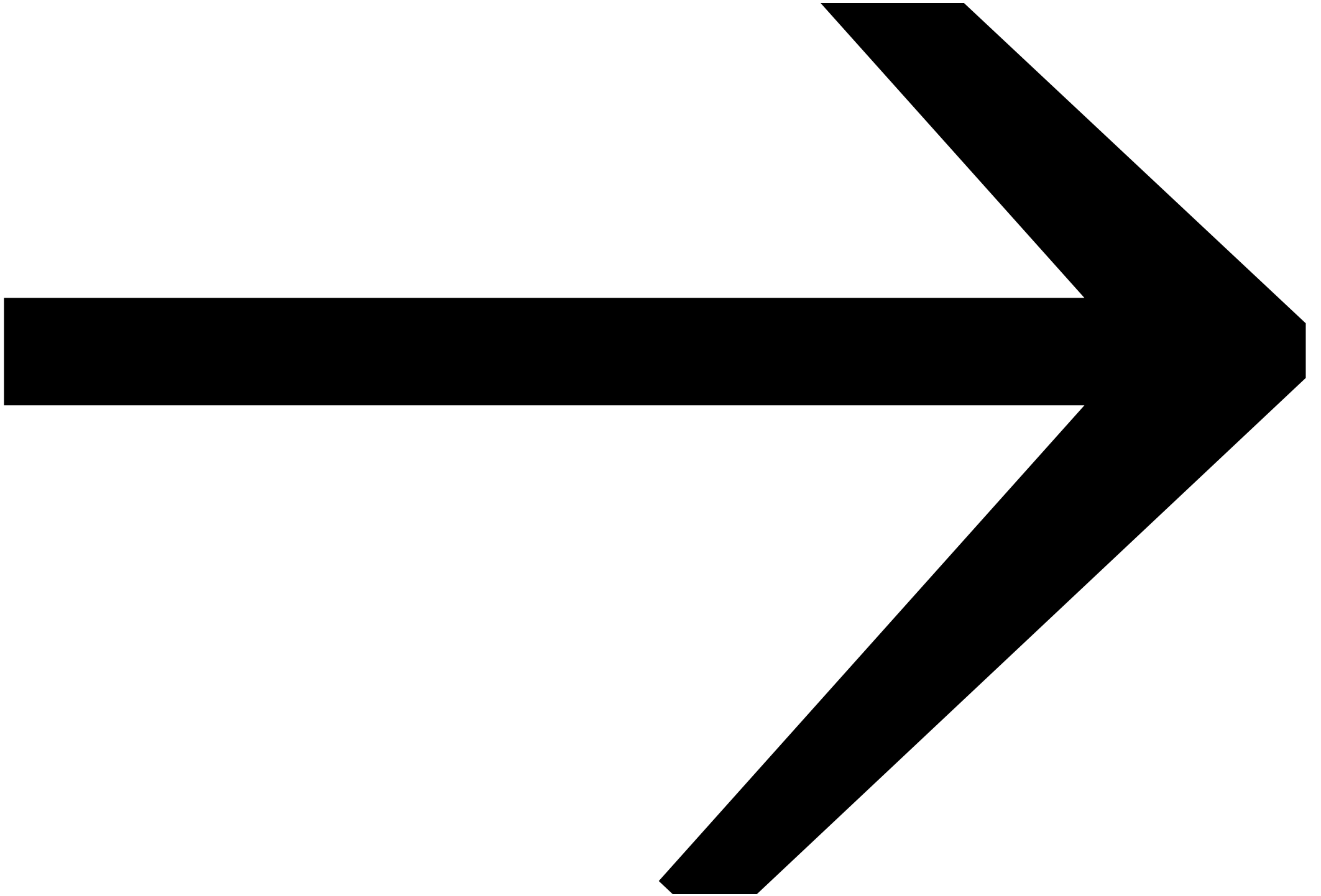
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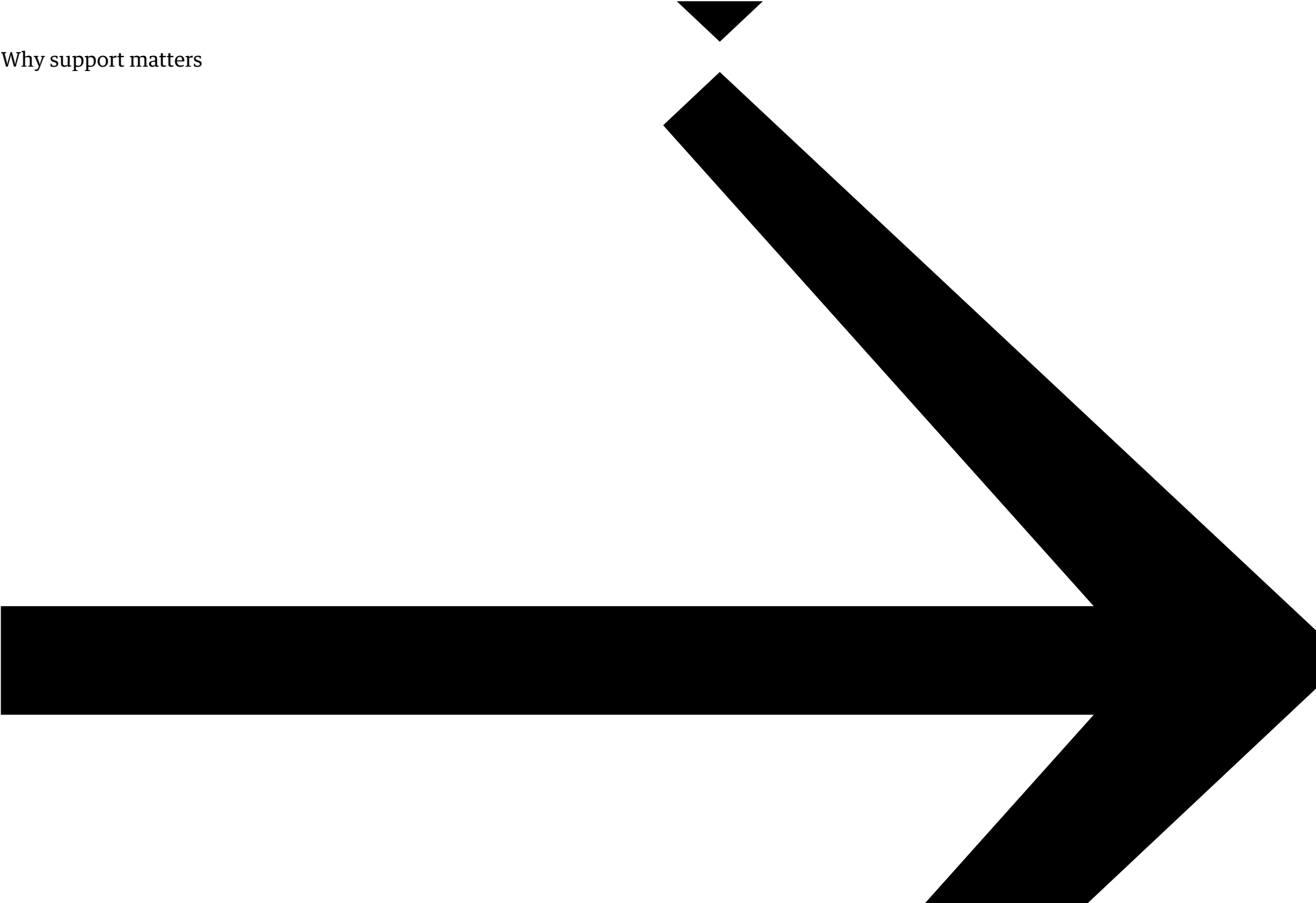
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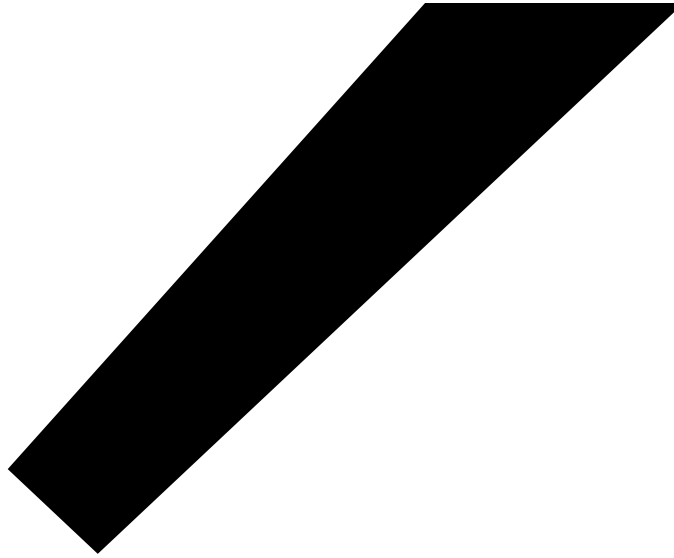
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