A capabilities approach to understanding and supporting autistic adulthood

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Abstract | There is little comprehensive research into autistic adulthood, and even less into the services and supports that are most likely to foster flourishing adult autistic lives. This limited research is partly because autism is largely conceived as a condition of childhood, but this focus of research has also resulted from the orthodox scientific approach to autism, which conceptualizes autistic experience almost entirely as a series of biologically derived functional deficits. Approaching autism in this way severely limits what is known about this neurodevelopmental difference, how research is conducted and the services and supports available. In this Review, we adopt an alternative research strategy: we apply Martha Nussbaum’s capabilities approach to research on autistic adulthood. In doing so, we identify areas where autistic adults thrive and where they often struggle, and highlight issues to which researchers, clinicians and policymakers should respond. The resulting picture is far more complex than conventional accounts of autism imply. It also reveals the importance of engaging autistic adults directly in the research process to make progress towards genuinely knowing autism and supporting flourishing autistic lives.

Autism is a lifelong neurodevelopmental difference that influences the way a person interacts and communicates with others and experiences the world around them1. For decades, autism research focused predominantly on autistic children2, in line with the very earliest descriptions of autism3,4 and the tendency for society to depict autism as a disability of childhood5. The result is a substantial lack of understanding about the opportunities and challenges that autistic adults face in building their futures, achieving their goals and living satisfying and fulfilling lives. These issues clearly matter, however, and in the past decade there has been an increase in publications on autistic adulthood, a new journal specifically dedicated to autism in adulthood, a notable increase in funding dedicated to adult-related issues6 and numerous policy interventions designed to assist autistic adults to live good lives7.

Serious obstacles nevertheless continue to prevent researchers, clinicians, educators, policymakers and the broader public from fully grasping the nature of contemporary autistic adulthood. Overcoming these obstacles is vital not only because they constrain understanding but because they also hinder efforts to inform and transform the services and supports that might enhance autistic adults’ lives.

Paramount among these obstacles is the orthodox approach taken in conventional autism research, in which there is an overfocus on ‘deficits’ or ‘impairments’ of autistic adulthood and an overemphasis on specific attributes of individuals as opposed to the broader contexts in which autistic adults live8,9. This conventional research paradigm derives both from long-standing conventions in medicine, which prioritize a putatively objective standard of ‘bodily health’ over a subjective understanding of ‘well-being’10, and from the developmental psychopathology literature, which stresses the importance of ‘patterns of maladaptation’ in shaping the life course of autistic people11. Consequently, individual autistic adults’ behavioural, cognitive and neural functionings are frequently compared with some typical or ‘normal’ level of ability that is held as the ideal ‘state of health’9; interventions and treatments typically aim to remediate these apparent shortcomings to align functioning with the accepted norm. This narrow focus on deficits results in a radically constrained understanding of the experiences that shape autistic lives, limiting the range of supports and services to those that seek to ‘change the individual’ rather than consider how to ‘change the world’. Conventional research efforts are also routinely conducted without meaningful input.
from autistic people themselves13, meaning that often the wrong questions are posed and findings are misinterpreted. Research of this kind can be said to be ‘lost in translation’91. As such, most research on autism prioritizes researcher-defined normative life goals without discovering how much they matter to a diverse range of autistic people14,15.

In this Review, we — a team of autistic and non-autistic researchers — propose an alternative way of approaching adult autism research. First, we provide some context by briefly discussing the diagnosis and developmental trajectories of autistic adults. Next, we describe Nussbaum’s capabilities approach16,17, which outlines ten central capabilities that enable people, whether autistic or non-autistic, to lead lives that are of value to them on their own terms rather than to meet a predetermined normative standard set by others. We then examine each of the ten capabilities in the context of available autism research. This approach enables us to evaluate the opportunities and challenges facing autistic adults, the forces shaping them and the ways in which services and other interventions might enhance the quality of their lives.

**Diagnosis and developmental trajectory**

Adult diagnosis of autism first became available in the 1980s [REF.18] and was further encouraged by changes in the *Diagnostic and Statistical Manual of Mental Disorders*, fifth edition (DSM-5) [REFS.19,20] several decades later. Many autistic adults initially seek their diagnosis following concerns about social relationships and mental health, sometimes precipitated by a personal crisis or by the diagnosis of their own children. For many, this search for diagnostic clarity is preceded by decades of feeling ‘different’ and of relationship or employment difficulties21,22. Challenges to adult autism diagnosis are discussed in BOX 1.

A growing number of adults self-identify as autistic without a formal diagnosis23. This self-identification is controversial in research and clinical communities but is often accepted in the autistic community, in part because, even in high-income countries, autistic adults often remain undiagnosed24,25 and, even when formally diagnosed, are only minimally supported2,7,23–25. Those diagnosed later in life may have higher self-reported autistic traits and poorer quality of life, especially mental health, than those diagnosed in childhood26.

Following the normative tendencies of the conventional approach to autism research, the vast majority of studies that have examined the developmental trajectories of autistic adults diagnosed in childhood focus on areas thought to be critical for achieving ‘good’ adult outcomes. In longitudinal studies, these outcomes are often defined in terms of a set of standard ‘life achievements’, on which autistic adults typically fare badly14,15. For example, autistic adults with and without intellectual disability followed from childhood are less likely than non-autistic people to hold down a job, live independently or have friends and intimate relationships24,14,15. Other longitudinal studies have examined whether people remain ‘autistic’ (that is, meet instrument and/or clinical thresholds for autism) as they move from childhood into adulthood. These studies show that the diagnostic status of individuals diagnosed in childhood generally endures into adulthood26,27, with the exception of a minority of individuals who no longer display sufficient core autistic features to warrant a clinical diagnosis, which is sometimes described as an ‘optimal outcome’28. Yet despite initial variability, many people show little change in researcher-defined ‘autistic symptoms’ as they move into adulthood29, potentially placing them at greater risk for poor psychosocial outcomes in adulthood30.

More detailed research on the quality of life of autistic adults also largely focuses on the achievement of standard life outcomes, irrespective of whether those outcomes are considered meaningful by autistic adults themselves23,14,25. Studies that have complemented standard, researcher-defined measures with more subjective, autistic person-led measures (such as quality of life) consistently demonstrate that outcomes are more positive when subjective factors are accounted for24,25. For example, an autistic person who is highly dependent on others for their care — a so-called ‘poor outcome’ according to the standard framework — might nevertheless be happy and subjectively enjoy a very good quality of life. Another autistic person who no longer meets the diagnostic criteria for autism — a so-called ‘good’ outcome — might struggle to find their way in the world and feel different and distant from others. Approaches that focus on researcher-defined measures in this way limit understanding and risk failing to grant autistic people the dignity, agency and respect they deserve.

In considering how to respond to these limitations, it is helpful to establish two clear aims. First, research into autistic adulthood must recognize that people’s life chances (opportunities each individual has to improve their quality of life) are shaped by a range of factors beyond the person, consistent with an ecological perspective31. That is, quality of life is influenced both by biological factors at the heart of the conventional

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**Box 1 | Challenges for autism diagnosis in adulthood**

In most countries, adults seeking an autism assessment and diagnosis face severe challenges, and the individual is expected to initiate and navigate the process31. Although there are published guidelines2,7,294, major differences exist between guidelines and actual experience273. Adults seeking diagnosis report lengthy waiting times and prohibitive costs295, and encounter clinicians who lack a nuanced understanding of autism3,273. Further, the guidelines are far from standardized in their recommendations for the use of adult diagnostic tools and there is much variation in practice2,7,294.

The process of adult autism diagnosis is also challenging owing to difficulties in recovering early developmental history and the self-reported tendency of many autistic adults to use strategies (masking or camouflaging) to minimize autistic features274,275. Although autistic adults of all genders have been reported to mask274,275, it is more often reported among women296, which could be one reason why twice as many men present to adult diagnostic services297. These findings dovetail with a growing recognition of gender bias in autism diagnosis2,7.

More research concerning adult autism diagnosis is needed. For example, little is known about the diagnostic experiences of autistic adults with intellectual disability24, about how autism is identified in different cultural contexts or about adult autistic for the use of adult diagnostic tools and there is much variation in practice2,7,294.

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A capabilities approach to autistic lives

Martha Nussbaum’s capabilities approach to quality of life, which has been widely used to analyse social disadvantage in multiple settings, satisfies both of the aims outlined above. First, according to the capabilities approach, a human ‘capability’ is not an intrinsic ability that a person has or does not have solely by virtue of who they are. Instead, ‘capability’ refers to the actual opportunity to be or do something that is facilitated or constrained by features of the person and by the broader contexts in which a person is embedded. The relevant contexts can include close family and household influences; everyday community interactions; educational institutions; economic factors, including the cost of living; services and supports, including accessibility and performance of healthcare institutions; and the broader social and political context, including social attitudes towards autism. Second, flourishing human lives are characterized by a set of these capabilities which enable a person to achieve any number of a range of outcomes, rather than by the attainment of a small number of pre-specified outcomes. These capabilities are considered foundations for a range of doings and beings; they shape what a person can do and, critically, who and how they can be in the world. Capabilities are not a narrow or specific set of achievements, nor are they possessions. Similarly, capabilities cannot be ranked or interpreted by a group of people, such as professionals, or reduced to a single score on a standardized scale. Instead, they refer to the preconditions for a broad range of ways of living.

According to Nussbaum, there are ten central capabilities that most people need if they are to be able to choose and create lives that are meaningful and fulfilling on their own terms (Table 1). In what follows, we outline how analysing the life chances of autistic adults through this lens can enable a far richer understanding of autistic adults’ lives of all abilities (see BOX 2) than the conventional research approach. We do so by highlighting the strengths and challenges of autistic adults in each of the ten central capabilities, and their causes, and consider the potential supports, services and changes in societal attitudes that might help to transform those challenges into strengths. Analysing these capabilities provides a way to examine the lives of autistic adults without narrow normative judgement, while also directing attention to issues that require intervention and support. Readers are advised that some of this material may be distressing and evoke difficult past associations.

Life. The first central capability is “being able to live to the end of a human life of normal length; not dying prematurely, or before one’s life is so reduced as to be not worth living”17. Autistic adults are currently at a substantial disadvantage in this capability. There are persistent patterns of premature mortality in the autistic population18,19. Autistic people are twice as likely to die prematurely as non-autistic people20, and this risk is greater for autistic women21,22 (but see REF.23) and those with intellectual disability20,24. The lives of autistic people are, on average, 16 years shorter than those of non-autistic people23. The risk of death is elevated in autistic people who experience poor physical health or chronic illness (including epilepsy)25–27. Little is known about the influence of social and economic factors, including access to healthcare, on these mortality rates, but it is widely hypothesized that an important contributor is the extent to which physicians listen to, and learn from, their autistic patients28.

Among the specific causes of premature mortality, there is a higher risk of suicide21,22. Suicide attempts are more frequent and more likely to result in death in autistic people than in non-autistic people23,24,25, possibly owing to co-occurring psychiatric conditions26. Research focused on understanding why autistic people are at increased risk of self-harm and suicide has identified individual risk markers common to those in the general population, including (younger) age27, low mood and rumination28. More work is needed to understand potentially unique risk markers for increased suicidality in autistic people, including broader interpersonal causes (such as thwarted belonging and perceived burdensomeness) which might mediate associations between autistic traits and suicidality29, and systemic issues (such as clinicians’ lack of knowledge7).

More generally, autistic quality of life in older adulthood (adults aged 50 years and older) — albeit as assessed using normative measures — is seen as considerably poorer than that in non-autistic older adults30. Social isolation and loneliness are major issues for all older adults, leading to greater risk of dementia and other serious medical conditions30. Both social isolation and loneliness might disproportionately influence older autistic adults, who might be more prone to reclusiveness31, despite many autistic adults describing a longing for interpersonal connection32. For example, in a study in which autistic adults’ experiences of growing older were elicited, one autistic participant said “I think I’m a born loner, quite frankly … Maybe I’m not the kind of person to have a life. Oh, I’d love it, with a person that would understand me”.32. There are few longitudinal and participatory studies focusing on autistic older people, including under-represented populations who might have poorer life satisfaction. Thus, little is known about how autistic adults can be supported to live a full and satisfying life into old age in diverse sociocultural contexts33,34.

Bodily health. The second central capability is “being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter”17. Once again, the evidence suggests that autistic adults are disadvantaged in this regard. Co-occurring physical conditions are common across the autistic lifespan35–38 and are more prevalent than in the general population.
Table 1  | Nussbaum’s ten central capabilities and their relevance for research on autistic adults

| Capability | Definition | Relevance to autistic adults | Individual autistic experiences |
|------------|------------|------------------------------|-------------------------------|
| Life       | Being able to live a life of normal length, not dying prematurely | Evidence suggests that socio-economic and other disadvantages lead autistic people to die younger than non-autistic people. There is limited knowledge of what ageing well means for autistic people and the most effective ways to support them during this period of their lives. | Many autistic people are acutely conscious of the challenges they face in this regard. One study participant reflected: “I recognise that I often don’t realise just how bad things have become. In the last year I have started thinking about suicide, even though I don’t want to die, and that has been the thing that’s made me realise how bad things might be.” |
| Bodily health | Being able to have good health, including reproductive health, adequate nourishment and shelter | Autistic adults’ constrained access to healthcare influences their bodily health. Homelessness and other housing concerns are higher among autistic adults than non-autistic adults. | One autistic adult, interviewed about his experiences of homelessness, described its profound effects on physical health: “I had become homeless… the ground was frozen at that time so it was quite cold… I had two pancakes a day and I lived off of water during those times… I went from something like ten stone down to six.” |
| Bodily integrity | Being able to move freely from place to place; being free from violent assault; to have opportunities for sexual satisfaction and reproductive choice | Bodily integrity is crucial for reducing victimization of autistic adults, including sexual violence. Safety on, and accessibility to, public transport and other forms of mobility are a particular concern. | In a study on experiences of interpersonal violence, one autistic participant emphasized the challenges in distinguishing safe from unsafe situations, including doubting their own intuition: “It’s harder for me to rely on instinct because in my childhood I was often told that I don’t have instinct so I was told to always doubt my gut.” |
| Senses, imagination and thought | Being able to use the senses; to imagine, think and reason; to have freedom of expression, including pleasurable experiences and avoiding non-beneficial pain | Autistic adults are often stereotyped as having restricted imagination or as being incapable of enjoying sensory experience. Greater recognition of distinctive autistic imaginative and sensory experiences is needed. | One autistic participant simultaneously describes the joys of stimming and its stigmatization: “I remember as a child spinning all the time and loving spinning and loving swinging and feeling that movement all the time, but then I also realised that there was a point where it wasn’t acceptable to be spinning anymore… so it actually still feels glorious if there’s nobody around and I can skip or I can spin and it’s like I’m breaking the rules.” |
| Emotions | Being able to have attachments to things and people and to love, grieve and feel a range of emotions; not having emotional development blighted by fear or anxiety | Loneliness and social isolation are acute for many autistic adults. Relationship advice and guidance could substantially improve well-being. | In a study on COVID-19 lockdowns, autistic participants reflected on the importance of friendships and other human company, emphasizing, as one autistic adult did, “how much I actually need human interaction and how much humans actually are somewhat a valuable component of my life.” |
| Practical reason | Being able to form a conception of the good and reflect about the planning of one’s own life. | Autistic adults often report executive function and planning challenges in everyday life and in life course planning. New support programmes offer promise for supporting autistic people’s goal-setting and decision-making skills. | Autistic research participants often comment on the challenges of planning in their daily lives: “Even if I feel totally relaxed and happy, you know, some days, I can’t formulate the plan so I don’t go out at all and that happens once or twice a week. So that is very disabling.” |
| Affiliation | Being able to live with, and show concern for, others; to engage in various forms of social interaction; being able to be treated as a dignified being; not being discriminated against | Peer groups and friendship networks are a priority for many autistic adults. Face-to-face services and community-building activities are of vital importance to maintaining well-being, including during crisis. | The importance of affiliation is noted by autistic participants reflecting on their peer network: “With my autistic friends… people are very sensitized to people being or feeling left out… so many of them seem to make a really big effort to stop that from happening. So it’s a much more accessible community for me, because I don’t have to make all the effort, which is how I feel with neurotypical people. Autistic people are willing to meet halfway.” |
| Other species | Being able to live in relation to the natural world | Autistic adults intensely value their relationship to the natural world. Access and support services are key to supporting this connection. | In a study using photovoice methodology, an autistic participant wrote a poem expressing her love of flowers she walked past every day: “Blue and blooming every which way, Blown in the breeze each and every day. I walk past you… half a mile.” |
| Play | Being able to laugh, play and enjoy recreational activities | Greater social acceptance is required of autistic people’s passions and interests. Harnessing autistic interests in other facets of life, especially in education and work, is important. It is also important to ensure recreational activities are accessible to autistic people. | In one study, some autistic participants pointed out that advantages or disadvantages were in the eye of the beholder: “Why is obsession bad and the ability to focus on something that you like [good], Why was Sir Isaac Newton bad when he was so obsessed about that apple falling from that tree?” |
for almost all conditions assessed, even when lifestyle factors are considered. Autistic adults with intellectual disability have distinctive needs and might be especially vulnerable to poor physical health.

Risks for most physical health conditions are further exacerbated for autistic women. Understanding the mechanisms for these differences in health outcomes is critical for reducing these inequalities. Moreover, further clarifying the temporal development of these health problems should inform how interventions are designed to prevent and treat them. There are presently very few studies on autistic people’s reproductive health. Autistic women report challenging experiences with menstruation, including a cyclical amplification of sensory differences and difficulties with emotional regulation, and autistic women are at greater risk for pregnancy complications. Autistic women also report significant deterioration in everyday quality of life during menopause. None of these concerns have yet been investigated in depth. Likewise, there are no studies specifically addressing the reproductive health experiences of autistic men, those with intellectual disability and/or those who are non-speaking; no studies have adopted a less gender-binary approach to reproductive health in autistic adults. This absence of research potentially leaves crucial areas of experience unsupported by clinicians and other policy interventions.

Autistic adults also face barriers to healthcare. Despite greater healthcare utilization, medication use and higher healthcare costs than the general population, autistic adults report more unmet health needs, lower utilization of preventative care and more frequent use of emergency departments than non-autistic adults. Healthcare settings are often inaccessible to autistic adults, with significant risk of sensory and social overwhelm, miscommunication and lack of autistic-informed care. Autistic people also experience reduced coordination of care compared with non-autistic people, particularly during the transition from paediatric to adult services. Thus, autistic adults are often left to fend for themselves in navigating the healthcare system, resulting in negative healthcare experiences and feelings of distrust.

Autistic adults also report poor patient–provider communication (in both directions): autistic adults often face difficulties identifying and articulating their physical health symptoms and professionals often do not appreciate the need to adapt their communication style for autistic patients and do not take their autistic patients’ concerns seriously. Clinicians’ limited knowledge and lack of confidence in understanding autistic adults’ specific needs further exacerbate these difficulties. Some tools have been developed to assess barriers to healthcare access experienced by autistic adults from their own perspective or from their caregiver’s or healthcare provider’s perspective. The person-related, provider-related and system-related barriers identified using these tools should facilitate future research that seeks to improve the care and health of autistic people. However, research designed in collaboration with autistic people is needed to assess the most effective ways of improving their healthcare experiences.

Many other external factors influence autistic adults’ physical health, such as access to affordable, appropriate housing. Initial studies suggest that autistic adults might be over-represented in homeless communities at rates substantially higher (12–18%) than adult population prevalence estimates (1%). The range of challenges facing autistic adults might predispose them to homelessness, and reduced social support networks might compound other risk factors, including unemployment, making it difficult for autistic adults to exit homelessness.

Other housing challenges also influence this crucial capability. Compared with other people with disabilities, autistic adults are less likely to live independently, leaving them vulnerable to the inadequacies of institutionalized housing. Formal institutional living and similar settings that purport to be community-based, but are often only nominally so, have been criticized for displacing people from their families and communities and for providing poor and unresponsive services to residents. Nonetheless, autistic adults continue to be over-represented in more restrictive and segregated settings.

In sum, the bodily health of autistic adults is severely compromised at present in many regards, owing to failings in clinical provision and in the broader social and economic context within which they must lead their lives.

**Bodily integrity.** The third capability is that people should be able to move freely from place to place; to be secure against violent assault; having opportunities for sexual satisfaction and for choice in matters of reproduction. This capability is underpinned by a person’s right to make decisions about their body.

There are good reasons to be concerned about autistic disadvantage in accessing this capability. Autistic

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**Table 1 (cont.)**

| Capability                  | Definition                                                                 | Relevance to autistic adults                                                                 | Individual autistic experiences                                                                 |
|-----------------------------|---------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------|
| Control over one’s environment | Political: being able to participate in political choices affecting one’s own life Material: being able to hold property on an equal basis with others and to have access to employment on an equal basis to others | Autistic self-advocacy organizations and workplace reforms, including new regulations and support mechanisms within paid employment, have the capacity to extend autistic agency and control | Opportunities for new experiences in tailored workplace programmes are often well-received. One autistic participant reported: “For three months, I’ve managed to gain experience which is absolutely priceless. I’ve not only felt like I’ve further improved on skills I’ve gained before joining this internship, but I feel like I’ve gained lots of new and different skills I could’ve never thought I would have achieved. It’s been absolutely great.” |

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**Overwhelm**

A term used by autistic people to describe a state caused by excessive sensory or social stimulation.
The capabilities approach focuses on the real opportunities that are open to each person to live in ways that are meaningful to them. Applying such an approach to research on autistic adulthood enables identification of the ways in which autistic people can thrive on their own terms and the nature of the obstacles to this thriving. Diverging from more conventional medical frameworks, the key to this approach is the value of personal autonomy: the belief that all people, including autistic people, should enjoy the right to be at least ‘part author’ of their own lives and that their quality of life should always be measured, at least in part, according to their own aspirations.

Although widely used in other settings, the capabilities approach is novel in the context of autism, partly because it has previously been suggested that this sort of autonomy-inflected approach is ill-suited to a substantial proportion of the autistic community. Non-speaking autistic people, those with intellectual disabilities and/or those with very high support needs have sometimes been considered unable to communicate or conceptualize their precise wishes in the ways the capabilities approach seems to require. From this perspective, the capabilities approach is applicable only to those who can make and articulate judgements about their own life purposes and not to the entire autistic population.

Some have called for a fine-grained approach to the heterogeneity within autism, suggesting that the autism spectrum should be split into those for whom an autonomy-inflected approach could be appropriately applied and those for whom the traditional medical model may be better suited. Similarly, others have called for the creation of a separate ‘profound’ or ‘severe autism’ diagnostic category for those with the most severe impairments.

We do not believe that we need to be this pessimistic. There is no clear scientific basis for segmenting the autism spectrum in the way that proponents of a separate ‘severe’ or ‘profound’ autism label suggest. Moreover, doing so poses grave risks, potentially excluding people deemed ‘severe’ or ‘profound’ from the concern, dignity and respect offered to others. Nonetheless, it is crucial for future research into autistic quality of life to consider people of all abilities. Such research should investigate whether augmentative and alternative communication can enable those with higher support needs to make their needs and desires known. Future research should also examine the effectiveness of available long-term services and supports to enable those with the greatest needs to fulfill key aspects of quality of life. This work would acknowledge the inevitable complexities of deploying the capabilities approach in these instances while recognizing that it remains possible to develop a broad and subtle framework for the evaluation of quality of life across the whole autistic community.

| Box 2 | Inclusivity and the capabilities approach |
|---|---|
| The capabilities approach focuses on the real opportunities that are open to each person to live in ways that are meaningful to them. Applying such an approach to research on autistic adulthood enables identification of the ways in which autistic people can thrive on their own terms and the nature of the obstacles to this thriving. Diverging from more conventional medical frameworks, the key to this approach is the value of personal autonomy: the belief that all people, including autistic people, should enjoy the right to be at least ‘part author’ of their own lives and that their quality of life should always be measured, at least in part, according to their own aspirations. |

Concerns about physical safety also influence the ability to move freely. Many autistic adults want to be able to access work and go about their daily activities within their communities, and parents often want this independence for their children too. Yet both groups worry about safety. Use of public transportation can be challenging for autistic adults owing to lack of accessibility and difficulties with wayfinding and traffic judgement. Furthermore, despite research showing that autistic drivers are more rule-abiding than non-autistic drivers and are no more likely to be at fault for a police-reported car crash, few autistic people take up driving, partly because of perceived difficulties in spatial awareness, motor coordination, processing speed and executive function. Consequently, autistic adults can remain reliant on their parents. As one autistic adult expressed in a focus group on understanding autistic adults’ transportation needs and barriers: “If I want to go shopping in the middle of the day I can’t. I have to wait for my mom to come home from work.”

Finding a balance between autonomy and safety is critical. Autistic children and adults can be more susceptible to wandering and, and parents sometimes advocate the use of measures such as tracking devices. Yet wandering can occur for many reasons and is often purposeful. Researchers and activists warn of the negative impact surveillance technologies can have on people’s independence and urge investment in alternatives such as community supports and safety skills training.

Bodily integrity is inextricably linked to other capabilities. Violations of bodily integrity have adverse effects on other capabilities, including mental health, bodily health, interpersonal relationships and sense of agency. Threats to bodily integrity are also likely to influence autistic people’s sense of sexual well-being and their freedom to achieve it. Long-held views of autistic people being uninterested in sexual experiences have been firmly quashed by research showing that autistic adults desire sexual relationships to a similar extent as non-autistic adults. Autistic adults in satisfying relationships are more likely to report greater sexual satisfaction, just like non-autistic adults. They also identify with a wider range of sexual orientations and gender identities and their sexual ‘debut’ occurs at a later age and they have fewer lifetime sexual experiences than non-autistic adults. The lack of qualitative studies on the realities of autistic adults’ sexual lives limits understanding, despite the fact that this topic is prioritized by the autistic community.

Senses, imagination and thought. The fourth capability focuses on being “able to use the senses, to imagine, think, and reason — and to do these things in … a way informed and cultivated by an adequate education … being able to use imagination and thought in connection with experiencing and producing [creative] works … Being able to have pleasurable experiences and to avoid nonbeneficial pain.” The dominance of the conventional medical model has meant that autism is often associated with deficits in this regard. There is often a presumption that autistic adults will struggle with
higher-order cognition or have low intelligence owing to poor performance on standard intelligence tests\textsuperscript{20}. This stereotype persists even though there is little evidence for it in the everyday experience of the autistic population\textsuperscript{13} and partly owing to the absence of formal transition planning\textsuperscript{12}. Consequently, autistic adults are at high risk of dropping out of university\textsuperscript{14}. There is also limited research on the destinations of autistic students\textsuperscript{13} and partly because they are hesitant to disclose their diagnosis or find it difficult to reach out for help\textsuperscript{12}.

Increasing numbers of autistic adults are enrolling in higher education\textsuperscript{14}, but barriers exist there too. Autistic adults rarely receive relevant supports and accommodations, partly because they are hesitant to disclose their diagnosis or find it difficult to reach out for help\textsuperscript{12} and partly owing to the absence of formal transition planning\textsuperscript{12}. Moreover, limited attention is given to their specific needs, strengths and preferences\textsuperscript{13,137}, including by school staff who lack confidence in supporting autistic students\textsuperscript{13,138}. Being excluded from\textsuperscript{13,139} or not completing\textsuperscript{13} school can have persisting negative effects on mental health and well-being.

The senses, imagination and thought capability also emphasizes the importance of being able to take pleasure from sensory experiences. Although research tends to focus on the challenges that autistic sensory differences — such as experiences of sensory overload — bring to people’s everyday lives\textsuperscript{13}, sensory stimuli can also be a source of pleasure\textsuperscript{13,141}. For example, one autistic adult reported enjoying “touching metal a lot … cold smooth metal is, like, just amazing”\textsuperscript{142}. There is also evidence that autistic adults with limited spoken communication in a supported living environment find joy in the everyday, for example in the sound of the washing machine on the last spin or the feel of bubbles while dishwashing\textsuperscript{14,148}.

However, these distinctive sources of pleasure are often pathologized. This is captured by the debate over certain ‘repetitive motor stereotypies’ such as hand-flapping, which have been reclaimed by autistic adults as ‘stimming’\textsuperscript{149}. These behaviours tend to be perceived as an individual problem with no clear purpose or function that prevent the person from learning skills and interacting with others\textsuperscript{150}. Stimming behaviours are often the target behaviour for interventions that promote ‘calm’ or ‘quiet’ hands\textsuperscript{151} (cf. Ref.\textsuperscript{152}). However, there is very little evidence that stimulating behaviours are harmful to autistic people or their peers (the same cannot be said for self-injurious behaviours, which might also be purposeful but are nevertheless harmful to the person). In fact, it now seems likely that stimulating behaviours can serve as a source of pleasure or reassurance or a form of self-regulation\textsuperscript{149}.

**Emotions.** The next capability is defined as “[b]eing able to have attachments to things and people outside ourselves; to love those who love and care for us, to grieve at their absence; in general, to love, to grieve, to experience longing … not having one’s emotional development blighted by fear and anxiety”\textsuperscript{17}. The empirical literature shows that autistic adults have more difficulties recognizing others’ emotions\textsuperscript{135,136} and identifying and describing their own emotions (alexithymia) than non-autistic people\textsuperscript{135,136}. However, emerging work suggests a far more nuanced picture: autistic adults describe feeling emotions and empathy intensely\textsuperscript{17} and often experience deeply satisfying emotional lives\textsuperscript{136}.

At their most extreme, the conventionally reported difficulties with emotions were thought to preclude autistic people from the capacity to love or desire meaningful romantic and intimate relationships\textsuperscript{143}. However, research is inconsistent with this claim\textsuperscript{160}. Romantically involved autistic adults report high relationship satisfaction\textsuperscript{135,139}. The strong bonds that autistic adults report with their partners, particularly with those who are also autistic\textsuperscript{162}, extend to their autistic children, with whom they describe an intense connection and love\textsuperscript{160}.

These reports speak strongly against an understanding of autism as a ‘disorder’ of affect. Rather than lack of interest, autistic adults often cite significant challenges with initiating and maintaining romantic relationships\textsuperscript{154}, including difficulties reading and interpreting others’ emotions\textsuperscript{154}, which can impact their capacity to remain romantically involved. The stereotyped assumptions of non-autistic people that autistic people are uninterested in interpersonal relationships might also be an obstacle\textsuperscript{163}. These challenges can intensify feelings of loneliness and are linked to significant negative emotional experiences and poor mental health\textsuperscript{164}. Autistic adults who desire intimate connection but whose needs are unfulfilled might be at particular risk of depression and low self-worth\textsuperscript{14,165}.

This loneliness, depression and poor self-perception can take a substantial toll on mental health and well-being\textsuperscript{14,164,166}. A substantial proportion of autistic adults experience a co-occurring psychiatric condition during their lifetime, with anxiety and mood disorders being the most common\textsuperscript{160,169}. Rates of co-occurring psychiatric conditions are somewhat lower for autistic adults with intellectual disability\textsuperscript{170}, but these rates...
Internalized stigma
When a person accepts negative stereotypes about autism and applies them to themselves.

Monotropism
A cognitive theory of autism, which suggests that the primary feature of autism is a tendency for a singular attentional focus.

Flow
An optimal state in which a person becomes fully immersed in an activity, resulting in intense concentration, creative engagement and the loss of awareness of time and self.

might be underestimated owing to a lack of detailed understanding in how best to characterize and measure mental health in this context. The risk of developing mood disorders increases with age and autistic adults are at elevated risk of developing post-traumatic stress disorder. Some mental health problems in autistic adults have been attributed to everyday discrimination and internalized stigma.

The reliance on mental health assessments and diagnostic criteria that were established in non-autistic people and a lack of necessary expertise among health professionals might result in an overestimation or underestimation of mental ill health in the autistic population. Some autistic characteristics might overshadow indicators of mental health conditions (for example, social withdrawal and sleep disturbance are common to both autism and depression), suggesting that co-occurring mental health conditions might go unrecognized. Similarly, mental health diagnoses might overshadow an autism diagnosis, resulting in misdiagnosis.

Mental health difficulties in autistic adults are likely to be compounded by the inadequacies of formal and informal supports. Autistic adults report a significantly higher number of unmet support needs than the general population, struggle to obtain appropriate post-diagnostic support and face challenges in accessing individually tailored treatment for mental health problems. As one autistic adult put it: "I haven't requested any, because people like me don't get support". There is a clear need for mental health interventions that are adapted to autistic people's needs and preferences.

Practical reason. The next capability, practical reason, is defined as "being able to form a conception of the good and to engage in critical reflection about the planning of one's own life". The three key elements of this capability — choosing what one wants to do, critically reflecting on that choice and making a plan to realize it — are fundamental to making full use of all the other capabilities.

It is sometimes assumed that people with cognitive disability, including some autistic people, are incapable of practical reason, failing even at the initial task of deciding what it is that they value or desire. Autistic people were traditionally thought to have impaired self-awareness. A substantial minority of autistic adults have co-occurring intellectual disability (29%) and some do not use speech to communicate, which can make it difficult for others to gain insight into their thinking. However, research demonstrates that autistic people have a deep capacity to reflect on many aspects of the self, regardless of their intellect or communication preferences.

The practical reason capability also requires people to be able to reflect critically on their choices, and to change their mind. Here, it seems that autistic people might approach decision-making differently to non-autistic people. Autistic adults make more logically consistent, rational decisions, are more circumspect in their decision-making, sample more information prior to making a decision, are less susceptible to social influence and are more deliberate in their reasoning.

However, first-hand accounts suggest that such an approach to decision-making can have its disadvantages. For example, autistic people report challenges changing their decisions, especially if the change is unanticipated or requires a shift in routine. Indeed, autistic people's tendency to focus intensely on topics or objects of interest (monotropism) can make it difficult to 'move on' or 'change gears'. Interrupting activities after such states of flow and difficulties starting new activities (autistic inertia) can lead to pervasive and often debilitating effects on autistic adults, including on their ability to design and execute a plan.

Many of the above skills come under the broader umbrella of executive function (higher-order processes that underpin goal-directed activity and enable individuals to respond flexibly to change and plan their actions accordingly). Problems with planning, organization and future-oriented thinking are common in autistic adults and are linked to adaptive difficulties, might be compounded by particular contexts (such as in parenting or the workplace) and are perceived to be real obstacles to achieving desired outcomes. Interventions and supports that focus on planning and decision-making are scarce, but those that do exist are associated with gains in executive function-related behaviours in real-world settings.

Affiliation. The next capability is "being able to live with and toward others, to recognise and show concern for other human beings, to engage in various forms of social interaction … and having the social bases of self-respect and nonhumiliation; being able to be treated as a dignified being whose worth is equal to that of others". Simply put, that the person is respected as a social being. Prima facie this might be the capability in which autistic adults might be expected to be at the greatest disadvantage. After all, the term 'autism' comes from the Greek autos, meaning both 'self' and 'by itself', and autistic people are often described as preferring a life of self-isolation. Dominant characterizations suggest that autistic people lack the motivation and/or cognitive building blocks for social interaction, which prevents them from establishing and maintaining the types of reciprocal relationships that are fundamental for this capability.

Research has repeatedly shown that autistic children and adolescents have fewer reciprocal friendships, are often on the periphery of social networks and spend less time with their friends outside school than their non-autistic counterparts. Autistic adolescents also report a growing awareness of feeling different from others despite wanting to 'fit in' and frequently experience social exclusion and bullying, which might exacerbate their challenges in making and keeping friends. These patterns persist into adulthood. It is therefore unsurprising that many interventions in adolescence and early adulthood focus on formal social skills training, with the aim of equipping autistic people to manage everyday social relationships on their own terms and, thereby, secure this capability.
However, such interventions fail to appreciate that autistic sociality is shaped by the sociocultural context in which people are embedded219,221,227. Autistic people can and do have fulfilling connections with others, even if negotiating those relationships can be challenging210. They are drawn to those who accept them for who they are214,215,216 and with whom they do not have to mask their autistic ways212,213. These friendships include (but are not restricted to) autistic-to-autistic interactions214,215. As one participant reported in a study on autistic adults' experiences of loneliness and social relationships: “though many of us have only met each other three to four times, it feels as if we have known each other forever. Because all of a sudden you are in a community with someone where you are on the same wavelength … it is a really strong experience”216. Such autistic-to-autistic interactions promote self-understanding211,214,217, positive self-identity217,218 and well-being219.

Isolation owing to the COVID-19 pandemic has also revealed that autistic people long for social connection in the same way as everyone else, both in terms of close, trusting relationships and fleeting, incidental interactions. As one autistic interviewee said when describing their lockdown experience: "I didn't realise how important that incidental human contact was to me. It was so incidental that it never really registered on my radar until it was gone"160. Autistic people's need for human connection and the extent to which social isolation plays a role in autistic people's mental health distress have been underestimated by conventional accounts.

The double empathy problem220 suggests that there is a misalignment between the minds of autistic and non-autistic people. This misalignment leads to a lack of reciprocity in cross-neurotype interactions and is the source of social communication difficulties between autistic and non-autistic people213,216. Empirical evidence suggests that non-autistic people have difficulties understanding the minds and behaviours of autistic people20,223, and that they are unwilling to interact with autistic people on the basis of initial judgements or interactions219,220. Thus, non-autistic people also interact less successfully with autistic people, compared with other non-autistic people224.

These cross-neurotype interaction difficulties can lead to stereotyping of and discrimination against autistic people. Although non-autistic people tend to deny feeling negatively inclined towards autistic people225, autistic people often report experiencing bullying, exclusion and discrimination. Attitudinal research has shown that considerable implicit biases are present, even among non-autistic people who report no explicit biases226, suggesting they may be unaware that they have negative attitudes towards autistic people. These implicit, negative biases are likely to be difficult to shift using short-term educational training programmes227. Such discrimination and stigma constitute a substantial barrier for autistic people seeking to develop social connections. Discrimination and stigma could be countered by widespread public acceptance campaigns (including those developed with autistic people228), and programmes that increase the number of everyday interactions between autistic and non-autistic people225,229.

**Other species.** The eighth capability requires that humans are “able to live with concern for and in relation to animals, plants and the world of nature”217. Prominent autistic naturalists (such as Temple Grandin) and environmentalists (such as Greta Thunberg) have captured the public's attention231. Yet there is remarkably little written about autistic people's connections to nature and non-human animals.

Research with parents of autistic children has revealed that natural elements (such as sand, mud, leaves, twigs and water) can keep children engrossed for extended periods of time220. Some autistic children also prefer interacting with animals over inanimate objects and humans232, and report strong attachments to pets224. Studies have therefore focused on the potential therapeutic benefits of interacting with nature for children, with some purporting to show 'reduced autistic severity' or improvements in family functioning following interaction with trained animals225.

Research with autistic adults also reveals benefits of interacting with animals and nature236. Nature and gardening are two of the interests most reported by autistic adults, particularly women, and the pursuit of these interests is positively associated with subjective well-being237. In a study using photovoice methodology, images of natural scenes were frequently included among the photographs shared by autistic adults, demonstrating the importance of nature in contributing to a good autistic life238. Autistic adults' autobiographies reveal the emotional depth of these connections to nature239, which some autistic people say offers respite from the intensity of an often inhospitable social world.

**Play.** The capability of play emphasizes the right to be “able to laugh, to play, to enjoy recreational activities”241. This capability is one in which autistic adults might excel. Researchers and clinicians often refer to autistic people's passions and interests as 'highly restricted', 'perseverative' or 'circumscribed', or as 'obsessions' or 'fixations', and as differing qualitatively (in content) and quantitatively (in intensity) from the interests of non-autistic people240. Yet autistic testimony attests that these passions are often a great source of joy and enjoyment241, which situates them within the play capability. Intense interests are common in autistic people237,242, and become more diverse over time243. They are not limited to the sciences or computers, as popular stereotypes suggest244, but extend broadly to a range of areas20,242 and might be more idiosyncratic in autistic adults with limited spoken language and/or intellectual disabilities245.

Autistic adults often view their capacity to pursue their passions as an advantage237,242, and become more diverse over time243. They are not limited to the sciences or computers, as popular stereotypes suggest244, but extend broadly to a range of areas20,242 and might be more idiosyncratic in autistic adults with limited spoken language and/or intellectual disabilities245.

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New agendas and approaches to autism research

Despite the large literature on autism since it was first identified in the 1940s, this research generally does not have a positive, meaningful impact on the day-to-day lives of autistic people and their allies. There has been an extensive focus on underlying biological questions and relatively little research on the design of services and supports, the social contexts within which autistic people live or the policy settings that influence their quality of life. Through advocacy and other means, autistic people are increasingly making it clear that they are dissatisfied with this mix and, in line with the emphases of the capabilities approach, want the massive public investment in autism research to provide a greater direct return. They want to address the imbalance in current autism research: research that has a direct impact on the daily lives of autistic people should be valued as much as research on the underlying biology and causes of autism.

Crucially, autistic people also want to have greater input into research decisions, beyond being passive research participants. This limited involvement in research has begun to change in the past decade. There is a slow but growing movement towards collaborating with autistic people and their allies as part of the research process, such that autistic researchers and community members are actively involved in making decisions about research. These decisions can include what kind of research is done, how it is done, how research results are interpreted and how the findings are used.

Such participatory research has a long history outside autism research. In these contexts, participatory processes that draw on the ‘practical wisdom’ of non-scientists have been shown to have a dramatic effect on both the research agenda and the effectiveness of the research. Participation itself can take many forms, ranging from being a consultant on a research project to sitting on a formal advisory board, being a full collaborative partner or even leading projects. The critical issue in participatory research is who makes the research decisions. In research involving community members only to a minimal extent (for example, through consultation), the researchers are typically in control. When that involvement deepens, researchers relinquish control to share decision-making power with community members.

There are some excellent examples of autism research that uses participatory approaches, but it is still very much in its infancy. Although there is much enthusiasm for involving autistic people in the decisions that influence them, researchers can be worried about how time-consuming participatory research can be, and finding it hard to relinquish control in research decision-making and worry that community members might introduce bias into otherwise rigorous research processes. These concerns could lead to tokenism when community involvement is attempted. Instead, researchers and community members need to appreciate that they each have different ‘experiential expertise’; they must take that expertise seriously to enable valuable insights for those involved in the research and for the research itself.

Autistic burnout

A community-driven term describing a highly debilitating condition involving exhaustion, withdrawal, executive function problems and generally reduced functioning, with increased manifestation of autistic traits.

Control over one’s environment. The final capability emphasizes the importance of “being able to participate effectively in political choices that govern one’s life … being able to hold property and having property rights on an equal basis with others; having the right to seek employment on an equal basis with others; having the freedom from unwarranted search and seizure”.

There is virtually no research on autistic adults’ engagement in mainstream political processes. Individuals with intellectual disability are less likely to vote than the general population, especially if they live in supported accommodation rather than with family. They often lack support and accessible information for political engagement and are even explicitly told they cannot vote due to their intellectual disability. More research is needed on autistic citizenship to identify precisely how these obstacles can be overcome.

Extant data suggest that autistic people might be more politicially disengaged than non-autistic people. This suggestion stands in contrast to high-profile autistic activists and political commentators, such as Australia’s Grace Tame and Eric Garcia from the United States, and increasing autistic involvement in self-advocacy since the 1990s. The autistic self-advocacy movement grew out of the self-advocacy efforts of people with intellectual and developmental disabilities in the United States and the United Kingdom, and is perhaps epitomized most by Jim Sinclair’s foundational essay (‘Don’t Mourn For Us’) which implored parents not to see their autistic child as a tragedy but, instead, to embrace their differences. Autistic and neurodiversity activists now promote individual self-advocacy, harnessing self-understanding and knowledge to ensure that individuals have greater control over their own lives. Such individual self-advocacy is complemented by collective advocacy, sometimes led by organizations run by and for autistic people (for example, Autistic Self-Advocacy Network), where autistic people collectively campaign on a range of issues and come together in dedicated autistic spaces and events. Consequently, self-advocates have begun to shift conceptions of autism from a disorder that needs to be eradicated, prevented or ‘fixed’ to a distinct way of being, which demands acceptance and emphasizes human rights and a positive autistic identity and culture.

There is much for autistic self-advocates to campaign about. Autistic people’s opportunities are constrained by others’ unjustified assumptions about their capacity. Autistic adults are at far greater risk of prejudice, stigmatization and discrimination in many facets of their lives, such as education, health, care, intimate relationships, community, justice and work. Moreover, to navigate a world that is not typically set up for them, autistic adults often (consciously or unconsciously) hide or mask aspects of their autistic self to keep themselves safe or adjust their abilities through compensation. Such adaptation can come at serious personal cost, including poor mental and physical health, negative self-perceptions and autistic burnout.

Work provides a particularly constrained environment. Autistic people face substantial challenges in gaining and sustaining meaningful employment, even relative to other disabled people, despite
Summary and future directions

Autistic people deserve to live long, healthy and creative lives of their own design. Just like all people, they need to be equipped with a set of fundamental capabilities to do so. In this Review, we have examined the lives and life chances of autistic adults through Nussbaum’s capabilities\(^{[14]}\).\(^{[25]}\)\(^{[26]}\)\(^{[27]}\)\(^{[28]}\)\(^{[29]}\)\(^{[30]}\) lenses. Doing so allows us to escape the narrowly normative focus on specific life outcomes and to consider the broader foundations for a range of possible good autistic lives. When approached in this way, the literature suggests that there are some capabilities in which autistic people have the potential to exceed despite conventional stereotypes to the contrary, such as emotion, affiliation, play, connections to other species, practical reason and control over one’s own environment. At the same time, the literature suggests that in these capability areas and others (especially life, bodily health and integrity), autistic adults are often constrained by a range of social, economic and other environmental disadvantages and barriers, which prohibit them from enjoying a good life that they have the right to expect.

This Review suggests two clear directions for future research. First, it will be important for researchers to more clearly identify these externally shaped disadvantages and find ways to alleviate them. That is, once researchers are collectively equipped with a fuller understanding of what currently prevents autistic adults from enjoying a particular capability, they should be able to begin the task of removing those constraints so that further opportunities are provided. Second, it will be equally important to encourage autistic people themselves to reflect further on the capabilities to which they aspire and the obstacles which they believe obstruct them. The capabilities reviewed here are only a starting point and further amendment might be needed to capture the breadth and specificity of autistic experience (see \ref{ref4});\(^{[31]}\) determining what autistic capabilities to add to this list can be resolved only through research that is genuinely participatory (see Box 3);\(^{[32]}\) that is, research that places the interests of autistic adults first and takes their own experience and expertise as seriously as any other input.

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Fletcher-Watson, S. et al. Making the future together: shaping autism research through meaningful participation. *Autism* 23, 943–953 (2019).

This co-produced paper identifies five topics relevant to building a community of practice in participatory research, offering a useful guide for early-career and more senior researchers.

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**Author contributions**

This Review was a collaboration between non-autistic researchers (E.P., U.F., R.L. and M.S.) and autistic researchers (G.H., M.H., W.L. and J.M.), who all actively participated in making decisions about the Review. E.P. and M.S. identified the theoretical framework in discussion with U.F., G.H., M.H., W.L., R.L. and J.M.; E.P., U.F., G.H., M.H., W.L., R.L. and J.M. identified the search terms. U.F. and E.P. conducted the literature searches. All authors identified areas of interest from across and within the capabilities and read and reflected on the existing literature in those areas, focusing in particular on the aspects of relevant papers that were least and most compelling and the next steps for research. E.P. and M.S. wrote the original draft of the manuscript. All authors contributed to reviewing and editing the manuscript. The analytic approach was informed by the authors’ training in education (E.P., U.F. and R.L.), psychology (E.P. and W.L.), anthropology (R.L.), nursing (G.H.), history (J.M.) and political philosophy (M.S.), as well as positionalities as autistic researchers and advocates (G.H., M.H., W.L. and J.M.). These participatory processes ensured that the Review was approached through a strengths-based, rather than deficits-based, lens.

**Competing interests**

E.P. reports grants from the Australian Government Department of Education, Skills and Employment, and sits on the Board of Directors for Amaze, the peak organization for autistic people and their families in Victoria, Australia, and the Disability Advisory Council for Australia’s Victorian State Government, for which she receives meeting attendance payments. M.H. is CEO of the not-for-profit organization Reframing Autism Ltd and co-chair of the Australasian Autism Research Council (unremunerated), and reports grants from the Australian Government Department of Education, Skills and Employment, and Autism CRC. He is a member of the Australasian Autism Research Council (unremunerated), a participant and advisor for Autism CRC and an ambassador for the I CAN Network, and receives royalties from books and occasional fees for workshop and invited addresses. R.L. reports grants from the Australian Government Department of Education, Skills and Employment, and Autism CRC. M.S. reports grants from the Paul Ramsay Foundation and from the University of Sydney, is an Associate Fellow at the Said Business School, Oxford and assists fundraising efforts with various philanthropic groups in his role as Director of the UCL Policy Lab. All other authors declare no competing interests.

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