

A capabilities approach to understanding and supporting autistic adulthood

Elizabeth Pellicano^{1,2}✉, Unsa Fatima¹, Gabrielle Hall¹, Melanie Heyworth^{1,3}, Wenn Lawson¹, Rozanna Lilley¹, Joanne Mahony¹ and Marc Stears⁴

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, which focuses on ten core elements of a thriving human life, 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 autism^{3,4} 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 live^{8,9}. 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

¹Macquarie School of Education, Macquarie University, Sydney, New South Wales, Australia.

²Department of Clinical, Educational and Health Psychology, University College London, London, UK.

³Reframing Autism, Sydney, New South Wales, Australia.

⁴UCL Policy Lab, University College London, London, UK.

✉e-mail: 1.pellicano@ucl.ac.uk

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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 process²⁴. Although there are published guidelines^{7,294}, major differences exist between guidelines and actual experience²⁹⁵. Adults seeking diagnosis report lengthy waiting times and prohibitive costs^{2,24}, and encounter clinicians who lack a nuanced understanding of autism^{75,174}. Further, the guidelines are far from standardized in their recommendations for the use of adult diagnostic tools and there is much variation in practice^{2,7,294}.

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 features^{274,275}. Although autistic adults of all genders have been reported to mask²⁷⁵, 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 diagnosis^{2,7}.

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 experiences in the Global South²⁹⁸. It is likely that autistic adults in many low and middle-income countries do not have access to formal diagnosis, post-diagnostic supports or the positive transformations in self-understanding and connections to a peer community that often accompany diagnosis^{181,217,261}.

from autistic people themselves¹², meaning that often the wrong questions are posed and findings are misinterpreted. Research of this kind can be said to be 'lost in translation'¹³. As such, most research on autism prioritizes researcher-defined normative life goals without discovering how much they matter to a diverse range of autistic people^{14,15}.

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 approach^{16,17}, 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. 1,19) 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 difficulties^{20,21}. Challenges to adult autism diagnosis are discussed in BOX 1.

A growing number of adults self-identify as autistic without a formal diagnosis²². 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 undiagnosed^{2,23,24} and, even when formally diagnosed, are only minimally supported^{2,7,23–25}. 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 badly^{14,15}. 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 relationships^{2,14,15}. 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 adulthood^{15,27}, 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 themselves^{31,32}. 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 for^{14,15}. 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 perspective³³. That is, quality of life is influenced both by biological factors at the heart of the conventional

medical model and a broader set of contextual factors as stressed by the social model of disability³⁴. Second, no one, autistic or not, has high quality of life if their life goals are primarily set by others. Thus, quality of life should not be measured by a standard set of outcomes judged to be important by researchers, clinicians or policymakers. Instead, the goals of each individual's varied human life should be at least partly set by the person themselves³⁵.

A capabilities approach to autistic lives

Martha Nussbaum's^{16,17} 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^{16,17} (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 population^{36,37}. Autistic people are twice as likely to die prematurely as non-autistic people^{36–38}, and this risk is greater for autistic women^{36,38} (but see REF.³⁷) and those with intellectual disability^{36–38}. The lives of autistic people are, on average, 16 years shorter than those of non-autistic people³⁶. The risk of death is elevated in autistic people who experience poor physical health or chronic illness (including epilepsy)^{36–39}. 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 patients⁴⁰.

Among the specific causes of premature mortality, there is a higher risk of suicide^{41,42}. Suicide attempts are more frequent and more likely to result in death in autistic people than in non-autistic people^{36,37,43–45}, possibly owing to co-occurring psychiatric conditions³⁶. 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) age⁴⁶, low mood and rumination⁴⁷. 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 suicidality⁴⁸, and systemic issues (such as clinicians' lack of knowledge⁴⁹).

More generally, autistic quality of life in older adulthood (adults aged 50 years and older⁵⁰) — albeit as assessed using normative measures — is seen as considerably poorer than that in non-autistic older adults⁵¹. Social isolation and loneliness are major issues for all older adults, leading to greater risk of dementia and other serious medical conditions⁵². Both social isolation and loneliness might disproportionately influence older autistic adults, who might be more prone to reclusiveness⁵³, despite many autistic adults describing a longing for interpersonal connection⁵⁴. 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"⁵⁴. 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 contexts^{55,56}.

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 lifespan^{57–59} and are more prevalent than in the general population

Table 1 | Nussbaum's^{16,17} 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 ^{36–39} 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" ²⁵
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 ^{25,67–69} Homelessness and other housing concerns are higher among autistic adults than non-autistic adults ^{79,80}	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" ⁸⁰
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 ^{96–99}	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" ²⁹³
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" ¹⁴⁹
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 ^{164–167} Relationship advice and guidance ¹⁵⁹ and greater efforts at ensuring social acceptance ²¹⁹ 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" ¹⁶⁷
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 ¹⁹³ New support programmes offer promise for supporting autistic people's goal-setting and decision-making skills ¹⁹⁹	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" ¹⁹²
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 ^{213,217} Face-to-face services and community-building activities are of vital importance to maintaining well-being ^{167,217} , 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" ²¹³
Other species	Being able to live in relation to the natural world	Autistic adults intensely value their relationship to the natural world ^{238,239} 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 morning and afternoon, You remind me to stay strong and always stay in bloom" ²³⁸
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?" ²⁴⁶

Table 1 (cont.) | Nussbaum's^{16,17} ten central capabilities and their relevance for research on autistic adults

Capability	Definition	Relevance to autistic adults	Individual autistic experiences
Control over one's environment	<p>Political: being able to participate in political choices affecting one's own life</p> <p>Material: being able to hold property on an equal basis with others and to have access to employment on an equal basis to others</p>	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" ²⁹⁰

for almost all conditions assessed^{43,58,59}, even when life-style factors are considered⁵⁸. Autistic adults with intellectual disability have distinctive needs⁵⁹ and might be especially vulnerable to poor physical health⁶⁰.

Risks for most physical health conditions are further exacerbated for autistic women^{58,61}. 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 them⁶². There are at present 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^{63,64}, and autistic women are at greater risk for pregnancy complications⁶⁵. Autistic women also report significant deterioration in everyday quality of life during menopause⁶⁶. 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 healthcare⁶⁷⁻⁶⁹. Despite greater healthcare utilization, medication use and higher healthcare costs than the general population⁷⁰, autistic adults report more unmet health needs⁷¹, lower utilization of preventative care⁷¹ and more frequent use of emergency departments^{71,72} 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^{67,73}. Autistic people also experience reduced coordination of care compared with non-autistic people, particularly during the transition from paediatric to adult services⁷⁴. Thus, autistic adults are often left to fend for themselves in navigating the healthcare system⁷⁵, resulting in negative healthcare experiences and feelings of distrust^{66,67}.

Autistic adults also report poor patient-provider communication (in both directions): autistic adults often face difficulties identifying and articulating their physical health symptoms⁷⁶ 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^{67,68,71}. Clinicians' limited knowledge of^{68,69} and lack of confidence in⁷⁵ 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 perspective⁷¹ or from their caregiver's or healthcare provider's perspective⁷⁷. 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^{71,78}. However, research designed in collaboration with autistic people is needed to assess the most effective ways of improving their healthcare experiences^{56,67,78}.

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%^{79,80}) than adult population prevalence estimates (1%⁸¹). 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 so⁸², have been criticized for displacing people from their families and communities and for providing poor and unresponsive services to residents^{83,84}. Nonetheless, autistic adults continue to be over-represented in more restrictive and segregated settings⁸⁵.

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"¹⁷. 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

Overwhelm
A term used by autistic people to describe a state caused by excessive sensory or social stimulation.

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 lives³⁵ and that their quality of life should always be measured, at least in part, according to their own aspirations.

Although widely used in other settings²⁹⁹, 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 community³⁰⁰. 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 suited³⁰⁰. Similarly, others have called for the creation of a separate ‘profound’ or ‘severe autism’ diagnostic category for those with the most severe impairments^{7,301}.

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^{302,303}. 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 known³⁰⁴. Future research should also examine the effectiveness of available long-term services and supports to enable those with the greatest needs to fulfil 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.

children are at substantial risk of experiencing multiple forms and repeated occurrences of victimization and abuse⁸⁶, and this vulnerability persists into adulthood^{87–90}. In particular, there are elevated rates of sexual victimization in autistic compared with non-autistic adults^{89,90}, especially in autistic women^{91–93} and those who identify as a gender minority⁹² or as a member of the LGBTQI+ community⁹⁴. This increased vulnerability might be exacerbated by the fact that autistic people often have reduced access to good quality, effective sexual education⁹⁵, which can impart vital protective knowledge, as well as by broader structural inequalities (for example, lack of access to healthcare^{67–69}).

Autistic adults also experience increased rates of physical assault^{87,92} and domestic violence, largely perpetrated by people known to them⁹⁰. Autistic women, particularly those who report multiple traumatic experiences, emphasize deeply distressing betrayals of trust⁹¹ and how they often “just couldn’t see it coming”⁹³. Worryingly, these already high victimization rates are likely to be an underestimate: autistic adults are less likely to report experiences of violence to the police⁸⁷ or even to confide in others⁸⁷. Autistic adults who experience victimization therefore receive neither the requisite mental health support nor the critical social support that could reduce the likelihood of developing post-traumatic symptoms.

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 communities⁹⁶, and parents often want this independence for their children too⁹⁶. Yet both groups worry about safety. Use of public transportation can be challenging for autistic adults owing to lack of accessibility⁹⁷ and difficulties with wayfinding and traffic judgement⁹⁸. Furthermore, despite research showing that autistic drivers are more rule-abiding than non-autistic drivers⁹⁹ and are no more likely to be at fault for a police-reported car crash¹⁰⁰, few autistic people take up driving¹⁰¹, partly because of perceived difficulties in spatial awareness, motor coordination, processing speed and executive function⁹⁶. 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”⁹⁶.

Finding a balance between autonomy and safety is critical. Autistic children and adults can be more susceptible to wandering^{102,103}, and parents sometimes advocate the use of measures such as tracking devices¹⁰⁴. Yet wandering can occur for many reasons¹⁰² and is often purposeful¹⁰⁴. 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^{104,105}.

Bodily integrity is inextricably linked to other capabilities. Violations of bodily integrity have adverse effects on other capabilities¹⁰⁶, including mental health¹⁰⁷, 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 experiences¹⁰⁸ have been firmly quashed by research showing that autistic adults desire sexual relationships to a similar extent as non-autistic adults^{109,110}. Autistic adults in satisfying relationships are more likely to report greater sexual satisfaction, just like non-autistic adults¹¹¹. They also identify with a wider range of sexual orientations^{94,109,112} and gender identities^{113–116}, their sexual ‘debuts’ occur at a later age¹¹⁷ and they have fewer lifetime sexual experiences¹¹² 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 community¹¹⁸.

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”⁹⁷. The dominance of the conventional medical model has meant that autism is often associated with deficits in this regard¹¹⁹. 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 tests¹²⁰. This stereotype persists even though there is little evidence for it in the everyday experience of the autistic population¹²¹. There is an even greater presumption of low intelligence in autistic people who are non-speaking or do not use traditional forms of communication¹²², who are routinely under-recruited in research¹²³. Similarly, researchers, clinicians and educators have long presumed that creative and imaginative skills and aspirations are limited in autistic people¹²⁴.

However, the predominant use of standard intelligence tests can lead to an underestimation of autistic people's intellectual ability¹²⁰, particularly in non-speaking people¹²⁵. Autistic people have also been shown to excel at producing novel responses on creative tasks¹²⁶ and are increasingly recognized for their creative talents¹²⁷, with major companies investing in autistic people's 'out-of-the-box' thinking¹²⁸. These strengths have been linked to autistic people's different way of perceiving the world, including detail-focused processing style¹²⁹ and enhanced perceptual abilities¹³⁰, which might be underpinned by heightened sensory perception¹³¹.

Nevertheless, autistic people are, in general, poorly served by the educational environments that might further enhance this capability¹³². They regularly encounter sensory overwhelm within the physical school environment¹³³, struggle with complex social expectations and interactions¹³⁴, experience bullying and social isolation¹³⁵, and are stigmatized by a presumption of low competence¹³⁶. Moreover, limited attention is given to their specific needs, strengths and preferences^{132,137}, including by school staff who lack confidence in supporting autistic students¹³⁸. Being excluded from¹³⁹ or not completing¹⁴⁰ school can have persisting negative effects on mental health and well-being.

Increasing numbers of autistic adults are enrolling in higher education¹⁴¹, 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 help¹⁴¹ and partly owing to the absence of formal transition planning¹⁴². Consequently, autistic adults are at high risk of dropping out of university¹⁴³. There is also limited research on the destinations of autistic students who complete higher education¹⁴⁴, so it is unclear how to best respond to these challenges.

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 lives¹⁴⁵, sensory stimuli can also be a source of pleasure^{146,147}. For example, one autistic adult reported enjoying "touching metal a lot ... cold smooth metal is, like, just amazing"¹⁴⁷. 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^{146,148}.

However, these distinctive sources of pleasure are often pathologized. This is captured by the debate

over certain 'repetitive motor stereotypies' such as hand-flapping¹, which have been reclaimed by autistic adults as 'stimming'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 others¹⁵⁰. Stimming behaviours are often the target behaviour for interventions that promote 'calm' or 'quiet' hands¹⁵¹ (cf. REF.¹⁵²). However, there is very little evidence that stimming 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 stimming behaviours can serve as a source of pleasure or reassurance or a form of self-regulation¹⁴⁹.

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"¹⁷. The empirical literature shows that autistic adults have more difficulties recognizing others' emotions^{153,154} and identifying and describing their own emotions (alexithymia) than non-autistic people^{155,156}. However, emerging work suggests a far more nuanced picture: autistic adults describe feeling emotions and empathy intensely¹⁵⁷ and often experience deeply satisfying emotional lives¹⁵⁸.

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 relationships¹⁵⁹. However, research is inconsistent with this claim¹⁶⁰. Romantically involved autistic adults report high relationship satisfaction^{93,161}. The strong bonds that autistic adults report with their partners, particularly with those who are also autistic¹⁶⁰, extend to their autistic children, with whom they describe an intense connection and love¹⁶².

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 relationships¹⁵⁴, including difficulties reading and interpreting others' emotions¹⁶¹, 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 obstacle¹⁶³. These challenges can intensify feelings of loneliness and are linked to significant negative emotional experiences and poor mental health¹⁶⁴. Autistic adults who desire intimate connection but whose needs are unfulfilled might be at particular risk of depression and low self-worth^{164,165}.

This loneliness, depression and poor self-perception can take a substantial toll on mental health and well-being^{164,166,167}. A substantial proportion of autistic adults experience a co-occurring psychiatric condition during their lifetime, with anxiety and mood disorders being the most common^{168,169}. Rates of co-occurring psychiatric conditions are somewhat lower for autistic adults with intellectual disability¹⁷⁰, but these rates

Sensory overload

A state that occurs when a person's sensory system becomes overwhelmed, possibly owing to difficulties processing and integrating perceptual information, causing significant distress.

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 context¹⁶⁸. The risk of developing mood disorders increases with age¹⁶⁸ and autistic adults are at elevated risk of developing post-traumatic stress disorder¹⁰⁷. Some mental health problems in autistic adults have been attributed to everyday discrimination and internalized stigma¹⁷¹.

The reliance on mental health assessments and diagnostic criteria that were established in non-autistic people^{168,172,173} and a lack of necessary expertise among health professionals¹⁷⁴ might result in an overestimation or underestimation of mental ill health in the autistic population¹⁷³. 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^{173,175}. Similarly, mental health diagnoses might overshadow an autism diagnosis, resulting in misdiagnosis¹⁷⁵.

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 population²⁵, struggle to obtain appropriate post-diagnostic support¹⁷⁶ and face challenges in accessing individually tailored treatment for mental health problems^{25,176}. As one autistic adult put it: “I haven’t requested any, because people like me don’t get support”²⁵. There is a clear need for mental health interventions that are adapted to autistic people’s needs and preferences¹⁷⁶.

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”¹⁷. 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 desire¹⁷⁷. Autistic people were traditionally thought to have impaired self-awareness¹⁷⁸. A substantial minority of autistic adults have co-occurring intellectual disability (29%¹⁷⁹) and some do not use speech to communicate¹⁸⁰, 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^{181,182}.

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^{183,184}. Autistic adults make more logically consistent, rational decisions¹⁸⁵, are more circumspect in their decision-making, sample more information prior to making a decision¹⁸⁶, are less susceptible

to social influence¹⁸⁷ and are more deliberative in their reasoning^{188,189}.

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 routine¹⁹⁰. Indeed, autistic people’s tendency to focus intensely on topics or objects of interests (monotropism)¹⁹¹ can make it difficult to ‘move on’ or ‘change gears’¹⁹². Interrupting activities after such states of flow and difficulties starting new activities (autistic inertia) can lead to pervasive and often debilitating effects on autistic adults¹⁹², 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)¹⁹³. Problems with planning, organization and future-oriented thinking are common in autistic adults¹⁸⁹, are linked to adaptive difficulties^{194,195}, might be compounded by particular contexts (such as in parenting¹⁹⁶ or the workplace¹⁹⁷) and are perceived to be real obstacles to achieving desired outcomes¹⁹⁸. 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 settings¹⁹⁹.

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”¹⁷. Simply put, that the person is respected as a social being¹⁷. 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-isolation¹⁶³. Dominant characterizations suggest that autistic people lack the motivation²⁰⁰ and/or cognitive building blocks²⁰¹ 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^{202,203}, are often on the periphery of social networks^{202,203} and spend less time with their friends outside school than their non-autistic counterparts²⁰⁴. Autistic adolescents also report a growing awareness of feeling different from others despite wanting to ‘fit in’^{205,206}, and frequently experience social exclusion and bullying¹³⁵, which might exacerbate their challenges in making and keeping friends. These patterns persist into adulthood²⁰⁷. It is therefore unsurprising that many interventions in adolescence and early adulthood focus on formal social skills training^{208,209}, with the aim of equipping autistic people to manage everyday social relationships on their own terms and, thereby, secure this capability.

Photovoice methodology

A qualitative research methodology in which participants take photographs to illustrate, and possibly prompt discussion of, their experiences.

However, such interventions fail to appreciate that autistic sociality is shaped by the sociocultural context in which people are embedded^{208,210,211}. Autistic people can and do have fulfilling connections with others, even if negotiating those relationships can be challenging⁹³. They are drawn to those who accept them for who they are^{154,159,161} and with whom they do not have to mask their autistic ways^{212,213}. These friendships include (but are not restricted to) autistic-to-autistic interactions^{214,215}. 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-understanding^{181,214,217}, positive self-identity^{217,218} 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"¹⁶⁷. 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 people^{221,222}. Empirical evidence suggests that non-autistic people have difficulties understanding the minds and behaviours of autistic people^{221,222}, and that they are unwilling to interact with autistic people on the basis of initial judgements or interactions²²¹⁻²²³. 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 people^{229,230}.

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"¹⁷. 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 time²³². Some autistic children also prefer interacting with animals over inanimate objects and humans²³³, and report strong attachments to pets²³⁴. 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 animals²³⁵.

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 offer 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"¹⁷. 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 people^{237,242} 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 areas^{237,242} 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 advantage^{181,237,241,246} that can be affirming and have positive implications for identity and self-concept²⁴³. Indeed, one autistic participant, who once "owned about 15,000 CDs," celebrated the capacity "to be intense in stuff"¹⁸¹. Passions and interests have been likened to experiences of flow^{237,247} and to monotropism¹⁹¹, which are driven by intrinsic (interest and knowledge) rather than extrinsic (prestige or achievement) motivation²³⁷. Finding others who share similar interests can form the basis of long-lasting friendships⁹³. Nevertheless, exceptionally high intensity

Box 3 | 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 return³⁰⁵. 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 autism³⁰⁶.

Crucially, autistic people also want to have greater input into research decisions^{307–309}. Autism research has traditionally been designed and conducted by non-autistic people. Autistic people, their family members and even practitioners have rarely been involved in the decision-making processes that shape research and its application^{12,13}, 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^{308,309}. 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 research³¹⁰. 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 research³¹¹. 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^{40,181,312,313}, but it is still very much in its infancy. Although there is much enthusiasm for involving autistic people in the decisions that influence them^{314,315}, researchers can be worried about how time-consuming participatory research can be, can find 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 attempted³¹². Instead, researchers and community members need to appreciate that they each have different ‘experiential expertise’³¹⁶; they must take that expertise seriously to enable valuable insights for those involved in the research and for the research itself³¹⁷.

of engagement may, in some circumstances, negatively impact well-being²³⁷.

The generally positive effects of engaging in one’s interests also extend to taking part in recreational activities. Autistic adults report relatively high levels of weekly participation in exercise and hobbies²⁴⁸. However, they participate in conventional social and recreational activities to a lesser extent than the general population²⁴⁹, despite saying these are important to them²⁵⁰. Future research should consider the possible reasons for this disparity and the constraints that autistic adults face when engaging in meaningful and satisfying leisure activities. Inaccessible and inhospitable environments might be barriers for autistic adults²⁵¹, and the effectiveness of programmes designed to support such participation appear to be limited^{251,252}. Enhancing the play capability is important because engaging in recreational activities might buffer the relationship between perceived stress and quality of life²⁵³.

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”²¹⁷.

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 population²⁵⁴, especially if they live in supported accommodation rather than with family²⁵⁵. They often lack support and accessible information for political engagement^{255,256} and are even explicitly told they cannot vote due to their intellectual disability²⁵⁶. More research is needed on autistic citizenship to identify precisely how these obstacles can be overcome²⁵⁶.

Extant data suggest that autistic people might be more politically 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 Kingdom²⁵⁷, and is perhaps epitomized most by Jim Sinclair’s²⁵⁸ 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^{259,260} and come together in dedicated autistic spaces and events²⁶¹. 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^{261–267}.

There is much for autistic self-advocates to campaign about. Autistic people’s opportunities are constrained by others’ unjustified assumptions about their capacity²⁶⁸. Autistic adults are at far greater risk of prejudice, stigmatization and discrimination in many facets of their lives, such as education^{141,269}, health^{40,72}, care²⁷⁰, intimate relationships²⁷¹, community¹⁷¹, justice²⁷² and work²⁷³. 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^{274,275} to keep themselves safe or adjust their abilities through ‘compensation’²⁷⁶. Such adaptation can come at serious personal cost, including poor mental and physical health^{277,278}, negative self-perceptions^{275,278} and autistic burnout^{279,280}.

Work provides a particularly constrained environment. Autistic people face substantial challenges in gaining and sustaining meaningful employment, even relative to other disabled people^{281–283}, despite

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.

possessing a range of skills that might be prized by employers^{127,246,282,283}. Autistic adults who do obtain employment are often in positions that fail to match up with their abilities (malemployment) or for which they are overqualified (underemployment)²⁸⁴. They can also face challenges maintaining employment²⁸⁵, owing to inhospitable work environments²⁸⁶, negative experiences with (and sometimes bullying by) colleagues²⁸¹, failure to have their needs and preferences met²⁸⁷, and experiences of discrimination, including following the disclosure of an autism diagnosis²⁸⁸. There is growing interest in paid short-term autism-specific employment programmes or internships, which are designed to reduce barriers to employment for autistic jobseekers, introduce them to workplace life and provide training in job-relevant skills^{289,290}. These initiatives show promising effects on autistic trainees' occupational self-efficacy^{289,290} but deserve sustained attention to determine whether they help autistic adults to secure and maintain suitable employment in the longer term. Research is also needed on what constitutes a successful employment outcome according to autistic people themselves, and how it should be measured²⁹¹.

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^{16,17} lens. 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 excel despite conventional stereotypes to the contrary, such as emotions, 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.²⁹²). Determining what autistic capabilities to add to this list can be resolved only through research that is genuinely participatory (see BOX 3); 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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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, the Australian Research Council, Australia’s National Disability and Insurance Agency’s Information, Linkages and Capacity Building Program, Australia’s National Health and Medical Research Council, Australia’s Cooperative Research Centre for Living with Autism (Autism CRC) and Simons Foundation Autism Research Initiative, and has received honoraria for invited talks from the International Society for Autism Research and Aspect Australia. G.H. 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 Australia’s National Disability and Insurance Agency’s Information, Linkages and Capacity Building Program. W.L. 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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