

A capabilities approach to understanding and supporting autistic adulthood

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Author contributions

This review was a collaboration between non-autistic researchers (EP, UF, RL and MS) and autistic researchers (GH, MH, WL and JM), who all actively participated in making decisions about the review. EP and MS identified the theoretical framework in discussion with UF, GH, MH, WL, RL and JM; EP, UF, GH, MH, WL, RL, and JM identified the search terms; UF and EP 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. EP and MS 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 (EP, UF, RL), psychology (EP, WL), anthropology (RL), nursing (GH), history (JM), and political philosophy (MS), as well as positionalities as autistic researchers and advocates (GH, MH, WL and JM). These participatory processes ensured that the review was approached through a strengths-based, rather than deficits-based, lens.

Competing interests

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Abstract

There is little comprehensive research into autistic adulthood, and even less into services and supports 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: applying 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 currently 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.

Introduction

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 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 a number of 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 longstanding conventions in medicine, which prioritizes a putatively objective standard of 'bodily health' over a subjective understanding of 'wellbeing'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' behavioral, cognitive and neural functionings are frequently compared to 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

90 shortcomings to align functioning with the accepted norm. This narrow focus on deficits results
91 in a radically constrained understanding of the experiences that shape autistic lives, limiting the
92 range of supports and services to those that seek to ‘change the individual’ rather than consider
93 how to ‘change the world’. Conventional research efforts are also routinely conducted without
94 meaningful input from autistic people themselves¹², meaning that often the wrong questions are
95 posed and findings are misinterpreted. Research of this kind can be said to be ‘lost in
96 translation’¹³. As such, most research on autism prioritizes researcher-defined normative life
97 goals without discovering how much they matter to a diverse range of autistic people^{14,15}.

98 In this Review, we – a team of autistic and non-autistic researchers – propose an
99 alternative way of approaching adult autism research. First, we provide some context by briefly
100 discussing the diagnosis and developmental trajectories for autistic adults. Next, we describe
101 Nussbaum’s capabilities approach^{16,17}, which outlines ten central capabilities that enable people,
102 whether autistic or non-autistic, to lead lives that are of value to them on their own terms rather
103 than to meet a predetermined normative standard set by others. We then examine each of the
104 ten capabilities in the context of available autism research. This approach enables us to evaluate
105 the opportunities and challenges facing autistic adults, the forces shaping them, and the ways in
106 which services and other interventions might enhance the quality of their lives.

107

108 **Diagnosis and developmental trajectory**

109 Adult diagnosis of autism first became available in the 1980s¹⁸ and was further
110 encouraged by changes in the DSM-5^{1,19} several decades later. Many autistic adults initially seek
111 their diagnosis following concerns about social relationships and mental health, sometimes
112 precipitated by a personal crisis or by the diagnosis of their own children. For many, this search
113 for diagnostic clarity is preceded by decades of feeling ‘different’ and of relationship or
114 employment difficulties^{20,21}. Challenges to adult autism diagnosis are discussed in Box 1.

115 A growing number of adults self-identify as autistic without a formal diagnosis²². This
116 self-identification is controversial in research and clinical communities but is often accepted in
117 the autistic community, in part because, even in high-income countries, autistic adults often
118 remain undiagnosed^{2,23,24} and, even when formally diagnosed, are only minimally supported^{2, 7,23-25}.
119 Those diagnosed later in life appear to have higher self-reported autistic traits and poorer quality
120 of life, especially mental health, than those diagnosed in childhood²⁶.

121 Following the normative tendencies of the conventional approach to autism research, the
122 vast majority of studies examining the developmental trajectories of autistic adults diagnosed in
123 childhood focus on areas thought to be critical for achieving ‘good’ adult outcomes. In
124 longitudinal studies, these outcomes are often defined in terms of a set of standard ‘life
125 achievements’, on which autistic adults typically fare badly^{14,15}. For example, autistic adults with
126 and without intellectual disability followed from childhood are less likely than non-autistic
127 people to hold down a job, live independently or have friends and intimate relationships^{2,14,15}.
128 Other longitudinal studies have examined whether people remain ‘autistic’ (that is, meet
129 instrument and/or clinical thresholds for autism) as they move from childhood into adulthood.
130 These studies show that the diagnostic status of individuals diagnosed in childhood generally
131 endures into adulthood^{15,27}, with the exception of a minority of individuals who no longer display
132 sufficient core autistic features to warrant a clinical diagnosis, which is sometimes described as an
133 ‘optimal outcome’²⁸. Yet, despite initial variability, many people show little change in researcher-
134 defined ‘autistic symptoms’, as they move into adulthood²⁹, potentially placing them at greater
135 risk for poor psychosocial outcomes in adulthood³⁰.

136 More detailed research on the quality of life of autistic adults also largely focuses on the
137 achievement of standard life outcomes, irrespective of whether those outcomes are considered
138 meaningful by autistic adults themselves^{31,32}. Studies that have complemented standard,
139 researcher-defined measures with more subjective, autistic-person led measures (such as quality
140 of life) consistently demonstrate that outcomes are more positive when subjective factors are

141 accounted for^{14,15}. For example, an autistic person who is highly dependent on others for their
142 care – a so-called ‘poor outcome’ according to the standard framework – might nevertheless be
143 happy and subjectively enjoy a very good quality of life. Another autistic person who no longer
144 meets diagnostic criteria for autism – a so-called ‘good’ outcome – might struggle to find their
145 way in the world and feel different and distant from others. Approaches that focus on
146 researcher-defined measures in this way limit understanding and risks failing to grant autistic
147 people the dignity, agency and respect they deserve.

148 In considering how to respond to these limitations, it is helpful to establish two clear
149 additional aims. First, research into autistic adulthood must recognize that people’s life-chances
150 (opportunities each individual has to improve their quality of life) are shaped by a range of
151 factors beyond the person, consistent with an ecological perspective³³. That is, quality of life is
152 influenced both by biological factors at the heart of the conventional medical model and a
153 broader set of contextual factors as stressed by the social model of disability³⁴. Second, no-one,
154 autistic or not, has high quality of life if their life goals are primarily set by others. Thus, quality
155 of life should not be measured by a standard set of outcomes judged to be important by
156 researchers, clinicians or policymakers. Instead, the goals of each individual’s varied human life
157 should be at least partly set by the person being researched themselves³⁵.

158

159 **A capabilities approach to autistic lives**

160 Martha Nussbaum’s^{16,17} capabilities approach to quality of life, which has been widely
161 used to analyze social disadvantage in multiple settings, satisfies both of the aims outlined above.
162 First, according to the capabilities approach, a human ‘capability’ is not an intrinsic ability that a
163 person has or does not have solely by virtue of who they are. Instead, ‘capability’ refers to the
164 actual opportunity to be or do something that is facilitated or constrained by features of the
165 person and by the broader contexts in which a person is embedded. The relevant contexts can
166 include close family and household influences; everyday community interactions; educational

167 institutions; economic factors including cost of living; services and supports including
168 accessibility and performance of healthcare institutions; and the broader social and political
169 context including social attitudes towards autism. Second, flourishing human lives are
170 characterized by a set of these capabilities which enable a person to achieve any number of a
171 range of outcomes, rather than by the attainment of a small number of pre-specified outcomes.
172 These capabilities are considered foundations for a range of doings and beings; they shape what
173 a person can do and, critically, who and how they can be in the world. Capabilities are not a
174 narrow or specific set of achievements nor are they possessions. Similarly, capabilities cannot be
175 ranked or interpreted by a group of people, such as professionals, or reduced to a single score on
176 a standardized scale. Instead, they refer to the preconditions for a broad range of ways of living.

177 According to Nussbaum, there are ten central capabilities that most people need if they
178 are to be able to choose and create lives that are meaningful and fulfilling on their own terms^{16,17}
179 (Table 1). In what follows, we outline how analyzing the life chances of autistic adults through
180 this lens can enable a far richer understanding of autistic adults' lives of all abilities (see Box 2)
181 than the conventional research approach has done. We do so by highlighting the strengths and
182 challenges of autistic adults in each of the ten central capabilities, their causes, and consider the
183 potential supports, services and changes in societal attitudes that might help to transform those
184 challenges to strengths. Analyzing these capabilities provides a way to examine the lives of
185 autistic adults without narrow normative judgement, while also directing attention to issues that
186 require intervention and support. Readers are advised that some of this material may be
187 distressing and evoke difficult past associations.

188 *Life*

189 The first central capability is “being able to live to the end of a human life of normal
190 length; not dying prematurely, or before one’s life is so reduced as to be not worth living”¹⁷.
191 Autistic adults are currently at a substantial disadvantage in this capability. There are persistent
192 patterns of premature mortality in the autistic population^{36,37}. Autistic people are twice as likely to

193 die prematurely than non-autistic people³⁶⁻³⁸, and this risk is greater for autistic women^{36,38} (but
194 see³⁷) and those with intellectual disability³⁶⁻³⁸. Autistic people also experience reduced life
195 expectancy, with lives that are on average 16 years shorter than those of non-autistic people³⁶.
196 The risk of death is elevated in autistic people who experience poor or chronic physical health
197 (including epilepsy)³⁶⁻³⁹. Little is known about the influence of social and economic factors,
198 including access to healthcare, on these mortality rates, but it is widely hypothesized that an
199 important contributor is the extent to which physicians listen to, and learn from, their autistic
200 patients⁴⁰.

201 Among the specific causes of premature mortality, there is a higher risk of suicide^{41,42}.
202 Suicide attempts are more frequent and more likely to result in death in autistic people than in
203 non-autistic people^{36,37,43-45}, possibly due to co-occurring psychiatric conditions³⁶. Research
204 focused on understanding why autistic people are at increased risk of self-harm and suicide has
205 identified individual risk markers common to those in the general population, including
206 (younger) age⁴⁶, low mood and rumination⁴⁷. More work is needed to understand potentially
207 unique risk markers for increased suicidality in autistic people, including looking beyond the
208 individual to broader interpersonal causes, including thwarted belonging and perceived
209 burdensomeness, which appear to mediate associations between autistic traits and suicidality⁴⁸,
210 and systemic issues, such as clinicians' lack of knowledge⁴⁹.

211 More generally, autistic quality of life in older adulthood (adults aged 50 years and
212 older⁵⁰) – albeit as assessed using normative measures – is seen as significantly poorer than non-
213 autistic older adults⁵¹. Social isolation and loneliness are major issues for all older adults, leading
214 to greater risk of dementia and other serious medical conditions⁵². Both social isolation and
215 loneliness might disproportionately influence older autistic adults, who might be more prone to
216 reclusiveness⁵³, despite many autistic adults describing a longing for interpersonal connection⁵⁴.
217 For example, in a study where autistic adults' experiences of growing older were elicited, one
218 autistic participant said, “I think I’m a born loner, quite frankly... Maybe I’m not the kind of

219 person to have a life. Oh, I'd love it, with a person that would understand me"⁵⁴. There are few
220 longitudinal and participatory studies focusing on autistic older people, including under-
221 represented populations who might have poorer life satisfaction. Thus, little is known about how
222 autistic adults can be supported to live a full and satisfying life into old age in diverse
223 sociocultural contexts^{55,56}.

224

225 ***Bodily health***

226 The second central capability is “being able to have good health, including reproductive
227 health; to be adequately nourished; to have adequate shelter”¹⁷. Once again, the evidence
228 suggests that autistic adults are disadvantaged in this regard. Co-occurring physical conditions are
229 common across the autistic lifespan⁵⁷⁻⁵⁹ and are more prevalent than in the general population for
230 almost all conditions assessed^{43,58,59} even when lifestyle factors are considered⁵⁸. Autistic adults
231 with intellectual disability have distinctive needs⁵⁹ and might be especially vulnerable to poor
232 physical health⁶⁰.

233 Risks for most physical health conditions are further exacerbated for autistic women^{58,61}.
234 Understanding the mechanisms for these differences in health outcomes is critical for reducing
235 these inequalities. Moreover, further clarifying the temporal development of these health
236 problems should inform how interventions are designed to prevent and treat them⁶². There are at
237 present very few studies on autistic people’s reproductive health. Autistic women report
238 challenging experiences with menstruation, including a cyclical amplification of sensory
239 differences and difficulties with emotional regulation^{63,64}, and autistic women are at greater risk
240 for pregnancy complications⁶⁵. Autistic women also report significant deterioration in everyday
241 quality of life during menopause⁶⁶. None of these concerns have yet been investigated in depth.
242 Likewise, there are no studies specifically addressing the reproductive health experiences of
243 autistic men, those with intellectual disability and/or those who are non-speaking; no studies
244 have adopted a less gender-binary approach to reproductive health in autistic adults. This

245 absence of research potentially leaves crucial areas of experience unsupported by clinicians and
246 other policy interventions.

247 Autistic adults also face barriers to healthcare⁶⁷⁻⁶⁹. Despite greater healthcare utilization,
248 medication use and higher healthcare costs than the general population⁷⁰, autistic adults report
249 more unmet health needs⁷¹, lower utilization of preventative care⁷¹ and more frequent use of
250 emergency departments^{71,72} than non-autistic adults. Healthcare settings are often inaccessible to
251 autistic adults, with significant risk of sensory and social **overwhelm**, miscommunication and lack
252 of autistic-informed care^{67,73}. Autistic people also experience reduced coordination of care than
253 non-autistic people, particularly during the transition from pediatric to adult services⁷⁴. Thus,
254 autistic adults are often left to fend for themselves in navigating the healthcare system⁷⁵, resulting
255 in negative healthcare experiences and feelings of distrust^{66,67}.

256 Autistic adults also report poor patient-provider communication (in both directions):
257 autistic adults often face difficulties identifying and articulating their physical health symptoms⁷⁶
258 and professionals often do not appreciate the need to adapt their communication style for
259 autistic patients and do not take their autistic patients' concerns seriously^{67,68,71}. Clinicians' limited
260 knowledge of^{68,69} and lack of confidence in⁷⁵ understanding autistic adults' specific needs further
261 exacerbate these difficulties. Some tools have been developed to assess barriers to healthcare
262 access experienced by autistic adults from their own perspective⁷¹ or from their caregiver or
263 healthcare provider's perspective⁷⁷, identifying person-, provider- and system-related barriers,
264 which should facilitate future research testing the effectiveness to improve the care and health of
265 autistic people^{71,78}. However, research designed in collaboration with autistic people is needed to
266 assess the most effective ways of improving their healthcare experiences^{56,67,78}.

267 Many other external factors influence autistic adults' physical health, such as access to
268 affordable, appropriate housing. Initial studies suggest that autistic adults might be over-
269 represented in homeless communities at rates substantially higher (12–18%^{79,80}) than adult
270 population prevalence estimates (1%⁸¹). The range of challenges facing autistic adults might

271 predispose them to homelessness, and reduced social support networks might compound other
272 risk factors, including unemployment, making it difficult for autistic adults to exit homelessness.

273 Other housing challenges also impact this crucial capability. Compared to other people
274 with disabilities, autistic adults are less likely to live independently, leaving them vulnerable to the
275 inadequacies of institutionalized housing. Formal institutional living and similar settings which
276 purport to be community-based but are often only nominally so⁸² have been criticized for
277 displacing people from their families and communities and for providing poor and unresponsive
278 services to residents^{83,84}. Nonetheless, autistic adults continue to be overrepresented in more
279 restrictive and segregated settings⁸⁵.

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

283

284 ***Bodily integrity***

285 The third capability is that people should be “able to move freely from place to place; to
286 be secure against violent assault; having opportunities for sexual satisfaction and for choice in
287 matters of reproduction”¹⁷. This capability is underpinned by a person’s right to make decisions
288 about their body.

289 There are good reasons to be concerned about autistic disadvantage in accessing this
290 capability. Autistic children are at substantial risk of experiencing multiple forms and repeated
291 occurrences of victimization and abuse⁸⁶ and this vulnerability persists into adulthood⁸⁷⁻⁹⁰. In
292 particular, there are elevated rates of sexual victimization in autistic, compared to non-autistic,
293 adults^{89,90}, and especially in autistic women⁹¹⁻⁹³ and those who identify as a gender minority⁹² or as
294 a member of the LGBTQI+ community⁹⁴. This increased vulnerability might be exacerbated by
295 the fact that autistic people often have reduced access to good quality, effective sexual

296 education⁹⁵, which can impart vital protective knowledge, and broader structural inequalities (e.g.,
297 lack of access to healthcare⁶⁷⁻⁶⁹).

298 Autistic adults also experience increased rates of physical assault^{87,92} and domestic
299 violence, largely perpetrated by people known to them⁹⁰. Autistic women, particularly those who
300 report multiple traumatic experiences, emphasize their overly trusting nature⁹¹ and how they
301 often “just couldn’t see it coming”⁹³. Worryingly, these already-high victimization rates are likely
302 an underestimate: Autistic adults are less likely to report experiences of violence to the police⁸⁷ or
303 even to confide in others⁸⁷. Autistic adults experiencing victimization therefore receive neither
304 the requisite mental health support nor the critical social support that could reduce the likelihood
305 of developing post-traumatic symptoms.

306 Concerns about physical safety also impact on the ability to move freely. Many autistic
307 adults want to be able to access work and go about their daily activities within their
308 communities⁹⁶, and parents often want this independence for their children, too⁹⁶. Yet both
309 groups worry about safety. Use of public transportation can be challenging for autistic adults
310 owing to lack of accessibility⁹⁷ and difficulties with wayfinding and traffic judgment⁹⁸.
311 Furthermore, despite research showing that autistic drivers are more rule-abiding than non-
312 autistic drivers⁹⁹ and are no more likely to be at fault for a police-reported car crash¹⁰⁰, few
313 autistic people take up driving¹⁰¹, partly because of perceived difficulties in spatial awareness,
314 motor coordination, processing speed and executive function⁹⁶. Consequently, adults can remain
315 reliant on their parents. As one autistic adult expressed in a focus group on understanding
316 autistic adults’ transportation needs and barriers: “If I want to go shopping in the middle of the
317 day I can’t. I have to wait for my mom to come home from work”⁹⁶.

318 Finding a balance between autonomy and safety is critical. Autistic children and adults
319 can be more susceptible to wandering^{102,103}, and parents sometimes advocate the use of measures
320 such as tracking devices¹⁰⁴. Yet wandering can occur for many reasons¹⁰² and is often
321 purposeful¹⁰⁴. Researchers and activists warn of the negative impact surveillance technologies can

322 have on people’s independence and urge investment in alternatives such as community supports
323 and safety skills training^{104,105}.

324 Bodily integrity is inextricably linked to other capabilities. Violations of bodily integrity
325 have adverse effects on other capabilities¹⁰⁶, including mental health¹⁰⁷, bodily health,
326 interpersonal relationships and sense of agency. Threats to bodily integrity are also likely to
327 influence autistic people’s sense of sexual wellbeing and their freedom to achieve it. Long-held
328 views of autistic people being uninterested in sexual experiences¹⁰⁸ have been firmly quashed by
329 research showing that autistic adults desire sexual relationships to a similar extent as non-autistic
330 adults^{109,110}. Autistic adults in satisfying relationships are more likely to report greater sexual
331 satisfaction, just like non-autistic adults¹¹¹. Autistic people identify with a wider range of sexual
332 orientations^{94,109,112} and gender identities¹¹³⁻¹¹⁶, their sexual ‘debuts’ occur at a later age¹¹⁷ and they
333 have fewer lifetime sexual experiences¹¹² than non-autistic adults. The lack of qualitative studies
334 on the realities of autistic adults’ sexual lives limits understanding, despite the fact that this topic
335 is prioritized by the autistic community¹⁸.

336

337 *Senses, imagination and thought*

338 The fourth capability focuses on being “able to use the senses, to imagine, think, and
339 reason – and to do these things in... a way informed and cultivated by an adequate education...
340 being able to use imagination and thought in connection with experiencing and producing
341 [creative] works... Being able to have pleasurable experiences and to avoid nonbeneficial pain”¹⁷.

342 The dominance of the conventional medical model has meant that autism is often associated
343 with deficits in this regard¹¹⁹. There is often a presumption that autistic adults will struggle with
344 higher-order cognition or have low intelligence owing to poor performance on standard
345 intelligence tests¹²⁰. This stereotype persists even though there is little evidence for it in the
346 everyday experience of the autistic population¹²¹. There is an even greater presumption of low
347 intelligence in autistic people who are non-speaking or do not use traditional forms of

348 communication¹²², who are routinely under-recruited in research¹²³. Similarly, researchers,
349 clinicians and educators have long presumed that creative and imaginative skills and aspirations
350 are limited in autistic people¹²⁴.

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

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

367 Increasing numbers of autistic adults are enrolling in higher education¹⁴¹, but barriers
368 exist there, too. Autistic adults rarely receive relevant supports and accommodations, partly
369 because they are hesitant to disclose their diagnosis or find it difficult to reach out for help¹⁴¹ and
370 partly due to the absence of formal transition planning¹⁴². Consequently, autistic adults are at
371 high risk of dropping out of university¹⁴³. There is also limited research on the destinations of
372 autistic students who complete higher education¹⁴⁴, so it is unclear how to best respond to these
373 challenges.

374 The senses, imagination and thought capability also emphasises the importance of being
375 able to take pleasure from sensory experiences. Although research tends to focus on the
376 challenges that autistic sensory differences – such as experiences of **sensory overload** – bring to
377 people’s everyday lives¹⁴⁵, sensory stimuli can also be a source of pleasure^{146,147}. For example, one
378 autistic adult reported enjoying “touching metal a lot... cold smooth metal is, like, just
379 amazing”¹⁴⁷. There is also evidence that autistic adults with limited spoken communication in a
380 supported living environment find joy in the everyday, for example in the sound of the washing
381 machine on the last spin or the feel of bubbles while dishwashing^{146, 148}.

382 However, these distinctive sources of pleasure are often pathologized. This is captured
383 by the debate over certain ‘repetitive motor stereotypies’ such as hand-flapping¹, which have
384 been reclaimed by autistic adults as ‘stimming’¹⁴⁹. These behaviours tend to be perceived as an
385 individual problem with no clear purpose or function that prevent the person from learning skills
386 and interacting with others¹⁵⁰. Stimming behaviours are often the target behaviour for
387 interventions that promote ‘calm’ or ‘quiet’ hands^{151, cf.152}. However, there is very little evidence
388 that stimming behaviours are harmful to autistic people or their peers (the same cannot be said
389 for self-injurious behaviours, which might also be purposeful but are nevertheless harmful to the
390 person). In fact, it now seems likely that stimming behaviours can serve as a source of pleasure,
391 reassurance or form of self-regulation¹⁴⁹.

392

393 *Emotions*

394 The next capability is defined as “[b]eing able to have attachments to things and people
395 outside ourselves; to love those who love and care for us, to grieve at their absence; in general, to
396 love, to grieve, to experience longing... not having one’s emotional development blighted by
397 fear and anxiety”¹⁷. The empirical literature shows that autistic adults have more difficulties
398 recognising others’ emotions^{153,154} and identifying and describing their own emotions
399 (alexithymia) than non-autistic people^{155,156}. However, emerging work suggests a far more

400 nuanced picture: autistic adults describe feeling emotions and empathy intensely¹⁵⁷ and often
401 experience deeply satisfying emotional lives¹⁵⁸.

402 At their most extreme, the conventionally reported difficulties with emotions were
403 thought to preclude autistic people from the capacity to love or desire meaningful romantic and
404 intimate relationships¹⁵⁹. However, research is inconsistent with this claim¹⁶⁰. Romantically
405 involved autistic adults report high relationship satisfaction^{93,161}. The strong bonds that autistic
406 adults report with their partners, particularly with those who are also autistic¹⁶⁰, extend to their
407 autistic children, with whom they describe an intense connection and love¹⁶².

408 These reports speak strongly argue against an understanding of autism as a ‘disorder’ of
409 affect. Rather than lack of interest, autistic adults often cite significant challenges with initiating
410 and maintaining romantic relationships¹⁵⁴, including difficulties reading and interpreting others’
411 emotions¹⁶¹, which can impact their capacity to remain romantically involved. The stereotyped
412 assumptions of non-autistic people that autistic people are uninterested in inter-personal
413 relationships might also be an obstacle¹⁶³. These challenges can intensify feelings of loneliness
414 and are linked to significant negative emotional experiences and poor mental health¹⁶⁴. Autistic
415 adults who desire intimate connection but whose needs are unfulfilled might be at particular risk
416 of depression and low self-worth^{164,165}.

417 This loneliness, depression and poor self-perception can take a substantial toll on mental
418 health and wellbeing^{164,166,167}. A substantial proportion of autistic adults experience a co-occurring
419 psychiatric condition during their lifetime, with anxiety and mood disorders being the most
420 common^{168,169}. Rates of co-occurring psychiatric conditions are somewhat lower for autistic
421 adults with intellectual disability¹⁷⁰, but these rates might be underestimated owing to a lack of
422 detailed understanding in how best to characterise and measure mental health in this context¹⁶⁸.
423 The risk for developing mood disorders increases with age¹⁶⁸ and autistic adults are at elevated
424 risk of developing post-traumatic stress disorder¹⁰⁷. Some mental health problems in autistic
425 adults have been attributed to everyday discrimination and **internalized stigma**¹⁷¹.

426 The reliance on mental health assessments and diagnostic criteria that were established in
427 non-autistic people^{168,172,173} and a lack of necessary expertise among health professionals¹⁷⁴ might
428 result in an over- or underestimation of mental ill-health in the autistic population¹⁷³. Some
429 autistic characteristics might overshadow indicators of mental health conditions (for example,
430 social withdrawal and sleep disturbance are common to both autism and depression), suggesting
431 that co-occurring mental health conditions might go unrecognised^{173,175}. Similarly, mental health
432 diagnoses might overshadow an autism diagnosis, resulting in misdiagnosis¹⁷⁵.

433 Mental health difficulties in autistic adults are likely compounded by the inadequacies of
434 formal and informal supports. Autistic adults report a significantly higher number of unmet
435 support needs than the general population²⁵, struggle to obtain appropriate post-diagnostic
436 support¹⁷⁶, and face challenges in accessing individually tailored treatment for mental health
437 problems²⁵. As one autistic adult put it: “I haven’t requested any, because people like me don’t
438 get support”²⁵. There is a clear need for mental health interventions that are adapted to autistic
439 people’s needs and preferences¹⁷⁶.

440

441 ***Practical reason***

442 The next capability, practical reason, is defined as “being able to form a conception of
443 the good and to engage in critical reflection about the planning of one’s own life”¹⁷. The three
444 key elements of this capability – choosing what one wants to do, critically reflecting on that
445 choice and making a plan to realise it – are fundamental to making full use of all the other
446 capabilities.

447 It is sometimes assumed that people with cognitive disability, including some autistic
448 people, are incapable of practical reason, failing even at the initial task of deciding what it is that
449 they value or desire¹⁷⁷. Autistic people were traditionally thought to have impaired self-
450 awareness¹⁷⁸. A significant minority of autistic adults have co-occurring intellectual disability
451 (29%¹⁷⁹) and some do not use speech to communicate¹⁸⁰, which can make it difficult for others

452 to gain insight into their thinking. However, research demonstrates that autistic people have a
453 deep capacity to reflect on many aspects of the self, regardless of their intellect or
454 communication preferences^{181,182}.

455 The practical reason capability also requires people to be able to reflect critically on their
456 choices, and to change their mind. Here, it seems that autistic people might approach decision
457 making differently to non-autistic people^{183,184}. Autistic adults make more logically consistent,
458 rational decisions¹⁸⁵, are more circumspect in their decision making, sample more information
459 prior to making a decision¹⁸⁶, are less susceptible to social influence¹⁸⁷ and are more deliberative
460 in their reasoning^{188,189}.

461 However, first-hand accounts suggest that such an approach to decision making can have
462 its disadvantages. For example, autistic people report challenges changing their decisions,
463 especially if the change is unanticipated or requires a shift in routine¹⁹⁰. Indeed, autistic people's
464 tendency to focus intensely on topics or objects of interests (**monotropism**)¹⁹¹ can make it
465 difficult to 'move on' or 'change gears'¹⁹². Interrupting activities after such states of **flow** and
466 difficulties starting new activities (autistic inertia), can lead to pervasive and often debilitating
467 effects on autistic adults¹⁹², including on their ability to design and execute a plan.

468 Many of the above skills come under the broader umbrella of executive function (higher-
469 order processes that underpin goal-directed activity and enable individuals to respond flexibly to
470 change and plan their actions accordingly)¹⁹³. Problems with planning, organisation and future-
471 oriented thinking are common in autistic adults¹⁸⁹, are linked to adaptive difficulties^{194,195}, might
472 be compounded by particular contexts (such as in parenting¹⁹⁶ or the workplace¹⁹⁷) and are
473 perceived to be real obstacles to achieving desired outcomes¹⁹⁸. Interventions and supports that
474 focus on planning and decision making are scarce, but those that do exist are associated with
475 gains in executive function-related behaviours in real-world settings¹⁹⁹.

476

477 *Affiliation*

478 The next capability is “being able to live with and toward others, to recognise and show
479 concern for other human beings, to engage in various forms of social interaction... and having
480 the social bases of self-respect and nonhumiliation; being able to be treated as a dignified being
481 whose worth is equal to that of others”¹⁷. Simply put, that the person is respected as a social
482 being¹⁷. *Prima facie* this might be the capability in which autistic adults might be expected to be at
483 the greatest disadvantage. After all, the term ‘autism’ comes from the Greek *autos*, meaning both
484 ‘self’ and ‘by itself’, and autistic people are often described as preferring a life of self-isolation¹⁶³.
485 Dominant characterizations suggest that autistic people lack the motivation²⁰⁰ and/or cognitive
486 building blocks²⁰¹ for social interaction, which prevents them from establishing and maintaining
487 the types of reciprocal relationships that are fundamental for this capability.

488 Research has repeatedly shown that autistic children and adolescents have fewer
489 reciprocal friendships^{202,203}, are often on the periphery of social networks^{202,203} and spend less time
490 with their friends outside school than their non-autistic counterparts²⁰⁴. Autistic adolescents also
491 report a growing awareness of feeling different to others despite wanting to ‘fit in’^{205,206}, and
492 frequently experience social exclusion and bullying¹³⁵, which might exacerbate their challenges
493 making and keeping friends. These patterns persist into adulthood²⁰⁷. It is therefore unsurprising
494 that many interventions in adolescence and early adulthood focus on formal social skills
495 training^{208,209}, with the aim of equipping autistic people to manage everyday social relationships
496 on their own terms and thereby secure this capability.

497 However, such interventions fail to appreciate that autistic sociality is shaped by the
498 sociocultural context in which people are embedded^{210,211}. Autistic people can and do have
499 fulfilling connections with others, even if negotiating those relationships can be challenging⁹³.
500 They are drawn to those who accept them for who they are^{154,159,161} and with whom they do not
501 have to mask their autistic ways^{212,213}. These friendships include (but are not restricted to)
502 autistic-to-autistic interactions^{214,215}. As one participant reported in a study on autistic adults’
503 experiences of loneliness and social relationships: “though many of us have only met each other

504 three to four times, it feels as if we have known each other forever. Because all of a sudden you
505 are in a community with someone where you are on the same wavelength... it is a really strong
506 experience²¹⁶. Such autistic-to-autistic interactions promote self-understanding^{181,214,217}, positive
507 self-identity^{217,218} and wellbeing²¹⁹.

508 Isolation owing to the COVID-19 pandemic has also revealed that autistic people long
509 for social connection in the same way as everyone else, both in terms of close, trusting
510 relationships and fleeting, incidental interactions. As one autistic interviewee said when
511 describing their lockdown experience, “I didn’t realise how important that incidental human
512 contact was to me. It was so incidental that it never really registered on my radar until it was
513 gone¹⁶⁷. Autistic people’s need for human connection and the extent to which social isolation
514 plays a role in autistic people’s mental health distress have been underestimated by conventional
515 accounts.

516 The double empathy problem²²⁰ suggests that there is a misalignment between the minds
517 of autistic and non-autistic people. This misalignment leads to a lack of reciprocity in cross-
518 neurotype interactions and is the source of social communication difficulties between autistic
519 and non-autistic people^{221,222}. Empirical evidence suggests that non-autistic people have
520 difficulties understanding the minds and behaviors of autistic people^{221,222}, and that they are
521 unwilling to interact with autistic people based on initial judgments or interactions²²¹⁻²²³. Thus,
522 non-autistic people also interact less successfully with autistic people, compared to other non-
523 autistic people²²⁴.

524 These cross-neurotype interaction difficulties can lead to stereotyping of and
525 discrimination against autistic people. Although non-autistic people tend to deny feeling
526 negatively inclined towards autistic people²²⁵, autistic people often report experiencing bullying,
527 exclusion and discrimination. Attitudinal research has shown that considerable implicit biases are
528 present, even among non-autistic people who report no explicit biases²²⁶, suggesting they may be
529 unaware they have negative attitudes toward autistic people. These implicit, negative biases are

530 likely to be difficult to shift using short-term educational training programs²²⁷. Such
531 discrimination and stigma constitute a substantial barrier for autistic people seeking to develop
532 social connections. Discrimination and stigma could be countered by widespread public
533 acceptance campaigns (including those developed with autistic people²²⁸), and programs that
534 increase the number of everyday interactions between autistic and non-autistic people^{229,230}.

535

536 *Other species*

537 The eighth capability requires that humans are “able to live with concern for and in
538 relation to animals, plants and the world of nature”¹⁷. Prominent autistic naturalists (such as
539 Temple Grandin) and environmentalists (including Greta Thunberg) have captured the public’s
540 attention²³¹. Yet, there is remarkably little written about autistic people’s connections to nature
541 and non-human animals.

542 Research with parents of autistic children has revealed that natural elements (such as
543 sand, mud, leaves, twigs and water) can keep children engrossed for extended periods of time²³².
544 Autistic children also prefer interacting with animals over inanimate objects and humans²³³ and
545 report strong attachments to pets²³⁴. Studies have therefore focused on the potential therapeutic
546 benefits of interacting with nature for children, with some purporting to show ‘reduced autistic
547 severity’ or improvements in family functioning following interaction with trained animals²³⁵.

548 Research with autistic adults also reveals benefits of interacting with animals and
549 nature²³⁶. Nature and gardening are two of the most reported interests by autistic adults,
550 particularly women, and the pursuit of these interests is positively associated with subjective
551 wellbeing²³⁷. In a study using **photovoice methodology**, images of natural scenes were frequently
552 included among the photos shared by autistic adults, demonstrating the importance of nature in
553 contributing to a good autistic life²³⁸. Autistic adults’ autobiographies reveal the emotional depth
554 of these connections to nature²³⁹, which some autistic people say offer respite from the intensity
555 of an often inhospitable social world.

556

557 *Play*

558 The capability of play emphasizes the right to be “able to laugh, to play, to enjoy
559 recreational activities”¹⁷. This capability is one in which autistic adults might excel. Researchers
560 and clinicians often refer to autistic people’s passions and interests as ‘highly restricted’,
561 ‘perseverative’ or ‘circumscribed’, or as ‘obsessions’ or ‘fixations’, and as differing qualitatively (in
562 content) and quantitatively (in intensity) from the interests of non-autistic people²⁴⁰. Yet autistic
563 testimony attests that these passions are often a great source of joy and enjoyment²⁴¹, which
564 situates them within the play capability. Intense interests are common in autistic people^{237,242} and
565 become more diverse over time²⁴³. They are not limited to the sciences or computers, as popular
566 stereotypes suggest²⁴⁴, but extend broadly to a range of areas^{237,242} and might be more
567 idiosyncratic in autistic adults with limited spoken language and/or intellectual disabilities²⁴⁵.

568 Autistic adults often view their capacity to pursue their passions as an
569 advantage^{181,237,241,246} that can be affirming and have positive implications for identity and self-
570 concept²⁴³. Indeed, one participant, who once “owned about 15,000 CDs”, celebrated the
571 capacity “to be intense in stuff”¹⁸¹. Passions and interests have been likened to experiences of
572 flow^{237,247} and to monotropism¹⁹¹, which are driven by intrinsic (interest and knowledge) rather
573 than extrinsic (prestige or achievement) motivation²³⁷. Finding others who share similar interests
574 can form the basis of long-lasting friendships⁹³. Nevertheless, exceptionally high intensity of
575 engagement negatively impacts wellbeing²³⁷.

576 The generally positive effects of engaging in one’s interests also extends to taking part in
577 recreational activities. Autistic adults report relatively high levels of weekly participation in
578 exercise and hobbies²⁴⁸. However, they participate in conventional social and recreational
579 activities to a lesser extent than the general population²⁴⁹, despite saying these are important to
580 them²⁵⁰. Future research should consider the possible reasons for this disparity and the
581 constraints autistic adults face engaging in meaningful and satisfying leisure activities.

582 Inaccessible and inhospitable environments might be barriers for autistic adults²⁵¹, and the
583 effectiveness of programs designed to support such participation appear to be limited^{251,252}.
584 Enhancing the play capability is important because engaging in recreational activities might
585 buffer the relationship between perceived stress and quality of life²⁵³.

586

587 *Control over one's environment*

588 The final capability emphasizes the importance of “being able to participate effectively in
589 political choices that govern one’s life... being able to hold property and having property rights
590 on an equal basis with others; having the right to seek employment on an equal basis with others;
591 having the freedom from unwarranted search and seizure”¹⁷.

592 There is virtually no research on autistic adults’ engagement in mainstream political
593 processes. Individuals with intellectual disability are less likely to vote than the general
594 population²⁵⁴, especially if they live in supported accommodation rather than with family²⁵⁵. They
595 often lack support and accessible information for political engagement^{255,256} and are even
596 explicitly told they cannot vote due to their intellectual disability²⁵⁶. More research is needed on
597 autistic citizenship to identify precisely how these obstacles can be overcome²⁵⁶.

598 Extant data suggest that autistic people might be more politically disengaged than non-
599 autistic people. This stands in contrast to high-profile autistic activists and political
600 commentators, such as Australia’s Grace Tame and Eric Garcia from the USA, and increasing
601 autistic involvement in self-advocacy since the 1990s. The autistic self-advocacy movement grew
602 out of self-advocacy efforts of people with intellectual and developmental disabilities in the US
603 and the UK²⁵⁷ and is perhaps epitomized most by Jim Sinclair’s²⁵⁸ foundational essay (“Don’t
604 mourn for us”) which implored parents not to see their autistic child as a tragedy but instead to
605 embrace their differences. Autistic and neurodiversity activists now promote individual self-
606 advocacy, harnessing self-understanding and knowledge to ensure that individuals have greater
607 control over their own lives. Such individual self-advocacy is complemented by collective

608 advocacy, sometimes led by organisations run by and for autistic people (for example, [Autistic](#)
609 [Self-Advocacy Network](#)), where autistic people collectively campaign on a range of issues^{259,260}
610 and come together in dedicated autistic spaces and events²⁶¹. Consequently, self-advocates have
611 begun to shift conceptions of autism from a disorder that needs to be eradicated, prevented or
612 ‘fixed’ to a distinct way of being, which demands acceptance and emphasises human rights and a
613 positive autistic identity and culture²⁶¹⁻²⁶⁷.

614 There is much for autistic self-advocates to campaign about. Autistic people’s
615 opportunities are constrained due to others’ unjustified assumptions about their capacity²⁶⁸.
616 Autistic adults are at far greater risk of prejudice, stigmatization and discrimination in many
617 facets of their lives, such as education^{141,269}, health^{40,72}, care²⁷⁰, intimate relationships²⁷¹,
618 community¹⁷¹, justice²⁷² and work²⁷³. Moreover, to navigate a world that is not typically set up for
619 them, autistic adults often (consciously or unconsciously) hide or mask aspects of their autistic
620 self^{274,275} to keep themselves safe or adjust their abilities through ‘compensation’²⁷⁶. Such
621 adaptation can come at serious personal cost, including poor mental and physical health^{277,278},
622 negative self-perceptions^{275,278} and **autistic burnout**^{279,280}.

623 Work provides a particularly constrained environment. Autistic people face substantial
624 challenges gaining and sustaining meaningful employment, even relative to other disabled
625 people²⁸¹⁻²⁸³, despite possessing a range of skills that might be prized by employers^{127,246,282,283}.
626 Autistic adults who do obtain employment are often in positions that fail to match up with their
627 abilities (malemloyment) or for which they are overqualified (underemployment)²⁸⁴. They can
628 also face challenges maintaining employment²⁸⁵, owing to inhospitable work environments²⁸⁶,
629 negative experiences with (and sometimes bullying by) colleagues²⁸¹, failure to have their needs
630 and preferences met²⁸⁷ and experiences of discrimination, including following the disclosure of
631 an autism diagnosis²⁸⁸. There is growing interest in paid short-term autism-specific employment
632 programs or internships, which are designed to reduce barriers to employment for autistic
633 jobseekers and give them an introduction to workplace life and training in job-relevant skills^{289,290}.

634 These initiatives show promising impact on autistic trainees' occupational self-efficacy^{289,290} but
635 deserve sustained attention to determine whether they help autistic adults to secure and maintain
636 suitable employment in the longer term. Research is also needed on what constitutes a successful
637 employment outcome according to autistic people themselves, and how it should be measured²⁹¹.

638

639 **Summary and future directions**

640 Autistic people deserve to live long, healthy and creative lives of their own design. Just
641 like all people, they need to be equipped with a set of fundamental capabilities to do so. In this
642 Review, we examined the lives and life chances of autistic adults through Nussbaum's
643 capabilities^{16,17} lens. Doing so allows us to escape the narrowly normative focus on specific life
644 outcomes and consider the broader foundations for a range of possible good autistic lives. When
645 approached in this way, the literature suggest that there are some capabilities in which autistic
646 people have the potential to excel despite conventional stereotypes to the contrary, such as
647 emotions, affiliation, play, connections to other species, practical reason and control over one's
648 own environment. At the same time, the literature suggests that in these capability areas and
649 others (especially life, bodily health and integrity) autistic adults are often constrained by a range
650 of social, economic and other environmental disadvantages and barriers, which prohibit them
651 from enjoying a good life that they have the right to expect.

652 This Review suggests two clear directions for future research. First, it will be important
653 for researchers to more clearly identify these externally shaped disadvantages and find ways to
654 alleviate them. That is, once researchers are collectively equipped with a fuller understanding of
655 what currently prevents autistic adults from enjoying a particular capability, they should be able
656 to begin the task of removing those constraints so that further opportunities are provided.
657 Second, it will be equally important to encourage autistic people themselves to reflect further on
658 the capabilities to which they aspire and the obstacles which they believe obstruct them. The
659 capabilities reviewed here are only a starting point and further amendment might be needed to

660 capture the breadth and specificity of autistic experience (see ref²⁹²). Determining what autistic
661 capabilities to add to this list is a question which can only be resolved through research that is
662 genuinely participatory (see Box 3); that is, research that places the interests of autistic adults first
663 and takes their own experience and expertise as seriously as any other input.

664

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Glossary

1463 **Overwhelm:** a term used by autistic people to describe a state caused by excessive sensory or
1464 social stimulation.

1465 **Sensory overload:** occurs when a person's sensory system becomes overwhelmed, possibly due
1466 to difficulties processing and integrating perceptual information, causing significant distress.

1467 **Internalized stigma:** when a person accepts negative stereotypes and stigma about autism and
1468 applies it to themselves.

1469 **Photovoice:** a qualitative research methodology in which participants take photos to illustrate,
1470 and possibly prompt discussion of, their experiences.

1471 **Flow:** an optimal state in which a person becomes fully immersed in an activity, resulting in
1472 intense concentration, creative engagement, and the loss of awareness of time and self.

1473 **Monotropism:** a cognitive theory of autism, which suggests that the primary feature of autism is
1474 a tendency for a singular attentional focus.

1475 **Autistic burnout:** a community-driven term describing a highly debilitating condition involving
1476 exhaustion, withdrawal, executive function problems, and generally reduced functioning, with
1477 increased manifestation of autistic traits.

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1 **Table 1. Nussbaum's^{16,17} ten central capabilities and their relevance for autistic adult**
 2 **research.**
 3

Capability	Definition	Relevance to autistic adults	Individual autistic experiences
1. Life	Being able to live a life of normal length, not dying prematurely	Evidence suggests socio-economic and other disadvantages lead autistic people to die younger than non-autistic people ³⁶⁻³⁹ . There is limited knowledge of what aging 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 .
2. Bodily health	Being able to have good health, including reproductive health, adequate nourishment and shelter.	Autistic adults' constrained access to healthcare impacts on bodily health ^{25,67-69} . Homelessness and other housing concerns are higher among autistic adults compared to 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 .
3. 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 emphasised 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 .
4. Sense, imagination and thought	Being able to use the senses; to imagine, think, and reason; to have freedom of expression, including pleasurable experiences and avoiding nonbeneficial 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 .
5. Emotions	Being able to have attachments to things and people and to love, grieve and feel a range of emotions; not	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 should substantially improve wellbeing	In a study on COVID-19 lockdowns, autistic participants reflected on the importance of friendships and other human company, emphasising, 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 .

	having emotional development blighted by fear or anxiety.		
6. 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 programs offer promise for supporting autistic people's goal-setting and decision-making skills ²⁹⁴	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 .
7. 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 wellbeing ^{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 sensitised 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 .
8. 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 fulfilling potential.	In the 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 .
9. 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 .
10. Control over one's environment	Political: being able to participate in political choices affecting one's own life. Material: being able to hold property	Autistic self-advocacy organisations 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 programs are often well-received. One autistic participant reported: "I mean, for three months, I've managed to gain experience which is absolutely priceless and I gained, 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 .

	on an equal basis with others and to have access to employment on an equal basis to others.		
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6 **Box 1. Challenges for autism diagnosis in adulthood**

7 In most countries, adults seeking an autism assessment and diagnosis face severe
8 challenges and the individual is expected to initiate and navigate the process²⁴. Although there are
9 published guidelines^{7,295}, major differences exist between guidelines and actual experience²⁹⁶.
10 Adults seeking diagnosis report lengthy wait times and prohibitive costs^{2,24}, and encounter
11 clinicians who lack a nuanced understanding of autism^{75,174}. Further, the guidelines are far from
12 standardized in their recommendations for use of adult diagnostic tools and there is much
13 variation in practice^{2,7,295}.

14 The process of adult autism diagnosis is also challenging owing to difficulties in
15 recovering early developmental history and the self-reported tendency of many autistic adults to
16 use compensation strategies (masking or camouflaging) to minimise autistic features^{274,275}.
17 Although autistic adults of all genders have been reported to mask²⁷⁵, it is more often reported
18 among women²⁹⁷, which could be one reason why twice the number of men present to adult
19 diagnostic services²⁹⁸. These findings dovetail with a growing recognition of gender bias in
20 autism diagnosis²⁷.

21 More research concerning adult autism diagnosis is needed. For example, little is known
22 about the diagnostic experiences of autistic adults with intellectual disability²⁴, how autism is
23 identified in different cultural contexts or about adult autistic experiences in the global south²⁹⁹.
24 It is likely that autistic adults in many low- and middle-income countries do not have access to
25 formal diagnosis, post-diagnostic supports or the positive transformations in self-understanding
26 and connections to a peer community that often accompany diagnosis^{181,217,261}.

27

28 **Box 2. Inclusivity and the capabilities approach**

29 The capabilities approach focuses on the real opportunities that are open to each person
30 to live in ways that are meaningful to them. Applying such an approach to research on autistic
31 adulthood enables identification of the ways in which autistic people can thrive on their own
32 terms and the nature of the obstacles to this thriving. Diverging from more conventional medical
33 frameworks, the key to this approach is the value of personal autonomy: the belief that all
34 people, including autistic people, should enjoy the right to be at least ‘part author’ of their own
35 lives³⁵ and that their quality of life should always be measured, at least in part, according to their
36 own aspirations.

37 Although widely used in other settings³⁰⁰, the capabilities approach is novel in the context
38 of autism, partly because it has previously been suggested that this sort of autonomy-inflected
39 approach is ill-suited to a significant proportion of the autistic community³⁰¹. Non-speaking
40 autistic people, those with intellectual disabilities and/or those with very high support needs
41 have sometimes been considered unable to communicate or conceptualise their precise wishes in
42 the ways the capabilities approach seems to require. From this perspective, the capabilities
43 approach is applicable only to those who can make and articulate judgements about their own
44 life purposes and not to the entire autistic population.

45 Some have called for a fine-grained approach to the heterogeneity within autism,
46 suggesting that the autism spectrum should be split into those to whom an autonomy-inflected
47 approach could be appropriately applied and those for whom the traditional medical model may
48 be better suited³⁰¹. Similarly, others have called for the creation of a separate ‘profound’ or
49 ‘severe autism’ diagnostic category for those with the most severe impairments^{7, 302}.

50 We do not believe that we need to be this pessimistic. There is no clear scientific basis
51 for segmenting the autism spectrum in the way that proponents of a separate ‘severe’ or
52 ‘profound’ autism label suggest. Moreover, doing so poses grave risks, potentially excluding
53 people deemed ‘severe’ or ‘profound’ from the concern, dignity and respect offered to

54 others^{303,304}. Nonetheless, it is crucial for future research into autistic quality of life to consider
55 people of all abilities. Such research should investigate whether augmentative and alternative
56 communication can enable those with higher support needs to make their needs and desires
57 known³⁰⁵. Future research should also examine the effectiveness of available long-term services
58 and supports to enable those with the greatest needs to fulfil key aspects of quality of life. This
59 work would acknowledge the inevitable complexities of deploying the capabilities approach in
60 these instances while recognising that it remains possible to develop a broad and subtle
61 framework for the evaluation of quality of life across the whole autistic community.

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 which 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 return³⁰⁶. 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 autism³⁰⁷.

Crucially, autistic people also want to have greater input into research decisions³⁰⁸⁻³¹⁰. Autism research has traditionally been designed and conducted by non-autistic people. Autistic people, their family members, and even professionals 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^{309,310}. 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 of autism research³¹¹. 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 on the effectiveness of the research³¹². Participation itself can take many forms, ranging from being a consultant on a

88 research project, sitting on a formal advisory board, being a full collaborative partner, or even
89 leading projects. The critical issue in participatory research is who makes the research decisions.
90 In research involving community members only to a minimal extent (for example, through
91 consultation), the researchers are typically in control. When that involvement deepens,
92 researchers relinquish control to share decision-making power with community members.

93 There are some excellent examples of autism research that uses participatory
94 approaches^{40,181,313,314}, but it is still very much in its infancy. Although there is much enthusiasm
95 for involving autistic people in the decisions that influence them^{315,316}, researchers can be worried
96 about how time-consuming participatory research can be, they can find it hard to relinquish
97 control in research decision-making, and they worry that community members might introduce
98 bias into otherwise rigorous research processes. These concerns could lead to tokenism when
99 community involvement is attempted³¹³. Instead, researchers and community members need to
100 appreciate that they each have different ‘experiential expertise’³¹⁷; they must take that expertise
101 seriously to enable valuable insights for those involved in the research and for the research
102 itself³¹⁸.

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