

# Unmet need, epistemic injustice and early death: how social policy for Autistic adults in England and Wales fails to slay Beveridge's Five Giants

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## Introduction

Social policies are not neutral, and their impacts vary. Many social policies meet the needs of the majority at the expense of minority groups: a form of *epistemic injustice* (Fricker, 2007). For example, minority groups are often excluded or silenced by the policy-making process (*testimonial injustice*). Their contributions, such as to government consultations, are distorted or misrepresented due to policy makers' discriminatory beliefs and reliance on incorrect or outdated stereotypes (Chapman and Carel, 2022). Furthermore, a lack of resources available to explain problems faced by minorities, due to their exclusion from collective, social meaning-making practices by the powerful majority (*hermeneutical injustice*), compounds structural prejudice (Fricker, 2007). While all groups are impacted by hermeneutical resources, the powerful majority benefits, while minority groups are unjustly disadvantaged. Remi Yergeau illustrates this point in relation to Autistic people: 'Despite autistic people's increased visibility and, indeed, increased participation in public policy and political advocacy, autistic stories are not the autism stories that circulate, dominate or permeate' (Yergeau, 2017: 4).

Autism is a normal part of cognitive diversity, affecting around 2% of the population, although variation in diagnosis by gender and ethnicity occurs (Centre for Disease Control (CDC) 2022). Being Autistic, however, is often experienced as a challenging disability in the UK and beyond, due to policies being based on outdated medical (deficit-focused) models of Autism which downplay societal impacts (Woods et al, 2018). Autistic people die between 16 and 30 years before our neurotypical peers and the suicide rate for Autistic people is nine times that of other adults (Mandell, 2018). However, over 80% of Autistic people would not accept a 'cure' for Autism if it existed (Bonnello, 2022). There has been growing recognition of neurotype being a core demographic attribute, for example through being

included in the 2011 Scottish Census. However, to date, the impact of being Autistic on social policy has not been explored. Furthermore, in general, neurodivergent people's ability to speak for themselves and to advocate for policies and services which meet their needs has not been widely recognised in the UK or elsewhere due to the privileging of parent voices (for example, in Italy: Sicilia et al, 2016), aiming to 'cure' our neurotype (for example, the USA *Combating Autism Act 2006*) and the adoption of tokenistic gestures such as 'Autism Awareness Day'. Catala et al, (2021) identify these types of epistemic injustice as disabling for Autistic people. This chapter is written by four Autistic academics, who have lived experience of inaccessible services arising from social policy, including benefits (Grant, 2023), employment (Grant and Kara, 2021) and healthcare (Williams, 2022).

The Autism Act 2009 (as revised by the *Think Autism Strategy*, 2014), required governments to develop and implement strategies to provide services for Autistic adults, with Local Authorities obliged to deliver these services. The current strategies, in the context of devolution are the English *National Strategy for Autistic Children, Young People and Adults: 2021–2026* ('Strategy') (Department of Health and Social Care (DHSC) and Department for Education, (DfE) 2021), and the Welsh *Autism Delivery Plan 2021–2022* ('Code of Practice') (Welsh Government, 2021a). The *Strategy* acknowledges that there is a lack of understanding and acceptance of Autistic people, and that significant change is required. It identifies six priorities for improving support, access, and addressing inequalities faced by Autistic people which include education, health, employment and criminal justice. *The Code of Practice* provides guidance to ensure that service requirements written into existing legislation placed on statutory services are met. That these additional policies are required indicates that existing social policy did not sufficiently address the needs of Autistic people.

One of the central pillars of the Autism Act 2009 was to improve the diagnostic pathway, which is echoed in the Welsh *Code of Practice*. However, Welsh diagnosis statistics show that only 0.5% of people are diagnosed as Autistic (Underwood et al, 2021), thus around three-quarters of Autistic people are not diagnosed (CDC, 2022) which hides their needs. Diagnostic pathways are not expected to significantly improve according to the Royal College of Psychiatrists (2020). Moreover, the Westminster Commission on Autism (2021) identified significant and growing dissatisfaction regarding diagnostic services, including long delays, lack of clarity about diagnostic pathways, insufficient time with health professionals and not feeling listened to. With significant barriers to obtaining a diagnosis, some of which particularly impact Autistic people's needs (Howard and Sedgewick, 2021), some Autistic people will remain undiagnosed indefinitely. Furthermore, misdiagnosis is common for Autistic people, with many English diagnostic services providing broad diagnoses like 'personality disorder' rather than

using more specific diagnoses included in diagnostic manuals, such as Autism (Allsop and Kinderman, 2021). However, many public services aimed at Autistic people cannot be accessed until a diagnosis is received (Westminster Commission, 2016).

Should an Autistic adult secure a diagnosis, there is no automatic service provision for them. Generic barriers to accessing public services can negatively affect Autistic people seeking public services. For example, public service staff often have inadequate resources to match demand, resulting in them using discretion when deciding who to help (Lipsky, 2010). Autistic people experience widespread stigmatisation and discrimination, in part due to dehumanising misinterpretations of differing communication styles (Williams, G. 2021) despite a lack of *neurotypical* empathy being central to mutual misunderstanding (Milton, 2012). Furthermore, public service staff are often subjected to targets and intensive monitoring, which can lead to those with more complex needs failing to benefit from the system (Lipsky, 2010). In this multiply challenging context, it is likely that Autistic people – and particularly those who are also marginalised in other ways, such as by their ethnicity (Jones and Mandell, 2020) – will have lesser access to public services than neurotypical peers. Moreover, access to public services in the UK is often via telephone, which is known to be so challenging for Autistic people to navigate that they are unable to access services intended for them (Grant et al, in preparation).

Having considered barriers around diagnosis and widespread systemic barriers to accessing public services, this chapter moves on to consider how UK social policy is experienced by Autistic people. We utilise a modern iteration of Beveridge's (1942) Five Giants: health (disease), education (ignorance), employment (idleness), poverty (want) and housing (squalor).

## Health

Health services in the UK are highly bureaucratic, prone to significant delays and are confusing for patients – even more so for marginalised groups (Robards et al, 2018). The National Health Service (NHS) long-term plan specifically includes access to healthcare for Autistic people as a priority, as well as social prescribing (NHS, 2019). However, without appropriate diagnoses, as described in the introduction, this aim cannot be realised. In addition to delayed diagnosis, 76% of diagnosed Autistic people have noted that their General Practitioner (GP) does not make any reasonable adjustments for them, despite the value of small accommodations such as additional processing time during appointments (Westminster Commission, 2016). Moreover, GP records may not be updated to show a diagnosis (Williams, K., 2022), and many Autistic people do not proactively disclose being Autistic during appointments due to fear of stigma, receiving worse

treatment, and even their children being taken into social care. Lack of clinician understanding of Autistic presentations of pain and distress are a further barrier to adequate care (Grant et al, in preparation). These findings are echoed in research with health professionals including a lack of knowledge and confidence in supporting Autistic patients (Corden et al, 2022). Furthermore, during COVID-19, Autistic people were involuntarily subjected to Do Not Resuscitate orders, showing dehumanisation in healthcare (Mladenov and Brennan, 2021).

Within England, Oliver McGowan Mandatory Training in learning disability and Autism will be introduced in 2022 for health and social care staff with the aim of increasing ‘understanding of people’s needs, resulting in better services and improved health and wellbeing’ (Health Education England, 2022: 1). The development of training materials was not Autistic-led, and this training is based on outdated understandings of Autism, such as the impaired theory-of-mind hypothesis which has a questionable evidence base (Williams, 2021). Additionally, an evaluation by the National Development Team for inclusion (NDTi, 2022) found that two of the three training packages presented for review had insufficient and low-quality evidence. Furthermore, while we agree that providing education in understanding Autism could lead to better care, such training can be viewed as shifting responsibility for inaccessible care to individual clinicians, rather than addressing structural and material factors (such as consistent underfunding) which make individualised care almost impossible to deliver in the NHS.

One of the greatest barriers reported by Autistic people to accessing healthcare is the challenges to using the telephone for booking appointments or talking to service providers, with nearly two thirds of Autistic adults (62%) reporting significant difficulties booking a GP appointment by telephone, compared to only 16% of non-Autistic respondents (Doherty et al, 2022). Furthermore, Doherty and colleagues identified that difficulties using the telephone to book an appointment were found to be significantly associated with almost all adverse health outcomes for Autistic people. An additional barrier to accessing healthcare is the sensory environment of clinical spaces, which can be too bright, too busy, and too loud while staff restrict the use of Autistic coping strategies (NDTi, 2020); digital healthcare could remove many of these barriers, although early evidence suggests it is not currently meeting Autistic needs (Williams, 2022).

A low-cost, largely tokenistic attempt to make healthcare more accessible to Autistic people, including by making changes to the sensory environment, is the use of Autism Health Passports, a short digital or paper-based record, containing individual Autistic people’s needs relating to communication and sensory environments. These are recommended by the UK National Institute for Health and Care Excellence (NICE, 2021). However, health passport tools and wider interventions, such as training and electronic prompts,

are almost all inadequately theorised, under evaluated and operating in a hostile context, so the passports do not seem to benefit Autistic patients (Ellis et al, forthcoming).

## **Education**

Being Autistic has known impacts on accessing education, including deficits in executive function, working memory and the need for additional processing time; all of which may become more disabling in an inhospitable sensory environment. Additionally, in a society where Autistic experiences are denied legitimacy, communication barriers and stigma may result in Autistic people being considered ‘troublemakers’ rather than Disabled. Neurodivergences are known to cluster, and around one third of Autistic people have co-occurring learning disabilities (CDC, 2022). These educational barriers impact Autistic children, who make up most children with Special Educational Needs in England, and account for 80% of children in alternative educational provision (formerly Pupil Referral Units). Only one fifth reach expected standards in writing and maths (HM Government, 2022). This failure has dramatic impacts on post-16 education opportunities available to Autistic adults, and Holmes (2022) notes that only 8% of students with a statement of special educational needs or an Education, Health and Care Plan (EHCP) progress to university compared to almost 50% of students without an identified additional need. The difference is even more stark for prestigious universities. Unsurprisingly, only 4% of Autistic people report feeling supported in education (DfE and DHSC, 2021).

Disabled Students Allowances (DSA) have been available since 1974 as a non-means-tested grant to assist with the disability related costs of higher education study. It is open to all Disabled students, including those who are Autistic. However, multiple systemic barriers have been identified by Lord Holmes’ (2022) review which have led to less than one third of students who declared that they were Disabled accessing the allowance, not to mention those who did not declare their disability. These barriers included a challenging application process, significant delays in processing applications (preventing support being in place at the beginning of study), the requirement for Disabled students to coordinate their own support – which has been described as akin to a ‘full time job’ – and inconsistent quality in provided support (Holmes, 2022: 6). These barriers would be challenging to any Disabled student, but particularly so to Autistic people, who often struggle with the executive functioning necessary to drive an application for DSA forward. When UK universities were initially required to implement support packages for Autistic people, they provided the minimum acceptable level of support (Madriaga and Goodley, 2010). More recently, EHCPs were designed to be used for those living in England with additional support needs,

including those linked to being Autistic, until the age of 25 years. In Wales, the Additional Learning Needs Code for Wales 2021 (Welsh Government, 2021b) has introduced a similar policy. However, both policies stipulate that this support is for those entering further education rather than higher education. Therefore, universities are not legally obliged to offer these, and students must apply for DSA instead.

Autistic students within UK higher education have reported numerous barriers to equal participation including navigating group work without adequate support, assessment accommodations marking them out as ‘other’, and being excluded from social activities (Madriaga and Goodley, 2010). This may be related to staff believing that they *are* accommodating Autistic students, when their actions while teaching show unconscious resistance to inclusive practices, partially in response to inadequate Autism training (von Below et al, 2021) or a hidden curriculum that disadvantages Autistic people (Byrne, 2022). Such exclusion from peers and teachers disadvantages students both at university and in their professional lives (Byrne, 2022), and relatively little mental health support is available for Autistic students (Mulder and Cashin, 2014) who are known to intensely feel the impact of such exclusion.

## Employment

Autistic adults who are unemployed have a lower quality of life than those in work (Mason et al, 2018). The Autism Act 2009 emphasises that Autistic people should be able to access employment. However, Autistic people are under-employed compared to neurotypical people, with 22% of Autistic people in paid work compared to 81% of non-Disabled people (ONS, 2021), although this figure is unreliable due to underdiagnosis. Autistic people face barriers to employment at every step of the employment journey, beginning with inaccessible recruitment practices, not having their communication and sensory needs met within the workplace (leading to challenges in completing work), feeling the need to ‘mask’ Autistic traits during interaction with colleagues, managers who do not understand Autistic needs, and bullying, harassment and discrimination (Booth, 2016). Additionally, senior managers may be prejudiced, discrimination may be justified on the grounds of it being best for the business, and Autistic strengths may go unrecognised (Djela, 2021). In this context it is unsurprising that only 18% of Autistic people report that they have good accommodations at work (Bonnello, 2022). The COVID-19 global pandemic made work more accessible for some Autistic people due to the use of remote working, which allowed the use of sensory strategies not possible to use within workplaces (Autistic UK, unpublished data). However, during the pandemic, Disabled employees were more likely to be made redundant (Citizens Advice, 2020), and politicians and

employers alike have pushed for a return to the office which would have a disproportionately negative impact for Autistic employees.

A range of government initiatives can be found within the UK with the *prima facie* aim of supporting Disabled people into work. There are no specific policies aimed solely at Autistic people, although some resources have been developed by the DWP and partner organisations run by neurotypical people, using outdated stigmatising language; these are yet to be evaluated (House of Commons, 2018). Within JobCentre Plus, the UK version of a ‘welfare office’, Disability Employment Advisors are intended to support Disabled people into work, using a ‘menu’ of support options that include advice regarding job seeking, training and various government initiatives such as referrals to for-profit job coaches. However, just 4% of Autistic adults considered the Autism knowledge of Jobcentre Plus staff to be ‘good’ (NAS, 2019).

For Autistic people who have made it into employment, Access to Work is an initiative to pay for the additional disability-related costs of being employed. For Autistic employees, a support worker may be provided, as well as training for managers and colleagues (to reduce discrimination) and coaching for the Autistic person to help them identify strategies to cope with barriers in the workplace. However, like DSA, it is difficult to access and bureaucratic in a way that is particularly challenging for Autistic people to navigate. This means that while 42% of Autistic adults feel that they require support to access employment, only 12% are in receipt of such support (NAS, 2019).

The Equality Act 2010 strengthened anti-discrimination legislation in the workplace, making it illegal for employers to refuse ‘reasonable adjustments’ relating to recruitment, promotion, pay and terms of employment. If Autistic employees feel that reasonable adjustments have not been made for them or they have been terminated due to discriminatory reasons, they can take their complaint to an Employment Tribunal. Employment Tribunals were initially intended to be a fast, cheap, and informal way of resolving employment disputes, but the system has become more cumbersome over time, relying on complex legal tests and restrictive judicial decisions, making the system inaccessible to unrepresented Disabled employees (William et al, 2019). Furthermore, Citizens Advice (2020) note that, in response to the COVID-19 pandemic, already significant delays have been exacerbated at a time when demand has increased, and the Employment Tribunal system is now in crisis.

## **Poverty**

Data on the prevalence on poverty among Autistic people is largely absent. However, in 2009 one third of Autistic people did not have access to

benefits or paid work (UK Parliament, 2009), and 82% who had applied for benefits said they needed support to apply (Left Brain Right Brain, 2009). Unsurprisingly, an international survey of Autistic people found that 63% have financial concerns, and concerns were higher among those aged under 50 years (Bonnello, 2022). Among Autistic adults in Australia, the mode income level was around one quarter of the mean income for full time employed adults (Cai et al, 2022), showing significant disadvantage. Furthermore, one third of Autistic children in America live in poverty (Life Course Outcomes Program, 2020). Evidence related to Disability more generally shows a 12% point difference in poverty rates between those who are Disabled and those who are not, which is linked to under-employment (Joseph Rowntree Foundation, 2022). Accordingly, we conclude that Autistic people, who are less likely to be employed than Disabled people overall (ONS, 2021), are more likely to live in poverty than their neurotypical peers.

Within the English National Autism Strategy, there is no content related to poverty or housing. Poverty relief is controlled by the Westminster government, not devolved, and this lack of focus impacts Autistic people in Wales as well as England. Overall, poverty relief for Disabled people is founded on Victorian values that assume claimants are undeserving (Grant, 2023). As Autism is a largely hidden Disability, and Autistic accounts of pain and distress are minimised as part of epistemic injustice, these narratives of undeservingness can play a larger role for Autistic claimants.

For Autistic people who attempt to claim benefits, there are likely to be many challenges. The major forms of out of work income maintenance, Employment and Support Allowance (ESA) and Universal Credit, have been identified as problematic for all users due to delays, low rates of benefits that are not uprated in line with inflation, sanctions, and bureaucratic processes (see Grant, 2023). ESA prioritises work ('Employment') and is aggressively conditional on the claimants' behaviour ('Allowance'). Access to ESA is based on the Work Capability Test, which has been identified as unfit for purpose, due to its focus on being able to do any job, not just those that are available to the claimant, and outsourcing testing to private for-profit companies (Warren et al, 2014). Assessors are required to have Autism training and 'points', demonstrating eligibility for the Allowance, can be awarded for Autistic impairments related to claimants' responses to change and communication (House of Commons, 2018). However, access to ESA and Universal Credit is particularly challenging for Autistic people because of the confusing bureaucratic process. At the time of writing, the results of an inaccessible and underfunded benefits system were exacerbated by the cost-of-living crisis, which particularly impacts the cost of food and fuel.

In addition to income maintenance policies, Personal Independence Payment (PIP), is designed to meet the additional disability-related costs



of living related to personal care and mobility (including journeys outside of the home). However, from its outset, PIP had the aim of reducing spending on disability living costs (Gray, 2017). The application process requires telephoning to obtain a form and then providing hand-written answers before a one-to-one interview where everything the person does can be used as evidence that they are not sufficiently Disabled (Grant, 2023). Claimant trust in PIP reaching correct and fair decisions is low due to lack of specialist assessors, lack of accuracy in recording interview contents and lack of transparency; the majority of appeals are awarded showing this lack of trust is evidence-based (Gray, 2017). Furthermore, within the reporting statistics, Autism is incorrectly classed as a psychiatric disorder, which as a category is the highest proportion of all claims, totalling 38%. However, this group is least likely to get an award following assessment, most likely to receive a short duration of award and least likely to have the award renewed (DWP, 2022). In addition, those who experience distress during journeys have been awarded less support than those with physical impairments (House of Commons, 2018), negatively impacting Autistic claimants who may find the sensory environment on public transport distressing.

## Housing

Securing adequate housing is often problematic for Autistic people, with around 12% being homeless (Garratt and Flaherty, 2021). Within the UK, Housing Benefit (HB), or the housing component of Universal Credit, contributes towards rent for those on a low income or who are out of work. However, Autistic people have identified that staff administering social housing and benefits are unlikely to understand Autism (DfE and DHSC, 2021), which is likely to result in worse outcomes for Autistic people (Lipsky, 2010). Further challenges include the *bedroom tax*, where the cost of additional bedrooms is not included within HB, disproportionately affecting people who live alone, due to a dearth of one-bedroom properties. As Autistic people's sensory needs mean living with others can be challenging, they are particularly likely to be penalised by the *bedroom tax*. This is of more concern for those under the age of 35 who are likely to be in receipt of the Shared Accommodation Rate (Clair, 2022). Furthermore, the amounts covered by these benefits for those who rent in the private sector are based on the Local Housing Allowance (LHA) Rate – the 30th percentile of rent costs in the Broad Rental Market Area – rather than the actual cost of rent, and many private landlords refuse to accept tenants in receipt of welfare (Bailey, 2020; Clair, 2022). Furthermore, annual increases to LHA do not track rental price increases, disproportionately affecting Disabled people (Clair, 2022). As discussed in the previous sections, Autistic people are less likely

to be in employment *or* be in receipt of appropriate benefits, for example, PIP, exacerbating their difficulty in meeting increasing housing costs.

Autistic people can experience joy in response to pleasant sensory experiences, however a challenging sensory environment in the home can cause severe distress. Due to lack of choice, many Autistic people will live in housing that does not meet their sensory needs and may be uncomfortably loud, too bright, visually cluttered, or have unpleasant textures or smells. Unpleasant sensory experiences can add to the ‘sensory load’ an Autistic person experiences; too high a sensory load can be overwhelming, and result in delayed processing, meltdowns (explosive reactions) or shutdowns (retreating inside one’s self and becoming non-speaking). This can also lead to burnout in the long term, where skills – such as talking – can be lost for months, years or never be regained (NDTi, 2020: 19). This in turn negatively affects physical health, executive function and one’s ability to engage in work or study.

Social care can range from organising ones’ own support in their own home, to being placed in incarceration-like residential units, where personal freedoms are severely limited. Within England, when Disabled – including Autistic – people are awarded social care funds they receive a Personal Budget and are required to organise their own care. This is paradoxical as only the most severely Disabled Autistic people will be awarded a budget and are likely to find organising their care particularly challenging (NAO, 2018). Furthermore, a lack of appropriate housing for Autistic people has been identified as increasing the likelihood of secure residential care (Joint Committee on Human Rights, 2019). Widespread abuse of institutionally housed Autistic people was identified in the Winterbourne View report a decade ago and in the more recent Mendip House review, both of which also identified that many of the residents should never have been living there (DHSC, 2012; Flynn, 2018).

Residential care for Autistic people is often inappropriately based on the principles of Applied Behaviour Analysis and its sister-approach Positive Behavioural Support, despite strong evidence that Autistic people experience Post-Traumatic Stress Disorder as a response to this approach and subsequent guidance that it should not be used in the UK (Gore et al, 2022). The Care Quality Commission (2020) have reported inappropriate use of restraint and the use of incarceration, including solitary confinement like conditions, which are not in the person’s best interest; both are associated with the death of Autistic people. To date there is a dearth of high-quality evidence for how Autistic adults should be supported by social care (DHSC, 2022). However, the DHSC (2022) recommended that social care for Autistic people should be based on a principle of autonomy, with the least possible intervention used, and that specialist social workers should be established to facilitate appropriate social care.

## **Discussion: What would good social policy for Autistic people look like?**

Our analysis shows that social policies in England and Wales consistently fail to meet Autistic needs in relation to all five of Beveridge's Giants. Overall, bureaucracy is rife throughout all areas of social policy, which is particularly difficult for Autistic people to navigate. This affects those seeking accommodations related to health, education (DSA), income maintenance (ESA and UC), disability-related costs of living (PIP), in work disability accommodations (Access to Work) and housing (HB). Policies are also largely created without sufficient input from Autistic people, and place responsibility on individual Autistic people and/or public servants, meaning that widespread systemic barriers prevent policies from meeting their stated aims. A lack of staff time and resources are a common barrier across the Giants, as has been understood for almost half a century (Lipsky, 2010). When this is accompanied by misunderstandings of Autism and the incorrect problematisation and stigmatisation of Autistic people (Milton, 2012), it is no wonder that these policies fail to support Autistic people. We believe that this systematic failure of social policy plays a part in the extremely high suicide rate of Autistic people compared to neurotypical peers (Mandell, 2018).

When we consider these social policies together, the knock-on impacts from one policy area to the next are clear. Starting with a lack of diagnosis, delays and the requirement that Autistic people navigate bureaucratic mazes mean that many fail to receive recognition of their impairments. Although a diagnosis is not a golden ticket that automatically guarantees support, often without it no other support can be received. Diagnoses are not always added to primary care records and do not guarantee that any accommodations will be made, so Autistic people are more likely to have unmet healthcare needs. Regarding education, Autistic children are failed by the system which leads to Autistic adults being less likely to attend further and higher education. Without qualifications that match abilities, Autistic people are underemployed. This impacts income significantly, with one third of Autistic people who are not working also not claiming benefits, resulting in significant poverty. With insufficient income, Autistic people have a high risk of becoming homeless. This may result in institutionalisation, which restricts our liberties and is known to negatively impact on our health, thus further exacerbating our disadvantage.

We propose that this systematic failure is rooted in epistemic injustice. Government consultations and policies are written from non-Autistic perspectives, providing limited opportunities for Autistic people to talk about the discrimination and barriers we face every day (Fricker, 2007). At times it can feel as though these are grounded in understandings which aim to

privilege our abilities – and lack of reliance on government support – without accepting the disabling nature of contemporary society and our inability to access said support. For instance, all four authors have succeeded in *some* academic environments, where barriers to participation have been removed. However, while we can excel at this work, we could not work (for example) as a bartender, due to the overwhelming sensory environment. There is currently no meaningful inclusion of these lived experiences within UK social policy, which is a form of hermeneutical injustice. In addition, when Autistic people try to explain these lived experiences, non-Autistic policy makers find it unbelievable or minimise the extent of the issue, because it is so far from their own lived experiences – an example of testimonial injustice. The construction of [Autism](#) as a medical condition and a mental illness by the Department for Work and Pensions can invalidate our experiences further.

For UK social policy to effectively address the Five Giants for Autistic people, first and foremost Autistic people need to be accepted and afforded the same epistemic validity as non-Autistic people. This process can be started through co-producing social policy as per the Welsh Government model (for example, see [Welsh Government, 2021c](#)). This should not be limited solely to [Autism](#) policy. As we have outlined, Autistic people do not exist in a silo. All social policy affects Autistic people; therefore, Autistic people's experiences and knowledge need to be included in the shaping of these wider policies. Should UK policy makers wish to be more inclusive of Autistic people when designing their policies, some *easy wins* are available. First, access to all public services should be available via email for everybody, instead of lengthy waits on hold followed by a telephone call, which is known to be *painful* to Autistic people ([Howard and Sedgewick, 2021](#)). The application process for DSA, ESA, PIP and Access to Work, all of which attract Disabled claimants, seems to have been deliberately designed to limit access. Requiring PIP application forms to be completed by hand is archaic and punishing to neurodivergent people who may otherwise use software to write for them. Second, as Autistic people's trust in the knowledge of public servants is low (and staff themselves report a lack of knowledge and confidence), widespread training in [Autism](#) should be delivered. Unlike the Oliver McGowan Mandatory Training, it should be designed and delivered by Autistic people, to ensure that those staff can reliably *understand* our needs. If our needs were better met in educational settings, our employment trajectories would improve, reducing poverty and homelessness as well as improving Autistic people's mental health. Third, a policy that would benefit many Disabled people in addition to Autistic people, would be to ensure the right to flexible studying and working including working from home whenever the type of study or work allows. Fourth, Autistic people should never be denied an advocate to speak on their behalf when accessing public services.

The popular understanding of [Autism](#) still centres around young, cis-gendered white men and boys. However, we know that many kinds of people are Autistic. Accordingly, an intersectional approach is essential to reduce disadvantage in government policy (Crenshaw, 1989). For example, one survey of Autistic adults found that half identified as lesbian, gay, bisexual and transgender (LGBT+), 19% as transgender and 56% as Disabled ([Bonnello, 2022](#)). For those Autistic people with additional marginalised identities – including being female, Black, Brown, or from another other minoritised ethnicity ([Jones and Mandell, 2020](#)), Disabled, or otherwise marginalised – there will be additional and cascading disadvantage. For example, the death of Esther Eketi-Mulo and her four-year-old son Chadrack show how a Black, refugee, Autistic and epileptic woman died alone in her home, with her son starving to death two weeks later. Multiple public service failures, embedded in systematic racism, ableism and bureaucracy led to these entirely preventable deaths ([Kourti, 2022](#)). In addition, to date there has been a dearth of research on the experiences of older Autistic people and this has yet to clearly focus on their *needs* ([Happé and Charlton, 2012](#)). Almost a decade ago, the [National Autistic Society \(2013\)](#) produced a report on the challenges facing older Autistic people and their families, making suggestions for policy-based changes. However, the English [Autism Strategy](#) does not mention Autistic older people or their specific needs, and references in the Welsh *Code of Practice* are extremely limited and lack specificity.

## Conclusion

Epistemic injustice has meant that social policies impacting the lives of Autistic people are currently based on deficit narratives about us, which have been outdated since the introduction of the 1960's Social Model of Disability. There is now an urgent imperative for all areas of social policy to comprehensively consider the needs of Autistic people through every level of policy making – not simply in [Autism](#)-specific policies. This should be actualised through meaningful co-production of policy with Autistic adults, using an assets-based approach that understands [Autism](#) as a neuro-difference, not a neuro-deficit. This should replace the use of tokenistic consultations which are often inaccessible to Autistic people, and particularly Autistic people with learning disabilities. It is especially important for an intersectional lens to be used, to ensure that the needs of Autistic people who are multifariously marginalised are met, and to ensure that the needs of older Autistic people are met. When social policy better meets the needs of Autistic people, we theorise that our early mortality rate and extremely high suicide rate will become closer to those of the general population.

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