

# Review: 'Dehumanizing policies' leave autistic people struggling to access health, education and housing

July 3 2023, by Aimee Grant and Kathryn Williams

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Credit: AI-generated image ([disclaimer](#))

[Around 3% of people](#) are estimated to be autistic and it is a lifelong disability. Most autistic people experience the sensory world differently, such as places being too loud or too bright. We also typically communicate in a more direct way than is usual.

In the UK, the Equality Act 2010 means that [autistic people](#) should receive reasonable adjustments—meaning organizations must make changes to how they provide their services to remove environmental and social barriers. Despite this, autistic people often experience society as highly disabling. We die between 16 and 30 years younger than non-autistic people, and have a suicide rate [nine times higher](#).

Autistic people are often misunderstood by non-autistic people who [fail to recognize](#) how autistic people show empathy. This misunderstanding is embedded in many government bodies, which can result in dehumanizing policies and services that do not meet autistic people's needs.

[We reviewed](#) the evidence from a range of government and non-government research and reviews to understand how well autistic people fair in relation to government services. We looked at the areas described by William Beveridge, founder of the UK welfare state, as ["the five giants"](#): health, education, employment, poverty and housing. Our findings, which focused on England and Wales due to differences relating to devolution, were bleak.

## 1. Health

Many [government services](#) designed to support autistic people are not available without diagnosis. However, in the UK, most autistic people [aren't yet diagnosed](#).

We found diagnosis waiting lists were long—for example, [more than 20 months](#) for people served by the Cardiff & Vale health board in south Wales. Across England, between June 2021 and 2022, the waiting list for an autism assessment rose from [88,000 people to more than 122,000](#).

Even with a diagnosis, autistic people often don't receive healthcare that

meets their needs. Some people don't even tell doctors they are autistic, because they expect to be treated badly. Of those who have told their GP, more than 75% said their GP didn't make [any reasonable adjustments](#), such as allowing extra processing time during appointments.

Being expected to phone to book appointments is also difficult for [nearly two-thirds of autistic people](#), yet many GP surgeries insist on phone calls to book appointments. Autistic people also report that clinical spaces [are painfully bright, busy and loud](#), which can make it harder for us to explain what is wrong to the doctor.

## 2. Education

Autistic people often struggle in educational institutions because they rarely meet our needs. This can mean, for example, that [autistic children](#) are labeled as "troublemakers" by teachers, rather than disabled.

Despite autistic people accounting for only 3% of the population, around [80% of those sent to pupil referral units](#) are autistic. This has lifelong effects, as [only 8%](#) of students with a "statement of special educational needs" or an education, health & care plan progress to university, compared with 50% of non-[disabled people](#).

For autistic people who do make it to university, the disabled students allowance (DSA) should pay for extra costs—but [less than one-third](#) of eligible students get DSA. In addition, the support provided by universities is often [poor quality or absent](#), leaving autistic students disadvantaged.

## 3. Employment

The UK's [Autism Act 2009](#) says that autistic people should be supported to be able to work. However, autistic people are [less likely to be in work](#) than non-autistic people.

[Access to work](#) is a UK government scheme to pay disabled people for the extra costs of working, but the application and claiming processes are complicated. Of the 42% of autistic adults who say they need help to access work, [only 12% are getting it](#).

## 4. Poverty

Autistic people are [more likely](#) to live in poverty than non-autistic people. [A 2009 report](#) found one-third of autistic people in the UK were not in paid work or getting benefits. One reason for this is that the benefits designed to stop disabled people living in poverty, such as the personal independence payment (PIP), can be hard to apply for, especially for autistic people.

And for people who manage to apply for PIP, autism falls within the "psychiatric disorders" category, which means they are [least likely to receive the award](#) and most likely to lose their PIP upon renewal.

## 5. Housing

Around [12% of autistic people are homeless](#). As rent typically costs far more than the amount of money awarded in housing benefit, and autistic people are less likely to be in work or have access to benefits, they are more likely to struggle to pay for housing.

This can be made worse by the "[bedroom tax](#)", which is when tenants in social housing have their benefit reduced if they have spare bedrooms. This affects [single people under 35](#) especially, as they are only eligible

for the [shared accommodation rate](#). Autistic people can find it hard to live with other people due to their sensory needs, and there are [few one-bedroom properties](#).

Autistic people who do not have somewhere to live are more likely to be [placed in secure residential care](#), where they are subjected to similar confines to people in prison, by staff who may have [limited understanding of autism](#). They can also be subjected to clinical "treatment" that has the same [questionable origin](#) as [gay conversion therapy](#), and which guidance states [should not be used](#).

The research supporting this approach, known as applied behavior analysis (ABA), is often riddled with [undeclared conflicts of interest](#). Those who experience ABA have been found to be [more likely to experience symptoms of post-traumatic stress disorder](#) (PTSD).

Worse, some autistic people in residential care have experienced [abuse by staff](#). In the most severe cases, [autistic people have died](#) due to abusive and/or negligent treatment while in residential care.

## **A cumulative impact throughout life**

In every area of [government services](#), we found policies that failed to account for known autistic needs. These failures have a cumulative impact throughout life. A lack of accommodations in education leads to less likelihood of securing accessible employment and greater reliance on benefits and social housing.

To improve this, the policy-making process needs to be made accessible to [disabled people](#) so that services meet our needs. This could include ensuring that consultation processes reach out to a broader range of [autistic people](#), and then meet their needs to submit evidence.

It is also important that [policy-makers](#) put evidence from the autistic community ahead of evidence provided by non-autistic "experts" who fundamentally misunderstand autism, can have conflicts of interest, and thus can not speak on our behalf.

Autistic lives depend on it.

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