

Finding financial help for an autistic adult (UK)



Our world is not designed for autistic people. This means that many autistic people need adjustments, accommodations, and support in order to live and thrive, and the need for this support often continues in adult life. This support can be expensive and place burdens on autistic people and their families.

This resource examines why help may be needed, what help is available in the UK and why more needs to be done.

Why support can be needed and the scale of the problem

According to a 2019 survey by the All-Party Parliamentary Group on Autism and the National Autistic Society, around 1 in 5 autistic adults in the UK need help with everyday tasks, such as washing, cooking and going out of the house, but only about a quarter of these people get the help that they need. Some autistic people are almost completely unable to look after themselves and need 24-hour care, while for others a few hours help a week can make a huge difference. But around 15% of all autistic adults in the UK need help with the most basic self-care tasks but are not receiving it. This is a massive failing in a developed society.

There is clearly a general lack of support available. Part of the reason may be that autism is an invisible condition, so the need for support may not be obvious to others. Additionally, autistic people often struggle with social skills, so may not be equipped to reach out for the help that they need. It can be a vicious circle of needing basic support while nobody notices, and you are unable to ask for help.

Given the issues with social interactions, it is no surprise that around 2 in 5 autistic adults need social support through groups and other similar provision, but less than half of them actually get the support that they need.

As lockdown has shown us, isolation can be hugely difficult for some and have devastating effects on lives even if other needs are well catered for.



Autistic people can find it very hard to make friends and participate in wider social activities as they may be uncomfortable with or find face to face communication difficult, and struggle with things like body language, tone, and eye contact. But while they may struggle with these skills and so with forming and keeping friendships, it does not make them immune to feeling lonely and isolated.

The internet has been a great benefit to some autistic people in reaching out to others through a medium with which they are more comfortable, but there is not substitute for some in person company with people who allow you to just be yourself!

The impact of this shortfall

Often the burden of attempting to fill the gap left in caring provision falls on the family of the autistic person. This can put added stress on their resources both in terms of time and finances, and leave caring relatives exhausted, affecting their own quality of life. While they would do anything for the relative that they love, some support to allow both them and the person they care for to move from merely existing to actually living and thriving would be very welcome.

What help is available

There are several financial benefits which autistic people may be entitled to in the UK. However, the system is complex and can be difficult to navigate, so many may need help to access the financial support that they need and are entitled to. While the system needs to change, we must all play our part by ensuring that autistic people that we know or know of are getting the help they need to access the support available.

Many autistic people are able to work and would love to do so, but only around 20% of autistic adults are employed in the UK. The reasons for this are many and varied and include a lack of understanding of autism among employers and difficulties for autistic people with common recruitment practices, such as interviews. Those that do work may struggle to progress for similar reasons and lack of provision of the adjustments that they need to thrive.



For those who are able to work and can show that they are seeking employment, Jobseeker's Allowance (JSA) is available.

If an autistic person or anyone else is unable to work, unemployed or on a low income (including from working), they can claim Universal Credit, a safety net benefit to help with living costs that is assessed according to your situation and financial situation. Receiving Universal Credit can also act as a passport to other financial assistance, such as free prescriptions.

Whether an autistic person is working or not, if they need help with care or mobility issues, they may be able to claim Personal Independence Payment (PIP), which is assessed based on needs and abilities rather than income related.

If you are struggling to navigate the benefits system and in financial difficulty, either as an autistic person yourself or as carer acting on their behalf or on your own (for example, if you are unable to work due to caring responsibilities), there is help and support available to help make sure that you get your entitlement.

Citizens Advice is always a good place to start, and your Local Authority should have details of other sources of help in your area.

The system is complex, and many people do not get all that they are entitled to. There is no shame in seeking help in navigating the system – many experts that deal with it every day find it difficult too!

Why more needs to be done

Autistic people have the same rights as every other person but are disabled by a world designed for a different way of thinking. While progress is being made in improving rights and access for some groups of disabled people (though more still needs to be done), those with invisible impairments, such as autism, are being left behind as the survey findings mentioned earlier show.

A particular issue for autistic people is that the very skills needed to seek help, such as interacting with others and navigating confusing bureaucracies, especially by telephone, can be the areas where they need help.

It is very much a self-sustaining issue unless there is outside intervention.

It is just not enough to ensure that adequate support is available (and whether the current levels of support are adequate is an open question), more must be done to ensure that the support actually reaches those that need it rather than leaving them trapped in a cycle of needing support to get support.

Yet autistic people have so much to give. The fact that there are any people at all in a developed society with day-to-day basic needs not being met is appalling and completely unnecessary. For other autistic people, a few small changes or a regular helping hand can open up the world to them.

Improving access to employment for autistic people is key and would bring benefits on several fronts. The autistic person would be fulfilling their potential and thriving, while bringing important and needed skills to the workplace, such as creativity and problem solving.



They would then be earning enough to support themselves without help from the benefits system, freeing resources to help others in need. Yet so many autistic people who could be loyal and valuable employees are left dependent on the state because they struggle with application forms and interviews, neither of which may be skills required to actually do the job in question.

Many autistic people need support. This can be with basic aspects of self-care, with avoiding isolation or with obtaining and keeping employment. This is to be expected with any group in society that is different from the majority and so finds that the system is not designed to accommodate them.



But because autism can be invisible and its impacts on a person may be in the areas needed to seek help, many autistic people continue to miss out on the assistance that they need.

There need to be changes in the system to ensure that help reaches all who need it and that such help is adequate for their needs.

In the meantime, those of us who are able must do all that we can to help ensure that autistic people who are currently being missed are given the support they need to thrive, whatever that may be.

