

People's Panel Survey

- 1. Population Health
- 2. Learning Disability Awareness

1 Introduction



1 Introduction

1.1 Background and objectives

This is a People's Panel survey looking at member views on the following topics:

- Population Health.
- Learning Disability, Down's syndrome and Autism awareness.

1.2 Approach

The survey was designed with input from the Staffordshire and Stoke-on-Trent Integrated Care Board during July 2024.

Each questionnaire contained a unique survey ID, to identify non-respondents for the survey reminder and to allocate the survey response to a given demographic profile for any further analysis.

Technical testing of the survey

As part of the design process, the questionnaire was tested as follows:

- 1. In-house, using a robust plan that fully tested the design and operability of the survey.
- 2. Piloting with five survey testers (non-panel members), who checked and reported on areas such as usability, complexity of wording, etc.
- 3. Software to check that the survey had an acceptable fatigue and accessibility score.

Fieldwork

The survey fieldwork period was as follows:

- 9th August 2024 Email invite to all panel members.
- 17th August 2024 Email reminder to all panel members who had not completed the survey.
- 28th August 2024 Final email reminder to all panel members still to complete the survey.
- 2nd September 2024 Survey closed.

New members joining the panel during the fieldwork period were also given the opportunity to participate in the survey. The survey completion date was extended by a further four days to allow members joining the panel towards the survey deadline time to take part.

During the fieldwork period, eleven members unsubscribed from the panel.

Net Scores (Net promoter score)

Two questions for the Population Health section of the survey and five questions for the Learning Disability, Down's syndrome and Autism section had **two positives** (very easy, easy), one neutral (neither easy nor difficult), and **two negatives** (difficult, very difficult). The net scores for these questions are shown at the end of this report.



Prize draw

All completed questionnaires were entered into a prize draw to win one of two £50 love2shop vouchers, to be spent either in the high street or online. The prize draw took place in September 2024 and the two winning panel members were sent their £50 vouchers via email.

Technical notes

Percentages - Due to rounding, not all percentages shown may equal 100%.

n= Where shown in this report, 'n=XX'' is the number of responses received for a given question.

Respondents' comments – Several questions gave the option for a respondent to explain further the reason for their answer. These comments are listed in full in this report.

There were more than 700 comments made in completion of the survey. Apart from checking and amending any spelling errors, comments are unchanged and shown as written by the respondent.

Where a comment may potentially identify a respondent, these have been omitted from the report.

Survey, data analysis and report production undertaken by Direct Data Analysis Ltd, who run the panel on behalf of the Integrated Care Board.

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2 Survey findings



Population Health

Population Health Management is a way of working to help frontline teams understand current health and care needs and predict what local people will need in the future.

Population health aims to improve physical and mental health outcomes, promote wellbeing and reduce health inequalities across an entire population, with a specific focus on the wider determinants of health (things like housing, employment, education).

From the panel members responding;



56.3% walked for travel (e.g. to get to work, the shops) at least once a week.



54.6% ate on average five or more portions of fruit and vegetables a day.



61.5% ate home-cooked food prepared from basic ingredients / from scratch as their main meal at least five times a week.



37.3% stated their physical activity levels were worse than they were before the Covid pandemic.

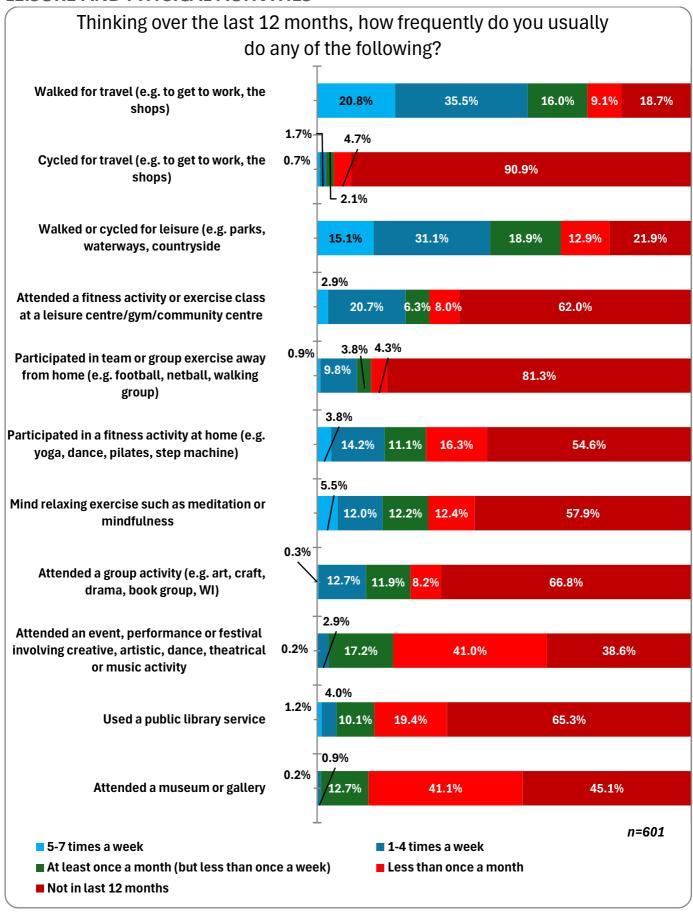


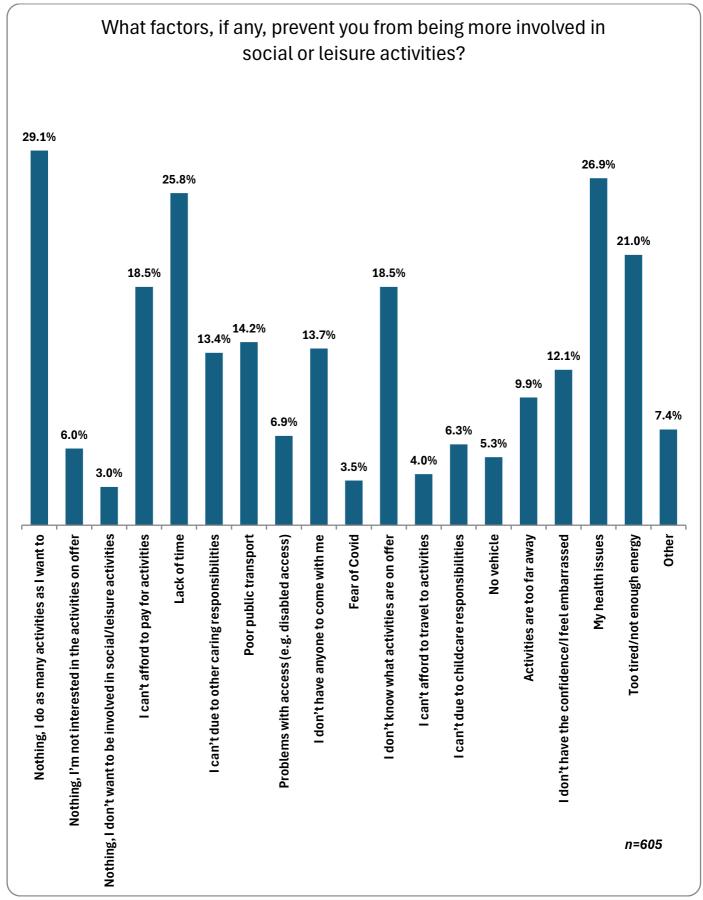
25.6% smoked or vaped more than they did before the Covid pandemic.



71.6% were happy to be living in their area.

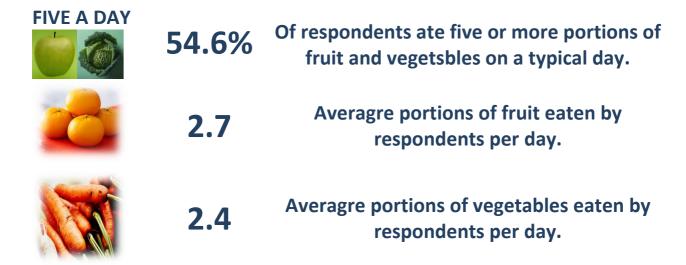
LEISURE AND PHYSICAL ACTIVITIES



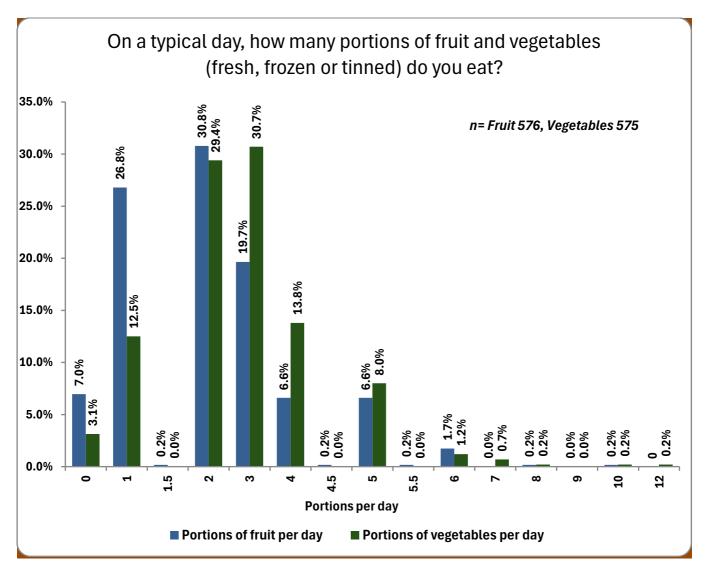


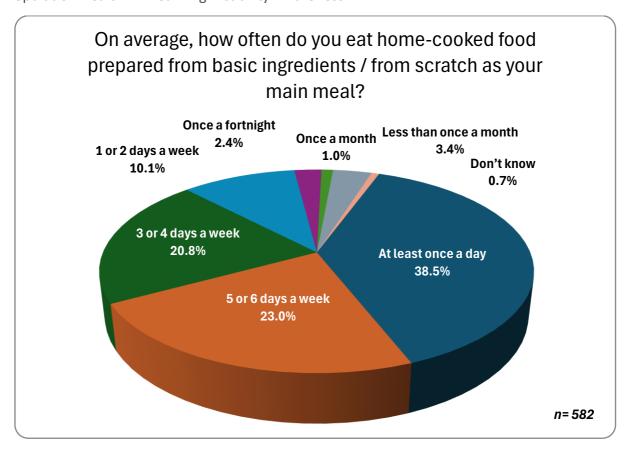
Respondents could select more than one response.

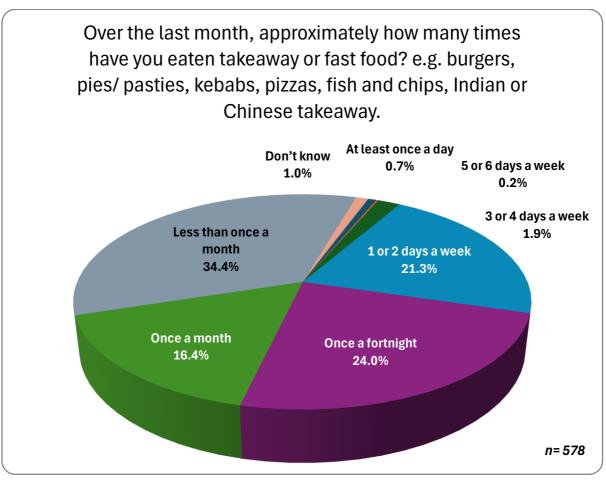
FOOD AND NUTRITION



Just 7% of respondents ate no fruit on a typical day, whereas just 3.1% ate no vegetables on a typical day.







Local Authority (Over the last month, approximately how many times have you eaten takeaway
	or fast food? Comments.
Cannock Chase	A treat.
Cannock Chase	A treat.
Cannock Chase	Convenience as working late.
Cannock Chase	Convenient.
Cannock Chase	Family treat.
Cannock Chase	It was enjoyable.
Cannock Chase	Lack of time.
Cannock Chase	Lack of time and energy due to new job.
Cannock Chase	Lack of time basically.
Cannock Chase	Time.
Cannock Chase	Weekend treat.
East Staffordshire	After football training as a treat for child.
East Staffordshire	As a holiday treat!
East Staffordshire	Carer didn't cook.
East Staffordshire	Choice.
East Staffordshire	Convenience.
East Staffordshire	Convenience.
East Staffordshire	Convenience, Safer.
East Staffordshire	Disabled and find it difficult to make every meal I need to eat.
East Staffordshire	Enjoy take aways for a treat.
East Staffordshire	I never eat takeaways as I don't like them much and the portions are huge.
East Staffordshire	If I do, it is for variety and/or to see family/friends.
East Staffordshire	Lack of time.
East Staffordshire	Moved house so didn't have the energy to cook as well as moving.
East Staffordshire	Never.
East Staffordshire	Sent to the seaside for the day. Fish and chips are a must!
East Staffordshire	Time/convenience.
East Staffordshire	Time and as a treat at the weekends so I don't have to cook!
East Staffordshire	Too tired.
East Staffordshire	We find it as a treat at the Weekend, but not always and only on a Saturday.
Lichfield	As a treat and something that we don't have that often.
Lichfield	Buy some frozen meals and add more veg.
Lichfield	Convenience and wanted a takeaway/fast food.
Lichfield	Convenience, pleasure.
Lichfield	Convince weekly treat.
Lichfield	Enjoyment.
Lichfield	I cannot use my kitchen as it is not adapted, and to eat foods made at home
	means buying the food, using electricity, travel, and carrying the food home.
	When you work out the cost involved, time and energy, it is quicker, cheaper,
	and more convenient to get the takeaway. I only probably only eat one hot
	meal a week, and one takeaway a week, mostly eat crackers and cheese.
Lichfield	I never eat fast food and never have takeaways.
Lichfield	I really hate cooking. I know it's silly, but I truly resent it.

Lichfield	It can take a while to make a healthy evening meal and sometimes I just don't have enough time.
Lichfield	It is difficult to prepare good curry/Chinese food which I enjoy, from scratch.
Lichfield	Lack of time.
Lichfield	Not at all.
Lichfield	Regular family treat.
Lichfield	Treat of a takeaway curry on a Friday.
Newcastle under	A pre-holiday treat.
Lyme	
Newcastle under	A treat.
Lyme	
Newcastle under	As a single mum, the prep and aftermath of cooking 3 times a day is enough. I
Lyme	prefer to eat in, but sometimes I like a break.
Newcastle under	As a treat.
Lyme	
Newcastle under	Choice.
Lyme	
Newcastle under	Convenience.
Lyme	Convenience even weekend due to children's exerting estivities
Newcastle under	Convenience over weekend due to children's sporting activities.
Lyme Newcastle under	Convenient.
Lyme	Convenient.
Newcastle under	Disabled. Lack of energy, too much pain.
Lyme	Disabled. Edek of effergy, too finder paint.
Newcastle under	Done on days that are too busy to have the time to prepare and cook the
Lyme	main meal.
Newcastle under	Don't like takeaways.
Lyme	·
Newcastle under	Family insists on Saturday night takeaway and on the odd occasions if I work
Lyme	late and too tired to cook, I get takeaway but that's once a month ish.
Newcastle under	It is easier and often cheaper to put a frozen ready made meal into the
Lyme	microwave than cooking yourself.
Newcastle under	It's an occasional treat for us.
Lyme	
Newcastle under	Just enjoy.
Lyme	
Newcastle under	Just wanted to have a change.
Lyme	
Newcastle under	Lack of time and convenient.
Lyme	Look of time to spek from sametak
Newcastle under	Lack of time to cook from scratch.
Lyme Nowcastle under	Lack of time special associan
Newcastle under	Lack of time, special occasion.
Lyme Newcastle under	Lots going on at home and lack of preparation time. Forgetting to take meat
Lyme	out of the freezer!
Lyllie	טענ טו נווכ ווככצכו:

Newcastle under Lyme	N/A.
Newcastle under Lyme	Newborn child- convenience.
Newcastle under Lyme	Nice treat.
Newcastle under Lyme	Occasional treat.
Newcastle under	Only as a treat, not regular healthy diet.
Newcastle under	Only had one takeaway in the last 2 months and this was for convenience and a treat.
Newcastle under	Quick and easy.
Newcastle under	Treat.
Lyme Newcastle under	Treat.
Newcastle under	Treat.
Lyme Newcastle under	We have takeaway as a treat, or because it's quick.
Newcastle under	We like them.
Lyme Newcastle under	When pushed for time.
Lyme South Staffordshire	Convenience and time.
South Staffordshire	Convenience because out for the day.
South Staffordshire	Lack of energy.
South Staffordshire	Meeting with Friends only have takeaways a few times a year as too much salt in them.
South Staffordshire	Out for a day at the seaside.
South Staffordshire	Something different.
South Staffordshire	Time and convenience.
South Staffordshire	Too busy to cook.
South Staffordshire	Too tired to cook. Disabled. Have severe forearm pain. Tennis or golfer's elbow. Had MRI Saturday. Can't chop veg, can't shake air fryer drawer. I have spinach, broccoli, blueberry, pomegranate seeds, ginger, lemon, milled linseed, Zoe 30+, mint, banana, peanut butter, oats, skimmed milk, water, cinnamon, turmeric all in the nutri bullet [Sic].
Stafford	As healthily as possible (as daft as that sounds) - preparing/cooking is very difficult with my health issues.
Stafford	Celebration.
Stafford	Convenience.
Stafford	Convenience and the off treat.
Stafford	Convenience.
Stafford	I never eat takeaways.

Stafford	Lack of time.
Stafford	Mental health, lack of energy or motivation to cook. Eating disorder - binging on food.
Stafford	My caring responsibility increased dramatically in the months preceding my father's death in July and my mother needing to move to a care home in August. Takeaways are usually a less than once a month treat.
Stafford	N/A.
Stafford	Never eat takeaway.
Stafford	Night off from cooking.
Stafford	Time/motivation/budget.
Stafford	Tired and family not interested in what I can cook.
Stafford	Work pressures cause me to work additional hours and late home.
Stafford	Working full time. Mom in an assessment bed an hour away from me, so not enough time to look after myself correctly.
Staffordshire Moorlands	Convenience.
Staffordshire Moorlands	Convenience.
Staffordshire	Convenience.
Moorlands	
Staffordshire	Cost.
Moorlands	
Staffordshire	Friday or Saturday night we have a Chinese or Indian.
Moorlands	
Staffordshire	Get home late and easy to put pizza in oven.
Moorlands	
Staffordshire	I don't eat take aways.
Moorlands	
Staffordshire	I prefer to prepare my own food.
Moorlands Staffordshire	Just fancied it.
Moorlands	Just failcled it.
Staffordshire	Lack of time, tiredness from work.
Moorlands	Lack of time, the directs from work.
Staffordshire	Other half thinks fish is healthy. Yerrkkk [Sic]. Doesn't compute the realities.
Moorlands	Lives in the old world and if they buy salmon, have no concept of how it was
	raised, and prefers it lathered in unhealthy sht**.
Staffordshire	Tiredness and lack of time.
Moorlands	
Staffordshire	To give me a rest.
Moorlands	
Staffordshire	Treat.
Moorlands	
Staffordshire	We have one treat night each week, Friday night takeaway night.
Moorlands	
Stoke on Trent City	A treat.
Council	

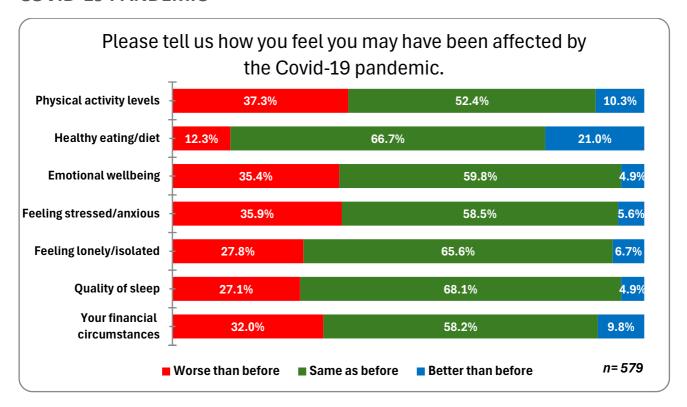
Stoke on Trent City Council	A treat on a Friday.
Stoke on Trent City Council	As a treat.
Stoke on Trent City Council	As a treat.
Stoke on Trent City Council	As a treat.
Stoke on Trent City Council	As a treat after exercise.
Stoke on Trent City Council	Being on a caravan holiday and being poorly led to relying on takeaway rather than cooking. I am single and look after 5 children.
Stoke on Trent City Council	Convenience.
Stoke on Trent City Council	Convenience/too tired to cook.
Stoke on Trent City Council	Convenient.
Stoke on Trent City Council	Don't eat fast food.
Stoke on Trent City Council	Due to caring responsibilities & my own health means I'm extremely tired.
Stoke on Trent City Council	During Covid we have got into the habit of batch cooking meals from scratch and freezing portions. We normally cook from fresh a couple of times a week and also eat a couple of times a week, meals which we have cooked previously but frozen. This is ideal for when you have had a busy day at work and do not have time to cook - you can still have a healthy home cooked meal.
Stoke on Trent City Council	Enjoyment.
Stoke on Trent City Council	For a change and wanting dirty greasy food.
Stoke on Trent City Council	I care for my son who buys lots of food (OCD) which I have to cook, but always use fresh vegetables with it, i.e. carrots, broccoli cauliflower and potatoes, or salad lettuce tomatoes cucumber pepper. We go out at least once a week for a meal so I can get him to socialise a little, otherwise he would be stuck in the house as he won't go out on his own. We normally do

	this after he has been to the gym, so he is already out of the house. We occasionally have fish and chips in and will choose a meal when out of meat potatoes and veg, occasionally a burger (not me but my son).
Stoke on Trent City Council	I don't eat food as I'm on a protein diet so having shakes only.
Stoke on Trent City Council	I hardly eat takeaways I cannot afford.
Stoke on Trent City Council	I have one takeaway as a treat.
Stoke on Trent City Council	I have been on holiday. Access to home cooking has been limited.
Stoke on Trent City Council	I never eat take away food.
Stoke on Trent City Council	Ill health and lack of time for husband.
Stoke on Trent City Council	It's a ritual with my autistic son.
Stoke on Trent City Council	Lack of time.
Stoke on Trent City Council	Lack of time.
Stoke on Trent City Council	Lack of time.
Stoke on Trent City Council	Lack of time.
Stoke on Trent City Council	Lack of time and convenience.
Stoke on Trent City Council	Lack of time, convenience, inadequate cooking facilities & utensils.
Stoke on Trent City Council	My disability.
Stoke on Trent City Council	Not much food in, convenient, treat for the kids.
Stoke on Trent City Council	Taken my grandchildren out for lunch, their choice of venue.
Stoke on Trent City Council	Time.
Stoke on Trent City Council	Time constraint due to unforeseen circumstances.
Stoke on Trent City Council	Treat whilst on annual leave.
Stoke on Trent City Council	Unplanned late coming home and too tired and hungry to cook.
Stoke on Trent City Council	Usually either due to lack of food in the house because I have been unable to go shopping or, because I don't have enough energy or feel too unwell to cook.

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Stoke on Trent City Council	Very rarely eat fast food. 😊
Stoke on Trent City Council	We were travelling, so mostly ate at cafe's or take outs due to my son's disability and limited diet.
Stoke on Trent City Council	When we are tired, on a garden volunteering day usually.
Tamworth	Being single, it is often difficult to cook a ready meal for one. Most of the supermarket products for cooking are geared up for families - I.e., there are no jars of lasagna sauce for one person, they are all for two or family size. Where jars/products are available for one person, they are almost as expensive as the same product for two people.
Tamworth	Chippy night is a part of our family life.
Tamworth	Don't know how to cook properly and convenience.
Tamworth	Don't eat fast food.
Tamworth	I don't eat fast food.
Tamworth	On holiday and had chips for lunch.
Tamworth	To give partner at least one day off from cooking as I can't stand and cook.
Tamworth	Unplanned extra time away from home.

COVID-19 PANDEMIC



Local	Please tell us how you feel you may have been affected by the Covid-19
Authority Area	pandemic. Comments.
Cannock Chase	Effect it has had on health care and waiting lists, appointment availability etc. This causes a lot of stress.
Cannock Chase	Had it three times and I was concerned about getting it again.
Cannock Chase	I am financially worse off as I couldn't work during the pandemic due to having COPD and eventually had to take ill health retirement.
Cannock Chase	I think that Covid changed my habits. I got so used to being at home alone and have never really regained my social habits. Especially now as everything is so expensive. I used to go out for social meals a lot before Covid, but I got used to always eating at home during the pandemic. Now, although I can afford, I can't justify the cost. I have spent the last 6 months giving everything I have to a new job as CEO. I am now starting to focus on finding a work life balance again and getting more social, but those habits from Covid are hard to shake off.
Cannock Chase	Inflation and cost of living.
Cannock Chase	Loss of confidence, anxiety, memory lets me down.
Cannock Chase	Lost my business.
Cannock Chase	Seem to get anxious about social situations more - happier to be at home even though I worked at work throughout pandemic. Finances never picked up after due to the general economic situation and not wanting to do overtime anymore. Generally struggling to stay asleep in general possibly due to increased anxiety.
Cannock Chase	The rises in the cost of living haven't been matched by my income.
Cannock Chase	Worry if long term impact of Covid.
East Staffordshire	Changes with friendships, to reduce drama in my life.

East Staffordshire	Cost of living rises lead to stress and affects emotional wellbeing.
East Staffordshire	Difficult to get going with things again.
East Staffordshire	Have been diagnosed with Post Covid Syndrome. Fatigue is an issue. Delayed applying for promotion impacting on finances. Mother died during restrictions in a care home. Struggled to accept at the time we could not see her and impact on kids of not being able to say goodbye to her.
East Staffordshire	I cannot see anything has changed for me on the whole! I just Carry on has normal.
East Staffordshire	I finished work in part due to working through Covid and realising there was more to life. However, this has resulted in a reduced income.
East Staffordshire	I have long Covid and now utterly debilitated, but the services to cater for this illness are poor and do not help clinically. Doctors just refer you as they don't know how to help and I won't get seen for maybe a year while I suffer immensely financially, physically and mentally, waiting for help! My family are left to pick up the pieces due to the lack of help out there.
East Staffordshire	I lost my husband about 4 weeks before the first Covid lockdown (not Covid related) and I was then thrown into living on my own in a house too big for me and not being able to see family and friends at this difficult time. It was a really bad year until I moved to a small house very close to one of my daughters. From this time life has been somewhat easier, though after a knee injury I was unable to walk the distances I used to and now use an exercise bike instead.
East	I retired early, primarily for health reasons but consequently have a very low
Staffordshire	income.
East Staffordshire	I was very anxious during the pandemic and have improved since.
East	It is a postcode lottery of support. Huge wait times, lack of GP knowledge and
Staffordshire	support. Benefits system don't fully recognise long Covid, lack of Government support.
Staffordshire East Staffordshire	support. Benefits system don't fully recognise long Covid, lack of Government support. It's not necessarily Covid, it's more people now seem to be nasty, both online and
East	support. Benefits system don't fully recognise long Covid, lack of Government support.
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East Staffordshire	support. Benefits system don't fully recognise long Covid, lack of Government support. It's not necessarily Covid, it's more people now seem to be nasty, both online and in person. I now dislike going out. Just feel really restricted in all areas. My husband passed away from Covid. My husband passed away in 2023. I have arthritis and other medical conditions. Never have slept well. Had cancer and now only work part time so income decreased. No longer a member of the local gym. Pandemic interrupted routines. Chronic illness symptoms got worse and mobility issues prevented returning to gym classes.
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East Staffordshire	The pandemic played a big part as activities I took part in before lockdown did not reopen. I was also suffering (and still am) from anxiety, insomnia and grief due to the death of my husband and 3 relatives before the pandemic, several friends during and after the pandemic, and having to have both my dogs put down during lockdown.
East Staffordshire	The relentless rise in interest rates has almost doubled our mortgage. Any wage increases have been swallowed up by general price increases. Consequently, we're more than £400 a month worse off.
Lichfield	Activity and diet worse due to cancer treatment, not due to Covid
Lichfield	Covid contributed to me needing ill health retirement.
Lichfield	Gave up health club membership because of Covid experience. Fear of catching Covid has meant less keen to participate in group activities. Since Covid - have felt more anxious about health.
Lichfield	I have been through a very rough 2 years. My right hip collapsed Sept 22, operated on Jan23. Due to using my Left leg to compensate for balance and mobility, my knee needed operating on I was due to have the operation Jan 24, but I was admitted to Hospital with Pneumonia, so my knee was operated on April 24. September 22 I was still working in a nursing home as the Senior Sister 3 nights a week. This has affected my anxiety and loneliness levels. I have had to relinquish my Nursing Pin number as I needed to Revalidate my Pin number, but due to the problems I have been through I could not do it. It has definitely affected my financial situation as well. I just loved my Career and had no intention of retiring until this happened.
Lichfield	In lockdown I had plenty of time with being furlough from work. This enabled me to spend a lot of time not only exercising but learning lots of new healthy recipes to cook. Now back in work I often don't have the time or effort for either.
Lichfield	Pandemic is a contributing factor, along with other factors.
Lichfield	Retired from nursing early.
Lichfield	Sleep is poor, but not sure why.
Lichfield	Very poor sleep patterns.
Newcastle under Lyme	 Cost of activities. As a pensioner I do not have much disposable income. My art class is £9.00 per week without materials. However, I get to interact with people of a like mind and I enjoy the company. The cost of quality fresh food, increase in yobbish behavior in and around town, especially around 3 to 5pm. I worry more which affects my sleep and overall mood.
Newcastle under Lyme	2020 health issues. COVID and lockdown all impacted on my physical and mental health. I've been deteriorating ever since.
Newcastle under Lyme	Afraid of getting Covid.
Newcastle under Lyme	Concerned that I may catch it again in crowds etc.
Newcastle under Lyme	Disability started having worked frontline social care as a nurse.
Newcastle under Lyme	During Covid my health has deteriorated, I struggle now physically and mentally.

Newcastle under Lyme	Had time to exercise more during lockdown as commuting less and fewer things to need to take the kids to.
Newcastle under Lyme	I am dependent on benefits due to my health conditions, so I worry a lot about my direct debts being paid at certain times of the month. I have reduced my spending costs down to the bare bone. Also, with this uncertainty concerning disability payment being changed to vouchers when I use my payments for the basics of life. My physical being has reduced lately due to limited movement in my hips impacting greatly on my walking and my movement leading to more stress on my mental health.
Newcastle	I feel that since having Covid my breathing has been affected and I often wake at
under Lyme	night. I do not know if this is a coincidence or not.
Newcastle under Lyme	I had to shield, plus no family close by once being in a 'bubble' was permitted. Led to loss in confidence and a sense of isolation which has taken a long time to shake off.
Newcastle under Lyme	I have long Covid which has brought about a lot of health issues for the last 3 years.
Newcastle under Lyme	I was diagnosed with Graves Disease which could have been caused by first Covid vaccination. Many hospital appointments and treatments with little effect, so vision slightly impaired.
Newcastle under Lyme	I was shielding then I caught it then it gave me even more health issues.
Newcastle under Lyme	I worked in the NHS all through Covid. I saw first-hand the effects of this disease. The fear of myself or family getting sick - never experienced anything like it.
Newcastle under Lyme	It could be the menopause or something else, but I do feel more anxious and struggling to get to sleep.
Newcastle under Lyme	It just seems that Covid has become an excuse for activities to be cut and to increase the cost of everything.
Newcastle under Lyme	Lost my son's personal carer as Covid vaccine caused her serious illness. As she was our driver to enable us to go out as and when we wished and also to access our caravan at the seaside. We no longer are able to go out shopping, or just for pleasure without making arrangements well in advance, only to find my son (severely disabled) is not well enough to go out.
Newcastle under Lyme	Lot of social orgs collapsed during Covid, less social involvement.
Newcastle under Lyme	My heart and lung issues have severely constrained our social activities, even still. This also impacts my mental health and has made me more withdrawn.
Newcastle under Lyme	My husband passed away in the pandemic. Last year my daughter moved away for work. We are very close and used to go everywhere together. Now I've got no one and get lonely. I am trying to move near my daughter.
Newcastle under Lyme	My pension is used on heating etc.
Newcastle under Lyme	My physical activity levels are worse than before as I have chronic asthma which is getting worse.
Newcastle under Lyme	No family or close friends nearby. No one single my age to socialise with.
Newcastle under Lyme	Not due to Covid but with pain from my condition.

Newcastle under Lyme	Retired during Covid - not on salary but pension.
Newcastle under Lyme	Sleeping badly due to the menopause.
Newcastle under Lyme	Two Indian people have duped my father for money.
South Staffordshire	Deteriorating MS.
South Staffordshire	Financial everything so expensive.
South Staffordshire	I had a health issue identified during Covid which is still not treated due to backlog in treatment. This issue has restricted my ability to exercise.
South Staffordshire	I stay up late watching TV, then go to bed with a YouTube video because I have pulsatile tinnitus, and the noise keeps me awake. I crave chocolate.
South Staffordshire	It has affected our business.
South Staffordshire	Lockdown affected my elderly parents dramatically and they went into a care home.
Stafford	Also lost both my parents during the pandemic and was working as a nurse. Overall, a very stressful time.
Stafford	As I've got older, my sleep pattern has got worse, especially in regard to going to sleep at night. It takes forever.
Stafford	Change in working patterns due in part to the pandemic.
Stafford	Covid has had such an impact on society life feels very different now.
Stafford	Death of spouse.
Stafford	Finances are worse due to cost-of-living increases which haven't been matched by income.
Stafford	I am a healthcare professional who worked through Covid and this obviously has a long-lasting impact on anxiety. Feel worse off financially due to increases to cost of living and pay increases not keeping up with this.
Stafford	I am generally more fatigued since Covid, so my energy and motivation levels have decreased significantly.
Stafford	I don't go to crowded public places anymore as you don't know if the other people are healthy or not. It causes me stress and anxiety.
Stafford	I had extra stress as I was a carer for my husband who had dementia. He has since died and I feel my physical and mental health has suffered.
Stafford	I had long Covid on top of asthma/copd. My 02 levels drop at the slightest thing. My limbs work fine and I miss walking, swimming, cooking (I'm a qualified chef), but can't manage it anymore.
Stafford	I have M.E and lung cancer so have to keep away from people.
Stafford	I no longer qualify for the vaccine even though I have bad health. I caught Covid and it made me very ill for two months. So now I worry about getting it again.
Stafford	I've never regained confidence in social events and lost social contacts as a consequence of Covid, e.g. book club closed.
Stafford	Increased caring responsibility.
Stafford	Lack of confidence. Anxiety level.
Stafford	Lack of sports facilities to play badminton.

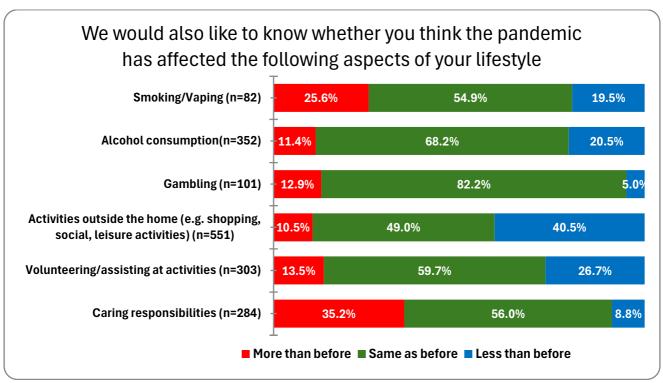
Stafford	Leg cramps.
Stafford	Loss of partner during Covid.
Stafford	Lost job due to Covid. Employed now, but haven't financially recovered. Used to go to the gym but restrictions changed what they offered and haven't returned to how it was before.
Stafford	Mental health issues. Couldn't cope with isolation. Regressed.
Stafford	Mostly linked to my mental health and anxiety around going out in general - not related to catching Covid, just being out.
Stafford	My partner no longer works; therefore, I have to work more.
Stafford	My wife passed away.
Stafford	N/A.
Stafford	Social activities suspended during the Covid period have never been restarted.
Stafford	The cost of living. Everything costs so much more. The cost of a weekly shop has almost doubled.
Stafford	Things are more expensive - electricity, groups never re-started, people are different. I am scared. Covid tried to kill me 2x the second time nearly succeeded. Having a disability, the gov, social services, NHS, treat me as a disposable expense. Past from pillar to post just to try and get treatments.
Stafford	Took voluntary redundancy in 2020, then unable to find a job at the same level due to impact of Covid.
Stafford	Uncomfortable in crowded indoor situations.
Staffordshire Moorlands	4 years older and arthritis hurts more.
Staffordshire Moorlands	Caring responsibilities.
Staffordshire Moorlands	I never got back into social activities after COVID.
Staffordshire Moorlands	I used to have a group of friends, and we would meet twice a week for a pub quiz and to socialise. Since lockdown, most of my friends have got into the habit of not going out. Also, the cost of living since Covid, I no longer have the spare cash to socialise more than once a month.
Staffordshire Moorlands	I was extremely ill with Covid and now have long Covid, which is really debilitating and has severely compromised my health.
Staffordshire Moorlands	It seems it's damaged my lungs.
Staffordshire Moorlands	It's very easy to slip into not doing something regularly, then not doing it at all. As my mobility has worsened over the last 18-24 months, I find it harder and harder to participate/go out, and it becomes a vicious circle.
Staffordshire Moorlands	Labour govt has just stopped our winter fuel allowance.
Staffordshire Moorlands	Less fit and older.
Staffordshire Moorlands	Lost a parent.
Staffordshire Moorlands	MPs' receiving 3.5k of energy allowance whilst removing pensioners fuel allowance. Institutions and businesses increasing prices and profiteering from disaster.

Staffordshire	My health has changed & I have medically retired & lost my income.
Moorlands	No. was a tall la callab offer at a way
Staffordshire Moorlands	My mental health affects me.
Staffordshire	My sleep pattern doesn't seem to be as good. It can vary more, but it may be age
Moorlands	related and worse sleep hygiene.
Staffordshire	Partner died during Covid restrictions.
Moorlands	5
Staffordshire Moorlands	Put on weight during Covid as concentrated on meals to get through. Although walked outside, felt unable to return to the gym and health issues now prevent me from going to gym. Being unable to socialise affected my emotional and physical wellbeing.
Staffordshire Moorlands	Seem to have an aversion to being in large crowds e.g. football matches, festivals.
Staffordshire Moorlands	Separated from husband, so income has gone down.
Staffordshire Moorlands	Since Covid, we no longer have an evening bus service. So, if I want to meet up with friends in the evening, I have to pay for a taxi. This has resulted in me going out a lot less and feeling a lot lonelier and more isolated.
Staffordshire Moorlands	Ten days after having Covid I was rushed into hospital and still being treated.
Staffordshire Moorlands	The pandemic had consequences for my relationship - too much time together and the period of reflection (less distraction) changed personal circumstances.
Staffordshire Moorlands	Unrelated accident of wage earner.
Staffordshire Moorlands	Yes.
Stoke on Trent City Council	(1) Too much work to do, colleagues expecting unrealistic output.(2) Ex GF died at the end of 2023.
Stoke on Trent City Council	Change in income impacts on mood stress levels and sleep - also 4 years older so less energy to involve in exercise and thus less socialising.
Stoke on Trent City Council	Cleaning more, disinfecting, hand washing.
Stoke on Trent City Council	Couldn't go out for my walks.
Stoke on Trent City Council	Covid and the move to staff working from home more has led to poorer services as there is a move away from face-to-face support and services and I'm not social media savvy or zoom.
Stoke on Trent City Council	COVID made me stay in for nearly 3 years and put on 3 stones of weight.
Stoke on Trent City Council	Diet levels, crap. No smell or taste since caught Covid October 2020.
Stoke on Trent City Council	Everything seems to be a challenge, whether that be financially, theoretically, or just life in general. Help is restricted and if you do get it is limited.
Stoke on Trent City Council	Feeling more intense with myself from being furloughed. I reevaluated my career path which needed me to quit a good job that doesn't suit me. Since then, I've struggled to find a good job.

Financial circumstances - significant cost of living increases since pandemic have affected my budget.
Friends have died.
Getting Covid a few times and long Covid made everything worse. No support, no help, services telling you, you now have to pay for help when you can't afford to pay anymore with services already not delivering support. The best thing about the pandemic; I finally didn't have to fight systems. You were left alone as you were in home, not having the daily challenges. We were all finally not having to deal with the systematic stresses and anxieties that the system's create. The feeling of loneliness and isolation was the same, but with a little difference, as that's what we mostly lived with each day. Only now, the whole population was getting a taste of what our everyday experiences/life are really like. The only difference is that now there's a complete opt out of integrating face to face hiding behind online which isn't helpful. Left out of society further, so now if you need help with tech, you now can't fight. The broke system's before Covid only were highlighted even more after Covid. This wasn't anything new we didn't already know was happening just that Covid helped to highlight this even more as the extra use showed the systems were already falling. Did Covid cause the issues? no, did it put the icing on the cake? Definitely did.
Had to build my business back up.
Had to leave work due to poor health.
Had to stop various physical and social activities. Diagnosed with myeloma during the pandemic, so not been able to resume.
Having had Covid twice (despite being fully vaccinated) & being extremely poorly with it, it's made me extremely nervous & also it affects my health more when the family I care for have it.
Husband has caught Covid 3 times, and his kidney function has been hit and reduced. Very stressful and we have to be careful around people. He works but this is where he picks up Illnesses from. Food bill has increased as food costs are high. Utility bills have doubled & petrol is expensive. It's not good.
I am getting older and feel tired, I believe due to this. So long as I have 8 hours sleep, I am fine. I find it harder to keep up with all the things my autistic son wants me to do around the house to help his OCD (i.e. vacuum most rooms every day, don't touch things without a cloth as it makes fingermarks). My son would not have any Covid vaccines and was terrified I would drop down dead when I had the first ones. So much so that I had to have them in secret. I wouldn't have any more though and had them mainly so I could go abroad not because I was frightened of catching Covid.
I feel lonely and the cost of living is so high I cannot afford to do things. Also, I've had major surgery and lost my teeth so feel like giving up.
I have anxiety regarding my health and finances, and I also no longer trust the health service to give me correct information.

Stoke on Trent City Council	I have got Long Covid, this affects all the options and more.
Stoke on Trent City Council	I haven't been out as much because I am immune compromised, so have to be careful where I go. Have wheelchair issues due to lack of service availability with wheelchair service, so unable to travel far. Excluded for safety from groups and social gatherings due to risk for picking up Covid. Friends tailed off due to me being unable to meet up. This all having an impact on the isolation factor. It's ongoing. I keep occupied and take care of my mental health though. Cost of living has increased so worse off.
Stoke on Trent City Council	I retired earlier due to lack of Covid mitigations and having CEV family members. The continuing lack of mitigation prevents me accessing social events.
Stoke on Trent City Council	I took up cooking my own meals during lockdown and learned to cook a wide range of healthy meals.
Stoke on Trent City Council	I'm recently retired and learning to live on a reduced income.
Stoke on Trent City Council	I'm still awake in the early hours, I cannot sleep. My husband wakes between 4 and 4.30 am.
Stoke on Trent City Council	Impact on other people I am supporting so indirect impact on me.
Stoke on Trent City Council	Inflation.
Stoke on Trent City Council	Isolation stopped many of the activities that I did. Most have not started again.
Stoke on Trent City Council	I've got taste and smell issues when eating.
Stoke on Trent City Council	Just don't feel like quality of life with cost of living.
Stoke on Trent City Council	Loss of confidence to travel.
Stoke on Trent City Council	My dog died so I don't walk as much.
Stoke on Trent City Council	My gym closed down and I used to go 4 times per week. Struggled to find a replacement, but now attend 2 exercise classes per week and walk 2-3 times per week.
Stoke on Trent City Council	My husband had two strokes during this period of time, followed by an 11.5hr operation and as per rules, I was not allowed to see him. He has since died. I felt totally isolated, helpless, overwhelmed with anxiety and very emotional. Most of these feelings remain.
Stoke on Trent City Council	My physical activity levels have worsened over the past two years due to Rheumatoid and Osteoarthritis.
Stoke on Trent City Council	None of the above are relevant. Covid has not affected me. Ageing has.
Stoke on Trent City Council	Not going for a walk around the shops in my lunch break anymore.
Stoke on Trent City Council	Retired and full-time carer at home.

Stoke on Trent City Council	Retired. Finances are a perpetual worry due to poor pension advice & planning.
Stoke on Trent City Council	Shielding significantly affected my mental health. I honestly believe that companies used the pandemic as an excuse to increase prices to both other businesses and consumers and have not reduced them even now.
Stoke on Trent City Council	Solitary confinement during lockdown.
Stoke on Trent City Council	Still recovering from the effects of imposed isolation as a single person with no available "bubble". Staying in someone else's home is more difficult; I find it difficult to relax.
Stoke on Trent City Council	Suffered from depression.
Stoke on Trent City Council	The economics.
Stoke on Trent City Council	Work.
Tamworth	Decided to take retirement 2 years before state pension.
Tamworth	Got used to lockdowns and lost the little confidence I had.
Tamworth	I have been diagnosed with a heart condition and it has impacted on my levels of fitness.
Tamworth	I have problems with walking and cannot walk as well as I would like. If I could be seen by anyone who cares, I may be able to find the answer to help me.
Tamworth	Lots of my friends are older than me and don't want to meet up as much since the pandemic.
Tamworth	My medication means that I am at risk from transferred infections. I also can't have Covid immunisation due to having bad reaction to the 1st vaccination.
Tamworth	My mental health has affected my ability to work, so I am worse off. It isn't primarily because of the pandemic, but it certainly hasn't helped.
Tamworth	One of the good things about lockdown was having plenty of free time at home to research and cook new recipes.
Tamworth	Retired.
Tamworth	Retirement.
Tamworth	While my physical activity levels increased considerably during lockdown (lots of cycling, walking, running), these dropped considerably after lockdown and when I resumed work. A lot of the group activities did not recommence for a while, and I did not re-join the gym. It is very difficult now to get motivated to go for a cycle ride or run on my own when I get home from work.
Tamworth	Worried about spreading COVID to my immunosuppressed husband.



Excludes respondents who answered 'Not Applicable'.

Local	We would also like to know whether you think the pandemic has affected the
Authority Area	following aspects of your lifestyle. Comments.
Cannock Chase	Alcohol use increased during lockdowns.
Cannock Chase	Elderly parents need much more support than before the pandemic.
Cannock Chase	Elderly relatives locally.
Cannock Chase	My husband's dementia has been affected adversely by the isolation.
Cannock Chase	Think being greatly restricted I appreciate my freedom more and so I'm making the most of it!
Cannock Chase	Volunteering from home - not available from the organisation before.
East	As I now don't work, I have more time to undertake activities
Staffordshire	
East	As mentioned, Covid has utterly wrecked my life.
Staffordshire	
East Staffordshire	Because I live really close to my daughter (who works awkward hours) I do a lot for my grandson i.e. meals, ferrying to and from school and generally being around if he needs me when she's at work. My son in law has his own business and works long hours too.
East	Caring of granddaughter as mum has long Covid.
Staffordshire	
East	I am now medically retired, need volunteering to give me purpose. Mum is older and
Staffordshire	needs additional help other than carers more and more.
East	I met my disabled husband online during the pandemic.
Staffordshire	
East	Long Covid has practically ruined my life.
Staffordshire	

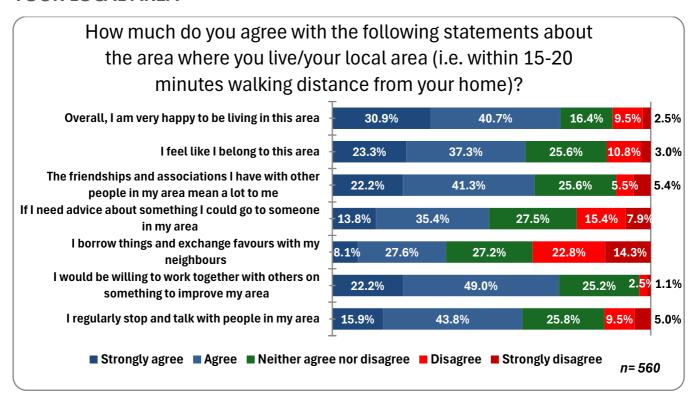
East Staffordshire	My son has stopped socialising since the pandemic.
Lichfield	Activities - I've moved, and things are easier to get to. Caring - my aunt has been going through cancer treatment.
Lichfield	Affected by cancer treatment not Covid.
Lichfield	Became aware of local good neighbors' scheme and now volunteer when I can.
Lichfield	I now volunteer for Canal & River Trust in a highly active role at least once a week.
Lichfield	I realised the importance of developing activity outside the home.
Lichfield	It just seems Covid is now used as an excuse to reduce the number of activities on offer. Also, since Covid, we no longer have an evening bus service, so I am unable to go to my local leisure centre after work unless I pay for a taxi both ways.
Lichfield	Lockdown - I was living on my own so drank and gambled more often out of boredom. These habits continued after lockdown ended.
Lichfield	No longer smoke. I care for my father-in-law, we recently lost mother-in-law.
Lichfield	Partner had hospital stay x 2 with Covid, resulting later with heart attack. Severe scars in lungs leave more vulnerable than previous as was in very good health prior to the virus.
Lichfield	The changes were mainly due to retiring in 2022, not directly as a result of the pandemic, though it's impact on my and my wife's work did contribute.
Lichfield	To many people in too close proximity. Bring back overnight shopping when less people shopping. All groups I was involved with closed and never re-opened due to losing funding.
Lichfield	Try to avoid crowds now.
Newcastle under Lyme	A close friend has had a stroke.
Newcastle under Lyme	A lot of the leisure activities did not reopen for a long time after lockdown and by the time they did, I had got out of the habit of attending, so did not re-join the gym.
Newcastle under Lyme	After going through something like that you realise that life is too short it can be taken away from you in an instant. So go out and do, and experience everything you want to.
Newcastle under Lyme	Dad died during Covid. Now live with mum.
Newcastle under Lyme	Don't go shopping much, use online. Don't go to crowded or busy places.
Newcastle under Lyme	Due to my husband's health and our granddaughter now living with us.
Newcastle under Lyme	Elderly parents need more support. Again, this may have happened with or without Covid.
Newcastle under Lyme	Feel like life is to short not to do what I want.
Newcastle under Lyme	Home deliveries from supermarket started during Covid & found them so useful. Have continued.
Newcastle under Lyme	Husband has chronic illnesses.
Newcastle under Lyme	I don't want to spend any significant amount of time with other people in a confined space.

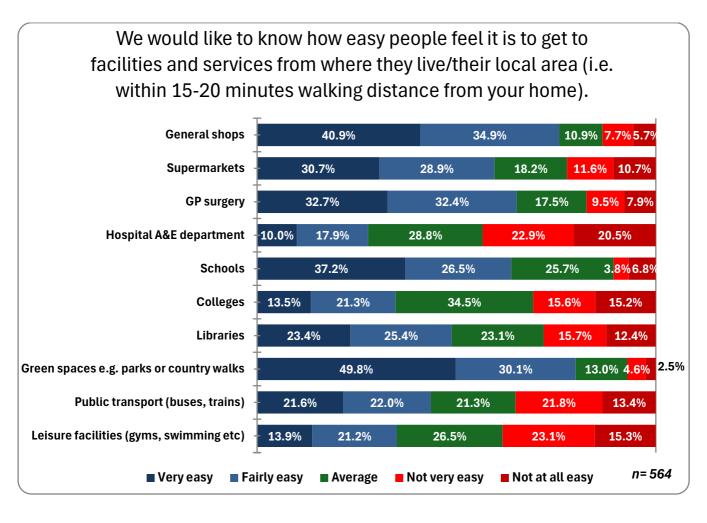
Newcastle	I have taken precautions of meeting people outside my home.
under Lyme	
Newcastle under Lyme	I play bridge regularly and numbers are significantly reduced since before Covid. This is partly explained by individuals getting older and having health issues, but many have just stopped going out, especially in the evening.
Newcastle under Lyme	Kids fractionally older.
Newcastle under Lyme	My partner has Alzheimer's.
Newcastle under Lyme	Newborn child.
Newcastle under Lyme	No longer have a driver for mobility car on a daily basis. Need to arrange one (not easy) to be available.
Newcastle under Lyme	Occupying my mind.
Newcastle under Lyme	Partner suffered from sepsis and now long-term recovery at my home.
Newcastle under Lyme	We still have shopping delivered. As an unpaid carer, I still have a duty to the person I look after and so I take extra precautions when out and about.
South Staffordshire	Parents health deteriorated due to lock down and shielding.
South Staffordshire	Parents need more care. They were affected by Covid and lost confidence.
Stafford	Ageing husband now in his 80s and quite dependent.
Stafford	Caring - mother's dementia worsened during Covid due to isolation.
Stafford	During the pandemic I did a lot of online exercise classes. After the pandemic I started attending these in person.
Stafford	Elderly parents are still reluctant to go out, so I have to do all shopping etc. for them.
Stafford	I am very active in animal welfare/adoption, and I can do this via social media/Internet.
Stafford	I avoid very busy or crowded places if I can.
Stafford	I have decided that as I am 86, life must be finite, so I am doing things; going out, holidays, buying the better food, eating out, etc. One cannot know how long good physical activity can last, so I might as well enjoy life.
Stafford	I now prefer to stay away from high population areas.
Stafford	I socialise less than before.
Stafford	Mom has dementia and MS and is currently in an assessment bed - a 2-x hour round journey.
Stafford	More stable life so feels able to commit time.
Stafford	My husband has been diagnosed with peripheral neuropathy.
Stafford	My mother has Parkinson's and has declined with her condition, so I help my father to care for her.
Stafford	Related to elderly parents.
Stafford	Trying to ease loneliness and be more involved in my community.
Stafford	Volunteering. Post pandemic, I resigned and did charity work in Africa.

Staffordshire Moorlands	As a consequence of distance, my elderly parents now live with us so that we can help with looking after them. Before and during Covid, they lived out of area some distance away and we made a decision to live together so we could be on hand more.
Staffordshire Moorlands	Didn't cope well with restrictions on social interaction and so focused on food and drink with dinner each evening.
Staffordshire Moorlands	Elderly family.
Staffordshire Moorlands	Husband requires more assistance.
Staffordshire Moorlands	Husband suffering from Alzheimer's. Caring takes up most of my time.
Staffordshire Moorlands	I have been left with breathing difficulties which makes everything so much harder.
Staffordshire Moorlands	I have elderly parents who had to shield. One has particularly poor mental and physical health.
Staffordshire Moorlands	Mental health, just nothing feels the same. Stress of having no money as the cost of living is having a massive effect.
Staffordshire Moorlands	Our autistic daughter's anxiety has increased during/since the pandemic. She is now selectively mute and requires constant care/accompaniment.
Staffordshire Moorlands	Parents health deteriorated as a direct result of the pandemic and needs more looking after.
Staffordshire Moorlands	Unable to leave home to go to activities. Used to volunteer but no time to do that as caring takes up all of my time.
Staffordshire	Volunteer for Lions, village hall and community hub. Feel that so many people are
Moorlands Staffordshire	struggling and want to do as much as possible to help. Volunteer on specific Covid duties in addition to regular volunteering which
Moorlands Stoke on Trent	continued . Mum became more ill and lonely and needed much more care Anxiety is really bad since the pandemic.
City Council Stoke on Trent	Caring responsibilities have increased due to parent being diagnosed with dementia.
City Council	
Stoke on Trent City Council	Caring responsibilities. My wife has dementia, and I am her full-time carer.
Stoke on Trent City Council	Caring responsibility has increased due to my daughter having had a cardiac arrest and been in a coma. She now needs more support than previously.
Stoke on Trent City Council	Drink small glass of wine at home most days. This started during Covid when we weren't allowed to go out to the pub.
Stoke on Trent City Council	Drinking more alcohol mainly through boredom and also habit.
Stoke on Trent City Council	During lockdown it made my son want to go out more because they were telling people to stay at home. Autistic reasoning I believe.
Stoke on Trent City Council	Elderly mother-in-law more dependent as lost confidence of doing activities outside the home.
Stoke on Trent City Council	Feel like I want to be with people and help the community so volunteering more. Doesn't cost me.

Stoke on Trent City Council	Having to care for family members with Covid & yourself with Covid; it's extremely difficult & tiring, affecting physical & mental health.
Stoke on Trent	
City Council	Husband has had Covid 3 times and his kidney function has been hit. Although working, his health has deteriorated and it's had a knock on effect for the family.
Stoke on Trent	I have already stated in other questions how I feel.
City Council	Thave already stated in other questions now ricel.
Stoke on Trent	I now care for my 90-year-old Mum as Covid affected her Independence
City Council	significantly.
Stoke on Trent	I was advised to take up some physical activity. I now swim 3 x a week. I also attend
City Council	a local group for people who have suffered bereavement.
Stoke on Trent	I've taken up opportunities that I've been offered.
City Council	
Stoke on Trent	Just bored lifestyle and feeling anxious and depressed.
City Council	
Stoke on Trent	Long Covid, impacting, but no help. No services and no support, as services now only
City Council	signpost to services that sign post again, saying they don't. Services get paid to just
	number push. So, end result is your health suffers, it takes its toll and hospital
	admissions happens as end result.
Stoke on Trent	More care of myself.
City Council	
Stoke on Trent	My daughter has found her mental wellbeing took a downturn and it's been
City Council	necessary to support her more than before. She needs a lot of mental health support but it's helping her.
Stoke on Trent	My mother's health is progressively declining and COVID affected her physical and
City Council	mental health negatively.
Stoke on Trent	People's health needs have increased. Long term conditions worsened due to being
City Council	unable to access safe health appointments.
Stoke on Trent	Services are cut and there are not the services locally. I've also noticed that Hanley is
City Council	losing services.
Stoke on Trent	This is a response to the impact experienced by someone else.
City Council	
Stoke on Trent	Volunteer with my therapy dog who has been assessed. Since COVID restricted
City Council	mixing - attend a care home every fortnight and a school weekly with my therapy
	dog and volunteer once a month at a Dementia café.
Stoke on Trent	Volunteering gets me out and meeting with people. Often called upon to do extra
City Council	due to Covid.
Tamworth	Due to retirement since Covid. I have more time to do things.
Tamworth	Have more time now retired.
Tamworth	Look after my grandson once a week - born after COVID.
Tamworth	My husband has dementia.
Tamworth	My mother's Alzheimer's deteriorated quickly during the pandemic. My father was
	also ill, leaving me as the primary care for my mum and him later.

YOUR LOCAL AREA





Learning Disability, Down's syndrome or Autism Awareness

The Integrated Care Board (ICB) is working with partners across the system to make Staffordshire and Stoke-on-Trent as open and inclusive as possible for people with Learning Disabilities, Down's syndrome and Autistic people.

The following questions could be answered by either a person with a Learning Disability, Down's syndrome, Autistic people, or a friend, relative or carer, based on their observations and experiences.

This section of the survey was answered by 144 respondents.

From the panel members responding;



Awareness – From the list of services provided:

The Ambulance Service was most aware (56.6%) in supporting persons with a Learning Disability, Down's syndrome or Autism.



Safety in the home

85.8% felt safe inside their home.



Feeling safe outside after dark

22.3% felt unsafe outside after dark in their local community.



Visiting the local town centre

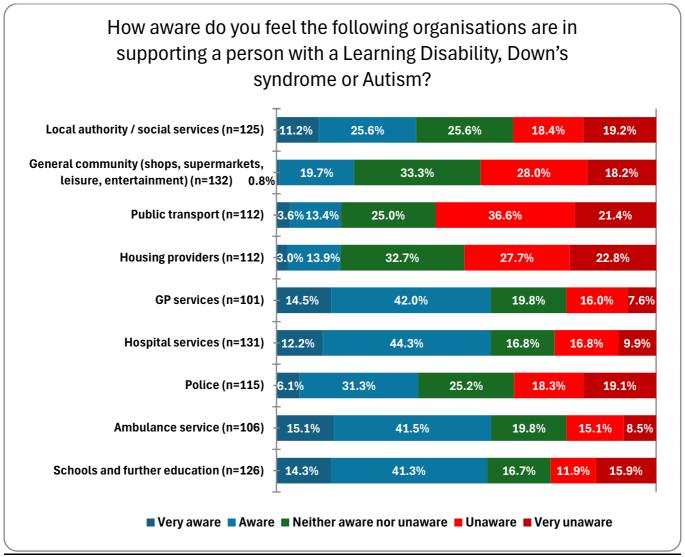
46.2% experienced issues specifically related to having a Learning Disability, Down's syndrome or Autism, when visiting their local town centre.



Obtaining information

The majority of respondents found it difficult, or very difficult to obtain information, advice or guidance from the services listed.

Just 8.2% (lowest) felt it was easy or very easy to obtain information, advice or guidance from their Benefits Department.



Excludes respondents who answered 'Not Applicable'.

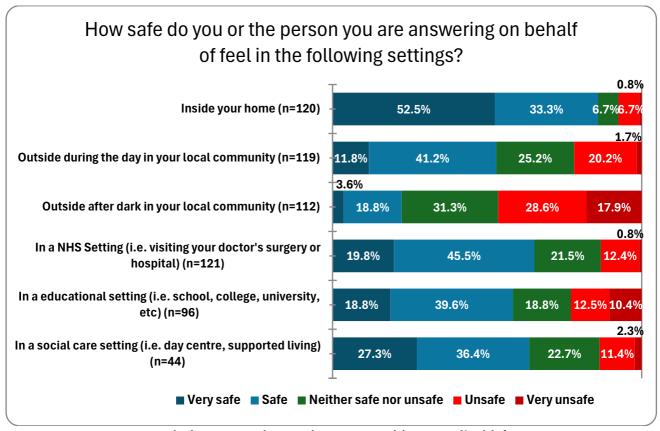
Local Authority Area	How aware do you feel the following organisations are in supporting a person with a Learning Disability, Down's syndrome or Autism? Comments.
Cannock Chase	Awareness varies with people and organisations involved. Patchy knowledge.
Cannock Chase	I think schools often do too much for children whose behaviour is obviously different, but ignore the quiet child who will eventually try to end their life because they can't cope at school, which is what happened with my son. Tried to kill himself at age 10 because he simply didn't understand school and didn't fit in.
Cannock Chase	Think it very much depends on the individuals within the organisations. Some supermarkets play lip service by having a quiet time, some organisations have strategies and protocols in place. Feel that despite efforts to highlight difficulties faced, people who have not experienced disability cannot understand the impact this has.
East Staffordshire	Drivers do not seem to understand difficulties experienced by autistic people.
East Staffordshire	It's rare you know what is happening in the local area.
East Staffordshire	My son has FASD, autism and ADHD. I've yet to come across a service that understands FASD. They have always taken him at initial face value and

	underestimated his executive functioning impairment. We struggled to get him in EHCP and education support.
East Staffordshire	My son has Foetal Alcohol Spectrum Disorder, autism and ADHD. When we had dealings with the police, they did not fully understand his limitations.
East Staffordshire	No support groups for teenagers or adults. No easy referral. Appalling SEN services.
East Staffordshire	People generally show kindness, but no understanding or adaptation of practical things that actually make a difference, without burdening the person to show gratitude for kindness that's actually not helped or at worst hindered.
East Staffordshire	Schools - assessments take too long. Shops - antagonistic towards some autistic children. Local Authority - unaware may be wrong heading, disinterested would be more appropriate.
East Staffordshire	Too many services expect people with autism to be able to use the telephone when so many cannot. The services then insist on talking through a third party instead of to the autistic person directly, even when that person is perfectly capable of dealing with things themselves.
Lichfield	I have an adult niece who is on the autistic spectrum and she has a learning disability. Based on her experiences, and even though she wears a lanyard alerting people to her disability, I don't feel that leisure facilities, or people in shops, or on public transport, show the degree of patience that she needs to be able to communicate with them. In terms of the Local Authority, I think it takes a passive approach to actively finding out what would be supportive. There is little continuity of Social Services staff due to turnover of staff so a continual need to repeat one's history.
Lichfield	Lack of knowledge in the area.
Lichfield	Not much public information available.
Lichfield	Seems to vary dramatically based on the individual you're dealing with in a system rather than the system as a whole.
Newcastle under Lyme	I have not had any reason to learn about this.
Newcastle under Lyme	I know the NHS has policies and procedures in place to support patients with autism and learning difficulties, but I was not aware that services do.
Newcastle under Lyme	Most services offered in support of the disabled with learning difficulties are overrun with work that prevents them being readily available. Social workers often work part time. GP services are usually only available if you attend the surgery, which without transport is impossible.
Newcastle under Lyme	My 10yr old daughter has dyslexia and dyscalculia. It has taken me 3 yrs to get Staffordshire Local Authority to issue her an EHCP, which has involved multiple professional assessments at a cost to myself, plus 2 tribunal appeals. I have received a very poor service from Staffordshire LA throughout this long process.
Newcastle under Lyme	My granddaughter is autistic, but I am unaware of the above.
Newcastle under Lyme	Police have very limited experience, and this is based on more than 3 interactions. Having a child with autism, I've had no help or input with social services. Housing providers consistently let my child down. It's hit and miss when seeing a GP; some have compassion and others have no clue at all.

Newcastle under Lyme	Police; not empathic or poorly trained to deal with people with hidden disabilities or mental health conditions.
Newcastle under Lyme	Schools have been and continue to be the biggest issue for us. Lack of understanding (even though they say they do). Believe they know better than parents. Some teachers are just downright cruel when dealing with my child. Not putting the right resources in place. Constantly firefighting and punishing for issues relating to my child's needs, and yet when they need to safeguard my child they don't and won't admit to failures. It is a constant battle, and I am literally fighting the system they have in place. I've been lucky to have outside resource to support me in meetings etc with school. The school system and the staff involved have seriously affected my own mental health. It is not fit for purpose.
Newcastle under Lyme	Some of them know basics about autism, but that doesn't mean they know how they need to adapt things or mean they're patient when I'm struggling.
South Staffordshire	Council wants people with a learning disability to go online to apply for an energy grant. My friend is on benefits, so the council know of how [Sic]. Why can't the money go to the vulnerable people? Why say they must apply online? She missed out because nobody at the council or CAB would help. She doesn't want a friend helping with her financial affairs either when the council should be sorting this. So, she remains in arrears with energy account because the council won't help her with her learning disability. We'll done!
South Staffordshire	Taught at high school SENCo.
South Staffordshire	Very little support given in hospital stay, no contact with LD nurses.
Stafford	A close friend has learning difficulties, and she hasn't been shown any extra help from most of these. Recently, the housing association had not applied for her council tax for free and she got sent fines and a bailiff letter. Then when they eventually decided to deal with it, the GP would not help with the forms. She faces a lot of issues because people, especially Government/NHS workers seem to think they can get away with it because she won't notice.
Stafford	I don't have these issues, but I have a son diagnosed with Aspergers Syndrome and ADHD. I live rurally and the service I've received over the years has been poor - we've basically had to muddle through with little or no help.
Stafford	I feel like there's a lack of training in disabilities in healthcare. Does not go into disabilities enough and it should not be online, it should be in person to make sure people are focusing, as with online training people can just rush through it. I think as we find out more people in society have disabilities, there needs to be mandatory training. In-person training courses about learning disabilities and mental health conditions and how best to manage them. These should be mandatory courses that are completed over a week. Public transport should display posters about disabilities. Please respect people who may be struggling, or at least make people aware why someone may behave the way they do. School should cover at least one lesson on disabilities and how people are different in society, so there's more of awareness of it and accepted as the new normal. The mandatory or recommend course healthcare workers do should be provided to police officers and social workers and anyone who works in authority or government body dealing with people.

Stafford	I have no close contact with people living with these conditions. I have not seen any information heightening awareness of help of support offered by the above referenced services.
Stafford	I presume that policies are in place, but I haven't personally seen examples of practice.
Stafford	My son goes to a special school in Lichfield, but it doesn't feel like he gets support at home. He is a young carer too. There is very little joined up support between school & our home life.
Staffordshire Moorlands	Both my son and daughter, who both have autism have experienced endless difficulties with all of the above with the exception of our local police who were absolutely fantastic when one of them went missing.
Staffordshire Moorlands	I am autistic but mask heavily as a lot of people do. I don't feel anyone really understands this or knows how to accommodate me.
Staffordshire Moorlands	My daughter is autistic and has ADHD. She has attended mainstream schools throughout her education. Both middle school and high school have failed to meet the provision of support stated in her EHCP. This has led to her becoming a school refuser and has caused her mental distress and mental health difficulties.
Staffordshire Moorlands	Our daughter is autistic, selectively mute, has OCD and anxiety. Symptoms have significantly increased with the pandemic. We have to fight for every iota of support. She is surviving in school and life, her progress and independence is inhibited by services that are poorly funded, poorly informed and that do not collaborate. She has no company/ friends and our community and life experience is that people are far from inclusive unless they have considerable lived experience. We are desperate to achieve support that is tailored to her needs, yet we battle against systems purporting to help in an attempt to any glimmer of hope of success [Sic]. Every service/opportunity operates during work and school hours. Services are frustrated at an inability to attend, yet there is a limit to time off work for working parents and children at a crucial stage of their education. I worry about what the future will hold when we are no longer here to care for her.
Stoke on Trent City Council	Always have to explain everything.
Stoke on Trent City Council	I don't tell that many people that I have autism, but when I wear my lanyard or mention it, they are very helpful. I do find that they are often very supportive towards me if I wear my lanyard because they can see straight away that I may have autism.
Stoke on Trent City Council	I have autism and very few people acknowledge it is something that affects me. Diagnosis took place but then there was no follow up. There isn't even a record of it from my GP in a list of conditions. I feel most places are unaware of autism, what it means and how to support those with it.
Stoke on Trent City Council	I used to work at an FE College prior to retirement and worked with learners who had learning disabilities, down syndrome and autism, so was fairly aware of the range of services provided then. I have been retired for several years so do not know the current level of services available.
Stoke on Trent City Council	I see every day where the clients of Lifeworks struggle in the community and with people who are working in services. This is why we advocate for them. It normally depends on the person and if they are of a caring understanding nature. Secondary, mental health services are not fit for autistic people as I know from

	how they have treated my own son. I am not happy that autism and ADHD is lumped together with LD as most of our clients don't have a LD, but a high IQ, so feel that they are talked down to and patronised as not being able to understand rather than being supported when communication is difficult for them.
Stoke on Trent City Council	It varies with who you are dealing with. Some have awareness but many employees do not.
Stoke on Trent	My daughter is autistic and she barely gets any support from school, and the
City Council	health service waiting list times are so long.
Stoke on Trent City Council	My son has had difficulties throughout education and is now being placed in a SEMH High School because there are no suitable schools that he can attend. I have tried to get a disability social worker for years but don't meet the criteria. I am a lone parent.
Stoke on Trent City Council	Not enough is being done for people with learning disabilities or people who have got general problems.
Stoke on Trent City Council	Personal experience; not much awareness around ASD.
Stoke on Trent City Council	Several have no proper training to understand and deal with autism. Likewise, mainstream schools very poor dealing with anything not the norm. E.g. autism, downs, Tourette's. ADHD, etc. In this day and age, we are still fifty years ago when these were referred to as backward, simple, or difficult!
Stoke on Trent City Council	Son has Dyspraxia; picked up at Uni. Should have been picked up at school and 6th form. Also, more than likely has ADHD and on autistic rainbow; hospital said they don't know. Covid came and that was it. Won't test him. Notice this more as he's got older but he's brill.
Stoke on Trent City Council	The GPs don't know how to communicate effectively and don't go the extra mile that is needed.
Stoke on Trent City Council	There is a general lack of understanding of these conditions across almost every public service.
Stoke on Trent City Council	There is not enough support or understanding for people with learning disabilities.
Stoke on Trent City Council	There's isn't enough training.
Tamworth	It's contextual to the individual member of staff. For example, a practitioner told my son that he didn't look autistic. Other than that, my GPs are excellent.
Tamworth	Laura ***** who is one of several social workers we have experience with is excellent.



Excludes respondents who answered 'Not Applicable'.



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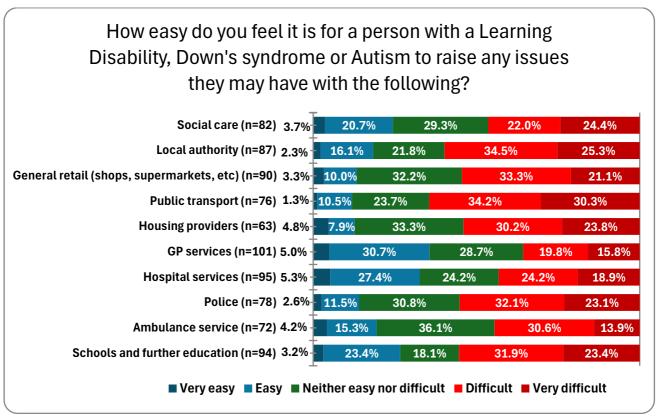
Local Authority Area	When visiting your local town centre, do you or the person you are answering on behalf of encounter any issues, specifically related to having a Learning Disability, Down's syndrome or Autism? Comments.
Cannock Chase	Anxiety related to autism.
Cannock Chase	Just the noise and general high numbers of people can bring on high anxiety.
Cannock Chase	The person is still very young. Have noticed frowns of disapproval from other shoppers if meltdown occurs. Have lots of experience in schools caring for autistic pupils and seen bullying, although school did a good job of educating students about issues and most students understood and tried to help pupils integrate and just be accepted. Good social needs department.
East Staffordshire	Deafness and inability to use cash cards in shops or cash machines.
East Staffordshire	I have not ticked unsafe but have ticked unapplicable because he will not go out due to huge social anxiety.
East Staffordshire	Not applicable as his social anxiety prevents him from visiting the town centre.
East Staffordshire	People avoid they won't engage.
East Staffordshire	People ignore the sunflower lanyard and do not give any reasonable adjustments when I am struggling to deal with confrontational situations.
Lichfield	Lack of understanding. Just often get called weird.
Lichfield	Lack of patience when my niece is trying to communicate what she wants when she goes into a shop. For example; more and more shops are introducing self-serve tills and removing or not staffing assisted cash

	tills/checkouts. This is a problem, not only for my niece but also other vulnerable groups such as elderly people.
Newcastle under Lyme	Been stopped by the drug users in the town. He has also been stopped by security guards for taking too long to choose a product. When I tried to deal with the situation there was no compassion.
Newcastle under Lyme	Judgemental people when there is a meltdown.
Newcastle under Lyme	Shops are too cluttered with counters, baskets and stands on which items are displayed. Keeping hands from grabbing items is impossible due to the lack of space to pass through the store.
South Staffordshire	My friend will only pay cash. Not all shops accept cash.
South Staffordshire	The public, including shopkeepers are unaware of the difference between an autistic meltdown and bad behaviour.
Stafford	Can't get there - no public transport and I have needed blue badge parking for years. There aren't enough disabled spaces and often non badge holders block them. Once went to St George's and used a space with my blue badge and got a hefty fine because I hadn't registered in advance, but nobody told me I had to. Won't go again because of this.
Stafford	Not all shops are accessible, even though they should be. The lack of changing places in the local area is poor so my daughter is restricted for how long we can go out, as she needs to use a hoist and changing bed for toileting needs.
Stafford	People cycle in pedestrian area is hard sensory wise. It's not good seeing ppl [Sic] dealing, doing, or effected by substances. Son could easily be sucked into helping a drugs gang as he has no awareness.
Stafford	Unsafe in towns.
Staffordshire Moorlands	Businesses are improving, but not all are inclusive. For example, if we go out for lunch to a cafe and it is it's a find a table, bring your number to the till scenario, daughter unable to wait alone, therefore we can't eat there [Sic]. We experience sensory overload, loud noises, hustle/bustle, it's overwhelming. Particular difficulty with chuggers, especially charity collectors who have to be somewhat assertive and don't realise/consider they are causing her distress by following/pressing for conversation. Inaccessibility of toilets, daughter is 15. Unable to use lifts, difficult when shopping if lift is only choice with shopping trolley as cannot use [Sic]. Often have to abort mission due to overwhelm/inaccessibility.
Staffordshire Moorlands	Dealing with crossing the road and coping with other people.
Staffordshire Moorlands	No. Why?
Staffordshire Moorlands Staffordshire Moorlands	Over stimulated by noises, people, lights etc. Overwhelmed by the environment, comments/looks from other people due to autism related behaviours.
Stoke on Trent City Council	Autism often comes with a variety of sensory issues which are hugely overwhelming in a town centre environment. I also feel like everyone else has got a social rulebook at some point in their life and I was sick that day [Sic]. I have trouble seeing why things have to be done a certain way and why. This can cause issues when people expect certain behaviour from you, then when you don't it's considered rude or like you're not fitting in.

Stoke on Trent City Council	Being put under pressure by people around them, not being able to think in the moment or be able to communicate what they need. Having a personal assistant or carer with them makes them feel safe and that someone can help them to communicate when necessary.
Stoke on Trent City Council	Communication.
Stoke on Trent City Council	Dyslexia, dyspraxia and dycalculia and mental health issues.
Stoke on Trent City Council	Feel unsafe, dislike what they see/feel.
Stoke on Trent City Council	I do not feel there is enough awareness of autism in the local community. If my son is having a meltdown or difficulties, I feel very judged by people around me.
Stoke on Trent City Council	I don't go out to town without another person. There are a few homeless people about. I have been approached by them before, usually to ask for money, but I always say no. They aren't always like that. I'd rather not be harassed by people who feel I am a target due to being disabled. Don't think it's my autism that makes them approach me, it's more the fact I am in a wheelchair and might be seen as an easy target by the odd individual. Sadly, I tend to avoid places where they might be.
Stoke on Trent City Council	It's hard as they are vulnerable. Having to find safe spaces is getting harder, and making sure the get support needed is hard. People are even more less tolerant and more aggressive.
Stoke on Trent City Council	Lack of understanding of needs.
Stoke on Trent City Council	No awareness of hidden disabilities. Get tutted at for using a lift if you have ASC.
Stoke on Trent City Council	Though some places are great others aren't. They need to have better training. Most cafes and restaurants are not accessible for wheelchair users.
Stoke on Trent City Council	Too busy and noisy.
Stoke on Trent City Council	Yes, I have very significant sensory issues and social difficulties, so I get overwhelmed to even get ready, look after myself, and make sure I have eaten food that doesn't disgust me. All the time I am getting overwhelming by the noise in my surroundings; in my kitchen etc. Then, if I go into town, it's loud noise from the cars on the road and other things going on, so I need to wear noise cancelling headphones which need to be charged because they are wireless. But the feeling of wearing headphones also overwhelms me. I am avoidant of speaking with people in my town/local area because I don't know what is expected of me and what to say. I can't give eye contact and I am overwhelmed by background noises, smells, my clothes, etc. If a shop worker recognises me and tries to make conversation, I am confused because I didn't plan for that interaction and it makes me feel alienated and lonely because, although I am from the local area, I don't feel a part of the community. I see other people talking to each other, learning their names and having

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	small talk. I don't think that will be possible for me, so it's sad, but I also would feel overwhelmed if I tried to make acquaintances because I would be obligated to maintain and confused about what that entails for me in my behaviour, speaking, face expressions, that's all too many details [Sic].
Tamworth	Lack of understanding and tolerance by shops and people in the area.
Tamworth	Shop lighting can cause sensory issues, particularly those with strip lights.



Excludes respondents who answered 'Not Applicable'.

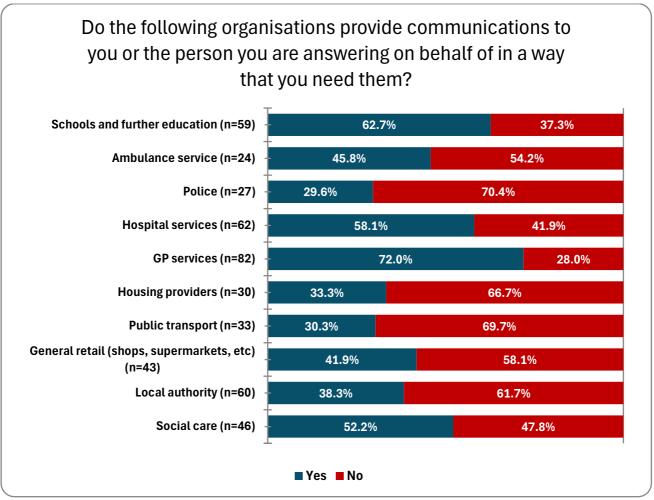
Local Authority Area	How easy do you feel it is for a person with a Learning Disability, Down's syndrome or Autism to raise any issues with the organisations listed? Comments.
Cannock Chase	Where I have chosen don't know; I would imagine that there are measures put into place since the Equality Act, but I do not know who you would first approach if an issue arose. Maybe this needs to be highlighted for all, not just customers with additional needs.
East Staffordshire	Because the issues are a labour the whole system not one specific place or person [Sic].
East Staffordshire	Dyspraxia is understood by very few people.
East Staffordshire	In my experience timescales are not adhered to and information is not volunteered. The tick for LA [in survey] is actually for LEA who did not keep to statutory EHCP timescales, did not volunteer any helpful solutions at annual reviews, and tried to reduce provisions already in place. A social care assessment produced a very inaccurate report.
East Staffordshire	Lack of understanding.
East Staffordshire	Most of these expect problems to be dealt with via phone calls or via emails. In some situations, I've sent many emails and been sent round in circles. I tried to go to the office to be told that everyone works from home, please ring the office; which I cannot.
East Staffordshire	Schools seem to fob you off around your children's needs and nothing gets done, or if it does it take years for any action. Police wise - it's rare anything is done. To be fair, you hear a lot of sirens at night but it doesn't make you

	feel better as it feels like it's a constant thing. Most nights you hear multiple police sirens all night, which raises concerns of what is going on.
East Staffordshire	They don't care or they make assumptions. No two children with autism are the same.
East Staffordshire	Too young.
East Staffordshire	Very difficult to arrange transport to and from hospital appointments.
East Staffordshire	We had to raise a formal complaint with the local authority regarding issues around education. This was a long and drawn-out procedure to get resolution.
Lichfield	I don't think schools and colleges have the right support in place. Whether this is due to the teacher or the school/college policy. It is hard for the student to be believed in many cases.
Lichfield	My brother simply wouldn't know how to raise a complaint, and when I've supported him, systems are either labyrinthine and complex, or too simplified to the point of being useless.
Lichfield	Access to local authority and social care staff is not easy, as cutbacks have meant less staff. Communication channels are not clear.
Lichfield	I have tried raising concerns but nothing changes and nothing happens. When you live on your own you learn to melt down in a corner in your own home.
Newcastle under Lyme	Again, with the police it comes down to a lack of empathy and training.
Newcastle under Lyme	He wouldn't feel safe with any of the situations.
Newcastle under Lyme	School have made it clear to me on a number of occasions that I am too involved, and I should leave them to 'manage' my daughter in school. They have formally complained to me via email when I emailed a teacher directly with concerns regarding my daughter.
Newcastle under Lyme	Staffordshire LA do not accept accountability for their failings and poor service in my experience.
South Staffordshire	For people with a learning disability or autism all of the above or most of them will be difficult. Systems are not in place to help LD or autism.
Stafford	Because it feel like they should be given a sheet to be able to do feedback and then give them back.
Stafford	He wouldn't know who to approach and who will want to help him.
Stafford	I may be wrong but not many services are trained in LD. Also, I've not seen any services making reasonable adjustments, such as easy read.
Stafford	My son is an adult now and in the past, it was very poor. At 16, he was 'abandoned' by child services and we received no report from adult services. It might be better now, although it took 4 years to achieve an ADHD diagnosis. I'm hoping this will make accessing services now a little easier.
Stafford	She doesn't know how.
Staffordshire Moorlands	If you are a masker or try to mask your issues, people do not appreciate the needs or difficulties I have and think I am causing issues if I ask for accommodation.
Staffordshire Moorlands	My daughter is selectively mute and struggles with communication in general. Little actual consideration/testing of mechanisms through the lens of different people with autism and/or mutism. I am largely my daughter's advocate.

Staffordshire Moorlands	No.
Staffordshire Moorlands	The doctors who had a good understanding of autism have left our practice and the ones who are there now have little to no understanding of autism at all.
Staffordshire Moorlands	These services are difficult to reach/contact. You do not get to speak to someone who is responsible.
Staffordshire Moorlands	Very little support from the LA when I have escalated the situation in school in terms of the provision laid out in her EHCP has failed to be adhered too.
Stoke on Trent City Council	I don't think they'd understand him.
Stoke on Trent City Council	I feel that raising concerns can make the system more of a challenge for you. When I have raised concerns in the past, I have had difficulties accessing the service afterwards. For example; being spoken to inappropriately or being refused support. I tried to complain about my son's school but there was a process that you had to follow before you were able to complain to Ofsted, but I couldn't get past the first stage. Once I pulled my son out of the school, I was no longer able to complain to Ofsted. The school let my son down immensely.
Stoke on Trent City Council	I had a problem with a hospital concerning a procedure once. It was not Stoke but was carried out badly, caused major problems. They knew what I was referring to when I complained, but they refused bluntly on two occasions to admit they were in the wrong. I ended up dropping the case. I was cross and felt I was being ignored. Don't use that hospital now so okay. Hard for us sometimes to be taken seriously. Still a lot of non-awareness around autism.
Stoke on Trent City Council	It is very difficult to generalise about people with learning disabilities, down's syndrome, or autism. But my experience working with individuals over several years is that many do experience real difficulties in raising issues of concern with a range of organisations.
Stoke on Trent City Council	Just don't feel accepted for the way I have my disabilities or issues.
Stoke on Trent City Council	Lack of understanding of these conditions.
Stoke on Trent City Council	No, I can't as it would be too long.
Stoke on Trent City Council	Nobody really knows how it is, how to respond to it. Even if you do tell them, there is no change in behaviour. Often, I'm asked how I'd like to be supported, but this often puts a lot of the onus and mental capacity on myself to work this out for people. It's not sustainable.
Stoke on Trent City Council	People, either in the community or in services don't always listen and give their opinions which can be stressful for people on the autistic spectrum. The person with autism may not be able to answer quick enough or may have misinterpreted the question. Also, when things are explained to them, they have to take time to process what is being said, so it may appear they are not listening. The person on the spectrum is likely to have extreme anxiety and being put under pressure will make this worse.

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Stoke on Trent City Council	Person with down's does not have the confidence or capability to complain.
Stoke on Trent City	Schools are the most challenging as they say they are trying to help, but due
Council	to a lack of training they are very unsure of what they are doing.
Stoke on Trent City Council	Support would be needed to raise any concerns.
Stoke on Trent City Council	There are not enough resources or support for people with neuro divergent conditions and these people often slip through the cracks and miss out on vital support that could help them.
Stoke on Trent City Council	They are met with hostility, there character attacked, belittled or told they should be grateful. Left with long term consequences that impact directly on their life that stop them living life as they should.
Stoke on Trent City Council	They do not listen or understand issues and are also not willing to help to diagnose mental health issues where children are concerned.
Stoke on Trent City Council	They need support in these situations.
Tamworth	My children and I, them as students and myself as a teacher, have all experienced disability discrimination. Refusal to adopt reasonable adjustments, informal exclusions, and spurious disciplinary action.

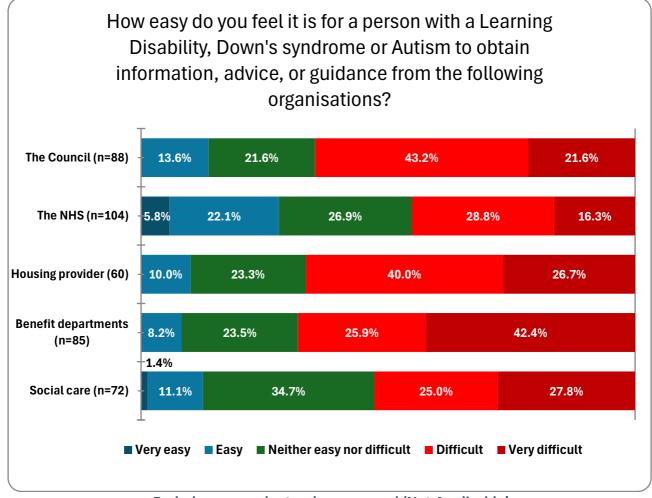


Excludes respondents who answered 'Not Applicable'.

Local Authority Area	Do the organisations listed provide communications to you or the person
	you are answering on behalf of in a way that you need them? Comments.
East Staffordshire	All expected me to do stuff via the telephone in the past, which I cannot do.
	No reasonable adjustments allowed apparently.
East Staffordshire	College do not communicate well about reasonable adjustments made.
East Staffordshire	Don't need to hear from them but would appreciate being able to contact
	them more easily as my brother's carer.
East Staffordshire	The local authority communicate through a Hub. I don't have a computer or
	laptop.
East Staffordshire	Written/email follow up. School state 'this is only informal, we don't need to
	do that'. But the request is to support my challenges with working memory
	and executive function, not to try and formalise any process. They don't
	seem to understand this.
Lichfield	Lack of training, understanding, and treating us as idiots. We are not! sort all
	that and you will be on your way to a good service.
Lichfield	No support or communication.
Lichfield	The assumption is that the person who is disabled will have someone acting
	as their advocate.
Newcastle under Lyme	Communication from Staffordshire LA is poor.

Newcastle under Lyme	I do have email correspondence with a member of the learning support team, which is an improvement. But, I do feel we need correspondence to be with the designated teacher.
Newcastle under Lyme	It needs to be regular and clear. They need to say what they're going to do in advance and give time to process that.
Newcastle under Lyme	Stop talking to him in ways that he can't understand and making him feel ignored.
South Staffordshire	Lack of privacy and time afforded so we can help our children understand what is happening.
South Staffordshire	My friend struggles with the housing provider and the council.
South Staffordshire	Take more time to ensure what's been said is understood by the person.
Stafford	GP throws lots of information to her which she can't take in all at once. They should word things differently and ask questions to check she understands. They should make notes she can take away with her so she can remember.
Stafford	We've never had any help, and I don't know what help is available - we just got used to going it alone.
Staffordshire Moorlands	Communication is often very patronising.
Staffordshire Moorlands	Direct communication with my daughter, not to me, in a non-confrontational way (daughters' definition of non-confrontational). She wants to be communicated with. Because she is selectively mute and is visibly distressed by being pressed specifically to return verbal communication, no one speaks to her! Just because she struggles to speak, doesn't mean she can't hear. Communicate in a way that accounts for her holistic needs, e.g. we have just received an appointment with CAMHS service; daughter is autistic, needs to understand what to expect when attending the appointment. Invitation has no indication of appointment purpose, nothing to reassure an anxious autistic young person. Communication is not considered and doesn't practice what we preach.
Staffordshire Moorlands	GPs need to listen to carers about the needs of the people they care for, especially when they do not have the confidence or are reluctant to see the GP directly because of the way they have been treated previously.
Staffordshire Moorlands	The language used is not clear enough and does not provide enough information. There is not an easy way for someone to communicated, and issues around autism are not understood. A parent or carer is often needed to support communication and explain things to the services involved.
Stoke on Trent City Council	An extra box would have been useful - sometimes/occasionally and that would have been ticked on most of the above categories.
Stoke on Trent City Council	Communication, or the lack of it - it's all online. This isn't helpful if you have to find help to do this and that help isn't available. In this city for some reason, no matter how much this is put across, it is not heard. Example at an NHS service event when asking what they are doing to reach out to those who can't use tech and stuck at home, it was stated how there was a really good new initiative reaching out at those isolated by going to market day events. When questioned how this was good to reach out to those stuck isolated in their homes, it was stated that someone there will be able to come and talk to them. I said, but these are the people that can't go out, and

Stoke on Trent City Council Stoke on Trent City	that isolated and vulnerable and are not using computers, they aren't the types that are going out, they are the ones your trying to reach but for some reason aren't understanding that they need communication in different ways, e.g. face to face, paper leaflets or verbal. Being left out of basic communication causes so many issues - missed appointment, misunderstanding and difficulty accessing. GP surgery ignores complaints and boundaries. I feel that EHCP's are very difficult to understand and navigate. There should
Council	be more support for parents to help them to understand and complete EHCP's.
Stoke on Trent City Council	I have answered no but not everyone is the same. Again, it is according to whether the person listens and helps. The best mental health nurse we ever saw had a son on the spectrum and she really got how my son felt and really helped him. I have had good and bad experiences and like I said previously had most of the bad experiences with secondary mental health and sometimes the GP. Neuro psychiatry are all lovely people and seem to go that extra mile. Social workers can come over as they know best and don't listen to the family or won't speak to the carer due to confidentiality. Triangle of care should be used so that everyone is able to feed into a care package.
Stoke on Trent City Council	I have indicated no to the organisations that I have not seen any information specifically designed to communicate with people with learning disabilities, down's syndrome and autism.
Stoke on Trent City Council	I think communication should be direct and not with the assumption that people are going to understand certain social norms or take things as 'common sense'. Common sense is a thing for those who are Neurotypical and largely think the same way. Neurodivergent brains are much more varied and often adapt to their own needs and troubles. This can vary widely, there is no 'common sense' when it comes to autism and other differently abled conditions.
Stoke on Trent City Council	I would like more information in letters. For example, if I have a medical appointment, the letter most often does not describe what will happen during the appointment or how long the appointment will last, the job description of the people helping you. All these things are questions in my mind and confusing information that would help to know.
Stoke on Trent City Council	More help and support for undiagnosed children.
Stoke on Trent City Council	No one uses easy read so my son can understand with greater independence. All letters are written as normal.
Stoke on Trent City Council	Uni support; difficult to get through to departments via student services or phone/email.



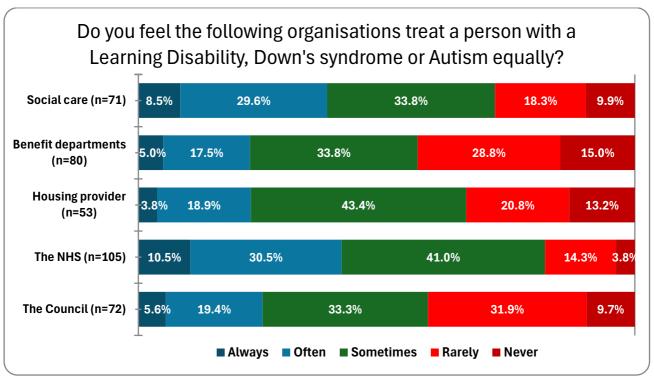
Excludes respondents who answered 'Not Applicable'.

Local Authority Area	How easy do you feel it is for a person with a Learning Disability, Down's syndrome or Autism to obtain information, advice, or guidance from the organisations listed? Comments.
Cannock Chase	Sorry, not had personal experience of this yet. In the past I have seen people access an advocate or befriender.
Cannock Chase	The whole system is designed for someone who can read and understand it. If my son didn't have my wife and I to read and explain to him he wouldn't be able to access many things.
East Staffordshire	All have expected me to use the telephone to get the information I require, which I cannot do.
East Staffordshire	Lack of knowledge and awareness of disability.
East Staffordshire	My brother is profoundly deaf and has learning difficulties. He cannot initiate contact via a phone and does not use the internet.
East Staffordshire	NHS-wise, it's utterly backlogged. We are four years in on a waiting list for our daughter and still no movement. You get passed around and no one solves anything. Benefits are utterly confusing and have no idea what you can or cannot apply for and the council are very much worthless and just won't help you, or make it difficult to try and solve anything.

East	No support commissioned for autistic adults with minimal or high-level support
Staffordshire	needs.
East Staffordshire	She would have no idea where to start.
Lichfield	As before, systems are either too complex or too simplified. Don't seem able to adapt to his individual needs, just have a generic way of communicating with those with disabilities.
Lichfield	If you viewed it as a journey for the person with a disability in trying to obtain information from these agencies and broke that journey down into stages, I think there are hurdles at each stage. From initial access - trying to find out who or what dept to contact - negotiating a website, physically trying to get through online or by phone, continuity of responder, format of information provided.
Lichfield	Local council doesn't have an office you can visit.
Lichfield	They don't listen. I actually got told, after saying; "I am autistic, could you explain that again I am not understating", their reply; "So is most of the country now, it's fashionable"!
Newcastle under Lyme	I have no experience of contacting the local council or benefits department with learning disability or autism issues, but I have had extreme difficulty and delayed response times both re other issues, including the phone just cutting off after listening to several directive messages. I can only imagine how much more difficult it would be for some disadvantaged folk.
Newcastle under Lyme	My son has no communication, so everything must be done by myself. I can communicate very easily.
Newcastle under Lyme	No one seems to have the time or want to help.
Newcastle under Lyme	Still waiting for full ASC diagnosis since 2019 daughter has had a working diagnosis no one commissioned apparently to review these children [Sic].
Newcastle under Lyme	This question is impossible to answer as each person will experience different levels of difficulty and ease in everything they do.
South Staffordshire	Council & housing again. Benefit application for those with a LD or autism is very difficult.
South Staffordshire	Services are often rushing to pass you on to the next person or pass you no [Sic].
Stafford	Because they need to make it more disability friendly. So easier to understand and offer someone to help them to go through the processes so in place across the day you have an AA approachable adult [Sic]. I feel like there should be one there for people with disabilities to go through and help them understand the process as well as help them to apply for housing etc, and make sure they have the support they need. These people have the relevant training to do these things and to support people with disabilities within their home or within a GP surgery, taking the pressure off mental health services and disability services. These people primarily would be based at a GP surgery, or they would be based with social workers who deal with people with disabilities or based with the council.
Stafford	We've always had to manage with little or no help, so we just learned to cope alone.
Stafford	Things aren't explained as easily as they need to be.
Staffordshire Moorlands	Convoluted and non-person-centred systems.

Staffordshire Moorlands	Difficult enough for me as an adult/parent to access/comprehend.
Staffordshire Moorlands	It's difficult to know who to contact and how.
Staffordshire Moorlands	The NHS and CAMHS have either not responded to multiple requests for advice, or operate waiting lists which are far too long to give meaningful help as and when needed.
Staffordshire Moorlands	There is very little understanding for people with autism across a number of sectors. Carers face the same challenges when trying to support the people they care for. There needs to be a move away from the red tape and tick box culture and more engagement about the individual needs of the person with autism. There is no consistency of approach between the sectors, and it can often be a postcode lottery of what services can be provided.
Stoke on Trent City Council	All require me as the carer to obtain. As before, communication isn't geared to our access needs.
Stoke on Trent City Council	Far too much red tape involved. Difficult to speak to one person. Total lack of communication between parties.
Stoke on Trent City Council	General awareness about what is available.
Stoke on Trent City Council	It is difficult for someone on the spectrum to communicate to services and to explain what they need or how they feel. They need someone who understands their condition and can give them time to process or explain how they feel. Sometimes appointments aren't long enough and if the person doesn't trust the professional, they will not open up and say what is wrong. It is up to a carer or PA to start a conversation or fill in where they are struggling.
Stoke on Trent City Council	It was hard to migrate over my benefits online. The system is not easy to use or understand, it was confusing. They are not clear about what they want in a way that is easy to understand sometimes.
Stoke on Trent City Council	No. Accessible information is not broken down. No translated documents, or lack of.
Stoke on Trent City Council	Not enough awareness or training to support neuro divergent people. Not enough resources in public facing roles to support this group of people.
Stoke on Trent City Council	The benefit system is a minefield. I am sure my daughter is entitled to help but it's so difficult to put claims in.
Stoke on Trent City Council	The individual isn't catered for it's all too often for the general public.
Stoke on Trent City Council	The SEND world is very difficult to understand and navigate. You do not get given information to help you to understand this world, you have to learn it yourself. It can be difficult to know what services are available. I felt with my son's journey, unless you know this world and know exactly what to say/what to ask for then you do not get the support. It feels like a carefully guarded secret that professionals do not want to give away.
Stoke on Trent City Council	The system is often bureaucratic. You ask someone on the front line or in contact with the public and you likely aren't going to get anywhere quick. They won't have information on hand or have any training in neurodivergence. The onus is on me with Autism.

Stoke on Trent City Council There isn't any help for autistic people, apart from charities that run social events, that are difficult to access because of public transport (lack) and being overwhelmed. I have adult services helping me, but their help is confusing, and I wish they would more clearly explain their jobs to me or things like that. I'm not sure what is going to happen. Stoke on Trent City Council We experience these every day, it's become the norm. Life is hard already fighting the NHS for 18 months through Christmas twice. Refusing to deal with the carer, because the autistic young person couldn't, but told despite the young person giving verbal, email and written consent for the carer to deal with it on his behalf with him in the room wasn't good enough and the charge just kept going up. I wasn't able to pay for a prescription certificate due to them saying the exemption stopped it being possible, but that the NHS, still due to him being 19 years old with an exemption, wouldn't process the exception, despite it saying on the NHS system. They still harassed the person with autism, despite even the opticians stepping in with the NHS link to help rectify this. Having to deal with UC is a job in itself as there nothing about young people with EHCPs in place when they have no help. They don't qualify for support, so they are treated as standard, with all the normal expectation without the skills that the LA have stopped them accessing to gain the skills. Don't have independent skills but the system treats them as full adults in charge of knowing what to do when the day before their birthdays they were seen as not having skills for their age never mind told they are adults. They drop of the edge OF ALL SERVICES. Wouldn't know how or who to contact for information or advice. Would not be able to call or email an organisation without support. Access to CAMHS was terrible. My son in particular had a difficult experience.		
City Council NHS for 18 months through Christmas twice. Refusing to deal with the carer, because the autistic young person couldn't, but told despite the young person giving verbal, email and written consent for the carer to deal with it on his behalf with him in the room wasn't good enough and the charge just kept going up. I wasn't able to pay for a prescription certificate due to them saying the exemption stopped it being possible, but that the NHS, still due to him being 19 years old with an exemption, wouldn't process the exception, despite it saying on the NHS system. They still harassed the person with autism, despite even the opticians stepping in with the NHS link to help rectify this. Having to deal with UC is a job in itself as there nothing about young people with EHCPs in place when they have no help. They don't qualify for support, so they are treated as standard, with all the normal expectation without the skills that the LA have stopped them accessing to gain the skills. Don't have independent skills but the system treats them as full adults in charge of knowing what to do when the day before their birthdays they were seen as not having skills for their age never mind told they are adults. They drop of the edge OF ALL SERVICES. Stoke on Trent City Council City Council		that are difficult to access because of public transport (lack) and being overwhelmed. I have adult services helping me, but their help is confusing, and I wish they would more clearly explain their jobs to me or things like that. I'm not sure what is going to
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	Stoke on Trent	Wouldn't know how or who to contact for information or advice. Would not be able
Tamworth Access to CAMHS was terrible. My son in particular had a difficult experience.	City Council	to call or email an organisation without support.
	Tamworth	Access to CAMHS was terrible. My son in particular had a difficult experience.



Excludes respondents who answered 'Not Applicable'.

Local Authority Area	Do you feel the following organisations treat a person with a Learning Disability, Down's syndrome or Autism equally? Comments.
East Staffordshire	All service nowadays are overloaded or just mandated to make it as hard as possible to get anything done. Lots of red tape and lack of empathy. NHS is on its knees and waiting lists are utterly disgraceful. The council are far too bureaucratic and focus on money rather than the public services and infrastructure. Trying to get help for learning needs etc is far too difficult and utterly frustrating, but this then causes more of a decline in health, making the time you do get to see one even harder to solve.
East Staffordshire	I have had services refused because I can't use the telephone. I was meant to be having a carers assessment 4 years ago I'm still waiting for it. I got my benefit assessment after waiting 18 months for them to start face to face ones again. The NHS have discharged me from departments and the council just won't answer why they were sending me money and where does it go? as it never hits my account.
East Staffordshire	It's hard to accommodate extra needs or demands on time in an already stretched system.
Lichfield	Jumping through extra hoops, disbelieved, things not sufficiently explained.
Lichfield	They just don't understand the conditions. They either treat you if your stupid, or don't or wont deal with you.
Lichfield	Very little consideration given to housing provision for people in this category, who at some point will need access to supported/assisted living as their own parent(s) become too old themselves to look after their son/daughter.
Newcastle under Lyme	Depends on the person who is the point of contact and their awareness and ability to communicate.

Newcastle under Lyme	Having been hospitalised during COVID, the hospital refused to allow entry to anyone to support my son. As a result, he sustained severe skin erosion which took 8 months to heal and caused him intense pain and discomfort.
Newcastle under Lyme	I don't think there has been enough education on the matter, or they just don't care.
Newcastle under Lyme	Regardless of my daughter's diagnosis, Staffordshire LA have taken 3 yrs to agree to an EHCP, which has caused her to fall further behind in her education by not receiving the support she deserves and is entitled to in order to thrive.
South Staffordshire	Do they treat them equally?
Stafford	Everyone has a bad day but feel like they treat people with disabilities like they've got no capacity and if they fail to not have capacity [Sic], they still treat them wrong. They should importantly encourage them to make decisions, but if they're not right then overrule them. Just feel like the quick fix for disabilities is medication and not treat and support them. Some people do need medications, but they need to be supported as well.
Stafford	From our experience my friend is often dismissed and not listened to, or is
	told incorrect information to placate her.
Stafford	No, they are all looked down upon and treated less than.
Staffordshire	I don't know, we have little experience in receiving treatment! We don't
Moorlands	need to be treated the same, we need our needs to be met!
Staffordshire	I have already answered this in the previous question.
Moorlands	
Staffordshire Moorlands	Really you absolutely MUST get the right people to develop these 'examinations' into complex personal experiences of living. You need a better Matrix.
Staffordshire	The NHS seems to prioritise physical needs over learning disabilities and
Moorlands	autism.
Staffordshire Moorlands	These issues and disabilities are seen as a problem.
Staffordshire Moorlands	They do not fully appreciate the difficulties faced by masking autistic people or those considered 'low support needs' due to fact they are heavily masking.
Stoke on Trent City Council	Difficult process.
Stoke on Trent City Council	Don't accept person cannot answer for themselves or understand the question.
Stoke on Trent City Council	How could they possibly treat people equally if they do not acknowledge its existence. Prepare for people to have it, training on communication and how to support them.
Stoke on Trent City Council	I have struggled to access support for my son for 11 years. If he had cancer, we would not have this difficulty. I have felt over the years like professionals have tried to blame my son's difficulties on my parenting. The system almost broke me at one point because my son was a danger to himself and others around, but I could not access support. I would say I have spent around £10,000 so far to get my son the appropriate support because I could not access this on the NHS.

Staffordshire and Stoke-on-Trent Integrated Care Board People's Panel

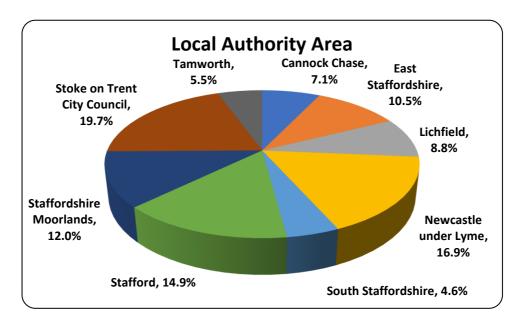
Stoke on Trent City Council	If anything, they are treated as being a burden that somehow, they get everything which they don't. You have to fight everything.
Stoke on Trent City Council	Lack of understanding of these conditions.
Stoke on Trent City Council	Quite often they speak to the person in a patronising way. If you have a high IQ and no LD you don't need to have easy read (which seems to be the answer for most things) you just need an understanding person who listens and treats you with dignity and respect. Not to rush you, but to explain things in a way that can be understood, or if you see the person struggling try to find a different way of explaining the same thing.

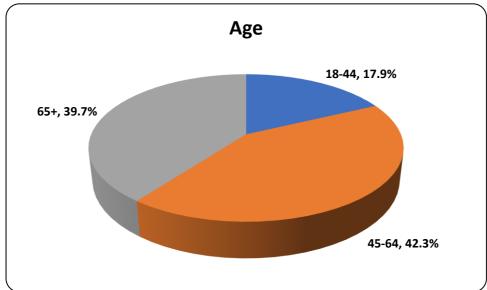
3 Respondent profiles



Demographics of the People's Panel are broadly representative of the profile for Staffordshire and Stoke on Trent (ONS 2021 Census data for Staffordshire and Stoke on Trent). ¹

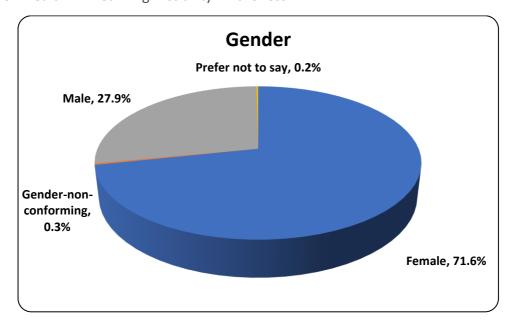
Breakdown of the 609 panel members who responded to the survey.

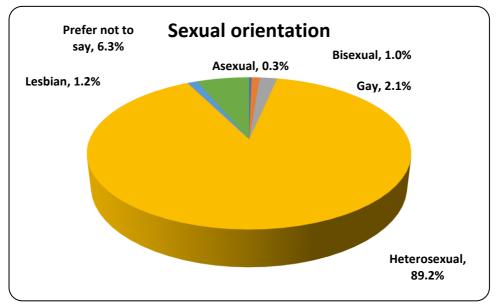


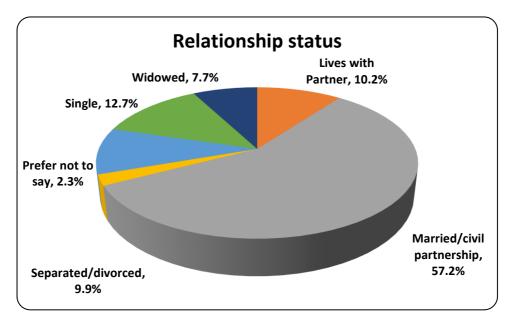


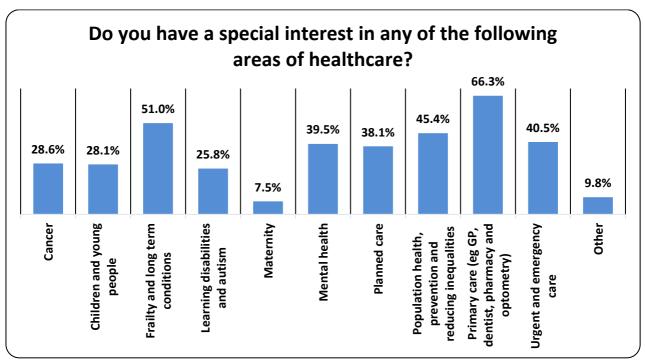
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¹ Staffordshire and Stoke on Trent have separate ONS Census data September 2024 (V2.0)

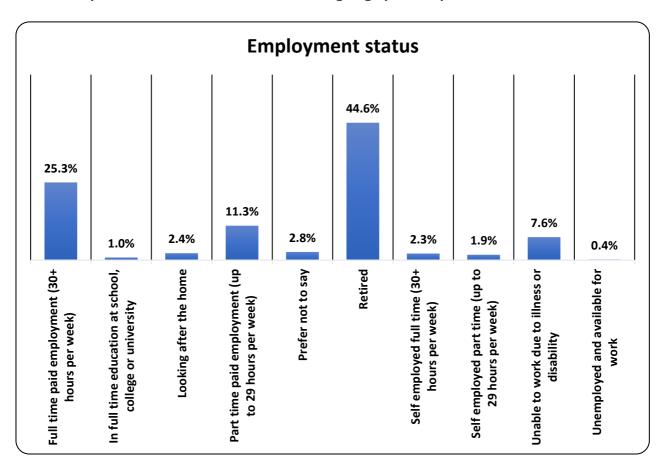


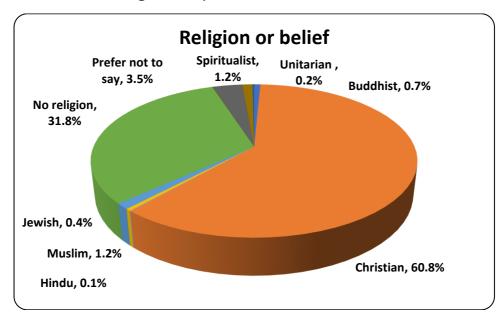


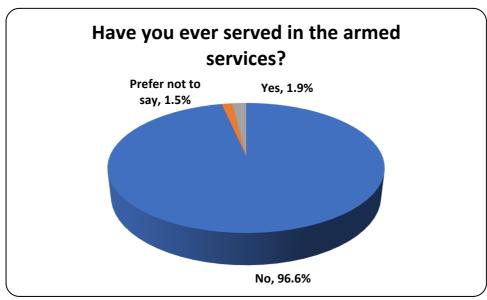


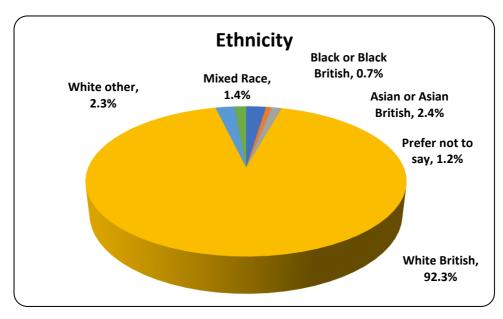


Special interest data is for members signing up to the panel from June 2023









Net Scores (Net promoter score)

The Net Scores are calculated using the total percentage of positive responses (very likely, likely) minus the total percentage of negative responses (unlikely, very unlikely). Neutral responses (neither likely, nor unlikely) are excluded from these calculations.

Please see the main section of the report for number of responses to each question.

