



**TOO MUCH**

**INFORMATION**

**“I get too much information. But some people don’t have enough.”**

**Why the public needs to understand autism better**



The National  
Autistic Society



## THE FACTS

## TOO MUCH INFORMATION

**99.5%** of people in the UK have heard of autism



But only **16%** of autistic people and their families think the public understand autism in a meaningful way



**87%** of families living with autism say people stare at their child's autistic behaviour



**74%** say people tut or make disapproving noises

Tut, tut, tut...



**55%** of the public get annoyed when parents can't control their children when they're having tantrums



**84%** of autistic people feel people judge them as strange



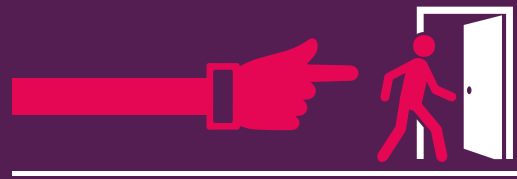
**70%** of autistic people feel people judge them as shy



**69%** of autistic people feel people judge them as anti-social



**28%** of autistic people have been asked to leave a public space because of behaviour associated with their autism



**79%** of autistic people and



**70%** of families feel socially isolated



**50%** of autistic people and families sometimes don't go out because they're worried how people will react to their autism



## FOREWORD

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Alex Marshall, the 10-year-old autistic star of our Too Much Information campaign film, explains, along with his family, why the public needs to understand autism better.



## INTRODUCTION

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Mark Lever, Chief Executive of The National Autistic Society, on why the charity has made improving public understanding its top priority.



## PART 1: BRIDGING THE GAP

### From awareness to understanding

08

Almost everyone has heard of autism, but most autistic people and their families feel like other people don't understand them. Families don't want or expect the public to have expert knowledge. But a bit of recognition of the challenges they face in public situations, and how they cope with those challenges, would go a very long way.



## PART 2: SHRINKING WORLDS

### The human impact of a lack of understanding

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Hundreds of thousands of autistic people and their families are experiencing social isolation because they are worried about how the public will behave towards them when they leave the house. The vast majority have experienced judgemental attitudes or hostility.



## PART 3: THE PUBLIC RESPONSE

### Small gestures have a huge impact

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We know that increased recognition of autism will mean members of the public are less likely to comment and tut, give judgemental looks or even ask families to leave places like cinemas and restaurants. But it also means people will know that they can take some helpful, proactive steps if they see an autistic person in difficulty.



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# FOREWORD

**Alex Marshall** is a 10-year-old on the autism spectrum. We first met him at the 2015 National Autistic Society AGM, when he and his dad, Ben, told us why it's vital that people understand autism better.

We were delighted when Alex auditioned to be the star of our Too Much Information campaign film, not just because he is a very talented young actor, but also because he and his family share our passion for improving public understanding of autism.

Here Alex's mum and dad, and Alex himself, explain why this is so important.

“ The first thing is that Alex is really positive about being autistic. And, if he can be positive, then obviously we should be positive too. The second thing is that our lives are easier when people understand that Alex is autistic and understand what his needs are. That's why it's so good to be involved with the Too Much Information campaign.

When Alex was filming, we were watching him from the balcony and there was a woman who gave this look, a little glance. Everybody watching with us said, 'That's the look!' We all knew it. It was that split-second look of contempt which says, 'Why can't you control your child?' As a parent, your focus is on trying to manage the situation. Then you've got people walking past you, looking at you. Not only is that upsetting, but it also doesn't allow you to do what you need to do, because you get more upset.

But when somebody does something positive, it makes such a huge difference. It's the difference between the first few days of your holiday being fantastic, or being completely horrible, while Alex is de-stressing from the travel. So, when people are positive about and understand Alex's autism, it makes a massive difference to all of us.

That's why we're so pleased that Alex has made the film and that we can tell everyone reading this report that it really, really matters that as many people as possible understand autism better and know not to judge if they spot that someone might be autistic.

– Ben and Kathryn Marshall

”

“ There are times when I need a lot of room. Sometimes this entire lounge may not be big enough. Sometimes when someone brushes past you, it can be as bad as someone pushing past you. I don't fully know why I find it hard, but I think it's about an invasion of space and physical contact when I'm not expecting it. Usually it's not things that people do intentionally which just spark it.

When I was making the film for The National Autistic Society, physically, I felt a bit tired, but it was awesome. It was like winning the lottery twenty gazillion times. Since my diagnosis a lot more people understand. It really helps when they understand as they can help with things I have trouble coping with. I really hope that the campaign will help lots of people who don't know about autism to understand and respect and be a little more careful. That little bit will make the difference to everyone.

– Alex Marshall, 10

”

# WHAT IS AUTISM?

**Being autistic means having a brain that's wired differently. And that can make someone see, hear and feel the world in a different way to other people.**

Sometimes everything is overwhelming. It's like all the senses are firing, all at once. Like there's no filter. Like getting too much information. Sometimes it can mean people are skilled in things that others aren't. Sometimes it means the things everyone else finds so easy are the most unbearable challenges you can imagine.

Around 700,000 people in the UK are autistic. But no two people experience autism in exactly the same way. Some people find it difficult to say what they need, and how they feel. While others find it hard to understand people, how they expect you to behave. It works both ways, though. Autistic people can feel misunderstood. Despite trying their hardest every day, it can feel like they always get it wrong.

Visit [www.autism.org.uk/autism](http://www.autism.org.uk/autism) for more information.

## Methodology

This report is based on focus groups undertaken for The National Autistic Society by Breathe Research, and on a series of surveys undertaken by our charity, YouGov (on our behalf) and nfpSynergy. Taken together, this data represents the perspectives of autistic people, the families of autistic people and people who have no known connection to autism in the UK.

- Qualitative examination of autistic people's experiences, and those of their families, in public. Participants were required to keep a diary in the week ahead of five structured group discussions. (Breathe Research, May 2015)
- Online survey about public understanding run by The National Autistic Society between May and July 2015. 7,532 respondents: 1,003 autistic people (13%); 4,409 parents or carers (59%); 545 family members (7%); 314 people who know someone on the autism spectrum (4%); 1,132 professionals (15%). Non-UK respondents were excluded from the final analysis.
- Focus groups exploring the response of people with no known connection to autism to ideas for increasing understanding of autistic behaviour and to assess their readiness to change behaviour. (Breathe Research, November 2015)
- Poll of 2,159 UK adults for World Autism Awareness Week 2015, exploring what they knew about autism. (YouGov for The National Autistic Society, carried out in February 2015)
- Survey of 1,000 adults in Britain. (nfpSynergy, 2005)
- Charity Awareness Monitor. (July 2015, nfpSynergy)
- Online survey by The National Autistic Society of 407 people living with autism in the UK, March 2015.

## Note on statistics and quotes

Unless otherwise stated, all statistics come from The National Autistic Society survey of over 7,500 people (2015) and quotes are either comments from that survey, or from Breathe Research's qualitative research for The National Autistic Society.

# INTRODUCTION

By Mark Lever

In 2015 we carried out a YouGov poll and found that over 99.5% of people in the UK had heard of autism. This means that, more or less, we're all aware of autism: "autism awareness" has arrived. But this hasn't solved very much.



**Only 16% of the autistic people and their families we spoke to think the public understand autism in a meaningful way. That gulf between awareness and understanding remains enormous.**

We've spent the past year investigating this gap. At first, the research we conducted was confusing. We'd asked some autistic people and families to keep a log of recent incidents when they'd experienced difficulties in public places or with members of the public. When participants fed back to us, many of the log sheets were sparsely populated or even blank.

Our first thoughts were of relief. The world was more autism-friendly and the public had a better understanding of autism than we'd expected. But we probed further, including surveying over 7,500 people, and what we found was even more shocking. The reason the log sheets were so empty was because public places were proving so difficult to manage that people had learned to avoid them altogether.

Our research showed that, over time, autistic people and families avoid the overwhelming or unfamiliar places where they face the "tuts" and judgemental looks, and become more and more isolated. By the time autistic people reach adulthood their world can look very small. Fifty per cent of autistic people and families living with autism sometimes stay at home because of concerns about how people will react.

It isn't that the public sets out to be judgemental towards autistic people. We believe they often simply don't see the autism; they just see the "tantrum" or the "difficult" person. And, autism is complex and it can be hard to know how to respond.

We want to help people to recognise autistic behaviour and understand how they should respond through our **Too Much Information** campaign. This report sets out the thinking behind that campaign: what autistic people and their families told us about the impact of the public's lack of understanding and, most importantly, what they want the public to understand and how they can be of most help – what would make the biggest difference.

Seventy three per cent of autistic people and 60% of their families told us that they change their own behaviour to reduce the chance of intolerance from the public. Our Too Much Information campaign will allow the public to find out how they can change their behaviour and help open up the world to autistic people.

A handwritten signature of Mark Lever in black ink, written over a horizontal line.

Mark Lever, Chief Executive  
The National Autistic Society

“

That gulf between awareness and understanding remains enormous.

”

# 1. BRIDGING THE GAP

## From awareness to understanding

### Awareness of autism is at an all-time high.

But in our survey of over 7,500 autistic people and family members of people on the autism spectrum, only 16% said that the public understand how autism can affect someone's behaviour.

So despite this increase in awareness, this is not translating into understanding. The public tend to have a rather narrow view of autism, led by on-screen stereotypes and clichéd headlines, so it's no wonder they aren't recognising autism when they see it.

### What the public know now

Many people do have some understanding of autism and its associated problems. For instance, most of the UK population (58%) know that autism affects everyone differently and 42% know that autistic people's senses can be affected by the condition.<sup>1</sup>

But even people with understanding may not identify potentially autistic behaviour in their everyday lives. Instead, many people just see a 'strange' man talking to himself in the park, or a 'naughty' girl having a tantrum on a bus. They may make judgements about someone's personality or the ability of their parents. For instance, 55% of the public get annoyed when parents can't 'control' their children when they're having tantrums.<sup>2</sup> It is these attitudes that are causing autistic people and families to become so socially isolated.

### What autistic people and their families want the public to understand

Autism is complex, and autistic people and their families don't expect or want people to be experts. But people told us time and again that they would be much more likely to show empathy and kindness rather than judgement if they understood and recognised:

- the situations that autistic people might find difficult to deal with
- the behaviours and coping strategies autistic people might respond with in those situations.

<sup>1</sup> YouGov, 2015 | <sup>2</sup> nfpSynergy, 2015



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understand how  
autism affects  
behaviour



The problem is that it is not visible to others that I am having sensory overload.

Autistic adult



## CLAIRE, NIALL AND MAX

Claire Davis' two-year-old son, Max, was diagnosed with autism last year. They live in Surrey.

“ My son's sensory issues make it really difficult to leave the house, he can become overwhelmed quickly and melts down – which means he starts kicking and screaming. This is distressing and highly stressful for me, particularly in busy places. But rather than asking if we're okay, most people assume he's having a tantrum and stare or tut. I often try to explain that he's on the autism spectrum but the responses I've got are so hurtful. I've had, 'Oh that excuse again', 'It didn't exist in my day', or even 'What's his special talent?'. Another person replied 'Oh, I'm so sorry'. Why is she sorry? I've got a lovely albeit very full-on two-year-old son! I'm already constantly questioning my own parenting and hearing things like this just makes life even more difficult.

My friends are supportive but can find his autism difficult to understand and Max struggles to join in with other children so my social circle is getting smaller and smaller. I do feel isolated at times and find I have to build up my confidence to go out in public with Max. I'm constantly thinking, how will he cope and how will others will respond to us? Our main social activities now tend to be having people round, going over to their houses or attending disability groups where people are much more understanding and we can control the environment. We had a week once when we just couldn't leave the house.

It's difficult to pick up on whether someone's autistic, particularly when they're Max's age and going through the 'terrible twos'. But it would make such a difference to me if people thought before they commented or stared – they've never met him before and have no idea what he's going through. I don't expect everyone to be an expert on autism but some acceptance and understanding would make a huge difference. ”



Claire, Niall and Max

© Haj Thomas / www.t3gallery.co.uk



**55%**  
of the public get annoyed when parents can't 'control' their child's tantrum

“ I feel isolated at times and find I have to build up my confidence to go out in public with Max.

Claire ”

And ultimately, showing some empathy and kindness is the small but critical step we need people to take.

In our survey, autistic people and their families ranked the things that they most wanted the public to understand about how autism can affect people.

The top five things were that autistic people may need extra time to take in information and respond to people; that autism can make people anxious in social situations; that unexpected changes or events cause anxiety for autistic people; that autistic people's senses are often extremely sensitive, including to noise, light, smell or colour; and finally that when these things get too much it can lead to uncontrollable 'meltdowns'.

Autistic people often explain how they can find it hard to filter things out. Background noise like people chattering or cars driving by might make it impossible to concentrate on the person talking to you. You might need a bit more time to process and answer the question someone has just put to you, but they've already started asking it again. An anxiety about a diverted bus that morning might continue to play fiercely on your mind as you try to go about your day.

With this in mind, it is no wonder that autistic people often find the public situations that others take for granted incredibly difficult to cope with. These situations can be unpredictable and uncontrollable. They can be hurried, crowded and full of frequent social interaction with unfamiliar people. They can be loud, bright and smelly. So it is in public spaces in particular, that autistic people can feel overloaded by too much information.

Autistic people may behave in ways that the public don't understand, especially when experiencing too much information. An autistic person might act in a repetitive way, tapping or flapping their hands or pacing around. Sometimes, they may have what's called a 'meltdown'. During a meltdown, the autistic person has no control over their behaviour. They may shout, cry, physically lash out or simply close down. They, and those with them, often just have to try their best to find a quiet, uncrowded space and wait for it to pass.

Our research showed that when people recognise that someone is autistic, and understand the differences in how they experience the world and the challenges this can present, they behave with more empathy and understanding.

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Over half a million autistic people feel socially isolated.

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### OUR SURVEY SAID...

The top five things autistic people and their families most want the public to understand about how autism can affect people are:

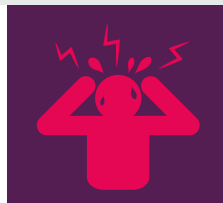
**1**

the need for extra processing time



**2**

anxiety in social situations



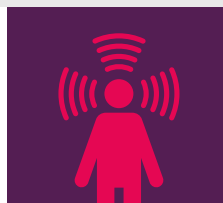
**3**

anxiety from unexpected changes or events



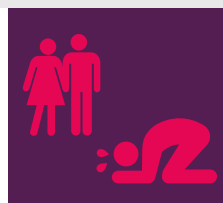
**4**

sensory sensitivity



**5**

that overload can lead to meltdowns





## BEN'S STORY

Ben Kenyon, 19, has a diagnosis of Asperger syndrome and lives in Rugeley, Staffordshire.

“ As I've grown older, I've learned how to suppress my emotions and keep my meltdowns to myself. But I remember having meltdowns in public when I was younger, often at school or out with my family. At school, I would be laughed at and called names, which often made the situation much worse and keep it going until I was escorted out of the room. In public, people have simply stopped and stared or given dirty looks to people with me, often my mum or my dad. At the time of my meltdown, I wouldn't notice or care but, afterwards, when I realised what had happened, I always felt ashamed of what I had done and how I had behaved.

Even now, at university, I'm worried about how people would act if I was to have a meltdown in public. So I try to avoid those situations where it might happen and frequently miss parties, social events and even seminars. For example, last week I forgot to do the reading for a seminar and became so worried about being asked something which I couldn't answer, that I didn't go to the seminar. That kind of pressure can trigger panics and meltdowns and I just can't put myself in that position.

Like many people on the spectrum, I often flex my hands and twirl them as a form of stimming, particularly if I'm feeling anxious. It makes me feel more in control, but people often find it odd and comment on it, referring to it as 'gay hands' as it looks like I'm making flamboyant gestures. I know they're just joking, but I find this very offensive and it means I keep my hands in my pockets when walking. ”



Ben

© keith morris / www.artswales.com

“ Even now, at university, I'm worried about how people would act if I was to have a meltdown in public.

Ben ”

“ Workers in our local supermarket tell shoppers he is a regular and something has upset him, leave him be and he will be okay soon. They also make sure they are at the self-scan checkout in case it goes wrong for him.

Parent of autistic adult ”

## 2. SHRINKING WORLDS

### The human impact of a lack of understanding

**Hundreds of thousands of autistic people and families in the UK often feel unable to leave their homes because they are worried about how other people will respond to their autistic behaviours.**

Going to the shops or to the park, the kind of everyday trip most people can take for granted, is something you can't do if you want to avoid the kind of judgement from members of the public that can stay with you for days.

#### How the public reacts now

Autistic people are too often treated by the public as though there is something wrong with them. Parents in our survey report that their children on the autism spectrum are labelled as naughty (75%)<sup>3</sup>, strange (75%) or funny (71%). Similarly, autistic adults think they are most often judged to be strange (84%), shy (70%) or anti-social (69%). Most typically, people stare, tut or actively avoid them.

When having a meltdown, already an extremely distressing – often embarrassing – situation for autistic people and their families, people's negative responses make it much harder to deal with. Eighty four per cent of autistic people told us that the public's reaction makes them more anxious. In these situations, people want some understanding and patience from the public – but that's often not what they get. As one autistic person told us:

**“People in certain settings don't have an open mind, which generates stress because they expect the same behaviour as themselves and are unforgiving in that expectation.”**

Drilling into our survey findings, we found that autistic people with higher and more complex support needs were more likely to be stared or tutted at, or experience people actively avoiding or even mocking and taunting them.

<sup>3</sup> Percentages are for combined total of those who reported this happening often or sometimes.

“

Just don't tut. I understand the staring I suppose, but the tutting and head shaking and pained looks are just awful and make me very sad.

Parent ”

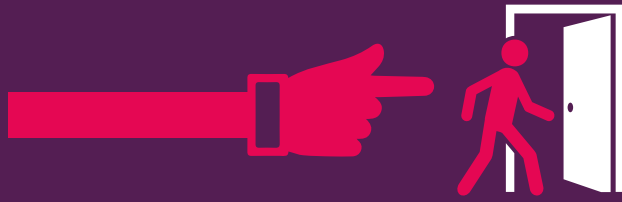
“

People have actually said to me 'you need to sort him out, he's well naughty'. It makes me so bloody angry.

Mum ”

## HOW MEMBERS OF THE PUBLIC RESPOND TO AUTISTIC BEHAVIOUR

**28%** of autistic people have been asked to leave a public space because of behaviour associated with their autism



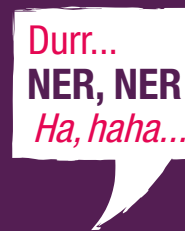
**87%** of families and **64%** of autistic people say **people stare**



**74%** of families and **48%** of autistic people say people **tut, or make disapproving noises**



**72%** of families and **53%** of autistic people say **people avoid them**



**45%** of autistic people say **the public mock or taunt them**



**38%** of autistic people and **21%** of families say that **people get aggressive**

Most shockingly, more than one in four autistic people have even been asked to leave a public place because of their autistic behaviour.

One parent of an autistic child told us:

“At a public pool about a year ago, we were asked to leave, but he was with his support worker. After some words were exchanged, a member of staff said, ‘children like him shouldn’t be here’.”

Or as Jacob’s mother told us, people don’t involve autistic people:

“The whole class were invited to the park, so I took Jacob along as well and he was like the weirdo, no-one went near him, no-one spoke to him.”

“

In 22 years, only one person has offered to help. Most stare and make comments.

Parent

”



## SARAH, MIA AND ELLA

Sarah Keaney is mother to twin four-year-old girls, Mia and Ella. They are both on the autism spectrum.

“ Taking my girls out anywhere is a challenge, even just to see family or friends.

Both Mia and Ella seek sensory stimulation, so they jump on furniture, spin, climb and get into other people's personal space. And people find it really hard to understand that Mia likes to lick things and sometimes, even bite herself.

I get used to people's stares, 'tuts' and comments about their behaviour. They've both been thrown out of a private nursery and social groups. I was simply told that 'they can't be here any more'.

Last year I took them to a music class. Mia finds it hard to keep still, so was running around the room. And I was running from Mia to Ella, getting more and more frantic. I could feel everyone's eyes on me. And then someone said, 'She's a bit difficult, isn't she?' When I explained that Mia was autistic, the response was 'I work with autistic children and they don't behave like that.' I explained, that as the mother of two girls on the spectrum, I was an autism expert, but was told that Mia was 'just having a bit of a tantrum'.

I got out of there as quickly as I could and never went back.

Things are getting better for the girls, particularly as their communication has improved. And I'm less likely to get upset and run away when people comment. But it's still really hard and it's worse when people don't understand but give unhelpful advice, or say the girls are 'naughty' or 'attention seeking'.



Mia, Sarah and Ella

“ I could feel everyone's eyes on me

Sarah ”

## A shrinking world

Often autistic people and their families have so many difficult experiences in public that they stop trying to leave the house. From our qualitative research there appeared to be a trend – while parents of younger children would find the criticism extremely hurtful, they would still go out, determined not to let it affect their daily lives. However, as those children became teenagers and adults, more and more simply stopped going out beyond the few places and people who they knew wouldn't judge them – often other autistic people and families. They had simply been worn down by the experience of being judged again and again. As one mother of an autistic child told us:

**“We're in a bubble, an autistic bubble.”**

People feel so misunderstood that they shut themselves away to avoid the stares, judgement, or even abuse. Most autistic people (79%) and their parents (70%) feel socially isolated. Half sometimes feel unable to leave the house because they are worried about how others will respond to their autism. If these figures from our survey are extrapolated for the 700,000 autistic people in the UK, it would mean over half a million autistic people feel socially isolated. They avoid parties, town centres, public transport and health services. This not only has an impact on the autistic person, but on the whole family.

Social connections disappear. One in four autistic adults responding to an earlier survey reported they have no friends,<sup>4</sup> and some have no personal relationships at all. While not all autistic people want those relationships, many (41%) do want more friends and 54% of those we surveyed reported they have lost friends because of how the friends responded to their autism, or have even lost contact with family members. The same applied to parents, with 40% saying they have lost friends as a result of how they responded to their child's autism.

And we know that social isolation can lead to both mental and physical health problems, with the impact of loneliness estimated to be as damaging as the impact of smoking 15 cigarettes a day.<sup>5</sup>

“

You become smaller and your world becomes a lot smaller.

Mum

”

<sup>4</sup> Bancroft, K. et al (2012). The way we are: autism in 2012. London: The National Autistic Society

<sup>5</sup> Campaign to end loneliness (2010) Available at: <http://www.campaigntoendloneliness.org/threat-to-health> (Accessed: X February 2016).

Choosing to live in a shrinking world is understandable as the focus for the family or the individual is on maintaining familiarity and safety, so they stick to the world they know, as this mum of a young adult with Asperger syndrome told us:

**“Around here everyone knows John.\* He’s fine to go to the local shops.”**

Better public understanding of autism would expand these worlds and improve the health and wellbeing of autistic people and their families. We can’t always change all the environmental factors that can make going out difficult, like crowded spaces and sensory challenges, but if the public understood autism better, it would mean anxiety about their reaction is less likely to contribute to these unacceptable levels of isolation.

“

I feel like a goldfish trapped in a bowl by an invisible wall of glass – looking out into a world I try so hard to join.

Autistic person

”

“

If you just have to explain to one person you can say, “Oh, they’re autistic”. But when you’re on the train and you’ve got a whole carriage full of people, you can’t just announce it to everyone.

Mum

”

\* This name has been changed to protect the identity of the individual.



### SOCIAL ISOLATION

**79%** of autistic people and **70%** of families feel **socially isolated**



**50%** of autistic people and families sometimes **don't go out** because of concern about people's reaction to their autism



**53%** of autistic people and **40%** of families have **lost friends** because of their negative response to autism

**73%** of autistic people and **60%** of their families told us they **change their own behaviour** to reduce the chance of intolerance from the public



**"Naughty"**  
**75%**

**"Strange"**  
**75%**

**"Funny"**  
**71%**

**Most common labels** parents felt their children were given by the public

# 3. THE PUBLIC RESPONSE

## Small gestures have a huge impact

**Better understanding and recognition can lead to kinder reactions towards autistic people's behaviour.** Most importantly, it means no more tutting, disapproving looks or asking families to leave public spaces.

But it also means people knowing what proactive steps might help when someone appears very anxious or is having a meltdown.

### How we want the public to react

We asked autistic people what they would like members of the public to do if they were visibly anxious or having a meltdown.

- Most (58% of autistic people and 64% of parents) want to be left alone to clear their head.
- But many (42% of autistic people and 36% of parents) do want someone to ask if they're okay or would like help.
- Most (61% of autistic people and 69% of parents) would appreciate an offer of a quiet space where they can relax.

As these responses suggest, different people may need different help. But we have worked with autistic people to create three easy-to-remember tips: take time, make space and imagine (or TMI for short).

The autistic people we consulted told us that the public understanding is what is needed and will make a huge difference to them and their families' confidence to leave the house and live a normal life.

“

Ask once, gently, if I'm okay and don't be upset if I can't answer 'properly.'

Autistic adult

”

“

Just be patient and don't pressure me while I re-orientate myself.

Autistic adult

”

When responding to someone autistic who's experiencing too much information, think TMI:

## **T** TAKE TIME

Give the person some time – it can take a while to recover from an information overload. Calmly ask them (or their parent or friend) if they're okay, but bear in mind they'll need more time to respond than you might expect.

You see, with so much going on around them, autistic people sometimes need more time to process information. So if you ever ask a question and don't get an answer right away, just wait. It might seem like the meltdown will never end, but it will. Be patient, and be there.

## **M** MAKE SPACE

Try to create a quiet, safe space as best you can. Ask people to move along and not to stare, turn off loud music and turn down bright lights – whatever you can think of to reduce the information overload, try it.

## **I** IMAGINE

Imagine feeling so overloaded that you just couldn't cope. Imagine the difference it would make if someone showed you a little kindness, rather than judging you as a 'naughty' kid having a tantrum, or a 'weirdo' flapping their hands. A little understanding can go a long, long way – just a nod or some words of kindness can really put someone at ease.

Finding it hard to imagine? Then find out from autistic people what it really feels like. Sign up for more information at [www.autism.org.uk/tmi](http://www.autism.org.uk/tmi).

“

It really, really matters that as many people as possible understand autism better and know not to judge.

Ben and Kathryn ”



## JO AND BEN

Jo Wincup's 15-year-old son, Ben, has a diagnosis of Asperger syndrome. They live in Seaton Delaval, Northumberland.

“Over the past 15 years, my family has almost got used to strangers staring and making comments – it still hurts but we've grown thick skins. But we've also seen the difference that public understanding can have. The kindness of one stranger, four years ago, still sticks in my mind and helped us through a very difficult time.

After a trip to the cinema, we went to a toy store but Ben became upset when they didn't have the exact bear he was looking for. All children at that age would be disappointed but his autism means that this can quickly escalate to a meltdown. So we quickly started walking to the nearest exit so he could get some air and calm down. But the crowds, bright light and range of smells became too much and he became overwhelmed. Ben lost control just as we left the shopping centre and arrived at the bus area and he started kicking me, shouting and swearing.

People were queuing for buses and started to stare, some even said really hurtful things. I can't quite remember what they said but it wasn't nice. This

upset Ben even more and he ran off into the bushes. I went after him but he refused to come out, shouting that people were staring at him and continuing to swear at everyone around him. I just wanted to cry, for the ground to swallow us up.

Then I heard another voice from the crowds, saying something along the lines of 'What are you doing? Do you not understand? Have you not heard of autism?' The stranger made her way over to us and knelt down before Ben. I was worried he was going to kick her but she managed to calm him down and helped us back to the car. I was so grateful that I was in floods of tears and wasn't really following what was going on but I remember her saying she worked with autistic children. Still in a daze, I thanked her and must have driven off. It's still one of my biggest regrets that I didn't ask for her name and stay in touch.

If she's reading this, thank you so much. You'll never know what a difference you made to us, just knowing that there are people out there like you who understand.”



Jo and her son, Ben



# ABOUT THE TOO MUCH INFORMATION CAMPAIGN

**Sometimes, autistic people can get overloaded by everything around them. It's like they're getting 'too much information'.**

All the sights, smells and sounds can make the outside world feel like an overwhelming place. For autistic people and their families, all the looks, judgements and tuts can make it feel like a lonely and isolated place.

Too Much Information is the biggest ever UK campaign to help the public to better understand how autistic people experience the world. We know that by doing this we can turn public judgement into empathy and kindness, and make sure autistic people and their families no longer feel excluded from public life.

You can help us make sure autistic people, and their families, get the understanding they need. To find out how, visit [www.autism.org.uk/TMI](http://www.autism.org.uk/TMI).

We rely on donations to tell the public about Too Much Information. If you can help us educate more people by donating, by providing media space or if you want to make your business more autism-friendly, get in touch at [corporate.partnerships@nas.org.uk](mailto:corporate.partnerships@nas.org.uk).

**Although the public are aware of autism (99%), they still don't understand it – how it can affect people and what autistic behaviour might look like.** This means that, all too often, families and individuals feel judged, excluded and unable to do the things most people take for granted in public – like going to a shopping centre or swimming pool.

Often, when an autistic person gets overloaded by too much information, all they and their families want is a bit more understanding from members of the public. Rather than judging and tutting, we want people to be sympathetic, accepting and ready to help.

### **About The National Autistic Society**

We are the UK's leading autism charity. Since we began over 50 years ago, we have been pioneering new ways to support people and understand autism. We continue to learn every day from the children and adults we support in our schools and care services.

Based on our experience, and with support from our members, donors and volunteers, we provide life-changing information and advice to millions of autistic people, families and friends so that more people can make informed decisions about their lives. And we support professionals, politicians and the public to understand autism better so that more autistic people of all ages can be understood, supported and appreciated for who they are.

**Until everyone understands.**

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Until everyone understands