



Ableism, Stigma and Discrimination: The Power of Language

Lived experiences, testimonies, and preferred terminology from young people with additional needs and disabilities living and accessing services in Surrey, UK.

Co-written by ATLAS members with the User Voice and Participation Team through group consultation.

Chapter 3 Personal Testimonies of Ableism, Stigma and Discrimination

Introduction

This section provides an insight into the conversations and testimonies shared during ATLAS sessions about our experiences of ableism, stigma and discrimination.

Testimonies are listed by the following themes:

- Exclusion through lack of consideration
- Interaction with services
 1. Accessibility
 2. Unrealistic goals
 3. Treatment of rare disabilities
- Education
 1. Accessibility
 2. Behaviour management
 3. Education Health and Care Plans (EHCPs)





- Public Attitudes
 1. Constant questions
 2. Minimalising disability
 3. Unsolicited advice

Exclusion through lack of consideration

“It’s in everything. Because when you haven’t thought about disabled people, usually you’re excluding them”

-ATLAS member

“It’s people not thinking, that’s where exclusion happens a lot.”

-ATLAS member

This theme of young people being actively excluded because of non-disabled people not thinking about disabled people comes up regularly in ATLAS. Members are frustrated that this happens despite disabled people being a very significant part of the worldwide population. There are [14.1 million disabled people in the UK](#) alone!





Interaction with services

1. Accessibility

“When they design a service, they don’t think of me. They’re not even interested in me coming, because they’re not making sure that I can.”

-ATLAS member

“When they don’t make something accessible for you and then ask you ‘why you didn’t come?’”

-ATLAS member

“Doctors booked me into a room upstairs despite having on my notes that I have limited mobility. I arrived in my wheelchair and they said that I had to work it out or rebook it. So, I had to drag myself up the stairs.”

-ATLAS member





2. Unrealistic goals

"I feel judged by doctors: 'don't you want to get better?' Well, yes of course, but not at the risk of making me worse."

-ATLAS member

"It's almost like an able body must be the goal. But I am not going to aspire to that because it's not possible for me."

-ATLAS member

3. Treatment of rare disabilities

Testimony from an ATLAS member with a young child:

My daughter is visibly impaired, and no one knows about the condition. Professionals judge me and ask if I know what I need to be doing.

The condition is not well known, 1 in 10,000 are born with this condition, and having to explain over and over what it is and that there are things she'll never be able to do is exhausting. People also find it hard to accept it's more about monitoring [rather than treatment].

Professionals think that she is an experiment they can work on because





she's so young. They know what the condition is and that there's no treatment, but they want to spend four hours looking at her eyes. She doesn't know what's going on. She doesn't like lights being shined in her eyes. She has glaucoma and cataracts.

It's hard knowing what activities she can take part in and what she can't, and people judge her for that. She needs more time and she goes towards lights and things rather than those without lights or sound.

There is also a backlash you get from genetic disabilities*.

*For context: someone with a genetic disability may experience stigma and discrimination for their reproductive choices. Questions and statements, may include:

- Why did you have kids?
- It's your fault they're like this.
- If only you'd known ...
- Don't you fear having more kids in case they're disabled too?

Education

1. Accessibility

"Schools are still failing to even offer the basic level of accessibility ... first, you just need to achieve the bare minimum."

-ATLAS member



For example:

- providing work in advance,
- using accessible font styles and sizes,
- line spacing,
- coloured backgrounds on presentations,
- providing coloured overlays during exams.

2. Behaviour management

"I went to a specialist school and ... one of the students liked to wear a hat for comfort reasons, they got asked to take it off and didn't. They ended up getting put in isolation because of it."

-ATLAS member

We feel that situations like this should come under reasonable adjustments. Wearing a hat should not affect a young person's access to education.



3. Education Health and Care Plans (EHCPs)

"They will tell you what you can do, they'll decide what your ability is, and then you will be prescribed to that and then you're not encouraged to go beyond that. It's like you trying to go beyond that is discouraged, because then they have to deal with the fall out. For example, if you push yourself too far and you have a meltdown or, you know, something happens"

-ATLAS member

"Mine was looking at a future volunteering and working in a charity shop ... I'm at university now"

-ATLAS member





Public Attitudes

1. Constant questions

"It's people constantly asking and expecting me to answer and educate them."

-ATLAS member

Testimony from an ATLAS member:

People will just come up to me and ask: what is wrong with you?

One of the times I really remember is in a hotel elevator and I was using a mobility aid. A lady in the elevator outright asked me why I needed the mobility aid, because I didn't match up with her idea of what disabled is. She wasn't a medical professional that needed to know, she was just nosey.

Members of the public can also ask disabled people very personal questions or question their life choices without consent:

"Should you have kids? Would you want them to have that?' and it's like, my life's not that fun, but it's not horrific."

-ATLAS member





2. Minimalising disability

"People trivialising your condition by saying something like: 'Oh yeah, I get that because I'm tired a lot'. I am literally exhausted."

-ATLAS member

"When I was younger, I would share that I was in pain and people would just say: 'well you're young, you just need to get on with it.'"

-ATLAS member

"People accuse you of lying: 'you can't be in that much pain because you're sat here talking to me. If I was in that much pain, I wouldn't get out of bed.' The world doesn't stop just because mine does."

-ATLAS member



SURREY
COUNTY COUNCIL



3. Unsolicited advice

Testimony from an ATLAS member:

Non-disabled people will give me solutions as if I have never thought of them before, for example: Have you tried setting an alarm?

It's not like they're saying, 'here is a service I have used, and I found it really useful, have you heard of it?' There is a really big difference between a disabled person sharing their lived experience with me to help me and someone else giving me unsolicited medical advice. It is an assumption that your disability can be solved, and they have the idea that will solve it.

For me, it really feels like they're saying to me: 'you're disabled because you're not smart enough.'

They're assuming the reason I'm disabled is because I haven't been innovative enough, I haven't thought about something enough.

It's easier for them to think about it that way because it is easier than accepting that there is something that can't be solved or recovered from... that something could happen to you and then you'd be stuck.

"I can meditate for hours, that doesn't make my body better. I do yoga, but I'm still chronically ill. I can't think my way out of disability."

-ATLAS member

