

# Making things more equal for adults with learning disabilities and autistic people

## Project background

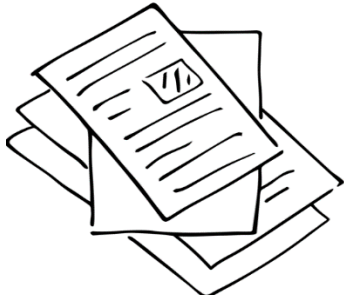
This project explores the inequalities faced by people living with learning disabilities and autistic people, and the ways in which they can be addressed.



SCIE established a co-production group of people with lived experience, 'the SCIE Fliers', to understand their experiences from the pandemic and views on what needs to be different.



A series of events with different sector partners was also facilitated, to showcase the work developed by the SCIE Fliers and progress the conversation further.



Through working with these groups, SCIE has developed a guidance document that aims to close the skills and knowledge gap in the workforce when it comes to supporting people with learning disabilities and autistic people.

### Access the guidance

(<https://www.scie.org.uk/tackling-inequalities/tackling-inequalities-guidance/>)

## Video-guide

The SCIE Fliers also met to create a video that can sit alongside the guidance as a helpful resource for professionals, and people too.

The group worked with an ethnographic researcher and videographer to storyboard and script the video, sharing what they feel is important to remember when supporting people with learning disabilities and autistic people.



### Access the video

([https://youtu.be/gbL2\\_Apo5kU](https://youtu.be/gbL2_Apo5kU))



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“

During the meetings, lots of valuable quotes and experiences were shared. This document is a summary of those discussions.

**“I am here; don’t forget about me.”**

We believe that people with learning disabilities and autistic people have a worse off experience of care and health support than people who do not have these conditions.

**“Yes, we do. This is so true.”**

## Delivering services

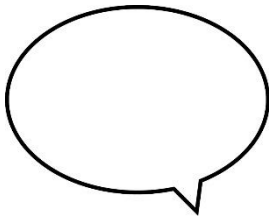


- Services should adapt what they offer for people with learning disabilities and autism.

**“They should include us and give us the opportunity to contribute.”**



- Focus on what can be achieved with the right support by involving people themselves, e.g. ‘quality checkers’, to feedback on services. People should be **paid** to do this job.



- Create space for people with learning disabilities and autistic people to let services know what they think, so that a positive change can happen.



- Organisations should work in partnership and collaborate so that everyone can see, sense and feel a positive impact.

**“Then it’s a benefit for me, and it’s a benefit for them!”**



- Different organisations should outline how they plan to work together effectively, in either:

1) Easy-to-understand words and pictures.

2) Videos and images.



So that their 'new ways of working' can be checked out publicly.



- This means that people with learning disabilities and autistic people can check whether organisations are actually doing the work they say they are.

**“I’m fed up wasting my time talking about the same things, when people don’t listen and nothing changes.”**



- Better services mean that those accessing them will feel much happier in themselves and in the care they are receiving.



- This will help to reduce social isolation and increase opportunities for physical and mental wellbeing.

**"That's easier said than done. I'm always isolated."**

## Labelling

**"We've got these labels, but labels are for jars not people."**



- Labelling isn't always a good thing, because people can look at others in a different way before getting to know them.

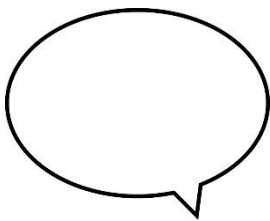


- Although sometimes, once someone has received a diagnosis, it can unlock some of the answers as to why they are the way they are.
- Wording and phrasing are always important and should be handled sensitively.

**“When I was at school, I got bullied and I got labelled because I stuck out and was different from everybody else. I wanted to be the same as everybody else, but I wasn’t, so I was putting pressure on myself to adapt to society’s norms.”**

**“It was trying to be somebody I could never be, so it was like trying to climb a mountain.”**

# Communicating



- One of the biggest difficulties people with learning disabilities and autistic people face is being understood.
- Especially if someone can't communicate clearly, then another person may have difficulty understanding what they want to say.
- This can be dangerous if they're in pain or distressed.
- It can sometimes be hard to articulate, which can be difficult for both the person talking and the person who is listening.
- Consider everyone's needs on an individual basis, be patient and listen to them.



**“People talk down to me because they see on my notes ‘autism/mild learning disability’.**

**Or they think that they have to talk loud or slowly so that I can hear them better.**

**Don’t assume things for me.**

**I want my choices to be chosen by myself.**

**I want total autonomy over my decisions.**

**I don’t want decisions made for me in ‘my best interest’.”**

## Types of support



- Look at what good support could look like for the individual, from their local community networks.



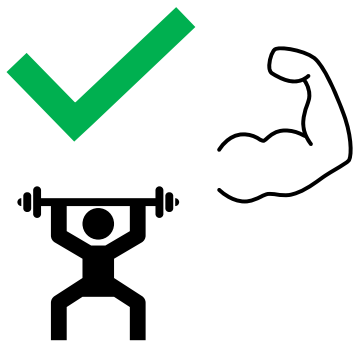
Signposting by itself isn’t the answer.



- Involve families and carers, where appropriate.

**“We need someone to journey with us.”**

## Person-centred care and support



- It is important to focus on people's strengths. This means what they can do well. Not what they can't do well.



- Find out what people want from their lives. Try to understand better the person you are supporting.

**“Luckily, I am someone who can speak up for myself, but not everyone can.”**

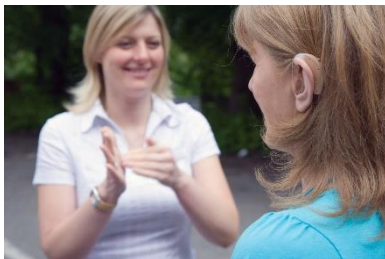


- Actively involve people with learning disabilities and autistic people in all decisions that affect them.

**“I went in to see the doctor on my own, so he had to talk to me.”**



- If we make sure that care packages meet a person's needs, then better outcomes and results are more likely.



- Potentially think about having someone with a similar lived experience to work with and alongside the individual, if they are comfortable with that. They can be there to support, but also as a link between the person and the professionals.

## Trauma-informed care



- Be more aware of and sensitive to the impact of traumatic things that a person may have experienced – such as abuse, neglect and serious illness.

- It is important to find a safe way and place to do this kind of work.



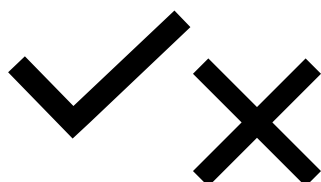
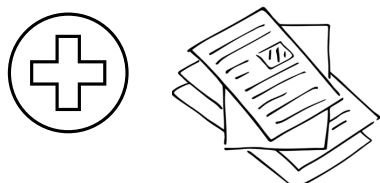
- Service professionals may need more training and support in this area.

**“If you shake the bottle of coke, you will bring all the fizz to the top and it will explode.**

**But if you handle it with care, the fizz will still come out, but it will be in a very manageable way.”**

## Hospital passport

**“It’s a starter, but as you get to know the person, it could change over time.”**



- A hospital passport can be a useful and accessible aid to producing a better health care experience.
- It should include important information about likes / dislikes, and preferences for support and communication, especially when going into hospital.
- It should also mention any possible reasonable adjustments needed.
- Health staff need to read the hospital passport.

**“Sometimes health staff don’t even look at them because they’re so busy. Or sometimes I forget mine.”**



- It would be good for people with learning disabilities and autistic people to be able to meet with nurses or doctors, even on the phone or online, before their appointments.
- There can also be a difference between what is written about someone and what they are actually like, so do remember to communicate directly with people.

## Support for carers and family members



- If carers and family members are to be active (and effective) partners in the person’s care and support, their own needs and wellbeing should be properly considered as part of the process.

## **SCIE Fliers: Our co-production group**

This easy read document was written by the SCIE Fliers:

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