

# Who, When, and How to Share?

A guide to making strategic and informed personal decisions around disclosing an autism diagnosis or autistic identity



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*Adapted from the 'Up to Me' programme developed by the Wisconsin Initiative for Stigma Elimination (WISE) and Patrick Corrigan*

**Note: This guide was developed as part of [a research study published in 2024](#) and will not be updated. The study involved participants completing the guide with peer support from trained autistic facilitators and an optional online forum. Throughout the guide, you will see references made to the facilitators and forum. However, as the study has ended, facilitator support is no longer available and the forum has been closed. You can still use this guide independently, but you may find some activities challenging to complete alone. Thus, we recommend that you work through the guide with the support of a trusted adult if you feel comfortable doing so (e.g., your parents, therapist, job coach).**

# Contents

1. Introduction	1
1.1. About the programme	1
1.2. Meet the team	2
1.3. What to expect	3
1.4. Setting the tone	4
2. When to Share	5
2.1. Weighing the pros and cons of disclosure in different settings	14
2.2. Weighing the pros and cons of different levels of disclosure	17
3. How to Share	18
3.1. Drafting your personal story	20
3.2. Choosing what to share from your story	23
3.3. Replacing hurtful self-beliefs in your story	26
4. Who to Share with	27
4.1. Identifying a good person to disclose to	30
4.2. Being prepared with responses and support	33
4.3. Putting it all together	35
5. Appendix	37
5.1. Information on legal rights	37
5.2. Information on support resources	44
5.3. References	45

# 1. Introduction

## 1.1. About the programme

Autistic adults can often face a dilemma of whether to conceal or reveal their autism diagnosis or autistic identity due to **stigma**. Clearly, to improve autistic adults' experiences of disclosure, it is crucial to reduce public stigma and create more inclusive environments. There are other programmes trying to do this. However, as change can be slow, we believe that autistic adults should also be empowered to make informed, strategic disclosure decisions. So, we have developed a programme that aims to support autistic adults in deciding who, when, and how they want to talk about their autism diagnosis or autistic identity.

**Stigma** can be described with three words:

- stereotypes (untrue beliefs),
- that lead to prejudice (unhelpful attitudes),
- that play out in discrimination (unfair behaviours).

Stigma can come in the form of:

- public stigma (stigma held by members of society towards autistic people),
- self-stigma (stigma internalised by autistic people themselves), and
- structural stigma (policies and processes that discriminate against autistic people).

This programme has been developed by a team of autistic and non-autistic members based on a combination of lived expertise and research evidence, including a recent systematic review and consultation survey conducted by the team. The strategies in this programme were drawn from an evidence-based programme called '[Honest, Open, Proud](#)' (HOP), originally developed by Patrick Corrigan and Jon Larson. In particular, this self-help guide was adapted from the '[Up to Me](#)' brief reflection booklet produced by the Wisconsin Initiative for Stigma Elimination (WISE) and Patrick Corrigan.

In this guide, we will first explore the pros and cons of disclosing your autism diagnosis or autistic identity. These will vary from person to person and situation to situation. Then, for times you want to disclose, you will learn strategies for sharing relatively safely and how to craft a message that best represents your goals. Throughout the guide, you will find quotes from autistic people taken from published research studies (you can find out more about these studies in Section 5.3 of the Appendix). Quotes are used to illustrate the different views and experiences that autistic people have. You may relate to some quotes more than others. This is to be expected as there is no "one size fits all" approach to disclosure.

We hope that by the end of the programme, you will be much more confident in deciding when, how, and to whom you want to disclose.

## 1.2. Meet the team



### **Emeline Han, lead researcher and programme developer**

Emeline is a PhD student at the Centre for Research in Autism and Education (CRAE), University College London (UCL). The aim of her PhD is to develop and evaluate a new disclosure decision-making programme for autistic adults. Emeline is passionate about conducting research that is participatory in nature and practically beneficial to the autistic community.



### **Katrina Scior, research supervisor**

Katrina is one of Emeline's PhD supervisors and is Director of the UCL Unit for Stigma Research. Her research mainly focuses on stigma associated with disability, mental health challenges, and ageing. She has expertise on the development and evaluation of interventions to address stigma and self-stigma, including recently adapting the 'Honest, Open, Proud' programme as a guided self-help and peer support intervention for mental health professionals (HOP-MHP).



### **Kana Umagami, programme developer and facilitator**

Kana is one of the autistic collaborators on Emeline's research project. She is currently writing up her PhD thesis on loneliness in autistic adults at the Centre for Research in Autism and Education (CRAE) at UCL. She values the research that produces practical outcomes in improving autistic people's lives and has been involved in several participatory research projects. With her educational background in Counselling, she is also passionate about supporting other autistic individuals and their families.



### **Eric Heath, programme developer and facilitator**

Eric is one of the autistic collaborators on Emeline's research project. He is an Advisor and Expert by Experience working across health and social care, including cross-government with the Department of Health and Social Care on the National Autism Strategy and the NHS at a regional and local level. He is a passionate advocate of the need for expert experience involvement in research and public policy, to ensure it represents the people it concerns, that it should be co-produced and that people's insight should not be expected to be provided purely voluntarily.



**Simone Dufresne, programme developer**

Simone is a PhD student at Tufts University in Medford, Massachusetts, USA. She was a visiting scholar at CRAE, supporting Emeline with the development of this guide. Her doctoral work focuses on autism in society: how autistic people adapt to the world around them, and how the world becomes more accessible. She is particularly interested in exploring programmes that address challenges from both societal and individual angles to promote well-being and success, however the individual defines them.



**Laura Crane, research supervisor**

Laura is one of Emeline's PhD supervisors, based at the Centre for Research in Autism and Education (CRAE) at UCL. Laura's research is quite broad in scope, but all the projects she works on have the goals of (a) positively impacting the lives of autistic people, and (b) being conducted *with* (rather than *on*, *about* or *for*) autistic people. Her research largely focuses on supporting autistic people in their educational journeys, but she has also done research on autistic people's experiences of diagnosis, healthcare and criminal justice.

### 1.3. What to expect

- We recommend that you work through this guide in three weeks corresponding to the three core sections of content: (1) when to share, (2) how to share, and (3) who to share with. Each section is expected to take about 60-90 minutes to complete.
- However, you may find that some sections are less relevant to you or some worksheets are more difficult to fill in at the present moment. You can choose to leave some parts blank and return to them later on in the programme or even after the programme is over. You will NOT be asked to provide any of your completed worksheets that are part of this guide.
- While using this guide, your assigned facilitator will send you weekly emails to check how you are getting on with the programme and answer any questions you may have.
- During this three-week period, you can also access the online peer forum to discuss your thoughts and reflections with other autistic adults who are participating in the programme, if you would like to.
- It is possible that you may become upset or anxious as you reflect on your past experiences of disclosure or potential experiences of disclosure in the future. If you do feel distressed at any point, you can contact your assigned facilitator, take a break, or withdraw from the programme altogether. Our facilitators can provide some support at a peer level, but they will NOT act as therapists, and they will direct you to appropriate sources of professional help as required (such resources have also been listed in the Appendix, Section 5.2, for your reference).

## 1.4. Setting the tone

Language is powerful. We recognise that the language we use to talk about autism can shape the way non-autistic people think about autistic people, as well as the way autistic people may think about themselves.

There is no universal agreement about the best way to talk about autism. For example, some autistic adults prefer to identify as a ‘person with autism’ to emphasise their value and worth as a person first before their diagnosis. However, other autistic adults prefer to identify as an ‘autistic person’, as it reflects autism as an intrinsic, central and positive (or neutral) part of their identity. Throughout this guide, we will use identity-first language since research has shown that it is the preference of many autistic adults in the UK. Nonetheless, it is your choice how you prefer to identify.

This resource will be grounded in the **social model of disability**, which means we believe that autistic people are not disabled by their autism, but by the interaction between their differences and the environment they find themselves in. This resource is also informed by the **neurodiversity paradigm**, which means that we see autism as a natural and valuable form of human diversity that comes with unique strengths and challenges.

The **social model of disability** sees disability as arising from the interaction between an individual’s characteristics and an environment filled with physical and social barriers.

**Neurodiversity** is the diversity of human brains and minds. The **neurodiversity paradigm** is a specific perspective that regards neurodiversity as a natural and valuable form of human diversity. According to this way of thinking, there is no one “normal” or “right” type of mind.

Therefore, we will avoid medical language such as ‘disorder’, ‘deficit’, and ‘impairment’, instead approaching autism as a different way of being and experiencing the world. We will also avoid using terms like ‘high functioning’ or ‘low functioning’ as we think it is more helpful to describe specific strengths and challenges, acknowledging that the needs of each autistic individual will likely vary across different aspects of their lives.

However, you may sometimes find it necessary or helpful to use these terms to describe your experience (e.g., using the term ‘Autism Spectrum Disorder’ when talking about your diagnosis), and we entirely respect your right to do this. The language that you want to use to share your story may change over time, as well as depend on the context and goal of your disclosure.

## 2. When to Share

### 2.1. Weighing the pros and cons of disclosure in different settings

In this section, you will first be introduced to the idea of weighing the pros and cons of disclosure. You will then be provided with some examples of reasons to disclose or not to disclose in several different settings. Finally, you will have the opportunity to identify your own reasons to disclose or not to disclose.

It is your choice whether to share with others that you are autistic, and you can make different choices in different settings. Let's consider how the setting may influence your decision to share or not to share. For the sake of this exercise, we will look at three different types of settings: 1) family/friends, 2) education/employment, and 3) public service providers (e.g., healthcare professionals, police officers).

As you read through the reasons why other autistic people have chosen to share or not to share in these settings, it might be helpful to ask yourself, "Which of these reasons are most important to me?" "What other reasons are important to me?" This will prepare you to fill in your Pros and Cons of Disclosure worksheets later.

It is possible that this exercise may remind you of some difficult situations. If you feel distressed at any point, remember that you can contact your assigned facilitator and/or seek professional help from mental health services listed in Section 5.2 of the Appendix.

#### Context 1: Disclosing to family members or friends



Reasons to disclose	Reasons not to disclose
<p>You no longer have to pretend, or hide who you are. Instead, you feel like you can be yourself around family and friends.</p> <p><i>“When I finally made up my mind to stop pretending. In that moment, such an enormous weight fell off my shoulders. Because you can finally stop being who you ought to be. Instead, you can be who you are.”</i></p>	<p>You may feel let down by unhelpful, dismissive or patronising reactions.</p> <p><i>“... when I told my dad ... he was ... ‘You don’t have autism, you’re perfect. There’s nothing wrong with you.’”</i></p>
<p>You may feel truly accepted for who you are by the important people in your life.</p> <p><i>“... blessed to have such lovely people around ... care enough about me not to be bothered by my weird quirks and funny ways ...”</i></p>	<p>You may encounter family members or friends who are not accepting and supportive. This can cause negative changes in your relationships.</p> <p><i>“... the implication ... I was automatically wrong, because I had this Asperger’s thing ... So that was unexpected, and I had to walk away.”</i></p>
<p>It opens up the opportunity for them to understand you better. This can strengthen and improve your relationships.</p> <p><i>“... he [husband] got really into researching it ... it’s really improved our relationship because he’s realised now that a lot of the arguments we had were me misunderstanding what he’d said and him misunderstanding how I’d reacted.”</i></p>	<p>You may be asked personal or intrusive questions that you are not prepared or want to answer.</p>
<p>They can help you and support you in situations where you need it.</p> <p><i>“... he’ll [husband] now take the lead in situations where he knows I’m not comfortable, whereas before he just thought I was being awkward.”</i></p>	
<p>You may feel empowered by educating your family and friends and combating stigma.</p> <p><i>“To educate others and break down stigmas, how I’ve learnt to come to terms with it.”</i></p>	

Context 2: Disclosing in education or employment



Reasons to disclose	Reasons not to disclose
<p>People might understand you and how you work better, and work better with you. You may feel able to work the way you do best.</p> <p><i>“from the moment I disclosed my autism to my supervisor, he was able to understand me better... he had the patience to allow me to work on my thesis in peace and quiet, at my own pace.”</i></p>	<p>People might see you and treat you differently after you disclose, including questioning your competence, abilities or work ethic.</p> <p><i>“It was like seeing someone’s estimation of me drop like a stone... they go from treating me like a peer to patronising me in the space of a heartbeat.”</i></p>
<p>It can reduce the stress of having to hide your autism diagnosis or autistic identity. This might improve your mental health and well-being.</p> <p><i>“Managing my physical and mental health became more important to me than hiding.”</i>  <i>“I feel able to mask* a little less and live more authentically, which is good for the well-being.”</i></p>	<p>People might not believe you if you do not fit their preconceptions of an autistic person.</p> <p><i>“I fear rejection and not being believed and the impact of that invalidation of my identity.”</i></p>

<p>To ensure your personal safety and legal protections.**</p> <p><i>“I think disclosure is important, because it has meant that I have the protections that go along with the Equalities Act. That is 100% absolutely crucial in my situation.”</i></p>	<p>People might judge you based on false stereotypes.</p> <p><i>“People might judge me before they know me, by assuming I fit a stereotype of Asperger's that they've seen portrayed in the media.”</i></p>
<p>To gain reasonable adjustments or accommodations that can help you to better manage your work or studies.</p> <p><i>“The decision was taken so as not to have any problems. Now no one asks me to go down the night before for meetings. They are organised to allow for early morning travel.”</i></p>	<p>People might focus on your autism instead of other aspects of yourself you want them to focus on.</p> <p><i>“I had been to job interviews where they knew about my diagnosis and spent all their time focused on that and not on me as if my only feature or personality or work was my autism.”</i></p>
<p>To gauge whether the environment is a right fit for you.</p> <p><i>“I used disclosing as a way of working out whether a job was for me. If potential employers reacted negatively to me disclosing my autism, how would they react to me asking for help with something or having a meltdown?”</i></p>	<p>You might face bullying and discrimination.</p> <p><i>“In the past, I've opened up... and told someone that I have ASD, and they've bullied me about it.”</i></p>
<p>You may help to improve autism awareness and acceptance in your institution more generally.</p> <p><i>“I used the disclosure of my diagnosis to improve the place for our autistic students and to provide autism training and support to other staff.”</i></p>	<p>It might not be necessary or relevant to the particular task.</p> <p><i>“It's a small piece of work, not very intense, and I don't see a reason to disclose. It's not worth the effort.”</i></p>

\* **Masking** (or camouflaging) happens when autistic people, consciously or subconsciously, hide their autistic traits and behaviours. Some autistic people find that masking helps them to ‘fit in’ and avoid public stigma, but it can also be very tiring and stressful to maintain, and add to self-stigma, low self-worth and poor mental health in the long run.

\*\* For more information on your legal rights, please see the Appendix.

Context 3: Disclosing to public service providers  
(E.g., healthcare professionals, police officers, etc.)



Reasons to disclose	Reasons not to disclose
<p>To help them understand you better so they can provide better services or support.</p> <p><i>“To help them understand me and hopefully treat me more objectively.”</i></p>	<p>Some providers may not understand what autism is or what it means to be autistic, so it may not change the way they interact with you.</p> <p><i>“Because ... it will just be ignored the same as the past.”</i></p>
<p>To explain to providers about autism-related differences that may affect the way you interact with them. This can help them not to misinterpret things you say or do, and communicate with you better.</p> <p><i>“To explain difference. That my communication style is not a case of suspicious behaviour or guilt.”</i></p>	<p>The provider may overestimate or underestimate your abilities, and misjudge you based on false myths, e.g., that all autistic people are intellectually disabled.</p> <p><i>“They think you’re mentally ill and/or stupid. I want to be taken seriously.”</i></p>

<p>To get reasonable adjustments or adaptations made so you can access services and get the support you need, in the way that you need it to be provided.</p> <p><i>"I always disclose to ask for extra support and to request reasonable adjustments."</i></p>	<p>Some providers may not believe you are autistic if you do not fit into their preconceptions of what autistic people are like.</p> <p><i>".. a medical doctor on a hospital ward refused to believe my autism diagnosis and forced me to do the AQ-50.. it was a frustrating and an invalidating experience."</i></p>
<p>If you don't have a formal autism diagnosis yet and you want to get one, your healthcare provider may be able to refer you for one.</p>	<p>It just may not seem relevant or necessary to do so at the time.</p> <p><i>"I don't necessarily think it's going to be a guaranteed solution, I would do it if I think it's relevant."</i></p>



Now that you have read some examples of why other autistic people have chosen to disclose or not to disclose in three main contexts, you can write down your own reasons in the worksheets provided over the next few pages.

You will not be expected to share these worksheets with anyone. Rather, this is practice so you can better learn how to make disclosure decisions like these in the future. Over the course of your life, you will have many opportunities to tell people that you are autistic. You can use these worksheets to weigh your personal pros and cons on each occasion in the different settings of your life.

While you are filling out the worksheets, remember:

- 1) Don't dismiss any pro or con. Write whatever comes to mind - there are no "silly" reasons.
- 2) Reaching the right decision for you is not as simple as adding up the pros and cons. Some pros and cons will be more important to you, and so should be considered more strongly when making a decision - you can put a star (\*) next to these items in your list. Only you can decide for yourself how these pros and cons balance.
- 3) Your decision can be yes, no, or to decide later. You may not be ready to make a decision about disclosing at this point. You may need additional time to gather more information about disclosure. You can return to the worksheets later on in this programme or even after the programme is over.
- 4) Your decision depends on the setting. You will need to think about pros and cons of disclosing your autism diagnosis or autistic identity separately for each setting that is important to you. We have included multiple blank copies of the worksheet that you can use to do this. Feel free to use as many as you need to - you don't necessarily have to complete all three copies.
- 5) Think about your reason for disclosing in that setting. When you talk about being autistic, what do you want to happen? Is your main goal to be understood, to get reasonable accommodations, to combat stigma, or something else? The answer to this will help you later when we consider what exactly you want to share to achieve this goal.
- 6) Think about possible reactions to your disclosure. In what ways are you expecting people to react? Are you prepared to respond calmly and confidently to unexpected reactions? Later, we will learn some strategies for how we can limit the possibility of experiencing negative reactions as well as prepare for negative reactions.

## Worksheet 1: Pros and Cons of Disclosure

First, choose a setting and a person within that setting whom you are considering disclosing to.

Setting: \_\_\_\_\_ To Whom: \_\_\_\_\_

Now, list the pros and cons of disclosing to this person. Don't censor any ideas. Write them all down. Put a star (\*) next to the pros and cons that you think are especially important.

Pros of disclosure	Cons of disclosure

What would be your main reason/goal for telling this person you are autistic?

Given the pros and cons I listed:

- I have decided I will tell this person I am autistic
- I have decided I will not tell this person I am autistic
- I have decided to postpone my decision to tell this person I am autistic

If you decide to disclose to this person, what do you expect will happen after disclosing?  
(Note that you only have to complete this section if/when you have decided to disclose.)

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If you decide to disclose to this person, what do you expect will happen after disclosing?  
(Note that you only have to complete this section if/when you have decided to disclose.)

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Pros of disclosure	Cons of disclosure

What would be your main reason/goal for telling this person you are autistic?

Given the pros and cons I listed:

- I have decided I will tell this person I am autistic
- I have decided I will not tell this person I am autistic
- I have decided to postpone my decision to tell this person I am autistic

If you decide to disclose to this person, what do you expect will happen after disclosing?  
(Note that you only have to complete this section if/when you have decided to disclose.)

## 2.2. Weighing the pros and cons of different levels of disclosure

It might seem obvious, but you can choose between different levels of disclosure in each setting. We describe five levels here, then guide you through considering the pros and cons of each level.

<b>Pros and cons of five different levels of disclosure</b>	
1. Social avoidance: Not telling anyone that you are autistic and avoiding situations where people may find out about it.	
Pros: You limit the possibility of encountering people that will treat you unfairly.	Cons: You lose the opportunity to meet people who may possibly be supportive.
2. Secrecy: Participating in activities, but keeping your autism diagnosis or autistic identity a secret.	
Pros: Like social avoidance, you may be able to withhold information from others so they have less power to hurt you, while still participating in activities that are important to you.	Cons: Hiding your autism diagnosis or autistic identity can be stressful and tiring. You may also miss out on the support that you need because people do not know that you are autistic.
3. Selective disclosure: Telling a few select individuals you are autistic, but not everyone.	
Pros: You may be able to find a small group of people who can understand you, accept you, and provide the support you need.	Cons: You may have difficulty keeping track of who knows and who doesn't. People you have disclosed to may also tell others.
4. Open disclosure: Making the decision to no longer hide that you are autistic, but not actively telling people that you are autistic.	
Pros: You don't have to worry about hiding or people finding out that you are autistic.	Cons: You may disclose to people who will not react well or hurt you with the information.
5. Advocacy: Actively seeking out and educating people about autism to challenge false beliefs about autism.	
Pros: You are fostering a personal sense of power in yourself. You are helping to combat stigma.	Cons: You may get hostile responses to your message. There will be people who disapprove of what you are advocating for.

Again, your choice may differ depending on the setting - for example, you may choose Level 3 (selective disclosure) in your personal life, and Level 5 (advocacy) in your professional life. Your choice may also change over time in each setting - for example, you may start off at Level 2 (secrecy) but progress to Level 3 (selective disclosure) as you get to know the environment and people better. However, remember that once you disclose, you can't take it back!

Let's consider the different levels of disclosure in the following scenario: Joy is an autistic woman who recently started university, and is wondering whether to tell people that she is autistic.

1

Joy may choose **social avoidance**, which means she decides not to tell anyone she is autistic and avoids situations where people may find out she is autistic. For Joy, this may look like attending lectures and seminars, but not having meals with her seminar groupmates. Joy may also join a music club given her interest in music but minimise her interactions with other club members.

Alternatively, Joy may choose **secrecy**, which means that she participates in social activities while keeping her autistic diagnosis/identity a secret. For Joy, this may mean getting to know people in her seminar group or music club. However, she does not tell any of her groupmates or fellow club members that she is autistic, and may find herself trying to mask her autistic traits while interacting with them.

2



3

Joy may also choose **selective disclosure**, in which case she would tell a select few individuals, but not everyone, that she is autistic. Joy may disclose to the university's disability support officer, her personal tutor, and a few of her seminar groupmates or close friends in her music club.

Another option for Joy is **open disclosure**, where Joy decides to no longer hide that she is autistic. For Joy, this may look like joining the university's autism society. She will not actively tell everyone she is autistic, but if someone asks her about her involvement in the society, she will answer them honestly.

4

5

The final option for Joy is **advocacy**. As an advocate, Joy will actively seek out and educate people about autism in order to change false ideas about autism. Together with the university's autism society, Joy may organise events to increase students' and staffs' understanding and acceptance of autistic people.

Now, pick a setting that is most relevant to you or recent in your life and consider the pros and cons of the five levels of disclosure outlined below. Don't worry if you find that some of the levels are less useful or more difficult to complete. You don't have to fill in the whole worksheet. You can also choose to leave some parts blank and return to them later.

## Worksheet 2: Pros and Cons of the Five Levels of Disclosure

Setting: \_\_\_\_\_

1. Social avoidance: Not telling anyone that you are autistic and avoiding situations where people may find out about it.	
Pros:	Cons:
2. Secrecy: Participating in activities, but keeping your autism diagnosis/autistic identity a secret.	
Pros:	Cons:
3. Selective disclosure: Telling a few select individuals you are autistic, but not everyone.	
Pros:	Cons:
4. Open disclosure: Making the decision to no longer hide that you are autistic, but not actively telling people that you are autistic.	
Pros:	Cons:
5. Advocacy: Actively seeking out and educating people about autism to challenge false beliefs about autism.	
Pros:	Cons:

**If you've decided while completing Section 2 that at this point in time telling others is not the right choice for you, you may wish to briefly review the next few sections to see whether any of the contents is relevant for you, but you do not have to complete them. In any case, you may find it helpful to review your decision by going over Section 2 again at some point in the future.**

## 3. How to Share

### 3.1. Drafting your personal story

In this section, you will be guided in crafting your personal story in an empowering way. If you've decided in Section 2 that you may want to disclose your autism diagnosis or autistic identity to someone, this will help you to think through the story you want to tell others. However, even if you've decided not to disclose, it can be helpful to think about the story you tell yourself.

Below, we provide an example of how one autistic adult, Joe, has chosen to craft his story. You can also watch a video of him sharing his story [here](#) and videos of other autistic people sharing their stories [here](#).

Joe's Story (transcribed from the video linked above on the NHS YouTube channel):

During my school days, my autism was more apparent to me as I knew I was different to most of my peers. I was diagnosed at the age of seven. I was assessed by a speech and language therapist and a clinical psychologist. I found it very difficult to be able to communicate with my peers as I could not initiate or be able to sustain conversations. However, my autism provided me with a good memory for school studies and enabled me to gain nine GCSEs and three A-levels.

After leaving school and becoming an adult, I started to view my autism differently as I realised that if this was taken away I would not have my own unique personality, and now today I enjoy having the opportunity to speak about my personal experiences of being on the autistic spectrum. My autism has enabled me to continue with higher education and to gain two degrees in history.

For me personally, I believe my diagnosis of autism is very positive as it has enabled me over many years to develop a good understanding about how autism impacts me on a personal level and this then enables me to think about how I can better manage some of the key challenges of being autistic; for example, my difficulties with sensory processing. I often feel the world is unpredictable and confusing. I find it difficult to process information at a fast pace. I encounter anxiety on a daily basis and this impacts on my everyday life. Currently, I am not able to travel independently, and I always require support from a carer.

For the future, I hope to gain more life skills, to manage my anxiety better and to become more independent. I would love to explore different places around the world and to be able to travel with support, including to be able to travel across the United States and Canada. One of my big dreams is to go outdoor skydiving.

These are some of my important final messages. Autistic people face many challenges because the social world is not designed for us. Autistic people have many important strengths and great potential to succeed through their own personal talents with the right support from people who take the time to listen and to understand our own individual needs. Autism needs everyone in society to come together and to have more understanding. We are not broken, we are unique.

Consider the following questions:

- 1) What are some of the things you liked about his story?
- 2) How does it reflect a story of self-acceptance?
- 3) How does it challenge stigma?
- 4) What parts might you have left out or said differently?
- 5) What other information might you add in your own story?

There are many different ways to share your story. But generally, it is important to recognise that your story tells people about your strengths, challenges, and needs in a way that they can understand and support you. The worksheet on the next few pages provides a template that might work for you.

Take your time to complete the worksheet. You can add any information important to you that the template does not include, or leave any parts blank and return to them later. Crafting your story is a process and your story will change over time. Your story will also vary depending on where you tell it. Later, you can select which parts of your story you want to tell in different settings/to different people. Remember, you are in control of how much you choose to share!



## Worksheet 3: Drafting your personal story

### **Your name and how you prefer to identify with autism**

In Section 1.4, we explained that many autistic people prefer to identify as 'autistic', while some prefer to identify as 'having autism'. You may wish to think about how you prefer to identify, for example:

- I am autistic
- I am on the autism spectrum
- I have autism
- I have a diagnosis of autism/Autism Spectrum Disorder
- I have Asperger's Syndrome

(Note: you may choose to identify in more than one of these ways, and your choice may vary in different settings)

### **Your experiences growing up, when and how you were diagnosed/discovered you were autistic**

Things you may want to think about:

- Were there any things that were particularly enjoyable/challenging for you when you were younger?
- How well did people around you understand you, your strengths and challenges?
- What was your journey in being diagnosed with autism or discovering you were autistic? (E.g., a teacher referred you to a clinician who gave you the diagnosis, or you read up about autism by yourself, did an online assessment and self-diagnosed)
- At what age did you receive an autism diagnosis or begin to self-identify as autistic?
- How did you feel when you were diagnosed with autism or discovered you were autistic?

### **Explanation of what autism is/means to you**

How would you describe autism/being autistic? For example, we explained our position in Section 1.4 that we consider autism as part of human diversity (i.e., neurodiversity), instead of viewing it as a 'deficit' or 'impairment'.

### **Your strengths and interests**

What are your interests/passions? What do you think you are good at? What have people told you that you are good at? For example, some autistic people find that they have some of the following traits:

- Strong attention to details
- Artistic and creative talents
- Mathematical and technical abilities
- Extensive knowledge and expertise in their areas of interest
- Character strengths such as honesty, loyalty and reliability

### **Your challenges and needs**

Are there any things that are particularly challenging for you? For example, have you recently experienced any obstacles that came in your way and you could not do what you wished you could? For example, some autistic people:

- May experience over- or under-sensitivity to lights, noises, and smells
- Can feel anxious or overwhelmed in social situations
- Find it difficult to recognise their own emotions and other people's emotions
- Find it stressful to deal with change or uncertainty
- Need extra time to process information

**How you want to be supported/treated**

When you are faced with the unique challenges you described above, has there been anything or anyone that made the situation better for you?

**Your goals/hopes for the future**

What are your ambitions for the future? Are there any things you would like to do/accomplish in the future?

**Final messages**

(You may want to emphasise your strengths again, and explain how many of the challenges you face are because the world has not been designed in a way that is suitable for autistic people. You may want to end off by telling listeners what they can do to make the world a more inclusive and supportive place for you and autistic people generally.)

### 3.2. Choosing what to share from your story

The setting and your goal of disclosing will determine what you choose to share from your overall story. Rarely will you share everything. For the worksheet below, consider two different settings/people to whom you think you have a good reason to share some of your story. In some situations, you may even decide to talk about your need for support or accommodation without telling people you are autistic.

#### Worksheet 4: Choosing what to share from your story

Setting/Person 1:
My reason to share some of my story in this setting/with this person is:
What are things from your story that you think are most important to share in this setting/with this person?
What are some things from your story that you will not want to include when you talk in this setting/to this person? (You believe is too personal, or the person might not understand, or isn't important for them to offer what you need from them.)

Setting/Person 2:

My reason to share some of my story in this setting/with this person is:

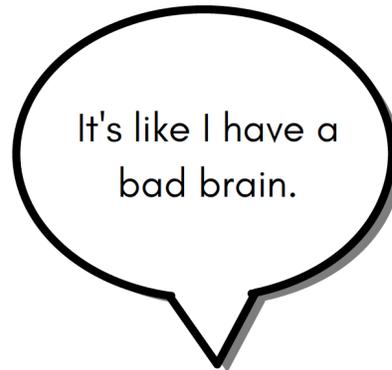
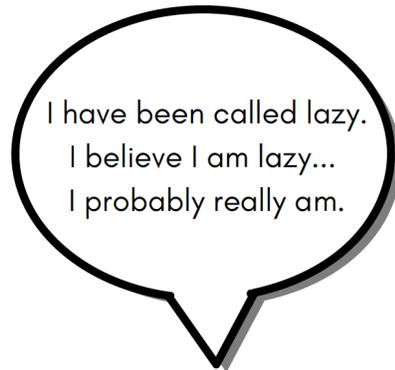
What are things from your story that you think are most important to share in this setting/with this person?

What are some things from your story that you will not want to include when you talk in this setting/to this person? (You believe is too personal, or the person might not understand, or isn't important for them to offer what you need from them.)

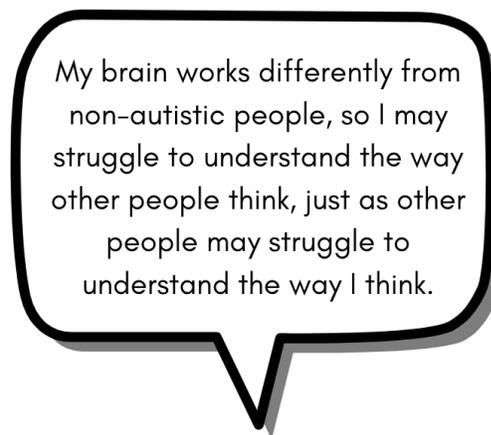
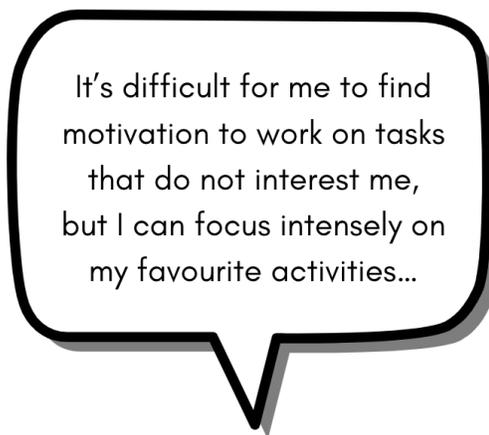
### 3.3. Replacing hurtful self-beliefs in your story

As you drafted your story, you might have noticed some words or ideas that you had written about yourself that did not feel very helpful for you to get what you need. The ideas may even have felt unhelpful for you to hold onto. These are known as hurtful self-beliefs or self-stigma.

Below are two examples of hurtful self-beliefs that autistic people have expressed about themselves.



These statements are not true, yet someone may think they are. It would be more helpful to say:



Sharing your hurtful self-beliefs can increase the other person's stigma towards you. Working towards turning those beliefs around, and being supported to do so, can help to decrease public stigma and self-stigma.

**Public stigma** happens when members of society carry unhelpful beliefs, attitudes, and behaviours towards autistic people.

**Self-stigma** (or internalised stigma) happens when autistic people believe those false ideas about autism and turn those hurtful attitudes and behaviours towards themselves. This may affect their sense of self-worth and mental health.

## Worksheet 5: Replacing hurtful self-beliefs

### **Identifying your hurtful self-beliefs**

Look back over your draft story and list any hurtful self-beliefs. Add any others that you notice you carry about yourself related to being autistic. (Don't worry if you haven't identified any - you can skip this section.)

### **Changing your personally hurtful self-beliefs**

Could you rephrase these hurtful statements in a more helpful way, as illustrated in the examples on the previous page? (Again, if you have not noticed any hurtful self-beliefs, you can skip this section.)

Long-held beliefs can be hard to change even when you know they are unhelpful. Changing your hurtful self-beliefs may not happen while you are completing this guide, but rather very slowly with time. If you find that self-stigma is affecting your mental health, you may wish to turn to mental health services such as those listed in Section 5.2 of the Appendix.



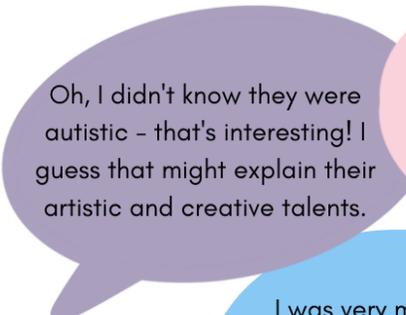
One way to 'test' a person prior to disclosure is to bring up something related to autism from a movie, TV show, or other form of media and to ask what the other person thinks of it. We are going to demonstrate how that might go and ask you to be the judge for whether the person's responses suggest that they are a good person to disclose to.

For example, you could bring up famous people who have shared about being autistic:



Recently, I've been hearing more famous people sharing openly that they are autistic. Did you know [names of famous people] are autistic? What do you think of their stories?

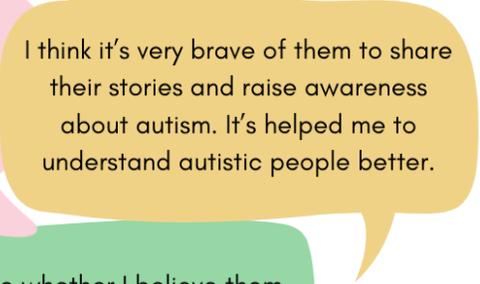
Take a look at some possible responses and decide for each one if you would find that person helpful to share with if your reason for sharing was to gain understanding and support:



Oh, I didn't know they were autistic - that's interesting! I guess that might explain their artistic and creative talents.



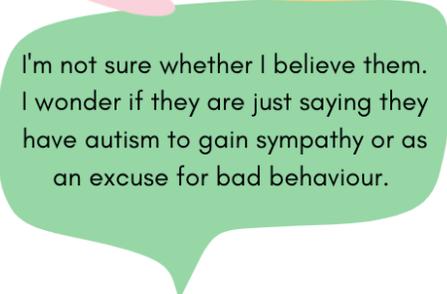
Yeah, it seems like autism is becoming more and more common these days. I wonder if it's because of the environment.



I think it's very brave of them to share their stories and raise awareness about autism. It's helped me to understand autistic people better.



I was very moved and inspired by their stories. It shows that autistic people can succeed in life if they get the right support.



I'm not sure whether I believe them. I wonder if they are just saying they have autism to gain sympathy or as an excuse for bad behaviour.

Now, look back over the responses and imagine that your reason for sharing was to educate others and challenge stigma. This time, what decisions about sharing would you make for each response?

Alternatively, you could bring up popular books or films featuring autistic characters:

Have you watched/read [name of book/film]?  
What did you think of [name of autistic character]?  
Do you know anyone like that?

Again, take a look at some possible responses and decide for each one if you would find that person helpful to share with if your reason for sharing was to gain understanding and support:

I haven't watched it but I've heard about it - it's about an autistic savant? Not all autistic people are like that, I've met some while volunteering and they were quite different.

Yes, I've read that. I have a cousin who is autistic and it's helped me learn how to interact with her better.

Yes, I've watched that show! It seems like autistic people are geniuses. There was an autistic student in my primary school who was really smart, although she was a little weird.

Yes, I've seen that. I don't know anyone who is autistic and I can't imagine dating/befriending an autistic person, it seems like it would be too difficult.

Now, look back over the responses and imagine that your reason for sharing was to educate others and challenge stigma. This time, what decisions about sharing would you make for each response?

## Worksheet 6: Testing a person for disclosure

**If you wanted to test a person before sharing your story, what topic (famous autistic person or character in a book, TV show, movie, etc.) would you feel comfortable bringing up to the person to test their reaction?**

We have provided some examples here. Do note that these examples may not be an accurate representation of all autistic people or yourself as an autistic person, and other people may have a stereotypical view of autism as a result of what they have seen in the media. However, you can educate them and dispel those myths (regardless of whether you choose to disclose or not).

Examples of famous people who have talked about being autistic:

Anthony Hopkins - actor

Daryl Hannah - actress and environmental activist

Elon Musk - entrepreneur

Greta Thunberg - climate change activist, also featured in the documentary 'I Am Greta'

Susan Boyle - singer

Examples of books, shows, and films featuring autistic people/characters:

Loop - Disney Pixar animated short film featuring a non-speaking autistic girl

Love on the Spectrum - reality TV dating show featuring autistic adults

Saga in The Bridge - character not explicitly autistic but displays autistic traits

Sheldon Cooper in The Big Bang Theory - character not explicitly autistic but displays autistic traits

The Reason I Jump - autobiography of a non-speaking autistic boy, later adapted into a documentary

Questions you might ask the person to test the waters:

What do you think of stories (shows, movies) like these?

What do you think of people like this in the story (show, movie)?

Do you know anyone like this?

Questions you might ask yourself to determine whether the person is a good person to disclose to:

Was the person's response sensitive and kind?

Was the person's response the kind of response you would want to get if you disclosed?

## 4.2. Being prepared with responses and support

You can prepare for how to respond to potential negative reactions to your disclosure. Even when you have done the work to identify your reason for sharing, selected parts of your story that are relevant to the situation, and ‘tested’ someone out before sharing, things can go in ways you did not want.

<b>How people might react to your disclosure</b>	
<b>Neutral/positive reactions</b>	<b>Negative/stigmatising reactions</b>
Sincere interest E.g., “I don’t know much about autism. Can you tell me more about what it’s like to be autistic?”	Disbelief/dismissal E.g., “You don’t look autistic!” / “We’re all a little bit autistic.”
Understanding E.g., “I see, now I understand why having a fixed routine is so important to you.”	Assumptions/stereotypes E.g., “So you’re like Rain Man?” / “What is your special ability?”
Acceptance E.g., “Thanks for telling me, I’m really glad that I got to know more about you.”	Judgment/blame E.g., “Maybe you wouldn’t be bullied if you tried to act normal and fit in more.”
Support E.g., “Is there anything I can do to support you?” / “How can I be a good ally to you?”	Fear/avoidance E.g., people distancing themselves from you or hanging out with you less after you disclose

Before you act on sharing part of your story with others, it is a great idea to prepare yourself for unexpected negative reactions. Here are some ways you can prepare for the conversation:

- Write out how you would react to the people’s reactions described in the table above.
- Talk to someone (e.g., your therapist or other trusted adult) who supports you about your plan to share.
- Ask that person to help you think of effective responses if the person reacts negatively.
- Consider these tips when deciding what to say in response to a negative/stigmatising reaction:
  - Calmly correct any false assumptions by providing some factual information and/or explanation of your circumstances.
  - Restate the reason you chose to share that you are autistic.
  - If you think this person might change their perspective and you want to “leave the door open”, end your responses with an invitation to talk more at a later time.

On the next few pages, we provide two examples of how to respond confidently to a stigmatising reaction.

Scenario 1: You disclose to your supervisor at work that you are autistic. They respond with disbelief and are dismissive.

You:

“I wanted to share with you that I am autistic. I’m hoping that we can make some adjustments to help me do my work better. I think having a flexible working schedule and moving my workstation to a quieter area in the office would really help me to focus and be more productive in my role.”

Supervisor:



“I don’t quite like that idea. I think it would damage team spirit, since you’d be working different hours from everyone else and your desk would be isolated. Besides, your work has been fine. I don’t see any problems, so surely autism can’t be affecting you that much? I’ve seen autistic people before, and you’re not like them.”

How you may respond:

- 1) Calmly correct any false assumptions by providing some factual information and/or explanation of your circumstances.**

“I understand your concerns, but I will still be working in the office most of the time, and I will attend all team meetings and discussions as usual. Although it may look like I have been coping well, I’m actually prone to experiencing sensory overload. It’s quite overwhelming and exhausting for me to keep up with the current working practices.”

- 2) Restate the reason you chose to share with them that you are autistic.**

“I chose to share with you that I am autistic because under the Equality Act\*, disability is a protected characteristic and autism is considered a disability. I understand that this gives me a right to reasonable adjustments in the workplace. I believe these adjustments I have suggested are reasonable and would really help me to do my best work here in the long run.”

**3) If you think this person might change their perspective and you want to leave the “door open,” end your response with an invitation to talk more at a later time.**

“I hope that you will reconsider my request. If there is any other information that you need from me, please let me know. I am happy to discuss how we can make these adjustments without affecting teamwork in the office.”

\*Note: The Equality Act 2010 only places a legal duty on employers to make reasonable adjustments if they know (or could be expected to know) that you are disabled, and if you’re placed at a substantial disadvantage because of your disability compared with people who don’t share your disability. In order to activate this legal duty, a certain level of disclosure and explanation on your part may be required. For more information on your legal rights, please refer to the Appendix, Section 5.1.

Scenario 2: You disclose to someone you have started dating, and they respond with assumptions and stereotypes.



You: “Since we’ve been seeing each other for a bit, I wanted to tell you that I am autistic. You might have noticed that knowing what to expect is really important to me, which is why I ask a lot of questions when we make plans. I also can get really focused on my work and hobbies, so I don’t always respond to calls or messages immediately, but I always do eventually. There might be other differences and I hope we can work through them if they come up.”

Date: “Oh, huh, I’ve never dated an autistic person before. Doesn’t that mean you don’t really interact with people? I thought autistic people were not interested in relationships and preferred to be alone.”

How you may respond:

- 1) Calmly correct any false assumptions by providing some factual information and/or explanation of your circumstances.**

“Yeah, those are stereotypes about autism that aren’t really true. I’m very close to my friends and I am looking for a partner, though finding the right person takes time.”

- 2) Restate the reason you chose to share with them that you are autistic.**

“Autism is a big part of who I am, so it’s important to me that the person I date knows and accepts me.”

- 3) If you want to leave the “door open,” end your response with an invitation to talk more at a later time. Set boundaries if you need to.**

“If you have any questions about what autism means for me, I’m happy to answer them. There are a lot of negative stereotypes about autism that can be hurtful to hear, so I hope it’s okay if I point these out if they come up, or shut down the conversation if I need to. I really like spending time together, and I hope we can continue to do that.”

Ways to manage during the conversation:

- Take a breath and allow yourself time to process and formulate your response to any hurtful or unhelpful reaction.
- Be kind to yourself by using positive self-talk (remember what you learnt in Section 3.3 on replacing hurtful self-beliefs).
- Walk away. Delay your response until you are ready or do not respond at all.
- Remember that the person may be having a difficult time understanding what it has been like for you if they have not had a similar experience.
- Allow yourself to make mistakes in deciding to whom you should share. When you feel ready, review what went well, what didn’t, and use what you learned in future opportunities for sharing.

### 4.3. Putting it all together

We now come to the end of the guide with a pause for reflection and direction. Below, we recap the key steps you may wish to go through when making disclosure decisions in the future. We also provide a final worksheet for you to summarise your own takeaways and consider how you will move forward after this programme. Feel free to write down any additional thoughts and/or discuss them on the forum.

The next time you are faced with a disclosure decision:

- 1) Write out the pros and cons of disclosing in that particular setting.
- 2) Remember that you can choose between different levels of disclosure: social avoidance, secrecy, selective disclosure, open disclosure, and advocacy. Your choice can also change over time.
- 3) Draft what you want to share beforehand. Remember not just to include your challenges but also your strengths, and to rephrase any self-stigmatising statements.
- 4) Ask yourself what is your reason for sharing in that situation. Knowing your goal will help you decide how much information to share.
- 5) Remember there are characteristics you can look for in a person to help you decide if that person will likely help you meet your goal after you disclose to them. Consider 'testing' that person out before disclosing to them.
- 6) Think about possible reactions to your disclosure and prepare for how you may respond to stigmatising reactions.

### Worksheet 7: Reflections and future directions

What are the main things you learned about disclosure and stigma from this programme?
What are the most important pros and cons of disclosure for you? (Section 2.1)
Might you disclose in some places, and if so, where? (Section 2.1)

What level of disclosure might work for you? (Section 2.2)
What do you think of how you outlined your story? How might you improve it? (Section 3.1 - 3.3)
To whom might you disclose? (Section 4.1)
How might you respond to possible stigmatising reactions from others? (Section 4.2)
Given all of this, what might you do in terms of disclosure in the future?

One of the things you might wish to do after this programme is to join a peer support group. You may find it helpful to know that you are not alone in making complex decisions about disclosure. You may also find that disclosure is easier when you stand together with other autistic people. For information on where you can find peer support and other services, please refer to Section 5.2 of the Appendix.

## 5. Appendix

### 5.1. Information on legal rights

It is important to know your legal rights as you consider disclosure. For example, you may want to know what your university's or employer's legal obligations are when you disclose that you are autistic. Or you may experience discrimination after disclosing that you are autistic and want to know what you can do. While we cannot give you legal advice, we outline a few main relevant laws here and point you to other resources that may be useful and organisations that may be able to help.

You may or may not consider yourself disabled, but autism has been recognised as a disability under the **Equality Act 2010**. This Act prohibits the following forms of discrimination against disabled people:

- **Direct discrimination** happens when someone treats you less favourably than they would treat a non-autistic person because you are autistic. An example of this might be an employer who decides not to hire you for the reason that you are autistic.
- **Indirect discrimination** happens when an organisation has a policy or practice that puts you at a disadvantage compared to a non-autistic person. This is unlawful unless the organisation is able to show there is a good reason for the policy and it is proportionate. An example of this might be an employer who requires all applicants for a particular job to pass a psychometric test.
- **Discrimination arising out of a disability** happens when you are treated unfavourably as a result of something arising as a consequence of your autism. An example of this might be an employer who dismisses you for being absent due to anxiety, and this anxiety is linked to your autism. However, this provision does not apply if the person or organisation did not know, and could not reasonably have been expected to know, that you are autistic.
- **Failure to make reasonable adjustments** happens when an organisation fails to make reasonable adjustments to ensure that you can access jobs, education and other public services as easily as non-autistic people. What is considered reasonable in the context will depend on a number of factors. Again, this duty does not apply if the organisation did not know, and could not reasonably have been expected to know, that you are autistic.
- **Harassment** happens when you are treated in an intimidating, hostile, degrading, humiliating or offensive way.
- **Victimisation** happens when you are treated unfairly or badly because you have made a complaint of discrimination under the Equality Act.

Remember that you are not legally required to tell anyone that you are autistic. After going through this programme, you may decide to tell some people for reasons such as gaining support or accommodations, but you do not have to tell anyone if you choose not to. You do not have to tell someone simply because they are in a position of authority. The Equality Act 2010 also makes it unlawful for employers to ask applicants about their health or disability until they have been offered a job, unless the information is necessary for the application process or a requirement of the job.

The information in this section should not be treated as an alternative to, or a substitute for, expert legal advice. The following organisations may be able to advise and support you on specific legal issues:

### **Equality and Human Rights Commission (England, Wales and Scotland)**

The EHRC website provides information on equality and human rights issues, including the Equality Act.

Website: [www.equalityhumanrights.com](http://www.equalityhumanrights.com)

### **Citizens Advice Bureau (CAB)**

CAB gives free, independent and confidential legal advice on a range of subjects. You can search for your local CAB by town or postcode on the national website.

England, Wales and Northern Ireland website: [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

Scotland website: [www.cas.org.uk](http://www.cas.org.uk)

### **The Law Centres Network**

Law Centres can provide free legal advice, casework and representation. You can find your nearest Centre at the websites below.

England, Wales and Northern Ireland website: [www.lawcentres.org.uk](http://www.lawcentres.org.uk)

Scotland website: [www.govanlc.com/salc](http://www.govanlc.com/salc)

### **Disability Law Service**

Disability Law Service provides free specialist legal advice for disabled people and their carers or families throughout the UK, including on disability discrimination.

Website: [www.dls.org.uk](http://www.dls.org.uk)

Telephone: 020 7791 9800

### **Romford Autism Hub Legal Advice Clinic**

The Romford Autism Hub Legal Advice Clinic is a partnership between the University of East London (UEL) and the Sycamore Trust UK. Sycamore Trust UK is a charity that provides services for autistic people, one of which being the Romford Autism Hub for autistic adults. At this Law Clinic, UEL student volunteers offer free, autism-specific legal advice to clients of the Romford Autism Hub living in the Havering area.

Website: <https://www.uel.ac.uk/schools/royal-docks/law-clinic>

Email: [autismhub@sycamoretrust.org.uk](mailto:autismhub@sycamoretrust.org.uk)

Telephone: 01708 749 816

### **Equality Advisory and Support Service (EASS)**

The EASS is aimed at individuals who need more specialist advice and support on discrimination law and human rights issues than other advice agencies and local organisations can provide.

Website: [www.equalityadvisoryservice.com](http://www.equalityadvisoryservice.com)

Phone: 0808 800 0082

Textphone: 0808 800 0084

### **Advisory, Conciliation and Arbitration Service (ACAS)**

If your enquiry relates to employment, including workplace discrimination, ACAS provides free advice to employees or job applicants.

Website: [www.acas.org.uk](http://www.acas.org.uk)

Telephone: 0300 123 1100

### **Care Quality Commission (CQC)**

The CQC is an independent organisation that inspects and regulates health and social care services in England to ensure that they meet fundamental standards of quality and safety. You can contact them to give feedback on your experience of care, whether good or bad.

Website: <https://www.cqc.org.uk/give-feedback-on-care>

Telephone: 03000 616161 (Monday to Friday, 8.30am to 5.30pm, excluding bank holidays)

## 5.2. Information on support resources

Making disclosure decisions, crafting your personal story, and changing hurtful self-beliefs are complex ongoing processes. We have compiled a list of support resources in case you want or need further help beyond this programme. Do note that inclusion of a service in this list does not imply that we endorse them, nor does the absence of a service imply that we do not endorse them.

### National charities and organisations

#### **Autism Alliance**

The Autism Alliance acts as an umbrella organisation for 16 autism-specialist charities across the UK. It represents many local and regional autism-specific charities as well as providing information for autistic people, parents/carers and families, including on their legal rights. Their members cover a variety of settings from residential, day services, schools, family support and pathways through to work. The Autism Alliance, or one of its member charities, may be able to help you to find support in your area.

Website: <https://www.autism-alliance.org.uk/>

### **National Autistic Society**

Formed in 1962, the National Autistic Society is the largest autism-specific charity covering the UK, providing support, guidance and advice. They operate residential services, alongside campaigning for improved rights, services and opportunities which aim to create a society that works for autistic people. Their national [Autism Services Directory](#) includes many of the support groups and regional branches they operate across the UK. In England, these are mainly located from the South East to the East Midlands. The directory is not comprehensive and may not include all support groups or charities in your area.

Website: <https://www.autism.org.uk/>

England and Head Office Email: [nas@nas.org.uk](mailto:nas@nas.org.uk)

Cymru (Wales) Office Email: [wales@nas.org.uk](mailto:wales@nas.org.uk)

Scotland Office Email: [generalenquiries.scotland@nas.org.uk](mailto:generalenquiries.scotland@nas.org.uk)

Northern Ireland Office Email: [northern.ireland@nas.org.uk](mailto:northern.ireland@nas.org.uk)

England and Head Office Telephone: +44 (0)20 7833 2299

### **Autism Cymru/Autism Wales**

Autism Cymru/Autism Wales (previously ASDinfoWales) is a resource run by the National Autism Team in Wales, which is funded by the Welsh Government. It provides information and advice for autistic people, parents/carers and families on education, employment and community services in Wales.

Website: <https://autismwales.org/en/>

### **Autism NI**

Autism NI is a charity based near Belfast which exists to support autistic individuals and their families, and campaigns to raise awareness of autism within the wider society. It provides advice, support and training across Northern Ireland.

Website: <https://www.autismni.org/>

Email: [info@autismni.org](mailto:info@autismni.org)

Telephone: 028 9040 1729

### **Scottish Autism**

Scottish Autism is a social enterprise providing training and autism-specific services in Scotland as well as advocating for good autism practice. It offers an Advice Line (via telephone, email or contact form on their website) for autistic people, parents/carers and families which is open Tuesday to Friday, 10am to 4pm (closed on weekends).

Website: <https://www.scottishautism.org/>

Email: [autism@scottishautism.org](mailto:autism@scottishautism.org)

Telephone: 01259 720044

Advice Line Telephone: 01259 222 022

## Peer support groups and networks

### **Ambitious Youth Network**

Ambitious about Autism, a UK national charity, has a rapidly growing online Ambitious Youth Network. Through the network, autistic people between the ages of 16 to 25 can connect with other autistic young people, sign up to peer support sessions, and access a range of opportunities to advocate and improve services for autistic young people. Opportunities include advising on toolkits and campaigns, developing presentations about autism awareness, writing blogs, and leading training sessions. The majority of these opportunities are paid.

Website: <https://ambitious-youth-network.ambitiousaboutautism.org.uk/>

Email: [participation@ambitiousaboutautism.org.uk](mailto:participation@ambitiousaboutautism.org.uk)

### **Asperger's Heroes**

Asperger's Heroes specialises in personal development for neurodiverse adults. They are based in Birmingham and offer free group workshops accessible via Zoom or in person. You do not need to have a formal diagnosis of Autism Spectrum Disorder (ASD) or Asperger's Syndrome to attend these workshops.

Website: <https://www.aspergers-heroes.com/>

Email: [david@aspergers-heroes.com](mailto:david@aspergers-heroes.com)

Telephone: 07905881942

### **Aspie**

Aspie is a social self-help and motivation group for adults with Asperger's Syndrome (aged 18 to 70+) based in Worcester. It provides a space where AS adults, partners/parents/friends) can meet, and feel welcome, accepted and supported. It facilitates a variety of activities that members can join and has its own counsellors who work with members individually as well as together to improve social and communication skills.

Website: <https://www.aspie.org.uk/>

Telephone: 01905 27825

### **Aupeer**

Aupeer provides free to access online peer support groups and one-to-one peer support sessions for autistic adults via Zoom. These spaces are facilitated by autistic people, providing a safe and friendly online place for autistic adults to discuss challenges, share knowledge and meet other individuals with similar identities. A formal diagnosis or a referral is not needed to access support.

Website: <https://www.aupeer.org.uk/>

Email: [hello@aupeer.org.uk](mailto:hello@aupeer.org.uk)

### **AutAngel**

Based in Reading, AutAngel is run by autistic people for autistic people, and they work together to strengthen the autistic community. AutAngel runs a variety of peer support groups and interest groups for autistic adults who live in and around Reading. Their website also has a calendar of autism-positive events held by autistic organisations accessible across the UK.

Website: <https://www.autangel.org.uk/>

Email: [info@autangel.org.uk](mailto:info@autangel.org.uk)

### **North Staffs Asperger/Autism Association (NSAAA)**

NSAAA is a subscription-based advocacy and support group for autistic individuals, parents and carers. It holds a range of different groups for autistic adults and young people.

Website: <https://nsaaa.org.uk/>

Email: [info@nsaaa.co.uk](mailto:info@nsaaa.co.uk)

Telephone: 01782 627002

### **Staffordshire Adults Autistic Society (SAAS)**

SAAS provides support to autistic individuals aged 16 and over, either pre-diagnosis, formally diagnosed or self-diagnosed. Their weekly socials are autism friendly, so that autistic individuals can socialise comfortably without having to 'mask'. They hold online social groups with a variety of topics and interests, including peer support for individuals to help them understand their autism and access the community. They also offer support for parents and families of autistic people and guidance for workplaces who either have autistic employees or autistic clients.

Website: <https://www.saascharity.org/>

### **Shropshire Autonomy**

Autonomy is a Shropshire-based advocacy, self-help and social group for autistic people with or without a diagnosis. It holds regular social activities in Shrewsbury and Telford and publishes a bi-monthly newsletter. Its Facebook group is open to anyone who wishes to join, wherever they are based.

Website: <https://www.shropshireautonomy.co.uk/>

Email: [autonomyshropshire@yahoo.co.uk](mailto:autonomyshropshire@yahoo.co.uk)

Telephone: 01743 821363

## Mental health services

### **Mind**

Mind, the mental health charity, offers information and advice. You can contact them if you need non-urgent information about mental health support and services that may be available to you.

Website: <https://www.mind.org.uk/>

Email: [info@mind.org.uk](mailto:info@mind.org.uk)

Telephone: 0300 123 3393

Text: 86463

### **Samaritans**

Samaritans is a charity aimed at providing emotional support to anyone in emotional distress, struggling to cope, or at risk of suicide throughout Great Britain and Ireland. Their telephone helpline is open 24 hours a day, 365 days a year.

Website: <https://www.samaritans.org>

Email: [jo@samaritans.org](mailto:jo@samaritans.org)

Telephone: 116 123

### **SHOUT**

If you would prefer not to talk but want some mental health support, you could text SHOUT to 85258. Shout offers a confidential 24/7 text service providing support if you are in crisis and need immediate help.

Website: <https://www.giveusashout.org/>

Text: 85258

### **Campaign Against Living Miserably (CALM)**

CALM offers mental health support via their telephone helpline and live webchat service, which are open from 5pm to midnight everyday, 365 days a year.

Website: <https://www.thecalmzone.net/>

Telephone: 0800 58 58 58

### **Health and Social Care Northern Ireland (HSC)**

If you are based in Northern Ireland, health and social care are provided by Health and Social Care Northern Ireland (HSC). You can use this webpage to find mental health services in your area:

<https://www.mindingyourhead.info/services>

### **NHS England**

If you are based in England, you can use this webpage to find and refer yourself to mental health services in your area: <https://www.nhs.uk/service-search/find-a-psychological-therapies-service/>. You can also use this webpage to find and call a local NHS urgent mental health helpline for support during a mental health crisis: <https://www.nhs.uk/service-search/mental-health/find-an-urgent-mental-health-helpline>

### **NHS Scotland**

If you are based in Scotland, you can use this webpage to find more information or seek urgent help and advice for your mental health through their NHS 24 service on this webpage: <https://www.nhsinform.scot/illnesses-and-conditions/mental-health/mental-health-support/mental-health-services-at-nhs-24>. More information about mental health services in Scotland can be found through the NHS Inform webpage: <https://www.nhsinform.scot/illnesses-and-conditions/mental-health>.

### **NHS Wales/GIG Cymru**

If you are based in Wales/Cymru, you can use this webpage to find or refer yourself to mental health services in your area: <https://111.wales.nhs.uk/encyclopaedia/m/article/mentalhealthandwellbeing>

### Finding support in your local area

Local authorities and Integrated Care Systems (ICSs) have a duty to commission services for autistic people at a local level. Local authorities may be county councils, district councils, unitary authorities, metropolitan districts in cities or boroughs if you live in London. An ICS may cover several local authorities and/or cross county boundaries. Your local authority and/or ICS website may include information about autism and services available in your local area though not all do.

The information these websites provide may not include every form of support in your area, which may be provided by support groups or charities. You may find that an internet search referencing your local area and “autism”, “peer support” or “support group” may help you to find more information on any groups or charities meeting in your local area - some of these also provide support and advice via social media, such as groups on [Facebook](#) or pages on [Twitter](#). The [National Autistic Society](#) (NAS) provides a national [Autism Services Directory](#) which includes some support groups and charities, though this is not comprehensive.

### 5.3. References

The quotes from autistic people used throughout the guide have been taken from the following published research studies:

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