Adapting digital networks and resources for autistic users

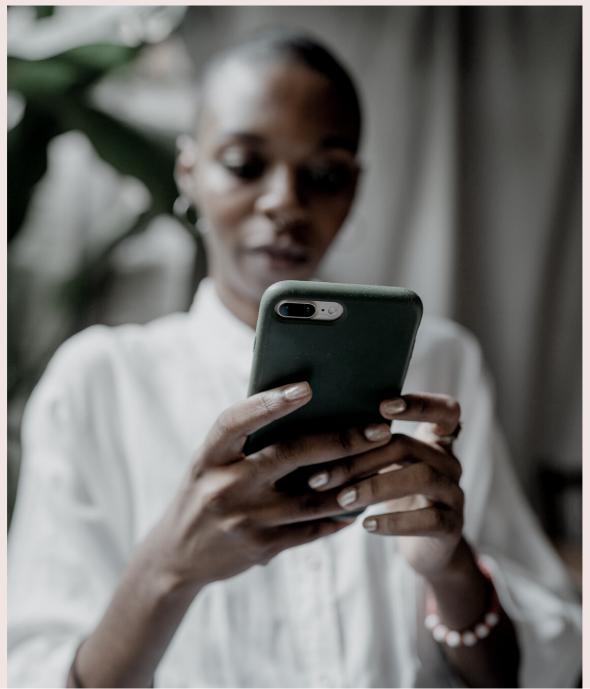
A toolkit for the third and public sector organisations











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Welcome

Welcome to Adapting digital networks and resources for autistic users: a toolkit for the third and public sector.

WHO IS THIS TOOLKIT FOR?

This toolkit offers practical support to any third and public sector professional who wants to adapt their use of digital platforms.

You don't need to have design or programming skills to be able to use this toolkit. The recommendations offered in this toolkit don't ask you to re-design digital platforms from scratch, but rather provide support on how to manage the content which populates your online platforms, and to provide appropriate level of guidance to users.

For those who do have the skills to design digital platforms or have a team of designers at disposition, we offer a separate toolkit specific to these needs, which you can find at www.autisticadultsonline.com/toolkits.

The tips offered in this guide are not just for platforms that are meant to be used exclusively with autistic users, but are applicable to any website, social media, and online group which may include autistic users.

Autism is largely underdiagnosed, and if you are using digital platforms with a public audience, chances are there will be neurodivergent people accessing your platforms. The adjustments recommended in this toolkit will **improve the user experience of your audience as a whole**.

Digital platforms are in constant evolution. Providing platform-specific instructions, for instance how to set up a Facebook group, would have condemned this toolkit to a short lifespan. Instead, we focused on concepts and approaches that can be applied to any platform you are working with (websites, social media platforms, online groups, forums, online courses).

Chapter 1 presents general guidelines on how platforms can be improved to better support autistic users. This information can be useful to readers who are already familiar with accessibility standards and would like to understand how to adapt these to better support autistic users.

Chapter 2, 3, 4, and 5 present practical suggestions cocreated with autistic users to address four specific challenges (first-time access, sensory overload, moderation, and guidance) which can be readily applied by anyone who manages online platforms.

TABLE OF CONTENTS

Welcome. page 1 A description of who this toolkit is for and how to use it. Chapter 1. Autistic Adults and Digital Platforms. page 4 Information on on how digital networking sites can pose challenges to autistic users. Chapter 2. Facilitating First-Time Access. page 8 Information on how to best support the first experience with your platforms. **Chapter 3.** Avoiding Sensory Overload. page 10 Information on how to minimise the chance of sensory overload for users visiting your platforms. Chapter 4. Moderating Online Communities. page 15 Information on how to moderate online groups which may include autistic users. Chapter 5. Providing Guidance. page 20 Information on how to create appropriate guidance to your platforms for your users. Chapter 6. Resources. page 23 A collection of references and resources about some of the topics discussed in this toolkit.

page 26 Thank you.

Chapter 1 Autistic Adults and Digital Platforms

In this section of the toolkit, you will find a brief description of the project which underpins the toolkit and the team who produced it.

This toolkit has been developed as a result of a two-year research project called **Autistic Adults Online** (www.autisticadultsonline.com) which looked at how online environments may enable or impede the social preferences of autistic people.

The research was informed by neurodiversity, a concept according to which the way people experience and interact with the world is varied and neurological differences should be embraced.

What is autism?

Autism is a form of neurodivergence. Although all autistic people have different strengths and challenges, they might share some common characteristics.

• Hypersensitivity to sound, touch, taste, smell, or light.



Chapter 1 Autistic adults and digital platforms

- Attention to detail and precision, tendency for literal thinking.
- Difficult interpreting and expressing one's own feelings and those of other people (alexithymia).
- Appreciating patterns, repetition, and predictable situations, while disliking unexpected event and routine changes.
- Difficulty socializing and interacting with others, although this only tends to happen in in interactions with neurotypical people (Crompton *et al* 2019).

We use the term 'autistic people' instead of 'people with autism' as identity first language is preferred within the autistic community in the UK (Kenny *et al*, 2016). We acknowledge, however, that differences in the use of terminology exist.

Our research found that many digital services are **not doing enough to** support the communicative and sensory needs of autistic users.

We identified a number of **challenges** that online platforms can pose to autistic users. We also found that autistic users develop **coping mechanisms** to mitigate these challenges.

Chapter 1 Autistic Adults and Digital Platforms

1	Use of emojis and GIFs: these can be difficult to understand, especially when their emotional meaning is nuanced and contextual.
2	Sensory overload: when there is an overwhelming amount of moving images, sounds, pictures or colours.
3	Audience uncertainty: it can be difficult to understand who has access to user-generated content and how to control privacy.
4	Conveying and interpreting meaning: being understood and understanding others on social media may require a lot of effort and induce anxiety about misinterpretation of one's messages.
5	Lack of space for interest-based interactions: many online platforms don't do enough to facilitate structured and purposeful conversations around shared interests.

Chapter 1 Autistic Adults and Digital Platforms

What should change

According to our research participants, online platforms can **improve users' experience** by taking the following actions:

- Enabling connections based on common interests.
- Clarifying norms and expectations, avoiding or clearly explaining jargon, and clarifying the meaning of emojis, GIFs, memes or other expressive devices.
- Organising content very clearly and allowing users to easily filter out unwanted content.
- Making it possible to understand and control which audience can access users' content.
- Helping protect mental health and establishing boundaries on usage.

While designers can work to **include autistic users as co-designers** in the development of platforms (<u>autisticadultsonline.com/toolkits</u>), a lot can be achieved by carefully **selecting and curating existing platforms**.

In the following chapters, we address how to think about specific issues related to four areas of practice which research participants found particularly crucial for the third and public sectors: first-time access, sensory overload, moderation, and guidance. The toolkit offers some **practical advice based on conversations** with professionals and autistic users.

Chapter 2 Facilitating first-time access

In this chapter you can find information on how to best support the first experience users have with your platforms.

What is it? First-time access is the first time someone approaches an online platform with the intention of using it.

Why is it important? Having a positive first experience when trying to understand how a new platform works or how to find the information the users need ensures they can be **comfortable** using the platform and returning to it if necessary.

"How are you supposed to engage with something when you can't see in through the virtual front door to see if you'd want to be part of it?"

Research Participant

BEST PRACTICE TO FACILITATE FIRST-TIME ACCESS

• Jargon of any kind should be avoided. If some jargon is necessary for any reason, there should be an easily found glossary page that users can refer to.

Chapter 2 Facilitating First-Time Access

Best practice to facilitate first-time access

- **Tutorials** which explain how the platforms work with step-by-step instructions are useful, but they should never be pop-ups. Pop-up windows are perceived as forceful, disruptive, and can induce sensory overload. Tutorials should instead be provided as a separate and **well-signalled website page**, that users can explore in their own time and go back to when needed.
- Avoid pop-ups that ask users to sign up for your services, especially in the first few seconds of their first visit. Users need to familiarise themselves with the content and nature of your platforms before they feel comfortable signing up. Sudden changes of content can induce sensory overload, especially when the user is making an effort to understand a new platform.
- Icons without a text explanation can be very confusing on first time access. It is best to **use buttons with text**, text alongside an icon, or icons which provide written text when hovered over.
- It is important to think that first-time access does not necessarily happen on your platform's homepage. Often users come from Google searches and **land on other pages** of your platforms, especially when they are seeking specific information. Ensure that each page they might land onto has an appropriate level of guidance. For more information on how to provide guidance, please refer to Chapter 6.
- Make sure to use the recommendations listed in Chapter 4 on sensory overload, to ensure that first-time access as nondisruptive as possible.

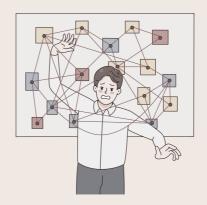
In this chapter you will find information on how to minimise the chance of sensory overload.

What is it? Sensory overload happens when an excessive external stimulus overwhelms a person's ability to cope.

Why is it important? Sensory overload happens in digital environments too and can interfere with the possibility of enjoying using a platform or accessing the necessary information.

Sensory overload can be triggered by too many images, strong colours, videos, content popping up unexpectedly, and auto-playing content. It can also be induced by excessive amount of information, especially when it doesn't seem organized and structured.

Sensory overload can make the user feel like they have **motion** sickness and can have a lasting impact.



Best practice to avoid sensory overload

- Auto-playing video and audio are some of the most triggering types of contents. These should be avoided wherever possible. If you are using social media platforms where you cannot fully control what type of content is posted, you can give guidance on how to disable auto-playing content by creating a brief step-by-step guide and placing it somewhere visible on the group or page. Some popular social media platforms allow users to disable auto-playing content, but how to do it is often not clear or intuitive.
- **Pop-ups** can be very disruptive, especially when they come up a few seconds after a user has started to engage with a platform. They should be avoided and disabled whenever possible.
- Options for **content sliding** through or a gallery of images that automatically refresh should be avoided.
- Links within a body of text can be distracting because users might accidentally click on them and be taken elsewhere. If you can, always set up your links so that they open on a different browser's tab, instead of moving the user away from where they are. Also, it is suggested to compile all relevant links in a list at the bottom of the page, so that the user can easily find them.
- Mobile versions of websites are often simplified and more intuitive.
 These could be used as a model to minimise the amount of content
 for desktop versions of websites too. This would also ensure better
 consistency amongst desktop and mobile platform

Best practice to avoid sensory overload

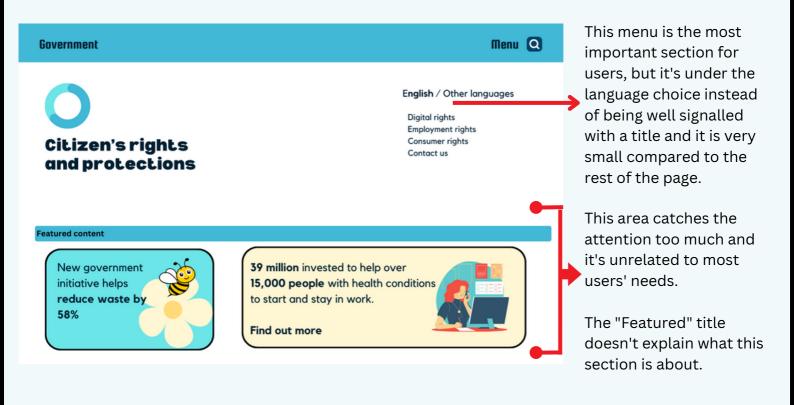
- Only use images that have a direct link to the written information provided in your platforms. Images that are unrelated or only tangentially related to the content can be distracting. Irrelevant images will also force users to scroll more to find the information they are looking for. Use the space for an illustration of the content, an infographic, or a recap of content instead.
- Accessibility widgets (muting colours, ADHD moving bars, etc.) can help some users, but they will not compensate for a poor design. Buttons to activate accessibility widgets should be clearly signposted.
- Always use design **guidelines for dyslexia** in your choice of colours, spacing, and fonts. You can find guidance about this in Chapter 7 of this toolkit.

"Another big issue with autoplay is that it's a huge risk for people with photosensitive epilepsy or things like migraine, which disproportionately affect autistic people"

Research Participant

An example. A Governmental website

(non-existing website for demonstration purposes)



The website represents a typical governmental website and was critiqued by our research participant. While not being particularly overbearing at first, it makes the experience confusing for several reasons.

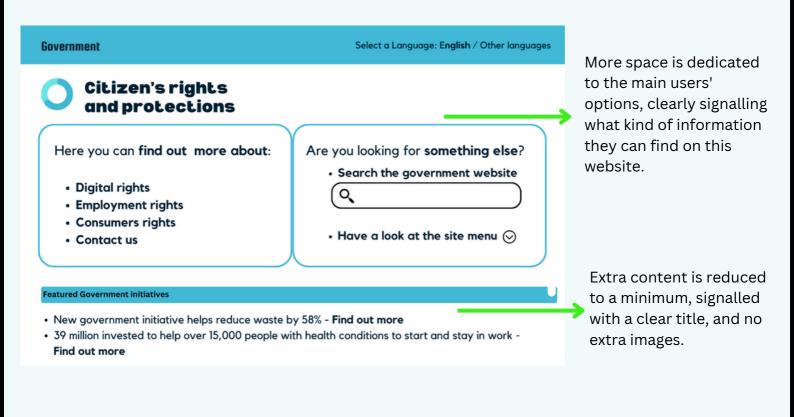
The "Featured" section is highlighted through colour and positioning, even though it doesn't clearly relate to the needs of most users of this platform.

The menu on the right upper side is simple and well designed, but small compared to the rest of the page and doesn't have a title to signal its importance.

This mismatch between elements' importance and their visual stance can possibly induce sensory overload in autistic users.

An example. A governmental website. How to make it better

(non-existing website for demonstration purposes)



Some suggestions to improve this design included:

- giving more visibility to the options which are more relevant to users
- explaining where to go to look for other type of information
- keeping extra content to a minimum and clearly explaining what it is
- not adding images unless they help explain the main content

In this chapter you can find information on how to moderate online groups which may include autistic users.

What is it? Moderation is the process of reviewing and monitoring user-generated content in online communities, forums, and groups to ensure that it meets certain standards and guidelines.

Why is it important? Good moderation helps users feel safe in an online space, reduces the risk of encountering negative interactions or hostile content, and ensures that conflict is addressed promptly.

Moderation in online spaces can be very complex (Aitkenhead *et al.* 2023). It is closely related to **guidance and clear rules**. Vague rules ("be kind") can be ambiguous. Users may interpret rules literally and can expect others to do so as well. As a result they can find the experience of using forums and groups confusing if others are adopting the rules with a higher degree of flexibility.



This is an area of practice where **more research is needed.** Our work highlighted more areas of reflection and future research than how-to answers on this topic and there are no size-fits-all solutions on moderation. Some areas that require more reflection and research are:

- <u>Resources</u>: moderation poses a question of resources. Groups led by volunteers are unlikely to be monitored 24/7 and moderation can take a toll on untrained volunteers. Many small organisations cannot afford to have staff designated to monitoring only.
- Power dynamics: some of our research participants noted that moderators who come from professional organisations and have received training are often fairer than elected volunteers, especially when they hold strong personal views. Moderation can at times become a personal issue if there aren't clear boundaries in place.
- <u>Size</u>: the size of online groups can impact the quality and consistency of moderation and more research is needed to evaluate how this can be managed.
- <u>Balance between rules and flexibility</u>: while explicit and precise rules should be a default, flexibility is often needed to allow for learning and interpretation.

We encourage academic bodies and charities to conduct more in depth research on how online communities are moderated and which moderation practices are effective to ensure inclusion.

Best practice to moderate online communities

- Start your list of rules and guidance with a paragraph on the **aims** and expected benefits of the online communities.
- Ensure users are aware of **privacy** (Is the group public or private? Who can access their content?).
- Vague rules like "be kind" can be confusing. Ideally, try to spell out
 which types of behaviours are not acceptable in the group (for
 example, no insults, no unsolicited feedback, no promoting
 personal businesses except on certain days, etc.)
- Having a small number of explicit rules tends to give better results in terms of moderation, while too many rules are off-putting and impossible to monitor for the moderator. Striking a balance between number of rules and specificity can be challenging.
 Inviting feedback from community members, or even deploying cocreative methods (Aitkenhead et al. 2023) can help shape rules collaboratively and ensure the perspective of users is taken on board.
- Spaces for **clarification** of rules, suggestions, and **discussion** in case of problems should be provided. Some users may welcome a clear workflow on what to do in case of problems and misunderstanding (for instance, using a dedicated forum channel to discuss a problem, contacting a moderator within a certain time frame, etc.).

Best practice to moderate online communities

• **Smaller groups** tend to be better monitored and offer better quality of interactions than big groups. As a group grows, consider the option of breaking it up in sub-groups, perhaps organised around different themes or sub-topics.

"I think if you have too many rules you can become too frozen to engage for concerns of getting something wrong especially if that could get you taken out a group you value".

Research Participant

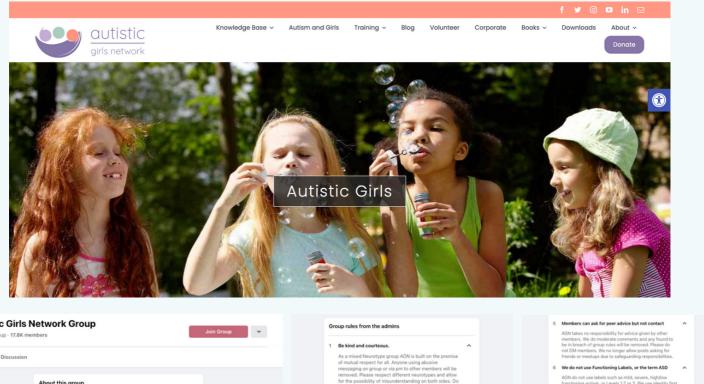




"Be Kind"-type rules are really tricky - I can see why they're necessary, but that sort of thing often ends up getting used more against autistic people who haven't got the tone quite right than against those who are actually causing harm but know the "right" words to do it with!"

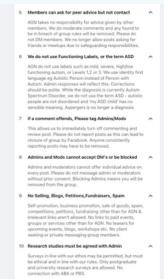
Research Participant

An example. Autistic Girls Network



About this group PLEASE ANSWER THE JOINING QUESTIONS OR YOUR REQUEST TO JOIN WILL NOT BE ACCEPTED. A community group by Autistic Girls Network charity, focused See more Private Only members can see who's in the group and what they post. Visible Anyone can find this group. History Group created on 13 December 2017. Name last changed on 11 June 2020. See more Members - 17.8 K Activity 44 new posts today Bis in the last month \$\$\$\$17,773 total members	ion	
TO JOIN WILL NOT BE ACCEPTED. A community group by Autistic Girls Network charity, focused See more Private Only members can see who's in the group and what they post. Visible Anyone can find this group. History Group created on 13 December 2017, Name last changed on 11 June 2020. See more Members - 17.8K Activity 44 new posts today 835 in the last menth 835 in the last menth	About this group	
Activity 44 new posts today 835 in the last month 21, 72,73 total members	TO JOIN WILL NOT BE ACCEPTED. A community group by Autistic Girls Network charity, focused See more Private Only members can see who's in the group and what they post. Visible Anyone can find this group. History Group created on 13 December 2017. Name last changed on 11 June	
44 new posts today 835 in the last month 21 77,773 total members	Members - 17.8K	
835 in the last month 17,773 total members	Activity	
	835 in the last month	
No new members in the last week	17,773 total members No new members in the last week	

1	Be kind and courteous.	^
	As a mixed Neurotype group AGN is built on the premise of mutual respect for all. Anyone using abusine messaging on group or via pm to other members will be removed. Please respect different neurotypes and allow for the possibility of misundestanding on both sides. Do not make posits seeking to cause a fight. Do not argue with Admins.	
2	No hate speech or bullying, no stirring trouble	^
	NO CUBE POSTS, NO MENTION OF RESTRAINT, NO ANTI- VAX POSTS, NO CBD POSTS, NO MEDICATION ADVICE POSTS, NO PRO ABA POSTS, NO COVID DENIAL POSTS. Failure to adhere to this rule will result in instant removal from group. No posts to incite debate on shown topics which will divide the group. That is not this group's purpose.	
3	Respect Everyone's Privacy	^
	Being in this group requires mutual trust. No sharing or screenshotting of posts in this or other discussion groups. Doing so will mean removal from the group. No screenshotting texts, emails or letters, even if names are blanked out. We consider future privacy also so pictures and videos only with permission; Urania children are not able to give permission.) We only accept requests from those with an established Facebook profile.	
4	AGN is not a support group	^
	AGN is a community where we can share ideas, celebrate successes, spread awareness, ideas for support and understanding. It is not a group to mean about autistic people. We will not approve post shat describe autistic people (or other neurophyses) in a overwhelmingly negative way – please reframe the post to sak how to support. Do not post pictures or videos of children in distress, No synthms is a trapely financially.	



autisticgirlsnetwork.org

The Autistic Girls Network campaigns for better recognition and diagnosis of autistic girls and non-binary young people and supports them in finding their identity and feeling understood. As part of its work, AGN runs a private Facebook Group with over 17k members, open to autistic and non-autistic people.

The group runs successfully and is well monitored even with the size of its audience. According to Cathy Wassel, founder of AGN, managing language and educating neurotypical audience on inclusivity is a key aspect in moderating the online group. Rules are applied strictly and an accurate description is provided to aspiring members, which are individually approved by moderators.

Chapter 5 Providing Guidance

In this chapter you can find information on how to create appropriate guidance to your platforms for your users.

What is it? Guidance is a body of information which clarifies aims, expectations, functioning, and rules of an online platform.

Why is it important? Providing guidance is important to ensure an accessible and comfortable experience of online platforms for autistic users. Clear, thorough but concise, and explicit guidance can improve the quality of engagement in digital platforms for autistic users.

Many of the topics we have explored in previous chapters are strongly related to providing clear guidance, whether it is on how to use platforms the first time a user accesses them, or how to interact with others on a forum.

Guidance can help **mitigate some of the challenges** posed by digital platforms we explored in Chapter 2. However, guidance is not going to be able to compensate for poor design.



"A map of any kind of environment is important to navigate or even get an idea of it (...). An accessible summary is helpful, which links to each section and allows you to gauge what each section is about, like a live contents page or document".

Research Participant

Chapter 5 Providing Guidance

WHICH AREAS SHOULD BE COVERED BY GUIDANCE?

Clear guidance should be provided on:

- Platform's aims.
- How the platform works.
- How to find information within a website or a forum.
- Instructions on how to personalize the platform, if possible to do so (how to hide auto-playing content, how to activate an accessibility widget, how to access a text-only version of a website).

For online communities, guidance should also cover:

- Aims of the community.
- How to join the community.
- A preview of the discussions and their content.
- Rules of behaviour and codes of conduct.
- Information on how to approach moderators or other users in case of misunderstandings or conflict.

Covering enough detail in guidance without producing an overwhelming amount of information can be a challenge. The tips in the next page can help assess what type of guidance you may need to add to your platforms.

Chapter 5 Providing Guidance

Best practice to provide guidance

- Summaries of content are useful: a **description** of what type of content and interactions to expect on a platform, a summary of content at the top of the page, and a summary of relevant links at the end of the page are recommended.
- **Sitemaps** that show the website structure are very useful and can help navigate the content. Some website platforms produce these automatically. Otherwise, it can be useful to provide a visual representation of the structure of a platform.
- It is better to avoid overly friendly language in guidance which can come across as patronising and to instead use **plain English** and a neutral tone.
- Guidance for online communities should include type of audience and an explanation of the aims of the community. This should come before rules and codes of conducts.
- Guidance should be presented through a **mix of plain text, simple voice-over video, and simple infographics**, allowing users the choice to pick the most suitable medium.
- Guidance could be recapped in key bullet points which can be expanded through drop-down menus for those users who wish to access more detailed explanations. This can help strike a balance between providing details while avoiding information overload, and it can help users decide how much information they want to absorb at a given time.

Chapter 6 Resources

In this chapter you can find a collection of references and supportive resources on some of the topics discussed in this toolkit.

Online resources

Autistic Adults Online Website

www.autisticadultsonline.com

It offers an overview of the research project, the research team, a blog including experiences of our participants, and a collection of resources.

Autistica Webinars

<u>www.autistica.org.uk/get-involved/join-an-expert-webinar</u> A range of expert webinars including topics on accessibility of physical and online spaces.

National Autistic Society

https://www.autism.org.uk/advice-and-guidancehttps://www.autism.org.uk/advice-and-guidanc

Other toolkits and guides

The Inclusive Design Starter Pack

www.inclusivedesignjam.com/learn/starter-guide
A beginner's guide to inclusive design which provides a solid foundation in concepts such as diversity & inclusion, accessibility, equity & justice, care & healing.

Chapter 6 Resources

The British Dyslexia Association

https://www.bdadyslexia.org.uk/

Offers advice on how to create dyslexia friendly materials and environments.

How to make your online content accessible

<u>digitalculturenetwork.org.uk/knowledge/how-to-make-your-online-content-accessible</u>

A general accessibility guide by the Digital Culture Network.

Resources to easily produce graphics and videos:

Creating graphics, infographics, and simple explainer content

www.canva.com

Canva offers a range of accessible free tools to create simple graphics without needing technical skills.

Making videos in PowerPoint

https://www.youtube.com/watch?v=hisnhKK94nl

A tutorial on how to use PowerPoint to create simple explainer videos.

Chapter 7 Resources

Publications

- Aitkenhead, G., Fantoni, S., Scott, J., Batchelor, S., Duncan, H., Llewellyn-Jones, D., ... & Tzovaras, B. G. (2023). How to co-create content moderation policies: The case of the AutSPACEs project.
- Barros Pena, B., Koteyko, N., Van Driel, M., Delgado, A., & Vines, J. (2023, April). " My Perfect Platform Would Be Telepathy"-Reimagining the Design of Social Media with Autistic Adults. In Proceedings of the 2023 CHI Conference on Human Factors in Computing Systems (pp. 1-16).
- Crompton, C.J., Ropar, D., Evans-Williams, C.V., Flynn, E.G. and Fletcher-Watson, S., 2020. **Autistic peer-to-peer information transfer is highly effective.** Autism, 24(7), pp.1704-1712.
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C. and Pellicano, E., 2016. Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), pp.442-462.
- Koteyko, N., van Driel, M., & Vines, J. (2022). Autistic sociality on Twitter: Enacted affordances and affiliation strategies. Discourse & Communication, 16(4), 385-402.



Thank you!

Thank you for exploring with us what can be done to make platforms more inclusive.

We would welcome your **feedback** on this toolkit to keep improving it in the future.

Could you tell us how you used the toolkit? In what ways was it useful or not?

Please use this link:

https://forms.gle/Siubc3Su3NijEAMB6

to tell us your thoughts.

A **special thank you** to the people who made this project possible:

- Our autistic research participants.
- All the staff at Autistica who supported this project.
- Autistic Nottingham and our Advisory Boards.

Follow project updates on our **website**: www.autisticadultsonline.com

or on Twitter at @Online_Autistic