

Making the most of social media:

How to engage with families of
children with rare conditions online

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What we'll cover today:

- Understanding your audience
- Creating your content
- Tracking engagement and growth
- Helpful (and free!) tools to support you

I would consider Contact and the parent carers in this group as my second family, and I would just like to say a huge thank you to everyone. This group has been a real lifeline for me!



Understanding your audience

- **Who** are you writing for? Parents, practitioners, young people?
- **Why** do they need your help or advice?
- **What** support can you offer them that isn't available elsewhere?
- **Where** are they most active online? Which platforms do they already use?

Public (open community)

Facebook page

- Already used by parents, especially younger families
- Wealth of engagement tools (livestreaming, Q&As, fundraising, advertising, auto-translating)

X (Twitter)

- Already used by parents and practitioners
- Option to create community spaces
- Limited post formatting and engagement tools available

Instagram and TikTok

- Popular with younger parents and young people
- Video-led format can feel more intimate despite lack of private community space

Private (closed community)

Facebook group

- Useful for families/young people already on Facebook
- Admin and engagement tools available
- Requires active moderation and group rules

X (Twitter) Community

- Useful for families/practitioners already on X
- Brings together content from all members
- Requires a premium subscription

WhatsApp

- Already used by most families and practitioners
- Secure (end-to-end user encryption)
- Better for smaller groups – no built-in moderation tools



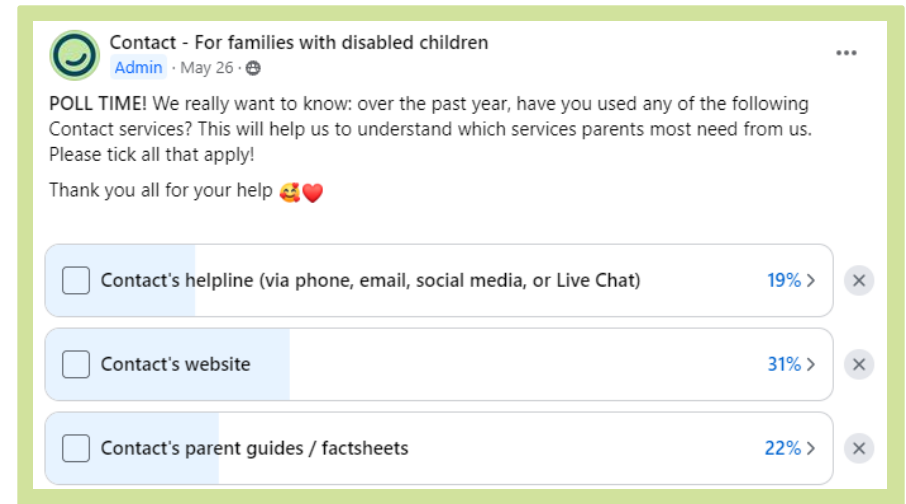
Creating your content

Put yourself in your audience's shoes

- As a parent/carer, what content would *you* find most interesting or relevant to your needs?
- What type of content are you most likely to engage with?
- What tone of voice and language is most appropriate and accessible?

Make your posts memorable

- Focus on the first line — To make them stand out and encourage further reading, your posts should open with the most interesting/important part of what you have to say
- Have a clear goal for each post — e.g. offer advice, encourage discussion, promote an event, raise awareness



Don't be afraid to ask for feedback and suggestions from your members!



Get creative!

- **Avoid text-only posts** — Social media is already saturated with content designed to grab your attention; text-based posts struggle to compete with videos and colourful imagery
- **Keep posts fresh** by including photos, graphics, videos, polls
- **Be mindful of formatting** — People are less likely to read through chunky blocks of text; add line breaks, keep sentences short, use emojis to make text more visually appealing

Contact - For families with disabled children
Published by Luana Salles · September 26 at 6:00 PM · 🌐

Parent carers, what advice would you give to someone who just found out their child has a disability?

The advice you wish you had received at the start of your SEND journey...

Contact - For families with disabled children
Published by Hootsuite · September 2 · 🌐

Amazing news! LEGO has started selling Braille bricks to help children who are blind or visually impaired to learn the touch-based alphabet 🙌

They're also offering a free course showing how the braille blocks can support inclusive and play-based learning — including ideas for fun activities: legobraillebricks.com



THEGUARDIAN.COM

Lego to sell bricks coded with braille to help vision-impaired children read

Bricks with studs corresponding to braille numbers and letters will be available to buy from Se...

Contact - For families with disabled children
Published by Hootsuite · September 7 at 6:15 PM · 🌐

A disabled child's Education, Health and Care Plan (EHCP) must be reviewed by the local authority at least once a year to look at their progress, make any changes and ensure it's up to date.

This is a formal process that must follow clear legal requirements — but we know from speaking to parent carers that this doesn't always happen.

Below is a breakdown of what an annual review should look like, but you can read more about the process and the timescales involved here 🙌 [con...](#) See more

**EHC PLANS:
THE ANNUAL REVIEW**

a step-by-step breakdown of the process

- 1 Each term, the local authority tells the school which EHC plans will need to be reviewed in the coming months
- 2 With at least 2 weeks' notice, the school organises a meeting between people involved in your child's education and invites them to send in written reports
- 3 The meeting takes place to review your child's progress and changes needed
- 4 Within 2 weeks of meeting, the headteacher compiles a report recommending any changes
- 5 Within 4 weeks of the meeting, the local authority makes a written decision to either make changes to the plan, leave it as is, or end it
- 6 Parents have 15 days to give their views on any proposed changes

Contact - For families with disabled children
Published by Hootsuite · September 8 at 6:55 PM · 🌐

Here's a good Disability Living Allowance tip for parent carers: call the DWP and ask for a posted form instead of completing it online or printing it yourself!

This way, the DLA form will be stamped with the date of your phone call — and any DLA your child gets will be paid from that date.

We all know how long and time-consuming the DLA form can be, so this handy trick will ensure you don't miss out on any payments while you're busy filling it in... See more

DLA TIP:

When applying for Disability Living Allowance, call the DWP and ask for the DLA form to be posted to you instead of doing it online. This way, the form will be stamped with the date of your phone call and any DLA your child gets will be paid from that date.

The form is long and can take time to fill in – so this trick will ensure you don't miss out on any payments!

For more DLA tips and advice videos, visit: www.contact.org.uk/dla-form



Tracking engagement and growth

- Social media isn't one-size-fits-all! Using analytics tools can help you to:
 - Better understand your followers
 - Experiment with new content ideas
 - Tailor future content accordingly
- Native analytics tools are available on all major social media platforms, but larger communities might want to use third-party insight tools for more in-depth data
- Examples of insights that are usually available include:
 - Engagement and reach (across page and per post)
 - Audience overview (gender, location, age group)
 - Best times to post based on when your followers are online

The screenshot shows a social media content management interface. At the top, there is a 'Content' header, a 'Create a post' button, and two dropdown menus for 'Last 90 Days' and 'Date'. Below the header, three posts are listed, each with a thumbnail, a text preview, and performance metrics. The first post is about a DLA dictionary, the second is about a focus group for neurodiversity, and the third is about free online workshops for autistic children. Each post has a 'Boost post' button next to its metrics.

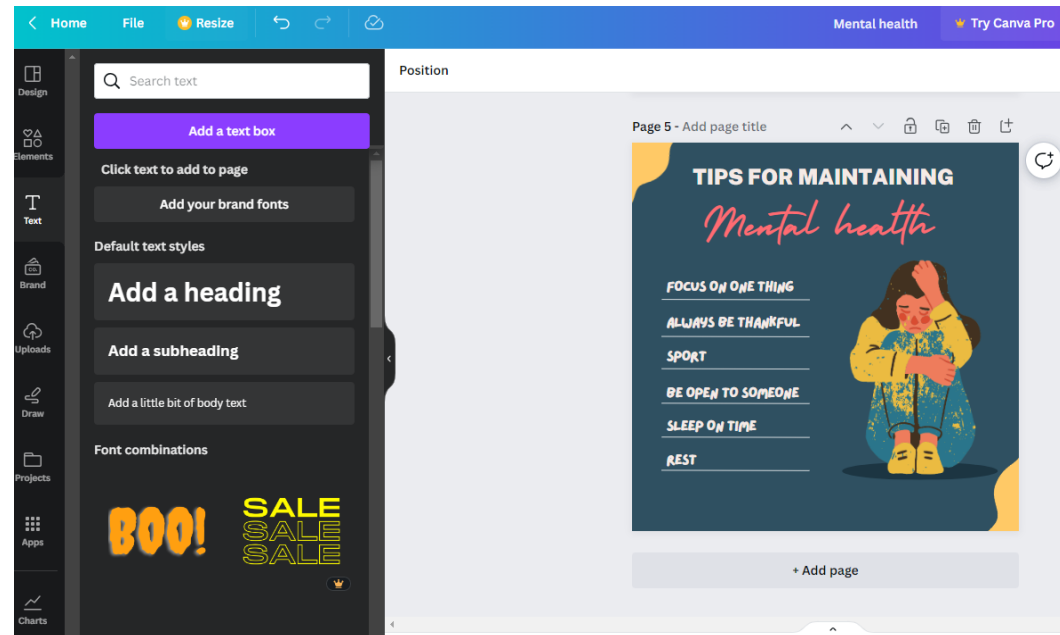
Post Content	Post reach	Engagement	Action
To decide what Disability Living Allowance award your child will get, the DWP uses specific definitions for certain terms in the form. Knowing what these terms mean can help you to fill out the DLA form more accurately — and may increase your chances of getting the right award for your child. See our DLA Guide for more advice 🍌...	10,418	1,336	Boost post
Our friends at the Council for Disabled Children are looking for parent carers to join a focus group on 6 October to explore what a whole-school approach to neurodiversity should look like. This includes the potential of deploying health specialists into mainstream primary settings — and how best to build a school environment that is supportiv...	1,406	47	Boost post
We have 20 FREE online workshops for parents of autistic children based in London or the Midlands coming up this October — no diagnosis required! October's sessions will cover advice on sensory processing, education, anxiety, support for siblings, parent carer wellbeing, and understanding autism. See what's coming up and book your place:...	4,764	297	Boost post



Free design tool - [Canva](#)

- (Relatively) easy to use design tool with lots of great social templates including videos and stories
- Premium version unlocks more images/templates/tools/brand fonts
- Great for ensuring images/videos are the correct size for the social platform
- Helpful training and resources in the [Canva Design School](#)

Images
graphics
templates
text/fonts
apps
charts



Canva - template library

- Template library - some templates/graphics are only available with the premium version which is free for non-profits
- Adapt the template to make it work for your content and style, and try to keep some consistency between each post image e.g. by restricting the number of fonts and colours you use between each post
- The templates can be random sizes so make sure you copy the contents of the template into a Canva design file that's the correct size (current social image/video sizes [are listed here](#)), but to keep it simple use 1080px by 1080px for Instagram and 1200px by 600px for FB, X, LinkedIn



Free scheduling tools

Benefits:

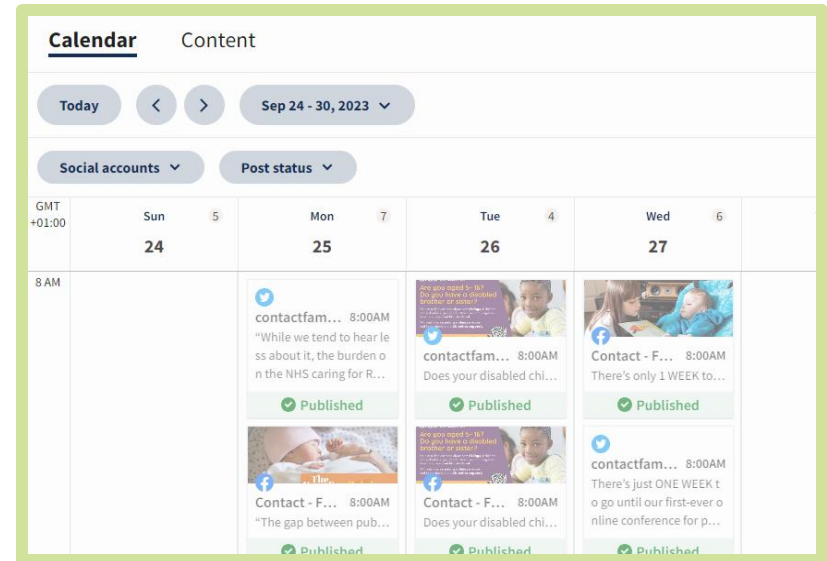
- Helpful if you have limited time – quick to post content across multiple social platforms
- Ability to schedule posts for the week ahead, or further in advance if you have an awareness day or seasonal events coming up
- Many tools include analytics including data around the best time to post
- Most have built in link shortening tools

Some tools with free plans:

- [Buffer](#) (Up to 3 social accounts)
- [CoSchedule](#) (Up to 2 accounts, plus marketing calendar)
- [Friends+Me](#) (Up to 2 social accounts)

Meta Business Suite:

- For scheduling posts on Facebook and Instagram
- Lots of other features including running paid ads, insights, notification centre, managing events



Free AI tools

There are many concerns around the use of generative AI including privacy, bias, security and accountability. We would recommend reading more around responsible usage and referring to an example [AI policy template](#).

Useful for repurposing content into social media posts, writing post copy from scratch, content ideas, creating a content calendar, generating hashtags, checking spelling/grammar.

It can be a great starting point, but it requires some manual work.

- The main free generative AI tools are [Google Bard](#), [Bing AI](#) and [ChatGPT](#), but the quality of the output is not as good as tools designed specifically for copywriting. The quality of the output also depends on what prompts you use - [this article](#) has some great tips for writing prompts
- Free AI writing features within social scheduling tools e.g. [Buffer](#) and [CoSchedule](#)
- [Grammarly](#) free version - AI driven text generation, basic writing suggestions, spelling/grammar, and tone detection
- Paid for copywriting AI tools are better than the free ones, such as [Jasper.ai](#)



Free link tools

Link shortening tools are great if you have a long URL, which is particularly useful for Instagram where links in posts aren't clickable.

They also mean you can track how many people have clicked on the link (you can also use Google Analytics for more advanced tracking)

Free tools include [Bitly](#) and [TinyURL](#).



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Published by Hootsuite · 2d · 🌐



We have 20 FREE online workshops for parents of autistic children based in London or the Midlands coming up this October — no diagnosis required!

October's sessions will cover advice on sensory processing, education, anxiety, support for siblings, parent carer wellbeing, and understanding autism.

See what's coming up and book your place:

👉 bit.ly/Autism-London (London families)

👉 bit.ly/Autism-Midlands (Midlands families)



@contactfamilies

UK disability charity for all families caring for a disabled child

School transport for disabled children Q&A

Support our #ChildTrustFund campaign

Support for families

News & updates

For your **Instagram bio link**, use a link tool such as [LinkTree](#), so that you can direct people to different resources/webpages.

