



Amaze Privacy Policy 2026 V2

Who are we?

Amaze is a charity (registered charity number 1078094) established in 1997, that offers a range of information, advice and support services to families of children and young people with special educational needs or disabilities, across Sussex. Amaze also manages the Compass Brighton and Hove scheme (Disability Register) which provides discounts on a wide range of leisure offers.

Amaze takes your privacy seriously and this privacy policy sets out how we will use and store your data, in full accordance with the UK General Data Protection Regulation (UK GDPR), the Data Protection Act 2018, the Data (Use and Access) Act 2025 (DUAA) which is being phased in between June 2025 and June 2026 and the Regulators Code of Fundraising Practice (2016). Amaze is registered with the ICO, registration reference: Z953110X.

What information will you collect about me?

We currently collect and process the following information, some of it is special category or sensitive data:

- personal identifiers, contacts and characteristics (for example, name and contact details)
- diversity information about you and any child/ren with Special Educational Needs and Disabilities (SEND) we support you with, such as gender, ethnicity, religion, disabilities, sexual orientation and age or age range
- details about your, or your child's, health issues
- details about your, or your child's, school and GP
- if we are helping you or your child to apply for benefits, we may need to ask for information such as hospital number, national insurance number and bank details for you to receive payments.

Most of the personal information we process is provided to us directly by you/your parent carer so that we can provide a service. The lawful bases we rely on for processing this information are **your consent**, **public task**, **legitimate interests** and **contract**. We ask for your consent to store and process your personal information and you may give this consent verbally or in writing. Once we have made you aware of this policy, if later you give us details of other children you would like support with, we will assume that consent applies extends to recording their details too. You can remove your consent at any time, where we rely on consent to process your data. You can do this by emailing us info@amazesussex.org.uk. We fulfil a **public task** when providing the SENDIAS service and

where we cannot ask for your explicit consent, we rely on this basis to process your data and provide you with advice.

We use **legitimate interests** as a legal basis for collecting the following data:

- SEND details of a child or young person's SEND. Amaze's purpose is to support families with SEND, this information allows us to evidence the needs of our families and to offer relevant support
- GP, school and address, we need this information to ensure families are eligible for our services which are funded by regions. It also helps us know the reach of our services which can lead to us identifying gaps in provision
- collecting emergency contact details for young people accessing groups. This is in the best interests of the young person.

We may also receive personal information indirectly, from the following sources, in the following scenarios.

- If you are a child or young person and we are working with your parent carer, we may receive this information directly from the person(s) who has parental responsibility for you. If you are over 16 years, we will ask your parent/carer to check with you that you consent to us processing your data. Where a person over 16 does not have capacity to make this decision we will follow the principles set out in the Mental Capacity Act 2005 and take consent from the appropriate decision maker. For this decision, this is likely to be the primary carer.
- From an external agency referring you to access one of our services. They must obtain consent from you first, before they pass us your data. We will request personal contact details, and details about why the referral is being made which is likely to include the health needs of your child.
- From other agencies working with you/your child. If we are supporting you to apply for benefits or to make an appeal against a benefits decision, we may need more information. With your consent, we may gather supporting information on your behalf such as clinic letters, assessments, reports and therapy programmes.

What are we going to do with your information?

We will use your personal information to **provide services or information to you**. We will also collate your personal details along with other people using Amaze; to create anonymised data for general reporting about our work and the impact it has to our funders, or to identify and provide trends about the needs of families with children and young people with SEND to service providers/partners.

What will you ask me to consent to?

When you contact Amaze we will ask you for basic personal information to support you and your family, we also collect information that we report in an anonymised format to evidence

our work to our funders. Where you do not want to share demographic data with us, such as gender or ethnicity, we will offer an option, 'I prefer not to say'. If we need to share information such as with a benefits application, we will ask for this additional/explicit consent from you. We will assume your consent extends to your other children with SEND, if you provide details of them after your initial consent.

If you receive advice from our SENDIASS or benefits service, we may ask if your record can be reviewed by an external assessor to ensure our advice is of sufficient quality.

Will you be sending me emails?

Within the course of supporting your family, workers may email you but if you choose not to be contacted in this way, please let us know.

We ask for permission from you to contact you about other things, these all require your separate permission:

- Newsletters/Updates
- Targeted Emails: These are emails about things we think you may be interested in, such as surveys, consultations, new groups. We may use the data we store about you or your child to decide whether to contact you. For example, when a child with Learning Disabilities reaches 14 years they are eligible to go on the Learning Disability register; we therefore email the parent carers of eligible children on the Compass register, around their 14th birthday to let them know.
- Fundraising – see fundraising section for more details.
- Under **The Data Use and Access Act 2025 (DUAA)**, as a charity we may contact you when we have provided you with support or you have expressed an interest in our work, unless they object.

You can opt in or opt out of all or any of these options at any time. You can unsubscribe from all emails by using the unsubscribe link in emails sent from Brevo (our email campaign software) or email us at info@amazesussex.org.uk to specify your choices.

Fundraising

We have a designated fundraising database called Beacon CRM. We always ask for specific consent to communicate with you about fundraising. We do not hold bank account or card details, we use third party software to do this, such as Stripe or JustGiving. We do keep a record of what you have donated and any direct debit reference. We use a tool called Zeffy to collect donations. This is a third-party tool for you to make donations or other payments to Amaze. We do not hold any payment details from you on this system. Zeffy uses a 'tip' system to fund its services, which is free to Amaze to use. You do not have to 'tip' to make a payment. Zeffy may use the details of people who have visited their website to target online advertising to users. This may mean you receive online advertising from Zeffy. If you wish to opt out of this advertising, please email privacy@zeffy.com.

The lawful bases for processing your data are '**consent**', '**legitimate interests**' and '**contract**'. We will process your data on our fundraising database if:

- you have consented to receive communications about Amaze fundraising
- you are fundraising for Amaze
- you have donated to Amaze through a third-party site such as 'Just Giving' and agreed to share your details with us
- you have contacted us directly about making a donation or leaving a legacy.
- you have taken part in the Amaze Lottery.

Lottery

The Amaze Lottery is hosted by a third-party, Sterling Management Centre Ltd trading as Unity. By signing up to the lottery you will agree to their privacy policy which can be viewed here, <https://www.unitylottery.co.uk/privacy-policy/>. From their site you can choose how Amaze communicates with you about fundraising. All personal data, except bank details, are passed securely from Unity to Amaze to be stored safely on our fundraising database.

Will we share your information with anyone else?

No. Unless we have your permission to do so, we won't share your personal information with any organisations or individuals outside of Amaze unless there are exceptional circumstances. These rare circumstances are:

- Amaze believes a failure to share your personal information would lead to a risk of significant harm to you or others.
- Amaze suspects or has knowledge of abuse
- Amaze believes a crime such as drug-money laundering or a fraudulent benefits claim has been made
- if you tell Amaze about a possible terrorism threat
- if disclosure is required by law, for example by the Police.

There will be some occasions we will need your consent to pass on personal information so that we can submit or process applications on your behalf e.g. for DBS checks, registering trustees with Charity Commission, supporting applications for disability benefits etc.

We will **never** sell, rent, or trade your personal data.

Specific consent for NHS Mental Health Data Set: Our ND Family Support Service, NDP Family Training and Navigation Service, Parent Groups & Befriending and Amazing Futures services are partially funded by the NHS. It is a mandatory requirement that we report to the NHS via NHS Digital, some information on who uses these services.

The information allows the NHS to monitor the value of the services, inform service improvements and monitor service performance, clinical interventions, patient experience and treatment outcomes. As we want to be open and transparent about your data, we will give you the option to 'opt-out'. For more details of what is shared, please see this page, <https://amazesussex.org.uk/data-sharing-nhs/>. (Appendix 1 – non-website version only).

Specific consent for Advice Quality Standard (AQS)

The DLA and PIP service is applying for AQS accreditation, this is a quality standard for not-for-profit organisations who provide advice and help on the law, access to services and related issues. Accreditation demonstrates our commitment to quality and current practices. To obtain accreditation, AQS assessors carry out many checks on our policies, procedures and work practices, including our case file management. Periodically AQS assessors visit the Amaze office and review case files for those who have received support from the DLA and PIP service. They can only review the file in the presence of an Amaze member of staff and cannot take away anything from the file. They review the file to check the quality of the support we have offered. In addition, we may be peer reviewed by a similar organisation to us and they may be asked to review some of our files anonymously. If you access the DLA and PIP service, we may ask you if an appropriate person (eg quality assessor or peer reviewer) can complete a confidential review of your file and the associated files of your child/ren as part of our quality assurance process. We will always ask for your permission to do this and there is no obligation for you to agree.

Where is your data stored?

All details about our clients (children and young people with special educational needs and disabilities, and their families) provided to Amaze staff or volunteers are input carefully and stored securely on a database called Charitylog. In addition, data may be stored in documents contained within the Amaze server. Email addresses may also be stored on 'Brevo' which we use to send bulk email messages. For certain elements of our service, we use other third-party software including EventBrite (for booking on to workshops) and JotForm to submit Compass registration and occasionally other forms. The information collected via these third parties is securely transferred to Charitylog.

We scan and save other supporting documentation (reports, letters etc) into the secure Amaze electronic filing system. We try to minimise paper records, but where they exist they are stored in locked filing cabinets before being returned to the family or shredded.

Sometimes you may be asked to access a third-party site for example to complete a survey, enrol on a workshop or submit a form. Where possible we minimise the amount of personal data we ask for and we check the website's security meets UK GDPR before asking you to use it.

How long do we hold your data for?

We follow national best practice and retention periods vary according to the nature of the record. Once the retention period has been reached your data will be anonymised.

Received advice or support in an Amaze service.	Records held by Amaze about you and your related child or young person will be made inactive and anonymised by removing all personal data after 6 years of our last contact with you. This is to provide continuity of service for you as your child goes through
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	key developmental stages as meets requirements for advice quality assurance.
Children and young People we have worked with directly	If Amaze supported you aged under 18 years through an advice service, Amazing Futures or Careers, we will keep your record until you are at least 25 years or 6 years after you end support. This is to in line with child protection law and meets requirements for advice quality assurance.
Other records.	If you have not received direct support from us, for example you have only accessed a Compass Card, we will keep your data for 3 years after our last contact or your Compass Card expires.
Data collected via third parties such as JotForm	We collect some data like Compass Card registration forms through JotForms. The data is securely transferred to CharityLog our main database and will be deleted from JotForm within 6 months of accepting or declining your application.

What are your rights about the information we hold about you?

You can ask to see the personal information that Amaze holds about you, this is called a subject access request, and you can choose to receive that personal information in paper or electronic form. If a request is made for a child's data and the data Amaze holds has been provided by another parent carer, the case will be considered carefully. Looking at the age of the children and if they are able to consent for this information themselves, the reasons for the request and if it is in the best interest of that child.

You have the right to ask us to correct any inaccuracies in the personal information that we hold about you and you can also choose to reuse your personal information for your own use. You can also ask us to delete any of the data we hold about you or restrict how we use it. We follow strict GDPR guidelines and our internal policies whenever handling your data. If that child is now over 16 years we may ask them directly if they would like their data removed even if the information was originally obtained by their parent carer. This would be if we thought it might be detrimental to the young person to delete their data, for example, they may want to make a benefit claim themselves. Where information has been given to Amaze about children from another parent carer, then the request will be discussed with them, unless there are safeguarding concerns. A decision to remove the data will be based on the best interests of the child. You also have the right to ask that we transfer the personal information you gave us to another organisation, or to you, in certain circumstances.

You can find more information about GDPR on this link <https://ico.org.uk/your-data-matters/>. You are not required to pay any charge for exercising your rights. If you make a request, we have one month to respond to you, contact us at info@amazesussex.org.uk.

What about our websites?

Amaze operates the following websites amazesussex.org.uk, amazingfuturesussex.org.uk/www.paccbrighton.org.uk, www.espcf.org.uk and at the

bottom of each website there is a link to the privacy statement for that website. These will tell you what information Amaze gathers from visitors to our websites, and what we do with it.

How can you get in touch with us?

If you would like to know more how we look after your personal information, or would like to request a copy of the personal information that we hold about you, you can contact our Data Protection Officer in the following ways:

phone: 01273 772289

email: info@amazesussex.org.uk

post: Amaze, Community Base, 113 Queens Road, Brighton, BN1 3XG

How to complain

If you have any concerns about our use of your personal information, you can make a complaint to us via our feedback form, (<https://amazesussex.org.uk/feedback/>) or using the contact details above.

You can also complain to the ICO if you are unhappy with how we have used your data.

The ICO's address:

Information Commissioner's Office; Wycliffe House; Water Lane; Wilmslow; Cheshire; SK9 5AF

Helpline number: 0303 123 1113

ICO website: <https://www.ico.org.uk>

VERSION CONTROL / RECORD OF CHANGES

Review date	Version	Section	Changes/Comments
Nov 2025/Feb 2026	5	All	Full Review of Policy Addition of Appendix 1
May 2026	6	New section	Specific consent for AQS

Appendix 1

About data sharing with the NHS

The Amaze ND Family Support Service is funded by the NHS, this includes Amaze NDP Family Training and Navigation Service, Parent Groups & Befriending and Amazing Futures. To enable the NHS to monitor the service and its impact on children and young people, we are required to submit information about who is accessing our service, to the Mental Health Services Data Set (MHSDS) via NHS Digital.

If you access one of these services, we will tell you about this and direct you to this document so that you are clear what is being shared. As Amaze want to be transparent, we give you the option to opt-out, but it is really important for Amaze to keep these services running.

If you have already chosen not to opt-out for one child and then tell us about your other child/ren with SEND you would like support around, we will assume your choice extends to them as well.

Parent carers: below are the personal details about **your child or young person** that we share with NHS Digital (names and full addresses are not shared):

- postcode
- date of birth
- GP practice
- gender
- whether their gender is the same as assigned at birth
- ethnicity
- the main reason (primary health need) for accessing the service, such as your child's autism or another neurodevelopmental condition

In addition, we report on the dates of any groups or one-to-one contacts you have with the service, absolutely no other details of the sessions are included.

Young people: below are the personal details we share with NHS Digital (names and full addresses are not shared):

- postcode
- date of birth
- GP practice
- gender
- whether your gender is the same as the gender assigned at birth
- ethnicity
- the main reason (primary health need) you are accessing Amaze

In addition, we provide details of how long you were supported by our service, when you attended a session (absolutely no information about what was discussed at these contacts is passed on) and the reason for ending support with us.

Who manages the information shared with the NHS?

The information collected about you/your young person is managed by NHS Digital, the national provider of information, data and IT systems in health and social care. The role of NHS Digital is to ensure that high quality information is used appropriately to improve patient care. It publishes key statistics and shares information to support important research and commissioning.

What is the data used for?

This is part of a national strategy called the Mental Health Services Data Set (MHSDS) which aims to deliver nationally consistent and comparable person-based information for children, young people and adults who are in contact with mental health or learning disability services. The data collected is passed to NHS Digital and supports evidence-based clinical practice and helps the NHS to demonstrate improved outcomes. It is also used to inform service improvements and monitor service performance and outcomes.

National NHS Data Opt-out

The NHS allows you to opt-out of any data they hold about you (not just for the MHSDS) being used for secondary healthcare research and planning. If you would like to opt-out of this, please visit <https://digital.nhs.uk/services/national-data-opt-out>.

How do I find out more?

If you have any queries about what NHS Digital does with your information or would like to know more please get in touch:

- tel: 0300 303 5678
- email: enquiries@nhsdigital.nhs.uk
- <http://digital.nhs.uk/home>

If you would like to know more about what Amaze does with your data, please read our [privacy policy](#) or contact us on info@amazesussex.org.uk.

*Updated February 2026