Privacy Notice

Reviewed: August 2026

Next review: August 2027

Autism Berkshire is committed to protecting your privacy and security. This policy explains how and why we use your personal data, to ensure you remain informed and in control of your information.

Since May 2018, Autism Berkshire has asked its supporters to “opt-in” for communications regarding services, fundraising and volunteering activities. This is due to a change to the rules which govern how we can communicate with you and a new regulation on personal data (the General Data Protection Regulation) which came into force on the 25th of May 2018.

Following the ending of the Brexit transition period on 31 December 2020, the UK government incorporated EU GDPR into the UK GDPR, which sits alongside an amended Data Protection Act 2018.

We introduced a new approach that relies on you giving us your consent about how we can contact you. This means you’ll have the choice as to whether you want to receive these messages and be able to select how you want to receive them (email, phone or post).

You can decide not to receive communications or change how we contact you at any time. If you wish to do so, please contact Autism Berkshire by emailing contact@autismberkshire.org.uk or writing to Autism Berkshire, Quadrant House, Reading, RG1 7QE or telephoning 01189 594 594.

We will never sell your personal data and will only ever share it with organisations we work with following prior consent from you or in the event of a safeguarding concern and if its privacy and security are guaranteed.

Any questions you have in relation to this policy or how we use your personal data should be sent to contact@autismberkshire.org.uk and addressed to The Data Protection Officer.

1. About us

Your personal data (i.e. any information which identifies you, or which can be identified as relating to you personally) will be collected and used by Autism Berkshire (registered charity no. 1076217, as Berkshire Autistic Society) For the purposes of data protection law, Autism Berkshire will be the data controller.

2. What information we collect

Personal data you provide

We collect data you provide to us. This includes information you give to us when registering for support or booking events with Autism Berkshire. This is likely to include personal details (name, date of birth, gender, email, address, telephone etc.).

Your involvement with Autism Berkshire will result in personal data being created. This will include services that you have accessed with Autism Berkshire.

Information we generate

We conduct analysis on the information we hold, which can in turn generate personal data. For example, by analysing feedback provided by you accessing Autism Berkshire services we are able to inform funders of the difference the services have made to families. No individual information will be passed to funders, apart from for Berkshire West Autism & ADHD Support Service and the Berkshire Adult Autism Support Service - *see below*. In relation to the Thames Valley Autism Alert Card, we only hold information on our system required for purpose of issuing the card to applicants.

Anonymised data

We may aggregate and anonymise personal data so that it can no longer be linked to any particular person. This information is used for reporting to funders (other than to the NHS Thames Valley Integrated Care Board) and helps us to show the difference the services we offer make to service users.

Information from third parties

We may collect information from social media where you have given us permission to do so, or if you post on one of our social media pages.

Sensitive personal data

We do collect and store sensitive personal data (such as information relating to health) about service users. We do take extra care to ensure your privacy rights are protected. This information is held on a secure database.

Berkshire West Autism & ADHD Support Service

The above service is provided by Autism Berkshire on behalf of the NHS Thames Valley Integrated Care Board to support children and young people and aged from 0 to 17, both prior to assessment and after diagnosis. The service is open to families with autistic children who are registered with a Berkshire West NHS area GP surgery and are presenting with a need relating to Autism and/or ADHD.

Autism Berkshire is providing the main services under this agreement. Autism Berkshire has subcontracted ADHD and sleep support to Parenting Special Children, a registered charity, number 1141172, with specialisms in ADHD and sleep difficulties. Autism Berkshire will seek your consent if we recommend a referral to Parenting Special Children, and will gain your consent before any information is shared with the charity.

In order that the Berkshire West Autism & ADHD Support Service contributes to the national access standards, the NHS ICB requires that the charity collects information about attendances and outcome measures of: workshops, home visits, and children and young people's groups and submits this to the NHS Mental Health Services Data Set (MHSDS). The data submitted includes date of birth of the child or young person, gender, ethnicity, postcode, name of GP practice and diagnosis, and date of attendance. If a parent or carer attends a workshop, this is reported as indirect contact and if a child attends a group, this is reported as direct contact.

The MHSDS has a number of uses including: commissioning services, clinical audit, research, service planning, inspection and regulation, monitoring government policies and legislation, local and national performance management and benchmarking, and national reporting and analysis.

The MHSDS statistics offer a comprehensive national picture of the use of specialist mental health, learning disabilities or autism spectrum services in England. It can be used by policy makers, commissioners, mental health service users, and members of the public.

Berkshire Adult Autism Support Service

The above service is provided by Autism Berkshire on behalf of the NHS Thames Valley Integrated Care Board, to support adults aged 18 and above, and their families, both prior to assessment and after diagnosis. The service is open to adults aged 18 and above and their families who are registered with an NHS GP surgery in the county of Berkshire and are presenting with a need relating to Autism.

In order that the Berkshire Adult Autism Support Service contributes to the national access standards, the Integrated Care Board requires that the charity collects information about attendances and outcome measures of workshops, social groups, advice meet-ups and other activities provided by the service and submits this to the NHS Mental Health Services Data Set (MHSDS). The data submitted includes date of birth of the autistic adult, gender, ethnicity, postcode, name of GP practice and diagnosis, and date of attendance. If an autistic adult attends a group or workshop,

this is reported as direct contact. If a parent or carer of an autistic adult attends a group or workshop, this is reported as indirect contact.

The MHSDS has a number of uses, including: commissioning services, clinical audit, research, service planning, inspection and regulation, monitoring government policies and legislation, local and national performance management and benchmarking, and national reporting and analysis.

The MHSDS statistics offer a comprehensive national picture of the use of specialist mental health, learning disabilities or autism spectrum services in England. It can be used by policy makers, commissioners, mental health service users, and members of the public.

Volunteers

If you are a volunteer (whether specifically for Autism Berkshire, or if you are helping us for other reasons - for example you work for another organisation which is running an event with us) then we may collect extra information about you (e.g. references, criminal records checks, details of emergency contacts, medical conditions, etc.). This information will be retained for legal reasons, to protect us (including in the event of an insurance or legal claim) and for safeguarding purposes.

3. How we use information

We only ever use your personal data with your consent, or where it is necessary in order to:

- enter into, or perform, a contract with you;
- comply with a legal duty;
- protect your vital interests;
- for our own (or a third party's) lawful interests, provided your rights don't override these.

In any event, we'll only use your information for the purpose or purposes it was collected for (or else for closely related purposes):

Marketing

We use personal data to communicate with people, to promote Autism Berkshire and its services and to help with fundraising. This includes keeping you up to date with our news, updates, campaigns and fundraising information.

Administration

We use personal data for administrative purposes (i.e. to carry out our services). This includes:

- receiving donations (e.g. direct debits or gift-aid instructions);
- maintaining databases of our volunteers and service users;
- fulfilling orders for services (whether placed online, over the phone or in person);
- helping us respect your choices and preferences

4. Disclosing and sharing data

We will never share your data with any third party without your permission.

5. Marketing

Since May 2018, Autism Berkshire has asked its supporters to “opt-in” for most communications. This includes all our marketing communications.

This means you’ll have the choice as to whether you want to receive these messages and be able to select how you want to receive them (post, phone, email, text).

You can decide not to receive communications or change how we contact you at any time. If you wish to do so, please contact Autism Berkshire by emailing contact@autismberkshire.org.uk or by writing to Autism Berkshire, Quadrant house, Broad Street Mall, Reading, RG1 7QE or telephoning 01189 594 594.

What does ‘marketing’ mean?

Marketing does not just mean offering things for sale, but also includes news and information about:

- our charity
- volunteering opportunities
- appeals and fundraising
- our events
- our services

Newsletters

Regular newsletters are emailed to service users and our members providing information regarding services, fundraising and other activities. Newsletters are sent to service users who have signed up to receive them. You can unsubscribe at any

time by using the links in the newsletters or by emailing a request to contact@autismberkshire.org.uk

Fundraising

As a charity, we rely on donations and support from others to continue to offer free and low-cost services. We will contact members and supporters with fundraising material and communications. This might be about an appeal or to suggest ways you can raise funds (e.g. a sponsored event or activity).

As with other marketing communications, we'll only contact you specifically about fundraising if you've opted into receiving marketing from us (and you can, of course, unsubscribe at any time).

Photographs, pictures, on our website or social media or virtual delivery of events

Permission will always be obtained for photographs and pictures.

The charity delivers some services online through the use of Microsoft Teams or Zoom for events. To ensure the security of data of participants, we will only ever send a link to these virtual events to those that have contacted us to indicate their wish to participate. Attendees should be aware that, by joining such an event, their name will be visible to other participants, as will their audio and video feed unless they choose to switch this off. The charity will not record or store these virtual events for later playback.

Information for parents

We take great care to protect and respect the rights of individuals in relation to their personal data, especially in the case of children. If your child is under 18, we'll only use his or her personal data with your consent.

6. How we protect data

We employ a variety of physical and technical measures to keep your data safe and to prevent unauthorised access to, or use or disclosure of your personal information.

Electronic data and databases are stored on secure computer systems and we control who has access to information (using both physical and electronic means). Our staff receive data protection training and we have a set of detailed data security procedures which personnel are required to follow when handling personal data.

All the data we store on Charitylog (our CRM database system) is stored within the **United Kingdom.**

Data in transit

Sending information over the internet is generally not completely secure and we can't guarantee the security of your data while it's in transit. Any data you send is at your own risk. We have procedures and security features in place to keep your data secure once we receive it.

7. Storage

Where we store information

Your information is stored on our CRM database, hosted by Charitylog. Charitylog is accredited to ISO9001 for quality management and to IS027001 for system security. Paper records, where necessary, will be kept in a locked, fireproof storage system at the Autism Berkshire offices to which only authorised staff have access. Where staff are working from home for an extended period, we may give permission for paper records to be taken off site, where such records are required for the member of staff to perform their duties, so long as they are stored in the same secure manner as when held at the charity's offices.

We will only use and store information for so long as it is required for the purposes it was collected for. We review what information we hold and delete what is no longer required.

8. Keeping you in control

We want to ensure you remain in control of your personal data. Part of this is making sure you understand your legal rights, which are as follows:

● the right to confirmation as to whether or not we have your personal data and, if we do, to obtain a copy of the personal information we hold (this is known as subject access request)

● the right to have your data erased (though this will not apply where it is necessary for us to continue to use the data for a lawful reason)

● the right to have inaccurate data rectified

Please keep in mind that there are exceptions to the rights above and, though we will always try to respond to your satisfaction, there may be situations where we are unable to do so.

9. Complaints

You can complain to Autism Berkshire directly by contacting our data protection officer using the details set out above. If wish to make a complaint (including a complaint about fundraising activity) which does not directly relate to your data protection and privacy rights, you can do so in accordance with our Complaints and Feedback Policy and Procedure, available on our website.

If you are not happy with our response, or you believe that your data protection or privacy rights have been infringed, you can complain to the UK Information Commissioner's Office, which regulates and enforces data protection law in the UK. Details of how to do this can be found at www.ico.org.uk

10. Links to other sites

Our website may contain hyperlinks to other websites. We are not responsible for the content or functionality of any of those external websites. We suggest you read the privacy policy of any website before providing any personal information.

11. Changes to this Privacy Notice

We will amend this Privacy Notice from time to time to ensure it remains up-to-date and accurately reflects how and why we use your personal data. The current version of our Privacy Notice will always be posted on our website.

This Privacy Notice was last updated on 01 August 2026.

12. Changes to version

Date	Major or Minor	Reason for change	Change
29/01/19	Minor	Annual Review	Changed date
31/05/20 V1.2	Minor	Response to Covid-19 pandemic	Added clause on virtual delivery of events
31/05/20 V1.2	Minor	Response to Covid-19 pandemic	Added clause on storage of information outside of office
31/5/20	Minor	Clarification of version	Added version numbers to front sheet and header
14/1/21	Major	Added section on Berkshire West CCG contract and Brexit changes	Under Introduction added end of Brexit transition period and incorporation of EU GDPR into UK GDPR. Under section 2 added Berkshire West Autism & ADHD Support Service and that we collect and upload personally identifiable data to the MHSDS Under Section 5 updated that post Brexit, all Charity Log information is stored in the United

			Kingdom
14/06/2022 V1.4	Minor	Thames Valley Autism Alert Card	Update re sharing info with TVP with consent for Thames Valley Autism Alert Card
24/08/2023	Major	Added section on Berkshire Adult Autism Support updated section about Berkshire West Autism & ADHD Support Service reflecting change of commissioner	Under section 2 added Berkshire Adult Autism Support Service and that we collect and upload personally identifiable data to the MHSDS Under section 2 in relation to Berkshire West Autism & ADHD Support Service edit made to reflect change of NHS commissioning body. Under section 2 in relation to Thames Valley Autism Alert Card, removed references to data sharing with Thames Valley Police after agreement ended by police.
12/08/2024 V1.6	No change		Up issued to version 1.6 no othe changes.
01/08/2025	Minor	Annual review	Changed logo to new registered address. Changed registered address in text and changed email from admin@autismberkshire.org.uk to contact@autismberkshire.org.uk
1/8/26	Minor	Annual review	Change logo. Remove reference to Covid 19 pandemic under Virtual Delivery page 6. Updated NHS commissioning body references to reflect establishment of NHS Thames Valley ICB. Update mention of Parenting Special Children's role as sub-contractor, removing reference to children's groups.