What information do we keep about you and how do we use it?

National Autistic Society

Under the Health & Social Care Act 2008 we are required to keep an accurate, complete and contemporaneous record in respect of each service user and to maintain this securely. Here are the answers to some of the questions you might have about your own or your family member's record.

What information do you keep about me or my family member undergoing assessment?

We keep information about you or your family member in a case record. This information helps us to conduct our assessment.

What information do you keep in the case record?

The information in your case record includes:

- Basic details about you, such as your name, address and next of kin;
- Contacts we have made with you, such as letters, telephone calls and visits to the clinic;
- Notes and reports about your health, and any treatment and care that you or your family member have received or need;
- Results of the investigations undertaken on the day of the assessment;
- Information from other health, education or care professionals as well as from relatives who care for you and know you well. All this information is removed after the final report is sent out.

Is my information kept confidential?

Yes. We have a legal obligation to keep your personal information confidential.

Who can access the case record in your organisation?

The information you provide us with will be available to all staff involved in your or your family member's assessment and care on the day. Information is made available on a need-to-know basis.

How is my or my family member's personal information stored?

All personal information is stored securely, both in digital and paper form.

Do you use my personal information or my family member's personal information for research purposes?

If we need to use information about your or your family member's assessment for audit or research purposes to improve our service, we remove your name and all other personal details which could identify you. If we need the information in a form that could identify you or your family member, we will always ask your permission first.

Do you use my personal information or my family member's personal information for teaching or marketing purposes?

We will only use your or your family member's personal information in this way with your written consent to do so.

Do you share information about me or my family member with other healthcare, education or social care providers?

At the point of referral, we seek permission from you or your family member to contact other service providers or professionals that you have identified as being involved in your care. This is done in your or your family member's best interests, to ensure that we can assess your suitability for our service and provide a thorough and informed diagnostic assessment. After the assessment, you will be advised about who should be informed of the outcome of your or your family member's assessment to enable you or your family member to access support and care according to need. It is generally advised that a copy of the report goes to your or your family member's GP. For assessments that are commissioned by your or your family member's Integrated Care Board (ICB), there is an expectation that the ICB receives a copy of the report as evidence that an assessment has been undertaken.

What if I want to see my case record or my family member's case record?

You have a right to see, or obtain a copy of, your case record under the Data Protection Act 2018. You will need to write to the Data Protection Officer and complete a form for identification and clarification purposes. In line with the law, we will respond within one calendar month of your application reaching the Data Protection Officer. We will then provide you with a copy of your or your family member's record. Alternatively, we may make an appointment for you to see the record at the centre where you had your assessment. You may be refused access to some or all of your case record if the information would cause serious harm to your or your family member's mental or physical health, or if the information relates to, or was provided by, someone else.

What if I need someone to see my case record or my family member's case record?

Other people who need to see your or your family member's case record can write to the Data Protection Officer on your behalf, as long as they have written permission from you. This includes a legal representative, such as a solicitor, or any person instructed by a court to support you (if the court decides that you are unable to do some things by yourself and need help from someone else).

Can I see my child's case record?

If you are a parent or guardian, you can ask to see your child's case record, but the General Data Protection Regulations (GDPR) state that any child over the age of 13 years can potentially make their own decisions about how their data is processed. If your child is old enough and has capability to decide about this, you may not be able to see their record without their consent. In this case, you will have to write to the Data Protection Officer and complete a Subject Access Request Form.

How do I get to see the case record of a deceased person?

If you want see the case record of a deceased person in relation to a claim, you need to write to the Data Protection Officer. You may not be able to see the record if it contains information that the person expected to remain confidential. In addition, the National Autistic Society may refuse access if we believe that the information would cause serious harm to the mental or physical health of any other person or would identify another person.

Can I access my case record if I'm living abroad?

Under the Data Protection Act 2018, you still have the right to apply for access to your UK case record even if you have moved abroad.

How do I update my personal details in my case record?

It is very important that we have your or your family member's correct details. If you change your name, address or telephone number, please inform us so that we can update these details on your case record.

How long will you retain my case record or my family member's case record?

Under the Health & Social Care Act 2008 there is no guidance on how long it is necessary to keep your or your family member's record. Our practice follows the NHS England standards of retaining records for children and young people until they are 25 (or 26 if they were 17 when the assessment ended). These standards are also endorsed by the British Medical Association, National Institute for Health and Care Excellence (NICE) and the Department of Health. For looked-after children, it is until the individual is 75 (see the arrangements for Placement of Children (General) Regulations 1991 and the Children's Homes (Amendment) Regulations 2011). For adults we follow the NHS mental health guidance, and the retention period is 20 years after assessment or 10 years after death.

NAS National Diagnostic and Assessment Service at the Lorna Wing Centre

Children & Young People - lornawingcentreyoungpeople@nas.org.uk

Adults & General enquiries - lornawingcentre@nas.org.uk

You can contact our Data Protection Officer at the address below for further advice.

Data Protection Officer - dataprotection@nas.org.uk