

Purpose

The purpose of this policy is to promote trust in East Sussex Parent Carer Forum (ESPCF) and the work we carry out on behalf of parent carers and their children and young people with special educational needs and disabilities (SEND).

The guiding principle is that information about a parent carer belongs to that parent carer and we will not pass on any information without their permission. We believe parent carers have a right to a forum which respects their need for privacy and for control over information about themselves and their caring situation.

Scope

This policy applies to all staff, committee and steering group members, representatives and volunteers of ESPCF. Staff and volunteers working for Amaze in support of ESPCF must abide by the Amaze Data Protection and Confidentiality Policy which adheres to the same confidentiality principles.

The data covered by this confidentiality policy includes:

- Information about the organisation, for example its plans or finances
- Person-identifiable information such as name, address, postcode, date of birth
- Information shared with ESPCF in regard to the views, opinions and experiences of parent carers
- Information about individuals, for example members, volunteers, and staff whether recorded electronically or in paper form and however it may be gathered.

General principles

The main role of any parent carer forum will be to collect the views and experiences of parent carers. This data must be collected, managed and maintained appropriately, and as such, ESPCF will follow the requirements of the ¹Data Protection Act 2018. Amaze's Data Protection and Confidentiality Policy provides guidance and the framework for ESPCF to meet the requirements of GDPR.

1. Information given by parent carers to ESPCF staff or volunteers will not be passed on to anyone outside of the forum without their permission, except in exceptional circumstances (see points 8 to 10 below). Information means anything the parent carer tells the forum about themselves and their caring situation. This includes the fact that they have been in contact with the forum.
2. Under no circumstances should a parent carer's personal information be discussed outside of the forum, including in social settings, unless consent is given for this by the parent carer.
3. ESPCF will record only the information it needs to fulfil the purpose of the forum i.e. to collect parent carer views and experiences. To support this, the forum will collect standard information

¹ This policy should be read in conjunction with Amaze's Confidentiality and Data Protection Policy

when parent carers become ESPCF members, for example name, address, child or young person's disability or additional need.

4. In accordance with the Data Protection Act 2018, any data held by ESPCF about an individual will be made available to them on request.
5. Any records will be kept safely and securely, and in accordance with the provisions of the Data Protection Act 2018. ESPCF operates within Amaze's data protection and confidentiality policy and uses Amaze's IT systems. However, access to data is restricted to ESPCF staff.
6. As part of ESPCF's work to improve and develop SEND (special educational needs and disabilities) services, the forum uses collective anonymous data to demonstrate and evidence the overall general experiences of parent carers. Sometimes ESPCF may want to provide more in-depth detail and on these occasions it will seek permission of the parent carers, even when the information will be presented anonymously.
7. In exceptional circumstances, ESPCF may share data with partners where explicit consent is given in order to try to resolve a specific issue.
8. In certain circumstances it may be necessary to breach confidentiality without consent. These include the following reasons (this list is not exclusive), which are underpinned by Amaze's Safeguarding Policy (which ESPCF operates within):
 - a) If ESPCF has reason to believe that a child, young person, or vulnerable adult is experiencing abuse, whether physical, sexual, emotional or financial
 - b) If ESPCF believes a parent carer to be in a life-threatening situation
 - c) If a parent carer tells ESPCF that they intend to leave the person they are caring for unattended for a period of time, which the forum believes would cause them harm or endanger their life
 - d) If required by law
9. The decision to breach confidentiality will be carefully considered by the ESPCF chair in liaison with the Amaze safeguarding lead. All decisions will be recorded with reasons.
10. Where possible, ESPCF will advise any parent carer in the situations outlined above to contact the appropriate agencies to get help and offer them continued support.

This policy will be reviewed annually by the ESPCF steering group or earlier if matters arise demonstrating gaps in its effectiveness or in light of any relevant legislation change.

Signed off: November 2021

Last review: March 2023

Next review due: March 2024

APPENDIX 1

CONFIDENTIALITY AGREEMENT FOR ESPCF VOLUNTEERS AND STAFF (NOTE STAFF OF ESPCF ARE REQUIRED ALSO TO SIGN AMAZE'S DATA PROTECTION AND CONFIDENTIALITY AGREEMENT)

As a member of ESPCF I understand that I must not disclose to any unauthorised person any confidential information about ESPCF or any of its parent carers, their families, volunteers and staff. Exceptions to this ruling can be made with the consent of the parent carer, volunteer or staff member, or where there is a perceived risk to personal or public safety.

The information divulged by parent carers is to be regarded as privileged. It is my duty to ensure that privileged information is not disclosed to any person not entitled to have such information. I understand that this continues indefinitely beyond my working/volunteering time at ESPCF.

I understand that when parent carers give information, it is in fact given to the organisation (ESPCF) and as such may be shared or discussed with those staff and/or volunteers on a need to know basis i.e. as part of the role of the forum to use the views and experiences of parent carers to improve and develop services. I am obliged to share privileged information with supervisors and team members who are involved in the work of the forum.

I understand that breach of this code of confidentiality may lead to me being asked to terminate my role.

On termination of employment or voluntary involvement, I will return any files, documents or other papers and property of every description within my possession belonging to ESPCF

Signed.....

Print Name.....

Date.....