

Ethics Committee Terms of Reference

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1. Introduction

1.1 Our vision is to ensure autistic children and young adults access an education which empowers a life full of choice, independence, and opportunity. The Ethics Committee was established in April 2019 and seeks to ensure research conducted by BeyondAutism or in conjunction with BeyondAutism is ethical in its methods and objectives.

2. Our values

2.1 At BeyondAutism we are:

Dedicated to delivering excellence

Developing expertise, outstanding services and positive engagement, always seeking to go above and beyond expectations.

Committed to Behaviour Analysis, underpinned by the science of Applied Behaviour Analysis and Verbal Behaviour

Contributing to research and ensuring our staff continually develop and share best practice that ensure aspirational outcomes are achieved for autistic individuals.

Respectful

Embracing diversity, showing integrity, acting with compassion, and always treating people with dignity.

Proud to challenge

Listening, changing thinking, shifting attitudes, and educating.

3. Our services

3.1 BeyondAutism is a charity dedicated to empowering people with autism to lead fuller lives. Through our Early Years, Schools, and Post-19 services. BeyondAutism teaches children and adults aged 15 months–25 years old with autism and related communication disorders. We also provide Outreach and Training services for parents, carers, professionals, and mainstream schools – delivering life-changing outcomes in education settings and at home.

3.2 We are extremely proud of the expertise that our staff hold. Our multidisciplinary team consists of Board-Certified Behaviour Analysts, Qualified Specialist Teachers, Speech and Language Therapists and Occupational Therapists. We are experts in educating children and young adults

with autism. Our practice is guided by behaviour analysis underpinned by applying the principles of Applied Behaviour Analysis (ABA) and Verbal Behaviour (VB). to teach students and arm them with the life skills they need to live as independent a life as possible.

4. Purpose

4.1 The Ethics Committee exists as part of the governance of any research conducted by or in conjunction with BeyondAutism.

4.2 The Ethics Committee will be responsible for advising, implementing, and reviewing procedures and guidelines relating to ethical issues arising from teaching, research and other related organisation activities. The Committee will oversee research integrity across the charity, including monitoring compliance with our vision, mission, and values.

4.3 The ongoing role of the committee will in part be proactive in relation to emerging issues but will principally be reactive in relation to providing guidance.

4.4 The Ethics Committee will:

- Review any research proposals from outside agencies or from within BeyondAutism (in line with the procedure detailed in these Terms of Reference):
 - Granting approval for research to proceed
 - Seeking clarification or advising amendments to proposals before approval
 - Dismissing any research proposals that do not pass approval by the committee.
- Review and monitor ongoing research within or in conjunction with BeyondAutism ensuring any ongoing research continues to comply with appropriate ethical guidelines and remains within the remit of the initial brief.
- Review and monitor case studies provided by our services that are for the purpose of purchasing of Continuing Education Units (CEUs), in line with ACE accreditation requirements for BCBA and BCaBA continuing education.
- Refer where necessary to external experts (co-opting) in a particular field if the Committee feels unable to make a decision regarding the ethical practice of a proposal. Further consideration to be given to appointing an external expert to the Committee in future structures of the Committee.
- Providing reports on research matters to SMT.
- Review of these terms every two years and recommend any variations to SMT.

5. Membership

5.1 The Ethics Committee will include:

- The Chair, appointed by the Ethics Committee and approved by SMT.
- Senior Leader from each BeyondAutism service.

- An Outreach Consultant from the Research and Learning Team
- Consultant Behaviour Analyst
- Marketing and Communications representative
- Fundraising representative
- Allied Health Professional (this should reflect the type of research being reviewed)
- Administrator to circulate research requested and activities related to meetings
- An external specialist as required (see 5.3)

5.2 Membership is three years, with the option of renewal for a further year.

5.3 The Committee may invite an individual to attend a particular meeting or to review a specific request based on the specialist advice required. Such individuals will not take-part in the final decision making.

5.4 The expectation is for all members to engage in all research requests and attend all meetings scheduled. Each member will bring their own scope of practice and competence to the Committee and their views are important in ensuring the best ethical decisions are made. If a member is unable to attend a scheduled meeting or unable to respond to a research request, they should inform the Chair as soon as possible.

6. Accountability

6.1 The Ethics Committee is a sub-committee and accountable to the Senior Management Team (SMT). The Chair will provide updates to SMT through the monthly Research and Learning Report. The CEO will report through to the Board of Trustees.

7. Meetings

7.1 It is expected that most of the work carried out by the Ethics Committee will be via email. However, it will be expected that the Ethic Committee meet three times a year to discuss the range of research requests being received, as well as moderating the responses from the Committee. Meetings will be organised by the Chair and dates shared in advance by the administrator.

8. Quorum for meetings

8.1 The quorum for meetings shall be at least 50% of members. Where quorum has not been reached, the meeting will be adjourned by the Chair. Where possible, the meeting will be rescheduled.

9. Review Procedure

9.1 Requests to engage in research activities with BeyondAutism, including internal research activities, should be made via email to ResearchAndLearning@BeyondAutism.org.uk. Such activities include, and not limited to:

- Accessing BeyondAutism's expertise in autism or behaviour analysis.
- Engaging directly or in-directly with BeyondAutism stakeholders in a research study.
- Advertising or promoting a research study to our stakeholder.

9.2 Requests made to the Ethics Committee should be done so in writing, and include:

- Name of the researcher
- Job title of researcher
- Organisation or institution supporting the research
- Rationale and purpose of the research
- Intended method for the research
- Evidence of ethical approval from the supporting organisation or institution (including feedback from the relevant ethics board)
- Copies of questionnaires or interview questions intended to be used
- Any research posters used for the study
- Details of the supervising person(s) involved in the study
- Sharing of information and resources
- Details regarding how BeyondAutism would support the piece of research

9.3 The procedure for managing requests:

1. Requests received to the Ethics Committee will be shared and reviewed on a weekly basis. Requests outside of term time may take longer to review and will be dependent on having the appropriate expertise available to review and approve, including at least 50% of the Committee available to respond.
2. The request and supporting information will be shared with the Committee for review via email.
3. Committee members should review the requests within 5 working days, providing their feedback via email to the Chair and Ethics Committee administrator*.
4. Approval and feedback should be based on the research:
 - a. Being in line with BeyondAutism's vision, values and strategic objectives.
 - b. Not conflicting with BeyondAutism's policies, specifically those relating to safeguarding, data management and code of conduct.
 - c. Not breaching with the Ethics Code for Behaviour Analysts (BACB, 2020) or the UK-SBA Code of Ethical and Professional Conduct (UK-SBA, 2022) when the research includes behaviour analytical interests (based on the information provided by the researcher).

- d. Seeking to improve the lives of autistic people.
 - e. Contributing to the understanding of how to support or provide education to autistic people.
 - f. Respecting the lived experiences of autistic people and the autistic voice. This includes the use of language and tone.
5. The Chair will review the feedback provided by the Committee and determine a final decision determined by a democratic majority*. The Chair will communicate the outcome to the Committee and the administrator will inform the researcher of the outcome. Decisions made by the Chair should be respected by all.

*For the Chair to reach a decision, at least 50% of the Committee must feedback to a request. In circumstances whereby less than 50% have responded, a second request of the Committee will be made.

10. Conflicts of interest

10.1 Ethics Committee members are required annually to complete a register of business interests. If a member's personal or financial interests conflict with those of BeyondAutism in any matter being considered by the Ethics Committee, the member must declare any such interest, withdraw from the meeting while the matter in question is being considered and not vote on any directly related decision.

11. Safeguarding

11.1 BeyondAutism has a particularly vulnerable cohort of students. Safeguarding is a golden thread throughout the organisation. It is of paramount importance to the Ethics Committee that its learners are protected from mistreatment and enabled and empowered to make choices and take control of their lives. The Committee promotes the liberty of the students served by BeyondAutism and will give due consideration to this when considering research proposals.

11.2 Whilst the Ethics Committee will have a Safeguarding Lead, it recognises that safeguarding remains the responsibility of the whole Ethics Committee (and indeed ultimately the responsibility of the Trustees of BeyondAutism). As an Ethics Committee, we recognise that safeguarding is the responsibility of 'every one of us, all of the time'.

11.3 The Ethics Committee shall comply with all safeguarding legislation and guidance and have in place:

- Sufficient Designated Safeguarding Leads (Alerting Managers) of appropriate seniority and with sufficient training to have responsibility for the protection and welfare of vulnerable adults and for liaison with the local authority, social services and other relevant agencies.

- Comprehensive and up to date safeguarding policy and procedure that meets all legal requirements and includes procedures for dealing with allegations of abuse of students by members of staff, other students or any other person either within the service or elsewhere.
- All members of the Ethics Committee will receive a safeguarding induction explaining how the service's safeguarding processes run. All members should feel confident requesting refresher training in this area or asking for further explanations if they are ever unsure or uncomfortable with anything they read in a policy or see in practice in the service.
- The Ethics Committee will review and approve relevant policies, in accordance with the organisation's policy review schedule.
- The Ethics Committee will scrutinise and raise questions regarding:
 - How any research conducted by or in conjunction with BeyondAutism complies with its statutory requirements, meets appropriate Ethical guidelines, abides by law and manages safeguarding – both internally and by working with key agencies, and student attendance data.

12. Joining the Ethics Committee

12.1 The Ethics Committee seeks to uphold the highest safeguarding standards possible to protect the vulnerable cohort of students within the service:

12.2 No person shall be entitled to act as a member of the Ethics Committee whether on the first or any subsequent entry into membership until he or she has signed a declaration of acceptance and willingness to act in conformity with BeyondAutism's "Code of Conduct" and the current terms of reference.

12.3 As with all BeyondAutism employees, a DBS check will be in place for each Committee member.

12.4 All members will have completed safeguarding training in line with the organisation's expectations.

Last review: October 2022

Date of next review: October 2024

Review group: Ethics Committee