An Ethics Committee in the Third Sector: Process and pitfalls

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View from Inside the Ethics Committee

This article describes the lessons learned from introducing and establishing an ethics committee in a large third sector care provider. The article hopes to encourage other organisations to introduce similar committees and to help avoid potential problems and give advice on how to navigate others. It also hopes to give researchers and students insight into how a committee works and therefore perhaps how to apply in a way that maximises the chances of ethical research being accepted and completed.

Why it started

Kibble Education and Care Centre is a charity and social enterprise that cares for and educates young people from age five to 25 across care services that include residential, through-care, secure, close support, fostering and semi-independent living. Kibble also has close links with training and university courses and in 2010 it became apparent that there were many research projects running in the services but without clear coordination or ethical gatekeeping. There was concern that young people could be exposed to intrusive, frequent and unethical research projects and so senior management agreed to the creation of an ethics committee.

How it was designed

The ethics committee is well established in academia and it was felt that this model would effectively transfer to Kibble. Procedures and standards known from university committees were reviewed and then a similar version was designed for Kibble by the internal Specialist Intervention Service. This service includes psychologists and therapy providers with experience of research. The design process focused on ensuring that there was enough consideration of ethical issues related to young people, and the potential risks to researchers given the needs of some young people in Kibble.

Membership

Key stakeholders from senior management, social work, education, quality assurance, therapeutic services and academia were invited to be involved and confirmed their membership. This membership included stakeholders that would either safeguard children, or be responsible for implementing or overseeing research projects. An initial meeting to confirm roles, procedures and standards was organised. The ethics process was advertised to all staff, who were informed that any research involving Kibble was required to be submitted to the committee. An exception occurred with research focussing on the role of the board. The committee felt this was outwith its remit.

At the outset the committee membership consisted of seven people, only one of which was external to the organisation. There was an identified co-ordinator who oversaw the process, ensuring tasks were allotted and completed within agreed timescales. Since then initial membership of the group has evolved and by 2011 there were 11 members, three of which were external. Thereafter there has been a steady membership of eight to ten members, three of which are external.

The scale of submissions and approval rates

Between October 2010 and October 2014, the committee reviewed 45 submissions, summarised in the table below.

Table 1. Submissions by year

2010	03
2012	18
2013	07
2014	08
Total	**45**

Of the 45 entries, 15 came from external candidates and seven resulted from students on placement within the organisation. Of the 23 remaining internal candidates, 11 (24% of all candidates) came from the same internal team and eighteen resulted from staff undertaking advanced formal education.

The approval rate for submissions, to date, has been 32 out of 45 (71%). Three of these passed after being resubmitted, with only two being finally declined after being resubmitted. One application was viewed as outwith the realms of the ethics committee and was passed to our executive director for review. Another was viewed as an internal evaluation and therefore not within the remit of the committee.

Only 10 applications were completely rejected due to the ethical implications for service users. In addition to ethical concerns, submissions needed to be resubmitted due to a lack of clarity within the proposal on what the study was focussing on, or for being very similar to recently completed research. Initially there was a high number of rejected or resubmitted proposals and so increased guidance and support was offered to researchers and is included in the committee's online information page.

At least 24 submissions have resulted in completed research projects with findings used from some of these to inform practice either within the organisation or the wider social care field. At least three of these have also been published.

The committee has continued to struggle to obtain copies of completed research from all but those directly involved with the agency either as staff or through involvement with our specialist interventions team. This is a target for improvement given the ethical concerns regarding research that is not disseminated and unable to inform practice.

To minimise difficulties for students completing academic pieces of research the committee has co-ordinated meeting dates around potential submission timeframes for universities. Where adjustments or resubmissions have been required, the committee has been extremely flexible in reading resubmissions to ensure that candidates are not disadvantaged.

Themes of Submissions

The submissions have focused on some key themes: education, staff development and wellbeing, the impact of legislation, relationships, foster care and living in the life space. In addition, other pieces focused on behaviour-based research such as absconding and sleep difficulties.

The breadth of research has been useful but also potentially reduced the coherency of research and the relevance to practice within the organisation. As such the committee suggested key themes upon which proposals should focus. The present areas of focus are:

- Gender outcomes;
- Evaluation;
- Throughcare and aftercare;
- Implementation of best practice;
- The impact of family work;
- Transitions.

Key Learning Points

Stakeholders

Having the endorsement from senior management proved to be very important in the committee having authority and ensuring researchers submitted projects. This included members of management themselves adhering to the committee's procedure when completing their own research projects.

External committee members have brought a wealth of experience from practice, research and management that has sharpened the committee's focus. The committee would be less efficient and forward thinking without the added dimension the external members have brought to the group.

The committee has had a number of administrators and coordinators due to staff turnover. This has resulted in some drift and loss of process between successive coordinators. Recently the committee have attempted to re-instate the active nature of the co-ordinator role to ensure consistency and an effective process.

The committee has agreed to review roles, responsibilities and processes on an annual basis to reduce future drift.

Consent

The greatest cause for debate during the five years of the committee's activity has been in relation to consent. Key questions were whether to use opt-in or opt-out consent, whether young people are able to give informed consent and the nature of consent that should be required from parents and/or social workers. These issues have continued to prompt debate and have resulted in a few pieces of research not being undertaken due to difficulties in obtaining consent from all parties. The level of return for consent forms from external stakeholders such as social work is unfortunately very low. It is hoped that the organisation's inclusion in the national framework for children's residential services may provide a mechanism for obtaining consent.

Role Boundaries

Increasingly the committee became aware that some of the members' critique focussed on matters that were not relevant to ethics, or that sat on the boundary between quality assurance and ethical concerns (e.g. providing researchers with feedback on graphics, posters and language used in order to increase its accessibility to young people). A key learning point has been in the difference between the committee's remit to comment on ethical considerations and how far this could extend to commenting on the quality of the research proposal.

Ethical Thresholds

The committee's aim has always been to *enable* ethical research. Initially, though, there was feedback from researchers that submitting had been unhelpful. This included the committee commenting on areas beyond its scope as detailed above but also the timescales for consideration. Reviewing this has been key, and now the committee advertises its sitting and submission deadlines for a year in advance and has agreed to return results to candidates within a week. As a committee it was agreed not to restrict the number of submissions for any one meeting and to date the most in one sitting reviewed is 6. These steps have helped ensure that researchers could work to deadlines set by universities.

Feedback

Clarity of feedback for candidates is of obvious importance. This is an area that has seen drift at times. Initially recording forms were sent to all candidates, but this gradually moved to verbal feedback with successive committee members. Written feedback is now given to all candidates in order to ensure clarity and support resubmissions.

Conclusion

Any residential care organisations introducing an ethics committee are likely to experience similar issues. Having high levels of clarity and process on roles, boundaries, consent and feedback will help ensure that the committee is welcomed and helpful in an organisation. Including members who are already experienced with a committee can be an effective way to achieve this.

The committee has been in place for over five years now. In terms of meeting its goals, it has coordinated research, precluded unethical research and safeguarded young people from excessive and intrusive research. In addition, it has been able to encourage research that has high relevance and utility for the care of young people in Kibble. It is hoped that the lessons learned will be built upon and ethical and valuable research will continue in Kibble Education and Care Centre.

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