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COPING:

Children of Prisoners, Interventions and Mitigations to Strengthen Mental Health

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COPING: Children of Prisoners, Interventions and Mitigations to Strengthen Mental Health

D09.2 Ethical Procedures Report (WP9)

1. Introduction

The European Parliament clearly states that research activities supported by the Framework 7 Programme should respect fundamental ethical principles, including those reflected in the Charter of Fundamental Rights of the European Union. The COPING consortium contains a wealth of experience in the conduct of ethically sound research in the target countries of Germany, Romania, Sweden and the UK, and more broadly in Europe. The academic partners in the consortium have experience in conducting research with vulnerable people to the highest ethical standards consistent with national legislation, European Union legislation, respect for international conventions and declarations, and their own institutional requirements. Furthermore, the partnerships contains two organisations (Eurochips and QUNO) with pan-European and international expertise to provide guidance to the academic partners and social enterprises involved in the provision of support to prisoners' families. In addition to recognising our responsibilities to the wider European community, we have, as a project initiated and led from a UK, institution, also paid specific attention to the legal requirements of the UK Data Protection Act 1988 and the Human Rights Act 1998. Moreover, given the child-centred focus of the project, particular emphasis has been placed on integrating the principles and rights enshrined in the UN Convention on the Rights of the Child (CRC) in the research design, its implementation and in considering the use to which findings will be put.

Ethical standards were agreed at the commencement of the project. These enabled us to establish an independent COPING framework of values and principles that is used to guide the overall project *across* all participating countries and which takes account of, but is not dependent upon, country-specific regulations. However ensuring ethical research in studies concerning vulnerable populations and sensitive issues is not simply a matter of compliance with a set of prescribed procedures. Beyond this, attending to ethical concerns in an international study has proved to be an organic process that requires ongoing reflection and sensitivity to country differences in culture, language, policy environment, socio-economic factors and, political climate. So, for instance, while the CRC provides a universal language on children's rights, these rights are given expression in different ways in different countries affecting for example, the age at which a child may give consent to participate in research *independently* of his/her parents or carers. In another example, sensitivity to race relations has meant that in one country, questions about race and ethnicity were not considered ethically appropriate and ethical approval was not given to capturing data on these variables, despite the fact that 25% of prisoners in that country are foreign nationals. These nuanced differences in ethics have significantly impacted strategies for data collection and at times have threatened the integrity of the *comparative* nature of the study. Charting our way through these ethical 'seas', has been time-consuming and challenging. However, it has also led to important knowledge about country differences both in terms of ethics and responses to prisoners and affected children that is itself, a valuable finding of the study. At the discursive level, these issues have generated intense discussion and have increased our understanding that international research requires a scrutiny of universal assumptions about ethics and may mean deconstructing and challenging ethical regulations which operate as a barrier to engaging especially marginalised or vulnerable groups. Furthermore, we have a greater understanding that ethical compliance in research with vulnerable populations is not about ticking boxes against pre-determined standards but is a dynamic and continuous process in which human needs, rights and cultural factors intersect with research objectives and methods.

This report describes the procedures, processes and systems in place to ensure that COPING meets all ethical obligations. It also incorporates details of the ethical challenges that have arisen during the course of the research and the ways in which these have been addressed. Overall, we feel that we have devoted a considerable amount of time and effort to the subject of ethics. We believe that this investment of resources has proven extremely worthwhile in terms of enabling us to ensure that this research is conducted according to the highest ethical standards. An additional benefit of this work is that it has given us considerable knowledge and understanding of comparative ethical issues, especially concerning research with children, across Europe. We intend to disseminate and share this expertise more widely through publications and conference presentations. (See Gallagher, B., Berman, A.H., Raikes, B., Schuster, M., Bieganski, J., Foca, L., Ullman, S. and Jones, A. (in preparation), for the first of these planned outputs.)

The report sets out the legislative, policy and governance mandates established at the commencement of the project and then discusses how the subject of ethics has been dealt with across the COPING project as a whole. This is followed by accounts of the arrangements for addressing ethical requirements in each of the four countries participating in the research (Germany, Romania, Sweden and the UK) and the specific issues that have arisen in respect of the individual work packages that involved data collection (WP1 - WP4).

2. Ethical Governance

Overall responsibility for ethical governance rests within the Centre for Applied Childhood Studies, University of Huddersfield and a specific work package – WP9 – was established to develop and manage the implementation of the ethical protocol, principles and procedures across the project. Dr. Bernard Gallagher (University of Huddersfield, England) has responsibility for this work package and specific responsibility for ethical management in the UK. His role is to ensure that ethical considerations are at the forefront of the management and coordination activities for which all Work Package Leaders are responsible and to liaise with those with lead responsibility for ethical management in the three partner countries, namely:

Germany: Dr. Matthias Schuetzwohl (Technische Universitaet, Dresden, Germany)
Romania: Ms. Liliana Foca (Asociatia Alternative Sociale, Romania)
Sweden: Dr. Anne H. Berman (Karolinska Institutet, Sweden)

3. Legislative Framework and Data Security

The research is being carried out in accordance with the ethics and data protection legislation of the participating countries, the World Medical Association policy statement on ethics, the *Declaration of Helsinki* (WMA, 2008), the British Psychological Society's *Ethical Principles for Conducting Research with Human Participants* (BPS, 2006) and the Social Research Association's *Ethical Guidelines* (SRA, 2003). The processing, storage, use and disclosure of personalised data for the purposes of this research is being conducted in accordance with approved practice under the relevant national legislation and with regard to the rights and freedoms enshrined within the European Convention on Human Rights. National legislation guiding the study is as follows:

- i. Sächsisches Landesdatenschutzgesetz 2007 (SächsDSG) – Saxony
- ii. Bundesdatenschutzgesetz (BDSG 2006) vom 25. August 2006 – Germany
- iii. Data Protection Act (1998) – United Kingdom
- iv. Law (2003:460) – Sweden
- v. The Personal Data Act (1998:204) – Sweden
- vi. Law 102/2005 (http://www.legi-internet.ro/autoritate_date_pers.htm) – Romania
- vii. Law 677/2001 - Romania

Data security has been implemented across all the research sites and complies with the International Standard ISO/IEC 17799 for data protection covering procedures for storage, encryption and transmission of personal data. The COPING study research sites are committed to protecting information about research participants and to upholding the standards on confidentiality and data security. The project has fostered a culture of individual accountability across the consortium with targeted, relevant, role-based training to ensure that all researchers have a clear understanding of how to use and share information securely. In the first instance, the COPING consortium members are required to conform to legislation and regulations in the countries in which the research is being carried out. At the implementation level, the appointed country-specific leaders work with Work Package leaders and project partners to ensure compliance and prior to the start of fieldwork approval was obtained from the relevant ethics committees in the participating research institutions:

- i. UK - The School Research Ethics Panel (School of Human and Health Sciences, University of Huddersfield) http://www.hud.ac.uk/sec/docs/DP_guidance_note_research.pdf and, http://www.hud.ac.uk/sec/docs/data_protection_policy.pdf
- ii. Sweden - The Swedish Regional Ethical Review Board <http://www.epn.se/start/startpage.aspx>
- iii. Germany - The Ethics Committee (Faculty of Medicine, Dresden University of Technology) http://tudresden.de/die_tu_dresden/fakultaeten/medizinische_fakultaet/struktur/kommissionen
- iv. Romania - The National Ethical Commission of Romania

4. Governing Principles

The application of the ethical principles as specified in the Description of Work is discussed in full within this report however a summary of the governing ethical principles are as follows:

4.1 Ethical protocol

As a study involving human subjects, the project raises important ethical issues with specific concerns regarding the involvement of children. These issues arise in *each* research site and therefore all participating organisations in each of the countries have been required to adopt a standard ethical protocol which was developed based on the full involvement/consultation with the participating organisations and formally adopted by all partners before commencement of the study.

4.2 Children's participation

The central aim of this research is to understand the impact that parental imprisonment has on children's psychological and social development and, to identify the needs that these children have. There is a growing consensus in the scientific literature that for any assessment of a child's problems and needs to be reliable then the inquiry must involve the child directly where this is appropriate. While there are important scientific and ethical reasons for involving children in research that is about them, this is also a rights issue and COPING actively promotes children's rights of expression as articulated within Article 12 of the CRC. Of fundamental importance in this child-centred project therefore is to establish from children themselves the meanings they attach to parental imprisonment. This is the overarching philosophy of the project.

4.3 Benefit to participants

Ethical research requires that there are benefits to those who are the focus of investigation. There are four main ways in which children and families, agencies and professionals benefit by participating in the project:

- i. Firstly, the study will identify the needs of children of imprisoned parents and ratchet public awareness of the plight of these children higher up the policy agenda

- ii. Secondly, the study will assess the extent to which existing services are meeting these needs and make recommendations for service improvement
- iii. Thirdly the study includes mechanisms for identifying immediate and acute needs of child participants with clear procedures to ensure that these needs are highlighted and that children have the opportunity to be referred on to appropriate services
- iv. In addition to these benefits, research and clinical literature shows that research participants can derive considerable benefit from expressing their views concerning their lives and the issues they face. Children of prisoners have fewer opportunities than other children to talk openly about their experiences because of stigma and our early experiences show that both them and their parents are deriving some therapeutic benefit from participation

4.4 Research methods

Study methods, instruments (surveys, questionnaires and focus group guides) have been designed to ensure that only data relevant to the objectives of the study are being gathered, that questions are phrased in such a way as to minimise offence and distress and are easy for participants to understand and respond to and that take up the minimum time needed to gather adequate information.

4.5 Consents and assents

Full and informed consent by research participants is a key principle underpinning the work and this is sought from all participants. The legal age of child consent is different in the participating countries [Germany (18 years), Romania (12), Sweden (15) and UK (18)] and as standard practice, the project is guided by the CRC definition of 'child' (any person under the age of 18 years) with the consent of the parent/carer/guardian being obtained as well as the child's informed *assent* where possible and appropriate. For any children in the care of the State, the consent of the corporate parent/legal guardian is also obtained. Obtaining consents from imprisoned parents, where they had joint or sole care of their children prior to their imprisonment is based on the legal requirements and regulations in each of the countries.

4.6 Post-research support

The research teams in each of the four participating countries have comprehensive and detailed policies and procedures in place to support the needs of children (and parents/carers) that arise as a result of their taking part in the research.

4.7 Confidentiality and anonymity

- i. Personal data is not being collected without the consent of the child or adult
- ii. The collection and analysis of data is only in fulfilment of the COPING research objectives and not for any other purpose
- iii. The collection of personalised data is strictly proportional to the needs of the research and we are clear to ensure this not unnecessarily intrusive
- iv. The data are accessed and shared only by designated members of the research teams
- v. No individual participant is identified or identifiable in any research reports.

4.8 Data security

- i. Access to computers, files and all electronic data generated by the project and recording equipment is password protected
- ii. A policy of adopting robust passwords (i.e. combining letters and numbers, uppercase and lower case characters) has been adopted

- iii. Data and reports are backed up on portable encrypted media (e.g. memory sticks) and stored separately and securely
- iv. Data that are electronically transferred between research sites are sent by secure transfer using encryption methods to ensure encoding, identification, and data integrity between applications
- v. Locked data storage facilities have been identified in each research site for all paper records
- vi. Paper records are shredded after use and disposed of using 'sensitive data' recycling procedures
- vii. Recordings of interviews will be destroyed once material has been transcribed
- viii. The deletion of digital files will be conducted to approved levels from a computer's hard disk so that they cannot be recovered
- ix. The participating institutions are required to ensure that data are securely held until completion of the research project and for a period of five years after completion
- x. A complete data set will be securely stored by the lead institution on a non networked computer for a period of five years after the completion of a research project

5. Management

There was one milestone associated with this WP. This was M9.1 - *Ethical Procedures Agreed* - with an expected date of M02. Broad agreement on the ethical procedures was reached by M01. The involvement of children in this research meant that ethics was an especially important subject but also one that raised quite acute, but also, sometimes, conflicting issues for the various countries taking part in the research. In light of this, further work had to be undertaken on ethics and a definitive document – the *Ethical Protocol* (Appendix A) - providing comprehensive details of the ethical procedures by which the research should be conducted, was not produced until M09. This additional investment of time and effort has, we feel, been worthwhile as it has meant that the ethical issues involved in the COPING research have been very fully considered and this has contributed to the high ethical standards by which the research has been carried out. In addition to the extensive consultation on ethics among members of COPING and with external organizations and experts, the ethical procedures for this research have also been discussed at meetings of the Management Board (MB), the Scientific and Technical Board (STB) and the International Advisory Board (IAB) – with the last of these fulfilling an independent advisory and oversight function. In view of the level of discussion and scrutiny to which the ethics of the COPING research have been, and continue to be, subject, it was decided that there was no need to set up the proposed and separate Ethical Research Advisory Group (ERAG).

6. Implementation

With the launch of the research, on 1st January 2010, the COPING team embarked upon a detailed programme of work, designed to ensure that the research was conducted according to strict ethical standards, while at the same time being cognizant of the differences that might exist between countries in respect of their specific approach to ethics. A series of methods have been utilized to ensure that all members of COPING are aware of, and committed to, ethical ways of working. These include: face-to-face training events; the electronic distribution and discussion of key ethics-related documents within COPING; on-going, informal electronic-based discussion of ethical issues within COPING; liaison and discussions with organizations and individuals who have expertise in ethics; and submission to ethics committees. The central aim of this work has been to: identify all of the ethical considerations that are pertinent to COPING; ensure all members of COPING have a thorough knowledge and understanding of these considerations; and guarantee that all of those involved with the research are able to respond appropriately to any ethical issues should they arise. We have, at the same time, used this work to identify the cultural and philosophical differences that exist between

countries in their approach to ethics, and the implications of these for the research, especially in terms of methodology and findings.

Every partner involved in COPING has been, and remains, fully committed to ensuring that this project is conducted in an ethical manner in respect of all of the groups participating in the research. There are four major groups of participants in this research. These are as follows:

- i. the children¹ of prisoners
- ii. these children's non-imprisoned parents/carers
- iii. these children's imprisoned parents/carers
- iv. stakeholders and caregiver

6.1 Training

A major launch event for COPING was held in Huddersfield (England) in M1. The launch event was also used to carry out the first training session on ethics. This training event was planned to ensure that all COPING members had an opportunity to contribute towards, were aware of and agreed with, the broad ethical procedures according to which the research was to be carried out.

Ahead of this meeting, members of COPING had been provided with a detailed *Ethical Management Implementation Plan* (Appendix B) that covered, in a comprehensive manner, the following four major responsibilities:

- i. Detailed tasks to be undertaken
- ii. Consortium member involvement
- iii. Task management
- iv. Work breakdown structure

The purpose in drafting and circulating the *Ethical Management Implementation Plan* was to make COPING members fully aware of the requirements that were involved in ensuring the research was ethical and to aid discussion in the subsequent training event. The focus of this first training event (Appendix C) was on identifying the standard ethical procedures by which the research should be conducted. There was broad agreement among COPING members as to what should comprise the central principles of these ethical procedures. These were as follows:

- i. All prospective participants should be given a full account of the COPING research, and in particular the nature of the study; what their participation would involve; how the information they provided would be used - and all of this prior to their being asked to consent to take part in the research.
- ii. An individual should take part in the research only if she or he has consented to do so.
- iii. Children (i.e. those persons under the age of 18 years) should take part in the research only if their parents/carers have **consented** to this.
- iv. Children should take part in the research only if they have **assented** to do so.
- v. All information – with one major exception - provided to the research should be treated in the strictest of confidence. (The one major exception being information indicating that a child may be at risk, which may have to be passed to an appropriate authority.)
- vi. No individual taking part in the research should be identified or identifiable in any report emanating from the research.

This first training session was also used to begin the process of highlighting and discussing specific issues and dilemmas that might arise in relation to ethical procedures. The initial issues and dilemmas to be identified were as follows:

¹ The COPING research involves children and young people between the ages of 7-17 years. The participants are, within this report and in the interests of brevity, referred to as child/children.

- i. Should consent for a child's participation in the research also be sought from the child's imprisoned parents/carer?
- ii. If such consent is sought from the imprisoned parent/carer, how should situations be handled where one parent/carer gives consent and the other does not?
- iii. What if a child wishes to take part in the research but his/her parent/carer does not?
- iv. What if an imprisoned parent/carer discloses any type of unreported criminal offence?
- v. Should ethical approval be sought *en masse* for COPING or for each WP separately?

It became clear, during the course of this training session, that there were differing philosophies behind, and approaches towards, *ethics* in each of countries taking part in COPING. It also became evident that there were some differences, between countries, in *legal* requirements, governing how research with human subjects should be carried out. It was recognised that each partner, in carrying out the research, would have to abide by the laws of their respective country. In regards to ethics, and in particular the above issues and any others that might arise, it was accepted that these would need to be subject to further discussion, over the coming months, to determine how they should be resolved in advance of the start of fieldwork.

Each country was expected to meet national requirements in terms of applying for, and obtaining, ethical approval. These requirements varied from country to country and these differences are set out below in the individual country reports.

A second training session was held during the course of the next consortium meeting, in Iasi (Romania), in M9. The focus of this training session was upon the draft *Ethical Protocol* that had been drawn up and which set out the detailed procedures by which the research should be conducted to ensure it was ethical. This protocol was distributed to COPING members ahead of this meeting in order that it might act as the basis for a considered discussion prior to reaching final decisions as to what the ethical procedures should comprise. The first version of the Ethical Protocol was released in M9. The major principles of the Protocol, adding to and/or amending the six listed above are as follows:

- i. Consent for children to take part in WP1 (*Identification of suitable cohorts of children*) will be needed from only the non-imprisoned parent/carer. (In Romania and Sweden, however, consent was sought from both the non-imprisoned and the imprisoned parent/carer.)
- ii. All individuals taking part in the research should be given an information sheet containing information about the research, which they could retain. (This is in addition to being given a verbal description of the research.)
- iii. All individuals taking part in the research should be asked to sign a consent form.
- iv. Prior to consenting to the research individuals should be made fully aware that: participation in the research is entirely voluntary; they can refuse to answer particular questions; they can withdraw from the research at any time they wish; and whatever decisions they make, none of these will have any adverse consequences for themselves or for any other individual known to them.
- v. That there should be a second exception to the promise of confidentiality; namely, that where we receive information that there is a threat to prison security, then this might have to be passed on to an appropriate authority.
- vi. All individuals taking part in the research – but especially children their non-imprisoned and imprisoned parents/carers – should be given written information concerning organisations that provide support, in case they wish to receive support as a result of any issue that has been raised during the course of the research.
- vii. All researchers who wish to have contact with children, in the course of the research, should be subject to police checks (if these are available in the country in question) to ensure that there are not any reasons why they should not work with children.
- viii. A risk analysis should be carried out to ensure that, in relation to both research participants and researchers, safeguards are maximized and risks are minimized.

In addition to the ethical issues listed above, others have been identified during the course of, and also outside of, these training sessions. One of these includes whether, and if so how, the research should go ahead with a family² if the child does not know that their parent/carer is in prison. (We were informed during the course of the research that some children are not told the reason for their parent/carer's absence or they are not told the real reason. They might, for example, be told that their parent/carer has gone abroad, is in the army or that she or he works in a 'special factory'.) We decided that families should be involved in the research only if the children in question are already aware that their parent/carer is in prison.

The above sessions, in M01 and M09, were also used to provide training to COPING members on the administration of the survey and the associated questionnaire in WP1, and the administration of the child-centred interviews in WP2. Training and re-fresher training courses have also been held within each COPING member country. One major purpose of this training has been to ensure – and as was required by the DOW – that WP1 and WP2 are carried out to the appropriate ethical standards.

Members of COPING have been in discussion with one another (largely by email), regarding ethics, throughout the course of the project. Some of this discussion has been concerned with issues around the two training sessions and the documents circulated in association with these events, but there has also been discussion as issues have arisen on a more *ad hoc* basis.

6.2 Safeguarding and empowering children

One of the concerns of the researchers – and one shared by some of the organisations approached to take part in COPING – is that the study might distress children, and in particular might add further to the stigma they experience. We wished to avoid these problems and this is part of the reason why we have placed a considerable emphasis in the research upon positive psychology (Seligman and Csikszentmihalyi, 2000). So although the COPING research is concerned with identifying difficulties that children encounter, there is also a considerable emphasis upon identifying their strengths, coping abilities and resilience, such that they might find participating in the research a positive, and even an empowering, experience. Moreover, the guiding principle of the COPING research is that it should be child-centred – the intention being that this research should provide children with a powerful and genuine opportunity to express their views concerning parental/carer imprisonment.

While we cannot guarantee that children have not experienced distress as a result of taking part in this research, we hope that through the above measures and the others outlined elsewhere in this report, that many children have found participating in this research a positive experience. The anecdotal evidence we have gained during the course of the fieldwork does suggest that at least some children (and also parent/carers) value the opportunity to share their experiences and views concerning the impact on their lives of parental/carer imprisonment.

7. GERMANY

7.1 Introduction

In Germany, all ethical principles are regulated by the German constitution in which fundamental rights of German citizens are anchored alongside with human rights. German legislation, executive authorities and jurisdiction are all bound by the constitution.

² The large majority of children who have taken part in COPING so far have been living in some sort of family environment i.e. they are living with a parent/carer to whom they are related in some way – often their birth mother or father. However, some children, such as those living in state (residential) care, will not be living in family situations. The term *family* is used throughout this report, for convenience sake, but it is recognised that this is not appropriate term for all children's living circumstances. It should also be recognised that in some families only the parent/carer or only the child took part in the research.

This part of this report in relation to ethics in Germany describes the ethical procedures by which the COPING study is being conducted at the Faculty of Medicine Carl Gustav Carus at the Technische Universität Dresden (TUD) for data collection in WP1, WP2, WP3, WP4, and at Treffpunkt e.V. (TRE) for WP1 and WP2.

All studies at the TUD involving human subjects (including research with human data) have to submit for ethical approval to the ethics commission (EC) of TUD. The EC follows the Helsinki convention developed by the World Medical Association (WMA) as a statement of ethical principles for medical research. The commission reviews information about the kind and amount of involvement of participants, and about proceedings for protecting participant's human rights and person related data. TRE was obligated to obtain the permission of the Bavarian Commissioner for Data Protection responsible for the area Central Franconia prior to starting the research project. The data protection authority carries the factual and local responsibility during the research project if private data is collected, used, disseminated, stored and shared by TRE.

7.2 Ethical procedures at TUD

TUD had to obtain ethical approval from the university's EC for all project phases in which human subjects were to be investigated. Research with human data was a feature of WP1, WP2, WP3 and WP4.

The ethical approval form is the basis upon which the EC makes its assessment. The following information has to be provided on the form: project description - outlining the aims, design, methods and expected results of the study; strategies for identification, recruitment and sampling of participants; and biometrical methods, sample size and power calculations. The benefit to participants also has to be discussed.

Researchers are obligated to obtain informed consent for all assessment and treatment procedures. The information sheets are part of the approval and include the following: a clear description of research procedures; what nature of an individual's participation will be; information about potential risks that might influence study participants; and about the right to refuse any part of the investigation or to drop out without consequences at any time. For the COPING project, the TUD EC undertook to obtain informed consent from the parents/carers for their own participation, and also for the child's participation, as well as consent from the children's. Parental/carer consent for the child is required if the child is younger than 18 years. Researchers and study participants enter into a social contract, using the information sheet and confirm this by signing the consent sheet.

In COPING, TUD is the leader of WP4 (Mapping of services and interventions for children of prisoners and their families) and performs this investigation throughout Germany. For that part, all relevant services involved in the mapping procedure were asked for informed consent. In addition, additional permission from ministries of justice in all federal states was obtained for all prisons in Germany to take part in the research.

Data protection is an important part of ethical procedure. All Participants are informed about handling and keeping person related data. They are asked to guarantee that all data provided to the research will be treated in confidence and anonymised according to the data protection act. Exceptions are planned offences by paragraph 138 StGB (criminal code). The person will be informed that should such information arise then this might have to be passed to an appropriate authority.

For COPING in Germany, the EC of TUD assessed whether the project complied with legislation. In addition, the criminological service of the ministries of justice gave its agreement to the procedure. Furthermore, the data protection procedure for WP1 and WP2 investigations were approved by the Bavarian data protection officer. On the part of study participants, agreement by signature can be given to the relevant paragraph within the consent sheet.

Interventions and training procedures are detailed in the approval such that the EC is able to assess a study's innocuousness, appropriateness and practicability. This includes all questionnaires and interview guides, which have to be submitted to the EC before they are used. They are submitted either with the first submission of the approval or later if they are developed during the course of the in

project. For COPING, the questionnaires in WP1 and the interview guides for WP2 in depth child interviews have been submitted.

All required documents are assessed by the members of the EC, which have professional competences in this area - among whom are medical specialists, biostatisticians, advocates and ecclesiastics - with extensive ethical knowledge. The EC holds a meeting once a month and votes on submitted approvals. We have applied for ethical approval to the EC of the Medicine Faculty of the TUD, providing them with the Ethical Procedure report and the decision from the University of Huddersfield Ethical Committee to grant ethical approval to HUD. The ethical approval, for TUD, was granted on 2nd September 2010, subject to submission of the final versions of the survey tools for WP1 and WP2. The EC feedback raised the following issues:

- i. Are there exclusion criteria for the children (for example, victim of abuse with increased vulnerability for re-traumatisation)?
- ii. Who will conduct interviews with the children (for example, what qualifications will interviewers have and will they be trained psychologists)?
- iii. What procedure is foreseen, if an offence becomes known within the interview?
- iv. It should be indicated, within information sheets, that there will, within the interview, be questions on the incarcerated parent/carer.
- v. What is the procedure where the custody of the child is shared?
- vi. Another problem is the influence of reimbursement, which could have a major impact upon an individual's decision to participate. In Germany, the each child receives €5 for taking part in WP1 and each family receives €30 for taking part in WP2. The EC suggested that this could effectively force participants to take part in the study.

After all considerations were clarified and remaining documents and questionnaires were submitted, the final ethical approval has been granted to Germany (M11).

If the wish is to involve minors in research, then consideration must be given to their different levels of ability to assess the meaning, amount and consequences of participation, and to their being able to give consent in a free way, not influenced, for example, by researchers, parents or other adults. Children of prisoners may be especially vulnerable to psychological problems compared to children in the general population, such that the issue of their protection becomes even more important. There is a dilemma between insistence on parental involvement and autonomy of children in decision making. In Germany the requirement of parental agreement is not directly age-related but dependent upon their competence to make a decision. In respect of the WP1 survey and WP2 interviews, all study participants have to give their consent. For COPING, it was decided by the researchers, in accordance with the EC, that for any person below the age of 18 years to take part in the research, consent be obtained from at least one parent/carer who has custody for the child. If the child is 18 years or older, then she or he can take part in the study without the consent of a parent/carer. If the parent/carer gives consent but the child refuses to take part, the child cannot be included in the study. As with all other participants, there will be no negative consequences for children if they refuse to take part in the research or any stage of it, or if they take part and subsequently drop out.

7.3 Ethical procedures at TRE

To obtain ethical approval for the WP1 survey and the WP2 interviews, TRE submitted a letter (M05, 11th May 2010) to the Bavarian Data Commissioner to inform the authority about the research project and to inquire about procedures concerning data protection. The Bavarian Commissioner for Data Protection requested the following documents (which were provided in M06, 16th of June 2010): consent forms, information sheets provided to participants, questionnaires and interview guidelines.

On 15th of July 2010, TRE received permission for the research project, and conditions for how data should be collected in the questionnaires and interviews, how data have to be stored by TRE and how data need to be transmitted to TUD, were defined. The handling of personal data has to be backed by

a participation consent form signed by the child and their legal representative. For minors, a further approval of the legal guardian is required.

TRE decided to expand the geographical scope of the survey as recruiting 250 prisoners' children exclusively within Bavarian borders would have been impossible. Prior to extending the research to other German states, the permission of respective state authorities for data protection was necessary.

TRE was informed that the jurisdiction of the data protection authority is determined solely by a company or organization's registered office. As the research is conducted by TRE in Nuremberg/Bavaria and no personal data from other states will be transferred, the authorization from the Bavarian Commission for Data Protection Center Franconia is sufficient. Based on such an authorization, the data protection authorities of 14 out of 15 other German states granted TRE their permission for cooperation with centres and care facilities for delinquents throughout Germany. Alongside working with counselling centres and care facilities for delinquents, TRE decided to try and work with Bavarian prisons, which in turn required permission from the Bavarian Ministry of Justice and Consumer Protection.

The Bavarian Ministry of Justice and Consumer Protection mentioned (on 11th March 2010) that prior to granting its final permission to the research, the project needs to be reviewed by the Research Centre of the Bavarian Prisons. This role the Research Centre is to review, coordinate, supervise and support external research projects conducted in the penal system. TRE was informed that in general there were no objections to a close cooperation with Bavarian penal facilities for this research, as long as each prison administration felt capable of managing the additional efforts, and could assure the ongoing security and order within the prison. TRE was further informed (on 10th May 2010) that for the final permission to be granted the following documents and details needed to be submitted to the Research Centre of the Bavarian Penal system for review: outline of project concept and research study; recruitment strategies; details of research staff; questionnaires; interview guidelines; consent forms; information provided to participants; authorization of the Bavarian Commission for Data Protection Central Franconia; and the Ethical Protocol for the COPING project. The Research Centre of the Bavarian Penal system sent their evaluation statement to the Bavarian Ministry of Justice and Consumer Protection. The latter granted final permission for the survey within the Bavarian prisons on 24th of August 2010 (M08).

The Research Centre informed all Bavarian Prisons about the COPING project and asked each prison to appoint an official contact person for the project. This contact person, ideally someone working in social services, is responsible for liaising between the prisoners who are deemed suitable to take part in the study and project staff from TRE, within the limits and circumstances of the prison's environment.

To date no ethical problems or questions emerged during the research project. The participants are carefully prepared for the interview situation by the project staff and are being thoroughly informed that their participation in this survey is completely voluntary. If the participant agrees to take part he or she is under no obligation to answer every question, has the right to terminate the interview at any moment and faces no negative consequences in any form. The interview is voluntary, conducted anonymously and project staff are bound by a professional non-disclosure obligation. However, Article § 138 of the German criminal code stipulates the duty to notify authorities in case of planned serious crimes, if those were to become known during the interview. Furthermore, all collected data and information are to be treated confidentially and are stored according to data protection instructions.

7.4 WP3

TUD has sought and obtained approval and permission to carry out the Coping research from the ethics commission of TUD. This includes approval for WP3. TRE was obliged to obtain the permission of the Bavarian Commissioner for Data Protection because this authority bears responsibility during the project insofar as private data will be collected, used, disseminated, stored and shared by TRE. The data protection authority granted permission to the project, including WP3. Further information about the ethics procedures is contained above.

Special information sheets and consent forms

Consent forms for the WP3 interviews are finished, they are similar to the forms used in WP1 and WP2. There are going to be WP3-focused information sheets also, but to date they aren't finished yet.

Special measures to support vulnerable adults or children.

We are going to conduct the WP3 interviews with the carers and children in a similar way as in WP2. We conduct the interviews at home, so they can feel safe and relaxed. We don't want them to put too much expenditure in this, so we spare them the travel expenses and the extra time and effort they would need in coming to us. Because of anonymity, we don't want to interview them in public and crowded places like restaurants or cafes.

Experiences and recent WP3-activities

Up until now we have been creating the WP3 country plan. We are working on new contacts and expanding our network, so we hope to get more interviews than are currently listed in the country plan. We conducted one interview with a social worker (stakeholder group: NGO staff involved in policy relating to children/families of prisoners), the second interview will be carried out in July. We haven't done anything regarding data analysis because we still don't know how the analysis should be carried out.

8. ROMANIA

8.1 Obtaining the authorization from the National Authority for Personal Data Processing

In Romania, unlike UK, Sweden and Germany, it is not a condition to have ethical approval in order to conduct research. Therefore, the first ethical requirement for research to be conducted is to be authorized by the National Authority for Personal Data Processing (NAPDP). This process involves filling out an online form on the webpage of the NAPDP, in which the applicant is required to provide the following information (where appropriate and via tick boxes): the purpose of processing personal information (scientific research); categories of persons under investigation (minors); which data is being processed (names of the children and family members, gender, date and place of birth, family situation, address, behavioural aspects); and what guarantees accompany the disclosure of personal data (written consent and Romanian Child Protection Law). The internal regulations that ensure the protection of personal data have been attached to the online form (Appendix D). The authorization for the COPING research was granted on June 8th 2010 (M06). A copy of the authorization is attached (Appendix E).

8.2 Ethical procedures

The ethical procedures undertaken in Romania were in line with COPING ethical principles and involved:

- i. Drafting Collaboration Protocols with four prisons in Romania that provided the databases with contact details on children with imprisoned parents. The prison staff working within the Psycho-social intervention Service made a preliminary selection of prisoners meeting the criteria (being a parent of one or more children aged 7 – 16 years). The prisoners were informed about the project and the research, and were asked if they would consent for themselves and their children to take part in COPING. Written consents were required from the prisoners.
- ii. Training the MA students that were selected as operators for WP1 survey and as interviewers for WP2, on the COPING Ethical Protocol. At the same time, the training offered the

opportunity for the students to discuss their expectations and concerns. The training took place at the end of October 2010 (M10).

- iii. Carers were first contacted by phone and/or with the help of community social workers. The nature of the research, and the way it would be carried out was explained to them, and they were asked to give preliminary verbal consent. A written consent was asked for during the survey visit. Most of the surveys took place in the family home.
- iv. In areas where there was concern about the safety of the operators, the students were accompanied by local police workers.
- v. Throughout the fieldwork period, the students were in permanent contact with the research team.
- vi. At the end of WP1 survey, the students took part in a debriefing session where they had the opportunity to discuss the challenges they faced during the fieldwork.
- vii. For WP2 a new Collaboration Protocol was drafted with the National Administration of Prisons. The Protocol includes a distinct chapter on the Ethics of the Research where the COPING ethical principles are mentioned.

8.3 Ethical issues

During WP1 and WP2 several aspects of ethical concern were pointed out by the fieldworkers:

- i. The WP1 survey was conducted before the Christmas holiday (November and beginning of December 2010) making discussions more sensitive towards family reunification on the part of carers and children.
- ii. Some of the families included in the research had poor living conditions (no heating, big family and a very small place to live) that required different settings for the interview to take place.
- iii. Some of the carers had never had the opportunity to talk about their experiences following their partner's imprisonment. Thus, it was sometimes hard to keep the carer on track with the questions included in the survey.
- iv. The students that operated the survey had encountered situations where they made considerable effort to explain the research because the carer was illiterate or had a very hard time in understanding the questions.

Responses

- i. Where questions were felt to be too sensitive for the child and/or parent/carer, the interviewers reminded them, in an understanding manner, of the fact it is their right not to offer an answer.
- ii. In cases where living conditions did not allow for the survey to take place, the community mayor's offices were used with the support of the social worker.
- iii. During the training, the students were provided a list of social services and organizations that could offer support to families in difficult situations. Where it was applicable, they tried to offer this information to parents/carers.

Dilemmas

- i. Bearing in mind the WP1 was developed before the Christmas holiday, the fieldworkers found it very difficult not to get involved in helping the children they visited at home for the survey. One approach was to identify NGOs working with children that had projects connected to the Christmas holiday.
- ii. It has also been a dilemma for the fieldworkers who interviewed parents/carers and children who were obviously in need for counselling with regards to their situation. Even though a list of possible contacts was available, in the case of persons living in rural areas and with very little money to travel to the nearby town, this solution was not felt as the optimal one to their dilemma.
- iii. During WP1, fieldworkers were asked by parents/carers about the situation of the imprisoned parent thinking they have seen them and could provide information that was not available to them owing to the fact they were poor and consequently could not visit them. The students

reported they could see parents/carers' disappointment in not having this information and would have wanted to have an answer. However, the policy of the research team was to use different fieldworkers to interview the non-imprisoned and the imprisoned parent/carer in order that there was no contamination of the data from the respective sources.

9. SWEDEN

9.1 Obtaining ethical approval

In Sweden, research involving human beings has been regulated by law since January 1, 2004, in The Act concerning the Ethical Review of Research Involving Humans (2003:460; lagen (2003:460) om etikprövning av forskning som avser människor). This legislation takes into account the European convention on human rights and biomedicine. The ethical review is undertaken within six separate Regional ethical review boards that convene at universities stipulated in the Act. For the Stockholm region, Karolinska Institutet is the university responsible for the Ethical Review Board. Each Board includes ten experienced scientists and five lay persons and is chaired by an experienced judge, all appointed by the government. The Central Ethical Review Board is responsible for supervision of the law, apart from the supervision provided by the National Board of Health and Welfare and the Swedish Data Inspection Board, where relevant. Appeals on decisions taken by a Regional ethical review board can be made to the Central Ethical Review Board. All information on the ethical review process is available on the official website on Vetting the Ethics of Research involving Humans, www.epr.se. While applications are submitted in Swedish, much of the information is also available in English, including the legislation itself. Additional statutes regulating ethical vetting procedures in Sweden include the Statute (2003:615) concerning the Ethical Review of Research Involving Humans, the Statute (2007:1069) with instructions for Regional Ethical Review Boards, and the Statute (2007:1068) for the Central Ethical Review Board.

Following changes to the Ethical Review Act in Statute 2008:192, research was understood to include not only 'scientific, experimental or theoretical work to obtain new knowledge', but also 'developmental work carried out on a scientific basis'. The Central Ethical Review Board clarified the meaning of theoretical work in a separate statement dated May 26th, 2008, where such work includes 'non-experimental observational research of various kinds, such as descriptive and analytical epidemiological research or other research not involving intervention which is accomplished with the help of registers, interviews and questionnaires' (see Appendix F).

Accordingly, it was necessary to submit the research conducted in Sweden within COPING for ethical review. COPING research, in Sweden, extends to several parts of the country, notably the cities of Norrköping, Malmö, Karlstad and their surroundings, as well as, lately, to Gothenburg and its surroundings. This might suggest that the board secretariats at the universities of Linköping, Lund, and Gothenburg would have had to be consulted, but given that the principal contact person for COPING research in Sweden is Dr Anne H. Berman in Stockholm, at Karolinska Institutet, it was sufficient to submit the project for review to the Stockholm Regional Ethical Review Board. The cost for review was 5000 SEK (approximately €530).

The project was submitted for review on May 19th, 2010, and a decision was communicated on June 3rd, 2010, whereby a condition for recruiting participants under 15 years of age to the proposed COPING research was stipulated as having offered the possibility of consent to *both* parents if they were *legal guardians* of the child (the legal age of consent for research purposes in Sweden is 15 years of age). KI assessed this stipulation as possibly leading to significant obstacles in recruiting children for participation in the COPING research, due to a) possible wide variations in the children's custody arrangements and as b) the recruitment procedure planned for COPING via the Bryggan NGO (RKS) premises, whereby the imprisoned parent's participation in the consent procedure might in practice be circumvented at *ad hoc* meetings between the staff and the family. For the latter

possibility, the ethical requirements would be satisfied through all efforts being made to inform the parent about the research and to allow the parent to 'opt out' of the research for his or her child, if desired. For this reason, and following consultation with the prefect of the Department of Clinical Neuroscience at KI, as well as with Professor Johanna Schiratzki, member of the International Advisory Board for COPING, an appeal was made on July 7th, 2010, to the Review Board whereby a detailed interpretation of the Board's June 3rd decision was enumerated, with the suggestion that all parents in prison be informed of the project via letters posted at each prison involved in the study, and the 'opt out' option being made explicit. The Board returned a decision on August 19th, 2010, and agreed to accept the KI interpretation, but stipulated that each *legal guardian* in prison be *personally informed* of the research. This necessitated a formal collaboration agreement with the Swedish National Prison and Probation Service (see below). See Appendix G for all communication regarding the original application for ethical review. An English version of the KI interpretation letter is contained in Appendix H.

Thereafter, KI and RKS have complied with the Board decision in all research procedure. It became necessary to seek additional ethical approval for COPING in Sweden on March 23rd, 2011, and permission was granted for this on May 5th, 2011. The permission concerned WP2 interviews with 40 non-imprisoned parents and up to 40 imprisoned parents, compensation to children and parents in WP2 with cinema tickets, focus group interviews and personal interviews with stakeholders within WP3, and extension of the recruitment areas in Sweden to Gothenburg via the Solrosen NGO, to all areas in Sweden where the UngaKRIS NGO for youth at risk is active, and to the Child and Adolescent Psychiatry Services in Stockholm and Gothenburg whereby children with imprisoned parents treated at the services would be offered information on participating in COPING. (See Appendix I for the additional ethical approval including the decision, as well as a copy of the Collaboration Agreement between the Swedish National Prison and Probation Service and KI (see below), and an additional consent form for imprisoned parents where they could agree to WP2 interviews with themselves.) The cost for the additional application was 2000 SEK (approximately €210). The total fee paid for ethical review for COPING Sweden was thus approximately €740.

9.2 Additional approval

An additional agreement was made with the Swedish National Prison and Probation Service (SNPPS) on February 15th, 2011, regarding collaboration between KI and the SNPPS regarding COPING. According to this agreement, which stretches between January 1st, 2010 and December 31st, 2012, brief reports (up to two pages) will be submitted on May 31st and November 15th, 2011, as well as May 31st and December 31st, 2012. In addition, the agreement stipulates that KI will follow the confidentiality regulations for the SNPPS while conducting the COPING research. (See pages 6-7 in Appendix I for a Swedish-language copy of the agreement.)

The collaboration agreement led to the necessity of translating the information letter to imprisoned parents of potential participants, already adapted into simple Swedish, into six additional languages: Arabic, English, Finnish, French, Russian and Spanish. (see Appendix J). This was because a relatively large proportion of the prisoners in Sweden (an estimated 30-40%) have a rudimentary knowledge of Swedish or do not speak the language at all.

9.3 Specific ethical procedures

In common with UK COPING colleagues, we followed standard ethical procedures requiring informed consent regarding participation in the research. For children under 15 years of age in Sweden, the parent or legal guardian's consent is a prerequisite for the child's participation. For children under 15 years, the child's own consent is not mandatory by law, but the child research participant must be informed 'as far as possible' about the research. The law explicitly states, however, that if a research subject under 15 years, understands the research and opposes it, he or she may not be subject to the research procedure, all according to §18, The Act concerning the Ethical Review of Research

Involving Humans (2003:460). In COPING, we required all children, including those under 15, to explicitly give their consent to participate in the research, in the spirit of Article 12, p. 2 of the Convention on the Rights of the Child, which states that children should 'in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child...in a manner consistent with the procedural rules of national law'.

The research in Sweden is conducted in complete confidentiality with one exception, for the case of a child's physical or mental health being endangered. Children at such risk must be reported to the Social Welfare Board (*Socialnämnden*) according to Ch. 14 Sec.1, the Social Services Act 2001:453 (*Socialtjänstlagen*).

The specific procedures we have been following in COPING research in Sweden are set out in Appendices I, J and K. These are briefly summarized below, in particular the points relating to the UK procedures:

Regarding police checks in Sweden, these are standard procedure for employees and volunteers at RiksBryggan (RKS), the NGO for children and families of prisoners in Sweden. At KI, these are not standard, so a check was made for each person involved in COPING research from KI; this involved requesting an extract from the National Police Registry. Only persons with a completely blank register are acceptable.

Children of prisoners have been and are being recruited through the following channels:

- i. At prisons/remand prisons in connection with visits to their imprisoned parent (see pp. 69-72 in Appendix G for a list of prisons).
- ii. Via contact information delivered by the imprisoned parent to the Child Ombudsman at the prison or to the RKS representative visiting the prison (see p. 8, Appendix I, consent form in Swedish language).
- iii. At RKS venues which the children visit on their own or together with an adult.
- iv. At state institutions for delinquent children 15-17 years old.
- v. At Child and Adolescent Psychiatry clinics in Stockholm and Gothenburg.
- vi. Via information posted on websites such as the SNPPS site for children of prisoners ([http://kriminalvarden.se/sv/Startsida-Barnsidor/Ar-du-8-17-ar-Vill-du-dela-med-dig-av-dina-erfarenheter-/](http://kriminalvarden.se/sv/Startsida-Barnsidor/Ar-du-8-17-ar-Vill-du-dela-med-dig-av-dina-erfarenheter/)) and other relevant sites with a link to the SNPPS site.
- vii. Via the authors of a recently published book in Swedish, entitled *Pappa och kriminell [Daddy and criminal]*, who may access children from families who do not have prior contact with Bryggan (RKS) or any other help organization (Malmborg & Stakset, 2011).

So far, most children have been recruited via the first three channels in item 2 above.

Regarding items iv-ix in the UK description below (pp.18-19), the procedure was the same in Sweden. The information sheet to parents/carers and children contained approximately the same information as the information to the imprisoned parent shown in Appendix J, but in slightly more detail (see pp 43-44 in Appendix G).

Consent forms for children are shown on pp. 45-46 in Appendix G, and the forms for parent/carers are on pp. 47-48 in Appendix G. The texts for these forms were adjusted slightly in the final questionnaires for WP1, which were printed in December 2010 following translation and back-translation of them, but the contents were approximately the same.

The WP2 interview procedures were introduced and explained prior to the WP1 interview/questionnaire procedure, since the informed consent for WP2 was included in the informed consent form for WP1. Following the WP1 questionnaire, a reminder was given regarding the possibility of a future WP2 interview.

9.4 Ethical issues and responses

Just as in the UK, there have been no issues raised regarding child protection or prison security. Our sample is skewed to a certain extent since the fieldworkers administering WP1 questionnaires are from Bryggan (RKS), the Swedish NGO targeting children and families of prisoners. This would suggest that only families open to communicating about their situations would be willing to participate in the research, and that we are unlikely to access families with issues of child protection. For example, one inmate has utilized the 'opt out' option for his children, communicating to us the personal ID numbers of his four children aged 9-12, none of whom know that their father is in prison, and who are therefore completely inaccessible to the research.

Regarding any possible harm caused to children participating in this research, we see this as so far highly unlikely, given that: the families we are accessing are probably better-functioning than the norm; they are open to contact with Bryggan; and that the WP1 questionnaires, while concerning sensitive issues, are far less interrogative than the WP2 interviews. Very few of the latter have so far been completed, so it is too early to say whether they will raise ethical issues similar to those experienced in the UK.

Two issues particular to Sweden have arisen. First, there is an issue with information channels between the researchers and the subjects. In few research areas is there such a distance between the two. Ideally, the subjects would be recruited at the time of prison visits, as occurs in the UK. However, Swedish prisons do not have Visitors Centres; visits are pre-arranged and the only type of group event that occurs at the prisons when families of prisoners congregate, is the occasional Family Day, for example held this spring at Hall prison. Given this situation, the researchers are dependent on collaboration with the prison staff, particularly the Child Ombudsman, for informing prisoners who are not already in contact with Bryggan (RKS). The formal agreement between KI and the SNPPS has facilitated matters at the prisons and the Child Ombudsmen have been more than willing to contribute to COPING and have set up posters (printed by the SNPPS) and distributed the information letters in Appendix J. However, the Child Ombudsmen, who are prison staff, have been perceived by the inmates with suspicion and they have connected COPING to the SNPPS despite all assurances to the contrary. Therefore, the collaboration with the SNPPS has contributed to an additional, unintended obstacle between the researchers and their subjects.

The COPING **response** to this has been, firstly, to try to see to it that information sessions at prisons are held by Bryggan staff, a strategy that has generated some new contacts with families of prisoners, or else that information given by the Child Ombudsmen is followed up by Bryggan staff. Secondly, a form has been constructed for the imprisoned parent to sign and communicate contact information to his or her children and non-imprisoned parent/carers (p. 8 in Appendix I). Finally, a letter from KI has been formulated for sending to the non-imprisoned parent/carers whose address the imprisoned parent has communicated, but with whom contact has not already been established (see Appendix K).

A second issue concerns the venue of the WP2 interviews. RKS is responsible for the safety and security of the research subjects (see p. 62 in Appendix G). This is a responsibility that can be maintained as long as the interviews take place on Bryggan premises. However, the interviews are, by research subject preference, often held at the child's home, and sometimes the researchers are from KI only. The COPING **response** has been to offer to hold the WP2 interviews at Bryggan, and to regard the transfer of venue from the Bryggan premises to the child's home as a temporary removal of Bryggan premises to the home, such that the home is temporarily under Bryggan auspices, and that KI researchers are functioning under the Bryggan aegis.

9.5 Dilemmas

The dilemmas described for the UK have not yet been experienced in Sweden, largely due to the small number of WP2 interviews conducted so far (5 of 40 projected interviews with children).

Regarding reimbursement, none such reimbursement was envisioned from the start of the project in Sweden. However, in view of the time, effort and goodwill extended by the children and their families, cinema tickets are now given to each child as well as each parent/carer participating in a WP2 interview. In view of the difficulties in recruiting children and their families to WP1, cinema tickets are also given to each child and each parent/carer who completes the WP1 questionnaire. The value of the cinema tickets is approximately €7; higher values in Sweden would necessitate reporting of income to tax authorities, a procedure which would require greater invasion of privacy than is the case at the moment, as well as increased administrative costs.

10. UK

10.1 Obtaining ethical approval

The major (ethical) requirement for (non-medical) research to be carried out by a UK university is for the research to receive approval from an ethics committee – one which is, invariably, based in, and made up of representatives from, the institution in which the research is being carried out (Draper and Wilson, 2007). These ethics committee are, though, intended to act as an independent body. (Where it is planned that research, in the UK, will involve health services i.e. patients, staff or records, then a separate and additional application, for ethical approval, would need to be made to a local 'health department' research ethics committee (Department of Health, 2011). This was not applicable in the case of the COPING research. The application for ethical approval for the research to be carried out in the UK was made to the *School Research Ethics Panel* (SREP) (School of Human and Health Sciences, University of Huddersfield). The application was made in March 2010 (M03) and was granted – once some specific additional questions had been addressed - in April 2010 (M04). Not all the research instruments (for example, questionnaires and interview schedules) and materials (for example, introductory letters, information sheets and consent forms) were finalized at the time ethical approval was sought or obtained. Therefore, this approval was granted on the understanding that copies of these instruments and materials would be sent to the committee, as each of them was developed, with the committee having to approve them before they were used. This process of submission and approval of research instruments and materials is on-going.

A copy of the (completed) ethics approval application form is shown in Appendix L. As is evident from this form, the UK researchers were expected to provide quite comprehensive information concerning, for example, permissions for the study, access to participants, confidentiality, anonymity and psychological support for participants.

The researchers in the UK were also required, as part of the process of seeking ethical approval, to complete a *Risk Assessment and Management Form*. Researchers are required to describe, in this form, the nature and level of risks that are posed to participants and fieldworkers, through the study, and the measures that are to be taken to minimise these. The *Risk Assessment and Management Form* that was submitted on behalf of the UK researchers is shown in Appendix M.

10.2 Additional approval

In keeping with the undertaking given in our application for ethical approval, we have sought and obtained approval and/or permission to carry out the COPING research, in the UK, from a number of relevant organizations. These comprise the *Ministry of Justice* (the central government department with responsibility for prisons), the *National Offender Management Service*³ (which oversees prisons operationally) and prison governors - who are the final authority as to whether research takes place in a given prison.

³ North West England region, where most of the fieldwork is being carried out

10.3 Ethical procedures

In terms of ethical procedures that they have had to follow, the COPING researchers in the UK have had to abide by what are seen, in the UK and a number of developed countries, as fairly standard ethical procedures (Babbie, 2007). These are indicated on the ethical application form. Possibly the only special procedure concerned the conditions under which we would have to deliberately breach confidentiality. In common with practice among researchers in general in the UK, we undertook to ensure the confidentiality of all information provided to us by all participants. However, we also agreed that where we received information that a child was at risk (of being maltreated), then this information might have to be passed on to an appropriate authority. Parents/carers and children are informed of this exception to the confidentiality undertaking prior to their participating in WP1 and then on a second occasion if they take part in WP2. However, in the case of the COPING research we also agreed – in view of the special context in which the research was being conducted - to pass on, to the prison service, any information we received concerning threats to prison security. Parents/carers and children were informed of this as well.

The principles of the ethical procedures that the COPING researchers followed in the UK are detailed in the documentation contained in Appendices A-C. The following section of this report sets out how these procedures were implemented:

- i. Prior to a researcher approaching any family, she or he was subject to a police check. The UK has a robust system of checking a person's suitability to work with children. These checks are carried out by an agency that has been specifically set up for this purpose – the *Criminal Records Bureau* (CRB) (Munro, Holmes and Ward, 2005). The CRB offers three levels of checks depending upon the degree of contact the individual in question wishes to have with children. All staff working on the COPING project and having contact with children were submitted to the highest level check.
- ii. The first approach to a family was made via the non-imprisoned parent/carer. They were given a description of the research and the conditions under which it would be carried out, and then asked if they wished to take part and whether they were agreeable to their children taking part.
- iii. The large majority of the above approaches were made to family members in prison visiting reception areas, prior to their entering the more official areas of the prison where their contact with the imprisoned parent/carer takes place. However, some families were recruited through other means including our contacts with organizations working with prisoners families in the community and via direct approaches to prisoners.
- iv. If the non-imprisoned parent/carer was in agreement, then the research was explained to the child and then she or he was asked whether she or he wished to take part.
- v. If the child did wish to take part, then she or he and her or his parent/carer and were asked to give written **assent** and **consent** respectively. The assent and consent forms (Appendix N) separated out the various components of participation so it was made even more clear to children and their parent/carers what it was that they would be involving themselves in. Children and parents/carers were also given a sheet providing written information about the research and the contact details of support organizations (Appendix O).
- vi. Children and also parents/carers were informed that they could have the questionnaire read to them if they wished. The primary purpose in making this offer was to avoid the embarrassment of their having to ask for such assistance where they had any difficulties in terms of literacy.
- vii. Parents/carers were asked to complete the questionnaire in private to ensure the confidentiality of the information they were providing.

- viii. Parents/carers, and even more so children, were told that they could ask questions whilst they were completing their questionnaires.
- ix. Once the questionnaires were completed, parents/carers and children were asked about the experience to establish whether the process had raised any issues for them that the researchers might need to address.
- x. Following this, WP2 (child-centred interviews) was introduced and explained to the parents/carers, and children and they were asked whether they were prepared – in principle – to take part in this second stage of the research.

10.4 Ethical issues, responses and dilemmas

Issues

As indicated earlier, two of our major concerns in terms of ethics related to the possible receipt of, and subsequent response to, reports involving either a) child protection or b) prison security. We have, thus far, not received any such reports, nor have we become aware of such concerns through any other means.

The over-arching goal of a research study, in terms of ethics, is that it does not cause harm to participants (Hardwick and Worsley, 2011). The fieldworkers have not experienced any instances where it is possible to say that the research caused **harm** to participants. There has, though, been a small number of instances where fieldwork staff have been concerned that the research **may** have had some adverse or undesirable – albeit less severe - impact upon research participants. Where this occurred, then this was especially likely in WP2 – *Child-centred interviews*. WP2 is specifically designed to provide children, and their non-imprisoned and imprisoned parents/carers, with a substantial opportunity to reflect upon, and express, their views concerning parental/carer imprisonment and their lives more generally. The adverse or undesirable impacts that may have occurred, in both WP1 and WP2, are as follows:

- i. Participants experiencing particular emotional difficulty in answering certain types of questions. The one question which some non-imprisoned parents/carers seemed to find especially difficult was that concerning the nature of the charge for which the child's parent/carer was in prison. One question which some children found difficult was that concerning the effect that their parent/carer's imprisonment had had upon them.
- ii. Some non-imprisoned parents/carers and children became visibly upset during the course of their WP2 interviews.
- iii. During the course of WP1 and even more so WP2, fieldworkers encountered some non-imprisoned parents/carers and/or their children who had quite acute needs that weren't being met. Some of these families were in touch with support agencies but this intervention did not appear to be sufficient.
- iv. The fieldworkers made considerable efforts to inform and empower parents/carers, and even more so children, about the research and in particular about their right to control it, for example, refusing to answer certain questions and terminating their involvement in the research if they so chose. However, the fieldworkers were aware of the power dynamics that might exist between themselves and family members, and especially children, whereby they [the family members] might feel hesitant about exercising this right.

- v. What was both an issue and a dilemma in the research with family members was that we were asking them some questions, both in WP1 (questionnaire survey) and WP2 (interviews), that were quite sensitive but we were doing this as strangers to the family members, and without having built up any rapport or trust with them.

Responses

The fieldwork staff are utilizing a range of measures in response to the above situations; the main ones of which are as follows:

- i. It is sometimes reiterated to participants that they should feel free not to answer any questions they do not wish to answer and also that they can withdraw from the research at any point they wish.
- ii. We explain to children that they can, if they wish, during their WP2 interview, be accompanied by their (non-imprisoned) parent/carer.
- iii. All families are provided with the contact details of major support organizations. Fieldworkers would, if they felt it appropriate, emphasise to families the potential benefit of their contacting these organizations. Fieldworkers sometimes also advised families to contact other organizations where it was felt a particular organization offered support relevant to a specific need that that family might have.
- iv. In an effort to address the issue of families who appear to need support, fieldworkers – in an effort to gain advice on ways forward - sometimes discuss (on an anonymous basis) the family with: their co-workers or more senior colleagues on the COPING project; colleagues within their institution but outside the COPING project; or with workers in relevant support organizations.
- v. If fieldworkers notice that a given question is causing distress or if they believe that a given question may cause distress, then they are free to cease asking this question or not ask it in the first place. (This applies primarily to the WP2 interview schedule but it also applies to the WP1 questionnaire where this is read out to a participant.)
- vi. A small amount of WP1 and much of the work in WP2 is conducted in family homes. In the interests of their personal safety, female fieldworkers do not attend family homes on their own but go with a colleague (female or male).
- vii. Some of the fieldworkers have, in seeking to provide advice to families about helping organizations, been able to draw upon and utilize their enhanced knowledge of available support agencies that they have acquired through being involved in WP4 (*Mapping of interventions*).
- viii. Researchers have been aware about the demanding nature of the in-depth WP2 interviews for all research participants, particularly children and young people. The informed consent process has been constructed to make sure that research participants appreciate the difficult subject matter being explored. This has been tempered by keeping a rounded emphasis on all aspects of research participants' lives. Where participants, particularly children and young people, have shown signs of distress during interview, researchers have dealt with this sensitively, reminding participants that they do not have to answer specific questions if they prefer not to.
- ix. Researchers have mainly not had opportunities to meet participants before interviews took place. This has assured researchers' independence, but has meant that participants have

been dealing with strangers. In a few cases researchers had met participants prior to interviews, for example at family days held in prisons and this proved beneficial.

Dilemmas

- i. We explain to children that they can be accompanied by their parent/carer in their WP2 interview if they wish. We have made these offers in the belief that some children might be reassured and less anxious if they have their parent/carer with them. However, while such an arrangement might appeal to children, it does have drawbacks in that the privacy of the child's information may be compromised and they may experience greater unease in articulating certain information in the presence of their parent/carer.
- ii. When fieldworkers encountered families who were in need, they often felt the urge to help families, as indicated above, either by encouraging them to seek help from agencies – either ones they already knew of, the ones we recommended as a matter of course or the more specific ones they were advised to contact. However, in encouraging families to obtain help, fieldworkers had to maintain a delicate balance in that they could not appear to be counseling families to take a certain course of action – given that this was not the purpose of the research and they were not qualified for this role.
- iii. Fieldworkers sometimes felt there was pressing need for a family to receive support from a helping agency but also believed that the parent/carer was unlikely to initiate this. As explained above, fieldworkers did sometimes seek advice, about such families, from support agencies - although the family was not identified. However, these approaches would not, in and of themselves, lead to support being provided to the family. Fieldworkers felt that the only way in which a family might receive professional support would be if they made a referral to a support agency. They did not, though, have the parents/carer's consent to do this, so the family might remain unsupported.
- iv. As explained above, the researchers in the UK had always intended to reimburse families for their time and effort for taking part in WP2. However, as WP1 progressed, it became clear that family members were also expending considerable time and effort in taking part in WP1. This was particularly the case if more than one child from a family was taking part, whereby the non-imprisoned parent/carer would have to complete a number of questionnaires. As a result, we resolved to also reimburse family members taking part in part in WP1 (each of whom received a £10 (GBP) voucher (approximately €12)). Whilst the research group came to feel that it was wholly appropriate, and indeed only ethical, to reimburse family members for the time and effort they had invested in the COPING research, they were also mindful of the fact that they did not want the reimbursement to act as an inducement or bribe to take part in the research. This may have been an especially high risk among the poorer families in the study – of whom there were many.

11. WP1 - Identification of cohorts of children

WP1 (*Identification of suitable cohorts of children*) incorporate a large majority of children who will take part in the COPING research. In addition, WP1 is the first point at which children engage with the study. For these reasons, a considerable amount of effort was invested in the design of the questionnaire that children are being asked to complete in WP1 – the intention being that this would reduce the risk of their experiencing any adverse reaction to taking part in this stage of the research. These measures are as follows:

- i. An ordering of questions such that the questionnaire began with quite routine questions (on socio-demographic characteristics), then moved on to increasingly sensitive questions, but

concluded with questions on the child's aspirations for the future, which they might find quite uplifting.

- ii. Use of simple language and concepts so that children would readily understand what was being asked of them.
- iii. Most answers in the form of tick boxes so children had to engage in the minimal amount of writing
- iv. The use of a very clear layout, with some graphics, to aid children's interpretation of the questionnaire.
- v. We also opted against asking children about their criminality, for as valuable as this information might have been (Murray and Farrington, 2005), we did not want to run the risk of adding to any stigma that these children might already be experiencing as a result of their parent/carer being in prison.

12. WP2 - In-depth interviews with children and young people, non-imprisoned and imprisoned parents/carers

The target for WP2 has been for each country to achieve interviews with 40 families. Each WP2 case aims to include an interview with a child or young person; an interview with their non-imprisoned parent/carer; and wherever possible, an interview with the imprisoned parent/carer. Detailed guides have been produced for each of these, and translated into the relevant languages. A number of ethical issues are dealt with in the guidance for these interviews. The guides stress the confidentiality of whatever research participants say, constrained only by the duty of the researcher to pass on to the relevant authorities information indicating that children or adults have been harmed, or information that could jeopardise prison security. Participants are reassured that names and identifying details will be anonymised in research reports; but equally that their point of view will be accurately reflected. All participants are informed about their right not to answer any question, if they prefer not to, without being asked reasons for this; and about their right to terminate the interview at any point, if they wish to do so. Consent procedures for all participants include the right to give or withhold consent for interview to be recorded.

Research participants can be given copies of the interview guide. If any participant requests a copy of the transcript of their interview, they are advised that this would need to be considered carefully. Issues for consideration include: whether there could possibly be any adverse repercussions for the participant if the transcript was seen by a third party; and how the transcript could be safely and securely delivered to the participant – again, without being seen by a third party.

The interview guides refer to the opportunity for families to receive a voucher (UK value £25 (GBP), or €30). This was built into the Description of Work for WP2. It was known that the interviews would make substantial demands on research participants and it seemed ethically sound that research participants' contributions should be acknowledged in this way.

The interview guides recognise the potential impact of family violence or issues of abuse within the family, on the research process. If aspects of the parent/carer's imprisonment are regarded as 'secret' or not shared openly with the child, this also will impact on the research. Additional points are covered in the three separate interview guides.

The **child centered interview guide** emphasises the importance of starting 'where the child is' and going at the child's pace. The guide stresses the right of a child or young person to be accompanied during the interview by a person of their choice. It acknowledges that the presence of a parent or adult may make an impact on the information provided by the child or young person. It was decided that the child's right to be accompanied, and supported as necessary, was more important than the principle of the child being able to speak independently from adult or parental influence. Non-

imprisoned parents/carers are advised of their right to be accompanied by a person of their choice. It is not expected that this person would be a child.

The **parent/carer guide** states that the views of the non-imprisoned parent/carer and the child should be obtained prior to the interview with the imprisoned parent/carer being arranged. This is to ensure that any adverse aspects of the relationship between the imprisoned parent/carer and the child or young person can be taken into account before the interview with the imprisoned parent/carer goes ahead.

The **guide for the imprisoned parent/carer** stresses the importance of their being given a clear voice in the COPING Research. The responsibility of the imprisoned parent for addressing issues caused by his/her incarceration are emphasised. The guide stresses that if the interview with the imprisoned parent could conceivably cause harm to the child or children involved, then it should not go ahead.

Comment

The safeguards and opportunities built into the WP2 interviews seem to have worked well. Several children interviewed have declined to answer specific questions, for example about more difficult aspects of relationships with parents. Being given this clear right has enabled them to move on to participate in other parts of the interview. One child asked for an interview to be terminated but indicated that he might be willing to resume the interview at a later date.

Unsurprisingly, a number of families have had high levels of need. Where appropriate, families have been advised about appropriate support agencies. The researcher's role is limited and has to be kept separate from ongoing therapeutic support provided by helping agencies.

13. WP3 – stakeholder and caregivers consultation

13.1 Background

WP3, even after the revised timeline agreed at the kick-off meeting in Huddersfield in January 2010, is due to begin and complete later than the other information-gathering WPs (WP1, WP2 and WP4). As a result, some of the ethical processes undertaken for other WPs, such as obtaining ethical consent from academic or prison authorities, have been completed and so are not separately needed for WP3. Moreover, because WP3 field research is yet to substantively begin, certain ethical issues may have yet to become apparent. However, the basis of the research, in the form of general and specific guides to conducting the consultations, provides a strong grounding for ensuring the research is carried out ethically.

13.2 Obtaining ethical approval

Ethical approval was sought in the four core countries to conduct the COPING research in general, rather than for specific WPs. This means that additional approval is not required for WP3. Moreover, the safeguards put forward by COPING partners when applying for ethical approval appear appropriate to ensure that there is a robust ethical framework in place for WP3. While the stakeholder consultations involve human subjects and (therefore) need to be conducted in an ethical manner, the stakeholders not already consulted for WP1 or WP2 are expected to consist largely or wholly of non-vulnerable adults, meaning that there are fewer protection issues to be aware of. For research outside the four core countries, the same ethical standards will apply, even though the information gathered will likely be less detailed or comprehensive. Because of time and resource constraints, COPING partners may be unable to consult all stakeholder groups (particularly prison-based ones in countries requiring additional ethical approval for such research), but will not proceed anywhere without obtaining ethical approval.

13.3. Ethical procedures

COPING partners have been given, and have been able to consult on, guides for conducting stakeholder consultations, including general guidance and guides for each specific stakeholder group. These guides include details of information to give to potential research participants (including suggestions on how this can be made accessible and user-friendly), how to ensure that prior, free and informed consent is given, and how to facilitate follow-up by research participants if they have any concerns or queries.

13.4 Review ethical practices of stakeholders (Task 9.5)

To facilitate this Task, a question has been inserted into the interview schedule for each stakeholder group, following discussions between some COPING researchers. This question does not ask directly about the ethical practices of stakeholders, as it was felt many of the stakeholders would be non-specialists in this area and unable to provide satisfactory answers. Instead, the following question was inserted into each interview schedule:

- When should children be involved in research like this?
- Supplementary questions: Is it important for researchers to hear about what children have to say about the impact of prison? Why/why not? What are the benefits of including children in this research? What things need to be in place to make it okay for children to participate? Do you have any experience of children being in this kind of research? Can you tell us about it/give details?

The following question was inserted into each focus group interview schedule:

- When should children be involved in research like this?
- Prompts: Is it important for researchers to hear about what children have to say about the impact of prison? Why/why not? What are the benefits of including children in this research? What things need to be in place to make it okay for children to participate? Do you have any experience of children being in this kind of research? Can you tell us about it/give details?

It is hoped that such questions will elicit the responses needed to adequately review the ethical practices of stakeholders, particularly in relation to child-centred research. As the WP3 consultations, through which stakeholders are consulted, are only just beginning, outcomes for this Task are not yet complete.

14. WP4 – Mapping of Interventions

With regards to WP4, there has, as yet, not been any obvious or direct ethical implications. We have contacted prisons, community-based specialised and non-specialised services, and mental health services for children and young people to request factual information about the interventions they offer. Clearly this requires some degree of time and effort from the respondents which might have a negative impact on the time they have available to spend with prisoners/families/children. However, it is difficult for us to determine what the precise effects are. One important fact to bear in mind, at least in the UK, is that although government ministries and prison authorities may approve research, individual prison and prison governors are not obliged to comply with any requests for information. This is at the discretion of individual establishments. Presumably, if they feel it will have a negative impact on service delivery, then they will choose not to participate.

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Appendix A – Ethical Protocol



COPING

**CHILDREN OF PRISONERS, INTERVENTIONS &
MITIGATIONS TO STRENGTHEN MENTAL
HEALTH**

WP9

Ethical Protocol

This Ethical Protocol describes the ethical procedures by which the COPING study will be conducted.

The Protocol uses the following format: first, it describes the ethical procedures in general terms, and then it describes whether there are any differences from this general plan in particular countries.

The main purpose of this Protocol is to serve as a single authoritative source as to the ethical procedures by which the research is to be conducted in order that it meets the ethical requirements of the country in which the research is being conducted.

Any differences, in ethical procedures, between countries, are likely to increase once the fieldwork begins and partners have to take decisions as to how to respond to particular issues that have arisen in their country. Once such a decision has been taken, it will be recorded (on an on-going basis) in this Protocol and all other partners should consider whether they should follow the same procedures in their country if the same situation arises. This Protocol will, therefore, also act as a record of all decisions that have been taken.

This Protocol will also be valuable when we write up our findings, as it will provide a definitive source regarding ethical procedures both overall and in particular countries.

Once the fieldwork starts and partners begin making decisions as to how particular situations should be responded to, a system will need to exist for disseminating and recording these decisions. I would suggest that all such decisions are sent to me (Bernard Gallagher) for discussion, before being disseminated to all other partners and eventually recorded in this Protocol.

Dr. Bernard Gallagher
Leader, WP9
University of Huddersfield

10th Sept. 2010

1. Permission and approval

1.1. Permission

Permission and/or approval (where applicable) will be sought from all relevant organisations for access to individuals whom we wish to take part in the research. This will consist, in the main, of prison-related agencies and/or government ministries, for access to prisoners and prison staff. It may also be necessary to obtain the permission/approval of these organisations in seeking to recruit parents/carers and children, and carry out research with them, on or near prison premises, in the course of their visits to prison. It may also be necessary to seek the permission and/or approval of other organisations, or their representatives, in order to access other individuals whom we wish to take part in this research. This will mainly consist of social services departments (social workers, residential social workers foster parents and children in state care) and NGOs. (The first of these may also require applications to be made to in-house ethical committees.)

Romania

Colleagues in Romani require (and have received) approval from the National Agency for Supervision and Protection of Personal Data.

2. Consent

2.1 Consent

Researchers will obtain the consent of all individuals for their **own** participation in the research. This includes children, non-imprisoned parents/carers, imprisoned parents/carers, prison officers, social workers, residential social workers, NGO staff and foster parents. (The EU does, I believe, refer to 'consent' in the case of children as 'assent', the implication being that they cannot consent in their own right to take part in research without their parent/carer's consent.)

2.2. Parental/carer consent

It is hoped that only the consent of the non-imprisoned parent/carer will be required for the child to take part in this study. However, these parents/carers will be asked as to whether they believe the consent should also be sought of the imprisoned parent/carer to the child taking part in the survey.

Romania

Consent will be obtained first from the imprisoned parent/carer. If he or she consents, then consent will be sought from the non-imprisoned parent/carer.

Sweden

*In general, researchers in Sweden are required, by their ethics committee, to obtain the consent of both parents/carers (i.e. the non-imprisoned **and** the imprisoned parent/carer) for children 14 years of age or younger to take part in the research. (This is, however, for the imprisoned parent/carer an **opt-out** scheme i.e. if the imprisoned parent/carer does **not** wish his or her child to take part in the research, he or she must reply to this effect. If there is no reply, this is taken as consent. If there is one parent who is the sole holder of custody/with sole parental responsibility, only his or her consent is required. There are additional rules for children in more specific situation, for example, children in the care of the state. Parental/carer consent is not required if the child is 15 years or older.*

2.3 Informed consent

All individuals (and organisations) who are approached to take part in the research will be fully informed as to the nature of the research and what their participation would involve. This is to ensure that their decision to participate is taken on a fully informed basis. (The only exception to this may arise in relation to whether or not children are informed that this is a study into children whose parents/carers are in prison or whether they are told it is a study into children whose parents/carers are "away".)

2.4 Information sheets

All participants will be given an information sheet, to keep, that fully describes the nature of the research and what their participation would involve (subject to the above proviso concerning parents/carers being “in prison”).

2.5 Signed consent

All participants who agree to take part in the research will be asked to complete and sign a consent form. They should be informed, though, that it is their decision as to whether they complete this form and in particular whether they provide their name.

2.6 Assurances

Individuals approached to take part in the research, and in particular children, non-imprisoned and imprisoned parents/carers, will be given the following additional assurances, prior to their being asked to take part in the research:

- That they do not have to take part in the research
- That they can refuse to answer any questions if they wish
- They can decide to withdraw from the research if they wish
- That none of the above decisions would have any negative consequences, especially for the imprisoned parent/carer

3. Confidentiality

3.1 Confidentiality

All participants in the research will be informed that all the information they provide to the research - with two exceptions - will be treated in the strictest confidence. These two exceptions are as follows:

- The first is where they indicate that a child (a person less than 18 years of age) is at risk. They will be informed that should such information arise then this might have to be passed to an appropriate authority.
- The second is where they indicate there is a threat to prison security. They would again be informed that should such information arise then this might have to be passed to an appropriate authority.

4. Anonymity

4.1 Anonymity

All individuals and organisations will not be identified, nor will they be identifiable, in any report (written verbal or other) emanating from this study. If names are used in any report emanating from the research, then these would be pseudonyms. If necessary, details of ‘cases’ would be altered in such reports (without changing the substantive nature of that case) in order to ensure anonymity.

4.2 WP1 (survey) anonymity

There is a specific intention, within COPING, to maximise the extent of anonymity surrounding WP1 (survey). The reason for this is that children and non-imprisoned parents/carers will be approached by relative - if not complete - strangers, in a setting in which they may feel quite vulnerable and asked quite personal questions. This increased anonymity is considered essential in terms of increasing the likelihood of children and parents/carers: a) taking part in the survey; and b) providing valid information.

5. Support

Participant support

All individuals taking part in the research will be provided with contact information for relevant organisations in case they need support as a result of any issues that have arisen during the course of their participation in the research. Participants will also be provided with the (office) contact details of the academics and NGO staff carrying out the fieldwork in case they wish to discuss any issues with them.

6. Research staff

6.1 Training

All researchers involved in this project will be given training on the ethical procedures that apply to this research.

6.2 Data protection

All research staff will be aware, or will be made aware, of data protection requirements concerning, for example, data collection, transfer, use and storage.

6.3 Police or related checks

All research staff who are to have contact with children in this study will first be subject to police checks, or their equivalent, to ensure that there are not any known reasons as to why they should not have contact to children (where applicable).

7. External scrutiny

7.1 Ethics committees

An application will be made (where appropriate) for ethical approval for the research to be carried out in each of the four main countries that are in COPING.

Romania

Colleagues in Romania do not have to submit the research proposals to an ethics committee but they will be following the ethical procedures described in this and earlier COPING documents.

7.2 Risk analysis

A formal risk analysis exercise will be undertaken in each country (where applicable) before commencement of fieldwork to ensure that safeguards to children are maximised and risks to researchers are minimised.

8. Updating

8.1 Ethical Protocol

It is possible that issues may arise during the course of the fieldwork that have implications in terms of ethical procedures. If this does occur, then these issues and how they should be resolved will be discussed with the leader of this work package (WP9, Ethical Management). Once a decision has been taken, it will be recorded in a revised draft of the Ethical Procedures, which will then be circulated to all COPING members

Appendix B – Ethical Management Implementation Plan



COPING: Children of Prisoners, Interventions & Mitigations to Strengthen Mental Health

Work Package 9 (WP9) Ethical Management - Detailed Implementation Plans (DRAFT)

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Introduction

The following comprises the detailed plans by which I believe WP9 (Ethical Management) should be carried out. These are draft plans only and I welcome feedback as to whether these plans should be amended or added to.

Summary

It is anticipated that all of the academic institutions and some, if not all, of the country NGOs will need to obtain ethical approval in order to take part in the research. The European Commission requires that it is satisfied, regarding ethical procedures, before the research begins. I (Dr. Bernard Gallagher) have responsibility for this work package (WP9). I intend to work with all consortium members and other relevant parties to ensure that the proposed ethical procedures for this research will be to the satisfaction of relevant ethics committees in each participating country and the European Commission. These procedures will be contained with a detailed Ethical Protocol. The other key elements of this process are, as I see them, as follows: the setting up of an Ethics Group, ensuring ethical management in each country, the carrying out of police checks on all researchers having contact with children, the provision of training, the carrying out of a risk analysis, and the provision of support to children and parents/carers.

1. Detailed tasks to be undertaken

1.1 Ethics group

An Ethics Group will need to be set up to oversee all of the activities under WP9 (Ethical Management). The precise membership of this group will need to be determined.

1.2 Ethical management

One person will need to be identified to take lead responsibility for ethical management in each country.

1.3 Ethical protocol

A draft Ethical Protocol will need to be drafted and circulated to all members of the consortium and other relevant parties. Feedback on the draft ethical protocol will need to be provided and collated. The draft will then need to be revised, and a final version produced and circulated.

1.4 Ethical approval

It is anticipated that each of the academic institutions intending to take part in the research will need to obtain approval, for their participation, from their respective ethics committee. It is possible that some (if not all) of the country NGOs will need ethics approval before taking part in the research.

1.5 European Commission

COPING will need to satisfy the European Commission of its ethical procedures before the research can begin. This will include all organisations providing evidence that they have received ethical approval, where applicable.

1.6 Police checks

Any researcher who is due to have direct contact with children will need to be subject to police checks in their respective countries (where possible). This will establish whether this agency has information that indicates that it would be inappropriate for any researcher to have direct contact with children.

1.7 Training

Training on ethical procedures will need to be provided to all individuals who are directly involved in carrying out data collection with human subjects and those responsible for supervising them. This will need to include training on how to respond to children who are distressed and how to respond to reports of situations where children may be at risk. The content of the training programme will need to be decided upon, as will the precise list of recipients who are to receive such training.

1.8 Risk analysis

A full risk analysis will need to be undertaken before commencement of data collection to ensure that safeguards to children are maximised and risks to researchers are minimised. This will entail the development and circulation of a draft risk analysis document. Feedback will then need to be provided on this document, after which it will be revised, and a final version produced and circulated.

1.9 Support

It will be necessary to set up systems for supporting children and parents/carers who want support after taking part in the research.

2. Consortium member involvement

2.1 Ethics group

It is hoped that the ethics group will be made up of a wide range of representatives from among the following: academic institutions (DRES, HUD, KI & UAIC), country NGOs (ASA, POPS, RKS and TRE), international NGOs (Eurochips - ECH and the Quaker United Nations Office - QUNO), and groups identified on the COPING organisational chart (International Advisory Group - IAG, Scientific Technical Board - STB, Management Team - MT, Child Centred Group - CCG and country groups - CGs.) Members of the Ethics Group will advise on most aspects of the ethical procedures of the research and in particular ethical management, drafting the Ethical Protocol, seeking ethical approval, training, risk analysis and support to children.

2.2 Ethical management

Each academic institution (DRES, HUD, KI & UAIC)-country NGO (ASA, POPS, RKS and TRE) partnership will need to nominate one person to have lead responsibility for ethical management in their country. This person will need to ensure that all researchers having direct contact with human subjects, and all those persons supervising them, abide by the Ethical Protocol (see below). A system will need to be established to ensure there is regular supervision and monitoring of researchers to guarantee that they abide by the Ethical Protocol.

2.3 Ethical protocol

A draft Ethical Protocol will be sent to all members of the consortium, plus the international NGOs (ECH and QUNO), and groups identified on the COPING organisational chart (IAG, STB, MT, CCG and CGs.), along possibly with other relevant groups, such as the TEDDY (Task-force in Europe for Drug Development for the Young) 'Network of Excellence'. This will give all of these organisations an opportunity to provide feedback on the Ethical Protocol. It is expected that all of the academic institutions (DRES, HUD, KI & UAIC) and country NGOs will provide feedback (ASA, POPS, RKS and TRE). It will be especially important for the leaders of WPs 1-4 - all of which involve research with human subjects - to provide feedback, as the Ethical Protocol will have a major bearing upon these work packages. It is hoped that the international NGOs and the groups identified on the COPING organisational chart will provide feedback on the Ethical Protocol. All groups and individuals involved, in any way, with the COPING research will have carry out their work according to the Ethical Protocol.

2.4 Ethical approval

It is anticipated that all of the academic institutions (DRES, HUD, KI & UAIC) and some of the country NGOs (ASA, POPS, RKS & TRE) possibly will have to obtain ethical approval from their respective ethics committees before taking part in the research. It is likely these academic institutions and country NGOs (where applicable) will need to provide a number of documents - either in draft or final version form - to their respective ethics committee in applying for approval. These are likely to include, among others, the following: questionnaires, interview schedules, consent and assent forms, and information sheets.

2.5 European Commission

It may be that where academic institutions (DRES, HUD, KI & UAIC) and country NGOs (ASA, POPS, RKS & TRE) require ethical approval, then they may have to provide evidence of having acquired this as part of COPING's bid to the European Commission for ethical clearance.

2.6 Police checks

All organisations whose employees are to have direct contact with children will have to apply for police checks on those employees. This is to ensure that this agency does not have information that indicates that it would be inappropriate for any of these individuals to have contact with children. It is likely that most, if not all, of these organisations will comprise the academic institutions (DRES, HUD, KI & UAIC) and country NGOs (ASA, POPS, RKS & TRE).

2.7 Training

Training on ethical procedures will be provided to all individuals who have direct contact with human subjects and all those persons who are responsible for supervising them. It is likely that most, if not all,

of these organisation will comprise the academic institutions (DRES, HUD, KI & UAIC) and country NGOs (ASA, POPS, RKS & TRE).

All academic institutions (DRES, HUD, KI & UAIC), country NGOs (ASA, POPS, RKS and TRE), international NGOs (ECH and QUNO) and groups listed on the COPING organisational chart (IAG, STB, EG, MT, CCG and CGs) will be given an opportunity to comment on a draft of the training programme.

2.8 Risk analysis

All academic institutions (DRES, HUD, KI & UAIC), country NGOs (ASA, POPS, RKS and TRE), international NGOs (ECH and QUNO) and groups listed on the COPING organisational chart (IAG, STB, EG, MT, CCG and CGs) will be provided with the opportunity to comment upon the draft risk analysis document. It is expected that all of the academic institutions and country NGOs will provide feedback. It will be especially important for these organisations, along with leaders of WPs 1-4, to provide feedback as they are likely to have the most knowledge concerning the risks involved in their particular country or work package. It is hoped that the international NGOs and (ECH and QUNO) and the groups identified on the COPING organisational chart (IAG, STB, EG, MT, CCG and CGs) will provide feedback on the draft risk analysis document. All groups and individuals involved, in any way, in the COPING research, will have to carry out their work in accordance with the risk analysis document.

2.9 Support

Academic institutions (DRES, HUD, KI & UAIC) and/or country NGOs (ASA, POPS, RKS and TRE) will have responsibility for identifying and organising sources of support to children and parents/carers who need this after taking part in the research, in their respective countries.

3. Task management

3.1 Ethics group

I will have the lead role in setting up the Ethics Group and it is possible that I will chair this group. It is hoped that this will enable efficient liaison between the Ethics Group and the rest of the COPING project. It is likely that much of the discussion within the Ethics Group will be by Skype conference calls and email, but there may also be occasional face-to-face meetings. The Ethics Group is likely to operate for the duration of the research project i.e. M01-M36.

3.2 Ethical management

I will, as work package leader, have overall responsibility for ethical management within the COPING project but I will be guided in this work by the Ethics Group. Each country will have a person with lead responsibility for ethical management. Most of my work will be with these lead persons, along with the WP leaders 1-9. Most of this communication will be by email. This work will last for the duration of the research project i.e. M01-M36.

3.3. Ethical protocol

I will, in conjunction with the Ethics Group, develop and circulate a draft Ethical Protocol. I will collate feedback and, based upon this, will revise the draft Ethical Protocol. I will then produce and develop the final version of the Ethical Protocol. Most, if not all, of this communication will be by email. This work will take place in M01-M03.

It is likely, during the course of the COPING research, that issues will arise that were not anticipated in the Ethical Protocol. Should such issues arise then these should be passed to the individual who has lead responsibility for ethical management in the country concerned, then to be passed on to me for discussion. It is likely that such issues will be straightforward to resolve but if they are not they will be passed to the Ethics Group for a final determination as to how they should be resolved. However such issues are resolved, any decision will be communicated to all members of COPING and allied organisations, by me and as soon as possible, with all Ethical Protocols being amended accordingly.

3.4 Ethical approval

It is yet to be decided as to whether ethical approval will be applied for en masse or whether each WP (1-4) will make applications independent of one another and at different points during the course of the research project. Whichever is the case, individuals who have lead responsibility for ethical management in a country will (with the support of their respective WP leader) have responsibility for providing all documents necessary for the application for ethical approval in that country (for example, research instruments, consent and assent forms, and information sheets).

I will have overall responsibility for ensuring that ethical approval is obtained in each country and that this is done on schedule. Most, if not all, of this work will be carried out by email. This work will be carried out in M01-M03.

3.5 European Commission

I will work closely with individuals who have lead responsibility for ethical management in each country to ensure that all the requirements of the European Commission, regarding ethical procedures, are met. I will have overall responsibility for collating all the information the European Commission requires in deciding whether to give ethical clearance to COPING. It is yet to be decided who will provide this information to the European Commission and how this will be done. Most, if not all of this work, will be carried out by email. This work will be carried out in M01-M04.

3.6 Police checks

The individual with lead responsibility for ethical management in each country will be responsible for ensuring that all organisations in that country, whose employees have direct contact with children, carry out police checks on those employees. I will have overall responsibility for ensuring that this is done. Most, if not all of this communication will be carried out by email. It is likely that this work will be carried out over most of the course of the research project as staff become appointed to work on different WPs: M01-M36.

3.7 Training

I will have responsibility for organising training on ethical procedures. This will include determining the content of this training and who should receive such training. I will be guided on this by the Ethics Group and the consultation exercise highlighted at 2.7. Most of the communication on this will be done by email. It is anticipated that the training will be provided in a single, face-to-face, group session. All of this work will be carried out from M01-M04.

3.8 Risk analysis

I will have responsibility for developing and circulating the draft risk analysis document. I will collate feedback and revise the draft document. I will then produce and circulate a final version of the risk analysis document. Either country leads for ethical management or WP leaders 1-4 will be responsible for ensuring that feedback on risk analysis is provided for each country. I will liaise with whichever persons have this responsibility. Most, if not all, of this communication will be by email. This work will be carried out in M01-M04.

3.9 Support

I will have overall responsibility for ensuring that there are systems of support set up for children and parents/carers in each country. Responsibility for this work in each country will rest either with whoever has lead responsibility for ethical management in a country or WP leaders 1-4. I will liaise with whichever persons have this responsibility. Most of this communication will be by email. It is likely that this work will last for the duration of the research project: M01-M36

4. Work breakdown structure

| | Activity | Key tasks to achieve activity | Who | Time line |
|----|---------------------|---|--|-----------------------|
| 1. | Ethics group | a. Decide upon membership of Ethics Group (EG) b. Set up Ethics Group c. Hold meeting of Ethics Group | Bernard Gallagher (BG), DRES, HUD, KI, UAIC, ASA, POPS, RKS, TRE, ECH, QUNO, IAG, STB, MT, CCG and CGs BG | M01 M01 M01-M36 |
| 2. | Ethical management | a. Identify one person in each country to assume responsibility for ethical management in that country b. Carry out ethical management of research | BG, DRES, HUD, KI, UAIC, ASA, POPS, RKS, TRE, BG, DRES, HUD, KI, UAIC, ASA, POPS, RKS, TRE | M01-M02 M01-M36 |
| 3. | Ethical Protocol | a. Develop and circulate draft Ethical Protocol b. Provide feedback c. Collate feedback and revise draft d. Produce and circulate final version e. Consider on-going amendments to Ethical Protocol | BG, EG BG, DRES, HUD, KI, UAIC, ASA, POPS, RKS, TRE, ECH, QUNO, IAG, STB, EG, MT, CCG and CGs BG BG BG, DRES, HUD, KI, UAIC, ASA, POPS, RKS, TRE, EG | M01-M03 M01-M36 |
| 4. | Ethical approval | a. Obtain for ethical approval | BG, DRES, HUD, KI, UAIC, ASA, POPS, RKS, TRE, | M01-M03 |
| 5. | European Commission | a. Meet requirements of European Commission for ethical clearance b. Provide information to European Commission in evidence of the above | BG, DRES, HUD, KI, UAIC, ASA, POPS, RKS, TRE, ECH, QUNO, IAG, EG, STB, MT, CCG and CGs BG, DRES, HUD, KI, UAIC, ASA, POPS, RKS, TRE, EG | M01-M04 |
| 6. | Police checks | a. Carry out police checks on all individuals having direct contact with children | BG, DRES, HUD, KI, UAIC, ASA, POPS, RKS, TRE, EG | M01-M36 |
| 7. | Training | a. Develop and circulate draft training programme b. Provide feedback c. Revise draft d. Produce and circulate final version | BG, EG DRES, HUD, KI, UAIC, ASA, POPS, RKS, TRE, ECH, QUNO, IAG, STB, EG, MT, CCG and CGs BG BG | M01-M04 |
| 8. | Risk analysis | a. Develop and circulate draft risk analysis document b. Provide feedback c. Revise draft d. Produce and circulate final draft | BG, EG DRES, HUD, KI, UAIC, ASA, POPS, RKS, TRE, ECH, QUNO, IAG, STB, EG, MT, CCG and CGs BG, EG BG, EG | M01-M04 |
| 9. | Support | a. Organise system of support to children and parents/carers | BG, EG, DRES, HUD, KI, UAIC, ASA, POPS, RKS, TRE | M01-M36 |

Appendix B2: Research Design Issues

1. Should we seek ethical consent from imprisoned parents/carers
2. What should we do if one parent/carer gives consent and the other does not?
3. What if a child assents to takes part in the research but a parent/carer does not give consent?
4. What if an imprisoned parent/carer discloses any type of unreported criminal offence?
5. Should we seek ethical approval en masse or for each WP separately?

Appendix C - WP9 Ethical Management Training Session

| | |
|--|---|
|  <p>Children of Prisoners, Interventions & Mitigations to Strengthen Mental Health</p> <p>Launch conference 20-21st Jan. 2010</p> <p>1</p> | <p>Introduction</p> <ul style="list-style-type: none">■ Dr. Bernard Gallagher■ Senior Research Fellow■ Centre for Applied Childhood Studies, University of Huddersfield■ Specialist subjects: child protection, children in state care and child welfare■ For example: international & internet CSA, stranger abuse and abduction, paedophile rings, therapeutic state care for CSA victims, young offenders <p>2</p> |
| <p>Ethics experience</p> <ul style="list-style-type: none">■ Concern with ethics throughout research career■ Served on Research Ethics Panel (School of Human and Health Sciences)■ Published <p>3</p> | <ul style="list-style-type: none">■ Work Package Leader – WP9■ Ethical Management <p>4</p> |
| <p>‘Aims’</p> <p>"make a presentation in which you outline a summary of the work you are responsible for and how you envisage its implementation"</p> <p>"this meeting is to initiate the planning and implementation process"</p> <ul style="list-style-type: none">- begin raising issues- building consensus <p>5</p> | <p>Methods</p> <ul style="list-style-type: none">■ Presentation■ Detailed implementation plans■ I'll take responsibility - to minimise your workload & maximise efficiency■ You can contribute as much - or as little (subject to certain minimum standards) – as you like <p>6</p> |

Notes

- Outline (based on documents and min. discussion)
- Personal interpretation
- Incomplete
- Imperfect
- Points – very welcome: now: → 3 years!
- Values (~ ethics)
- Country differences!
- Clarification, contest, add to, explore

- Apologies for mistakes in names, terms etc

7

WP9 Ethical Management – key elements

- | | |
|------------------------|------------------|
| 1. Ethics Group | 6. Police checks |
| 2. Ethical management | 7. Training |
| 3. Ethical protocol | 8. Risk analysis |
| 4. Ethical approval | 9. Support |
| 5. European Commission | |

8

1. Ethics group

- Guiding or advising ethical aspects of research and me
- All aspects of ethical management
- Representatives of range of organisations
- Email/virtual meetings/in person
- Entire course of project

9

2. Ethical management

- One person with lead responsibility for EM in each country
- My liaison with this person and/or WP leaders 1-4

10

3. Ethical Protocol

- Comprehensive document – all procedures by which COPING conducted, to ensure it is ethical (for example: consent, assent, information, disclosure, researcher safety, support
- Wide consultation!
- Foundation to EM!

11

4. Ethical approval

- All academic institutions (and some/all country NGOs?) require ethical approval before research
- Academic institution/NGO responsibility (including documents)
- Country lead/WP leader (1-4) oversight
- My oversight

12

5. European Commission

- EC must be satisfied of EM before research starts
- May include evidence of ethical approvals

13

6. Police checks

- All persons having direct contact with children: police checks
- Academic institution/country NGO responsibility
- Oversights
- Country differences?

14

7. Training

- Training on ethical procedures for all those involved in data collection & those supervising them
- Training programme – consultation
- Training programme – recipients?

15

8. Risk analysis

- Risk to participants? Response?
- Risk to researchers? Response?
- Risk analysis - document

16

9. Support

- Children
- Parents/carers
- Needs identified during course of research

17

Research Design

Issues?

1. Should we seek ethical consent from imprisoned parents/carers
2. What should we do if one parent/carer gives consent and the other does not?
3. What if a child assents to takes part in the research but a parent/carer does not give consent?
4. What if an imprisoned parent/carer discloses any type of unreported criminal offence?
5. Should we seek ethical approval en masse, or for each WP separately?

18

Appendix D – Registration in the National Register of Personal Data (Romania)



Asociația Alternative Sociale
Str. Cuza Vodă nr. 8A
Municipiul Iași
Județul Iași
Cod poștal 700036

În atenția:
Domnului Catalin LUCA, director executiv

Stimate domn,

Vă informăm că notificarea transmisă on-line de către operatorul Asociația Alternative Sociale a fost înregistrată la registratura generală a autorității de supraveghere sub nr. 11104 din 3 iunie 2010. Urmare a acestei notificări, precum și a remiterii primei pagini din formularul de notificare, semnată și ștampilată în 7 iunie 2010, precizăm următoarele:

Prelucrarea notificată, inclusiv transferul de date în state din Uniunea Europeană, a fost înscrisă în registrul de evidență a prelucrărilor de date cu caracter personal sub **nr. 16928**. Acest număr de înregistrare trebuie menționat, conform art. 24 alin. (2) din Legea nr. 677/2001, pe orice act prin care datele cu caracter personal sunt colectate, stocate sau dezvăluite, numai în cadrul prelucrării de date efectuate în scopul declarat.

Referitor la secțiunea VIII, menționăm că operatorul de date cu caracter personal are obligația de a furniza persoanelor vizate toate informațiile prevăzute la art. 12 din Legea nr. 677/2001, modificată și completată. Informarea trebuie să fie adecvată circumstanțelor specifice de prelucrare (respectiv modalității de prelucrare a datelor, suportului pe care datele sunt colectate, etc.) și se poate realiza în scris, prin intermediul documentelor prin care datele personale sunt colectate și/sau prin afișarea unei note informative la sediul operatorului sau pe pagina web, modalitatea „verbal” nefiind suficientă. În acest sens, vă informăm că operatorii au posibilitatea de a obține și adapta modele de note de informare din „Ghidul de completare a notificărilor”. Informațiile conținute de nota de informare trebuie corelate cu cele din formularul de notificare, cu privire la scopul prelucrării, categoriile de date prelucrate și destinatarii cărora le vor fi dezvăluite.

Secțiunile IX și X se completează cu datele cu caracter personal necesare realizării scopului prelucrării, în condițiile reglementate de art. 4 alin. (1) lit. c) din Legea nr. 677/2001, modificată și completată, potrivit cărora datele cu caracter personal destinate a face obiectul unei prelucrări trebuie să fie **adecvate, pertinente și neexcesive** prin raportare la scopul sau scopurile corelate în care sunt colectate și ulterior prelucrate. În acest sens, vă atragem atenția asupra prelucrării datelor cu caracter personal ale minorilor și menționăm că operațiunile de prelucrare a datelor cu caracter personal ale minorilor sunt susceptibile de a prezenta riscuri speciale pentru drepturile și libertățile lor, motiv pentru care este necesar ca operatorul să aibă în vedere asigurarea unei protecții eficiente a minorilor.

Menționăm că potrivit dispozițiilor art. 24 alin. (3) din Legea nr. 677/2001, modificată și completată, orice schimbare de natură să afecteze exactitatea informațiilor înregistrate, trebuie comunicată autorității de supraveghere în termen de 5 zile.

Datele dumneavoastră personale sunt prelucrate de Autoritatea Națională de Supraveghere a Prelucrării Datelor cu Caracter Personal, potrivit notificării nr. 2447, în conformitate cu Legea nr. 677/2001, în scopul îndeplinirii atribuțiilor legale de înregistrare a notificărilor și statistică. Datele pot fi dezvăluite unor terți în baza unui temei legal justificat. Vă puteți exercita drepturile de acces, de intervenție și de opoziție în condițiile prevăzute de Legea nr. 677/2001, printr-o cerere scrisă, semnată și datată, trimisă pe adresa autorității.

Completarea/modificarea notificării nr. 16928 ca urmare a apariției unor schimbări în activitatea operatorului și/sau la solicitarea autorității de supraveghere, se realizează prin modalitatea on-line, accesând adresa de internet a autorității, www.dataprotection.ro, secțiunea „Depune notificarea”, cu ajutorul numărului de notificare și a codului de înregistrare electronică a notificării primit pe e-mail la momentul transmiterii formularului on-line. După efectuarea on-line a completării/modificării notificării se va informa autoritatea de supraveghere, în cel mult 30 de zile, prin remiterea prin poștă a primei pagini a formularului de notificare, semnată și ștampilată, în original. În caz contrar, nu vor fi luate în considerare completările/modificările efectuate de operator, urmând ca notificarea să fie anulată din sistemul electronic de evidență. Atașat primei pagini, vă rugăm să ne transmiteți copia mesajului electronic primit din partea autorității de supraveghere intitulat „confirmare înregistrare document”, în care figurează numărul de înregistrare al formularului de notificare în Registrul General al instituției noastre.

În același timp menționăm că informațiile cuprinse în notificare, așa cum reiese din conținutul rubricii „Declarație” de pe prima pagină a formularului, sunt furnizate pe propria răspundere a operatorului, întreaga responsabilitate a exactității și corectitudinii informațiilor revenindu-i acestuia.

Totodată, vă aducem la cunoștință că de pe site-ul autorității de supraveghere aveți posibilitatea de a obține informații cu privire la obligațiile ce revin operatorilor în contextul prelucrării datelor cu caracter personal reglementate prin Legea nr. 677/2001, modificată și completată, precum și informații privind înființarea, organizarea și funcționarea Autorității Naționale de Supraveghere a Prelucrării Datelor cu Caracter Personal.

VIEPREȘEDINTE,

Prof. univ. dr. Florin NEGOIȚĂ



Appendix E – Research Authorisation (Romania)

I. Operatorul

| | | | | | |
|---|-------------------------------------|------------------------------------|--------------------------|---------------------------|-------------------------------------|
| Numele/Denumirea operatorului: ASOCIATIA ALTERNATIVE SOCIALE | | | | | |
| Adresa/sediul: IASI, STR. CUZA VODA NR. 8A | | | | | |
| Cod postal | 700036 | Tara | ROMANIA | Judetul | IS |
| Localitatea | IASI | Sectorul | | | |
| Tel: | +40332405476 | Fax: | | CIF: | |
| Email: office@alternativesociale.ro <small>(pe aceasta adresa se va primi confirmarea inregistrarii formularului in Registrul General al ANSPDCP)</small> | | | | | |
| Persoana fizica: | <input type="checkbox"/> | Persoana fizica autorizata: | <input type="checkbox"/> | Persoana juridica: | <input checked="" type="checkbox"/> |
| Sector public | <input type="checkbox"/> | Autoritate centrala | <input type="checkbox"/> | Autoritate locala | <input type="checkbox"/> |
| Sector privat | <input checked="" type="checkbox"/> | Altele | | | <input type="checkbox"/> |
| Membru al unei asociatii <small>(in sensul art. 28 din Legea nr. 677/2001):</small> _ | | | | | |

II. Reprezentantul operatorului situat intr-un stat tert

| | | | | | |
|--|--------------------------|------------------------------------|--------------------------|---------------------------|--------------------------|
| Numele/Denumirea reprezentantului: | | | | | |
| Adresa/sediul: | | | | | |
| Cod postal | | Tara | | Judetul | |
| Localitatea | | Sectorul | | | |
| Tel: | | Fax: | | CIF: | |
| E-mail: | | | | | |
| Persoana fizica: | <input type="checkbox"/> | Persoana fizica autorizata: | <input type="checkbox"/> | Persoana juridica: | <input type="checkbox"/> |
| Sector public | <input type="checkbox"/> | Autoritate centrala | <input type="checkbox"/> | Autoritate locala | <input type="checkbox"/> |
| Sector privat | <input type="checkbox"/> | Altele | | | <input type="checkbox"/> |
| Membru al unei asociatii <small>(in sensul art. 28 din Legea nr. 677/2001):</small> | | | | | |

IV. Scopul prelucrării

| | |
|--|---|
| 1 <input type="checkbox"/> resurse umane | 20 <input type="checkbox"/> servicii de consiliere legala si reprezentare in justitie |
| 2 <input type="checkbox"/> gestiune economico - financiara si administrativa | 21 <input type="checkbox"/> servicii financiare - bancare |
| 3 <input type="checkbox"/> selectie si plasare forta de munca | 22 <input type="checkbox"/> rapoarte de credit |
| 4 <input type="checkbox"/> reclama, marketing si publicitate | 23 <input type="checkbox"/> colectare debite/recuperare creante |
| 5 <input type="checkbox"/> servicii de sanatate | 24 <input type="checkbox"/> servicii de asigurari si reasigurari |
| 6 <input type="checkbox"/> educatie si cultura | 25 <input type="checkbox"/> tranzactii imobiliare |
| 7 <input type="checkbox"/> protectie si asistenta sociala | 26 <input type="checkbox"/> servicii hoteliere si de turism |
| 8 <input type="checkbox"/> urbanism si amenajarea teritoriului | 27 <input type="checkbox"/> monitorizarea/securitatea persoanelor, spatiilor si/sau bunurilor publice/private |
| 9 <input type="checkbox"/> fond funciar | 28 <input type="checkbox"/> servicii de comunicatii electronice |
| 10 <input type="checkbox"/> cadastru si publicitate imobiliara | 29 <input type="checkbox"/> constatarea si sanctionarea contravențiilor |
| 11 <input type="checkbox"/> taxe si impozite | 30 <input type="checkbox"/> prevenirea, cercetarea, reprimarea infractiunilor, mentinerea ordinii publice |
| 12 <input type="checkbox"/> evidenta populatiei si stare civila | 31 <input type="checkbox"/> alte activitati desfasurate in domeniul dreptului penal (precizati) |
| 13 <input type="checkbox"/> evidenta electorala | |
| 14 <input type="checkbox"/> emitere autorizatii/licente | |
| 15 <input type="checkbox"/> statistica | |
| 16 <input checked="" type="checkbox"/> cercetare stiintifica | 32 <input type="checkbox"/> alte scopuri (precizati) |
| 17 <input type="checkbox"/> administrarea justitiei | |
| 18 <input type="checkbox"/> activitate notariala | |
| 19 <input type="checkbox"/> activitate politica | |

V. Temeiul legal al prelucrării*

Precizați actele normative specifice domeniului de activitate:

* *Atenție! Se completează numai pentru Notificarea specială.*

VI. Categoriile de persoane vizate

- | | |
|--|--|
| 1 <input type="checkbox"/> clienți/potențiali clienți | 14 <input type="checkbox"/> pasageri |
| 2 <input type="checkbox"/> consumatori/potențiali consumatori | 15 <input type="checkbox"/> membri |
| 3 <input type="checkbox"/> debitori | 16 <input type="checkbox"/> titulari ai drepturilor reale |
| 4 <input type="checkbox"/> pacienți | 17 <input type="checkbox"/> electori/sustinători ai partidelor politice |
| 5 <input type="checkbox"/> cadre medico-sanitare | 18 <input type="checkbox"/> subiecți ai unei cercetări, publicatii sau emisiuni radio-tv |
| 6 <input type="checkbox"/> farmaciști | 19 <input type="checkbox"/> justitabili |
| 7 <input type="checkbox"/> cadre didactice | 20 <input type="checkbox"/> contribuabili |
| 8 <input type="checkbox"/> studenți | 21 <input type="checkbox"/> abonati |
| 9 <input checked="" type="checkbox"/> minori | 22 <input type="checkbox"/> angajați |
| 10 <input type="checkbox"/> beneficiari ai serviciilor de protecție și asistență socială | 23 <input type="checkbox"/> membrii familiei persoanei vizate |
| 11 <input checked="" type="checkbox"/> beneficiari ai serviciilor publice locale | 24 <input type="checkbox"/> altele (precizați) |
| 12 <input type="checkbox"/> beneficiari ai asigurărilor | |
| 13 <input type="checkbox"/> vizitatori | |

VII. Motivele care justifică aplicarea prevederilor art. 11, art. 12 alin. (3) sau (4) ori ale art. 13 alin. (5) sau (6) din Legea nr. 677/2001

scopuri statistice cercetare științifică cercetare istorică altele

VIII. Modul în care persoanele vizate sunt informate asupra drepturilor lor

în scris* prin afișare la sediu* verbal exceptat prin lege**

prin afișare pe pagina web***

* Se atașează modelul noticii de informare

** Potrivit art. 12 alin. (3) sau (4) din Legea nr. 677/2001.

*** Se menționează adresa URL a paginii WEB.

IX. Categoriile de date prelucrate

- | | |
|---|---|
| 1 <input checked="" type="checkbox"/> numele si prenumele | 16 <input type="checkbox"/> profesie |
| 2 <input checked="" type="checkbox"/> numele si prenumele membrilor de familie | 17 <input type="checkbox"/> loc de munca |
| 3 <input checked="" type="checkbox"/> sexul | 18 <input type="checkbox"/> formare profesionala - diplome - studii |
| 4 <input type="checkbox"/> porecla/pseudonimul | 19 <input checked="" type="checkbox"/> situatie familiala |
| 5 <input checked="" type="checkbox"/> data si locul nasterii | 20 <input type="checkbox"/> situatie militara |
| 6 <input type="checkbox"/> cetatenia | 21 <input type="checkbox"/> situatie economica si financiara |
| 7 <input type="checkbox"/> semnatura | 22 <input type="checkbox"/> date privind bunurile detinute |
| 8 <input type="checkbox"/> date din actele de stare civila | 23 <input type="checkbox"/> date bancare |
| 9 <input type="checkbox"/> date din permisul de conducere/certificatul de inmatriculare | 24 <input checked="" type="checkbox"/> obisnuinte/preferinte/comportament |
| 10 <input type="checkbox"/> nr. dosarului de pensie | 25 <input type="checkbox"/> imagine |
| 11 <input type="checkbox"/> nr. asigurarii sociale/asigurarii de sanatate | 26 <input type="checkbox"/> voce |
| 12 <input type="checkbox"/> caracteristici fizice/antropometrice | 27 <input type="checkbox"/> date de geolocalizare/date de trafic |
| 13 <input type="checkbox"/> telefon/fax | 28 <input type="checkbox"/> altele(precizati): |
| 14 <input checked="" type="checkbox"/> adresa (domiciliu/resedinta) | |
| 15 <input type="checkbox"/> e-mail | |

X. Categoriile de date cu caracter special

- | | |
|---|--|
| 1 <input type="checkbox"/> date cu caracter personal care denota originea rasiala a persoanelor vizate | 11 <input type="checkbox"/> date privind starea de sanatate |
| 2 <input type="checkbox"/> date cu caracter personal care denota originea etnica a persoanelor vizate | 12 <input type="checkbox"/> date genetice |
| 3 <input type="checkbox"/> date cu caracter personal care denota convingerile politice ale persoanelor vizate | 13 <input type="checkbox"/> datele biometrice |
| 4 <input type="checkbox"/> date cu caracter personal care denota convingerile filozofice ale persoanelor vizate | 14 <input type="checkbox"/> date privind viata sexuala |
| 5 <input type="checkbox"/> date cu caracter personal care denota convingerile religioase ale persoanelor vizate | 15 <input type="checkbox"/> date privind savarsirea de infractiuni |
| 6 <input type="checkbox"/> date cu caracter personal care denota apartenenta sindicala a persoanelor vizate | 16 <input type="checkbox"/> date privind condamnari penale/masuri de siguranta |
| 7 <input type="checkbox"/> date cu caracter personal care denota apartenenta la un partid politic a persoanelor vizate | 17 <input type="checkbox"/> date privind sanctiuni disciplinare |
| 8 <input type="checkbox"/> date cu caracter personal care denota apartenenta la o organizatie religioasa a persoanelor vizate | 18 <input type="checkbox"/> date privind sanctiuni contravenionale |
| 9 <input type="checkbox"/> codul numeric personal | 19 <input type="checkbox"/> date privind cazierul judiciar |
| 10 <input type="checkbox"/> seria si numarul actului de identitate/pasaportului | 20 <input type="checkbox"/> altcic(precizati): |

XI. Categoriile de destinatari

| | | | | | |
|----|-------------------------------------|--|----|--------------------------|---|
| 1 | <input type="checkbox"/> | persoana vizata | 13 | <input type="checkbox"/> | societati de asigurare si reasigurare |
| 2 | <input type="checkbox"/> | reprezentantii legali ai persoanei vizate | 14 | <input type="checkbox"/> | organizatii profesionale |
| 3 | <input type="checkbox"/> | imputemicitul operatorului | 15 | <input type="checkbox"/> | organizatii politice |
| 4 | <input type="checkbox"/> | partenerii contractuali ai operatorului | 16 | <input type="checkbox"/> | asociatii si fundatii |
| 5 | <input type="checkbox"/> | alte companii din acelasi grup cu operatorul | 17 | <input type="checkbox"/> | mass-media |
| 6 | <input type="checkbox"/> | autoritati publice centrale/locale | 18 | <input type="checkbox"/> | angajatorul/potentialul angajator al persoanei vizate |
| 7 | <input type="checkbox"/> | servicii sociale si de sanatate | 19 | <input type="checkbox"/> | agentii de selectie si plasare a fortei de munca |
| 8 | <input checked="" type="checkbox"/> | instituti de invatamant si educatie | 20 | <input type="checkbox"/> | organizatii de cercetare a pietei |
| 9 | <input type="checkbox"/> | furnizorii de servicii si bunuri | 21 | <input type="checkbox"/> | altele(precizati): |
| 10 | <input type="checkbox"/> | societati bancare | | | |
| 11 | <input type="checkbox"/> | birouri de credit | | | |
| 12 | <input type="checkbox"/> | agentii de colectare a debitelor/recuperare a creantelor | | | |

XII. Garantiile care insotesc dezvaluirea datelor catre terti

| | | | | |
|---|---------------------------------|-------------------------------------|-----------------|---|
| <input checked="" type="checkbox"/> | consimtamantul persoanei vizate | <input checked="" type="checkbox"/> | acte normative* | <u>Legea 272/2004 privind protectia SI PROMOVAREA DREPTURILOR COPILULUI</u> |
| <input type="checkbox"/> | alte garantii (precizati): | | | |
| <i>*Se precizeaza numarul, data si titlul actului normativ.</i> | | | | |

XIII. Incheierea operatiunilor de prelucrare si destinatia ulterioara a datelor

| | | |
|---|--|--|
| <input checked="" type="checkbox"/> | data estimata* | <u>01.01.2011</u> |
| <input type="checkbox"/> | data certa a incetarii operatiunilor de prelucrare** | |
| | prin: | <input type="checkbox"/> prelucrare in alt scop cu consimtamantul persoanei vizate |
| | | <input type="checkbox"/> stergere <input type="checkbox"/> distrugere <input type="checkbox"/> arhivare |
| | | <input type="checkbox"/> transformare in date anonime si stocate exclusiv in scopuri statistice, de cercetare istorica sau stiintifica |
| | | <input type="checkbox"/> transferare unui alt operator |
| <i>* Se completeaza la data depunerii notificarii.</i> | | |
| <i>**Se completeaza la data incheierii tuturor operatiunilor de prelucrare.</i> | | |

XIV. Transferuri de date in strainatate

1. In state din Uniunea Europeana
2. In alte state din Zona Economica Europeana
3. In state carora Comisia Europeana le-a recunoscut prin decizie un nivel de protectie adecvat

Precizati statele:

Precizati scopul transferului, prin mentionarea indicativului respectiv de la rubrica IV:

Precizati datele/categoriile de date transferate, prin mentionarea indicativului respectiv de la rubrica IX

Precizati datele sau categoriile de date cu caracter special, prin mentionarea indicativului respectiv de la rubrica X

4. In alte state decat cele de la punctele 1, 2 si 3

Precizati statele:

Precizati scopul transferului, prin mentionarea indicativului respectiv de la rubrica IV:

Precizati datele/categoriile de date transferate, prin mentionarea indicativului respectiv de la rubrica IX

Precizati datele sau categoriile de date cu caracter special, prin mentionarea indicativului respectiv de la rubrica X

Transfer in baza art 29 alin (4) din Legea nr 677/2001*

Transfer in baza art. 30 din Legea nr. 677/2001

** Se anexeaza copia contractului incheiat intre importatorul si exportatorul de date.*

XV. Masurile luate pentru asigurarea securitatii prelucrarii*

Regulament intern

Document atasat: 12/55443/1646masuri_secunitate.doc

* Se realizeaza o descriere generala care sa permita aprecierea preliminara a masurilor luate pentru asigurarea securitatii prelucrarii. Se anexeaza documentul/ele continand politica de securitate a prelucrarilor de date cu caracter personal sau extrase din politicile interne ale operatorului care contin aceste masuri.

XVI. Sistemul de evidenta utilizat si legaturile cu alte prelucrari de date sau sisteme de evidenta

Sistem manual

Sistem automatizat

Mixt

Prelucrarea are legatura cu alte sisteme de evidenta/prelucrari: Da

Nu

In cazul in care ati bifat *da*, precizati daca sistemul de evidenta este situat:

pe teritoriul Romaniei

in strainatate

Appendix F – Statement of Central Ethical Review Board (Sweden)

CENTRAL ETHICAL REVIEW BOARD

26 May 2008

Concerning changes made to the Act (2003:460) concerning the Ethical Review of Research Involving Humans (the ethical review act) etc

As a result of SFS 2008:192, a number of changes have been made to the Ethical Review Act. These changes came into force on 1 June 2008.

As a consequence of one of the changes, a new definition of the concept of research has been introduced into section 2. According to the new wording "research" is understood to mean not only scientific, experimental or theoretical work to obtain new knowledge, but also developmental work carried out on a scientific basis, with the exception of that which is carried out as part of a programme of study at an institute of higher education at a basic or advanced level.

It transpires that the new definition has given rise to certain problems of interpretation. The Central Ethical Review Board wishes to point out that in this context "theoretical work" must be intended to include non-experimental observational research of various kinds, such as descriptive and analytical epidemiological research or other research not involving intervention (including research in the course of which treatment is carried out) which is accomplished with the help of registers, interviews and questionnaires.

In addition, the changes to the legislation mean that all research that comprises treatment of so-called sensitive personal information is to be subject to an ethical review, whether or not the subject of the research has explicitly given their consent.

Moreover, it must be pointed out that while it is true that such work as is carried out by a student within the framework of a programme of study at an institute of higher education at a basic or advanced level does not need to be reviewed according to the provisions of the ethical review act, a regional review board may, at the request of the applicant, give an advisory statement concerning such work.

(This addition to the Statute (2003:615) concerning the Ethical Review of Research Involving Humans, came into force on 1 July 2008).

Appendix G – Ethical Review Communications (Sweden)



PROTOKOLL 2010/5:8

2010-08-19

Sammanträde i Stockholm

Avdelning 5**Ordförande**

Birgitta Widebäck

Ledamöter med vetenskaplig kompetensClaes-Robert Julander (*företagsekonomi*), vetenskaplig sekreterare (deltar ej i ärende 2010/871-31/5)Ulrik von Essen (*offentlig rätt*), vetenskaplig sekreterare i ärende 2010/871-31/5Siv Fischbein (*specialpedagogik*)Ulla Manns (*genusvetenskap och idéhistoria*)Ilona Koupil (*ojämlikhet i hälsan*) (deltar ej i ärende 2010/1185-31/5)Staffan Marklund (*arbetsliv*)Gert Helgesson (*medicinsk etik*)Ann-Charlotte Smedler (*psykologi*)Sten-Åke Stenberg (*sociologi*)Karin Helmersson Bergmark (*sociologi*)**Ledamöter som företräder allmänna intressen**

Maria Modig

Anders Rehn

Annika Sandström

Elisabeth Wennerholm

Anne Wompa

Övriga

Elisabeth Nordeman, administrativ sekreterare

§ 1 Ordföranden förklarar sammanträdet öppnat.

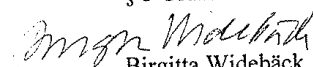
§ 2 Ordföranden förordnar Ulrik von Essen att tjänstgöra som vetenskaplig sekreterare i ärende 2010/871-31/5.

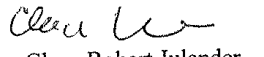
§ 2 Den administrativa sekreteraren anmäler att den vetenskaplige sekreteraren sedan föregående möte den 3 juni 2010 har fattat fyra beslut i ärenden som avser ändring av ett godkännande.


§ 3 Ansökningar om etisk granskning av forskningsprojekt, se **Bilaga**.

§ 4 Ordföranden meddelar att nästa sammanträde i avdelning 5 äger rum den 23 september 2010.

§ 5 Ordföranden förklarar mötet avslutat.


 Birgitta Widebäck
 Ordförande


 Claes-Robert Julander
 Protokollförare
 Vetenskaplig sekreterare


 Ulrik von Essen
 Protokollförare och vetenskaplig
 sekreterare i ärende 2010/871-31/5

| Adress | Besöksadress | Telefon | Fax | E-post | Hemsida |
|----------------------------|---------------------------------|---------------|---------------|-------------------------|------------|
| FE 289 171 77 Stockholm | Nobels väg 12 A 171 65 Solna | 08-524 800 00 | 08-524 866 99 | kansli@stockholm.epn.se | www.epn.se |

Appendix H – English Version of KI Interpretation of Ethical Review (Sweden)



**Karolinska
Institutet**

Anne H. Berman, PhD
Licensed psychologist &
psychotherapist
Specialist in clinical psychology

July 7, 2010

Department of Clinical Neuroscience
Center for Psychiatric Research

Basis for interpretation of the Ethical Review Board decision for Coping - Sweden

Decision: 2010/849-31/5 from meeting on 3 June 2010, notified 2010-06-16

Content of the decision: *The Board approves research provided that both the parents/guardians are given the opportunity to consent to the research when the children are younger than 15 years.*

Introduction

The above decision makes participation in the COPING-research project in Sweden contingent on **both** parents/guardians¹ being given the opportunity to give consent ... when the children are younger than 15 years. Of course, it is optimal from the viewpoint of the research group, that both parents/guardians provide consent for child participation. Given the unique circumstances that can exist for children for whom one or both parents are detained, and given the research design, our view is that the Ethical Review Board's decision can be interpreted in the manner described below

This interpretation is motivated primarily by the fact that the children's situation may be such that it is **not** the parents/guardians, who are responsible for the **actual** care of the child. The parents/guardians can be detained (see p. 1), may have chosen to voluntarily place the child under the Social Services Act (see p. 2) or the child may be placed under a compulsory care order according to The 1990:52 Act with special provisions for the care of young people (see p. 3). A different interpretation of the decision is likely to result in a substantial proportion of children - perhaps those with less advantageous conditions - being excluded from the study to the detriment of the full illumination of the situation of children, which is the basic purpose of the COPING project.¹

Based on Dr. Anne H Berman's extensive experience with research in prisons, and the experience of interviewers from the non-profit organization Riksbryggan of children whose parents are in prison, non-custodial parents, parents in prison, and other adults who care for children in this group, we believe that the detained parents generally will feel positively about this research project, which aims to improve conditions for their children in the community. We want to ensure that parents/guardians are given the opportunity to consent to the research

¹ Tr note: Parent/guardian could also be translated as "legal holder of parental responsibility," meaning the parent that has legal custody of the child with the right to make decisions over the child's welfare.

by means of a general newsletter, posted at prisons and detention centers in Sweden (see Annex 1) for two reasons:

i. We are concerned that **requiring** consent from the parents in prison will logistically mean that the recruitment of children for the first stage of the research project will take place in two stages. This, in turn, can lead to a situation where children for whom consent is delayed - for reasons unrelated to the parent's attitude but rather due to practical difficulties in communication with the research team - will not be able to participate in research even though they themselves want to participate, and even though the non-imprisoned parent or the person who is caring for the child has consented to the child's participation. This in turn can lead to a selection bias for children in the project, with a predominance of children from more orderly conditions included in the study.

ii. We understand that the Board's decision is based in the intention to safeguard the integrity of the parent's custody. The research group is very keen to protect the detained parent's privacy and **the interviewers will make every effort to make contact with the detained parents, both for interviews that occur in a prison/remand center, as well as for interviews that occur at Riksbryggan's premises.** Our wish to send information about the project to all detained parents in Sweden derives from our concern to ensure that information on the project reaches the parents, and that the imprisoned parents, who want to oppose the child's participation, should have contact information for the research group readily available at the prison.

If the interview has already occurred, and the imprisoned parent/guardian subsequently decides the child should not participate, the research group will exclude the child's data from the study (see Appendix 1). Here, one could argue, that child has in this case already participated in the interview and been "exposed" to the research process, against the will of the imprisoned parent. We would like to point out, that the Board, in its ethical review of our application, has not put into question that children would somehow be harmed by participating in the research.

The background to our interpretation is that the custody issues for the children concerned are much more complex than anticipated by the International Advisory Board (cf. Grant agreement no. FP/-HEALTH-2009 241 988, Annex 2) in connection with Swedish participation in the project. This is mainly for the following reasons:

1) COPING - even though it is a comparative research project – is designed with British legal conditions as a base n (cf. Grant agreement no. FP/-HEALTH-2009 241 988, Annex 2). Decision-making powers in the context of joint custody and social welfare care, including the capacity to agree to interviews with children, is constructed differently in English and Swedish law. The actual carer/home parent (i.e., the adult with whom the child is actually living) has a slightly wider sole competence to make decisions regarding the child under English law compared to Swedish law.

2) Some concepts in the Swedish ethics application were translated so that a conceptual shift occurred. The original concept of "Parent /carer" was translated as

parent/guardian. The Swedish terminology more suited to the original is the guardian /home parent/foster parent.

3) The recruitment of 250 children, 7-16 years old, for a combined questionnaire / interview of about 30 minutes takes place in different ways in the four countries involved in COPING. In Sweden, the recruitment takes place to a larger extent *outside* prison premises compared to other countries (this because Riksbryggan's supporting activities for children with parents in prison have no direct counterpart in the other states). This means that the imprisoned parent is not always available.

The recruitment of children in Sweden will take place at the following locations:

- (1) At jails / prisons when the children visit their detained parents, accompanied by an adult
- (2) Riksbryggan's premises, which the children visit either alone or accompanied by an adult
- (3) National Board of Institutional Care (SiS) institutions (only children 15-16 years old will be interviewed, and they are legally capable of consenting on their own so the parental consent requirement is irrelevant).

Meaning of informed consent in the COPING project

Accompanying guardians / home parents / foster parents are asked to give consent and to answer the questionnaire SDQ (*Strengths and Difficulties Questionnaire*) in the parent version. The permission covers the first survey/interview of approximately 30 minutes and, for 40 of these children, a more extensive interview *at a later date*. The consent form also indicates that consent also includes participation in a possible future investigation in a few years of each of the 250 children included in the cohort.

Interpretation of the Ethical Review Board's decisions in concrete cases

From our point of view, the Ethical Review Board decision 2010/849-31/5 can be interpreted as follows in the particular cases concerned by the study.

Participation in the research can take place when the **child is 15 years** or older and provides his or her own consent to participate in the research. When the child is 14 years or younger, the following applies.

1. When the child is 14 years or younger he/she **can participate in the research if:**

(a) the accompanying parent is the sole holder of custody (legal parental responsibility) and provides consent, or,

(b) the accompanying parent is the joint holder of custody, provides consent and the other parent is imprisoned. The imprisoned parent has then received information about the project via postings at all prisons / detention facilities (see Annex 1). The opportunity to give consent is fulfilled by this information since the detained parents have had the opportunity to communicate with the research team if s/he does not want their child to participate.²

2. When the child is 14 years or younger and living in a foster home under Ch. 6 Sec.1, the Social Services Act 2001:453 or in “homes for care and housing” (HVB-homes in Sweden) according to Ch. 6 Sec. 2 SSA on behalf of the social welfare authorities following parental approval (so-called **voluntary placement**), guardians must be allowed to consent to the child's participation in the study according to the following procedure:

(c) when the child has only one legal parent/guardian (legal holder of parental responsibility), who is imprisoned, the interview will be able to take place at the time of recruitment to the study based on information letter to all parents in prison, or,

(d) when at least one of the parents/guardians is not in prison and has contact with the foster parent, the foster parent / HVB-parent can consent to the research. The non-imprisoned guardian is informed by letter about the research, either through the address which the research team receives from the accompanying adult / foster parent or through another scheduled contact that naturally occurs between the guardian and the family home / HVB-home, or,

(e) when parents/guardians do not have contact with the family home or can not be reached to give consent, consent will be presumed using the following approach.

That the guardian agrees that the child be cared for by someone else can be interpreted such that his/her consent is presumed regarding a number of questions concerning the child's everyday life, which fall within Ch. 6, Sec. 11 Parental Code. To presume consent seems particularly appropriate in situations where the guardian can not be reached and the issue is not a decision of serious significance for the child's future (cf. Ch. 6, Sec. 13 Parental Code).

Legal parents/guardians (*legal holders of parental responsibility*) **will still be offered the opportunity by mail to consent** to the child participation, but the presumed consent as described above will apply to the child's participation, i.e., in those cases the foster parents are given the opportunity to consent. If a parent/guardian later explicitly opposes the child's participation, the child's information will be excluded from the research database.

3. When the child is cared for under the 1990:52 Act with special provisions for the care of young people, the rights of the parents/guardians is suspended under Sec. 11 3-4 - The 1990:52 Act with special provisions for the care of young. The Act with special provisions for the care of young people states that:

“The Board or the person to whom the Board has given the responsibility of caring for the child, should supervise the young person and, to the extent necessary for implementing the care, decide on his or her personal circumstances. During the care period, the Board has the same responsibility as the parents/guardians for fulfilling the young person's fundamental rights under Ch. 6 Sec.1 in the Parental Code.”

The **actual care** of these children in this case may be exercised by:

(f) a so-called "foster family parent" on behalf of the Social Welfare Board without parental consent under the Act with special provisions for the care of young people

(g) a "home for care and housing" (HVB-home) on behalf of the Social Welfare Board without parental consent under The Act with special provisions for the care of young people

For the above children, consent will be given by the person charged with caring for a child, and according to Sec.11 the Act with special provisions for the care of young people, this consent will replace the guardian's consent for the child's participation in the research. At the same time, **the parents/guardians will, however, in accordance with the Ethical Review Board's decision 2010/849-31/5, be given the opportunity to consent in writing by mail.** If the guardian explicitly via letter opposes the child's participation, the child's information will be excluded from the research database.

These interpretations of the Board decision 2010/849-31/5 are supported by the fact that Swedish law is currently moving towards giving a larger leeway for conversation with children without parental consent (see the amendments to the SSA Ch. 11 Sec.10, Govt. proposition 2009/10: 192 and Ch. 6 Sec.15 in the Education Act 2010: 800). These developments are well in line with the observations made by the UN Committee on the Rights of the Child in General Comment No.12 (2009) The Right of the Child to Be Heard.

Attachments

1. Information letter about COPING for imprisoned parents.
2. 2nd Grant agreement no. 241 988 FP/-HEALTH-2009

Appendix I – Additional Ethical Approval (Sweden)



PROTOKOLL 2011/5:5

2011-05-05

Sammanträde i Stockholm

Avdelning 5

Ordförande

Gerhard Gammer

Ledamöter med vetenskaplig kompetens

Claes-Robert Julander (*företagsekonomi*), vetenskaplig sekreterare

Siv Fischbein (*specialpedagogik*)

Sven Ove Hansson (*filosofi*)

Ilona Koupil (*ojämlikhet i hälsan*)

Staffan Marklund (*arbetsliv*), deltar ej i ärende 2011/588-31/5

Jerzy Sarnecki (*allmän kriminologi*), deltar ej i ärende 2011/487-31/5

Teresa Simon Almendal (*skatterätt*)

Ann-Charlotte Smedler (*psykologi*), deltar enbart i ärendena 2011/488-32/5, 2010/1909-

31/5, 2011/473-31/5, 2011/487-31/5, 2011/502-31/5, 2011/504-31/5, 2011/538-31/5,

2011/570-31/5

Sten-Åke Stenberg (*sociologi*)

David Titelman (*psykologi*)

Ledamöter som företräder allmänna intressen

Maria Modig

Anders Rehn

Elisabeth Wennerholm

Anne Wompa

Administrativ sekreterare


Ann-Christin Becker


§ 1 Ordföranden förklarar sammanträdet öppnat.

§ 2 Den administrativa sekreteraren anmäler att den vetenskaplige sekreteraren sedan föregående möte den 7 april 2011 har fattat 6 beslut i ärenden som avser ändring av ett godkännande.

§ 3 Ansökningar om etisk granskning av forskningsprojekt, se **Bilaga**.

§ 4 Ordföranden förklarar mötet avslutat och meddelar att nästa sammanträde i avdelning 5 äger rum tisdagen den 31 maj 2011.


Gerhard Gammer
Ordförande


Claes-Robert Julander
Protokollförelse, vetenskaplig sekreterare

| Adress | Besöksadress | Telefon | Fax | E-post | Hemsida |
|----------------------------|---------------------------------|---------------|---------------|--|--|
| FE 289 171 77 Stockholm | Nobels väg 12 A 171 65 Solna | 08-524 800 00 | 08-524 866 99 | kansli@stockholm.epn.se | www.epn.se |

Regionala etikprövningsnämnden
i Stockholm

Protokoll 2011/5:5

Utdrag ur protokoll från sammanträde den 5 maj 2011 i avdelningen 5.

Amendment

Diarienummer

2011/488-32/5

Ursprungligt diarienummer

2010/849-31/5

Föredragande

Jerzy Samecki

Sökande: Karolinska Institutet

Behörig företrädare: Jan Hillert

Projekt: Tillägg till COPING - Barn med föräldrar i fängelse
- osynliga brottsoffer med behov av interventioner som
stärker den psykiska hälsan. (EPN:s beslut 2010-08-19)

Forskare som genomför projektet: Anne H Berman

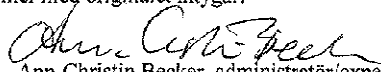
BESLUT

Nämnden godkänner forskningen.

Beslut expedierat till behörig företrädare.

Kopia för kännedom till ansvarig forskare.

Att utdraget överensstämmer med originalet intygar:



Ann-Christin Becker, administratör/expedierat. 2011-05-09



**Karolinska
Institutet**

Anne H Berman, fil dr, docent
Leg psykolog, leg psykoterapeut
Specialist i klinisk psykologi

Institutionen för klinisk neurovetenskap
Centrum för psykiatriforskning

Stockholm
23 mars 2011

Regionala etikprövningsnämnden i Stockholm
Box 289
171 77 STOCKHOLM

Tillägg avseende etikprövningsnämndens beslut i ärende 2010/849-31/5

Den 19 augusti 2010 beslutade den regionala etikprövningsnämnden i Stockholm att godkänna forskningsprojektet "COPING – Barn med föräldrar i fängelse – osynliga brottsoffer med behov av interventioner som stärker den psykiska hälsan" under förutsättning att informationsbrev skickas till alla berörda frihetsberövade som har vårdnaden om barn under 15 år.¹

Utöver det som beskrevs i den ansökan som låg till grund för beslutet, har följande verksamheter i forskningsprojektet tillkommit som behöver underkastas nämndens kompletterande prövning.

- 1) Inom ramen för delstudie 2 "Intervjustudie med barn till frihetsberövade föräldrar" (s. 7 i ansökan) kommer 40 barn att delta i semistrukturerade kvalitativa intervjuer. I ansökan skrevs att barnens icke-frihetsberövade förälder skulle lämna kompletterande information. I och med att projektet är ett EU-projekt med 4 samarbetande länder har det efter etiknämndens godkännande blivit tydligt att det utöver intervjuer med 40 barn även sker intervjuer med:

- 40 icke-frihetsberövade föräldrar
- Upp till 40 frihetsberövade föräldrar

Alla dessa intervjuer är semistrukturerade kvalitativa intervjuer och avser att undersöka barnens situation ur ett föräldraperspektiv samt hur frihetsberövande påverkar föräldrarollen, både hos den icke-frihetsberövade föräldern och den frihetsberövade föräldern.

¹ Detta var en ändring av beslutet den 3 juni 2010 om att godkänna forskningen under förutsättning att båda vårdnadshavarna ges möjlighet att lämna samtycke när barnen är under 15 år.

Den icke-frihetsberövade föräldern lämnar samtycke till att själv bli intervjuad i samband med samtycket till att barnet blir intervjuad i delstudie 1, "Enkätstudie med barn till frihetsberövade föräldrar", se bilaga 4.3 i ansökan.

Sedan den 15 februari 2011 finns ett formellt samarbete med Kriminalvården kring projektet (se bilaga 1). Detta bedöms underlätta möjligheten och förutsättningarna för att intervjua de frihetsberövade föräldrarna. Se bilaga 2 för samtyckesblankett och bilaga 3 för intervjuguide med de frihetsberövade föräldrarna.

- 2) Som kompensation för deltagande i delstudie 2 ämnar vi överlämna biobiljetter till barn och förälder vilket inte var beslutat när etikansökan inskickades.
- 3) I delstudie 3 "Intervjuer med aktörer på området" konsulteras yrkesgrupper som kommer i kontakt med barn till frihetsberövade föräldrar. Även anhöriga (föräldrar) samt barn själva kommer att konsulteras i intervjuer. Syftet är inte, till skillnad från delstudie 2, att fokusera på personliga erfarenheter utan att undersöka behov hos gruppen barn med frihetsberövade föräldrar generellt. Inga personliga frågor kommer att ställas men det finns dock en möjlighet att intervjupersonerna kommer att delge personliga erfarenheter i intervjuerna varför vi bedömer att nämndens kompletterande etikprövning för genomförandet av studien är nödvändigt. Delstudie 3 beskrevs i ansökan till etikprövningsnämnden men bedömdes inte då falla under etikprövningslagen (s. 8 i ansökan).
- 4) Vi avser att vidga rekryteringsområdet för deltagare till delstudie 1 "Enkätstudie med barn till frihetsberövade föräldrar". I etikansökan angavs att deltagare till studien rekryteras via RiksBryggan och de lokala Bryggorna⁷, via utvalda fängelser och häkten (specificerades i bilaga till etikansökan) samt via Statens institutionsstyrelses särskilda ungdomshem. Då ytterligare rekryteringsställen bedöms vara nödvändiga för att få ett tillräckligt stort urval samt för att få en större spridning på deltagarna kommer följande verksamheter för rekrytering att inkluderas i studien:
 - Föreningen Solrosen, Göteborg vilka bedriver stödverksamhet för barn och ungdomar med en familjemedlem i fängelse
(<http://www.raddningsmissionen.se/verksamhet/solrosen>)
 - Organisationen Unga Kris, för ungdomar i ålder 13-25 år
(<http://www.ungakris.com/>)
 - BUP (Barn och ungdomspsykiatri) via psykologer i Stockholm och Västra Götalandsregion, som får kännedom om att ett barn i utredning eller behandling har en förälder som är frihetsberövad.

⁷ RiksBryggan är en ideell förening som arbetar med barn vars föräldrar är föremål för kriminalvård. RiksBryggan är riksförening för lokalföreningarna (Bryggorna) som finns i tio städer i Sverige.

RikBryggan kommer fortfarande att stå för forskningsdeltagarnas säkerhet i samband med att de deltar i studien.

Undertecknad forskare som genomför projektet (kontaktperson) intygar härmed att forskningen kommer att genomföras i enlighet med denna komplettering till tidigare ansökan.

Stockholm, den 23 mars 2011

Anne H Berman

Kontaktuppgifter

Adress:

Box 170 70

104 62 Stockholm

E-postadress: anne.h.berman@ki.se

Telefon: 070-424 53 60



Kriminalvården

Överenskommelse

Mellan Kriminalvården, 601 80 Norrköping, nedan kallad KV och institutionen för Klinisk Neurovetenskap, Centrum för psykiatrforskning, Karolinska institutet, Stockholm, nedan kallad utföraren, har följande överenskommelse träffats.

Uppdrag: Utföraren åtar sig att genomföra studien i enlighet med projektförslaget "COPING – Att stärka barn med frihetsberövade föräldrar". Projektets specifika syfte är att:

- Öka kunskapen om den psykiska hälsan samt återhämtningsstrategierna bland barn till frihetsberövade föräldrar, såväl lokalt i fyra europeiska länder, däribland Sverige, som ur ett EU-perspektiv.
- Identifiera samhällsinterventioner som syftar till att förbättra barnens förutsättningar i samhället samt utvärdera i vilken utsträckning dessa kan uppfylla barnens stödbehov.
- Undersöka uppfattningar hos olika aktörer kring den aktuella målgruppen, öka medvetenheten bland beslutsfattare om gruppens behov samt utfärda rekommendationer för framtida förändringar som beräknas öka välbefinnandet hos barn med frihetsberövade föräldrar samt minska risken för att barnen själva inleder en brottslig karriär

Utföraren ska vid redovisning av resultat redogöra för hur KV kan tillgodogöra sig erhållna resultat, exempelvis genom rekommendationer till myndighetens ledning.

KV åtar sig att, i rimlig utsträckning, säkerställa den tillgänglighet till klienter, personal, intern information och myndighetsspecifik kompetens inom KV som krävs för att projektet skall kunna genomföras.

Ansvarig hos utföraren: Fil. Dr, leg psykolog Anne H Berman, institutionen för Klinisk Neurovetenskap, Centrum för psykiatrforskning, Karolinska Institutet, Stockholm.

Ansvarig får endast bytas ut mot annan person efter det att ett sådant byte godkänts skriftligen av KV.

Uppdragstid: 2010-01-01 – 2012-12-31

Produkt: Skriftliga redogörelser om viktigare händelser i projektet, resultat som uppnåtts samt aktuell status. Sådana redogörelser bör redovisas halvårsvis under uppdragstiden med en första rapport 31 maj 2011, en andra 15 november 2011, en tredje 31 maj 2012 och slutrapport senast 31 december 2012. Statusrapporterna ska vara kortfattade (upp till två A4-sidor). Till redogörelserna ska kopior bifogas på manus/motsvarande som producerats under perioden.

Slutrapporten ska vara en skriftlig rapport som belyser och svarar på projektets syfte/frågeställningar som finns angivna under "uppdrag" ovan. Rapporten ska vara skriven så att dess innehåll är förståeligt för en icke-specialist. En populärvetenskaplig sammanfattning som beskriver resultaten från studien samt anger relevansen för Kriminalvården ska bifogas.

Vidare åtar sig ansvarig utförare eller annan kvalificerad person hos utföraren att, utan ytterligare ersättning medverka vid upp till 2 heldagsseminarier, eller motsvarande, enligt KV:s önskemål, i syfte att sprida eventuellt relevanta resultat av studien internt inom KV. KV betalar de omkostnader som är förknippade med detta.

All skriftlig rapportering ska lämnas i digital form, för närvarande i programvara MS Word och/eller Excel (för PC). Eventuell illustration/grafik skall även bifogas separat i programvara som svarar mot Microsoft produkter.

Produkterna ska vara KV tillhanda senast den 31 maj 2011, 15 november 2011, 31 maj 2012 och 31 december 2012.

Kontaktperson hos KV: Lowisa Svedling, Kriminalvårdens huvudkontor, Vetenskapliga rådets kansli / Utvecklingsenheten, 601 80 Norrköping, e-post lowisa.svedling@kriminalvarden.se, 011-496 33 32.

Ersättning / Betalning: Utöver tillgång till Kriminalvårdens klienter utgår ingen ersättning.

KV äger den produkt som tas fram inom ramen för uppdraget. Utföraren har nyttjanderätt till eventuella data för vidare bearbetning, och att för egen forskning utnyttja och redovisa samtliga resultat. För publicering av data/material krävs KV skriftliga medgivande om det aktuella materialet producerats under samma kalenderår som publicering avser ske. Efter uppdragstidens utgång är utföraren fri att föfoga över materialet.

Utföraren förbinder sig att tillse att de personer som ska utföra uppdraget informeras om och iakttar den sekretess som gäller inom KV.

Utrustning som köps in för uppdragets utförande och bekostas av medel som beviljats från KV ska efter uppdragstidens slut lämnas till KV.

Denna överenskommelse får inte överlåtas till annan utan KV skriftliga medgivande. Om överlåtelsen sker utan vederbörligt godkännande äger KV rätt att säga upp överenskommelsen med omedelbar verkan.

Part äger rätt att säga upp överenskommelsen till omedelbart upphörande om motparten bryter mot sina åtaganden enligt överenskommelsen och inte, inom 30 dagar efter att ha erhållit skriftligt meddelande om bristen, vidtar rättelse.

Tvist angående denna överenskommelses tolkning eller tillämpning ska lösas i förhandling mellan parterna. Om rättslig prövning är tillämpligt ska frågan lösas i skiljenämnd.

Denna överenskommelse har upprättats i två (2) likalydande exemplar, av vilka parterna tagit var sitt.

Norrköping 2011-01-30

Martin Grann
Utvecklingschef
Kriminalvården

Stockholm 2011-02-15

Anne H Berman
Fil. Dr, Leg psykolog
Karolinska Institutet



BILAGA 2

**SAMTYCKESBLANKETT FÖR INTAGNA FÖRÄLDRAR
SOM LÄMNAR KONTAKTUPPGIFTER FÖR ATT EVENTUELLT SJÄLVA BLI INTERVJUADE**

I COPING-projektet ingår intervjuer med upp till 40 frihetsberövade föräldrar, vars barn har blivit intervjuade inom ramen för projektet.

Jag är villig att själv bli intervjuad inom ramen för COPING-projektet.

Ort och datum

Namnunderskrift

Namnförtydligande

Kontaktuppgifter till dig inom Kriminalvården:

Namn: _____

Ev kontaktperson: _____

Adress: _____

Postnummer och postort: _____

Telefonnummer: _____

E-post: _____

Om du inom kort kommer att bli frigiven, ange också kontaktuppgifter i frihet:

Namn: _____

Adress: _____

Postnummer och postort: _____

Telefonnummer: _____

E-post: _____

Appendix J – Information Letter (all language versions) (Sweden)



كوبيينغ (COPING) – حول الأطفال الذين يكون أحد أبويهم في السجن/الحبس الاحتياطي

هل لديك أطفال؟

نوجّه هذه الرسالة إلى الآباء والأمهات الذين لديهم أطفال في سن 8-16 عاماً.

نقوم بالمشاركة في مشروع بحثي تابع للاتحاد الأوروبي يسمّى كوبيينغ (COPING). تشارك في المشروع أربع دول هي: السويد وألمانيا وبريطانيا ورومانيا.

يهدف المشروع إلى تحسين حياة الأطفال الذين يكون أحد أبويهم في السجن أو في الحبس الاحتياطي. نأمل في تقديم المزيد من المساعدة للأطفال وعائلاتهم.

كيف يشارك الأطفال؟

نريد أن نجري مقابلات مع 250 طفلاً (8-16 عاماً). حيث يجيب الأطفال على أسئلة تتعلق بحالهم. كما أنهم يجيبون على أسئلة تتعلق بعائلاتهم ومدارسهم وأوقات فراغهم. كما أن الشخص الذي يعتني بالطفل (أحد الأبوين أو شخص آخر) سيجيب أيضاً على الأسئلة.

نحن القانمون على هذه الدراسة نلتزم بواجب كتمان السرّ. ولا نسمح لأي شخص آخر بالاطلاع على الأجوبة. ولا نخبر أحداً بأسماء المشاركين.

هناك حالة واحدة تجعلنا نخرق قاعدة كتمان السرّ. وهي في حال أنّ الشخص الذي يجري المقابلة سمع بأن طفلاً دون سن 18 عاماً يتعرض للخطر أو يحتاج إلى المساعدة، يجب علينا حينها ووفق القانون¹ أن نبلغ عن ذلك إلى إدارة الخدمات الاجتماعية. ويتوجب علينا في مثل هذه الحالة ذكر اسم الطفل من أجل حمايته.

هل توافق على مشاركة طفلك؟

الأطفال الذين يودون المشاركة سيجيبون على الأسئلة التي سنقوم بطرحها عليهم. وتوجّه الأسئلة من قبلنا إلى الأطفال أثناء زيارتهم إلى السجن أو الحبس الاحتياطي. كما أننا نسأل الأطفال في منظمة بريغتان (Bryggan). وهي منظمة تساعد الأطفال الذين يتواجد أحد من أبويهم لدى مصلحة الرعاية الجنائية.

يتوجب على الأب أو الأم، الموجود خارج مصلحة الرعاية الجنائية، أن يقرر بنفسه إن كان يرغب بمشاركة طفله في هذا المشروع وذلك إذا كان عمر الطفل يتراوح بين 4 سنوات و14 سنة. ويمكن للأب أو الأم المتواجد ضمن مصلحة الرعاية الجنائية أن يرفض مشاركة طفله في هذه المقابلات. أما الأطفال الأكبر سناً، 15 أو 16 سنة، فيمكنهم أن يقرروا بأنفسهم ما إذا كانوا يريدون المشاركة. ولا يحتاج الوالدان إلى الموافقة أو الرفض.

إذا كنت موافقاً على مشاركة طفلك في المقابلة فلا تحتاج إلى فعل أي شيء.

إذا كنت لا تريد أن يشارك طفلك، تحدث مع وكيل شؤون الأطفال (barnombud) في السجن/الحبس الاحتياطي. كما يمكنك الاتصال مع منظمة بريغتان (Bryggan) أو معهد كارولنسكا.

Niina Koivumaa, RiksBryggan
Drottninggatan 38, 652 52 Karlstad
niina.koivumaa@bryggankarlstad.se
073-658 61 21

Sara Ullman, Karolinska Institutet
Centrum för psykiatrforskning
Box 17070, 104 62 Stockholm
sara.ullman@ki.se, 073-673 41 61

¹ علينا أن نبلغ لجنة الشؤون الاجتماعية عندما تعرض أحد الأطفال للخطر، وذلك وفقاً للفقرة 1 من الفصل 14 من قانون الخدمات الاجتماعية (socialtjänstlagen)



COPING – a study of children with mother or father in prison or jail

Do you have children?

This letter is for you, who are a parent with children 8-16 years old.

We are participating in an EU research project called COPING. Four EU countries are participating: Sweden, Germany, Romania and the United Kingdom.

The purpose of the project is to improve life for children who have a parent in prison or jail. We hope it will lead to more help for the children and their families.

How do the children participate?

We want to interview 250 children 8-16 years old. The children will answer questions about how they feel. They will also answer questions about their family, school and free time. The person who is taking care of the child (parent or other person) will also answer questions.

We who are working in the study keep what we learn confidential (secret). We will not show the answers to anyone else. We will never tell anyone else the participants' name.

There is one case where we must break confidentiality (secrecy). If the interviewer finds out that a child under 18 is in danger or needs help, we must register this with the social authorities according to the law.¹ In that case, we must tell them the child's name, in order to protect him or her.

Is it OK for your child to participate?

Only children who want to participate will answer the questions. We will ask children who are visiting prison or jail if they want to participate. We will also ask children visiting Bryggan, an organisation that helps children with a parent in the criminal justice system, if they want to participate.

If the child is 8-14 years old, a parent **outside** the criminal justice system (the one who is taking care of the child) must agree to the child's participation. You, who are a parent within the criminal justice system, can say no to the child's participation. Children who are older, 15 or 16 years old, can decide by themselves if they want to participate or not. The parent does not need to say yes or no.

If it is OK for you that your child be interviewed, you do not need to do anything.

Do you not want your child to participate? Talk to your child representative (barnombud) at the prison or jail. You can also contact us at Bryggan or Karolinska Institutet.

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¹ According to Ch. 14 Sec.1, the Social Services Act 2001:453 (Socialtjänstlagen) we must report to the Social Welfare Board (Socialnämnden) when a child is in danger.



COPING – lapsista, joiden isä tai äiti on joutunut vankilaan tai tutkintavankeuteen

Onko sinulla lapsia?

Tämä kirje on tarkoitettu vanhemmille, joilla on **8-16-vuotiaita** lapsia.

Osallistumme EU:n tutkimusprojektiin nimeltä COPING. Siihen osallistuu neljä EU-maata: Ruotsi, Saksa, Iso-Britannia ja Romania.

Projektin tarkoituksena on parantaa toisen vanhemmistaan vankilaan tai tutkintovankilaan menettäneiden lasten elämänlaatua. Haluamme parantaa lapsille ja heidän perheilleen annettavaa apua.

Miten lapset voivat osallistua?

Haluamme haastatella 250:tä lasta (8–16-vuotiaita). Lapset vastaavat omaa vointiaan koskeviin kysymyksiin. He vastaavat myös perhettään, kouluun ja vapaa-aikaansa koskeviin kysymyksiin. Myös lapsen huoltaja (vanhempi tai muu henkilö) vastaa kysymyksiin.

Meillä on tutkimuksen suorittajina vaitiolovelvollisuus (salassapito). Emme näytä vastauksia kolmansille osapuolille. Emme koskaan paljasta osallistujien nimiä.

Yhdessä tapauksessa meidän pitää rikkoa vaitiolovelvollisuutemme. Jos haastattelija saa tietää, että alle 18-vuotiaan lapsen turvallisuus on vaarassa tai että tämä tarvitsee apua, meidän tulee lain¹ mukaan tehdä tästä ilmoitus sosiaalipalvelulle. Silloin meidän tulee ilmoittaa lapsen nimi hänen suojelemisekseen.

Hyväksytkö lapsesi osallistumisen?

Vain lapset, jotka itse haluavat osallistua, vastaavat kysymyksiin. Esitämme kysymykset lapsille, jotka ovat käymässä vankilassa tai tutkintavankilassa. Kysymykset esitetään myös Bryggan-järjestön toimintaan kuuluville lapsille. Bryggan-järjestö auttaa lapsia, joiden toinen vanhempi kuuluu kriminaalihuollon piiriin.

Jos lapsi on 8–14-vuotias, hänen kasvatuksestaan vastaavan, kriminaalihuollon piiriin **kuulumatottoman** vanhemman pitää päättää, saako lapsi osallistua tutkimukseen. Jos sinä kuulut vanhempana kriminaalihuollon alaisuuteen, voit kieltää lapsesi osallistumisen. Vanhemmat lapset, esim. 15- tai 16-vuotiaat, saavat itse päättää, osallistuvatko he vai eivät. Vanhemman ei tarvitse tällöin sallia tai kieltää osallistumista.

Jos sallit lapsesi osallistuvan haastatteluun, sinun ei tarvitse tehdä mitään.

Etkö halua lapsesi osallistuvan? Keskustele laitoksen/tutkintavankilan lapsiasiamiehen (barnombud) kanssa. Voit myös ottaa yhteyden meihin, Brygganin tai Karoliinisen instituutin työntekijöihin.

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¹ Sosiaalipalvelulain (Socialtjänstlagen) 14 luvun 1 §:n mukaan meidän pitää ilmoittaa sosiaalilautakunnalle, mikäli epäilemme lapsen turvallisuuden olevan vaarassa.



COPING – pour les enfants dont l'un des parents est détenu

Vous avez des enfants ?

Cette lettre s'adresse aux détenus qui ont des enfants de **8 à 16 ans**.

Notre établissement participe à un projet de recherche de l'Union européenne dénommé COPING. Les États de l'Union européenne qui y participent sont : la Suède, l'Allemagne, la Grande-Bretagne et la Roumanie.

L'objectif du projet est d'améliorer la vie des enfants dont l'un des parents est détenu. Nous espérons améliorer l'aide prodiguée aux enfants et à leurs familles.

Comment les enfants participent-ils ?

Nous souhaitons interroger 250 enfants (de 8 à 16 ans). Nous demanderons aux enfants comment ils vont. Ils répondront aussi à des questions sur leur famille, leur école et leurs loisirs. La personne qui s'occupe de l'enfant (parent ou autre personne) répondra aussi à des questions.

Tous ceux qui effectuent cette étude sont soumis au secret professionnel. Les réponses ne seront communiquées à personne d'autre. Nous ne disons jamais le nom des participants.

Il n'existe qu'un seul cas de rupture autorisée du secret professionnel : si l'interrogateur apprend qu'un enfant de moins de 18 ans est en danger ou a besoin d'aide, la loi suédoise¹ l'oblige à signaler le cas aux services sociaux. Il doit alors divulguer le nom de l'enfant dans le but de le protéger.

Êtes-vous d'accord pour que votre enfant participe au projet ?

Seuls les enfants qui désirent participer seront interrogés. Nous interrogeons les enfants lors de leur visite à la prison ou la maison d'arrêt. Nous interrogeons aussi les enfants de Bryggan, une organisation qui aide les enfants dont l'un des parents est pris en charge par l'administration pénitentiaire.

Si l'enfant est âgé de 8 à 14 ans, l'un des parents se trouvant **hors** de l'administration pénitentiaire et ayant la garde de l'enfant doit donner son autorisation pour que l'enfant participe. Les parents dans l'administration pénitentiaire peuvent refuser la participation de l'enfant. Les enfants plus âgés, de 15 ou 16 ans, ont le droit de décider seuls s'ils veulent participer. Le parent n'est pas consulté.

Si vous acceptez que votre enfant réponde à nos questions, vous n'avez besoin de rien faire.

Si vous refusez que votre enfant soit interrogé, informez le représentant des enfants (barnombud) de votre prison/maison d'arrêt. Vous pouvez aussi nous contacter à Bryggan ou à l'Institut Karolinska.

Niina Koivumaa, RiksBryggan
Drottninggatan 38, 652 52 Karlstad
niina.koivumaa@bryggankarlstad.se
073-658 61 21

Sara Ullman, Karolinska Institutet
Centrum för psykiatrforskning
Box 17070, 104 62 Stockholm
sara.ullman@ki.se, 073-673 41 61

¹ En vertu de la loi suédoise sur le service social (Socialtjänstlagen), chapitre 14, article 1, nous sommes tenus de signaler à la Commission des affaires sociales lorsqu'un enfant est en danger.



COPING – исследование о детях, родители которых (отец или мать) сидят в тюрьме или следственном изоляторе

У Вас есть дети?

Это письмо для родителей, имеющих детей в возрасте **8-16 лет**.

Мы принимаем участие в научно-исследовательском проекте Евросоюза под названием COPING. Участниками проекта являются четыре страны Евросоюза: Швеция, Германия, Великобритания и Румыния.

Цель проекта – улучшить жизнь детей, у которых один из родителей сидит в тюрьме или следственном изоляторе (СИЗО). Мы надеемся, что, благодаря этой работе, можно оказать более действенную помощь детям и их семьям.

Как участвуют дети в этом проекте?

Мы хотим провести интервью с 250 детьми в возрасте 8-16 лет. Дети ответят на вопросы о своем самочувствии. Они также ответят на вопросы о своей семье, школе и досуге. Мы опрашиваем и тех, кто взял на себя заботу о воспитании ребенка (родителя или какое-то другое лицо).

Занимаясь исследовательской работой, мы соблюдаем обязательство о неразглашении служебной тайны (требование о конфиденциальности). Мы никому не показываем полученные ответы. Мы никогда не разглашаем имена участников. Только в одном случае мы нарушаем это правило. Если интервьюер узнает, что ребенок в возрасте до 18 лет находится в опасности или нуждается в помощи, согласно законодательству¹ страны, мы должны заявить об этом в органы социальной службы (socialtjänsten). Тогда нам придется сообщить имя ребенка, чтобы взять его под защиту.

Вы не против того, чтобы Ваш ребенок принял участие в проекте?

На наши вопросы будут отвечать только дети, изъявившие желание участвовать в проекте. Мы опрашиваем детей, посещающих тюрьму или СИЗО. Мы задаем вопросы и детям, с которыми встречаемся в организации Bryggan («Причал»). Эта организация помогает детям, у которых один из родителей находится в учреждении системы исполнения наказаний.

Если ребенку только 8-14 лет, то один из родителей, отвечающий за его воспитание и не имеющий **никакого отношения** к системе исполнения наказаний, должен дать согласие на вовлечение ребенка в проект. Родитель ребенка, находящийся в учреждении системы исполнения наказаний, может возразить против участия ребенка в опросе. Дети старшего возраста, 15 или 16 лет, сами принимают решение о таком участии. Родителям не нужно давать свое согласие на это.

Если Вы согласны, чтобы у ребенка брали интервью, Вам не нужно ничего делать.

Вы против участия Вашего ребенка в проекте? Поговорите с уполномоченным по правам ребенка (barnombud) в тюрьме или СИЗО. Вы также можете обратиться к нам в организацию Bryggan или в Каролинский институт (Karolinska Institutet).

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Box 17070, 104 62 Stockholm
sara.ullman@ki.se, 073-673 41 61

¹ Согласно ст. 14 § 1 Закона «О социальной службе» (Socialtjänstlagen) мы обязаны заявлять в муниципальную комиссию по социальным случаям, когда ребенок находится в опасности.



COPING – sobre niños que tienen a la mamá o al papá en la cárcel o en prisión preventiva

¿Tiene hijos?

Esta carta es para usted que tiene hijos entre **8 y 16 años de edad**.

Estamos participando en un proyecto de investigación de la UE que se llama COPING. Participan cuatro Estados miembros de la UE: Suecia, Alemania, Gran Bretaña y Rumania.

El objetivo del proyecto es mejorar la vida de los niños que tienen a su padre o su madre en la cárcel o en prisión preventiva. Esperamos conseguir más ayuda para los niños y para sus familias.

¿Cómo participan los niños?

Queremos entrevistar a 250 niños (de 8 a 16 años). Los niños responden a preguntas sobre cómo se sienten. También contestan preguntas sobre su familia, su escuela y su tiempo libre. La persona que se ocupa del niño (el padre, la madre u otra persona) también contesta preguntas.

Quienes trabajamos en este estudio estamos obligados a guardar secreto profesional (confidencialidad). No le mostramos las respuestas a nadie. Nunca informamos los nombres de los participantes.

Hay un caso en que el secreto profesional se suspende. Si el entrevistador oye que un menor de 18 años está en peligro o necesita ayuda, está obligado por ley¹ a hacer una denuncia al servicio social. En ese caso se debe dar el nombre del menor para protegerle.

¿Acepta que su hijo participe?

Únicamente los niños que desean participar responden a las preguntas. Preguntamos a los niños que van a las visitas a las cárceles o las prisiones preventivas. También hacemos preguntas a los niños en Bryggan, una organización que ayuda a los niños cuyo padre o madre está en un establecimiento de Kriminalvården.

Si el niño tiene entre 8 y 14 años, el padre o la madre que no está en la cárcel o en prisión preventiva, debe dar su consentimiento para que el niño pueda participar en el proyecto. Si usted está dentro del Kriminalvården puede negarse a que su hijo participe. Los niños mayores, que tienen 15 o 16 años, pueden decidir ellos mismos si quieren participar. El padre o la madre no necesitan decir sí o no. **Si usted acepta que su hijo sea entrevistado, no necesita hacer nada.**

¿No desea que su hijo participe? Hable con su representante de menores (barnombud) en el establecimiento penal/la prisión preventiva. También se puede poner en contacto con nosotros en Bryggan o en el Instituto Karolinska.

Niina Koivumaa, RiksBryggan
Drottninggatan 38, 652 52 Karlstad
niina.koivumaa@bryggankarlstad.se
073-658 61 21

Sara Ullman, Karolinska Institutet
Centrum för psykiatriforskning
Box 17070, 104 62 Stockholm
sara.ullman@ki.se, 073-673 41 61

¹ Según la Ley de Servicio Social (Socialtjänstlagen) cap. 14 § 1, cuando un menor está en peligro, la situación debe ser denunciada ante la Comisión de Asuntos Sociales.

Appendix K – Letter to Non-Imprisoned Parent-Carer (Sweden)



**Karolinska
Institutet**

Anne H Berman, fil dr, docent
Leg psykolog, leg psykoterapeut
Specialist i klinisk psykologi

Institutionen för klinisk neurovetenskap
Centrum för psykiatriforskning

Stockholm
27 april 2011

Brev till dig som har barn 8-17 år med en frihetsberövad förälder

Hej,

Vi har fått din adress från den frihetsberövade föräldern till ditt/dina barn.

Vi tar kontakt med dig därför att vi deltar i ett EU-forskningsprojekt som heter COPING.
Projektets mål är förbättra livet för barn som har en förälder i fängelse eller häkte.

Vi behöver veta mer om hur barnen mår och hur de har det med sin familj, skola och fritid.
Den person som tar hand om barnet (förälder eller annan person) svarar också på frågor.

Vi hoppas att du och ditt/dina barn vill delta i en intervju. Ta gärna kontakt med oss:

Forskningsassistent, socionom Sara Ullman, 073-673 4161, sara.ullman@ki.se
Projektansvarig, docent, leg psykolog Anne H Berman, 070-4245360, anne.h.berman@ki.se

Vi samarbetar i detta projekt med ideella organisationen Bryggan, det går också bra att kontakta verksamhetsledarna för:

Stockholms Bryggan, Madelein Löfgren, 0735-105724, madelein@bryggan.a.se
Riksbryggan, Niina Koivumaa, 073-6586121, niina.koivumaa@riksbryggan.se

Om vi inte har hört något från dig inom några dagar, ringer vi om vi har fått telefonnummer från den frihetsberövade föräldern.

Med bästa hälsningar,

Anne H Berman
COPING-ansvarig, Sverige

Appendix L – Ethics Approval Application Form (UK)

THE UNIVERSITY OF HUDDERSFIELD

School of Human and Health Sciences – School Research Ethics Panel

OUTLINE OF PROPOSAL

Please complete and return via email to:
Kirsty Thomson SREP Administrator: hhs_srep@hud.ac.uk

Name of applicant: **Dr. Bernard Gallagher - on behalf of COPING team (UK)**

Title of study: **Children of Prisoners: Interventions and Mitigations to Strengthen Mental Health (COPING)**

Department: Behavioural and Social Sciences

Date sent: 22nd March 2010

| | |
|-----------------------|--|
| Issue | Please provide sufficient detail for SREP to assess strategies used to address ethical issues in the research proposal |
| Researcher(s) details | <p>COPING is a major, pan-European, EU-funded, research study of children of prisoners. The Principal Investigator on the study is Prof. Adele Jones.</p> <p>The research is being carried out by four separate country-based research teams, in Germany, Sweden, Romania and the UK. This application relates only to the research that is to be carried out in the UK. Ethical approval for research in these other countries will be sought, by agencies, within each of these countries.</p> <p>The research involves a large number of colleagues from across the School of Human and Health Sciences, the Nationwide Children's Research Centre and an NGO - POPS (Partners of Prisoners - which works with families who have a member in prison). Dr. Gallagher has responsibility for the ethical management of the research in the UK. Dr. Gallagher is applying for ethical approval for all stages of the research, in the UK, in this application.</p> <p>Members of the research team in the UK (but also the three other participating countries) have, between them, a vast amount of experience in social and psychological research, and also with the methodologies that it is proposed using in this study.</p> |
| Supervisor details | N/A |
| Aim / objectives | 1. Enhance understanding of the mental health needs of children of prisoners |

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| | <p>2. Explore childhood resilience and coping strategies, and assess the value of these concepts for planning interventions</p> <p>3. Bring together European and international perspectives to investigate the nature and extent of mental health problems affecting children in this group</p> <p>4. Identify relevant and effective policy interventions to ameliorate the mental health implications for affected children</p> <p>5. Raise the awareness of policy makers to the needs of this under-researched group</p> |
| <p>Brief overview of research methodology</p> | <p>This is a three year project that consists of four main stages. The months (M) between which each stage is to be conducted, during the course of this three year period (M1 – M36), are indicated below.</p> <p>1. Survey of children of prisoners (M1-M12)</p> <p>A largely questionnaire-based survey among 250 children (aged 7-16 years) and their non-imprisoned parents/carers. Children will be asked to complete the Goodman Strengths and Difficulty Questionnaire (SDQ) and the Rosenberg Self-Esteem Scale (SES), which assess behaviour and self-esteem respectively. The non-imprisoned parent/carer would be asked to complete the parent version of the SDQ. The child and non-imprisoned parent/carer will also be asked a small number of questions about their family background (for example, lifestyle, family composition, protective and risk factors in the child's life and the imprisoned parent's/carer's history). It is anticipated that this work will be carried out with children whose parents/carers are in prisons in north west England. The survey would be administered either within a prison setting, the offices of POPS or the family's/child's home. The survey would be administered by members of the research team in conjunction with POPS.</p> <p>Sampling</p> <p>Adults attending prison visiting centres will be approached, at random, to take part in the survey. Adults who are visiting a co-parent/carer in prison and who have aged 7-16 years will be eligible to take part in the survey</p> <p>Awareness-raising</p> <p>The researchers, in conjunction with POPS, hope to undertake an awareness-raising phase, in respect of the survey, prior to the start of fieldwork. We are hoping that this reassure children and parent/carers about the research before they are approached formally to take part in it.</p> |

Non-participating children and families

There is little or no reliable data on the children of prisoners. This includes even very basic data such as their numbers and socio-demographic characteristics. This means that we would not have any way of determining how representative our sample was of all children of prisoners. We are proposing, therefore, to ask non-imprisoned parents/carers, of families who refuse to take part in the survey, for some basic information about their situation, for example, age and gender of children and parents/carers, precise child-parent/carer relationships, location of prison, length of sentence and offences committed. The collection of this information would be subject to the same ethical procedures as the main survey, for example, consent forms and information sheets.

2. Child-centred interviews (M12-M22)

Interviews would be carried out with a stratified random sample of the above children. The children would be stratified according to their Total Difficulties score on the SDQ. Interviews would be carried out with 35-40 children. The purpose of the interviews would be to obtain a detailed insight into the lives and views of children of prisoners. Children will be asked about a wide range of aspects of their lives, such as family life, education and leisure and the impact of their parents'/carers' imprisonment. The interviews will not be concerned only with areas of difficulty but will also explore coping strategies. The non-imprisoned and imprisoned parents/carers of the above children would also be interviewed, and on the same range of topics. The survey would be administered either within a prison setting, the offices of POPS or the family's/child's home.

3. Stakeholder and caregiver consultation (M18-M28)

Interviews would be held with stakeholders and carers who are involved with children who have a parent in prison. The stakeholder group would include prison staff, NGO staff and social workers. The carer group would involve foster carers, the staff of institutional homes providing care for children, and the relatives and parents of children who have a parent in prison. The objective of this stage of the study is to broaden the collection of evidence about the needs of children, and the extent to which the existing provision of interventions, support and criminal justice processes is aligned with these needs.

4. Mapping of services and interventions (M1-M28)

A mapping exercise will be carried out to identify, map and document mental health care, and community-based services and interventions for children of prisoners. This will be largely an internet-based search but there will be some contact with agency workers (from NGOs, for example, and probably all by telephone) in order to obtain additional information on services provided.

All the above interviews (stages 2-4) will, subject to the research participant's consent, be tape-recorded. (In the case of prisoners, this will also be subject to the permission of prison governor.)

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| Permissions for study | <p>Families</p> <p>I and my colleagues will meet with The Prison Service regional office for north west England and individual prison governors, to obtain permission for: fieldwork to be carried out on prison premises; approaches to be made to prisoners' families; and for contact to be made with prisoners. (Fieldwork will be carried out in a small number of male and female prisons.)</p> <p>Agency workers</p> <p>The chief officers of any agency in which it is hoped to carry out interviews with agency staff or other relevant stakeholders will be approached for permission to carry out these interviews. These chief officers will include prison governors, the directors of children's services departments and the chief executives of NGOs.</p> <p>In light of the sensitivity of this study, the research team believes that it is most appropriate to begin the process of seeking these permissions only after they have received ethical approval from SREP. (In fact, the National Offender Management Service, which incorporates The Prison Service, requires appropriate ethical approval to be granted before considering requests for permission to be granted.)</p> |
| Access to participants | <p>Families</p> <p>Families would be approached to take part in the survey during the course of their visits to the imprisoned parents/carers. These approaches would be made in conjunction with POPS. (POPS provides support to the families of offenders mostly in the north west region of England. POPS provides support to thousands of families each year.) Initially, the non-imprisoned parent/carer would be approached, the study explained to him/her, s/he would be given an information sheet and then asked if s/he wished to take part.</p> <p>If this parent/carer agreed to take part in the survey, then their child(ren) would be approached, given an explanation of the research, provided with an information sheet and asked if they wished to take part in the research.</p> <p>The researchers would be guided by the non-imprisoned parent/carer as to whether consent should be sought from the imprisoned parent/carer for the child's participation in the survey stage of the research.</p> <p>If family members agreed to take part in the survey, then they would be asked to sign a consent form. Once this stage of the research was complete, a random sample of these families would be asked if they wished to take part in the in-depth interview stage of the research.</p> <p>If these participants wished to take part in the interview stage, they would be given separate</p> |

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| | <p>information sheets and would be asked to sign an additional consent form.</p> <p>It would be made clear to non-imprisoned parents/carers, children and imprisoned parents/carers that they have a right to refuse to take part in the research, decline to answer particular questions or withdraw from the research at any point, and that if they do any of these, this would not have any adverse consequences for any member of their family – least of all the imprisoned parent/carer.</p> <p>Agency workers</p> <p>Members of the research team will either ask chief officers of targeted organisations to identify participants for the research or they will identify such participants themselves. These participants will ultimately be approached by a member of the research team, the study would be explained to them, they would be provided with an information sheet and they would be asked to sign a consent form if they wished to take part. It will be made clear to all agency workers that they can refuse to take part in the research, decline to answer particular questions or withdraw from it at any point, and that if they do either of these, then this would not have any adverse consequences for them or their organisation.</p> |
| Confidentiality | <p>Every participant in the research would be informed that all the information they provided to the research - with two exceptions - would be treated in the strictest confidence.</p> <p>The first exception would be where they indicated that any person was at risk. They would be informed that should such information arise then this might have to be passed to an appropriate authority.</p> <p>The second exception would be where they indicated there was a threat to prison security. They would again be informed that should such information arise then this might have to be passed to an appropriate authority.</p> |
| Anonymity | <p>Every participant in the research would be given an assurance of anonymity - subject to the above exceptions. If names are used in any report emanating from the research, then these would be pseudonyms. If necessary, details of 'cases' would be altered in such reports (without changing the substantive nature of that case) in order to ensure anonymity.</p> <p>As it would not serve any purpose, we would not record any names of children or parents/carers during the course of the survey. This will help preserve anonymity but also help reassure participants.</p> |
| Psychological support for participants | <p>Families</p> <p>Children and their parents/carers will be given cards and/or lists with the contact details of one or more appropriate support agencies.</p> |

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| | <p>Agency workers</p> <p>It is expected that agency workers would be able to access existing support services within their organisation. However, they will also be given a card and/or list with the contact details of relevant support organisations.</p> |
| <p>Researcher safety / support (attach complete University Risk Analysis and Management form)</p> | <p>It is not expected that this research will give rise to any significant researcher safety or support issues. However, a full consideration of the issues that might arise and the way in which they have been, and would be addressed, is contained in the detailed Risk Analysis and Management form.</p> |
| <p>Identify any potential conflicts of interest</p> | <p>N/A</p> |
| <p>Please supply copies of all relevant supporting documentation electronically. If this is not available electronically, please provide explanation and supply hard copy</p> | |
| <p>Information sheet</p> | <p>A draft of the child information sheet is attached. We have not yet designed the other information sheets that we will need but they will – with appropriate modifications - be similar in content and format to the child information sheet.</p> |
| <p>Consent form</p> | <p>A draft of the child consent form is attached. We have not yet designed the other consent forms that we will need but they will – with appropriate modifications - be similar in content and format to the child consent form.</p> |
| <p>Letters</p> | <p>It is planned that initial contacts with families will be in the form of face-to-face meetings as they come to prison to visit imprisoned parents/carers. It may be that POPS will embark upon some publicity work in the run up to the fieldwork and also facilitate these initials contacts. We will not, therefore, be using letters to contact would-be participants for this stage of the research.</p> <p>Approaches to other participants i.e. agencies and other stakeholders, will be by letter initially. These letters have not yet been drafted but will follow a fairly standard format for such letters, and will also be accompanied by appropriate information sheets and a copy of the Research Protocol.</p> |
| <p>Questionnaire</p> | <p>The first stage of this study – the survey of children of prisoners – will be mostly, if not entirely, questionnaire-based. This will be the only stage of the research to use questionnaires. The survey will consist, in the main, of three standardised questionnaires: the SDQ (child version, attached), the SDQ (parent version, attached) and the SES (attached). The child and non-imprisoned parent/carer will also be asked a small number of more general questions - as outlined above, under Methodology.</p> |

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| Interview schedule | Interviews schedules will be used in the second and third stages of this research – the in-depth child interviews, and the stakeholder and caregiver consultations, respectively. These schedules have not been designed yet but they will cover the topics outlined above – under Methodology. Special care will be taken in drafting the questions for children (but also their parents/carers) to ensure due sensitivity. These interviews are also designed to identify coping and resilience on the part of children (and their parents/carers), and so family members should, therefore, find them uplifting. |
| Dissemination of results | The dissemination of results from this study constitutes a separate <i>work package</i> within the overall COPING project. The organisation with the lead for this work package is the Paris-based EUROCHIPS (European Network for Children of Imprisoned Parents) organisation – a Europe-wide initiative to promote the well-being of children who have a parent in prison. EUROCHIPS has planned an extensive dissemination programme, including a project website (with child-centred pages), workshops and meetings, child-centred dissemination work and a raft of publications in academic and professional journals, and publicity material. Led by EUROCHIPS, the results of the COPING study will be targeted at numerous European-level and other international organisations, for example, UNICEF, the Committee on the Rights of the Child and WHO. |
| Other issues | <p>Criminal Record Bureau (CRB) checks</p> <p>All research staff who are to have contact with children will be subject to CRB checks (unless they have been given CRB clearance already as a result of their current work with children).</p> <p>Data protection</p> <p>All the research staff fully understand the importance of data protection. They will all be made fully aware of the University's Data Protection Guidance Note and the legislation upon which it is based (largely the Data Protection Act 1998).</p> |
| Where application is to be made to NHS Research Ethics Committee | N/A – data will not be collected from the health sector |
| All documentation has been read by supervisor (where applicable) | <p>Please confirm. This proposal will not be considered unless the supervisor has submitted a report confirming that (s)he has read all documents and supports their submission to SREP</p> <p>N/A</p> |

All documentation must be submitted to the SREP administrator. All proposals will be reviewed by two members of SREP. If it is considered necessary to discuss the proposal with the full SREP, the applicant (and their supervisor if the applicant is a student) will be invited to attend the next SREP meeting.

If you have any queries relating to the completion of this form or any other queries relating to SREP's consideration of this proposal, please do not hesitate to contact either of the co-chairs of SREP: Professor Eric Blyth e.d.blyth@hud.ac.uk; ☎ [47] 2457 or Professor Nigel King n.king@hud.ac.uk; ☎ [47] 2812

Appendix M – Risk Assessment and Management Form (UK)

THE UNIVERSITY OF HUDDERSFIELD: RISK ANALYSIS & MANAGEMENT

| ACTIVITY: Research ('COPING' – Children of Prisoners, Interventions and Mitigations to strengthen Mental Health) | | | Name: Dr. Bernard Gallagher (on behalf of the COPING (UK) team) | |
|---|---|----------------|--|--|
| LOCATION: UK-wide possibly but probably mainly in north-west England. The specific locations are as follows: prisons, the offices of POPS* and other agencies, and family homes *POPS (Partners of Prisoners) is one of the largest voluntary providers in the UK of support to the families of prisoners, and is a key member of this research consortium | | | Date: 1.1.10 - 31.12.12 | Review Date: N/A |
| Hazard(s) Identified | Details of Risk(s) | People at Risk | Risk management measures | Other comments |
| 1. Researchers will be going into prison visiting areas to recruit families (i.e. non-imprisoned parents/carers and their children) to take part in a survey. | We believe there is no particular or foreseeable risk attached to this work. | Researchers | Although we believe there is no particular or foreseeable risk attached to this work, there will be safeguards in place to ensure that anything untoward does not occur. In particular, researchers will be working under the supervision of both prison staff – who are ultimately responsible for the running of prisons – and POPS. This should reduce the minimal risk still further. Researchers will be on prison property only with the permission of the prison governor. | Interviewers will carry mobile phones at all times when they are involved in any fieldwork (except where this may be forbidden, such as certain parts of prison premises). Researchers will be given training in all aspects of the research, including risk management. |
| 2. Researchers will be administering a survey to families either in prison visiting areas, at the offices of POPS or in family homes | Again, we believe there is no particular or foreseeable risk attached to this stage of the work when it is carried out in prisons or the offices of POPS. There is a slightly heightened degree of risk to the researcher's personal safety when s/he is carrying out interviews in family homes. | Researchers | When this work is carried out in prisons it will be in relatively public areas. When it is carried out in POPS offices, there will be members of POPS staff nearby. If interviews are carried out at a family's home, the researcher will inform his/her line manager of this arrangement in advance. This will include the names and address of the interviewees, and the date of the interview. On the day of the interview, the researcher will contact his/her line manager when s/he arrives at, and when s/he leaves, the interview. The researcher will contact his/her line manager should any issues relating to safety arise. | As above |

| | | | | |
|--|---|--------------------|--|-----------------|
| <p>3. Researchers will be interviewing children and their non-imprisoned parent/carers in prison visiting areas, the offices of POPS or in family homes.</p> | <p>As above</p> | <p>Researchers</p> | <p>As above</p> | <p>As above</p> |
| <p>4. Researchers will be interviewing prisoners in prison</p> | <p>We believe there is no particular or foreseeable risk attached to this work.</p> | <p>Researchers</p> | <p>When this work is carried out, it will be done with the consent of the person who is imprisoned, with the permission of the governor, under the supervision of prison staff and in a relatively public place.</p> | <p>As above</p> |
| <p>5. Researchers will be interviewing stakeholders in relation to the needs of children with parents/carers in prison and the ability of existing services to meet these needs.</p> | <p>We believe there is no particular or foreseeable risk attached to this work.</p> | <p>Researchers</p> | <p>When this work is carried out it will be subject to the same safeguards as are outlined above in 2. and 4. i.e. with all relevant consent and permissions, and monitoring of researcher' whereabouts.</p> | <p>As above</p> |
| <p>6. Researchers will be involved in a largely-internet-based search to identify UK-wide interventions for the children of prisoners</p> | <p>We believe there is no particular or foreseeable risk attached to this work.</p> | <p>Researchers</p> | <p>This work will be office-based and carried out with normal supervisory arrangements in place. This work may involve further information being gathered from agency workers but all of this work is expected to be done via telephone.</p> | <p>None</p> |
| <p>7. Researchers will be involved in an area of relatively sensitive work, which may occasionally highlight</p> | <p>It is possible that researchers could find these incidents distressing.</p> | <p>Researchers</p> | <p>All researchers will be working under a structured, supervisory system. There will be regular de-briefings and all researchers will be made aware of the occupational health services provided by the University.</p> | <p>None</p> |

| | | | | |
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| <p>more acute issues (e.g. families with problems).</p> <p>-----</p> <p>8. Children, their non-imprisoned parent/carer and their imprisoned parent/carer will be asked about potentially sensitive areas of their lives.</p> | <p>-----</p> <p>It is possible that these respondents will find these topics distressing – although this is more likely to be an issue in the interview stage as opposed to the survey stage.</p> | <p>-----</p> <p>Children, non-imprisoned parents/carers and imprisoned parents/carers</p> | <p>-----</p> <p>All respondents will be provided with a briefing both before they agree to take part in the study and again before they engage in the survey or interview stage. The survey and subsequent interviews will be fairly neutral/fact-finding, about the effects, if any, of parental/carer imprisonment on a child. The survey and interviews will also be concerned with identifying areas of coping and resilience, which the respondents should find uplifting.</p> <p>All respondents will be given the contact numbers and website addresses of organizations that are appropriate to the needs they might have as a result of taking part in the survey or interview stage of this research.</p> | <p>-----</p> <p>None</p> |
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Appendix N – Child Assent Form (UK)

THE CHILDREN'S WELL-BEING SURVEY

Survey Consent Form (Child)

Before you take part in the study, please double check the information I have given you, make sure you are happy with it, and then tick each of the boxes and sign this form to show that you have agreed to take part in this survey.

I have had the study properly explained to me and I have had a proper chance to ask questions

I give permission for anything I say to be used in any report coming out of the study but only on the condition that I will not be named and that it will not be possible to identify me in any other way.

I have been told that all the information I give will be confidential, which means that it will not be shared with anyone else outside of the research team, but with one exception (see next line)

I realise that if I give any information about anyone, including me, who is being, or might be, hurt by anyone, then this information might have to be passed on to someone else.

I know that I can refuse to take part in this survey, choose not to answer certain questions and drop out at any point if I want.

Please write your name here:

Please put your signature here:

Date:

Name of Researcher:

Signature:

Date:

Appendix O – Family Information Sheet



COPING: What is life like having a parent in prison?

If you have a parent in prison, what is life like without them?

We would like to try and improve life for children and families with a parent in prison.

To do this we need to hear from people like you who are already in this situation to help with our research.

This leaflet will give you more information about how you can help and what is involved.

About the project

The official title of this project is: Children of Prisoners, Interventions and Mitigations to Strengthen Mental Health, or simply COPING. The project involves researching how children and young people are affected by having a parent in prison. This is a European research project involving England, Germany, Romania and Sweden.

Who will be doing the research?

The research in the UK will be done by staff from the University of Huddersfield, working with Partners of Prisoners and Families Support Group (POPS), an organisation which supports families and children where a parent is in prison.

What kind of research is taking place?

The research will involve finding out the views of children, young people, their families and sometimes others who know them well.

The first stage involves 250 children and young people who have a parent in prison completing a questionnaire. Your parent or carer will also be asked to complete a questionnaire.



Anybody aged between 7 and 16 can take part including brothers and sisters from the same family, along with their parent or carer.

You will be asked about how life has changed since your parent went into prison: what life is like day to day, at home, at school and during your spare time.

Where will you complete the questionnaire?

You can complete the questionnaire at the Visiting Centre when you are visiting your parent in prison.

Will there be anyone to help fill in the questionnaire?

Yes. A member of staff from the Visiting Centre or research team will be on hand to help you to fill in the questionnaire, answer any questions you have, and help with reading, or arrange for an interpreter to assist you if English is not your first language.

How long will it take to fill in the questionnaire?

The questionnaire will probably take about half an hour.

What will happen after filling in the questionnaire?

The second stage will involve 40 of the children and young people who have completed the questionnaire, from different families, being asked to take part in a face to face interview with one of the research team.



What will the interview be about and who is involved?

The interview will be about how you think having a parent in prison has affected you and your family. If you would be happy to be interviewed, please tell a member of staff at the Visiting Centre.

We would also like to interview your parent or carer to find out how they have been effected.

We would also like to interview your parent who is in prison. However, we will ask you and your parent or carer about this first.

Where will the interviews take place?

This is up to you, wherever you will feel most comfortable. This could be at your home, at the POPS Office in Manchester, or somewhere else if you prefer.

How long will the interview take?

The interviews will probably take about an hour.

What will happen after the questionnaire and the interviews?

Once the questionnaire and interviews have taken place, the researchers will write a report on what they have found out. The report will include your views and descriptions of what it is like to be a child or young person with a parent in prison. It will also include information on services available to help children, young people and their families in this situation.

This will also be carried out in Germany, Romania and Sweden.

Once completed, the report will be sent to governments and other influential bodies across Europe. When the researchers present their findings we may ask you to be involved. This is because we believe that you and your families are the experts in understanding what it is like to have a parent in prison.

How will you be thanked for taking part?

After the interviews you will receive a £25 voucher, to say thank you for your time and effort in helping us with our research.

What changes will there be after the research?

We don't know yet what the changes will be. However, we hope that there will be more understanding about how having a parent in prison affects children and young people.

We hope that governments and support agencies will learn from the research how to improve the lives of children and young people who are affected by having a parent in prison. This could mean improvements for children and young people when contacting and visiting parents in prison. It could also mean improvements for children, young people and their parents or carers at home, whilst the parent is in prison and when they return home.

What do I need to do to take part?

All you need to do is speak to the parent or carer and then tell a member of staff at the Visiting Centre that you would like to take part.

You and your parent or carer will be asked to sign a consent form and will be given the questionnaire to fill in.

What should I do if I have questions about the research?

If you have any questions or would like further information please contact a member of POPS or one of the researchers using the contact details below.

POPS
Tel: 0161 7952693
E-mail: mail@partnersofprisoners.co.uk

Researchers
Tel: 01484 472808
E-mail: coping.eu@hud.ac.uk