PROJECT DELIVERABLE

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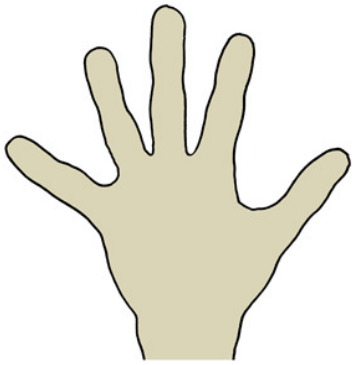
224216

Project acronym:
HANDS

Project title:

Helping **A**utism-diagnosed teenagers
Navigate and **D**evelop **S**ocially



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Summary:
This deliverable reports on the establishment of the Ethics Board within the Hands-project and on the activities of the board during Year 2 of the project period i.e. from June 2009 to May 2010.

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Table of content

Revision History

Submitted for review on July 8, 2010.

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Overview

The function of the Ethics Board (EB) is described in section 2.1.4 in the Description of Work approved by the Commission (Appendix A). This Annual Report reports on the activities of the EB during Year 2.

The EB has been supported administratively by the main project partner AAU who has allocated Dr. Thomas Ploug, an expert in IT-Ethics to act as the secretary to the EB.

The membership of the EB has not changed in Year 2.

Meetings and other activities

The EB has held two meetings and been in discussion between meetings on the EB closed Moodle discussion board.

The first meeting was held in Stockholm on the 3rd of June 2009 and the second in London 25th of May 2010, both in conjunction with general meetings of the consortium. The EB Chairperson, Professor Søren Holm, has also participated in the HANDS workshop in Aalborg on Dec. 1, 2009.

Minutes from the meetings have been included as Appendix B and C.

Discussions and approvals

1. At the meeting in Stockholm EB discussed the applications ”Overview and Cognitive Psychology” and ”Applicability in the Learning Environment”. The latter was approved by EB without any changes. The former included a crossover-design according to which some children should have their support systems withdrawn after prototype 1 testing. The EB therefore suggested that the project design was reconsidered. After a redesign this application has also been approved by EB.

2. No major changes to the basic research design in the ongoing approved research proposals have been proposed by the consortium.

The EB has approved minor amendments to the ongoing research including the use of the Social Responsiveness Scale (SRS) for baseline and post-intervention assessment. This scale is observer-scored and will be completed independently by a teacher and a parent.

3. In developing the HANDS toolset prototype 2 two new functionalities with ethical implications have been proposed as possible parts of the toolkit: a) GPS activated functions and logging and b) further interface developments including a 'social agent'. The EB has had in-depth discussions about both.

a. GPS functionality

In relation to GPS activated functionalities the EB sees an important distinction between continuous logging of GPS data, and location specific activation of functionalities with discrete logging of data concerning the activation. Continuous logging potentially infringes spatial privacy in significant ways.

The EB further discussed who should have access to activation data and decided that a policy should be developed for each participating school. In discussion with the consortium the EB developed the following principles for ethical use of GPS in the HANDS toolset:

1. Continuous logging of GPS data should not be implemented in the HANDS toolset
2. GPS controlled activation of HANDS functionality should be negotiated with users and only be used with consent from both users and parents
3. Location specific logging of GPS data should only be activated in cases where a functionality is activated, it should not be used for monitoring whether a user visits an 'undesirable' location
4. Each school should adopt an explicit policy concerning parents' possibility to request specific information about logged GPS information. This policy can be either:
    a. Teachers can disclose logged GPS information to parents, but only if the parents specifically request such disclosure
    b. Teachers cannot disclose logged GPS information to parents if the parents specifically request such disclosure

The policy should apply across the school to all users and parents

b. Social agent

Since all choices of guidance may influence the specific behaviour of the child and since the social agent is only used for the purpose of guiding the children through the software in the HANDS toolset, the EB sees no in principle problem in implementing an avatar/social agent in the toolset.

It was, however noted that there is some risk that some children with an autism spectrum disorder will relate to the social agent as a real person. This may lead to psychological, social or behavioural problems of various kinds. A careful evaluation of this risk must be carried out for each individual child before a social agent is made part of their individualised HANDS toolset.

In some sense there is thus a paradox. If the child realises that the social agent is not a real agent, the agent is unlikely to be very persuasive, but its implementation does not raise significant ethical issues. If the child perceives the social agent as a real person, the persuasion is likely to be more effective, but raises far more significant ethical questions.

3. Approvals

The EB has evaluated and approved the following proposals for research in HANDS Phase 2: a) The Applicability in the Learning Environment: Evaluation of HANDS applicability in mainstream schools, b) Applicability in the Learning Environment: Implementation and Evaluation Prototype 2, c) Overall Project Evaluation Framework and Cognitive Psychology Testing.

Appendix A – Description of the Ethical Board in the approved "Description of Work"

The Ethical Board (EB)

As part of the HANDS project an Ethical Board (EB) will be established. The board will follow the practical system development as well as the empirical sub-projects in HANDS from beginning to end. In order to do so, it is essential that the members of the Ethical Board include

i) respected members of the scientific community and industry, without violating any IPR or regulations in the CA,
ii) specialists in the care and the education [of] children and young people with ASD,
iii) persons qualified in computer ethics and ethical theory in general,
iv) persons representing the interests of the young people with an autism diagnosis and their families,
v) members independent of the research within HANDS.

EB should consist of 6-8 members elected by the HANDS project leader and the chairman of EB in agreement. The chairman of the EB will be Professor Søren Holm, Director of the Centre for Ethics, Law and Society, Cardiff University (see CV in Appendix I).

All partners will be asked to propose persons to be considered for membership of the EB. The members will appointed by the chairman of the EB and the project coordinator in cooperation.

It will be the responsibility of EB to

i. discuss general ethical questions related to HANDS
ii. discuss and ethically evaluate the system requirements of the systems which are supposed to be tested and used by children and young people with an autism diagnosis
iii. discuss and ethically evaluate all clinical tests involving children and young people with an autism diagnosis (including practical plans and questions regarding consent).

The EB is supposed to report all discussion and evaluations to the co-ordinator of Hands. In addition there will be an annual report from EB.

There will be separate EB meetings organised by the Project Management in corporation with EB chairman. In addition, the members of the EB will be invited to the general project meetings. EB is expected to hold 3-4 meetings

through the project. The Project management will provide secretarial assistance for the EB meetings. The minutes from the EB meetings including all advices regarding tests and experiments will be sent to the Project Management who will take further action.

EB should during the entire project period carry out a constructive dialogue with the members from the groups involved in the ''hands on'' practice and with the HANDS researchers working with ICT ethics.

All partners are supposed to describe all ethically relevant problems in a format which makes it possible to discuss the problems at the EB meetings. In some cases EB will probably also be able to discuss the problems over e-mail or using video conferences. In particular, all clinical tests involving young people with an autism diagnosis should be presented and approved by EB before they are carried out. All decisions made by EB on ethical issues must be followed by the consortium members. In question of doubt the project board makes the final decision.

In case of clinical trials and experiments involving young people with an autism diagnosis the responsible researchers will be asked to report to EB. In particular, it will be important that all ethically relevant events during the empirical research are reported.

The members of EB monitor the global trends in their fields, and the tasks of the EB is to provide HANDS / the Commission with a brief yearly review of the project, to focus on the long-term vision of the project and to make strategic recommendations to the project management board. The EB will in addition to this, oversee the implementation of the projects activities with regards to the research, networking of researchers, dissemination of information and exploitation of results as well as the integration of these four components. It is envisioned that the EB on top of their formal tasks also will provide HANDS with more informal advices.

Appendix B –

Minutes of Ethical Board of HANDS meeting in Stockholm, 3 June, 2009.

Present:

Richard Mills (RM), Søren Holmstoel (SHS), Søren Holm (SH), Zsuzsanna Szilvasy (ZS), Thomas Ploug (TP).

Absent with apology:

Dawn Hill (DH), Anne Gerdes (AG), Jesper Hållén (JH).

Point 1. Welcome

a) Presentation of members.
b) EB has three purposes: Dealing with the sensitive issues recognized by the EU commission to be attached to the HANDS project. Dealing with the issues brought to the EB by the researchers. Ensuring that the same standards are applied among the various partners in the HANDS project without imposing strict uniformity of procedures.

Points 2, 3 and 4: Applications and data storage

Ethical Board of HANDS-project
Response to applications ”Overview and Cognitive Psychology” and ”Applicability in the Learning Environment”.

The response covers seven issues numbered accordingly.

I. Data storage and exchange between partners.

a) Destruction of data:
Comment: Project board has to make a decision on date of destruction before the next PB meeting. EB suggests that data is destroyed after 10 years from project end date. A straight answer must be available to participants.

b) Centralized versus de-centralized storage of data:
Comment: Data must be stored in a secure manner. Whether or not this entails centralized or decentralized storage we shall leave to PB to

decide.

II. Feedback to parents, children and teachers on results of Cognitive Testing.

Comment: On the one hand, feedback may create bias among the participants and therefore undermine the value of the testing. On the other hand, parents may want to know. EB finds that on balance the openness is to be preferred ethically as well as pragmatically. Moreover EB finds that few parents are likely to be requesting this information. Finally, the problem of bias may simply be solved by the explaining the results to the parents, children and teachers. There are to be made no distinctions between parents, children and teachers unless standard practice on such testing in the school makes such distinctions.

III. Informed consent

a) Teachers' consent:
Comment: Consent is required on the grounds that it is considered best practice. Among others, it adds to the level of information among the staff at schools and aids fidelity and consistency.

b) "Child Consent Form":
Comment: The information in the consent form should be individualized and communicated in a way that is more sensitive to needs of the child as negotiated between teachers and parents. Thus it may e.g. be based on pictogram, photos or the like. The current form presupposes normal communicative skills. Information must individualized. The number of questions in the "Child Consent Form" is appropriate. Signature is not vital. In the absence of signature a witness and signature of that witness is required.

c) "Parental Consent Form":
Comment: Point 2 must be added the following clause at the end "… and information already held by the school that may be of value for this project". (Parents must also consent to information that is already held by the school that may come to be used in the project).

IV. Anonymity.

Comment: Persons in the dataset is anonymous (no names) but not non-

identifiable (the information make a person uniquely identifiable – at least among the researchers). Using a self-explanatory code for persons may make test-persons uniquely identifiable to other persons. Hence better coding may be a good idea.

V. Project design (crossover-design).

Comment: Returning to a daily life without support systems carries a significant risk of causing harm and distress to the children participating in the testing. Especially for the children having become dependent upon the support systems. This in turn may be disruptive and detrimental to the child's education, and may cause distress to parents and other siblings. Secondly, as a pragmatic consideration, the parents are considered less likely to join the project if they know in advance that their children may suffer the loss of their support system. Thirdly, the childrens' commitment to the project is considered likely to be diminished if they know that the support systems may be withdrawn after prototype 1 testing. The EB therefore suggests that the project design is reconsidered.

VI. Generally:

Comments: EB suggests that the schools prepare for the possible disappointment caused by their children not being included in the project.

VII. Length and format of applications:

Comment: Too many papers. Reference to appendices must be by pagina. Reference to headline numbering in project description. All ethical considerations must go into the application form and not in the appendices.

Point 5: Future meetings:

Next general meeting with EB meeting will be held in London 25-27th of May, 2010.

Point 6: AOB

a) Moodle:

Future handling of applications: Upload of applications. Soren and Thomas highlights ethical aspects. Other suggestions to ethical issues are emailed to Thomas and added to the already highlighted issues. Thereafter the issues are discussed for no more than three weeks. Soren and Thomas draft a response to the applicants. The response is made available for discussion on Moodle for one week.

b) Annual report:

EB must provide an annual report to the EU Commission. Please send a brief (3-4 lines) and relevant description of yourself to be used in this report to Thomas (ploug@hum.aau.dk)

Appendix C –

Minutes of EB meeting, London 25th of May, 2010

Present: Søren Holm, Zsusanna, Anne Gerdes, Dawn Hill, Thomas Ploug

Absent with apology: Jesper Hållén, Richard Mills, Søren Holmstoel

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Agenda

1. New applications
2. Prototype 2: GPS functionality
3. Prototype 2: Social agent

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AD 1)
New applications will be uploaded to the EB Moodle. Many of the issues in the applications have been addressed in previous meetings. Upon upload further discussion will follow.

One issue may be dealt with here in London. The second phase involves the use of The Social Responsiveness Scale (SRS) aimed at mapping the social impairment characteristic of the person with an autism diagnosis. This scale is observer-scored and will be completed by a teacher and a parent before and after the use of HANDS. The EB approves of the use of this test.

AD 2)
Important distinction between a continous logging of data and logging when persons enter specific areas. Even in the second sense the logging may be used for surveillance – one would be able to tell when a person enters a certain area and act on this information.

a) What data is logged?
Location, time, interaction and potentially direction

b) Who should have access to the data?

- Differentiated access to data between teachers, parents and researchers
- Teachers: Data may support any activity on behalf of the teacher except for the particular purpose of tracking the user.
- Researchers: Data in anonymised form may be freely accessed.
- Parents: Clear policy required. It may provide same access as teachers or deny such access. May be negotiated at school level. The policy should be

available to the children using the phone and they should be informed of the content of the policy.

Note that the EB cannot fully address the issue of implementing the GPS feature into the HANDS toolset on the basis of the available information. More information is therefore required before final approval can be given.

This information has been obtained from the Project Board and a set of ethical principles for GPS use developed.

AD 3)
Since all choices of guidance may influence the specific behaviour of the child and since the social agent is only used for the purpose of guiding the children through the software in the HANDS toolset, the EB sees no problem in implementing an avatar/social agent in the toolset.

It should be noted, however, that there is some risk that some children with an autism diagnosis will relate to the social agent as a real person. This may lead to problems of various kinds. Hence EB recommends that special attention is given to this potential problem.

In some sense there is thus a paradox. If the child realises that the social agent is not a real agent, the agent is unlikely to be very persuasive, but its implementation does not raise significant ethical issues. If the child perceives the social agent as a real person, the persuasion is likely to be more effective, but raises far more significant ethical questions.