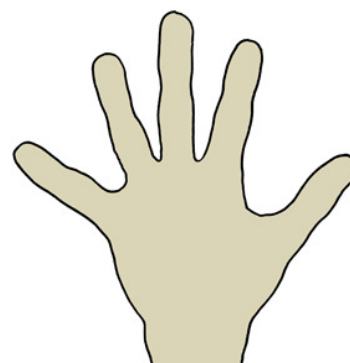# HANDS DELIVERABLE 7.4.1

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D7.4.1 REPORT ON THE ETHICS OF HANDS

CONTENT

1. INTRODUCTION

In the wake of the immense technological breakthroughs in recent years and their extensive implementation into virtually all areas of daily living a number of ethical questions and considerations have been raised and debated. Together these discussions have come to form part of the rapidly growing field of computer or ICT ethics. This relatively new field of research shares many of its topics with the existing fields in the greater landscape of applied ethics, but is marked by the specific focus upon the ways in which information and communication technology – computers in particular – may transform and hence revitalize the relevant issues and problems.

As reflected by the HANDS-project, information and communication technology (ICT) are also becoming increasingly important in supporting the social function of people with a range of disabilities. This raises a number of ethical issues about the justification for developing such tools, the possible obligation to provide them, and issues around experimentation and testing. In this specific context ICT tools often have to be validated and shown to be effective in a quite different way than is required in the context of ordinary, commercially available applications and tools. In this report we will first consider the justification for, and obligation to develop and provide such tools; and then in the following section consider the specific research ethics problems that the development raises. In the third section more general problems are considered, and finally, in the fourth section, a value-sensitive strategy for the future development of ICT tools for young people with ASD is is sketched. As will be evident the considerations of informed consent – in the second section – has attracted some attention by the researchers as well as the Ethical Committee of the HANDS project, and therefore will be given extensive attention in this report. Before moving on this section, we shall, however, start by considering the ethical reasons for pursuing the development of tools for young people with ASD. These reasons clearly have a bearing on the reasonableness of conducting the experiments involved in the HANDS-project.

One of the driving forces behind the HANDS project is the desire to better the conditions for participation in social life for young people with ASD. This desire plays a main role in justifying the tests conducted in the project. Thus the main justificatory reason for conducting the relevant research and tests is based on considerations of the potential contribution to a greater degree of social inclusion of this group and on considerations of equality of opportunity. Following Rawls, equality of fair opportunity may be construed as the requirement that people initially endowed with similar abilities and skills be given similar life chances – or, to put it slightly differently, that people with the same initial abilities, talents and aspirations should have equal prospects of success in the different areas of social life. More specifically, Rawls is requiring, that for people with similar initial abilities, talents and aspirations their prospects of success in the competition for positions associated with significant benefits should be independent of their initial membership of a certain social class. In this rather narrow sense the de facto exclusion of young people with ASD from the labour market does not seem to be a violation of the requirement of

equality of fair opportunity. After all, the young people with ASD do indeed lack some of those basic skills – communicative as well as social skills – required for a wide range of jobs, and this lack is not due to their initial membership of a certain social class but rather, for all we know, to a complex combination of genetic and environmental factors.

Equality of opportunity may, however, be construed in a wider sense. Thus the requirement of equality of opportunity may be extended to other forms of inequality than those due to initial membership of a certain social class – for instance inequality in opportunities caused by lack of communicative, social and self-management skills resulting in turn in exclusion from the labour market. Since young people with ASD respond positively to behavioural-cognitive intervention leading to improvements in the relevant skills, and since they often have non-impaired or even exceptional intellectual capacities it seems to make sense to require equality in opportunity for this group with respect to at least some positions in society. The implication of such a requirement is that society should act so as to secure this equality, hence that society should undertake efforts to provide the young people in this group with the required communicative and social skills etc.

An extension of the requirement of equal opportunity to cover inequalities based on disabilities of the specific kind suffered by young people diagnosed with autism seems justified on the same grounds as for inequalities in opportunities based upon social class. If the latter is considered wrong on the grounds that no one should suffer inequality of opportunity simply because of the "lottery of nature", then this seems to equally apply to inequality of opportunity suffered because of autism.

We shall leave such considerations aside here and instead focus upon a possible objection to the extension of the requirement of equal opportunity suggested above. Thus the extension may be contested on the grounds that it simply does not do the trick. Young people diagnosed with autism may be claimed never – not even on the basis of behavioural-cognitive interventions – to be able to participate in fair competition for advantageous positions. Therefore, a requirement of equal opportunity extended to accommodate for the special situation of the young people in this group ultimately does not improve their prospects of success in the competition for positions and not least the benefits associated with these. The underlying problem is here that a conception of social

justice that would limit this to a requirement of equal opportunity is simply inadequate. Thus it seems as if even this extended requirement would allow for certain groups to be excluded from the labour market – and more generally from participation in all those areas of social life requiring communicative, social and self-management skills – in those cases where this exclusion is due to certain initial incapacities or disabilities that cannot be remedied to an extent providing equal opportunity.

One possible solution to the problem raised is to acknowledge the inadequacy of limiting social justice to equality of opportunity as defined above. Social justice – one may claim – is also a matter of more generally providing opportunities for the disabled to partake in a social life and achieve the benefits associated herewith. Therefore, occasionally one should let the disabled be allowed into positions they would not have gained in ordinary competition – and perhaps even extend the range and character of positions available for this group such that may have unique opportunities for developing and exercising their talents.

With regard to the HANDS project both these trains of thought is relevant. Thus, as previously outlined, the HANDS project aims at assisting the young people with ASD in developing communicative, social and self-mastering skills through the use of smartphones. As such the HANDS project may, first of all, be an important step for some of the young people with ASD in developing the skills required in order to compete for advantageous positions alongside the less disabled. In short, the HANDS project may contribute to social justice by providing equal opportunity of getting certain advantageous positions for a certain group of young people with ASD, i.e. the extraordinarily skilled. Secondly, by providing communicative, social and self-mastering skills the HANDS project may also for the great majority of young people with ASD be a valuable step towards satisfying some of the very basic requirements of being at all able to enter the labour market. For some it may not be a way into the labour market but simply an aid in establishing a social life and network. In short, the HANDS project may contribute to social justice by providing opportunity of being at all included into the labour market or of being included in social life more generally. Whichever way social justice is construed it thus seems as if the HANDS project and the technology offered young people with ASD may contribute towards building social justice.

It is worth noting, finally, that the arguments presented in this section may sustain permanently equipping the young people with ASD with technological devices such as smartphones. Although the smartphones are initially given to the young people as part of a process in and through which they are supposed to develop certain skills ultimately rendering the assistance of the smartphones superfluous, it may not be possible to satisfy this ambition. The young people with ASD may simply fail to develop the relevant skills. However, it may very well be that the smartphones in themselves provide the assistance preconditioning selective inclusion in the labour market and the establishing of a flourishing social life and network more generally. If so then social justice as discussed above could be taken to require the continued support of the young people with ASD by means of smartphones or similar electronic devices.

The latter scenario would, it seems, have very interesting implications for the status of the technological devices. In this scenario, the devices would potentially move from being temporary, therapeutic instruments to being an integral part of the identity and life of the person with ASD. They would become an integral part of those goals, plans and projects pursued by the individual with ASD. The increased dependency on these devices and the settling of expectations concerning their availability in this scenario seems to add to the ethical aspects of the case in question. The increased dependency and the settled expectations may – for reasons of autonomy – be taken to require the continued support from a whole range of suppliers, teachers and researchers as smartphones require extensive maintenance such as updating of software and hardware. Before introducing the smartphones in longer term assistance of young people with ASD for reasons of social justice the potential of increasing dependency and building expectations should be weighed against the ability of society to subsequently satisfy the seemingly legitimate requirement of sustaining an infrastructure capable of maintaining the smartphones. Further exploration of this scenario falls outside the scope of this article. The ethical significance of expectations is, however, touched upon below.

2. THE ETHICS OF TESTS AND EXPERIMENTS IN HANDS

Although the longer term scenarios involving assisting the young people with ASD by technological means abounds with interesting ethical aspects, this section is dedicated to the analysis of the tests conducted as part of the HANDS project. As will be outlined conducting tests with a group of young people with ASD may raise problems of consent that are not easily overcome. The conclusion reached points toward more general problems concerning the traditional requirements for consent in various contexts.

The main problem encountered in these tests concerns the dual role of the teachers of the young people with ASD. The teachers both play their ordinary role as teachers but are also an active part, both substantially and formally, in the research conducted. The teachers are thus active in both designing and conducting tests involving the handheld devices in the different educational settings in which they interact with the young people. Their involvement in the research is formally acknowledged through their membership qua schools in the HANDS consortium. The dual role of the teachers present a problem for the attempt to protect and promote the personal autonomy of the young people with ASD through acquiring informed consent before their participation in the relevant test.

At first it is worth briefly considering whether young people with ASD qualify for protection and promotion of their autonomy. Although the young people may suffer from poor communicative, social and self-mastering skills they do, however, to varying degree possess the ability to rationally form and identify with goals, plans, preferences and values, and to pursue these in action. The young people are also capable of deliberating competently about the impact of various forms of interventions in their lives. They possess, what is considered to be conditions of decisional competence, the capacity i) to understand what the effects of participation in a given test are, and ii) to reason about the possible consequences of participation as compared to non-participation and how these consequences may affect their overall goals, and finally iii) to apply their values and preferences in an evaluation of the possible outcomes of participation or non-participation and on this basis make a choice between the possible outcomes. The capability of these young people to deliberate competently about their goals and plans, preferences and values is acknowledged in Danish law in which young people generally are considered competent alongside others at the age of 18. Hence in so far as personal autonomy is

considered worthy of protection and promotion by acquiring informed consent for certain interventions, then at least a significant section of the young people with ASD should provide informed consent before participating in tests – or at least be able to influence the decision-making of someone acting as a surrogate for them. Having established the need to involve to varying degree the young person in the process of acquiring consent before the relevant test we may now further analyze the problem of the dual role of the teachers. Let us first look at related problems in the field of medical therapy and research.

The particular problem of physicians assuming the dual role of therapist and researcher originates in the conflicting interests associated with each of the roles respectively. In providing treatment the physician is supposed to act in the best interest of the patient. That is, the physician is supposed to act with the purpose of enhancing and protecting the health of the patient. In research, however, the physician is supposed to act in the interest of people other than the subject. That is, the physician is supposed to act with the purpose of building knowledge that will in turn benefit patients other than the research-subject. These interests are conflicting since they cannot always both be satisfied by one and the same intervention. Thus conducting experimental research often involves intervening in the life and health of individuals in ways associated with little certainty of bringing about an improvement in the health of the research-subjects, trials involving placebo being an obvious case. Assuming patients to generally entertain an interest in receiving the best possible therapy such trials in the interest of future patients clearly conflict with the interest of the research-subject.

The conflicting interests underlying therapy and research is generally considered to pose a problem for the negotiation of informed consent for experimental treatment – especially in those cases where the physician negotiating informed consent assumes the dual role of therapist and researcher. In negotiating informed consent it is clearly important that the patient is made aware of the conflicting interests pertaining to therapy and research, and that consequently intervention will not necessarily be in the best interest of the patient. Without the understanding of this conflict, the patient will not be able to pursue his own interests and goals – hence the personal autonomy is ultimately threatened. Therefore, the question arises of how to ascertain the patient's understanding of this matter – specifically in those cases where the physician assumes a dual role. In these special cases the patient

approaches the physician as therapist, and may be expected to believe the physician to act in his or her best interest. As this is not necessarily the case, the real question thus becomes how to rid the patient of this belief. Based on a common-sense epistemology the obvious way to rid someone of a false belief is to inform them of the falsity of the belief – i.e. to inform the patient of the character of experimental as opposed to therapeutic treatment. It has been claimed, however, that a physician's declarations of this kind simply are not sufficient to remove such beliefs if the physician assumes the dual role of both therapist and researcher. The asymmetry in the medical knowledge of the physician and patient, the dependency of the patient upon the physician and generally the vulnerable situation of the patient have all been listed as conditions that threaten to blind the patient of the fundamental fact that the physicians proposal to participate in experimental treatment may not be in his or her best interest. Consequently, the patient may end up subjecting his or her will to that of the physician. More specifically, it has been argued that the relationship between therapist and patient is characterised by trust, and that proposals made from one of the parties in such relationships tend to be assumed to be in our best interest. Consequently, decisions to act on such proposals are not entirely autonomous.

In considering the issue of informed consent and the dual role of the teacher's in the HANDS project all of the above listed conditions threatening the autonomy of patient are relevant. However, we shall here present a different and perhaps more adequate way of conceptualising the problems related to the dual role of teachers or physicians for that matter – a framework taking into account those conditions threatening autonomy which were outlined above. In short, we shall here describe the problem of acquiring informed consent when assuming a dual role using the notions of power and settled expectations. The notion of power will be used to account for the role of the teachers or physicians, whereas the notion of settled expectations will be used to clarify the state of young people with ASD, or patients more generally.

In recent literature on the power of the physician, three distinct forms of power have been distinguished, namely aesculapian, charismatic and social power. Aesculapian power is constituted by theoretical knowledge, practical skills as well as experience in applying knowledge and skills to a variety of situations. In short, aesculapian authority or power is constituted by disciplinary knowledge. Charismatic power is related to the possession of

certain personal characteristics such as courage, decisiveness, firmness, kindness and so on. Finally, social power is defined with reference to social status. One of the relevant sources of social status is the authority delegated to certain professions by society. By enjoying the authority of e.g. defining and deciding, in the case of medicine, what counts as an illness and appropriate treatment etc., status is conferred to each of the members of this profession. Social status is further influenced by socio-economic conditions such as income, education and the like. Of all three forms of power it holds that in certain situation they provide their possessor with the ability to influence – perhaps even control – the deliberations and choices of other people in ways and to an extent which would not have been possible without these powers.

The notion of expectations and settled expectations is only marginally explored. In recent works they have been argued to carry moral weight derived from the moral value of personal autonomy. For present purposes it suffices to note that expectations are interwoven with the exercise of autonomy. If personal autonomy is defined as the ability to rationally form and identify with goals, plans, preferences and values, and to pursue these in action (see previous section), then the exercise of autonomy is intertwined with the formation of expectations. Thus to form and pursue plans, goals and values is strongly dependent upon and influenced by beliefs concerning the present state of the world as well as expectations concerning the future ways of the world. A person's plan, for instance, to pursue education may rest on expectations concerning the availability of educational institutions, access to these, financial support, the state of the labour market, parental support and so on. Now, at this point it is worth noting that expectations may have very different origin. They may originate in a complex mixture of transient hopes, dreams and optimism – or fears, dystopian pessimism. They may also have their origin in evidence such as personal experiences, the testimonies and encouragements of others, information provided through various media, and so on. In any case, expectations may – regardless of their epistemological reasonableness in light of evidence or ethical reasonableness in light of common morality – survive over time as an integral part of a person's plans for his or her life. Such temporally stable expectations are what we above referred to as "settled expectations".

Having identified three forms of power of the role of physician and defined the notion of settled expectations, we are now in a position to further characterise the problem of the dual role of the teachers in the HANDS project, and more generally.

Characterising the situation of the teacher's acting in the dual role of both teachers and researchers, all three forms of power distinguished above are relevant. The relevance of the aesculapian power follows from the two-sided character of the relationship between the young people with ASD and their teachers. On the one hand, the relationship is analogue to the patient-physician relationship. The teachers possess a theoretical and practical knowledge of how the deficiencies in the skills of the young person – poor social, communicative and self-mastering skills – may be remedied or compensated. On the other hand, the relationship is also similar to the student-teacher relationship. The teachers are also teachers in the more mundane sense in which a teacher is someone that possesses certain disciplinary knowledge to be passed on to students.

The relevance of the charismatic power is perhaps more questionable. However, given the specific lack of skills associated with the diagnose of autism it seems plausible that the firmness, decisiveness and leadership exhibited – albeit to varying degree – by teachers may provide them with charismatic power in relation to the group of young people with ASD.

Finally, and very importantly, a few words on the relevance of the concept of social power for an adequate understanding of the relationship between the young person with ASD and their teachers. The social power enjoyed by the teachers is significant. The students are placed in special schools in which the teachers are given social power in both roles in their two-sided relationship with the young people. In participating in therapy the teachers are given the power to contribute to the assessment of the severity of the disorder, to influence decisions on the therapeutic means, but also, and not least, to implement therapeutic measures on a daily basis. In their ordinary role as teachers they are given the power to, in short, direct the behaviour of the young people in the learning environment.

The asymmetry of power between the young people and their teachers thus shows in various ways. This asymmetry must inevitably affect the formation of expectations among the young people with ASD. More specifically, there is reason to suspect that the

asymmetry of power will favour the formation of the expectation that acting on proposals made by teachers are conducive to an improvement of their condition, and that such proposals are non-negotiable. Let us briefly elaborate. It seems that in many cases an asymmetry in theoretical and practical knowledge of relevance for one's wellbeing would lead one to expect that proposals made by the knowledgeable are conducive to increased wellbeing. Asymmetry in charismatic power may further sustain such expectations as the personal characteristics underlying charismatic power – for psychological reasons – tend to add to the persuasiveness of proposals already expected to express more profound knowledge. Finally, and perhaps most importantly, the social power – the privilege to define and implement relevant therapeutic measures and to direct behaviour – known to be granted by society is likely to produce the expectation that proposals made in the relevant context are all directives. In sum then there is reason to suspect that the young people with ASD will form the expectation that the teachers' proposals are non-negotiable directives that will improve their conditions. Adding time to this picture does not seem to change much concerning the content of the expectations formed under the exercise of the various powers. That is, there is little reason to think that there will be evidence – or other factors influencing the maintaining of the expectations – that will change the content of the expectations formed under the influence of the powers of the teachers. Hence, there is reason to think that such expectations will become settled expectations.

The first point to be made here is that the problem of the dual role of the teachers is that the settled expectations – concerning the context in which a proposal to participate in research is made – are likely to induce the consent of the young person with ASD on the grounds that such proposals are expected to be non-negotiable proposals that will better the condition of the young person. As such proposals are indeed negotiable – hence the requirement of informed consent – and by nature may not be the in the best interest of the young person, the inducement of consent is obviously a problem. The second and more important point to be made here is this: Given that it is the settled expectations that induce consent the problem is not really solved by informing the young person of the change in context from that of a therapeutic and educational context to that of research context, and that consequently consent may be withheld. Settled expectations are not simply removed by declaring a change in context – they are likely to have been formed by the exercise of the various powers over a considerable span of time.

This issue of settled expectations is not unique to the teacher – student relationship. It does indeed occur in the doctor – patient relationship, and it is surprising that it has not received more attention in the literature on research ethics.

Can it be overcome, so that valid consent can be gained from the young people with ASD? Given the social impairments of young people with ASD it would not be productive to involve someone they did not know in the process. They might not be willing even to talk to a stranger. Another possibility is to make the change of context even more explicit and plausible, for instance by conducting the discussions about research participation outside of the school. But this seems unlikely to be sufficient per se. A strong involvement of parents may be of help. In many cases parents will have significant insights into the plans, values and preferences of the young person with ASD, and may be in a better position to judge if participation in testing is in accordance with the plans, preferences and values of their child as they have been revealed in various ways over the years. Although the parents may be better at judging than others, it has to be noted, though, that they also inevitably will have formed expectations concerning proposals made by the therapeutic team of teachers and therapists providing daily care of their child. They will have been influenced by the same powers as their child – not only in their encounter with the providers of care to their child but also in their own encounters with the health service providers. Hence there is reason to suspect that they may have formed relevantly similar expectations to proposals coming from the health care providers more generally.

Even with the best of intentions it is thus unlikely that a consent can be gained that is valid in all situations. This means that those conducting the tests must be sensitive to any signal of resistance or unease during the actual testing in order to, as far as possible ensure that participants can withdraw.

In the attempt to increase the likelihood of getting valid informed consent the HANDS project has established its own procedures for acquiring informed consent. First of all, as described in D1.5.1, an Ethical Board (EB) has been established. The EB has 7 members all of whom are independent of the development and testing of the HANDS software. Every trial or experiment involving teenagers with autism must be presented for the HANDS EB for approval before the empirical research can be undertaken at any of the four partner schools. In addition, several researchers have had to apply for approval at local ethical

committees before undertaking the clinical tests or experiments. The HANDS EB have been supervising the researchers in acquiring informed consent requiring, among others, written consent from both parents and the young people with ASD on the basis of extensive information from both teachers and therapists. The consent form applied had been developed by the EB and then requested to be further individualised at the local, national level of the schools participating in the research project. Moreover the consent form emphasized the possibility of withdrawing from the research at any time desired. The possibility of withdrawing from the tests is known to have been made use of by at least one of the young people with ASD – and the withdrawal happened with explicit reference to this clause in the consent form. This experience seems to provide support for the above conclusion concerning the importance of including explicit reference to the possibility of withdrawing from research.

3. ETHICAL PROBLEMS IN RELATION TO THE USE OF THE HANDS TOOLSET

As outlined in the introduction the main ethical concern for the EB as well as the researchers investigating the ethical issues raised by the HANDS has turned out to be the problems related to acquiring informed consent. However, two other issues have also attracted some attention, namely the relationship between persuasion and manipulation and the risk of the young people getting addicted to the devices in question. These are further elaborated upon below.

Persuasion and manipulation

Coercion, persuasion and manipulation are notions distinguishing different ways of influencing the thoughts and attitudes, choices and actions of people. As is evident the mobile devices provided to the young people with ASD are intended to influence their behaviour in various ways. Moreover, it is an explicit aim of the HANDS-project to find persuasive ways of influencing the behaviour of the young people. Hence three questions immediately present themselves: 1) What is to be understood by coercion, persuasion and manipulation?, 2) to what extent do the specific features of the mobile devices provided to

the young people qualify as persuasive, coercive or manipulative ways of influencing behaviour?, and 3) what is the ethics of coercion, persuasion and manipulation?

A recent survey of the literature on coercion points to convergence on the following components of a coercive proposal communicated from a coercer to a coercee: 1) it is intentional, 2) it claims willingness to harm the receiver – or gives rise to a belief in such willingness, 3) it contains a message incorporating a threat of harm to the receiver, 4) it results in the compliance of the receiver, 5) other choices of action are available to the coercee, 6) the coercee's choice of action are at least in part the result of the threat, i.e. the choice of action is constrained.

Defining persuasion in contrast to coercion, persuasion may be associated with an intentionally communicated message absent any claim of willingness to harm, absent a threat, and with alternative choices of action and no constraints on the choice of action. Compatible with this understanding is a recent practical reasoning approach to persuasion according to which persuasion is simply a matter of influencing a choice of action by means of presenting the facts of the matter – or simply to point out the good and evil consequences that will ensue from a given course of action. The idea is that by pointing out the relevant good and evil consequences one may come to affect the practical reasoning of a person and thereby in turn their choice of action – these facts may simply persuade a person to adopt a certain course of action.

The third notion – manipulation – is commonly used in the wide sense of controlling something or someone. In recent literature it has been used to designate the influence exercerted upon others through the control of the content and supply of information. Others have noted that manipulation is characterised by being aimed at benefitting the manipulator.

Although each of these definitions is in need of further refinement, they do provide sufficient insight into the defining characteristics of coercion, persuasion and manipulation for our present purposes. That is, they provide sufficient insight to describe some of the key features of the mobile devices given to the young people with ASD as part of the HANDS project.

As a first observation note that many of the features of the mobile devices provided to the young people with ASD fundamentally are just, what may be characterised as, digitalised versions of already existing assistive artefacts for the young people with ASD such as pictograms, schedules etc. At first sight it seems as if such assistive artefacts cannot in themselves be construed as coercive or manipulative influence. After all they are in themselves just ways of assisting the young individual with ASD. They may be considered persuasive in the sense that they – e.g. a pictogram to aid in using public transportation – can be construed as a way of pointing out the good, and indirectly the evil, consequences that may result from a given course of action. The mobile devices add to the functionality of the pictograms, schedules etc. by incorporating the possibility of prompting advice in particular settings and contexts. Again, however, there seems to be little reason to think that such context-sensitive advice on how to use public transportation in itself may be coercive or manipulative.

However, in a wider perspective such a feature could have been perceived by the young individual with ASD to be coercive. Imagine a situation in which it was communicated to the individual by teachers and therapists that if he or she did not follow the advice of the mobile devices they would somehow be punished. In this situation there is reason to think that the advice from mobile phones would be perceived as a threat satisfying the criteria 1-5 above ("Coercion in the background"). There are two reasons for questioning that the individual may come to perceive the advice from the mobile devices in this way. First of all, there seems to be no relevant difference between the mobile devices and the already existing assistive measures such as pictograms. There is little reason to think that these measures – pictograms etc. – are perceived to be coercive or manipulative in any of the senses found above. And even if so perceived, this do not point to a property of the technology, but rather a property of the context in which it is used. In short, there would be a problem with the implementation of the technology and not the technology itself. Secondly, to enforce such a threat against the individuals moving outside of schools and into the greater public arena seems to require surveillance of some sort.

Ethical problems related to the use of GPS in Hands

Using the GPS technology in the smart phones it is possible to implement a functionality based on the information regarding the location of the smart phone. It is the original plan to integrate a GPS functionality as part of the Hands toolset. This functionality will allow for tracking of devices and the use of these at particular locations.

Some examples may illustrate the potential: "When standing at the bus stop a prompt appears telling you what to do; When going to the grocery store alone a reward is given; When entering the playground a social-SSSI appears with information".

The functionality could be applied whenever the location of the smart phone (and its user) is close to certain locations relevant for the individual teenager and specified by his or her teacher.

The GPS functionality will involve logging location data of the smart phone. It will be logged whenever the smart phone is close to one of the specified locations, and it will also be logged whether or not the user interacts with the functionality implemented on the phone when help is offered from the system.

The log data on the HANDS server will at least be available to the teacher and to the HANDS researchers. In every specific case the teenager and the parents will be asked to give informed consent on the basis of precise information about the individually tailored functionality.

The Ethical Board of HANDS has been asked to evaluate the ethical problems related to the use of a GPS functionality. EB has listed the following important principles:

1) Continuous logging of GPS data should not be implemented in the HANDS toolset, and

2) GPS controlled activation of HANDS functionality should be negotiated with users and only be used with consent from both users and parents, and

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.

The requirement of informed consent and the prohibition against continuous logging etc. also seems to provide protection against invasions of coercive and manipulative character.

Ethical problems related to the use of a social actor in Hands

Due to the fact, that users (and in particular teenagers with an autism diagnosis) do not necessarily want to follow advices from a computer, the early idea in the consortium was that the HANDS toolset should be designed as a personalised coach system. It should be possible for the teacher to give the tools a kind of an identity and personality that the teenager could relate to and rely on. A kind of a social actor was imagined. An example of a social actor is shown in the figure below. (This figure was used in the original project application, Annex 1.)

This personalization may in some cases support the persuasive function of the HANDS tools. Obvious, such a tool if implemented in the toolset will only be used in relation to participants of the HANDS project, if there are teachers who find this tool relevant in relation to the teenagers they are working with.

In relation to the ethical problems related to the use of *an on-screen social actor* to provide advice to the young individual with ASD the main concern is here that the young individual will relate personally to the social actor, and that the advice provided from the mobile phones for this reason will turn into a coercive or manipulative influence on the behaviour of the individual. It seems reasonable to suppose that the use of a personal actor may influence the way in which not only a young person with ASD but any person will relate to the advice provided by a mobile device. The question thus becomes whether this change in the relation turns the advice into coercive or manipulative influence. It does not seem so. Thus there is little reason to think that a stronger personal attachment to the mobile device – and this is obviously a difference in degree – in itself changes the way in which advice is perceived. Comparing with everyday life situations in which advice is

provided, it does seem as if the degree of personal attachment to the person who is providing the advice do change the influence of the advice upon our decisions – it does not, however, in any way constrain our choice in the way coercive threats do, and neither does it amount to manipulation in the sense given above. It seems to hold that personal advice in itself do not suspend critical judgement on many occasions – but rather only increases the willingness to take the information given into account in one's considerations. The advice offered maintains the character of persuasion – the direct or indirect pointing out of the good or evil consequences that may ensue from the adoption of a given course of action – by someone to whom we feel more personally attached.

It should be noted that these considerations of the role of stimulating a stronger personal relation to the mobile devices through the use of a social actor have been limited by the fact that the consortium has decided not to implement a social actor.

The ethics of coercion, persuasion and manipulation

As should be evident coercion and manipulation runs counter to values such as personal autonomy, where autonomy, in short, may be defined as the ability to form plans, goals and values for one's life and to pursue these plans, goals and values in action without the undue influence of others. Coercion and manipulation clearly threatens the autonomy by limiting the options of choice through threats or the withholding of information – that is, coercion and manipulation limits the possibility of forming and pursuing one's own plans, goals and values. Persuasion, on the other hand, does not seem to be met with this problem. On the contrary, it seems as if persuasion to some degree strengthens personal autonomy by providing what may be valuable information on which to base one's choice of action. In so far as we are right in characterising the advice provided by the mobile devices in the HANDS project as persuasive influence upon choice of action, there seems to be associated with this advice no ethical problems.

The risk of addiction

Three related issues of addiction may emerge in individuals with autism spectrum disorders, in relation to the use of a (mobile) device for cognitive support, such as in HANDS. These three issues may similarly lead to seemingly obsessive use of the device, with accompanying strong emotional responses to the withdrawal of the device. These three issues have three different psychological backgrounds at their core, and have different professional implications; and also, their ethical implications may be different. The three psychological backgrounds and related issues seem to be the following:

i) Addiction. In our view, this may be the same phenomenon as it may be among non-ASD individuals. It seems to be debated in the literature whether computer addiction indeed exists, although it seems un-debated that many people, and especially teenagers and young adults use computers (e.g. computer games) so excessively that it interferes with daily life and social relations. This phenomenon in itself, though seems clearly maladaptive, does not appear as specific to autism spectrum disorders.

ii) Dependence on 'prompts'. It is a well-known phenomenon in the psycho-educational treatment of autism spectrum disorders that, in the process of intervention (e.g. teaching new skills or specific behaviours), a novel behaviour becomes 'prompt-dependent'. Using prompts to help initiate the appropriate behaviours is a natural and adaptive part of the toolkit of intervention regimes. However, it is an important aspect of the well-designed individual intervention to avoid that the behaviour become dependent on the prompt. It is usually done by a gradual and well-timed withdrawal of the prompt. If this process is not adequately coordinated, the behaviour(s) may become dependent on (a) specific prompt(s). This is maladaptive, as precludes spontaneity and independence.

iii) Restricted interest. As it is well-known, atypically restricted and repetitive focus of interest is most often an important, definitive aspect of autism spectrum disorders. The actual content of this restricted interest changes across individuals, and it also changes within individuals with development and time. Now, it is quite possible that, in some individuals, use of the mobile device and/or specifically the HANDS Mobile software become the focus of such a restricted interest. This and the previous phenomenon, too, seem to be related to the atypical (impaired) organisation of so-called executive functions,

the psychological mechanisms dedicated to flexible and goal-oriented organisation of behaviour and cognition.

In sum, the three phenomena may be quite similar on the surface (excessive use of the mobile device/HANDS toolset), but the underlying backgrounds may be quite different. The professional should be able to tell them apart, however. The first phenomenon is not autism-specific, and seems to be approachable by cognitive-behavioural therapies, if arises. The last two phenomena are more autism-specific, but should be manageable by an adequate application of standard autism-specific psycho-educational toolkit.

Other Ethical problems related to the Hands Toolset

It is obvious that there are other ethical problems related to the Hands toolset that the ones mentioned above. At least two other problems have been carefully studied by the Hands partners and reported in separate conference papers:

- The question of credibility in relation to the Hands toolset has been studied carefully by the Hands partners. To what extend is it acceptable to make the Hands toolset credible? In addition, it should be noted that credibility may foster system dependability. Therefore, the challenges consist of controlling the benefits of developing an embodiment relation - in which the readiness-at-hand of the smart phone allows for effortless interactions. Such questions have been discussed in (Øhrstrøm, 2010) and in (Gerdes and Øhrstrøm 2010).

- There are obvious ethical problems related to the use of rewards in persuasive design. This problem has been studied in (Bertel 2010).

4. TOWARDS A VALUE-SENSITIVE STRATEGY FOR THE FUTURE DEVELOPMENT OF ICT TOOLS SUPPORTING YOUNG PEOPLE WITH ASD

Within the HANDS project the approach differs significantly from the mainstream approach used in persuasive technology studies, since it is a very important focus in

HANDS to develop and employ ethical standards for Value Sensitive Design in relation to the HANDS project and to employ these standards during the development process in a close cooperation between the researchers working with ICT ethics, the system developers, the teachers and the teenage users. According to (Friedman, Kahn, Borning, 2002) Value Sensitive Design (VSD) is "a theoretically grounded approach to the design of technology that accounts for human values in a principled and comprehensive manner throughout the design process." The HANDS project is an empirical experiment where VSD is a demand and VSD will be integrated in the Persuasive Technology design process in HANDS. The idea is that relevant ethical considerations in this way may be integrated in the design process as such and in the system development.

As suggested by Anders Albrechtslund in his paper, "Surveillance in Mixed Spaces: Persuasion and resistance" (appendix to D4.2.1) we may relate to the concept of participatory surveillance in order to explain what VSD should involve in the context of Hands. The concept of participatory surveillance is closely associated with the idea of sharing. In the Hands context this becomes relevant if the teenager conceive the availability of the information about him and his activities as a kind of sharing these data with others. In this way this sharing of data (participatory surveillance) is just similar to the kind of surveillance which is important for maintaining friendships by checking up on information other people share.

In the appendix to D4.2.1, Anders Albrechtslund has also argued that the participatory surveillance perspective on the HANDS toolset can be helpful with regards to the dichotomy between persuasion and manipulation. The guiding principle for determining if the designed technologies are persuasive or manipulative could with advantage be based on how well they the young people with ASD are empowered. As pointed out by Anders Albrechtslund, the HANDS toolset should not be thought of as just an instrument, but as a potentially empowering technology for young people with ASD.

Obviously, the importance of the dichotomy between persuasion and manipulation has to do with the focus on the value of personal autonomy. In fact, in the above discussion we have been able to identify the following main values in the HANDS project:

- Social inclusion: The design and features of the mobile device empowers the young individual to partake and navigate in social life.

- Personal autonomy: The design of the toolset of the HANDS mobile devices does not exert coercive or manipulative influence on the user.

- Protection of privacy: The design protects privacy through limited possibilities of logging and surveillance of the young people with ASD.

Clearly, participatory surveillance will only work if the Hands activities are based on these values. And without participatory surveillance the Hands functionalities cannot be used in a satisfactory manner. For this reason, it is essential that all system developers (including all teachers who are using the Hands toolset in their communication with the teenagers) actually perform their activities with a constant and clear focus on the significance of these values.

It should be pointed out that the values mentioned above are rather general. For this reason, it also important as a part of the VSD strategy that there is an ongoing debate within the Hands project about the more precise and concrete meaning of the values in the actual context. Here the use of illustrative examples may be useful. In this way the ethical debate is significant if we want to establish as solid basis for a VSD strategy. In fact, the there is a growing understanding of the fact, that ethics is important when design issues are discussed (see e.g. Verbeek, 2006).

5. CONCLUSION

We have discussed some important problems related to the ethics of the Hands project. This has led to the identification of three values which are essential in Hands. This has also been related to participatory surveillance. In fact, the Hands project as a whole – in particular seen as a communicative process – may lead to a deeper understanding of the potential and the problems we have to face if we want to make use of value sensitive design in practice.

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