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Should Artificial Intelligence be Used to Empower People with Profound Intellectual Disabilities?

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Abstract

People with profound intellectual and multiple disabilities (PIMD) often communicate on a pre-symbolic level and use unconventional behavioural signals to express their needs. Hence, the exact understanding of their needs is often not possible even for very familiar persons. This significantly restricts the participation of people with PIMD in all areas of life. However, advanced Information and Communication Technologies (ICT) allow to create smart systems which can, potentially, intelligently interpret these non-symbolic behaviours and translate them into actual needs of people with PIMD. This way, people with this type of disability can be empowered to take actions themselves, especially when their direct support person (DSP) is not available. The INSENSION project investigates if ICT can be employed to create a smart solution capable of supporting people with PIMD and if such a system can be successfully used in practice within the project. This paper discusses ethical issues deriving from the use of Artificial Intelligence (AI) technologies within the context of PIMD. Issues like the target group's inability of giving consent to use these technology-based solutions, which can potentially enable a level of self-determination previously not available to them, need to be addressed. However, not enabling AI for use by people with PIMD would entail refusing them the possibility to benefit from the potential of achieving a certain level of independence. Therefore, a system like INSENSION must be designed and provided.

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1 Introduction

The INSENSION project focuses on creating and validating an Information and Communication Technologies (ICT) system capable of recognizing the meaningful non-symbolic behaviours of people with profound intellectual and multiple disabilities (PIMD, also referred to as PMLD – profound multiple learning disabilities) and, through putting them into the context of what happens around a specific individual at the time of a given behaviour, allowing the needs of these people to be met with the use of assistive applications. While the primary envisaged application aims to facilitate communication with other people, other uses can be imagined such as turning up the heating in the room when the person with PIMD protests against the cold or playing back their favourite music for relaxation.

The INSENSION platform uses advances in computer vision and audio signal analysis to recognize gestures, facial expressions, vocalizations and psychophysiological states. Further on, similar techniques, additionally extended by readings from ambient sensors, are used to understand the context of the behaviours of people with PIMD. A combination of these methods for automatic analysis of data acquired from the primary end user – the person with PIMD – using cameras, microphones and other relevant Internet of Things devices, constitutes the intelligence of the developed system.

The primary goal of the project is to verify whether creation of the system in question is possible from the technical point of view and whether the system will be smart enough to act accurately on behalf of the primary end user. However, several additional questions arise when discussing real-life usage of such a system. These questions relate, inter alia, to the privacy of the primary end users, the extent to which the system should act on its own once it is able to recognize the meaning of a given behaviour of a person with PIMD, the possibility of allowing the system to act as a prosthesis for verbal communication for a person who is biologically unable to use verbal communication. All these questions are also subject of the research conducted within the project and have been included as important design issues to be solved with the participation of representatives of the secondary users group – direct support persons (DSPs), e.g. relatives or professional caregivers.

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This paper starts with presenting the characteristics of PIMD in Section 2, leading to the description of the concept and functionality of the INSENSION system in Section 3. Section 4 discusses the ethical issues related to the use of a system based on Artificial Intelligence (AI), like the one to be created within INSENSION. Finally, conclusions are presented in Section 5.

2 Background

2.1 Profound intellectual and multiple disabilities

The group of persons with PIMD is relatively small but increasing in numbers (Bellamy et al. 2010). Proving this statement by means of exact numbers is nearly impossible due to a lack of quantitative data concerning the prevalence of this population (Fornefeld 2004). One of the reasons for that is the challenging task of defining PIMD because of the characteristic heterogeneity concerning the causes, forms and manifestations of the disability within people affected (Axelsson et al. 2014). The *International Classification of Diseases 11th Revision (ICD-11)* provides a first orientation by declaring a “below average intellectual functioning and adaptive behaviour that are approximately four of more standard deviations below the mean (approximately less than the 0.003rd percentile)” (World Health Organization 2019) as characteristic. Typically, the intellectual disability goes along with below average adaptive behaviour, physical or sensory impairments as well as complex health needs like epilepsy (World Health Organization 2019; Nakken & Vlaskamp 2007). In this rather medical perspective, other influencing factors besides the intellectual disability itself are not taken into account. Therefore, the *International Classification of Functioning, Disability and Health (ICF)* – also published by the World Health Organization – offers a consistent and standardized terminology for describing the bio-psycho-social aspects of the consequences of illness. The model of ICF is presented in Fig. 9.

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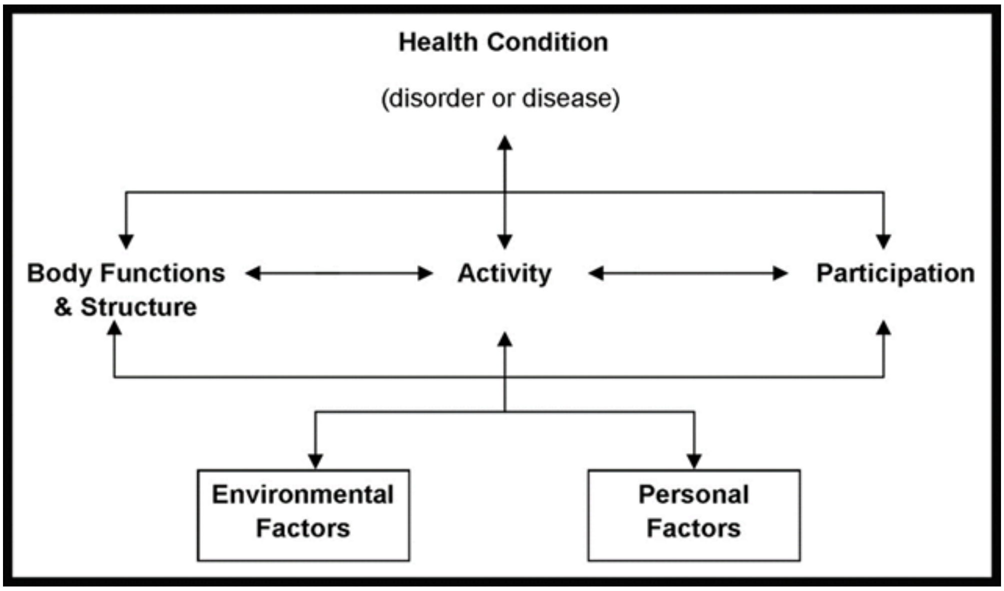

Fig. 9: *The Model of International Classification of Functioning, Disability and Health.*

All of the illustrated factors can have a positive or negative impact depending on the persons' situation. In the ICF conception, the particular disorder or disease (e.g., a genetic syndrome) is seen as a kind of starting point of the reasoning, which does not automatically lead to actual restricted participation. The health condition influences specific body functions and structure concerning, inter alia, motor competencies or intellectual abilities. To what extent these factors lead to a disability depends on personal factors (e.g., intrinsic motivation towards a particular activity) and environmental factors (e.g., support of parents or prevalent politics). Disability itself is also seen as a situational phenomenon, as the severity of the disability depends on the specific activity. In conclusion, the model illustrates the above-mentioned heterogeneity by taking into account contextual factors as well (DIMDI German Institute of Medical Documentation and Information 2017; World Health Organization 2001).

2.2 Communication

People with PIMD often communicate on a pre-symbolic level because they did not (yet) learn the understanding of symbols like pictures or pictograms and usually do not use verbal language due to their intellectual disability or motor impairments (Bellamy et al. 2010; Maes et al. 2007). Hence, their body's own behaviour signals need to be perceived and interpreted by their environment in order to understand their needs. Interaction partners must focus on specific gestures, facial expressions, vocalizations and

DOI: 10.3217/978-3-85125-668-0-06

physiological parameters (Brady et al. 2012; Carnaby 2007) to understand the three reasons of preverbal communication (Rowland 2013; Rotter et al. 1992):

• demanding objects or actions that the person wants

• protesting, when the person does not want a specific object or action

• commenting a social interaction

These signals are highly individual as they usually occur on an unconventional level. Therefore, common conventional signals like nodding or the pointing gesture are not used (or at least not with the same meaning). Since most of the current technological devices for supporting the communication between people with and without disabilities require the understanding of symbols, these forms of Augmentative and Alternative Communication (AAC) are often not suitable for people with PIMD.

The lack of verbal language and the enormous individuality of used behaviour signals lead to restrictions in communication and, consequently, in self-determination and participation. Concerning the satisfaction of their needs, people with PIMD are highly dependent on others(grouped within environmental factors in the ICF conception). This high need for support ranges over their whole life span (Axelsson et al. 2014; Nakken & Vlaskamp 2007). Therefore, individuals with PIMD need to interact with others even to get their basic needs fulfilled, but the number of interaction partners who are actually capable of accurately perceiving and interpreting these specific and highly individual behaviour signals is usually very limited. In most cases, the differentiation between pleasure and displeasure is by all means possible for close DSPs, whereas the exact understanding of more complex needs or specific emotions like fear, disgust, surprise or sadness is often quite difficult even for familiar persons (Petry & Maes 2006).

3 Artificial intelligence supporting people with PIMD

Section 2 described the characteristics of PIMD and the needs of people living with this type of disability in relation to achieving the highest possible quality of life. Like with any other disability, its characteristics define the type of tools capable of enabling a high level of self-determination. The ability of self-determination is an important aspect of living a happy life. Therefore, it is crucial to enable any person with disability, including people with PIMD, to have a level of self-determination as high as possible by using relevant tools.

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Within the context of other types of disabilities, these tools include for example a wheelchair for a person with motor impairments or a white cane for a person with visual impairments. People with PIMD require the employment of ICT solutions to achieve the same goal.

3.1 The challenge

Looking at the nature of PIMD, it primarily results in limiting people's abilities to communicate with others and to meaningfully interact with their environment. This prevents these people from fulfilling their needs on their own. They need to rely on others, particularly those that can understand their highly individual, usually non-symbolic communication schemes. The caregivers supporting them act as interpreters of the specific non-symbolic 'language' of a given individual with PIMD. This non-symbolic 'language' is composed of facial expressions, gestures and vocalizations, therefore DSPs look and listen to notice a specific behaviour. Since non-symbolic behaviours are reactions of people with PIMD to whatever happens around and/or to the given individual with PIMD, caregivers interpret these behaviours depending on these happenings. Once they understand the particular need expressed with the use of specific non-symbolic behaviours, the DSP can perform an action leading to fulfilling that need.

The way in which the caregivers of people with PIMD work to fulfil the needs of these people directly demonstrates the desired functionality of a solution that could perform similar tasks. This functionality should be related to allowing:

• to visually recognize and distinguish between facial expressions and gestures, and to hear and distinguish between vocalizations,

• to recognize (visually and acoustically) and to understand what is happening around the individual whom the developed solution strives to support,

• to notice the correlation between particular behaviours and particular elements of the situation around the supported individual,

• to interpret all the information mentioned above as a particular need of the supported individual,

• and finally, to fulfil that need.

Such a list of abilities defines the general picture of how the technological prosthesis enabling people with PIMD to make decisions on what to do next on their own should be constructed. Since processing of information is heavily involved, this solution should be based on ICT and operate in a cycle as presented in Fig. 10.

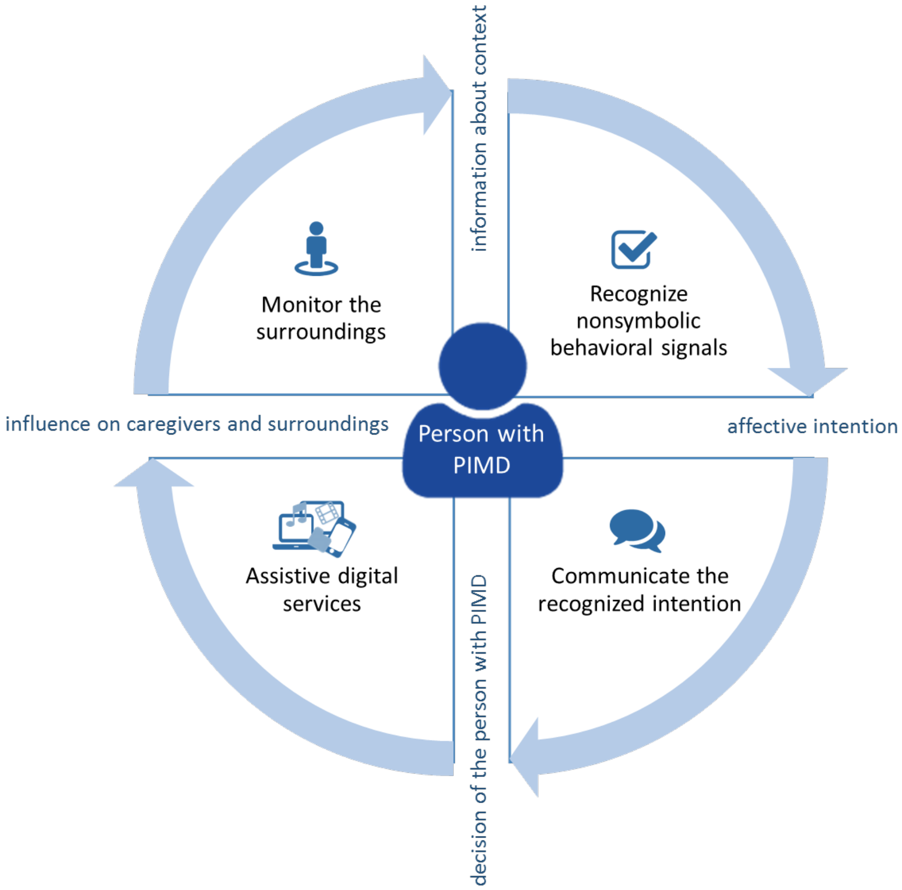

Fig. 10: *The operating cycle of the INSENSION system implementing a self-determination prosthesis for people with PIMD.*

Because the meaningful behaviours of people with PIMD are usually reactions to happenings around them, the ICT system that is supposed to support their self-determination must monitor the environment of the individual it supports. This way, it is able to collect information about the context of any behaviour of that person. The second step is to recognize the facial expressions, gestures, vocalizations and physiological parameters of the supported individual in order to recognize complex non-symbolic behaviours comprised of a number of such signals. Combining the recognized non-symbolic behaviour with information about the context allows to interpret it as an intention

M. ENGELHARDT (1), Michal KOSIEDOWSKI (2), T. KRÄMER (1), J. TYRAKOWSKA (3)
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of the supported person, for example as a *demand* to prolong a situation that makes them feel comfortable or as a *protest* against a situation that makes them feel uncomfortable. From this moment, the assistive ICT system is ready to communicate the identified intention of the supported individual to the ICT-based assistive services or applications that interpret the affective intention of the supported individual as a decision to perform a specific action with the use of the functionality available within these services. The actions performed on behalf of the supported individual either preserve the situation around them or change it according to their needs, thus influencing their environment.

3.2 The technical solution

The INSENSION system is foreseen as a system working in the close vicinity of an individual with PIMD (Fig. 11). It uses various sensors to collect data from the primary end user and from the environment around them ranging from cameras and microphones to sensors measuring such parameters as air temperature. Afterwards, the collected data is analysed and compared to the behaviour patterns defined based on the human knowledge on the non-symbolic interaction schemes of the user and interpreted as decisions of the user as to what to do next. These decisions are communicated to specialized assistive service or applications, which perform actions aimed at executing the decision of the user. These actions may relate to involving human caregivers to provide the assistance, supply direct support to the user without any DSP, or influencing the environment with the use of relevant actuators.

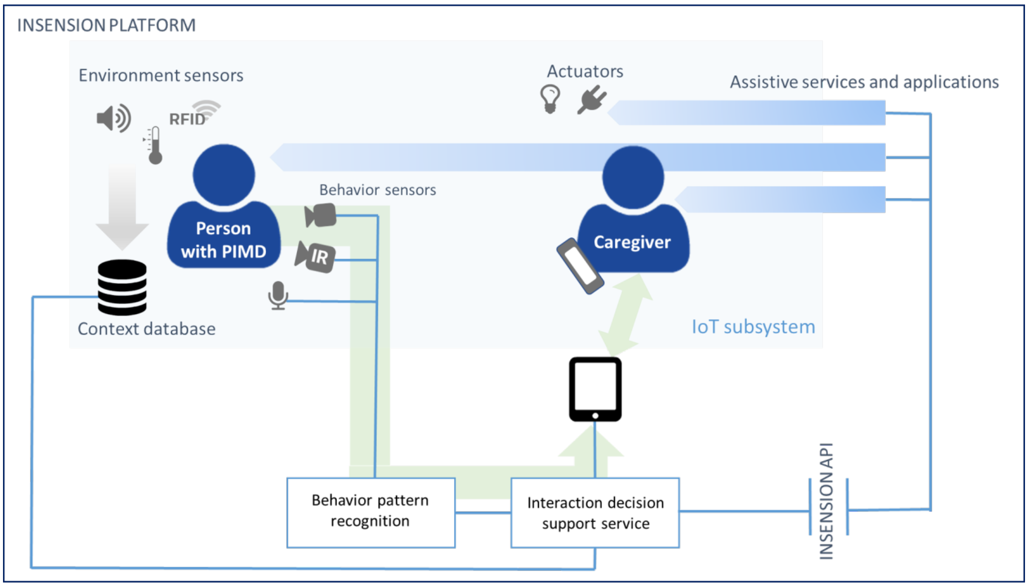

Fig. 11: *The general concept of the INSENSION system.*

On the technical level, this system contains two major types of components that enable it to process and interpret the data collected from the user, i.e. non-symbolic behavioural signals and data on the environment constituting the context of the user's behaviour (Kosiedowski et al 2019). The first type are the so-called recognizer components, which are used to: (1) recognize people's faces and their facial expressions, (2) recognize gestures, (3) recognize vocalizations and sounds, and (4) recognize the affective physiological response of the given individual. The second type of component is constituted by the Interaction Decision Support Service. Fig. 12 presents the placement of these components in the logical architecture of the system.

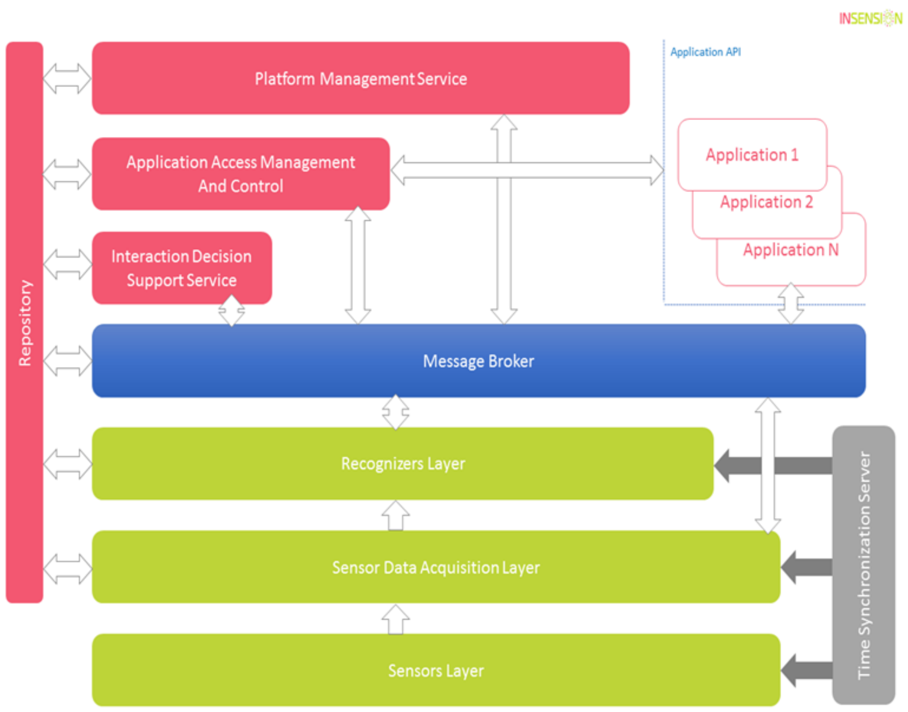

Fig. 12: *The logical architecture of the INSENSION system.*

The recognizers are created with the use of machine learning techniques that allow the specific recognizer components to learn how to notice the required items and events in the video and sound collected with the use of the system's cameras and microphones. This training phase allows to build the relevant numerical models of faces, facial expressions, gestures and vocalizations/sounds. The models are built using real data collected from the users and their environment, i.e. video and sound recorded there. to the system compares the video and sound recorded during actual system operation with these models in order to find occurrences of behaviours fitting those models. Thanks to this, the system is able to recognize visually and acoustically what the user does with their face and body, whom the user sees and what the user 'says' or hears. Fig. 13 presents example facial expressions and gestures recognized by the relevant system components:

M. ENGELHARDT (1), Michal KOSIEDOWSKI (2), T. KRÄMER (1), J. TYRAKOWSKA (3)
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Fig. 13: *Examples of facial expressions and gestures recognized in people with PIMD by the INSENSION system components.*

In the next step, the Interaction Decision Support Service attempts the interpretation of the recognized behavioural signals. This is done through determining the behaviour state of the user, i.e. whether the person feels ‘pleasure’, ‘displeasure’ or has ‘neutral’ attitude, and through finding out whether the given behaviour was a communication attempt, i.e. whether the user expressed their ‘protest’, ‘demand’ or ‘comment’. This is possible because human experts provide this component with knowledge on how to interpret specific behaviours of a particular individual with PIMD. The next step is to understand the reason of a given behaviour state and/or communication attempt. This is again done based on the knowledge provided by the human experts. Thanks to this, the Interaction Decision Support Service is capable of interpreting for example:

• the presence of a particular DSP near the supported user as causing ‘pleasure’,

• the fact that the temperature is lower than desired by the user as causing ‘displeasure’,

• a digital player playing a particular song as causing ‘demand’ for more of this music or

• the fan being switched off as causing ‘protest’.

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Being able to recognize behavioural signals, to determine the behaviour states and communication attempts as well as to identify the cause of a given behaviour allows the INSENSION system, on the one hand, to put these three items together as specific intentions of the supported user that should be attended to. On the other hand, the system can create a space for providing ICT-based assistance to the user, thus increasing the level of their self-determination. In this project, this is done with the use of specialized assistive services and applications.

3.3 The opportunities

The ability of the INSENSION system to interpret behavioural signals of people with PIMD as their potential decisions on what should happen around them next opens a wide range of opportunities to deliver specialized assistive applications and services. These assistive applications and services can support the user and the DSPs in a number of life scenarios. In order to define these scenarios, a series of focus workshops took place with the participation of formal and informal DSPs. These workshops were held in Poznan and Krakow, Poland, as well as in Heidelberg, Germany, using Design Thinking (Kelley and Kelley 2013) in combination with the Walt Disney Method (Dilts 1991) to define the INSENSION system usage scenarios.

The scenarios identified by the workshops participants included supporting people with PIMD while transiting from the care of one DSP to another DSP; supporting people with PIMD during the night, particularly when they wake up; enabling people with PIMD to react to external circumstances such as weather that might influence their needs. Scenarios like these can be facilitated using a proper combination of applications and services that can execute relevant actions based on the decisions of the person with PIMD as interpreted by the system. At the moment, three applications that allow facilitating the above-mentioned scenarios are foreseen:

Communication application, allowing the person with PIMD to communicate with other people, e.g. informing them about their current need (‘I need to relax’) or attitude (‘I don’t feel well today, this is probably because of the bad weather’);

Multimedia player, allowing the person with PIMD to decide if and what music or video is to be played in their room, based on feeling ‘pleasure’ or ‘displeasure when no song is played, or on ‘demanding’ or ‘protesting’ when a particular song or type of music is played;

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Control of room devices, enabling the person with PIMD to switch particular devices on or off, for example switch on the heating device when they feel ‘displeasure’ caused by low temperature.

An example assistive scenario based on the interviews with DSPs performed during the aforementioned workshops could potentially be realized with the use of the developed system and the applications listed above. It is related to a situation when the person with PIMD stays alone, e.g. during the night in their own bedroom. In this situation, the system, which constantly monitors the behaviours of its user, recognizes with the gesture recognizer that, for example, the person shakes his or her head characteristically. At the same time, the room sensors report that the temperature is slightly lower than usually. Due to the known fact that this particular person has a significant aversion to cold, his or her behaviour can be interpreted by the Interaction Decision Support Service as displeasure caused by low temperature. Such a message is sent to the application controlling the devices installed in the bedroom. As a result, the heating device is switched on and the room temperature can be increased to a level that is not causing displeasure and is accepted by the user. This way, the person with PIMD can control the temperature in his or her bedroom in a self-determined manner, without the need of intervention from a DSP.

While the above-listed scenarios and applications need to be studied during the course of this project, they illustrate how an AI system like INSENSION can use its capabilities to change the situation of people with PIMD, from waiting for the care to be delivered to requesting the care to be delivered, and, where possible, fulfilling a need by themselves.

4 Ethical issues

Human autonomy also includes the ability to decide whether and with whom to communicate. Everyone is familiar with the desire to withdraw or not to communicate to anybody. For people with PIMD, it is much more complex to realise this basic need. As described in Section 2.2, interaction partners often have no choice but to interpret behaviour signals communicatively to get an insight in the person’s wishes and needs as well as strengthen their participation. However, this leads to a risk in two ways. On the one hand, it has to be possible for people with PIMD to withdraw or to signal that they do not want to communicate in a specific situation. On the other hand, misinterpretations of the observed behaviour may arise, especially by unfamiliar persons, potentially leading to

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wrong reactions. Concerning both aspects, a high degree of empathy is required in order to reconcile the necessary caring, communicative attention and respect for autonomy (Klauß 2002).

Therefore, the realisation of the INSENSION project brings forth ethical issues on two different levels:

1) Concerning **research ethics**, attention must be put on the involvement of vulnerable groups without having their explicit consent to participate in the particular research.

2) Regarding **human-machine interaction**, the relation between the human being and the technology – whether it is complementing or replacing – constitutes a crucial point.

Both aspects are part of the project's considerations and will therefore be part of the following discussion.

4.1 Research ethics

Research is never neutral, but it always has a positive or negative impact on the test person. Therefore, research ethics, especially regarding vulnerable groups, have to deal with the questions if the specific interventions of the researcher are acceptable for the test person and how protection of the participating person is provided if it proves necessary (Dederich 2017).

Historically, significant violations of human rights, in particular during the Second World War, have shown that the main component of an ethical approach is the protection of participating persons by ensuring (Calveley 2012; Dederich 2017; MacInnes 1999; Schnell & Heinritz 2006):

• their well-being,

• the voluntary nature of their participation,

• the maintenance of their physical and psychosocial integrity,

• the protection and confidentiality of gathered information (i.e., personal or health-related data).

However, perceiving this protection as the only aspect is a rather short-sighted approach. While medical studies, especially in Europe, are often based on the Declaration of Helsinki, a guideline that has been revised several times up to its current version (General

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Assembly of the World Medical Association 2014; Thiel 2013), studies within the field of special needs education can be based on the ethical framework of Beauchamp and Childress (Beauchamp & Childress 1989). The latter focuses on the risks and benefits of participation in comparison to non-participation and identifies four orienting principles: autonomy, justice, beneficence and non-maleficence. These principles have no hierarchy or strict evaluation procedure. In some cases, their implications may be in conflict with each other, which makes it necessary to weigh them in each individual case. In turn, three concrete rules can be derived from this framework (Fuchs et al. 2010):

• The initial focus is on the informed consent, which describes a process of transparent clarification of the research procedure in order to receive an agreement by the involved persons concerning the participation in the research process. An ongoing reflection during the actual research process and well-defined abort criterions are also included.

• The second aspect describes the above-mentioned risk-benefit evaluation in more detail with the question of who (i.e. the test person, the specific target group as a whole or just the researcher) could benefit from this research.

• The third aspect deals with the fair selection of test persons.

4.1.1 Ethical implications concerning research involving people with intellectual disability

In recent years, the amount of empirical research, both qualitative and quantitative, on the lives of people with intellectual disabilities has raised significantly. In order to change the perspective from research about people with intellectual disability (ID) to research with and for people with ID, alternative research approaches, such as the emancipatory research paradigm, have been developed. Although it is clear that this approach is not suitable for all kinds of research, there is a broad consensus concerning the aim of including this group within the research process. However, the informed consent is always a good method of prevention of disadvantages or harm for the test persons. If this cannot be provided on a verbal level, suitable alternative forms of communication for the specific person, i.e. images, pictograms or symbols, are required (Dederich 2017; Mietola et al. 2017).

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4.1.2 Ethical challenges concerning people with PIMD

Although asking for informed consent in alternative ways such as “emancipatory research paradigm with its emphasis on self-empowerment has made some disabled voices heard, it has not been able to offer alternative approaches to include those who are the most silenced” (Mietola et al. 2017, 264). Due to the above-mentioned difficulties in communication and interaction between people with PIMD and their environment, there is a lack of empirical studies (Maes et al. 2007) and descriptions concerning ethical research approaches.This probably makes people with PIMD the most vulnerable and marginal group in society and research (Mietola et al. 2017).

However, the crucial question is if people with PIMD should be excluded from research due to the mentioned difficulties in finding an ethically correct form of research with this group. Furthermore, how should the fine line between deriving benefits arising out of research findings and considering ethical implications be walked?

4.1.3 Recommendations

In order to make best-interest decisions, some key points should be included in the research process. Due to the incapability of providing direct informed consent by the person with PIMD, close DSPs should be informed about the research approach in terms of the benefits, risks, procedure and their own involvement. They should get the opportunity to ask questions, but they should also be asked questions. Even though the decision to participate is made by the DSPs, the persons with PIMD and their benefit from the research are in focus all the time. Of course, DSPs will always have their own interests and points of view. Although only consent by proxy is possible in many cases, it is particularly important to take the perspective of people with disabilities to the greatest possible extent. This procedure is justified by the fact that an advantage for the DSPs does not per se mean an improvement for the person with PIMD. During the whole research process, permanent and transparent reflection and analysis with possible readjustment should be performed by both the researchers and the DSPs involved to ensure the continuation of the research project. In case of doubt, i.e., if the test person or one of the DSPs involved feels uncomfortable, they should leave the study (Calveley 2012; Coons 2013; Dederich 2017; Mietola et al. 2017).

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4.2 Ethics in human-machine interaction

Regarding technological assistance within the care over vulnerable target groups, especially regarding the use of humanoid robots, deep-rooted fear of a loss of closeness and affection arises. The increasing humanization of robots and AI implies the risk of a dehumanization of care. A study of Butter et al. (2008) lists these concerns according to their level of security:

• There are slight concerns regarding cleaning robots as well as technical aids like electric beds or wheelchairs capable of avoiding obstacles.

• There are medium concerns regarding robots responsible for tasks where improper execution decreases safety of humans (e.g., service robots managing transport ways).

• There are large concerns regarding the use of care robots in direct interaction with care receivers (e.g., provision of medicine or food).

The closer the technology gets to the person, the bigger the scepticism concerning its use gets. According to Becker et al. (2012) the acceptance towards robots depends on whether their use leads to personnel reduction or whether it implies time savings leading to more time for direct interaction with the care receiving persons.

Another crucial point within the context of technical assistance in care, especially when it comes to people with PIMD, is autonomy: To what extent can technology contribute to more autonomy without restricting the person's self-determination in an unforeseen manner (Dabrock 2019)? The risk of an abuse of power by technology, connected to a loss of autonomy by the person with PIMD, needs to be considered at any time due to the fluent transition from necessary care to paternalistic care (Falkenstörfer 2018).

The INSENSION system deals with these challenging issues in different ways. On the one hand, the system can support the caregiver by increasing the certainty of having interpreted the behaviour signals of an individual with PIMD accurately, based on the technological analysis of these signals. Furthermore, the system can provide new information by pointing out needs which had not been considered before.

On the other hand, it can enable experiences of self-empowerment for the person with PIMD by means of the connection to assistive applications and services like the ones presented in Section 3.3. In consequence, the experience of being able to have impact on

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their environment using even slight behaviour signals could potentially initiate further learning processes in the person with PIMD.

5 Conclusions

In this paper, the INSENSION system, aimed at supporting people with PIMD, was presented. These people are often not able to use any type of symbolic communication, hence their ability for self-determination is usually non-existing. However, the recent advances in ICT, which delivered technologies such as AI into the reach of the average person, create an opportunity to build a sort of prosthesis of verbal communication for a person who is biologically unable to use verbal communication.

The INSENSION system, which is currently under development, is an attempt at employing those novel technologies for the benefit of people with PIMD. Designing this system allows to examine not only whether developing such a system is possible from the technical point of view, but also to study if and how such a system can positively impact the lives of people with PIMD. At the current stage of the research conducted within the project, it has been confirmed empirically that AI components to recognize relevant non-symbolic behaviours can be developed (Kosiedowski et al 2019). Further work aims to integrate these components into a coherent system capable of executing full assistive scenarios. At the end of the project, a comprehensive field study is planned on the actual impact of the developed system.

The project investigates the potential of AI to empower people with PIMD to act by themselves, especially when no DSP is around. The benefit that this technology may bring to the person with disability using it, potentially shifting the point of decision from the DSPs to the person with PIMD, must be a strong pro argument when deciding if this technology should be made available to them. Although it is hard to find an ethically correct way of research, it would be even more “unethical to exclude persons with PIMD from research that could provide insights about their subjective experiences, and about how to promote their well-being” (Mietola et al. 2017, 264). The same way of thinking concerning the practical use of the final technological product seems to be the only right choice.

M. ENGELHARDT (1), Michal KOSIEDOWSKI (2), T. KRÄMER (1), J. TYRAKOWSKA (3)
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