INSENSION

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Personalized intelligent platform enabling interaction with digital services to individuals with profound and multiple learning disabilities

INSENSION REQUIREMENTS

Deliverable D1.1

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EXECUTIVE SUMMARY

This document presents the INSENSION requirements that form the base of the creation of the INSENSION system. It starts with an introduction on the project's idea of a responsive environment in the context of people with disabilities and submits the pedagogical foundation for the whole project. Therefore, the target group is introduced and associated with the use of Assistive Technology. Subsequently, the approach to assessing the non-symbolic behaviour signals of the test persons is explained which leads to the presentation of the created standard tool. Moreover, the selection of scenarios for using the INSENSION system in the lives of people with profound and multiple learning disabilities is evinced. Finally, application use cases were defined based on the information gathered from three focus group workshops.

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1 INTRODUCTION

The goal of the INSENSION project is to design and develop an ICT platform that should be the user interface for people with profound intellectual and multiple disabilities (PIMD, also referred to as PMLD – profound and multiple learning disabilities) to process the information collected from the world around them and to communicate their needs to others with the use of advanced technologies previously not available to them. The following technologies are planned for this purpose: gesture recognition, facial expression recognition, vocalization recognition, unobtrusive physiological parameters monitoring, Internet of Things and behaviour pattern recognition.

However, the aim of improving the quality of their life, increasing their ability to self-determination and enriching their life by enabling a kind of interactive environment is no new intention. In fact, the idea of the importance of a responsive environment was described before without any technological devices by Ware (1996). This positive environment is characterized by three aspects, in which people have the opportunity (1) to lead the interaction and (2) to give responses to activities of others but also (3) to get responses to their own activities. This defines the responsive environment as something not very special. To give an example for such an environment, the development of communication skills is characterized by the fact that parents already consider the actions of the children as intentional and behave accordingly, although these actions are not performed intentionally yet. This interaction is the base for the communicative, social and cognitive development of the children. Nevertheless, this is often not the case in the context of PIMD because the behaviour signals of this group are more idiosyncratic, less active and harder to read with the result of fewer responses of the caregivers as well which hinder the further development.

The INSENSION project has the intention to counteract this problem and to expand the idea of a responsive environment by using the mentioned technology. In the best case, this offers better opportunities for people with PIMD.

Research that involves people requires pedagogical foundation – the special conditions of PIMD pose an additional challenge. These will be discussed in detail in chapter two by the combination of an attempt to define the target group, the general Human Needs, the Development of Communication Skills and the use of Assistive Technology in this field. In addition, chapter three covers the Assessment of Communication Skills and Inner States in People with PIMD and. Subsequently, the areas of application of the INSENSION system are explained in a closer look.

2 PEDAGOGICAL FOUNDATION

The Idea of Man forms the foundation of all pedagogical acting, especially, when focusing people with disabilities. The historical review shows a serious change in attitude towards people with intellectual disabilities, which included in its darkest hour extinction, exclusion from relevant areas of life and deprivation of educational content. Nowadays, our society is responsible for providing with the same or rather adjusted opportunities and living conditions as people without disabilities. During the last decades, specific guiding principles like the subsequently listed examples of the United Nation worked as an orientation in the changing processes (United Nations):

- respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- non-discrimination
- full and effective participation and inclusion in society

- respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- equality of opportunity
- accessibility
- equality between men and women
- respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

Trying to name the specific group of people that is considered in the INSENSION project provides a consistent terminology on the one hand but also suggests being confronted with a relatively homogeneous group on the other hand. Notwithstanding which term is used (people with profound and multiple learning disability, people with extensive support needs, etc.) you need to be aware of the enormous heterogeneity of this group of people.

The situation of people with disabilities concerning their communication with the environment depends on various factors like, for example, the severity of their disabilities, which comes along with the individual communication skills.

Fundamentally, for pedagogical work in the context of disability, there needs to be assumed that also people with PIMD are in fact able to communicate but in a very individual way. This high individuality complicates finding a common way of understanding between people with PIMD and their environment. Finding an effective and suitable solution for this problem must be one of the main aims of pedagogical efforts (Fröhlich, 2010).

2.1 International Classification of Functioning, Disability and Health (ICF)

The International Classification of Functioning, Disability and Health (ICF) – published by the World Health Organization (WHO) – offers a consistent and standardized terminology for describing the bio-psycho-social aspects of the consequences of illness. The model illustrates the above-mentioned heterogeneity by considering contextual factors as well. The severity of the disability depends on the specific activity whereby disability itself is also seen as a situational phenomenon (DIMDI German Institute of Medical Documentation and Information, 2017; World Health Organization, 2001).

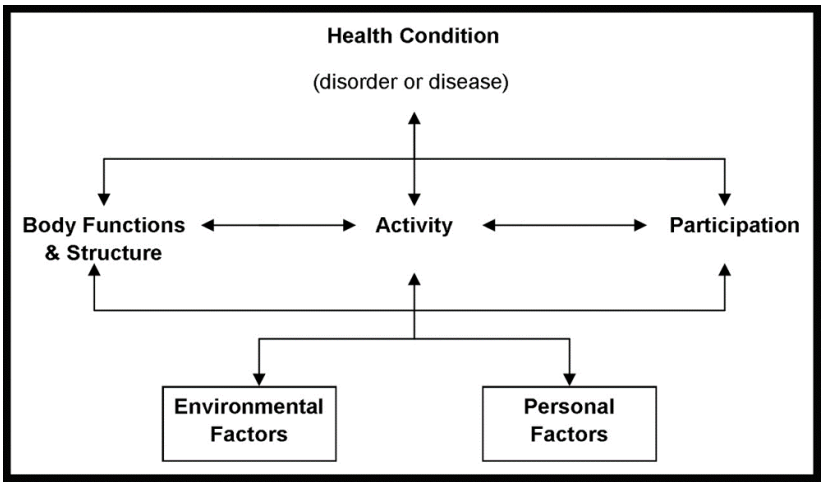


Figure 1: The Model of International Classification of Functioning, Disability and Health

To show the potential influence of the INSENSION system on the participation of a person with PIMD the above presented model will be explained by means of an example.

2.1.1 Health Condition

The fictitious example will deal with a woman with the diagnosis Rett Syndrome. This syndrome mostly affects females since in affected males the genetic mutation in nearly any cases leads to intrauterine death.

2.1.2 Activity

The ICF describes Activity as "the execution of a task or action by an individual" (World Health Organization, 2003), in this case communication with other persons in the environment. This allows taking a closer look on how far the woman with Rett Syndrome is capable of participating in this chosen activity. Hence, the subsequent explanations of the other ICF areas are orientated towards communication.

2.1.3 Body Functions and Body Structure

The Body Structure in Rett Syndrome shows a genetic brain disorder due to a genetic mutation of the X chromosome. These structural conditions accompany specific Body Functions like a regression of social, verbal and adaptive skills. In most cases, verbal language is completely missing. In addition, the Rett Syndrome is often associated with profound intellectual disability and impaired motor skills. As a result, unaided walking is not possible, and, in many cases, a wheelchair is necessary. Moreover, there are specific sensory disorders with a disturbed integration of sensorial stimuli. Motor stereotypes like, for example, washing movements of hands, clapping or kneading are another characteristic. In 80%, an epilepsy accompanies the Rett Syndrome.

2.1.4 Personal Factors

The Personal Factors list those individual skills and attitudes that directly or indirectly influence the participation of the woman in the chosen activity. In our case, this could be factors like the woman's motivation and willingness to be heard and understood. Moreover, gathered experiences in interaction situations could have an impact as well. Of course, her communication skills, especially the communication behaviour repertoire, play a significant role.

2.1.5 Environmental Factors

How far the woman with Rett Syndrome is able to participate in communication situations also depends on several Environmental Factors that work either as a facilitator or as a barrier. These include policies, social norms, attitudes and expectations concerning dealings with people with disabilities. In addition, caregivers, i.e., family or professionals, can provide important encouragement comprising, inter alia, secure relationships or active commitment for and sensitive handling of their child's needs. Regional policy making and legislation influence crucial factors like financial support and material resources. For example, Augmentative and Alternative Communication or Assistive Technology, like the INSENSION system, aims to improve the way of communication of the affected person.

2.1.6 Participation

Against the background of the given framework, it is now possible to take a closer look on how the woman is involved in a specific life situation. Taking into account that the close caregivers probably are able to correctly interpret her behavioural signals her participation in communication situations with these interaction partners seems to be possible. Being confronted with unknown persons that do not know how to interpret her behaviour correctly could be much more difficult and restrictive. Especially in the latter case, the INSENSION system could work as a facilitator to improve the participation of the woman in interactions, by recognizing and interpreting her individual communication behaviour and complementing her individual requirements.

2.2 Human Needs

"Human needs are the necessary conditions and aspirations of full human functioning" (Hamilton, 2009, p. 201) The manifestation of those needs differs from individual to individual and their satisfaction depends on various personal end environmental factors. In the context of PIMD, satisfying these needs is significantly impeded by the complications in their communication.

Maslow – as one of the most important representatives of the humanistic psychology – defined the subsequently explained five different human needs and sorted them by means of their priority. He emphasizes that the physiological needs are the strongest ones and that committing oneself to the further needs supposes the satisfaction of these physiological instincts (Maslow, 1981).

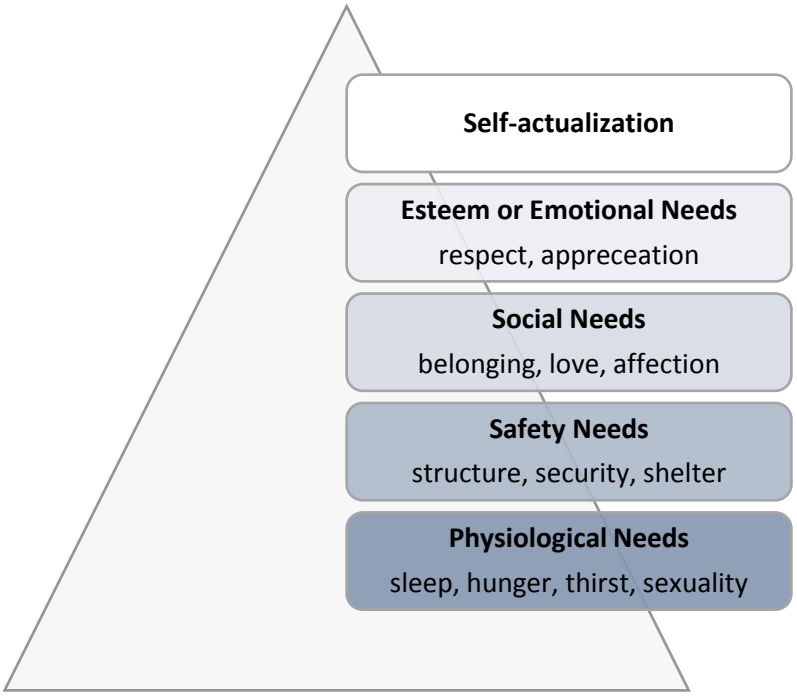


Figure 2: Maslow's Hirarchy of Needs

2.3 Development of Communication Skills

Many people with disabilities are restricted in their communication opportunities due to the fact that they do not master verbal skills. However, the satisfaction of their needs – and along with that also their personal well-being – can only be achieved by communicating them and being understood correctly. To describe the communication skills of people with disabilities Kane and Rowland recommend taking a close look at the early development of communication within children without disability. These early communication skills can be classified into seven levels (Kane, 1992; C. Rowland, 2013):

Table 1: Development of Communication Skills

LEVEL	DESCRIPTION	PARTICULARITIES IN THE CONTEXT OF DISABILITIES
1. Pre-Intentional Behaviour	– behaviour shows the general state of the person but is not used consciously – important signals: body movements, facial expressions, vocalizations – age: 0-3 months of age	– less opportunities for parents to interpret and react to child's signals due to long stays at hospital – different and incomprehensible signals (e.g., no eye-contact in blind children) – slower learning processes
2. Intentional Behaviour	– behaviour is under control of the person but not used to communicate intentionally – important signals: body movements, facial expressions, vocalizations, eye gaze – age: 3-8 months of age	– show less interest, are more passive – show less signals and reactions to interaction offers; as a result, parents overstimulate or offer too little – challenging behaviour as an attempt to communicate can burden the relationship
INTENTIONAL COMMUNICATION		
3. Unconventional Communication	– pre-symbolic (no symbols are used) – intentional use of behaviours – behaviours are not socially acceptable for older persons – important signals: body movements, vocalizations, facial expressions, simple gestures (e.g., tugging on others) – age: 6-12 months of age	– have difficulties to understand that they can reach their goals with the help of others – have difficulties to understand the connection between their signals and the reaction of the environment – have less joy in imitation and observing others; impeded transition to conventional communication – impeded intuitive acting of parents due to atypical behaviour of their child – many people with PIMD stay at this level (for the INSENSION target group it is characteristic not to pass on to the next level)
4. Conventional Communication	– pre-symbolic (no symbols are used) – intentional use of behaviours – socially acceptable behaviours (in part culture-specific) – important signals: pointing, nodding or head-shaking, waving, looking from a person to the desired object – age: 12-18 months of age	– some children with milder disability stay at this level for a very long time or forever – experience of failure despite of specific exercise – risk of obsessive fostering by parents

SYMBOLIC COMMUNICATION		
5. Concrete Symbols	– these symbols physically resemble what they represent – important signals: sounds, objects, pictures, iconic gestures – no separate stage but signals are used together with gestures and words – stage is often skipped by individuals – age: 12-24 months of age	– impeded transition to use of words – better prospects in gestural communication
6. Abstract Symbols	– important signals: speech, brailled or printed words, manual signs – no physical similarity between the symbols and what they represent – these symbols are used one at a time – age: 12-24 months of age	
7. Verbal Language	– two- or three-symbol combinations (e.g., "want milk") – consideration of grammatical rules – age: from 24 months of age	

2.4 Assistive Technology within People with Profound and Multiple Learning Disabilities

Assistive Technology (AT) covers a wide range of devices and their applications to help people with disabilities and special needs. By supporting their daily tasks, the main goals of AT are on the one hand the promoting of self-determination and on the other a better quality of life. Only the combination of the rapid development of technical possibilities and, simultaneously, suitable pedagogical interventions can result in the highest possible outcome for people with disabilities. This research interest can be explained by the increased attention to the rights of this group of people (e.g., via *the Convention on the Rights of Persons with Disabilities*) as well as the improved possibility to reach an inclusive society. The necessary interaction with the social environment needs to be enhanced by different tools of AT to reduce personal isolation, passivity and social withdrawal (Lancioni, 2013; Stasolla, Perilli, & Boccasini, 2016).

Two broad categories of users who have gained benefit from such technology are defined: (1) people with extensive motor impairment but no intellectual disabilities and (2) users with PIMD, which means a combination of intellectual, motor and sensorial disabilities. More precisely, the first type of user utilizes AT in school, medical or home settings for educational or rehabilitative purposes to promote literacy (Stasolla et al., 2016). Users of the second category, which is the focus of the INSENSION project, are supported by the following AT devices (Lancioni, 2013; Stasolla et al., 2016):

- *microswitches*: allowing the user to get access to a preferred stimulation or to foster movement fluency
- *combination of two microswitches*: enabling a choice between to stimulations
- *speech-generating devices*: combining a microswitch and a voice output
- *spatial orientation systems*: supporting the user by auditory or visual direction indications or by corrective feedback

- *computer-aided instruction systems*: providing a verbal or pictorial presentation of personal needs (i.e., leisure, communication, video, music etc.)
- *microswitch clusters*: aiming to strengthen adaptive response and reducing challenging behaviour

These electronic tools offer the ability to control the environment instead of relying on parents or caregivers to influence the surrounding area or get the preferred stimulation. However, before implementing such programs Stasolla suggests taking into account the targeted behaviours, tasks and environments because beneficial effects for these people will only be achievable if a rigorously individualized and strictly suitable solution is realized (Lancioni, 2013; Stasolla et al., 2016). The INSENSION project considers these aspects by aiming to create a personal responsive environment with technical support.

2.5 CONCLUSION

One main objective of the INSENSION system is a better understanding and satisfaction of the needs of a person with PIMD that is in the limelight. Inspired by Maslow´s *Hierarchy of Needs*, the subsequent model illustrates in the green areas the different needs of an individual. There is no hierarchy shown in the model because Maslow's prioritization suggests that reaching self-actualization seems to be a nearly unattainable goal in the context of disabilities – especially when it comes to people with PIMD.

The specific manifestation of these human needs differs from person to person and depends on environmental and personal factors. These factors that are also part of the above-mentioned ICF model can involve both possibilities and limits.

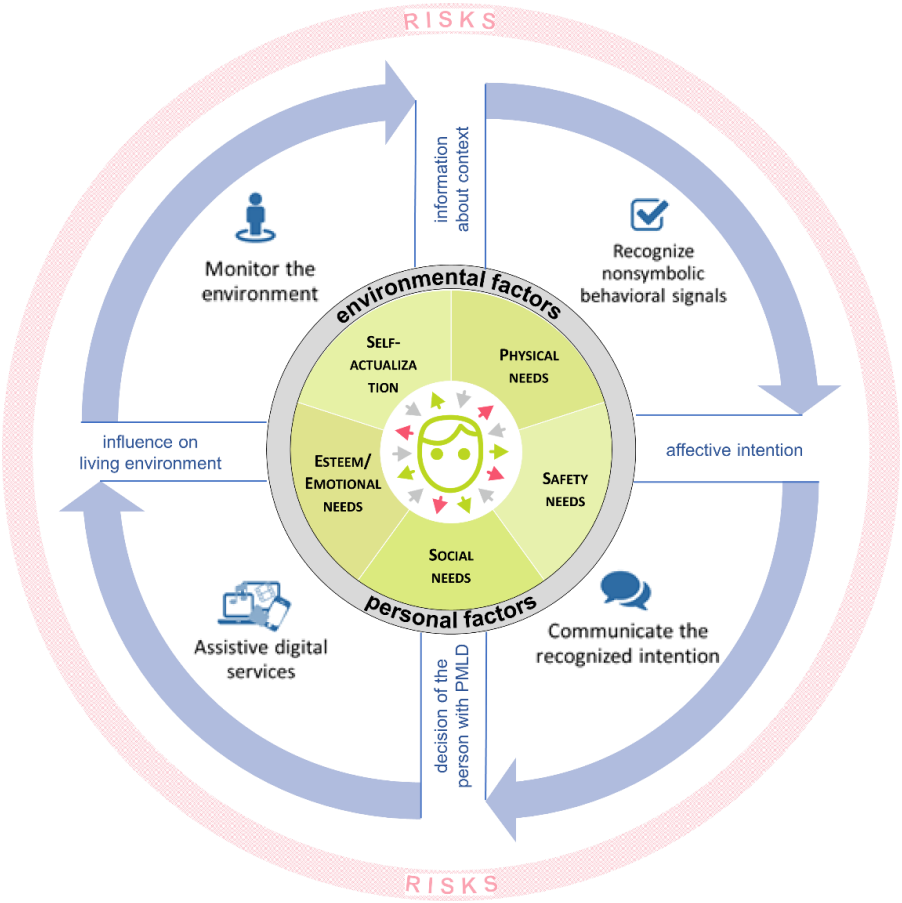


Figure 3: Pedagogical Foundation within the INSENSION project

The set of capabilities that arises out of the environmental and personal factors is aimed to be extended by the INSENSION system as it is illustrated in the concept of the INSENSION platform (blue circle; PSNC, 2017, p. 11).

However, there are several pedagogical and ethical risks that arise out of the project's conception. Therefore, some of those aspects that need to be considered are listed below:

- awareness of the wide heterogeneity and individuality of the target group
- maintenance of privacy and social retreat instead of permanent surveillance
- guaranteeing data protection
- no over-interpreting of the behaviour (not every behaviour is meant to be communication)
- respecting the person's choice of who shall or shall not be addressed
- respecting the person's choice of which content shall or shall not be communicated
- maintenance of social interaction (supporting the caregivers instead of replacing them by the system)

3 Assessment of Communication Skills and Inner States

3.1 Description of the Assessment Model

The standard tool of the assessment will be created to gather the non-symbolic behaviour signals of each individual with PIMD. The subsequent model illustrates the structure of the assessment.

The inner circle shows the eight determined assessment areas that can be divided up into *General Data* (grey segments) on the person and *Information on Communication and Inner States* (blue segments) as illustrated in the second circle.

By whom the specific data will be raised is shown in the green areas. The standard tool will collect data based on the expertise of the parents and professional caregivers by video recording communication scenarios in the three premises of Na Tak and at the chosen test person's private home. A paper-based assessment (questionnaire) for the parents and professional caregivers will be an additional data source. The data captured from parents and professional caregivers includes all of the eight assessment areas (*General Data* as well as *Information on Communication and Inner States).* The questionnaire is filled in by at least one family member and at least one professional caregiver of the chosen test person at the beginning of the assessment period. Possibly, there will be another period of elicitation with the questionnaire in case of its revision.

In addition, the assessment is complemented by the technological devices that will gather *Information on Communication and Inner States*. The outer semicircle lists the technological partners and shows the exact responsibilities in this part of the assessment.

The five subareas shown in the left part of Figure 5 can be interpreted as communication behaviour relating to inner states. *Challenging Behaviour* constitutes a very specific field within people with disabilities, especially, regarding manifestations that are typical for specific genetic syndromes. Moreover, this subarea can hardly be raised technologically. For these reasons, this field is supposed to serve as a separate subarea in addition to the four technologically collectable data sectors and forms a separate part in the questionnaire. The behaviour signals belonging to the other four subareas are not very meaningful in their own right but need to be put in a context or rather be interpreted against the background of specific inner states. Therefore, these assessment sections got translated into the inner states *Mood*, *Pain*, *Pleasure* and *Displeasure or Distress* that supplement the level of *Preverbal Communication* and the aforementioned field of *Challenging Behaviour*.

The level of preverbal communication provides information on the person's communication skills focusing on their use of various behaviour signals. This knowledge enables stabilizing already existing skills as well as initiating the next level of communication. The field of inner states splits up into mood, pain, pleasure and displeasure. To be able to improve the quality of life, it is important to know what kind of behaviours a specific individual with PIMD shows, e.g., in a situation of pain or to express pleasure.

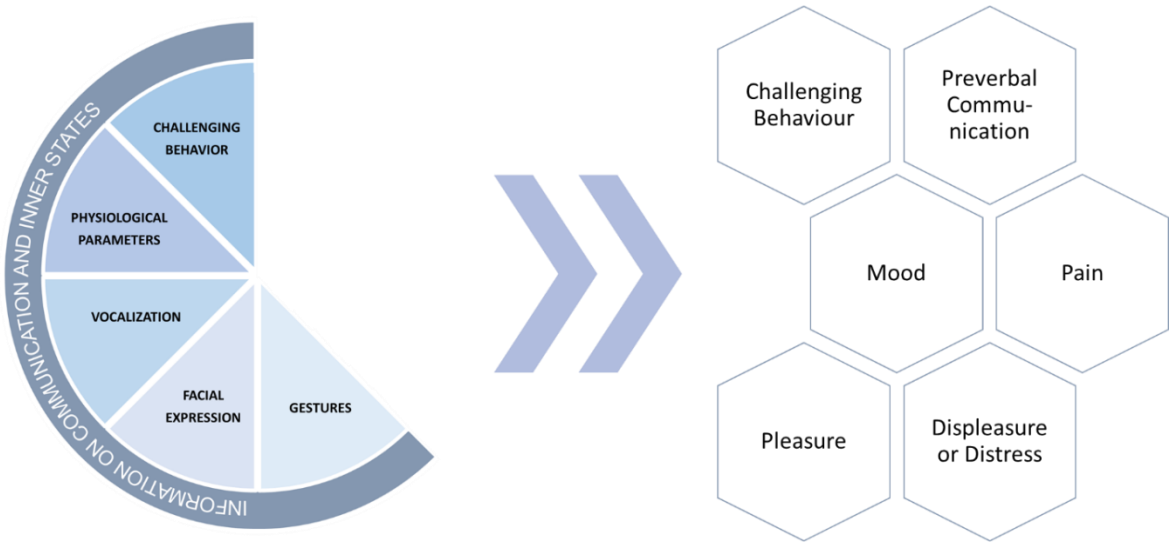


Figure 5: Transformation of the Assessment Model to the Paper-Based Assessment

These new formed sections will be analysed by means of the INSENSION standard tool – a combination of several diagnostic test methods. Which existing diagnostic tests were taken into account or served as an orientation is explained in the chapter below.

3.2 Overview of Assessment Tools

For the creation of the INSENSION standard tool a great range of diagnostic tests and checklists was reviewed and validated against the background of the INSENSION requirements. Appendix 7.1 lists all reviewed tests and their validation to justify why they have been selected or rejected. Subsequently, those diagnostic methods that are graded relevant and suitable are presented assorted according to the different assessment sections.

Table 2: Overview of the Chosen Diagnostic Tests and Sources for the Paper-Based Assessment

ASSESSMENT AREAS AND SECTIONS		CHOSEN DIAGNOSTIC TEST OR SOURCE
GENERAL DATA	Personal data	Oriented towards – Hall, Arron, Sloneem, and Oliver (2008) – Vos et al. (2012)
	General competencies	
	Additional Information	
INFORMATION ON COMMUNICATION AND INNER STATES	Preverbal Communication	– *Preverbal Communication Schedule (PVCS)* by Kiernan and Reid (1987) – Rotter, Kane, and Gallé (1992)
	Challenging Behaviour	– *Aberrant Behavior Checklist (ABC)* by Aman and Singh (1986)
	Mood	– *Mood and Anxiety Semi-structured Interview (MASS)* by Charlot et al. (2007)
	Pain	– *Non-communicating Adult Pain Scale (NCAPS)* by Lotan, Moe-Nilssen, Ljunggren, and Strand (2009)
	Pleasure	Oriented towards – *Disability Distress Assessment Tool (DisDat)* by Regnard et al. (2007) – Roemer, Verheul, and Velthausz (2017)
	Displeasure or Distress	

Prospectively, not all of the chosen tests will be taken one to one but modified according to the INSENSION requirements in some cases. Concerning the sections *Challenging Behaviour*, *Preverbal Communication*, *Mood* and *Pain*, the items were taken one to one except for the NCAPS that rather serves as an orientation due to some important indications within the context of adulthood.

The listed texts serve as an additional guideline when no suitable diagnostic test was found. For the paper-based assessment, relevant and appropriate segments are selected in order to complement each other in a reasonable way. Besides, the complete paper-based assessment will be translated into Polish and is listed in Appendix 2.

4 SCENARIOS

This chapter aims to classify the variety of life situations of people with PIMD in order to identify the areas of application of the INSENSION system. The possible scenarios can be classified according to the *life stages* and the *areas of life*, which is illustrated in the table above. The *Life Stages* are divided into *Preschool* and *School*, *Adulthood* and *Seniority*, whereas the *Areas of Life* consist of *Work* and *Living*, which splits up in *Housing* and *Leisure*.

Table 3: Overview of the (Chosen) Scenarios

<table>
<tr><td></td><td></td><td colspan="7">AREAS OF LIFE</td></tr>
<tr><td></td><td></td><td colspan="3">WORK</td><td colspan="3">LIVING</td><td></td></tr>
<tr><td></td><td></td><td colspan="3"></td><td colspan="3">HOUSING</td><td>LEISURE</td></tr>
<tr><td rowspan="4">LIFE STAGES</td><td>EARLY CHILDHOOD</td><td colspan="3">Kindergarten
Pre-School
Early-Intervention</td><td colspan="3" rowspan="2">Living Together with Parents</td><td rowspan="4">Different Leisure Activities Depending on Age and Interest</td></tr>
<tr><td>SCHOOL AGE</td><td colspan="2">Special school</td><td>Inclusive School</td></tr>
<tr><td>ADULTHOOD</td><td>Work-Oriented Program</td><td>Sheltered Workshop</td><td>Open Labour Market</td><td>Residence</td><td>Ambulant
– Assisted Living
– Inclusive Living</td><td>Living Together with Parents</td></tr>
<tr><td>SENIORITY</td><td colspan="6">Large Scale Institution
Day-Structure & Housing</td></tr>
</table>

All of these listed possible scenarios are explained in detail and provided with an example in Appendix 3. The INSENSION system should be implemented in the above marked four scenarios, because of several reasons:

(1) Basically, all people with PLMD should benefit from the completed INSENSION system regardless of age or life situation. Therefore, it should be tested in the first three life stages during the project (early childhood, school age, adulthood).
(2) The stadium of seniority can be neglected at the moment because the characteristics do not differ significantly from those of adulthood.
(3) Each of the three life stages has specific requirements, tasks and objectives:
    a. *Early Childhood – Early Intervention:*
    In this life stage, especially people with PIMD need support as early as possible, which is usually implemented in **individual settings** of early-intervention and in-

cludes the following areas: sensory learning, motor skills, social and emotional development or communication and speaking.

b. *Early Childhood – Life at Home with Parents:*
This scenario offers impressions of another specific surrounding: **the private home with the parents as caregivers**. The parents as those persons who are probably closest to our test persons since their birth enrich the system by providing their knowledge and showing their way of interaction.
In addition, the INSENSION system aims to be installed at home as well. Therefore, this scenario offers the opportunity to test the use of the system in a private surrounding.

c. *School Age – School:*
A typical situation in this age takes place in lessons at school. These are usually **group situations**, in which students with PIMD interact with teachers or other students with or without disabilities and the teacher.

d. *Adulthood – Work-Oriented Program:*
This scenario involves situations in individual settings as well as group settings, but first and foremost, it offers impressions of the **widest age span** along the life stages. Until this point in time anybody developed individual behaviours, some even got gridlocked in their way of behaving.

This list shows the unique selling points of the different areas so that the choice of the scenarios gets justified. On the one hand, using the marked scenarios guarantees gathering as many different impressions during the assessment as possible. On the other hand, this choice of scenarios enables the INSENSION system to be in tune with the requirements of various situations under different conditions.

5 Application Use Cases

To complement the knowledge of requirements of nonsymbolic interaction gathered by means of the INSENSION questionnaire, three focus group workshops took place in order to define those situations, which are the most challenging in the life of people with PIMD for themselves and their environment. These application use cases supported identifying ideas on which digital applications and services would be of greatest interest to the target group including any that is related to enable communication with other people and facilitate interaction with these services using the INSENSION platform. Hereafter, the procedure of the focus group workshops will be explained before presenting the particular results of each single workshop.

5.1 Focus Group Workshops

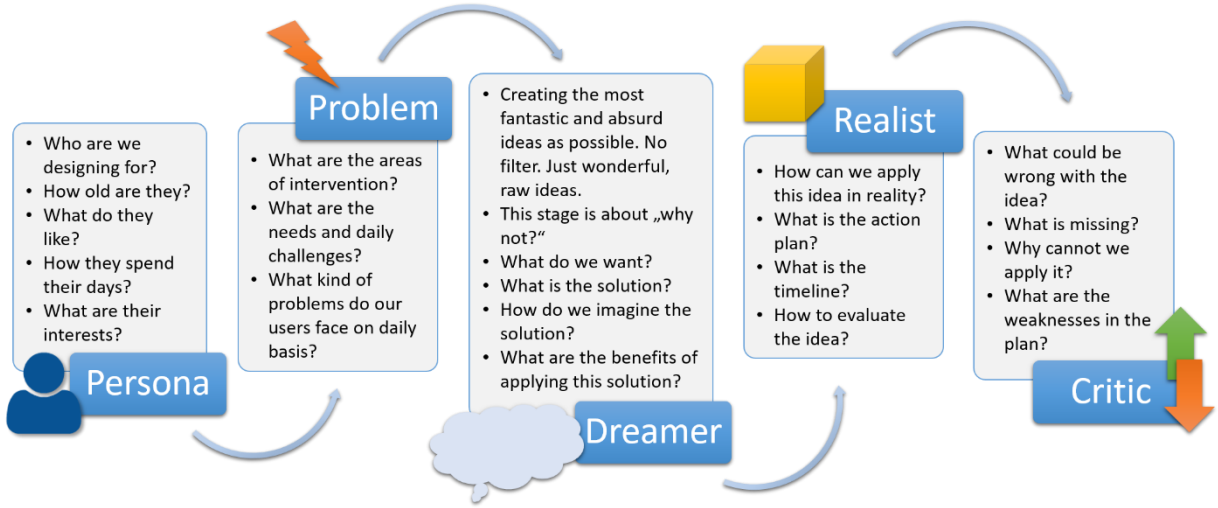
In order to define application use cases within the context of people with PIMD and to think of possible solutions, which provide remedy for these challenging scenarios, a multiperspective approach is necessary. Hence, the participants represented a number of groups with different perspectives on and connections to the topic. Relatives of persons with PIMD as well as professional caregivers provided their expertise and experience with the target group itself whereas specialists in Information and Communications Technology (ICT) and representatives of the area of provision of aids (POA) focused on options of technological support. The subsequent table shows an overview of the number of each participating group per workshop.

Table 4: List of focus group workshops

Workshop		Relatives	DSPs	ICT & POA	Sum
I.	**Heidelberg**, Germany (30.11.2018)	3	4	2	9
II.	**Poznań**, Poland (11.12.2018)	4	3	5	12
III.	**Kraków**, Poland (11.02.2019)	5	4	2	11
					total: 32

The workshops were oriented towards particular methods of the Design Thinking approach like the creation of personas to exemplify the target group (Dark Horse Innovation, 2016). Additionally, they were moderated according to the Walt-Disney-Method by (Dilts, Epstein, & Dilts, 1991) which splits

the conversation in three parts: dreamer, realist, critic. The whole procedure of each focus group workshop is visualized below.



5.1.1 Workshop I: Transitions

The first workshop took place on 30.11.2018 in Heidelberg, Germany. To not only focus on national perspectives, this workshop was conducted in addition to the two Polish workshops, which were envisaged from the beginning of the project. The composition of the participating group is illustrated below.

Table 5: Workshop I - Participants

Area	Relatives	Professional Caregiver	Sum
Early Childhood	1	1	2
School-Age	0	1	1
Adulthood	2	2	4
ICT	2		2
			total: 9

Based on the presented personas and the creation of their fictitious daily routines, the participants defined **transitions** within the life of people with PIMD as the challenging situation they wanted to focus on. Hence, they collected the following ideas thinking of the perfect solution for the mentioned scenario if there were no limitations:

Figure 6: Workshop I - Dreams

Concerning the concrete realization of creating an application, which provides useful information for new DSPs or other unknown people, the participants saw the base in regulations and participation of politics, health insurance funds, authorities and payers. They identified the need of having one person who is primarily responsible for organization and coordination issues. Furthermore, they agreed about the necessary participation of relatives, professional caregivers, direct environment and advocacy groups to define aims and provide experiences, data as well as creating the setting. To complement this information, the expertise of medical doctors and therapists is needed. Additionally, the participation of experts in ICT (especially for software programming) and engineers for the construction and realization of the technological solution was stated. Regular meetings of all these participants need to be envisaged to guarantee individualized planning for each person with PIMD.

Keeping in mind the risks these ideas may imply, the participants of the workshop focused on respecting the privacy of the individual with PIMD as well as maintaining the person-centeredness and not treating the particular family as a research project. Due to the high number of participants needed to realize their idea, they also discussed the risk of a lack of cooperation, having different interests and organizational problems, which may occur. From technological point of view, there is always the risk of not collecting enough data to realize the planned idea.

5.1.2 Workshop II: Nights

The second workshop took place on 11.12.2018 in Poznań, Poland. The composition of the participating group is illustrated below.

Area	Relatives	Professional Caregiver	Sum
Early Childhood	2	1	3
School-Age	1	1	2
Adulthood	1	1	2
ICT & POA	5		5
			total: 12

Based on the presented personas and the creation of their fictitious daily routines, the participants defined **nights** as the challenging situation they wanted to focus on. Hence, they collected the following ideas thinking of the perfect solution for the mentioned scenario if there were no limitations:

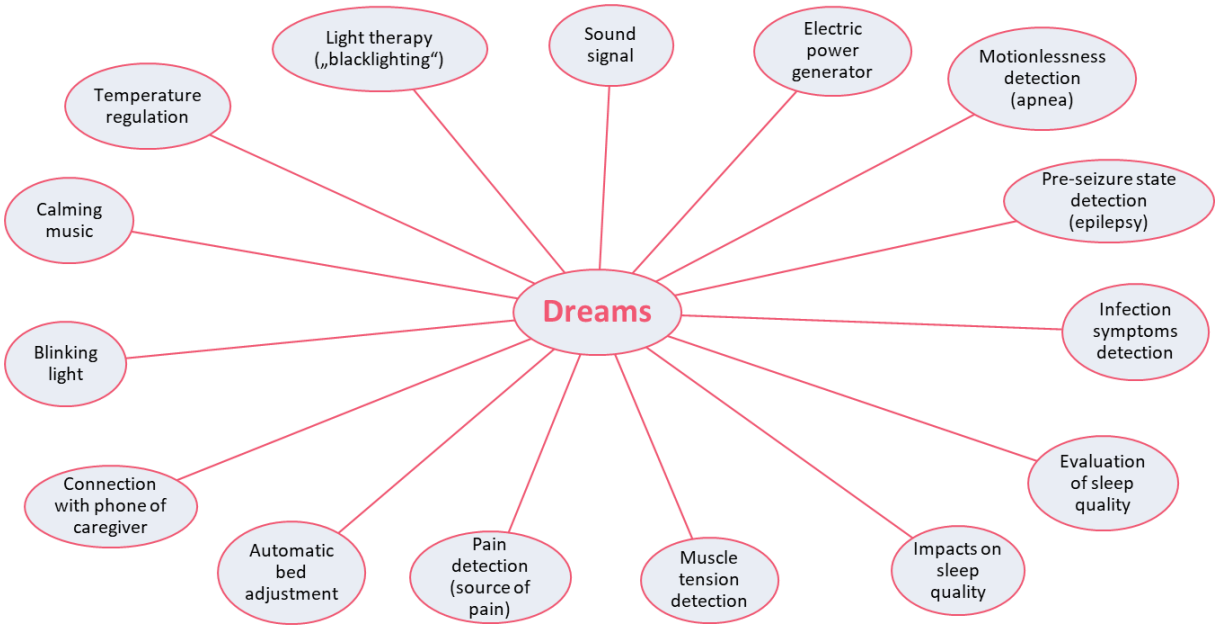


Figure 7: Workshop II - Dreams

Concerning the realization of night monitoring, the participants of the workshop discussed features like phone notifications and an optional blinking light for the caregivers in addition to a live camera feed in the person's room. Since weather and its changings affects mood and sleep, weather warnings should be included. Early pain detection as well as an automatic detection of the need for changing diapers by a change of humidity were also discussed as helpful features to prevent sleep disturbances. Different forms of music interventions in case of sleeplessness were mentioned, e.g. playing calming music or sounds and suggesting new music.

Keeping in mind the possible problems of night monitoring, the participants discussed the case of wrong interpretations and agreed upon the feature of an easy system reset. In terms of usability, an easy system operation is requested in order to be able to add functions step by step.

5.1.3 Workshop III: Impact of external factors on a person's mood

The third workshop took place in Kraków (Poland) on 11.02.2019. The composition of the participating group is illustrated below.

Area	Relatives	Professional Caregiver	Sum
Early Childhood	1	2	3
School-Age	2	1	3
Adulthood	1	1	2
ICT	2		2
			total: 10

Based on the presented personas and the creation of their fictitious daily routines, the participants defined **the impact of external factors on a person's mood** as the challenging situation they wanted to focus on. Hence, they collected the following ideas thinking of the perfect solution for the mentioned scenario if there were no limitations:

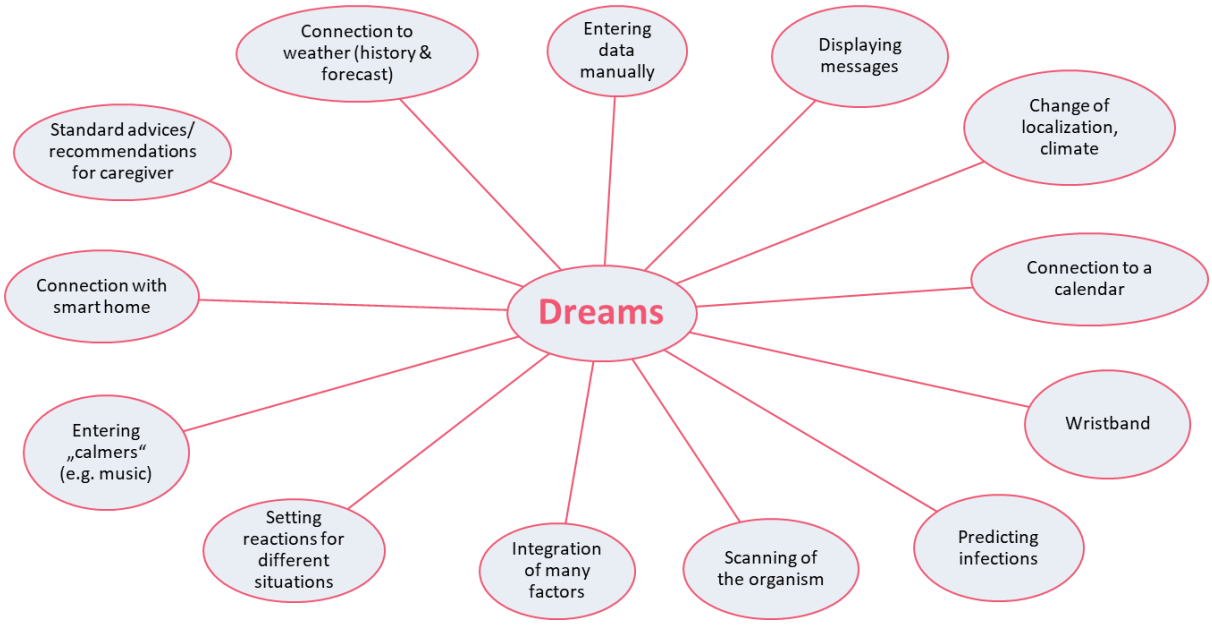


Figure 8: Workshop III - Dreams

Concerning the concrete realization of predicting a person's mood against the background of external factors, the participants of the workshop decided to include weather parameters, i.e. air pressure, moon phases, storms, temperature, forecast, pollution. Additionally, the application should be synchronized with a calendar to enable, for example, a division between school days and free days. In combination with personalized data like the normal temperature of a specific individual with PIMD, the application should list all factors that could have impacted this person's mood. Based on this information, a possible need for action should be recommended to the particular caregiver.

Keeping in mind all critical issues connected with this idea, the participants stated the huge amount of data, which is needed for the realization in combination with the need for usability. In some cases, it might be difficult to find a trustworthy source of data to rely on, e.g. weather information.

5.2 Definition of Application Use Cases

Based on the findings and all ideas created within the focus group workshops, three application use cases were defined:

1) Focus on communication
2) Use of multimedia player
3) Smart room/ smart home with robotic assistance device

Each application aims at providing remedy in the defined areas of intervention (i.e., transitions, night, impact of external factors on a person's mood) by increasing the self-determination and improving the quality of the person's life. Concerning the realization of the envisaged solutions, the inclusion of secondary users (caregivers of persons with PIMD) plays an important role, especially in terms of usability. These results are input to Work Package 4, which deals with designing and developing exemplary digital services for the pilot trial.

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7 APPENDIXES

7.1 OVERVIEW OF ALL ASSESSMENT TOOLS

ASSESSMENT TOOL	FURTHER INFORMATION	VALUATION	
		NEGATIVE	POSITIVE
Level of Preverbal Communication			
Nichtsprachliche Kommunikation: Erfassung und Förderung (Rotter et al., 1992)	**Content:** – three basic contents of communication: protest, demand, comment **Method:** – triggering communication behaviour by creating specifically structured situations **Aim:** – identification of level of preverbal communication	– national; no English version	– lucid overview of preverbal communication – similar to the Communication Matrix (increases validity)
Pre-Verbal Communication Schedule (PVCS) (Kiernan 1987)	**Content:** – target group: students with minimal verbal or signing skills **Method:** – checklist via external assessment – detailed observations of what means the child or adolescent uses to communicate, e.g., attention, needs, wishes, refusals **Aim:** – establishment of the use of speech or signs, symbols or other form of non-verbal communication	–	– conform target group – international
The Triple C: Checklist of Communication Competencies (Bloomberg, West, Johnson, &	**Content:** – target group: adolescents and adults with severe disabilities – focusing on six levels of pre-intentional and intentional	– inaccuracy of items – items are poorly "translatable" into	

Iacono)	communication **Method:** – checklist on the base of observation in daily life filled in by family members and professional caregivers **Aim:** – assignment of six levels of preverbal communication	the requirements of technical devices	
Communication Matrix (Rowland & Fried-Oken 2010)	**Content:** – alternative forms (electronic devices, voice-output systems, Braille, sign language, 3-dimensional or picture symbols) – pre-symbolic communication (gestures, body movements, sounds, eye gaze, facial expressions) – typical forms of communication (such as speech and writing) **Method:** – checklist via external assessment – triggering communication behaviour of four different content in specifically structured situations **Aim:** assignment of seven levels of preverbal communication (Pre-intentional Behaviour, Intentional Behaviour, Unconventional Pre-Symbolic Communication, Conventional Pre-Symbolic Communication, Concrete Symbols, Abstract Symbols, Language)	– not suitable to all project purposes	– similar to “Nichtsprachliche Kommunikation: Erfassung und Förderung“ (increases validity) – international
Communication and Symbolic Behavior Scales (Wetherby & Prizant 2003)	**Content:** – observation areas: areas: social, speech, symbolic – target group: 6 and 24 months and children up to 72 months who exhibit atypical development **Method:**	– items are poorly "translatable" into the requirements of technical devices – limited target	

	– checklist based on parent report or observation by a qualified professional **Aim:** – identification of communication skills and often-overlooked indicators of symbolic development	group – focus on symbolic communication	
Communication Complexity Scale (CCS) (Brady et al. 2012)	**Content:** – 11 levels of communication encompass the categories of perlocutionary (pre-intentional), illocutionary (intentional) and beginning locutionary (symbolic) communication development **Method:** – criterion-referenced assessment for researchers and clinicians – expressive communication summary score **Aim:** – description of communication levels that reflect increasing degrees of coordination between referent and communication partner, and increasingly sophisticated forms of communication – identification of the most sophisticated communication behaviors demonstrated by the individual	– the study proves the difficulty in distinction of the different levels	– conform target group
Affective Communication Assessment (Coupe et al. 1987)	**Content:** – four basic reasons to communicate: to refuse things; to obtain things; to engage in social interactions (positive/negative); to provide or seek information **Method:** – checklist via external assessment – structured diagnostic observation tool	– inaccuracy of items	– user-friendly handling – conform target group

	– mostly in combination with video recordings **Aim:** focus on likes/dislikes		
General areas of development (i.e., communication, gross motor skills, fine motor skills, life skills, orientation, etc.)			
Paderborner Entwicklungs-Raster für Schwerst-mehrfachbehinderte (mit Sehschädigung) (PERM) (Faber & Rosen Klaus 1997)	**Content:** – nine observation areas: gross motor skills, fine motor skills, food intake, passive communication, active communication, visual perception, auditory perception, cognition, social behaviour **Method:** – checklist via external assessment **Aim:** – detailed assessment of individual competencies – initial point for fostering	– too extensive – items are not related to specific situation – items are poorly "translatable" into the requirements of technical devices	– conform target group
Leitfaden zur Förderdiagnostik mit schwerstbehinderten Kindern (Fröhlich & Haupt 2004)	**Content:** – areas of development that children without disabilities show in their first year of life – observation areas: relationship between caregiver and child, response to voice and language, verbal utterances, response to sensory offers, hand movements/games, movements of the whole body, spatial experience, drink and eat, interaction with caregivers **Method:** – checklist via external assessment – systematic observation **Aim:** – assessment of competencies	– no English version – items are too accurate – classification in different developmental ages not necessary – items are poorly "translatable" into the requirements of technical devices	
VADEMECUM	**Content:**	– no English version	

(Schlienger 1988)	– target group: children of the age of one month to three years – observation areas: physical development, seeing and grasping, hearing and speaking, independence, feelings and community ability **Method:** – checklist via external assessment – must partly be carried out in the natural environment **Aim:** – creation of a development profile with sector-specific developmental ages and identification of a risk area	– too accurate items – items are poorly "translatable" into the requirements of technical devices	
Progress Assessment Chart (PAC) of Social and Personal Development (Gunzburg 1991)	**Content:** – observation areas: self-help (eating, mobility, toilet/washing, dressing), comprehensibility, social adjustment, employment (fine/gross motor skills) – focus: small-scale development of life skills for the group of people with severe intellectual disabilities **Method:** – checklist via external assessment – systematic observation and reporting on the social behaviour of children and adults with intellectual disabilities **Aim:** – assessment of life skills and adaptive behaviour – development of basic living skills	– too extensive – items are not related to specific situation – items are poorly "translatable" into the requirements of technical devices	– additional focus on people with PIMD
Beobachtungsbogen zu kommunikativen Fähigkeiten – Revision (BKF-R) (Scholz, Wagner, & Stegkemper 2018)	**Content:** – assessment of communicative and communication-relevant competences of children, adolescents and adults – observation areas: situation-specific communication, basic communication skills, perception, orientation, motor skills	– open-ended questions	– focus on specific situations

	Method: – checklist via external assessment – multi perspective – structured diagnostic observation tools **Aim:** – presenting the similarities and differences in the assessment of each individual caregiver as a basis for possible support		
Adaptive Behaviour Assessment System, Second Edition (ABAS-II) (Harrison & Oakland 2004)	**Content:** – assessment areas: communication, community use, functional academics, home living, health and safety, leisure, self-care, self-direction, social, work – target group: people with learning difficulties, ADD/ADHD, motor disorders, speech and language disorders, hearing disorders, neuropsychological disorders – age: birth – 89 years **Method:** – checklist via external assessment (professional caregivers, parents, teachers, etc.) **Aim:** – assessment of adaptive skills functioning – evaluation of areas of functioning – determination of strengths and weaknesses – specification of training goals	– too extensive	– multi-perspective assessment
Vineland Adaptive Behavior Scale (Sparrow, Cicchetti, & Balla 2005)	**Content:** – 381 items – observation areas: communication, daily living skills, socialization, motor skills (fine/gross), maladaptive behaviour – target group: birth to 89 years	– no focus on people with PIMD – content of items increases quickly – inaccuracy of items	– English and German version

	Method: – checklist via external assessment – behaviour rating scale typically completed by parent, caregiver, and/or teacher; self-rating option for adults **Aim:** – complete assessment of adaptive skills across the life span		
Wessex Scales (Kushlick, A., Blunden, R. & Cox 1973)	**Content:** – incontinence, mobility, speech, self-help, literacy, sensory **Method:** – checklist via external assessment – brief disability rating scale: Not able, Partly able, Able **Aim:** – measurement of relevant behaviour characteristics of people with intellectual disabilities in large scale surveys	– inaccuracy of rating	
Other unused and un-analysed assessments: – Kommunikationsprofil (Kristen 2004) – Beobachtungsinventar (Hedderich 2006) – Elterninterview zu praktischen und sozialen Kompetenzen (EPS) (Sarimski 2007)			
Mood			
Mood and Anxiety Semistructured Interview for Patients with Intellectual Disability (MASS) (Charlot, Deutsch, Hunt, Fletcher, & McLlvane 2007)	**Content:** – symptoms of mood disorders – target group: adults with severe to profound intellectual disabilities **Method:**	– focus is more on adulthood	– focus on people with PIMD

	– checklist via external assessment – assessed by mental health professional – answered by informants **Aim:** – identification of symptoms of mood disorders (including anxiety, worry, depressed mood, anhedonia)		
Mood, Interest and Pleasure Questionnaire (MIPQ) (Ross & Oliver 2003)	**Content:** – informant-based measure of two aspects of affect for people with severe and profound intellectual disabilities – 25-items: Mood subscale (12 items); Interest and Pleasure subscale (13 items) **Method:** – checklist via external assessment – informants rate aspects of participants' behaviours which are correlated with affect on five-point Likert scales **Aim:** measuring the level of mood, interest and pleasure	– not suitable to all project purposes	– conform target group conform extent
Scale for the Assessment of Negative Symptoms (SANS) (Andreasen 1984)	**Content:** – affective flattening, alogia, avolition-apathy, anhedonia-asociality and attention **Method:** – rating scale **Aim:** – assessment of negative symptoms in schizophrenia	– no focus on people with PIMD	
Scale for the Assessment of Positive Symptoms (SAPS) (Andreasen 1984)	**Content:** – hallucinations, delusions, bizarre behaviour, positive formal thought disorder **Method:**	– no focus on people with PIMD	

	– rating scale **Aim:** – assessment of positive symptoms in schizophrenia		
Pain Scales and distress Scales			
Non-Communicating Children's Pain Checklist-Revised (NCCPC-R) (Breau, McGrath, Camfield, & Finley 2002)	**Content:** – 30 observations to be assessed – target group: children and adolescents (3 to 18 years) with intellectual disabilities who are not able to communicate their pain with facial expression, gestures or verbally **Method:** – checklist via external assessment – scale from 0 (=not at all) to 3 (=very often) – each item is rated retroactively for a behaviour observed over two hours **Aim:** – detection of pain		– English and German version – items are "translatable" into the requirements of technical devices – focus on children and adolescents (possible combination with NCAPS)
Non-communicating Adult Pain Scale (NCAPS) (Lotan, Moe-Nilssen, Ljunggren, & Strand 2009)	**Content:** – target group: adults with intellectual disabilities **Method:** – checklist via external assessment **Aim:** – detection of pain		– items are "translatable" into the requirements of technical devices – specific focus on adult-hood (possible combina-tion with NCCPC-R)
Disability Distress Assessment Tool (DisDat) (Regnard et al. 2007)	**Content:** – observation areas: facial signs, skin appearance, vocal sounds, habits, body posture, body observation – target group: people with severe intellectual disabilities **Method:** – checklist via external assessment		– items are "translatable" into the requirements of technical devices (also physiological parame-ters) – accurate analysis of behaviours in stress sit-

	– comparison of contented and stressed behaviour **Aim:** detecting of distress		uations
Face, Legs, Activity, Cry, Consolability (FLACC) (Merkel, Voepel-Lewis, Shayevitz, & Malviya 1997)	**Content:** – observation areas: face, legs, activity, cry, consolability (3 items each) **Method:** – checklist via external assessment **Aim:** – detecting of pain	– inaccuracy of items – not adaptable to individual behaviours	
Kindliche Unbehagens- und Schmerzskala (KUSS) (Büttner et al. 1998)	**Content:** – validated on children without disabilities up to 4 years for postoperative pain – observation areas: crying, facial expression, hull posture, impairments, agitation **Method:** – checklist via external assessment **Aim:** – detecting of postoperative pain	– inaccuracy of items	
EDAAP – Pain Scale (Belot 2012)	**Content:** – the scale includes 11 criteria, each criterion is rated 0 to 3, 4 or 5 points – observation areas: muscle tone, facial expressions, body expression, interaction during care, communication, social life & interest in the environment, behavioural disorders **Method:** – checklist via external assessment **Aim:**	– no English version – items are poorly "translatable" into the requirements of technical devices	

	– detecting of pain		
Pain and Discomfort Scale (PADS) (Bodfish, Harper, Deacon, & Symons 2001)	**Content:** – observation areas: facial expressions, body movements – target group: individuals with little or no expressive language **Method:** – rating scale **Aim:** – identification of pain and discomfort in people with mental retardation	– no focus on people with PIMD but mental retardation – lack of specificity	
Other unused and un-analysed assessments: – BESD-Skala (2006) – BISAD-Skala (2012)			
Challenging Behavior			
Aberrant Behavior Checklist (ABC) (Aman & Singh 1986)	**Content:** – 58 items – observation areas: irritability/agitation, lethargy/social withdrawal, stereotypic behaviour, hyperactivity/non-compliance, inappropriate speech – target group: people with intellectual disability **Method:** – symptom checklist via external assessment – rated by anyone with knowledge of the person being assessed (e.g., parents, special educators, psychologists, direct caregivers, nurses, etc.) – rating from 0 (not at all a problem) to 3 (the problem is		– combined community and residential manuals – user-friendly – detailed overview

	severe in degree) **Aim:** – identification of challenging behaviour		
Challenging Behaviour Interview (CBI) (Oliver et al. 2003)	**Content:** – recording of occurrence of five operationally defined topographies of challenging behaviour: self-injurious behaviour, physical aggression, verbal aggression, disruption and destruction of property or the environment, inappropriate vocalizations – target group: people with moderate to severe intellectual disabilities **Method:** – time period of one month – first step: identifying type of challenging behaviour via external assessment – second step: assessing the severity via external assessment **Aim:** – identification of challenging behaviour	– no focus on people with PIMD –	– conform target group
The Diagnostic Assessment for the Severely Handicapped II (DASH II) (Matson 1995)	**Content:** – measure of comorbid psychopathology in people with severe and profound intellectual disabilities – 84-item measure consists of 13 subscales: anxiety, depression, mania, PDD/autism, schizophrenia, stereotypies, self-injury, elimination, eating, sleeping, sexual/organic/impulse control **Method:** – multidimensional informant-based behaviour 3-point rating scale **Aim:**	– too extensive	– conform target group – multidimensional assessment

	– identification of challenging behaviour		
The Repetitive Behaviour Questionnaire (RBQ) (Moss, Oliver, Arron, Burbidge, & Berg 2009)	**Content:** – 19 items – observation areas: stereotyped behaviour, compulsive behaviour, insistence on sameness, restricted preferences and repetitive speech – target group: children and adults with intellectual disabilities, verbal and non-verbal individuals, for individuals who fall within the autistic spectrum – behaviour accompanied by brief definition and examples **Method:** – checklist via external assessment over the preceding month – rating scale ranging from "never" to "more than once a day" **Aim:** – identification of repetitive behaviours	– focus only on one manifestation of challenging behaviour	
Diagnostic Interview for Social and Communication Disorders (DISCO) (Leekam, Libby, Wing, Gould, & Taylor 2002)	**Content:** – based on a concept of a spectrum of autistic disorders **Method:** – interviewer-based schedule for use with parents and caregivers **Aim:** – diagnosing disorders of the autistic spectrum	– main focus on people with autism	
Child Behaviour Checklist (CBCL) (Döpfner, Plück, & Kinnen 2014)	**Content:** – observation areas: anxious/depressed, social problems, withdrawn – target group: children and adolescents in the age of 6 to 18 **Method:** – checklist via external assessment	– no focus on people with PIMD	– German and English version

	Aim: – assessment of behavioural problems, emotional abnormalities, somatic complaints and social skills		
Verhaltensfragebogen bei Entwicklungsstörungen (VFE) / Developmental Behaviour Checklist (DBC) (Einfeld 2007)	**Content:** – 96 items – target group: people with intellectual disabilities (4-18 years) **Method:** – checklist via external assessment (primary caregivers) – rating from 0 (= not applicable as far as known) to 2 (= very applicable o. often applicable) **Aim:** – detection of behavioural disorders and emotions	– no focus on people with PIMD	– German and English version

7.2 THE PAPER-BASED ASSESSMENT

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PAPER-BASED ASSESSMENT

This questionnaire aims to gather *General Data* as well as *Information on Communication and Inner States* of the person[1].

The questionnaire is supposed to be filled in by a caregiver that knows the person for at least six months.

The whole document consists of six sub-questionnaires concerning a specific assessment area each:

(1) General Data

(2) Preverbal Communication

(3) Challenging Behaviour

(4) Mood

(5) Pain

(6) Pleasure and Displeasure/Distress

You yourself can decide whether you fill in all of them at once or each sub-questionnaire separately. Please keep in mind that the completion takes time and therefore should not be done in a stress situation but in a relaxed atmosphere.

Each sub-questionnaire consists of a list of different behavioural and activity descriptions. In some cases, it may be possible that the person cannot carry out certain behaviours or activities due to **physical impairment (PI)** or **sensory impairment (SI)**. For example, the imitation of a waving movement or clapping hands may not be possible or only possible to a limited extent because of spasticity or increased muscle tension. If this is the case, please mark this at the particular sections in the questionnaire.

[1] Please note that the term *person* is used throughout to refer to the person with disabilities being rated. This may be a child of school age, an adolescent, or an adult.

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Sub-Questionnaire about the General Data

Instructions for completing

This sub-questionnaire gathers information on the following aspects:

- General data on the evaluator
- General data on the person with profound intellectual and multiple disabilities:
  - Medical status
  - General competencies
  - Additional Information (e.g., likes and dislikes)

The aim is to get a brief overview of the person as a starting point. These questions should be answered in a short way because most areas will be focused in detail in the following sub-questionnaires.

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1. INFORMATION ON EVALUATOR		
1.	Type of Relationship	☐ Private reference person: ☐ Parents ☐ Other ☐ Professional reference person: ☐ Teacher ☐ Therapist: _____ ☐ Other educator: _____

2. PERSONAL DATA ON PERSON BEING RATED		
1.	Personal Identifier (e.g., pseudonym, combination of letters or numbers; the personal identifier provides the immediate pseudonymization. This way, different questionnaires can be differentiated.)	
2.	Gender	☐ Male ☐ Female ☐ Non-Binary
3.	Date of Birth (month/year)	
4.	Age	
5.	Form of housing	☐ Parental home ☐ Residential facility ☐ Assisted Living ☐ Inclusive Housing/ Shared flat ☐ Other: _____
6.	Day-structuring Institution	☐ Kindergarten ☐ Special school ☐ School (inclusive) ☐ Day care centre ☐ Sheltered Workshop ☐ Open Labour Market ☐ Other: _____ ☐ None
7.	Further Comments	

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Today's date:

3. MEDICAL STATUS & GENERAL COMPETENCIES

1.	Diagnoses (e.g., syndromes like Rett-syndrome, autism, intellectual disability)	☐ yes (please specify)	☐ no	☐ unclear
2.	Challenging Behaviour (e.g., stereotypes, self-injury, hitting)	☐ yes (please specify)	☐ no	☐ unclear
3.	Perceivable Physiological Parameters (e.g., fast breathing, sweating, conspicuous muscle tone)	☐ yes (please specify)	☐ no	☐ unclear
4.	Use of Vocalization (e.g., different sounds in different situations)	☐ yes (please specify)	☐ no	☐ unclear
5.	Use of Facial Expression (e.g., smiling, crying, eye brows)	☐ yes (please specify)	☐ no	☐ unclear
6.	Use of Gestures (e.g., movement of arms/hands/legs)	☐ head ☐ torso ☐ arms ☐ hands ☐ legs ☐ feet	 ☐ left ☐ left ☐ left ☐ left	 ☐ right ☐ right ☐ right ☐ right
	Further Comments (e.g., uncontrolled muscle movements due to spasticity)			
7.	Motor Skills a) Cannot walk b) Can walk with human help c) Can walk with walking aid d) Can walk independently	 ☐ yes ☐ yes ☐ yes ☐ yes ☐ no	 ☐ no ☐ no ☐ no ☐ unclear	 ☐ unclear ☐ unclear ☐ unclear
	e) Further Comments (e.g., use of a wheel chair, long-term recumbent)			
8.	Hearing Skills a) Hearing Impairment b) Deafness	 ☐ yes ☐ yes	 ☐ no ☐ no	 ☐ unclear ☐ unclear
	c) Further Comments			

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9.	Visual Skills a) Visual Impairment b) Blindness	☐ yes ☐ yes	☐ no ☐ no	☐ unclear ☐ unclear
	c) Further Comments			
10.	Gastrointestinal Difficulties (e.g., stomach problems, reflux, constipation)	☐ yes (please specify)	☐ no	☐ unclear
11.	Heart Abnormalities or Circulatory Problems (e.g., inborn heart lesions)	☐ yes (please specify)	☐ no	☐ unclear
12.	Lung or Respiratory Problems (e.g., asthma/bronchitis)	☐ yes (please specify)	☐ no	☐ unclear
13.	Skin Problems (e.g., eczema, dry skin)	☐ yes (please specify)	☐ no	☐ unclear
14.	Epilepsy	☐ yes (please specify)	☐ no	☐ unclear
15.	Cerebral Palsy	☐ yes (please specify)	☐ no	☐ unclear
16.	Other Illnesses/Medical Problems (e.g., headache, backache, other muscle aches, infections, incontinence)	☐ yes (please specify)	☐ no	☐ unclear
17.	Current Medications (including interactions between medications and side effects, medication refusals)	☐ yes (please specify)	☐ no	☐ unclear
18.	Further Comments			

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4. ADDITIONAL INFORMATION			
1.	Special Sympathies (e.g., towards specific caregivers or other persons)	1)	
		2)	
		3)	
		4)	
		5)	
2.	Special Antipathies (e.g., towards specific caregivers or other persons)	1)	
		2)	
		3)	
		4)	
		5)	
3.	Important Preferences or Interests (e.g., social interaction, singing, cuddling, preferred food/drink, toy, various kinds of touching/massage)	1)	
		2)	
		3)	
		4)	
		5)	
4.	Important Dislikes, Aversions or Reluctances (e.g., brushing teeth, shaving, disliked food/drink, taking something away, various kinds of touching/massage)	1)	
		2)	
		3)	
		4)	
		5)	
5.	Important Routines, Rituals or Special Settings (e.g., activity on a regular basis, verbally explained and slow actions in blind people, specific caregivers for specific actions)	1)	
		2)	
		3)	
		4)	
		5)	
6.	Further Comments		

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Today's date:

Sub-Questionnaire about *Pre-Verbal Communication*

Based on: Pre-Verbal Communication Schedule (PVCS) by Kiernan & Reid (1987); modified by Smidt

Instructions for completing

The following questions will ask for your opinion about particular behaviours of the person. You can decide between "never", "rarely", "usually" or "yes", "no" in terms of how often you observe these behaviours:

never	=	The described behavior has not yet been observed.
rarely	=	The described behavior has been observed at least once, but is not typical of the person's behavior.
usually	=	The described behavior is typical for the person and it usually occurs.

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Today's date:

1. NEEDS AND PREFERENCES		yes	no	unclear
1.	Enjoys particular activities or events (e.g., being in the car, having a bath, watching TV)	☐	☐	☐
2.	Likes music	☐	☐	☐
3.	Enjoys being with other people while playing a game, looking at books, being read to	☐	☐	☐
4.	Enjoys close physical attention (e.g., being tickled or hugged)	☐	☐	☐
5.	Has favourite objects (e.g., toys, blanket, keys)	☐	☐	☐
6.	Has food which he/she particularly like	☐	☐	☐

2. VISION AND LOOKING		yes	no
1.	Blinks at a hand passing over his/her face	☐	☐
2.	Fixates on a stationary object	☐	☐
3.	Turns and looks at an object introduced silently into his/her visual field	☐	☐
4.	Tracks moving objects	☐	☐
5.	Examines another person's face by looking from one feature to another	☐	☐

3. USE OF VISUAL CUES		usually	rarely	never
1.	Shows interest in pictures, picture books or catalogues	☐	☐	☐
2.	Show ability to recognise visual cues (e.g., by selecting favourite food, DVD boxes, find a favourite app on a tablet, recognition of familiar people in the distance)	☐	☐	☐
3.	Plays matching games based on visual cues; match items (e.g., object to object, object to picture etc.)	☐	☐	☐
4.	Recognises people from photos	☐	☐	☐

4. CONTROL OF HANDS AND ARMS		yes	no
1.	Releases objects held in his/her hand	☐	☐
2.	Grasps and holds an object with all fingers acting together, the thumb not being opposed to the fingers	☐	☐
3.	Grasps and holds an object with all fingers acting together, the thumb being opposed to the fingers	☐	☐
4.	Uses both hands equally well	☐	☐

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5.	Uses arms in normal everyday movements without difficulty	☐	☐
6.	Uses objects, which require him/her to use his/her index finger (e.g., to press buttons)	☐	☐
7.	Picks up objects with only thumb and first finger opposed	☐	☐

5. SOCIAL INTERACTION WITHOUT COMMUNICATION		usually	rarely	never
1.	Watches other people with interest	☐	☐	☐
2.	Responds to familiar people differently from strangers (e.g., by smiling, moving to them or showing excitement)	☐	☐	☐
3.	Sits beside, snuggle up to or touch a familiar person	☐	☐	☐
4.	Initiates eye contact with another person, when they are near	☐	☐	☐
5.	Goes and stands by another person "hovering" for attention (but does not touch, try to make contact, or make sounds to get attention)	☐	☐	☐

6. HEARING AND LISTENING		yes	no
1.	Attends by looking at or towards another person who is talking to him/her	☐	☐
2.	Turns his/her head to look in direction of sounds	☐	☐
3.	Changes body movement in response to another person's voice	☐	☐
4.	Turns his/her head to look in the direction of another person talking or singing	☐	☐
5.	Stops crying (or making other dress noises) in response to another person's voice	☐	☐
6.	Reacts differently in different tones of voice (e.g., quiet conversation vs. shouting)	☐	☐
7.	Bangs or hits things (e.g., toys or musical toys) with apparent intent to make sounds	☐	☐
8.	Makes comfort sounds (e.g., cooing) on hearing music or can stop crying	☐	☐

7. DEVELOPMENT OF SOUNDS		yes	no
1.	Makes noises (e.g., grunting or moaning)	☐	☐
2.	Makes open vowel sounds (e.g., aaa, eee, ooo)	☐	☐
3.	Makes a consonant sound (e.g., "lll", "b")		
4.	Makes mmm or sss sounds	☐	☐

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5.	Makes a consonant sound (which may be combined with a vowel e.g., buh, muh)	☐	☐
6.	Repeats the same syllable two or three times (e.g., ma, ma, ma)	☐	☐
7.	Combines two different syllables (e.g., da-ba, ee-aa, lah-dah)	☐	☐
8.	Babbles with sounds close to normal speech, possibly with a recognisable word or two	☐	☐
9.	Babbles with the intonation of the babbling following the form of normal speech (e.g., a string of babble which rises and falls like a 'real conversation')	☐	☐

8. CONTROL OF SPEECH MUSCULATURE		usually	rarely	never
1.	Has normal breathing	☐	☐	☐
2.	Swallows normally, with control of the tongue	☐	☐	☐
3.	Chews normally, with control of jaw and lips	☐	☐	☐
4.	Has the ability to blow a tissue	☐	☐	☐
5.	Has the ability to suck through a straw	☐	☐	☐

9. CONSISTENT USE OF NOISE		usually	rarely	never
1.	Makes sounds that do not appear to be related to the activity, and cannot be seen as having any communicative purpose	☐	☐	☐
2.	Makes noises consistently in relation to the play situation or activity (e.g., making car-like noises when playing with a car)	☐	☐	☐

10. EXPRESSION OF EMOTION (NON-COMMUNICATIVE)		usually	rarely	never
1.	Laughs or chuckles when relaxed or happy	☐	☐	☐
2.	Smiles when relaxed or happy	☐	☐	☐
3.	Cries when in pain or distress	☐	☐	☐
4.	Expresses anger or frustration by squealing or shouting	☐	☐	☐
5.	Hits or otherwise attacks other people in anger or frustration	☐	☐	☐
6.	Kisses another person as a meaningless routine	☐	☐	☐

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11. MUSIC AND SINGING		usually	rarely	never
1.	Listens to music with clear evidence of enjoyment (e.g., will turn radio to music, or come to the TV when music is on, or becomes quiet and/or smiles when music is on)	☐	☐	☐
2.	Beats in response to music but not necessarily in time	☐	☐	☐
3.	Dances to music	☐	☐	☐
4.	Taps or beats drum or tambourine in time	☐	☐	☐
5.	Sings or hums simple tunes without words, or with babble	☐	☐	☐
6.	Joins in with other people when they are signing	☐	☐	☐
7.	Sings when another person sings the first phrase of one of his/her songs	☐	☐	☐
8.	Sings clearly (tunes that are easy to recognise)	☐	☐	☐
9.	Dances in time to music	☐	☐	☐
10.	Sings simple tunes with words correct despite having no speech	☐	☐	☐
11.	Sings tunes with complex melodies without words	☐	☐	☐
12.	Sings complete tunes as opposed to phrases	☐	☐	☐
13.	Sings tunes with complex melodies with words correct	☐	☐	☐

12. GIVING		usually	rarely	never
1.	Shows an object to another person spontaneously and gives it if requested	☐	☐	☐
2.	Gives objects to other people without being asked and without them necessarily wanting the objects	☐	☐	☐

13. COMMUNICATION THROUGH PICTURES OR OBJECTS		usually	rarely	never
1.	Points to the picture of an object to indicate a preference or need when given a selection of pictures (e.g., to a picture of an ice-cream or object in a catalogue)	☐	☐	☐
2.	Gives another person an object related to the solution of a problem he/she wants the other person to solve (e.g., keys to open a door)	☐	☐	☐
3.	Looks for a picture of an object to represent a need (e.g., of an ice-cream to show he/she wants an ice-cream)	☐	☐	☐
4.	Shows a picture of an object only to draw attention to the object (not to ask for the object) (e.g., a picture of another student to indicate their presence)	☐	☐	☐

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5.	Shows an object (not a picture) only to draw attention to the presence of another object (e.g., showing you a miniature car to draw attention to a real car that he/she has seen)	☐	☐	☐

14. COMMUNICATION THROUGH MOVEMENTS, GESTURES AND LOOKING		usually	rarely	never
1.	Goes limp or lie on the floor or pavement in order to resist (e.g., if he/she does not want to go somewhere)	☐	☐	☐
2.	Reaches out to be lifted or hugged	☐	☐	☐
3.	Waves goodbye without prompting when another person is leaving or when he/she is leaving	☐	☐	☐
4.	Uses a simple gesture to indicate needs (e.g., pretends to drink, points to pants to indicate need to go to the toilet)	☐	☐	☐
5.	Waves goodbye to indicate that he/she wants another person to go away	☐	☐	☐
6.	Approaches and touches another person to get attention	☐	☐	☐
7.	Pushes another person's hand away when he/she does not want help or does not want interference	☐	☐	☐
8.	Pushes or pulls another person to induce him/her to go somewhere or get something he/she wants (e.g., pulls another person to the bathroom when he/she wants to go)	☐	☐	☐
9.	Pushes or pulls another person only to show them something or someone	☐	☐	☐
10.	Touches an object he/she wants and then glances at the other person and object alternatively until the other person responds	☐	☐	☐
11.	Points with hand and/or arm to distant objects to draw attention to them	☐	☐	☐
12.	Points with hand and/or arm to distant object he/she wants whilst looking alternatively at the other person and the object	☐	☐	☐
13.	Looks at something he/she wants but does not look at another person and does not display joint attention, to indicate to the person that they might want this object	☐	☐	☐
14.	Looks at something he/she wants and then looks back and forth between the object and the person until the person responds. This is known as joint attention	☐	☐	☐

15. COMMUNICATIVE USE OF SOUNDS		usually	rarely	never
1.	Approaches another person and make sounds/vocalise to get attention	☐	☐	☐
2.	Vocalises simply to draw attention to an object (equivalent to "look, there it is")	☐	☐	☐

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3.	Has a one-to-one conversation with another person (e.g., take turns in making sounds)	☐	☐	☐

16. EXPRESSION OF EMOTION (COMMUNICATIVE) AND MANIPULATION OF EMOTION		usually	rarely	never
1.	Squeals or shout if he/she is angry or frustrated, with clear evidence of intention to communicate	☐	☐	☐
2.	Smiles when he/she wants something (equivalent to "can I have?")	☐	☐	☐
3.	Frowns at another person in order to express displeasure or questioning (rather than just being upset)	☐	☐	☐
4.	Kisses or hugs other people as an expression of affection	☐	☐	☐
5.	Cries, the crying being directed at another person (i.e., the person stops crying as soon as he/she has the other person's attention, despite the fact that the other person has done nothing yet)	☐	☐	☐
6.	Pinches, scratches or hits another person when they frustrate him/her. The focus person stops and calms down as soon as the frustration stops	☐	☐	☐
7.	Pinches, scratches or hits other people in order to hurt them i.e., not just for attention but with understanding of hurting	☐	☐	☐
8.	Smiles at or hugs another person who is irritated with him/her in order to make them less angry	☐	☐	☐
9.	Hits or threatens to break objects deliberately in order to provoke anger or irritation in other people, or to attract attention	☐	☐	☐
10.	Will act silly in order to provoke a reaction	☐	☐	☐
11.	Smiles or laughs in order to make another person irritated or angry	☐	☐	☐
12.	Threatens to hit or hurt another person to provoke anger in a teacher, instructor or parent	☐	☐	☐

17. MOTOR IMITATION

Answering this part works best by direct testing. Go through the items and then repeat the set twice (preferably in a different order). Please cross in how many cases of the three repetitions the behaviour was imitated. Note if the person has a physical impairment, which hinders him or her to perform the action.

		0/3	1/3	2/3	3/3
1.	Imitates putting objects in a container	☐	☐	☐	☐
2.	Imitates smacking a table with his/her hand	☐	☐	☐	☐
3.	Imitates clapping hands	☐	☐	☐	☐
4.	Imitates tapping a pencil on the table	☐	☐	☐	☐

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5.	Imitates putting hands on head	☐	☐	☐	☐
6.	Imitates waving goodbye	☐	☐	☐	☐
7.	Imitates standing up or sitting down	☐	☐	☐	☐
8.	Imitates poking tongue out	☐	☐	☐	☐
9.	Imitates a simple action which has been remembered from previous observation (e.g., holding a telephone, rocking a doll)	☐	☐	☐	☐
10.	Imitates a sequence of actions which has been remembered from previous observations (e.g., bathing a doll and putting it in bed)	☐	☐	☐	☐

18. VOCAL IMITATION		usually	rarely	never
1.	Imitates non-speech noises in response to speech by another person	☐	☐	☐
2.	Imitates speech noises in response to speech by another person	☐	☐	☐
3.	Imitates speech sounds made by adults (e.g., ma, ba, ooo)	☐	☐	☐
4.	Imitates blowing through his/her lips when you do so (blow a raspberry)	☐	☐	☐
5.	Imitates a cough when you cough near him/her	☐	☐	☐
6.	Imitates his/her own sounds when they are played to him/her on an audio recording	☐	☐	☐
7.	Imitates the happy sounds of other people when he/she hears them	☐	☐	☐
8.	Imitates animal noises when you make them at him/her	☐	☐	☐
9.	Imitates words when they are spoken to him/her but does not necessarily use words for communication	☐	☐	☐
10.	Imitates the distress sounds of other people when he/she hears them	☐	☐	☐
11.	Imitates the voice intonation patterns of other people	☐	☐	☐
12.	Imitates words but only with a delay (i.e., will not imitate the other person's words immediately, but may repeat them spontaneously five minutes later or the next day)	☐	☐	☐
13.	Imitates words when the word or phrase is said by the other person and will imitate with a delay of five minutes or more, but not necessarily for communication	☐	☐	☐

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19. UNDERSTANDING OF NONVERBAL COMMUNICATION

Answering the first part of this section works best by direct testing. Go through the items and then repeat the set twice (preferably in a different order). Please cross in how many cases of the three repetitions the behaviour was imitated. All described behaviours are done without verbal cues. Do not make an entry if the person only responds if he/she is addressed verbally at the same time.

		0/3	1/3	2/3	3/3
1.	Takes a neutral object from another person when it is offered to her (e.g., a book or tissue)	☐	☐	☐	☐
2.	Takes another person's hand when it is held out to her	☐	☐	☐	☐
3.	Looks to where the other person is pointing when the other person has his/her finger on the object	☐	☐	☐	☐
4.	Looks at an object to which the other person is pointing when the object is within two metres from the person who is pointing	☐	☐	☐	☐
5.	Cooperates when being physically guided or prompted, and then repeats the desired action independently (e.g., being guided in dressing)	☐	☐	☐	☐
6.	Looks to where the other person is pointing when the object is more distant than two metres from the person who is pointing	☐	☐	☐	☐
7.	Follows simple directions (e.g., come here, sit down, go) when gestures are used without speech	☐	☐	☐	☐
8.	Looks at an object when a person directs the focus person's attention to an object by looking at him/her and the object repeatedly (without pointing)	☐	☐	☐	☐

		usually	rarely	never
9.	Looks away, avoids eye contact or closes his/her eyes when another person is trying to get her to look by pointing, if he/she does not want to look	☐	☐	☐
10.	Responds by turning away or running off if a person is holding out their hand or arms, asking him/her to come	☐	☐	☐

20. UNDERSTANDING OF VOCALISATION AND SPEECH		usually	rarely	never
1.	Responds to his/her name	☐	☐	☐
2.	Stops an activity when told "no" or "stop"	☐	☐	☐
3.	Hands or points to six or so different familiar objects which are laid out in front of him/her when asked to "show me" or "give me"	☐	☐	☐
4.	Responds to simple spoken requests without gestures (e.g., "come here", "sit down", "stand up", "go", "hush")	☐	☐	☐
5.	Points to parts of his/her body on quest ("show me …")	☐	☐	☐

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6.	Follows simple directions like "get your jacket", "close the door", "take off your shoes" without gestures or cues	☐	☐	☐
7.	Points to or goes to four or five familiar people on request ("show me …")	☐	☐	☐
8.	Shows four or five pictures in a book when requested ("show me …")	☐	☐	☐
9.	Responds appropriately to questions like "where is your bag?" or requests like "go and get your shoes" when the objects are not in view	☐	☐	☐
10.	Follows spoken directions like "put the spoon in the cup" where there is an action and two objects	☐	☐	☐
11.	Points to or goes to four or five places in the house, school, or centre on request, "show me" or "take me to"	☐	☐	☐
12.	Puts hands over his/her ears if he/her does not want to do what is asked	☐	☐	☐
13.	Understands sentences with adjectives in them (e.g., "give me the little ball")	☐	☐	☐
14.	Understands instructions containing words like "on", "in" and "under" without gestures	☐	☐	☐

21. USE OF COMMUNICATION THROUGH SYMBOLS, SIGNS OR SPEECH		Words	Signs	Symbols
1.	Approximately how many words, signs or symbols, or equivalent in terms of pictures, does the focus person use spontaneously at least once a week?			

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Today's date:

Sub-Questionnaire about *Challenging Behaviour*

Based on: Aberrant Behaviour Checklist (ABC) by Aman and Singh (1986)

Instructions for completing

The ABC—Community rating scale is designed to be used with person living in the community.

Please rate this person's behaviour for the last four weeks. For each item, decide whether the behaviour is a problem and cross the appropriate item:

- Not at all a problem
- The behaviour is a problem but slight in degree
- The problem is moderately serious
- The problem is severe in degree

When judging this person's behaviour, please keep the following points in mind:

a) Take relative frequency into account for each behaviour specified. For example, if the person averages more temper outbursts than most other person you know or most others in his/her class, it is probably moderately serious (2) or severe (3) even if these occur only once or twice a week. Other behaviours, such as noncompliance, would probably have to occur more frequently to merit an extreme rating.
b) If you have access to this information, consider the experiences of other care providers with this person. If the person has problems with others but not with you, try to take the whole picture into account.
c) Try to consider whether a given behaviour interferes with his/her development, functioning, or relationships. For example, body rocking or social withdrawal may not disrupt other persons, but it almost certainly hinders individual development or functioning.

Do not spend too much time on each item—your first reaction is usually the right one.

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Today's date:

		Not at all a problem	The behaviour is a problem but slight in degree	The problem is moderately serious	The problem is severe in degree
1.	Excessively active at home, school, work, or elsewhere	☐	☐	☐	☐
2.	Injures self on purpose	☐	☐	☐	☐
3.	Listless, sluggish, inactive	☐	☐	☐	☐
4.	Aggressive to other children or adults (verbally or physically)	☐	☐	☐	☐
5.	Seeks isolation from others	☐	☐	☐	☐
6.	Meaningless, recurring body movements	☐	☐	☐	☐
7.	Boisterous (inappropriately noisy and rough)	☐	☐	☐	☐
8.	Screams inappropriately	☐	☐	☐	☐
9.	Talks excessively	☐	☐	☐	☐
10.	Temper tantrums/outbursts	☐	☐	☐	☐
11.	Stereotyped behaviour; abnormal, repetitive movements	☐	☐	☐	☐
12.	Preoccupied; stares into space	☐	☐	☐	☐
13.	Impulsive (acts without thinking)	☐	☐	☐	☐
14.	Irritable and whiny	☐	☐	☐	☐
15.	Restless, unable to sit still	☐	☐	☐	☐
16.	Withdrawn; prefers solitary activities	☐	☐	☐	☐
17.	Odd, bizarre in behaviour	☐	☐	☐	☐
18.	Disobedient; difficult to control	☐	☐	☐	☐
19.	Yells at inappropriate times	☐	☐	☐	☐
20.	Fixed facial expression; lacks emotional responsiveness	☐	☐	☐	☐

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Today's date:

		Not at all a problem	The behaviour is a problem but slight in degree	The problem is moderately serious	The problem is severe in degree
21.	Disturbs others	☐	☐	☐	☐
22.	Repetitive speech	☐	☐	☐	☐
23.	Does nothing but sit and watch others	☐	☐	☐	☐
24.	Uncooperative	☐	☐	☐	☐
25.	Depressed mood	☐	☐	☐	☐
26.	Resists any form of physical contact	☐	☐	☐	☐
27.	Moves or rolls head back and forth repetitively	☐	☐	☐	☐
28.	Does not pay attention to instructions	☐	☐	☐	☐
29.	Demands must be met immediately	☐	☐	☐	☐
30.	Isolates himself/herself from other children or adults	☐	☐	☐	☐
31.	Disrupts group activities	☐	☐	☐	☐
32.	Sits or stands in one position for a long time	☐	☐	☐	☐
33.	Talks to self loudly	☐	☐	☐	☐
34.	Cries over minor annoyances and hurts	☐	☐	☐	☐
35.	Repetitive hand, body, or head movements	☐	☐	☐	☐
36.	Mood changes quickly	☐	☐	☐	☐
37.	Unresponsive to structured activities (does not react)	☐	☐	☐	☐
38.	Does not stay in seat (e.g., during lesson or training periods, meals, etc.)	☐	☐	☐	☐
39.	Will not sit still for any length of time	☐	☐	☐	☐
40.	Is difficult to reach. contact, or get through to	☐	☐	☐	☐

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Today's date:

		Not at all a problem	The behaviour is a problem but slight in degree	The problem is moderately serious	The problem is severe in degree
41.	Cries and screams inappropriately	☐	☐	☐	☐
42.	Prefers to be alone	☐	☐	☐	☐
43.	Does not try to communicate by wards or gestures	☐	☐	☐	☐
44.	Easily distractible	☐	☐	☐	☐
45.	Waves or shakes the extremities re-peatedly	☐	☐	☐	☐
46.	Repeats a word or phrase over and over	☐	☐	☐	☐
47.	Stamps feet or bangs objects or slams doors	☐	☐	☐	☐
48.	Constantly runs or jumps around the room	☐	☐	☐	☐
49.	Rocks body back and forth repeatedly	☐	☐	☐	☐
50.	Deliberately hurts himself/herself	☐	☐	☐	☐
51.	Pays no attention when spoken to	☐	☐	☐	☐
52.	Does physical violence to self	☐	☐	☐	☐
53.	Inactive, never moves spontaneously	☐	☐	☐	☐
54.	Tends to be excessively active	☐	☐	☐	☐
55.	Responds negatively to affection	☐	☐	☐	☐
56.	Deliberately ignores directions	☐	☐	☐	☐
57.	Has temper outbursts or tantrums when he/she does not get own way	☐	☐	☐	☐
58.	Shows few social reactions to others	☐	☐	☐	☐

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Today's date:

Sub-Questionnaire about *Mood*

Based on: Mood and Anxiety Semi-Structured Interview (MASS) by Charlot et al. (2007)

Instructions for completing

For each question, several exemplary behavioural descriptions are listed. Choose one of the following options to describe how often the specific behaviour of the person was observed:

never	=	The described behaviour has not yet been observed.
rarely	=	The described behaviour has been rarely seen or heard, but it is present.
often	=	The described behaviour has been seen or heard a few times, but not permanently (not all the time)
always	=	The described behaviour has been seen or heard almost all the time; You could observe this behaviour if you would be present only for a short time.

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Today's date:

1. EXCESSIVE ANXIETY AND WORRY		never	rarely	often	always
1.	Appears anxious (has fearful expression; doesn't seem relaxed; can't "chill out")	☐	☐	☐	☐
2.	Appears "needy"; clingy	☐	☐	☐	☐
3.	Seems to have nightmares	☐	☐	☐	☐
4.	Freezes	☐	☐	☐	☐
5.	Cries or whimpers in a fearful manner	☐	☐	☐	☐

2. IT IS HARD TO CONTROL THE WORRY		never	rarely	often	always
1.	Is hard to soothe or comfort this person	☐	☐	☐	☐
2.	Appears anxious, tense, agitated even after efforts to support or soothe	☐	☐	☐	☐

3. RESTLESSNESS/TENSENESS		never	rarely	often	always
1.	Tense facial expression (furrowed brow); seems "nervous/jumpy" or "on edge"	☐	☐	☐	☐
2.	Signals feeling anxious, nervous, worried, afraid, or scared	☐	☐	☐	☐

4. EASILY FATIGUED		never	rarely	often	always
1.	Looks tired; seems to have low energy	☐	☐	☐	☐
2.	Naps during the day (sleeps)	☐	☐	☐	☐
3.	Appears tired or signals wanting to go to bed	☐	☐	☐	☐
4.	Signals emotions like feeling tired	☐	☐	☐	☐
5.	Has dark circles under eyes	☐	☐	☐	☐

5. DIFFICULT CONCENTRATING		never	rarely	often	always
1.	Is not able to focus attention and to concentrate in general	☐	☐	☐	☐
2.	Seems stressed or agitated by demands that require concentration	☐	☐	☐	☐
3.	Skips from activity to activity; just can't stay on task	☐	☐	☐	☐
4.	Easily distracted by external stimuli (e.g., noise); gets easily off task	☐	☐	☐	☐
5.	Noise or chaos provokes agitation	☐	☐	☐	☐

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Today's date:

6. IRRITABLE MOOD		never	rarely	often	always
1.	Appears irritable; signals feeling irritable; signals things like "I'm mad"	☐	☐	☐	☐
2.	Seams grouchy, "grizzly", angry, "grumpy"	☐	☐	☐	☐
3.	Has low threshold for outbursts of anger; slightest thing "set them off"	☐	☐	☐	☐
4.	Has many agitated outbursts during which affect appears angry and/or irritable (not frightened)	☐	☐	☐	☐

7. MUSCLE TENSION		never	rarely	often	always
1.	Clenches fist	☐	☐	☐	☐
2.	Moves rigidly or stiffly	☐	☐	☐	☐

8. COMPULSIONS		never	rarely	often	always
1.	Checks, i.e. goes back to room over and over to make sure things are safe or set aside	☐	☐	☐	☐
2.	Washes and cleans; washes hands over and over and over; showers many times daily	☐	☐	☐	☐
3.	Orders; straightens; has to have things just so; lines things up; picks up lint; etc.	☐	☐	☐	☐
4.	Hoards things with no sense (not just collecting)	☐	☐	☐	☐
5.	Touches; tapes in a ritualistic way; seems like has to touch certain things	☐	☐	☐	☐
6.	Compulsive self-injurious behaviour; hits self over and over in the same place; wants to be restrained (note if person becomes anxious or agitated if prevented from performing the compulsive behaviour)	☐	☐	☐	☐
7.	Picks skin	☐	☐	☐	☐
8.	Pulls out eyelashes	☐	☐	☐	☐

9. DEPRESSED MOOD		never	rarely	often	always
1.	Has a sad appearance, i.e. looks sad; miserable; moping; downcast	☐	☐	☐	☐
2.	Smiles and laughs little	☐	☐	☐	☐
3.	Signals "I'm sad"	☐	☐	☐	☐
4.	Signals "I don't care"	☐	☐	☐	☐
5.	Cries	☐	☐	☐	☐

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Today's date:

10. ANHEDONIA		never	rarely	often	always
1.	No cares about or enjoys things; can't seem to have any joy	☐	☐	☐	☐
2.	Refuses or shows little interest in activities	☐	☐	☐	☐
3.	Reinforces things are not motivating	☐	☐	☐	☐
4.	Engages in escape and avoidance based aggression or self-injurious behaviour	☐	☐	☐	☐
5.	Withdrawn behaviour; isolating self; decreased social behaviour	☐	☐	☐	☐

11. PANIC ANXIETY		never	rarely	often	always
1.	Heart pounding; racing pulse	☐	☐	☐	☐
2.	Sweats	☐	☐	☐	☐
3.	trembles, shakes	☐	☐	☐	☐
4.	Hyperventilates; short of breath; takes quick shallow breaths; pants	☐	☐	☐	☐
5.	Has feelings of choking; swallows difficult; puts hands on throat	☐	☐	☐	☐
6.	chest pain; clutches chest	☐	☐	☐	☐

12. APPETITE OR WEIGHT					
12.1 DECREASED APPETITE/WEIGHT		never	rarely	often	always
1.	Eats very little	☐	☐	☐	☐
2.	Marked weight loss (about 10% of body weight or more)	☐	☐	☐	☐
3.	Meal refusals	☐	☐	☐	☐
4.	Is agitated during meals; tries to hide food; tries not to eat or to eat less	☐	☐	☐	☐
12.2 INCREASED APPETITE/WEIGHT		never	rarely	often	always
1.	Eats very much	☐	☐	☐	☐
2.	Marked weight gain (about 10% of body weight or more)	☐	☐	☐	☐
3.	Steals food; has agitated behaviours related to food seeking	☐	☐	☐	☐

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Today's date:

13. MOTOR ACTIVITY LEVEL					
13.1 PSYCHOMOTOR AGITATION onset or increased restlessness, i.e.:		never	rarely	often	always
1.	Paces	☐	☐	☐	☐
2.	Fidgets or shows other signs of physical restlessness	☐	☐	☐	☐
3.	Has difficulty remaining seated	☐	☐	☐	☐
4.	Moves constantly	☐	☐	☐	☐
5.	Gets up and down from seat	☐	☐	☐	☐
13.2 PSYCHOMOTOR RETARDATION		never	rarely	often	always
1.	Is inactive	☐	☐	☐	☐
2.	Does not participate in conversations (not nonverbal e.g. via notation; eye contact)	☐	☐	☐	☐

14. SLEEP PATTERN					
14.1 SLEEPING LESS		never	rarely	often	always
1.	Has difficulty falling asleep	☐	☐	☐	☐
2.	Wakes up too early in the morning	☐	☐	☐	☐
3.	Wakes up in the middle of the night, eventually falls back asleep	☐	☐	☐	☐
4.	Up and down all night	☐	☐	☐	☐
5.	Sleeps little or not at all at night	☐	☐	☐	☐
6.	Sleeps 0 – 4 hours a night	☐	☐	☐	☐
7.	Goes to sleep much later than usual	☐	☐	☐	☐
8.	Increase in problem behaviors at night	☐	☐	☐	☐
14.2 SLEEPING MORE		never	rarely	often	always
1.	Sleeps much more than before; sleeps 11 or more hours per night	☐	☐	☐	☐
2.	Takes frequent naps during the day	☐	☐	☐	☐
14.3 DECREASED NEED FOR SLEEP		never	rarely	often	always
1.	Sleeps less than 6 hours per night with minimal signs of fatigue the next day	☐	☐	☐	☐
2.	Does usual day time activities in the middle of the night	☐	☐	☐	☐
3.	May appear tired but can't sleep except briefly; seems "driven"	☐	☐	☐	☐

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Today's date:

15. ELATED MOOD		never	rarely	often	always
1.	Smiles excessively out of context (different to just showing happiness)	☐	☐	☐	☐
2.	Laughs excessively, inappropriately	☐	☐	☐	☐
3.	Seems "high", overly excited or too excited	☐	☐	☐	☐
4.	Vocalizes excessively loud;	☐	☐	☐	☐

16. RAPID OR PRESSURED VOCALIZATION		never	rarely	often	always
1.	Vocalizes very fast	☐	☐	☐	☐
2.	Vocalizes or screams a lot; makes many noises	☐	☐	☐	☐
3.	Vocalizes non-stop or very rapidly, etc.	☐	☐	☐	☐
4.	Has decreased ability to listen; interrupts frequently	☐	☐	☐	☐

17. HYPERACTIVITY		never	rarely	often	always
1.	Races around the room; runs	☐	☐	☐	☐
2.	Intrudes into others' space	☐	☐	☐	☐
3.	In constant motion; "hyper"	☐	☐	☐	☐
4.	Rapid motor movements; does things in a "sped up" fashion	☐	☐	☐	☐

18. REDUCED DISINHIBITION		never	rarely	often	always
1.	Strips clothes off in public places	☐	☐	☐	☐
2.	Reacts with signs of discomfort (aggressive behaviour, screaming, etc.) when limits are set for activities close to the body (e.g. pleasurable activities)	☐	☐	☐	☐
3.	Inappropriate behaviour such as constant touching, hugging, holding or searching for handshake; cannot be distracted from this behaviour	☐	☐	☐	☐

19. MOOD SWINGS		never	rarely	often	always
1.	has rapid changes in affect or mood lasting minutes to hours but not days	☐	☐	☐	☐

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Today's date:

Sub-Questionnaire about *Pain*

Based on: Non-communicating Adult Pain Scale (NCAPS) by Lotan et al. (2009)

Instructions for completing

How often has the person shown these behaviours in the last 10 minutes? Please cross for each behaviour.

If an item does not apply to this person (e.g., this person cannot reach with his/her hands), then indicate "not applicable" for that item.

At the end of the observation time, indicate how frequently (how often) each item was seen or heard. This should not be based on the person's typical behavior or in relation to what he/she usually does. A guide for deciding the frequency of items is below:

not at all	=	not present at all during the observation period (note if the item is not present because the person is not capable of performing that act, it should be scored as "NA")
just a little	=	seen or heard rarely (hardly at all), but is present
fairly often	=	seen or heard a number of times, but not continuous (not all the time)
very often	=	seen or heard often, almost continuous (almost all the time); anyone would easily notice this if they saw the person for a few moments during the observation time
not applicable	=	this person is not capable of performing this action

The questionnaire is divided up in two parts:

(1) Information on behaviour during non-painful situations (left side)
(2) Information on behaviour during painful situations (right side)

Please do not shy away from crossing the same behaviour signals for both parts if the person shows these behaviours in painful situations as well as in non-painful situations. It is an important information which behaviour signals are not explicit in their meaning!

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Today's date:

1. Vocal Reaction

		During a Non-Painful Situation					During a Painful Situation				
		not at all	just a little	fairly often	very often	not applicable	not at all	just a little	fairly often	very often	not applicable
1.	Moaning, whining, whimpering (fairly soft)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
2.	Crying (moderately loud)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
3.	Screaming/yelling (very loud)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
4.	A specific sound or word for pain (e.g., a word, cry or type of laugh)					☐	☐	☐	☐	☐	☐

2. Emotional Reaction

		During a Non-Painful Situation					During a Painful Situation				
		not at all	just a little	fairly often	very often	not applicable	not at all	just a little	fairly often	very often	not applicable
1.	Not cooperating, cranky, irritable, unhappy	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
2.	Being difficult to distract, not able to satisfy or pacify	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

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Today's date:

3. Facial Reaction

		During a Non-Painful Situation					During a Painful Situation				
		not at all	just a little	fairly often	very often	not applicable	not at all	just a little	fairly often	very often	not applicable
1.	Furrowed eyebrows, raising eyebrows	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
2.	A change in eyes (squinting of eyes, eyes opened wide, eye frowning)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
3.	Turning down of mouth, not smiling	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
4.	Movements of lips and tongue (e.g., lips puckering up, tight, pouting, or quivering, teeth grinding, tongue pushing),	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

4. Body Language

		During a Non-Painful Situation					During a Painful Situation				
		not at all	just a little	fairly often	very often	not applicable	not at all	just a little	fairly often	very often	not applicable
1.	Less movements; less activity	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
2.	Stiff spastic; tense; rigid	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

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Today's date:

5. Protective Reaction

		During a Non-Painful Situation					During a Painful Situation				
		not at all	just a little	fairly often	very often	not applicable	not at all	just a little	fairly often	very often	not applicable
1.	Gesturing to or touching part of the body that hurts					☐	☐	☐	☐	☐	☐
2.	Protecting, favouring or guarding part of the body that hurts					☐	☐	☐	☐	☐	☐
3.	Flinching or moving the body part away, being sensitive to touch	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
4.	Moving the body in a specific way to show pain (e.g., head back, arms down, curls up, etc.)					☐	☐	☐	☐	☐	☐

6. Physiological Reaction

		During a Non-Painful Situation					During a Painful Situation				
		not at all	just a little	fairly often	very often	not applicable	not at all	just a little	fairly often	very often	not applicable
1.	Change in facial colour	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
2.	Respiratory irregularities: Breath holding or gasping	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

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Today's date:

7. Further Comments	
Please feel free to make any additional comments	

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Today's date:

Sub-Questionnaire about *Pleasure and Displeasure/Distress*

Based on: Disability Distress Assessment Tool (DisDAT) (Regnard, R. et al. 2007); (Roemer, M. et al. 2017)

Instructions for completing

Please take some time to think about and observe the person, especially his/her appearance and behaviours when he/she shows pleasure and displeasure/distress.

We have listed words in each section to help you to describe the signs and behaviours.

You can cross the word/words that best describe the signs and behaviours when they show pleasure and when they show displeasure/distress.

The questionnaire is devided up in two parts:

(1) Information on behaviour that shows pleasure (left side)
(2) Information on behaviour that shows displeasure/distress (right side)

Please do not shy away from crossing the same behaviour signals for both parts if the person shows these behaviours in pleasure situations as well as in displeasure/distress situations. It is an important information which behaviour signals are not explicit in their meaning!

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Today's date:

1. Use of Vocalization								
1.	Sounds in General	Sounds of Pleasure				Sounds of Displeasure/Distress			
Cross the words that best describe the total sounds		**Volume:**	☐ high	☐ medium	☐ low	**Volume:**	☐ high	☐ medium	☐ low
		Pitch:	☐ high	☐ medium	☐ low	**Pitch:**	☐ high	☐ medium	☐ low
		Duration	☐ short	☐ intermit-tent	☐ long	**Duration**	☐ short	☐ intermit-tent	☐ long
		Description of sound/ vocalisation:	☐ crying out	☐ wailing	☐ scream-ing	**Description of sound/ vocalisation:**	☐ crying out	☐ wailing	☐ scream-ing
			☐ groan-ing/ moan-ing	☐ shouting	☐ gurgling		☐ groan-ing/ moan-ing	☐ shouting	☐ gurgling
		☐ other (please specify):				☐ other (please specify):			
2.	Specific Sounds	Sounds of Pleasure				Sounds of Displeasure/Distress			
Write down commonly used sounds (write it as it sounds: e.g., "tizz", "eeiow", "te-tetete")									

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Today's date:

2. Use of Facial Expression						
1. Appearance in General	Appearance of Pleasure			Appearance of Displeasure/Distress		
Cross the words that best describe the total facial appearance	☐ passive	☐ laughing	☐ smiling	☐ passive	☐ laughing	☐ smiling
	☐ frown	☐grimace	☐startled	☐ frown	☐grimace	☐startled
	☐ frightened			☐ frightened		
	☐ other (please specify):			☐other (please specify):		
2. Appearance of Eyes	Appearance of Pleasure			Appearance of Displeasure/Distress		
Cross the words that best describe the appearance of eyes	☐ good eye con-tact	☐ little eye con-tact	☐ avoiding eye contact	☐ good eye con-tact	☐ little eye con-tact	☐ avoiding eye contact
	☐ closed eyes	☐ staring	☐ sleepy eyes	☐ closed eyes	☐ staring	☐ sleepy eyes
	☐ "smiling"	☐ winking	☐ vacant	☐ "smiling"	☐ winking	☐ vacant
	☐ tears	☐ dilated pupils	☐ eyebrow movement	☐ tears	☐ dilated pupils	☐ eyebrow movement
	☐ other (please specify):			☐ other (please specify):		
3. Movement of Jaw	Movement of Pleasure			Movement of Displeasure/Distress		
Cross the words that best describe the movement of jaw	☐ relaxed	☐ drooping	☐ grinding	☐ relaxed	☐ drooping	☐ grinding
	☐ biting	☐ rigid		☐ biting	☐ rigid	
	☐ other (please specify):			☐ other (please specify):		

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Today's date:

4.	Movement of Nose and Mouth	Movement of Pleasure			Movement of Displeasure/Distress		
Cross the words that best describe the movement of nose and mouth		☐ wrinkling	☐ nose move-ments	☐ mouth tense	☐ wrinkling	☐ nose move-ments	☐ mouth tense
		☐ lip move-ments	☐ tongue movements	☐ tongue out-side	☐ lip movements	☐ tongue move-ments	☐ tongue out-side
		☐ loss of saliva	☐ corners of mouth retracted		☐ loss of saliva	☐ corners of mouth retracted	
		☐ other (please specify):			☐ other (please specify):		

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Today's date:

3. Use of Gestures						
1.	Body Posture	Posture of Pleasure			Posture of Displeasure/Distress		
Cross the words that best describe the sitting and standing		☐ normal	☐ rigid/ no movement	☐ movement change	☐ normal	☐ rigid/ no movement	☐ movement change
		☐ floppy	☐ jerky	☐ slumped	☐ floppy	☐ jerky	☐ slumped
		☐ restless	☐ tense	☐ still	☐ restless	☐ tense	☐ still
		☐ leans to side	☐ able to adjust position		☐ leans to side	☐ able to adjust position	
		☐ other (please specify):			☐ other (please specify):		
2.	Movement of Head	Movement of Pleasure			Movement of Displeasure/Distress		
Cross the words that best describe the movement of the head		☐ normal	☐ rigid/ no movement	☐ movement change	☐ normal	☐ rigid/ no movement	☐ movement change
		☐ floppy	☐ withdrawn	☐ shaking	☐ floppy	☐ withdrawn	☐ shaking
		☐ leans to side	☐ nodding		☐ leans to side	☐ nodding	
		☐ other (please specify):			☐ other (please specify):		

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Today's date:

3.	Movement of Hands and Arms	Movement of Pleasure			Movement of Displeasure/Distress		
Cross the words that best describe the movement of hands and arms		☐ normal	☐ rigid/ no movement	☐ movement change	☐ normal	☐ rigid/ no movement	☐ movement change
		☐ outstretched arm/hand	☐ rubbing	☐ clapping	☐ outstretched arm/hand	☐ rubbing	☐ clapping
		☐ hitting	☐ manipulating	☐ grabbing	☐ hitting	☐ manipulating	☐ grabbing
		☐ throwing	☐ pushing	☐ hands on eyes	☐ throwing	☐ pushing	☐ hands on eyes
		☐ hands on ears	☐ hands opened	☐ hands closed	☐ hands on ears	☐ hands opened	☐ hands closed
		☐ other (please specify):			☐ other (please specify):		
4.	Movement of Feet and Legs	Movement of Pleasure			Movement of Displeasure/Distress		
Cross the words that best describe the movement of feet and legs		☐ normal	☐ rigid/ no movement	☐ movement change	☐ normal	☐ rigid/ no movement	☐ movement change
		☐ outstretched leg/feet	☐ floppy	☐ kicking	☐ outstretched leg/feet	☐ floppy	☐ kicking
		☐ wobbling	☐ rubbing		☐ wobbling	☐ rubbing	
		Way of Walking:			**Way of Walking**:		
		☐ better	☐ normal	☐ worse	☐ better	☐ normal	☐ worse
		☐ other (please specify):			☐ other (please specify):		

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Today's date:

4. Physiological Parameters						
1. Skin Appearance	Appearance of Pleasure			Appearance of Displeasure/Distress		
Cross the words that best describe the skin appearance	☐ normal	☐ pale	☐ flushed	☐ normal	☐ pale	☐ flushed
	☐ sweaty	☐ clammy		☐ sweaty	☐ clammy	
	☐ other (please specify):			☐ other (please specify):		
2. Body Observations	Observations of Pleasure			Observations of Displeasure/Distress		
Describe the pulse, breathing, sleep, appetite and usual eating pattern as good as possible (e.g., eats very quickly, takes a long time with main course, eats puddings quickly, "picky")	Pulse:			Pulse:		
	Breathing:			Breathing:		
	Sleep:			Sleep:		
	Appetite:			Appetite:		
	Eating pattern:			Eating pattern:		

7.3 Overview of the Scenarios

7.3.1 Work

7.3.1.1 Early Childhood

General Description

The field of Early Childhood Special Education has been affected by psychology, health sciences, child development and sociology among others and can be divided into kindergarten, preschool and early-intervention.

As a rule, preschool children attend kindergarten, which offers extended and more holistic experiences beyond their family environment. The care time differs between part-time and full-time care. There are special education kindergartens, which are only attended by children with disabilities, as well as inclusive ones, which are additionally attended by children without disabilities.

Those children who are not ready yet to start school for various reasons have the opportunity to attend pre-school to get prepared for specific school requirements.

Early-intervention considers both children with disabilities and those who are threatened by disabilities and the respective families. Therefore, it includes various content-related, organizational and institutional support measures. The objective is to identify as early as possible those reasons that hinder the further development. Therefore, an interdisciplinary team of professionals supports the children and their parents in close cooperation. There are different aspects of early-intervention: sensory learning, motor skills, social and emotional development or communication and speaking (Bernasconi & Böing, 2015; McLean, Sandall, & Smith, 2016; Stöppler, 2017).

Example

One example for sensory learning is the concept of *Basal Stimulation* (A. Fröhlich) which addresses three different perception systems:

(1) Experiencing physical boundaries of the own body getting direct body contact by their caregiver is part of the somatic system.
(2) The vestibular system means the experience of gravity and spatial position, for example trough hammocks or trampolines.
(3) The sensing of vibration, for example through music with strong bass or a massage cushion, is part of the vibratory system.

6.3.1 Work

7.3.1.2 School age

General Description

School lessons and teaching means intentional educational processes for a student group guided by a teacher. Both knowledge building and the development of individual preferences are important to strive in schools for students with PIMD.

The learning topics are determined in an individual curriculum for each student, an adapted version of the curriculum of regular schools. These topics get prepared by the teacher according to the skills of the students. In this way even a very heterogeneous group is enabled to work together on one subject, every single student according to his skills getting specific individual support. This can be implemented in special education classes as well as in classes mixed with both students with and without disabilities (inclusive class). Being taught within an inclusive setting can have a positive impact on the student's adaptive behaviour and social competences among others (Kleinert et al., 2015; Omonsky, 2017; Terfloth & Bauersfeld, 2015).

Example

To give an example, let's pretend a very heterogeneous student group with the learning topic *Goethe's theory of colours*:

Students with PIMD who work on a very basal level get stimulated with various sensory impressions like e.g. experiencing light in different colours or coloured water. Those students who need to do some kind of active work, like using concrete objects, colour water or mix different colours to see the mixing result. Students who use pictures and models for the acquisition of the learning topic work on the colour circle or read picture books concerning colours. Using factual texts or reading poems on colours is an option for students who are able to use abstract and symbolic learning material. Primarily, these learning activities are realized in group situations. In some cases, an individual treatment situation is possible as well.

6.3.1 Work

General Description

Participation in working life has a high priority in our society as it fulfils various functions:

(1) guaranteeing material livelihood
(2) assigning social status by belonging to a specific profession
(3) enhancing self-esteem and identity development
(4) forming and maintaining social relationships
(5) structuring everyday life by dividing it into leisure and work time

Therefore, it is important that adults with disabilities get the opportunity to receive a work-oriented daily structure as well and benefit from the aforementioned advantages. Aspect (4) and (5) should particularly be considered in working contexts with people with PIMD. As a whole, four different possibilities for people with intellectual disabilities should be mentioned here:

- working directly and inclusively on the open labour market
- working in a sheltered workshop, which means an economically oriented institution especially for people with disabilities
- attending a day care centre for people with disabilities, which offers several activities
- attending a work-oriented program primary for people with PIMD, which provides a wide range of support offers (e.g., various therapy measures) that structure the day by separating work and leisure time, place of residence and workplace

As a whole, the main objective for the group of people with PIMD should be to provide work-oriented activities in all mentioned possibilities (Blick, Litz, Thornhill, & Goreczny, 2016; Hiemstra, Vlaskamp, & Wiersma, 2007; Sansour, 2018 in press; Stöppler, 2017).

Example

An example of the last-mentioned institution is the gathering of experiences in different work-related contexts. This can be initiated by spatial and positional changes. For instance, when washing paintbrushes, this group of people could experience how the water discolours, when working with wood, they could feel the untreated wood in contrast to polished smooth wood or be involved in the transport of objects.

6.231 Work

7.3.1.4 Seniority

General Description

Due to the fact that in seniority there is no work routine any more the information on everyday life in this life stage is listed below in the area of life *LIVING.*

7.3.2 Living – Housing

7.3.2.1 Early Childhood & School age

General Description

As a rule, children of this age live together with their parents. However, infants as well as children with disabilities often have to spend long periods in hospital after their birth because of various occurring complications (e.g. premature birth, cerebral palsy or epilepsy). Unfortunately, this separation between parents and child could affect their bond which may causes a negative impact on the social-emotional development.

6.3.2 Living – Housing

General Description

The international discussion on living conditions of people with PIMD concerning the opportunities of housing is determined by the objective to live as normal as possible. In fact, they have the same residential needs as people without disabilities and are not just an object of care anymore.

Moreover, the inhabitants should have different opportunities for a self-determined life. In addition, living has a social function, for instance, ensuring individual retreat of a restless environment. There are four different housing opportunities for people with PIMD:

(1) large scale institution
- as a rule, it offers a combination of several services like health services, school, living and housing or leisure opportunities

(2) assisted living residence
- shared house within an institution especially for people with disabilities
- 24/7-care

(3) ambulant assisted living (inner-city flat or ambulant care)
a. assisted living
- only people with disabilities
- professional caregiver

b. inclusive living
- cohabitation of people with and without disabilities
- care by roommates and professional caregiver

(4) living together with parents at home

(Bernasconi & Böing, 2015; Marlow & Walker, 2015; Ministerium für Kultus, Jugend und Sport Baden-Württemberg, 2009)

Example

A general example for self-determined living is the opportunity for people with PIMD to influence the design of their personal rooms. This includes, for instance, the choice of the furniture, its colour or location, personal pictures or belongings. One first step is the freedom of choice by choosing two or more given design options.

6.3.2 Living – Housing

General Description

Ageing of people with disabilities, especially the life stage of seniority, is a field that requires further attention to guarantee the consideration and satisfaction of their specific needs.

Those elderly people with disabilities who are not able to meet the challenges of their work institution any longer get retired. For this reason, their housing institution needs to make arrangements for structuring everyday life and providing the services they need. Either the caregivers in the residential or ambulant living institutions or the caregiving parents at home have to fill this order. Hence, a proactive support is necessary to be prepared for future changes. The most important objectives of day-structuring measures and providing services are listed below:

(1) maintenance of skills and lifelong learning opportunities (e.g., training of life skills, creative work, memory training, training of sensory perception, stimulation)
(2) mentoring of social and mental or psychological development (e.g., conversations about ageing, biography)
(3) support measures for communication (e.g., gestures, pictograms, symbols, acoustic signals, Augmentative and Alternative Communication)
(4) participation in cultural and social life (e.g., leisure offers: meeting family or friends, attending clubs or music concerts)
(5) maintenance of health (e.g., exercise, healthy eating, personal care support)

(Innes, McCabe, & Watchman, 2012; Pollmächer & Holthaus, 2013)

Example

To give an example, losing the day-structuring measures of a sheltered workshop can be a very challenging change in the life of a person with disabilities. Therefore, it is important to offer tasks and several possibilities to spend the new gained free time in a meaningful way. Offers like regularly placed group meetings or doing excursions can be attended as well as measures concerning ageing itself (e.g. therapeutical interventions). Having a structured everyday life helps meeting the challenges of this new life stage and prevents sinking into a kind of depression caused by lack of experiences of self-efficacy.

7.3.3 Living – Leisure

7.3.3.1 All life stages

General Description

Leisure as a kind of proper time or social time integrates different stages of life from early childhood to seniority and influences the well-being and health of disabled people in a positive way. It includes various aspects that complement each other but, in some cases, even seem to be inconsistent with one another:

- leisure behaviour within or beyond family environment (e.g., communication, media)
- leisure in clubs and associations (e.g., sports, cultural or social activities)
- leisure and leisure education in kindergarten or for adults with disabilities
- leisure in ambulant or residential housing institutions for people with disabilities
- travel opportunities for people with disabilities

(Christensen, 2013; Klauß, 2005; Markowetz, 2012; J. L. Rowland, 2014)

Example

To give an example, there are different offers for people with disabilities to spend their free time in regularly placed group meetings (also inclusive ones) of different content or for specific age groups. A music group could be a possible choice for someone who is interested in music and social activities. It provides many interaction situations: meeting friends, comparing notes on various topics, listening to or making music (e.g. singing, playing an instrument, body percussion), attending music workshops or concerts.