

# Engagement, not Dependence: Ethically Designing Assistive Systems for Users with Cognitive Impairments

Thomas Kosch  
kosch@informatik.hu-berlin.de  
HU Berlin  
Berlin, Germany

Albrecht Schmidt  
albrecht.schmidt@ifi.lmu.de  
LMU Munich  
Munich, Germany

Thomas Grote  
thomas.grote@uni-tuebingen.de  
University of Tübingen  
Tübingen, Germany

Paweł W. Woźniak  
Chalmers University of Technology  
Gothenburg, Sweden  
pawel.wozniak@chalmers.se

## ABSTRACT

Assistive systems supporting users with cognitive impairments are commonplace in sheltered living facilities. Assistive systems may collect data or analyze user behavior to tailor services for the users' type and level of impairment. However, ways to integrate ethical standards into the design and deployment of assistive systems for users with cognitive impairments are not yet established. We conducted a qualitative inquiry inspired by literature in ethics to address this. We interviewed caretakers and tenants with cognitive impairments in a sheltered living facility. We present four themes that describe the lived practice of ethics when using assistive systems: *AUTONOMY & INDEPENDENCE*, *CONFIDENCE IN TECHNOLOGY*, *MOTIVATION*, and *COMMUNAL LIVING*. Combining the themes with ethics theory, we derived five design implications for the ethical design of assistive systems. Our work proposes boundaries in which new assistive systems can be designed ethically and guide future assistive systems for marginalized populations.

## CCS CONCEPTS

• **Human-centered computing** → **Accessibility design and evaluation methods**; *Accessibility technologies*; Accessibility systems and tools.

## KEYWORDS

Accessibility, Cognitive Impairment, Assistive System, Ethics, Sheltered Living

## ACM Reference Format:

Thomas Kosch, Thomas Grote, Albrecht Schmidt, and Paweł W. Woźniak. 2022. Engagement, not Dependence: Ethically Designing Assistive Systems for Users with Cognitive Impairments. In *Nordic Human-Computer Interaction Conference (NordiCHI '22)*, October 8–12, 2022, Aarhus, Denmark. ACM, New York, NY, USA, 13 pages. <https://doi.org/10.1145/3546155.3546662>

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*NordiCHI '22*, October 8–12, 2022, Aarhus, Denmark

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<https://doi.org/10.1145/3546155.3546662>

## 1 INTRODUCTION

According to the *World Report on Disability* [69], approximately 15% of the world's population is affected by a type of cognitive impairment<sup>1</sup>. This is manifested by difficulties in processing content, information retention, or decision-making during everyday actions such as cooking, shopping, or social interaction [71]. With the demographic change contributing to an aging society, the number of persons with cognitive impairments, temporarily or permanently, is expected to rise in the future [22, 28]. Government-driven and voluntary organizations exist to provide specialized training for persons with cognitive impairments to achieve basic life skills.

In Western Europe, sheltered living facilities, operated by the local government or non-profit organizations, commonly accommodate tenants with cognitive impairments. In these housing communities, 20 to 30 people live together and receive supervision from caretakers in daily life skill acquisition to enable independent living in shared apartments. These apartments consist of four to six persons with cognitive impairments who help each other and do not rely on a caretaker. Extensive training by specialized caretakers is required to achieve independence. However, sheltered living facilities are confronted with worker shortages, reducing the amount of individual training for people with cognitive impairments. Overwork, a decrease in supervision quality for persons with cognitive impairments, and even burnout might be the result [1].

One way of tackling these challenges is designing assistive computing systems for persons with cognitive impairments. These devices have recently received attention as they provide autonomous in-situ assistance [12, 61]. Such systems aim to empower users with cognitive impairments by providing complementary task-relevant support [45]. Concurrently, assistive computing is a strong theme in Human-Computer Interaction (HCI), advocating the design of technology that caters to the needs of marginalized groups [75]. Past deployments of assistive systems showed that they enhance the task-related performance of users with cognitive impairments [4, 44]. In the context of daily living activities, design implications for assistive systems during communal cooking activities have been presented [57]. However, weaving such technologies into everyday life requires assessing their ethical qualities [91]. Assistive systems may persuade and motivate persons with cognitive impairments to perform current tasks [51, 53], but they may also change social

<sup>1</sup>[www.who.int/teams/noncommunicable-diseases/sensory-functions-disability-and-rehabilitation/world-report-on-disability](http://www.who.int/teams/noncommunicable-diseases/sensory-functions-disability-and-rehabilitation/world-report-on-disability) - last access 2022-08-15

relationships connected to particular actions [57]. Furthermore, assistive systems can collect data, where it is difficult for users with cognitive impairments to provide informed consent and understand how data is processed [6, 77]. Consequently, as more and more assistive systems are developed, and given HCI's mission as a means of empowerment [75], there is an urgent need to understand how to design assistive systems ethically and establish ways to do so effectively. Recently, the HCI community has recognized ethical challenges in researching and deploying technological artifacts for marginalized groups [8, 66, 86]. While there is community consensus around designing such technologies ethically, it is unclear how these principles emerged. Thus, we must redefine the ethical process of designing and conducting studies of assistive systems [67]. This paper establishes how assistive systems for users with cognitive impairments can be designed ethically, contributing to an emerging field targeting the inclusion of persons with impairments in computing and AI ethics [82].

However, there is unawareness of the current ethical practices when working with people with cognitive impairments. To understand *how* and *where* ethical pitfalls that occur when employing autonomous assistance for marginalized populations, we decided to briefly survey relevant literature in philosophy considering relevant aspects of preserving the user's integrity. We base our study on recent work in philosophy concerned with the protection of vulnerable users concerning ethics contrary to common approaches found in disability studies [10]. We explore guiding ethical principles in philosophy for deploying assistive systems used by persons with cognitive impairments. While prior work has separately investigated assistive systems and philosophical aspects of accessibility, we bridge this gap by first reviewing fundamental ethics literature concerning protecting vulnerable populations. Based on this, we translate these concepts by conducting a qualitative inquiry with caretakers and tenants of a sheltered living facility.

## CONTRIBUTION STATEMENT AND CONTEXT

In this work, we study the current practices of employing assistive systems in sheltered living facilities to understand the ethical requirements for such technologies. We chart four themes that represent important ethical aspects for assistive systems supporting persons with cognitive impairments by conducting eight interviews with sheltered living personnel and nine tenants with cognitive impairments. This paper makes three key contributions: (1) We report the ethical practices within sheltered living facilities by conducting interviews with caretakers and tenants. (2) We conduct a thematic analysis of the interview data which leads to the four themes: *AUTONOMY & INDEPENDENCE*, *CONFIDENCE IN TECHNOLOGY*, *MOTIVATION*, and *COMMUNAL LIVING*. (3) Finally, we connect the ethical considerations with our empirical findings and present five design implications for considering ethical aspects when deploying assistive systems in sheltered living facilities. Our findings bridge the gap between the practice of using assistive systems and their respective implementation of ethics from a philosophical view.

### Context: Sheltered Living Facilities

Sheltered living facilities offer people with cognitive impairments assistance with learning everyday tasks. Their main goal is to teach

elementary skills in an organized way that can be reapplied in an independent living environment. When tenants do not rely on the intervention of a caretaker, they can move to a shared apartment where up to six former tenants live independently together and help each other. A caretaker assists a newly rehoused tenant until relevant skills have been achieved and assesses the development within the independent apartment. To enable more autonomy, assistive systems in both sheltered living facilities and independent apartments are commonly employed to enable self-training and support remote monitoring by caretakers. We worked in collaboration with a sheltered living organization operating as both a sheltered living facility and independent living houses<sup>2</sup>. The tenants can autonomously interact within and outside the facilities (e.g., buying groceries) and are supported by their caretakers at routine tasks (e.g., cleaning, cooking) or when help is needed. Living independence is achieved through extensive training by specialized caretakers in houses where usually 20 to 30 persons live together. The equipment within these facilities does not include specialized household equipment. It restricts itself to regular necessities to not diminish the overall training effect and to prepare the tenants for independence [73]. However, complex activities such as work [41] or communal cooking activities [56, 57] are commonly becoming augmented by assistive systems, partially compensating for skilled work shortages in the care sector. For example, the sheltered living facilities we investigated distribute smartphones to foster remote communication with caretakers and their families. Furthermore, experimental projection-based guidance systems are used to augment worktables on which tenants cook or work. Finally, since most of the tenants are non-readers, so-called "talkers" were deployed. A talker is a text-to-speech smartphone application that reads out written text from the screen or a photo to a person. These have proved efficient since most of the tenants possess a smartphone and are proficient in using it. Besides providing support, such systems allow monitoring of the individual development progress without the presence of a caretaker. Such a system may affect the caretaker-tenant relationship [70], need approval from a data protection supervisor [88, 90], and require informed consent from the included parties [47]. In the current context, data protection is handled by the sheltered living organization, and consent is given by the tenant or legal guardian, depending on cognitive impairment.

## 2 RELATED WORK

Supporting persons with cognitive impairments has been the focus of previous research. The following sections provide an overview of previous research about assistive systems for users with cognitive impairments. We then provide a focused literature review about the ethical considerations arising from current practices of deploying assistive systems.

### 2.1 Ethical Considerations of Assistive Systems

Recent literature has shown that assistive systems are commonly employed in sheltered living facilities and work organizations to support persons with cognitive impairments during daily activities.

<sup>2</sup>The collaboration is part of a larger government-funded project investigating the impact of assistive technologies on persons with cognitive impairments.

Assistive systems aim to include persons with cognitive impairments in daily tasks and provide communal activities at home [72]. Although more and more labor is transitioning into care work [60], a prevalent caretaker worker gap in Western Europe still exists. Consequently, assistive systems become an addition to support caretakers during their daily work. Assistive systems rely on various sensor measurements integrated into the home environment [49]. However, permanent data collection is incompatible with the need for privacy protection [80]. Instead, recent developments in Artificial Intelligence (AI) use contextual data more commonly to enhance the overall system performance [2]. Data usage and protection must be communicated well for users with cognitive impairments [26, 27] to enable acceptance [18, 33] while keeping stable social structures [38]. Users with cognitive impairments are asked for consent before processing their data [13, 23]. While standards exist to obtain consent from users with dementia [63, 77], obtaining consent from a general population is difficult due to the individual types of cognitive impairments. Consequently, there is a growing need to establish ethical data collection means for assistive systems. Our work explores this issue by studying current practices at sheltered living facilities that accommodate persons with cognitive impairments. The next section focuses on previous evaluations of assistive systems for empowering users with cognitive impairments.

## 2.2 Empowering Users with Cognitive Impairments

Empowering marginalized groups through computerized systems became a relevant theme in HCI research [75]. Current assistive systems focus on their functional needs, where it is crucial to link the users' desires when engaging in activities between caretakers and the assistive system itself [36]. In this context, Mihailidis et al. [64] developed and evaluated a feedback application that supports hand-washing activities for people with dementia. Their results show that simple auditory cues helped persons with dementia to resume their intended activity. Kosch et al. [57] presented design recommendations for creating an intelligent kitchen supporting users with cognitive impairments. Dawe [31] investigated how the adoption of assistive systems can be fostered using qualitative inquiries. This method was later used to understand the design requirements for mobile phone users with cognitive impairments [32]. Finally, research was conducted on supporting episodic memories by applying appropriate cues for patients affected by dementia [59] to foster their independence. Besides assisting users with cognitive impairments in home environments, the United Nations Convention on the Rights of Persons with Disabilities [58] describes how to ensure the fundamental rights of people with impairments, including their integration into daily work activities. Hence, recent developments for assistive systems have been employed in workplaces. In a study that compares several feedback modalities regarding cognitive support efficiency, visual in-situ feedback has shown to be more accepted than auditory or tactile feedback [46, 54, 85]. Funk et al. [44] incorporated projections to support persons with cognitive impairments during work assembly tasks. Positive short-term and long-term effects were measured and observed regarding worker performance [41–43] and impact on social behavior [4]. Gamification [35] has also been evaluated regarding its feasibility

as a motivating factor to increase workplace task engagement. Several studies have shown that persons with cognitive impairments benefit from gamification in terms of motivation and efficiency during work tasks [51], along with the gain of an improved work atmosphere and enhanced worker performance [52, 53]. Previous work developed and evaluated assistive systems and gamification in efficiency and effectiveness. The presented examples show that assistive systems are used in more and more aspects of the lives of people with cognitive impairments. We highlight the critical aspects of understanding ethics for marginalized populations according to the existing literature in philosophy before investigating how assistive systems can implement ethical considerations.

## 2.3 Philosophical and Ethical Considerations

This section highlights some of the main ethical concerns related to developing assistive systems for users with cognitive impairments. Initially, we ground the user by describing the importance of ethical reasoning in developing assistive systems.

**2.3.1 Background: Current Ethical Practices.** For our considerations, we assume the role of the ethicist<sup>3</sup> working with assistive systems. This includes analyzing new technology's risks, clarifying conceptual requirements, and examining possible value conflicts on a personal and societal level related to assistive systems. The ethicist must also identify why a certain technological development is beneficial on ethical grounds and determine the measures needed to mitigate undesirable effects. This requires collaboration between ethicists, designers, developers, and end-users.

The principles of “autonomy”, “justice”, “benevolence”, and “non-maleficence” are cornerstones ethical cornerstones. We conduct a systemic review using these search terms in the Stanford Encyclopedia of Philosophy<sup>4</sup> about assistive systems for marginalized populations. Using a systemic approach, we decouple general ethical considerations irrelevant to this paper's objective. Furthermore, the Stanford Encyclopedia of Philosophy is an established source containing peer-reviewed information on fundamental philosophical and ethical aspects<sup>5</sup>. Consequently, we acknowledge that our principles do not cover the whole spectrum of ethical issues. Care should be exercised that this outline is far from exhaustive. Instead, it aims to sensitize the reader to crucial ethical issues and introduce the HCI community to relevant literature on ethics. Our research team included an ethicist who was previously involved as an ethics advisor in projects investigating assistive systems for persons with cognitive impairments. We reviewed current data collection and assessment practices, how informed consent is retrieved, and how autonomy is preserved when users use assistive systems. We identified key areas of where applied ethics work addressed assistive technologies: *Empowerment through Technology, Autonomy, Informed Consent, and Social Aspects*.

The four aforementioned philosophical aspects of the work represent an ethical perspective on our work. The questions of *Empowerment through Technology, Autonomy, Informed Consent, and Social Aspects* were identified as crucial by different stakeholders in past

<sup>3</sup>This section contains an explanatory philosophical discourse and we assume writing style similar work in applied philosophy as an ethicist was part of our research team.

<sup>4</sup><https://plato.stanford.edu> - last access 2022-08-15

<sup>5</sup><https://plato.stanford.edu/about.html> - last access 2022-08-15

research projects [26, 27, 57]. An ongoing project with group discussions and workshops involving academic and industry partners, including end-users and ethicists, deepened the relevance of the mentioned ethical aspects. Consequently, we turn to the body of philosophical ethics to establish the principles for designing ethical systems for users with cognitive impairments. Establishing principles also plays a prominent role in ethical theorizing in general. Privacy, for instance, is a major topic whenever technologies are used to track behavior, and autonomy and consent are at stake whenever technologies influence behavior [6, 66]. Further, the relevance of these principles is well-established within the applied ethics community [7, 87].

**2.3.2 Empowerment through Technology.** Assistive systems physically and cognitively support persons with cognitive impairments to support them living independently. For instance, an assistive system could function as an externalized memory for a person with memory weakness. From a philosophical point of view, this raises interesting questions about the mind’s boundaries and the ethical consideration of whether assistive systems could nudge users with cognitive impairments into specific undesired behavioral patterns even though the initial intent is benevolent [24]. Another example of being hesitant about current practices of *Empowerment through Technology* is the underlying understanding of cognitive impairments, where assistive systems are seen as an additional tool that extends cognitive capacities [16, 48]. Such a model tends to overlook the role of social environments and interactions in shaping the cognitive development of its users. Nonetheless, while there might be clear limits to how much empowerment is achieved through assistive systems, their benefit for helping users with cognitive impairments lead better lives cannot be denied.

**2.3.3 Autonomy.** *Autonomy* is one of the main pillars of modern ethics. The term describes the capacity of a person to exhibit self-governance [20] and that this acting is motivated by personal reasons. The necessary conditions for being autonomous are much debated in the relevant philosophical literature [3, 19]. Nevertheless, a user must possess a certain set of psychological capacities, such as the ability to self-reflect to be autonomous. Additionally, a technological artifact must possess higher-order evaluative judgments on what matters to them [3, 39]. In the context of assistive systems, autonomy as an ethical criterion is supposed to ensure that the person, and not the technology, exhibits control [19]. There are some challenges to using autonomy as an ethical criterion within the context of persons with cognitive impairments [30]. Yet, there are good reasons for retaining autonomy as an ethical principle. For example, if someone with a cognitive impairment does not meet the requirements for full-fledged autonomy, they might still have certain beliefs, desires, and values that express what matters to them. One ethical criterion for developing assistive systems should be that these do not interfere with their user’s values and desires. These concerns are particularly vivid if considered in the context of technologies that can convince users to exhibit particular behaviors [11]. It remains a question of how to foster socially desirable behaviors and provide rewards ethically.

**2.3.4 Informed Consent.** The problem of cognitive demand also applies to *Informed Consent* and privacy [37, 65]. Assistive systems

may collect fine-grained data on a person and infringe upon their privacy if this intention is not communicated with the respective users. Previous work mentions the term “datafication” in the context of care work to track health states [50]. Whereas strict guidelines governing the collection and storage of personal data have been established, it is still a problem to sensitize users to issues related to information privacy [68]. One factor is the high degree of abstraction regarding privacy issues. Many users find it difficult to grasp the content of informed consent and terms of service documents or to appreciate their relevance [17, 84]. While many decisions concerning welfare are deferred to caretakers, supervisors, or legal guardians, we still consider it crucial that users with cognitive impairments have authority over their interests, processed data, and privacy [74]. Practices to inform and retrieve consent from users with cognitive impairments are highly relevant.

**2.3.5 Social Aspects.** We need to consider how assistive systems affect the *Social Aspects* of users with cognitive impairments. Assistive systems strive to support legal guardians and users individually and in collaborative scenarios. In the context of sheltered living, previous work emphasized the integration of collaborative components that foster the social interaction between legal guardians and users [15, 25, 34], which eventually results in improved care work. Consequently, it is one of the critical ethical aims to ensure that not merely the technology but also the social setting between legal guardians and users of the care relationship is designed to promote the welfare of users with cognitive impairments.

## 3 METHOD

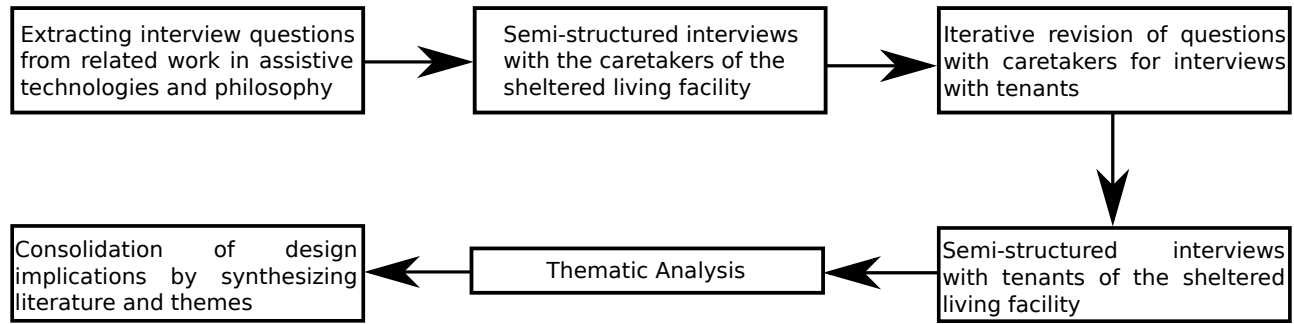
We conducted a series of interviews with caretakers and tenants from a sheltered living facility<sup>6</sup> to gain an understanding of how ethics for assistive systems and for users with cognitive impairments are currently practiced. Upon completing the interview, we created a script for interviewing the tenants together with the caretakers. The interviews with the tenants concerned about their current use of assistive systems and their perception of ethics were held afterward. Figure 1 provides an overview of the research process.

### 3.1 Data Collection: Interviews

An existing research collaboration between universities and social work organizations allowed us to conduct interviews with caretakers and tenants who work and live at sheltered living facilities. We provided refreshments in a dedicated room and conducted one-on-one semi-structured interviews in two sessions. We based our interview script on the aspects of ethics we previously identified in the literature review and in the collaboration within a project that included caretakers, ethicists, end-users, and HCI researchers.

Eight caretakers were interviewed about their understanding and perception of assistive systems in their organization. We conducted semi-structured interviews with caretakers from the sheltered living facility. We explored their views about ethics in their work, how ethical considerations were part of their duties, and day-to-day encounters with ethical questions. We then investigated how

<sup>6</sup>In the following, we refer to tenants with cognitive impairments of the sheltered living facility as *tenants*. The personnel of the sheltered living facility is referred to as *caretakers* or *supervisors*.



**Figure 1: Procedure of the conducted interviews.** We started by elaborating on interview questions regarding assistive systems from related work and ethics in philosophy. With these questions, we conducted semi-structured interviews with caretakers. Afterward, semi-structured interviews with tenants were conducted with a reviewed set of questions for the tenants.

those employees perceived future challenges to ethics and ethical guidelines for future assistive systems. We inquired about their perception of existing technical interventions in sheltered housing and how they affected the tenants' well-being and the caretakers' work. Later, we discussed reward systems and practiced ways to motivate tenants to perform and enjoy professional work and house chores. We queried them about data collection policies and how consent to data collection was handled. We asked how informed consent was obtained when using assistive systems. Finally, we inquired about the ethical challenges of introducing new assistive systems to sheltered housing. Upon obtaining consent from the caretakers, the entire interview was audio-recorded anonymously. The total recording time of the interviews with the caretakers was 158 minutes and 30 seconds ( $M = 19:21$ ,  $SD = 4:43$ ).

The next step in our research was conducting interviews with tenants about their perception of assistive systems and their experiences of using them. To that end, we consulted the caretakers on the optimal ways to interview the tenants, minimizing any disruption to their daily routines. The questions were iteratively revised together with the caretakers for further semi-structured interviews with tenants. This included translating questions into plain language that would be understandable for the tenants and ensuring that no question could have triggered a negative experience. This process ensured that the interview did not negatively affect the well-being of the tenants. Interviews were aborted immediately when any cues for discomfort were expressed by the tenants or identified by the caretakers. We paid attention to involving an experienced caretaker who, amongst others, is proficient in detecting discomfort through behavior and speaking patterns. No interview was aborted due to discomfort.

We conducted nine interviews with tenants of the sheltered living organization to gain insights into their awareness of the ethical aspects of their assistive systems. A caretaker, supervisor, or legal guardian who was well known to the tenants was present in the room during the interview. This way, we ensured that cues for discomfort could be identified early. The interview would be immediately terminated in such a case. We informed the tenants about the course of the study, their right to withdraw from the interviews anytime they wanted, and that the interviews were anonymously recorded before starting the interviews. Afterward,

we asked for their consent in addition to retrieving proxy consent from at least one close legal guardian, caretaker, or supervisor [62]. Finally, the experimental procedure was reviewed by the sheltered living facility, the appropriate governmental ministry for research and education, and the institutional ethics board. The questions and answers were as concisely as possible since tenants have a structured day that should not be disrupted largely. Interruptions during or before a scheduled task make it more difficult for a person with a cognitive impairment to achieve their daily goals. The longer they are distracted by the interviews, the more likely they will not return to their original task [83]. Consequently, we decided to conduct a single round of interviews that is kept as short as possible. The total recording time of the interviews with the nine tenants was 92 minutes and 57 seconds ( $M = 10:13$ ,  $SD = 3:19$ ).

The interview started after the tenant gave written or verbal consent and the accompanying legal guardian, supervisor, or caretaker. We began the interview by asking the tenants which technologies they were familiar with. Next, we inquired how assistive systems were used, how they supported the tenants during their daily lives, and whether they were satisfied with this support. Then we interviewed them about their awareness of the potential tracking capabilities of such technologies to tailor their functionalities to a tenant's individual needs. Next, we discussed the possible advantages and disadvantages of such data collection, then asked if they would be willing to provide consent for such systems and how this consent would be preferably given. Finally, we asked if and how rewards were communicated.

### 3.2 Participants

We recruited eight caretakers (aged between 21 and 58 years,  $M = 35.5$ ,  $SD = 14.23$ ) who had a mean work experience of 4.38 years ( $SD = 2.45$ ) and who held different positions at sheltered housing organizations as the organization provides work and other activities for persons with cognitive impairments in addition to sheltered living. We selected caretakers in various roles, from senior management to hands-on house caretakers, where all caretakers had at least two years of supervision experience. We intended to gain the best possible insight into their lives, which required us to claim parts of the caretakers' work time. Therefore, we limited our study to intermittent periods when they were performing administrative

**Table 1: Left: An overview of the interviewed caretakers. The caretakers assume various roles within the sheltered living facility. Right: Tenants who were included in the interviews. Tenants are supported within the sheltered living organization in the context of work and daily life skills. Most tenants have unspecified cognitive impairments and are legally considered cognitively impaired. Two tenants are affected by Trisomy 21 and autism.**

PID	Gender	Age	Position	Experience	PID	Gender	Age	Type of Impairment
C1	male	58	Work council	Six years	T1	female	59	Trisomy 21
C2	female	46	Housing officer	Two years	T2	male	58	Mental impairment
C3	female	21	Caretaker	Two years	T3	female	35	Mental impairment
C4	male	31	Housing officer	Nine years	T4	male	64	Mental impairment
C5	male	30	Caretaker	Four years	T5	female	37	Mental impairment
C6	female	26	Caretaker	Two years	T6	female	39	Mental impairment
C7	male	51	IT manager	Five years	T7	male	36	Autism
C8	female	21	Caretaker	Five years	T8	male	41	Mental impairment
					T9	male	42	Mental impairment

work. Consequently, the choice of caretakers and interview length assured that no time originally scheduled for work with the tenants was used for the study.

We then interviewed nine tenants (aged between 35 and 59 years,  $M = 45.67$ ,  $SD = 11.34$ ). Tenants were voluntarily interviewed outside their working hours during the time dedicated to recreation in their daily schedules. All tenants used assistive technologies daily for private entertainment and communal activities like cooking. Together with the caretakers, we identified participants who were regular users of multiple technologies to build a rich account of their lived experiences. Table 1 provides detailed information about the caretakers and tenants, including their cognitive impairment. Caretakers and tenants were not directly compensated for the interviews as the organizations were part of a joint research project with our university. Hence, the sheltered living facility received funding from the research project, which was used to improve the infrastructure and life quality of the tenants. Ethical approval for all study components was given in a threefold process: First, we obtained consent for the study from the tenants, conveyed verbally in plain language, and their legal guardians. We then presented the study concept to the sheltered living facility, which the therapists and housing officers approved. Finally, the responsible government authority and the institutional ethics board gave ethical approval for the intended study. An applied ethicist and a specialized caretaker oversaw participants' proper execution and treatment throughout the study.

### 3.3 Analysis

All interviews were transcribed verbatim and imported into Atlas.ti<sup>7</sup> for analysis. We used a thematic analysis process with open coding [14]. Two authors open-coded 25% of the interview material in an initial coding round. The theoretical concepts from ethics described above served as guidelines that defined the scope of our inquiry and thus facilitated data selection. The coding tree was then iteratively refined until an agreement was reached on the relevant codes between the coders. The data was then equally divided between two researchers and coded using the established coding tree. Next, a final discussion session was held where codes were grouped

and refined. We identified four themes in the data: AUTONOMY & INDEPENDENCE, CONFIDENCE IN TECHNOLOGY, MOTIVATION, and COMMUNAL LIVING.

## 4 FINDINGS

We present each of the themes we identified in the data, describing them with excerpts from the interviews<sup>8</sup>. We use the participant IDs from Table 1 to indicate the participants. The qualitative data may emphasize the caretakers' opinions over the tenants' opinions. However, the impression of an imbalance of content is incorrect. Although tenants were asked similar questions, the opinions and statements appeared shorter because tenants preferred concise statements. In our analysis, we ensure that the opinions of caretakers and tenants contributed equally to our findings by balancing code counts.

### 4.1 Autonomy & Independence

The first theme from the data describes how assistive systems currently support tenants by giving them more independence. First, we noted that the caretakers were impressed by the independence of tenants during daily tasks:

*“Our tenants can decide by themselves, for example, what and when they cook.” (C2)*

The caretakers were also surprised by how well tenants handle technological artifacts. For example, most tenants were proficient with technologies such as smartphones and tablets. Yet, technologies available to tenants were often used in simpler forms to reduce complexity. For instance, tenants used speed dial keys on the smartphone home screen to efficiently perform calls:

*“I can do phone calls by myself by just pressing a button.” (T8)*

However, employing systems with higher complexity raised concerns about their usage difficulty for the tenants and what strategies would be employed to reduce this complexity. The caretakers recognized assistive systems as an opportunity to improve the life quality of the tenants and stressed the importance of training and

<sup>7</sup>www.atlasti.com - last access 2022-08-15

<sup>8</sup>Quotes presented in this paper have been transcribed from their original native language into English.

involving the caretakers in the process of introducing new artifacts to the sheltered housing environment:

*“There are still many dependencies left because people with cognitive impairments are not able to install such systems by themselves. A dependency on the caretaker remains.” (C2)*

The tenants’ experiences often included a certain threshold of complexity. While a new artifact may have been initially intimidating, once the technology was mastered, the tenants were eager to use it:

*“I started to use the microwave since I can use it. It is calmer. I do not have to do many things at the same time.” (T9)*

However, the participants recognized the drawbacks of assistive systems. The caretakers were particularly cautious of the prescriptive nature of assistive systems. By providing too extensive instructions, assistive systems could limit the already partially limited autonomy of the tenants. One caretaker stressed the importance of a higher form of autonomy that required engaging tenants in daily tasks and social life. In this context, the caretaker mentioned that genuine engagement in communal activities is only possible when assistive systems are designed to fulfill their goal of training tenants towards their independence:

*“We are always talking about engagement. However, this is only possible if tenants act autonomously.” (C2)*

Tenants also reported that performing tasks with other tenants and caretakers created an atmosphere that increased overall engagement. Caretakers were necessary partners while performing certain tasks, while others would be performed with another tenant. One tenant reflected on how they were better able to shop for groceries together with others:

*“I cannot go to the grocery store alone. I am always going with other tenants or with a caretaker. I need help during shopping and cooking from a colleague or caretaker.” (T5)*

Another caretaker stressed that autonomy was an essential aspect of independence. However, the caretaker believed that current assistive systems did not provide an experience that would support long-term independence. Assistive systems should methodically convey knowledge instead of providing instructions “mechanically”. Hence, assistive systems should foster practical skills and transfer thinking instead of step-by-step instructions:

*“We have to ask ourselves what we want to achieve with assistive systems. We proclaim autonomy and inclusion. However, current solutions are not thoroughly thought through in terms of gaining own long-term independence.” (C5)*

Finally, a caretaker expressed concerns about assistive systems merely changing dependencies instead of reducing them. One caretaker was concerned about the negative social effects of extensive assistance:

*“I worry that if people get too used to tablets, they will neglect the social structures around them.” (C6)*

## 4.2 Confidence in Technology

This theme describes privacy and how data was handled between the sheltered living facility and the tenants. We characterize the lived practice of data handling and obtaining consent in a sheltered living facility. The caretakers or legal guardians generally gave informed consent. However, this raised ethical concerns regarding the use of assistive systems without informing the tenant:

*“I would not say that informed consent should not be provided by the legal guardian; however, I think that caretakers and legal guardians do not always inform tenants sufficiently. The tenant should understand what they agree with before using assistive systems.” (C5)*

One way of mitigating issues with obtaining consent and reducing the ethical burden on caretakers involved the family of the tenants in the consent process. The family could communicate potential ethical issues to the tenant, which eases the decision process:

*“We have another caretaker for the parents who informs them about potential privacy issues. The parents are usually the highest authority and can enforce stricter data privacy regulations.” (C1)*

When the assistive system was deemed helpful, it was an acceptable trade-off to inquire tenants about their awareness of potentially providing data to a third party. For example, currently employed displays helping tenants to cook independently were considered acceptable. The tenants accepted the automatization of simple processes:

*“I like how the displays help me to cook.” (T5)*

Some tenants were explicit about their perceptions of privacy. They stressed that they did not feel comfortable sharing their data with a third party. This included communication with relatives and caretakers primarily through messaging services such as instant messaging or direct phone calls:

*“I disagree with that [people are overhearing phone conversations]. Not everyone should know everything that I am talking about!” (T2)*

Tenants had a well-developed idea of privacy rules and who could be trusted with the data within the sheltered living facility. When prompted about overhearing phone calls, one tenant indicated that they were fully comfortable sharing information with persons who supervise them, such as caretakers and family, but not other tenants:

*“It is fine when a caretaker listens to my phone calls. I do not want others to listen to my phone calls except for the caretakers and my father.” (T7)*

In another attempt to help tenants understand the consequences of how their data was used, the sheltered living organization prepared forms in plain language. These were distributed to tenants so they would have the information available.

*“Information forms are written in easy language. Also, the newspapers and information sheets are formulated in plain language.” (C3)*

Another principle the sheltered living organization implemented was informing all the parties involved in the data handling practices.

Transparency in how data was handled and protected was a key concern:

*“Legal guardians and tenants must be informed about the advantages and disadvantages which may occur by providing data. We urge people to protect the data; not everybody feels comfortable sharing it.”* (C8)

### 4.3 Motivation

The next theme in the data describes how practitioners motivate the tenants to work and participate in other activities. Ensuring that the tenants were engaged in their activities and had a sense of achievement was an overarching goal for caretakers and tenants. Tenants stated that the completion of a task was a reward per se. When asked how they worked together with the caretakers to accomplish chores, a tenant commented that the independent accomplishment of a task was a source of pride:

*“Somebody was visiting me recently. Moreover, I have excellently cleaned up my room by myself. I did not need anyone to remind me about this.”* (T1)

Another key source of motivation for performing everyday tasks was the social environment. Positive comments from familiar persons amplified feelings of accomplishment:

*“Today, Ms. H [name edited] entered my room and told me I had the cleanest room she had seen.”* (T1)

Some of the caretakers were excited about the possibilities an assistive system could offer for motivating tenants. Gamification was perceived as a potentially effective means of creating a good working atmosphere in which tenants become motivated to accomplish their tasks and surpass themselves:

*“It would be nice if there were a flashing heart or claps from an audience. A system has to teach the tenants playfully. And if it comes to play, the tenants are motivated.”* (C1)

Several tenants used their private smartphones to play games. While smartphones were used for communication with caretakers and relatives, they were primarily perceived as a source of fun. Reward mechanisms, such as high scores, were an important topic in leisure time:

*“My favorite game is candy crush, which I can play on a smartphone. I use my phone for the game most of the time.”* (T1)

However, gamifying the work experience was also a potential threat to how the tenant community was organized. One caretaker was worried about a possible competition that might have ensued if assistive systems awarded points for completed tasks. He wondered about how tenants would perceive differences in achievements between them:

*“And how will a person with XY points in one week be treated? The reward system sounds like an alarm bell to me. How will the group treat someone with 90 points compared to someone with 40 points?”* (C8)

Another caretaker was wary that an effective reward system could lead to open conflict:

*“There is often a battle regarding work performance in our sheltered working facilities. This pushes the others, and they believe that they need to perform better to keep up.”* (C8)

Caretakers assumed that assistive systems were usually accompanied using building a playful experience or providing a reward system. While the engagement was a key concern, they also recognized that a tenant who could be motivated was particular to the particular tenant. A possible mismatch between a personality and a reward mechanism in an assistive system could result in an unneeded change that would strain the tenant. Another caretaker expressed explicit ethical concerns about providing rewards to the tenants. The caretaker believed that the tenants should be offered the same standards as other adults and thus not rewarded for everyday actions. Here, explicit gamification and rewarding systems were perceived as derogatory towards the tenants. The caretaker stressed the accomplishment of the task itself should be perceived as rewarding. Furthermore, taking care of one’s own everyday needs was perceived as empowerment:

*“The topic of reward systems is a difficult one because our tenants are grown-up people. Moreover, somehow, we have to preserve their dignity. I am not sure if we should reward our tenants because they can do regular tasks by themselves. I believe that the caretakers need to support them to the extent that they develop cognitively. More importantly, our tenants need to believe in themselves instead of a reward system.”* (C2)

### 4.4 Communal Living

The last theme describes the change in the dynamics of how tenants and caretakers collaborate through an assistive system. It is worth noting that sheltered living facilities in Western societies have been experiencing a shortage of qualified workers. Thus, assistive systems were perceived as an opportunity to lessen the workload of caretakers and increase the independence of tenants:

*“That everything is getting digitized makes it clear that some tasks will be computerized. However, I think that a machine will never replace the personal relationship between caretaker and tenant.”* (C3)

Assistive systems, such as screen readers or digitized interactive instructions, did not eliminate the need for a caretaker. The social trust in the caretaker was prevalent. One tenant had been testing projection-based cooking assistance systems<sup>9</sup> still strongly preferred cooking with the supervision of a caretaker:

*“It would not make me proud to cook this by myself. I am not sure if I would be able to cook without my caretaker. I think I would not do it.”* (T9)

The caretakers recognized sheltered living facilities as an essential social and psychological factor beyond teaching tenants how to perform everyday tasks and effectively providing them with a workplace. Practitioners found little use for assistive systems in

<sup>9</sup>We investigated the use of novel assistance modalities using participative design in addition to the presented study within the project with the sheltered living facility before this study. This includes a cooking assistance system mentioned by the participant.



this area, and humans would be needed to demonstrate how to use assistive systems in the context of sheltered living:

*“It is also a question of psychological interaction: You have to have somebody to talk to. There is somebody regularly, and I do not think this will change in the future.” (C2)*

These words resonated with the tenants’ opinions, who valued the sense of community. One tenant mentioned that chores were more enjoyable when performed with members of the community rather than with assistive systems:

*“I usually do not want to cook alone. It is way more enjoyable to cook with other colleagues or caretakers.” (T2)*

A key barrier in developing skills was communicating instructions and ensuring they were understood. For example, the reading or comprehension of narrated text was sometimes too complex for the tenants. One tenant, who could not read or follow audio instructions, stressed this need regarding how instructions should have been communicated. While the tenant was eager to follow instructions, they were not provided in an accessible form:

*“I use pictures to understand instructions. This is complex for me.” (T2)*

## 5 DISCUSSION

In this section, we summarize our results and present design implications for assistive systems for the tenants. The implications below focus on the design of assistive systems that account for ethical considerations in sheltered living facilities. We contribute measures that should be applied to existing and future technologies used by people with cognitive impairments. We also explore future directions for assistive systems to ethically support the tenants in independent living settings.

### 5.1 Ethical Design of Assistive Systems

Our study shows that assistive systems support tenants after mastering a particular technology, as revealed in the theme *AUTONOMY & INDEPENDENCE*, integrating with the ethical aspect *Empowerment through Technology*. We find that the design of assistive systems should foster the abilities of tenants through finding a “sweet spot” for individual assistance rather than “over empowering” them. Mismatching user assistance can lead to frustration and even dehumanization of the user. We anticipate this aspect as an essential research pillar. With decisions increasingly driven by AI, the need for including persons with cognitive impairments in AI ethics increases [9, 76]. “AI Fairness for People with Disabilities” [81, 82] must be a substantial component of future system designs. Understanding and providing *Informed Consent* is an essential aspect of *Autonomy*. The contemporary practice is to obtain *Informed Consent* through a proxy (e.g., legal guardian, caretaker, supervisor) when the user is not legally capable. Providing *Informed Consent* is a complex ethical aspect that should be discussed with the tenants, their family members, and legal guardians, which conforms with the theme *CONFIDENCE IN TECHNOLOGY*. Consequently, we experienced that *Informed Consent* is often conveyed through a proxy (e.g., family members or legal guardians) instead of involving

tenants more often in this process as we have seen it with simplified versions of consent by translating it to plain language. The absence of *standardized global processes* for obtaining consent in disability research requires further research in ethically obtaining permission to participate in disability-related studies. In contrast, standardized process for specific disabilities exists (e.g., dementia [63, 77]). The theme *MOTIVATION* shows that assistive systems impact *Autonomy* and the *Social Aspects* of the tenants’ daily routines. We find that assistive systems should preferably motivate tenants through the autonomous achievement of the daily task. While tenants may be proficient at playing and participating in games, caretakers emphasized direct comparisons of the individuals’ performances as a potential threat of the *Social Aspects*. Caretakers found a consensus in fostering the tenants’ *Autonomy* through emphasizing task completion as a reward per se.

Finally, the *COMMUNAL LIVING* theme intersects with the *Social Aspects*, where the collaboration between tenants and caretakers should be a high priority. Caretakers identified that social ties, regardless of whether with the family or members of the sheltered living facility, play an important role in the development of the tenants. Our work shows that finding a balance between autonomous and collaborative assistance is a crucial design task for assistive systems.

### 5.2 Autonomy in Collaborative Settings

One of the highly present goals in both the philosophical considerations and interviews is autonomy. Developing and maintaining autonomy in a sheltered living facility is a complicated task since individualized special training is necessary to achieve it, which requires extensive resources. Since household or work tasks can differ in their complexity, a majority of the tasks are distributed according to a tenant’s skill level. However, the interview findings show that tasks should be assigned to extend or improve the skills of tenants, which is currently scarcely practiced. Therefore, tasks assigned to tenants should contain a diverse spectrum to foster new skills.

Letting assistive systems decide the user’s cognitive skill level matches practical tasks is a research field in its infancy. Especially in the context of the studied marginalized population, the constant assessment of cognitive states, function, and abilities can lead to unfair treatment by quantifying skills. Previous work pointed out the dangers of “AI injustice”, where assessments between disabled and non-disabled users might lead to an unfair distribution of tasks. Consequently, research in AI ethics should focus on unbiased autonomous task assignments in the future, if at all [9, 55, 76, 81, 82]. Nonetheless, we see significant opportunities for using assistive systems in collaborative settings. The *COMMUNAL LIVING* theme depicts cooking as an activity where an assistive system can conform to the ethical requirements while fostering collaborative activities. Empowerment may be enabled through collaborative learning, where tenants at different disability levels can learn from each other. Further, supplying the tenants with tasks matching their ability levels ethically motivates them. Consequently, designers should study the specific skills involved in a task before creating an assistive system.

### 5.3 Design Implications for Ethically Designing Assistive Systems

Based on the literature and our results, we propose five design implications that can aid in designing and building assistive systems that consider ethical aspects of particular importance when working with tenants.

**5.3.1 Account for Trust in the Caretaker.** Our data highlighted the importance of the relationship between the caretaker, tenant, and legal guardian. Our findings show that caretakers and tenants build amicable relationships, resulting in the value of respect between each other. Caretakers communicate and train the skills necessary for the tenants to gain independence as outlined in the *AUTONOMY & INDEPENDENCE* theme. Legal guardians are required to be involved in the design process of assistive systems, as we found in the *CONFIDENCE IN TECHNOLOGY* theme. As the *COMMUNAL LIVING* theme indicated, assistive systems cannot merely act as a replacement for supervisors but rather augment the relationship between tenants and supervisors. **If assistive systems offer functionalities for communication, these should support input and output modalities aligning with the current understanding of the tenant. Negatively affecting the social environment of a tenant can have consequences that effectively limit their autonomy.**

**5.3.2 Simplify and Convey Informed Consent.** The need to obtain informed consent from the tenants irrespective of the legal obligations was present in the ethics literature we reviewed and considered necessary by sheltered living professionals. Consequently, **establishing clear and understandable ways of obtaining consent is a crucial consideration for any assistive system.** Most communication with the tenant is performed verbally during training and supervision, so the information should be provided in accessible language. As it is often found on traditional informed consent forms, legal language must be simplified to plain language to be understood by all parties. Our work shows that, contrary to most studies where a standard consent form is to be used for all participants, users with cognitive impairment require that consent be obtained in a customized form, which maximizes the autonomy of the specific participant. Admittedly, this is still an area where much empirical testing is required [5].

**5.3.3 Practice Care with Integrating Reward Systems.** The theme *MOTIVATION* and the ethical views on *Social Aspects* as well as *Autonomy* suggest that a balance between meaningful rewards and social structures must be established. While the integration of gamification was seen as positive, practitioners also identified connected ethical threats. Most importantly, our interviews revealed that reward systems could dehumanize or even disrespect tenants when mismatching the tenant's expectations and cognitive skills. We argue that current gamification concepts require more research in this context [79, 89]. **Our results reveal that the tenants themselves saw the successful accomplishment of daily tasks as a reward. Future reward strategies could, for example, offer unique task-related self-reflection opportunities for tenants.**

**5.3.4 Promote Independence while Limiting Risk.** We learned that providing independence is one of the critical goals of sheltered living facilities within the *AUTONOMY & INDEPENDENCE* and *Motivation*. While our participants stated that **reward systems have the potential to foster independence and motivation, they also pointed to several issues leading to unjust assessment and the accompanying creation of conflicts among tenants.** Especially caretakers were worried about reducing the value of tenants through autonomous reward systems, a valid argument being discussed in present research [9, 76]. The theme *COMMUNAL LIVING* showed that social aspects of assistive systems can be designed with independence in mind [8] and that assistive systems can further limit risks by supporting collaborative scenarios for persons with impairments [29].

**5.3.5 Navigate Social Structures.** The *AUTONOMY & INDEPENDENCE* theme highlights that while assistive systems often address a single task performed by a single user, most tenants are part of a collective living arrangement. At the same time, assistive systems are never outside of a social context and must respect the social structures and interactions [10] in the living facilities. **Maintaining social structures leads to autonomy as supports living independently in complex social environments.** Moreover, the ethical aspect *Social Aspects* and the theme *COMMUNAL LIVING* inform that tenants were eager to accept new artifacts, but only under the supervision of the caretaker who would make sure that the new technology would not disrupt how a living facility was organized. New technologies, such as smartphones or tablets, can be introduced with a caretaker or other tenants to see if the user is comfortable with the new artifact and ensure they can optimally benefit from it.

### 5.4 Limitations and Future Work

The interviews were conducted in sheltered facilities in Western Europe, introducing a geographical bias to our results. Sheltered living organizations are managed differently in other regions, and our results may not fully apply to those settings. However, we will contrast our findings against the practices of other care communities [21]. This includes multiple engagements with tenants from the same care facilities to increase the volume of the data by different ethical considerations. The ethical aspects discussed in this paper reflect recent findings from the field of philosophy. While these are far from exhaustive, they form theoretical grounding for ethically compliant assistive systems that must be investigated iteratively in real-world environments. Furthermore, a necessary element of our method was interviewing tenants in the presence of caretakers and specialists from the sheltered living facility. We cannot exclude the possibility that answers to the interview questions were biased in favor of the caretaker's opinion. Hence, we continue this line of research by working closely with users with cognitive impairments by drawing from previous experiences reported in past research [40] through participatory design. We will develop and extend existing methods [32, 78] which evaluate assistive systems that aim to support users with cognitive impairments.

## 6 CONCLUSION

In this work, we proposed design implications for the ethical design of assistive systems for people with cognitive impairments.

We reviewed relevant literature on the ethics of autonomy for marginalized groups. Based on this review, we interviewed employees and tenants from a sheltered living facility about the ethical aspects of assistive systems. We identified four different themes in the interview data: AUTONOMY & INDEPENDENCE, CONFIDENCE IN TECHNOLOGY, MOTIVATION, and COMMUNAL LIVING. We present five design implications which are intended to provide signposts for future assistive computing systems: *account for trust in the caretaker, simplify and convey informed consent, be careful with building reward systems, promote independence through limiting risk, and navigate social structures*. We are confident that these design implications will contribute to ethical assistive systems that enable independent living for users with cognitive impairments.

## ACKNOWLEDGMENTS

This work is supported by the German Federal Ministry of Education and Research as part of the project KoBeLU (Grant No. 16SV7599K).

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