

# Understanding Behavioral Manifestations of Obsessive-Compulsive Disorder in People with Intellectual Disabilities—A Qualitative Study

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## Abstract

**Background:** There is limited knowledge about obsessive-compulsive disorder (OCD) in people with intellectual disabilities (IDs). This paper describes the manifestation of compulsive behaviors associated with OCD at the behavioral level in people with ID in institutionalized settings. The aim was to gain nuanced insight into appropriate understanding and classification in this specific context, and derive implications for research and practice. **Methods:** Individual cases of people with ID ( $n = 7$ ) were studied to assess compulsive symptoms through two days of on-site observation of the person with ID within the institution, guided group discussions ( $n = 28$ ), and semi-structured interviews with key informants and caregivers of the person with ID ( $n = 20$ ). Caregiver ratings of the compulsive behavior checklist were compiled. Data were analyzed using qualitative content analysis. **Results:** All forms of OCD were present. Characteristics of compulsive behaviors in people with ID at the behavioral level included less complex and more obvious compulsive acts, immediate responses, signs of tension, motor restlessness, facial expression changes, repetition, need for predictability, time-consuming behaviors, and aggressive reactions when these acts were interrupted. Some of the compulsive behaviors corresponded to the ICD-11 OCD code 6B20, and others to compulsions as a psychological symptom (MB23.4). **Conclusions:** OCD may manifest atypically at the behavioral level in people with ID, posing significant challenges for accurate classification due to symptom ambiguity. Follow-up differential diagnostic studies are needed to more accurately identify and differentiate OCD symptoms in people with ID. Further, disorder-specific guidelines for recognizing OCD in people with ID are needed for institutionalized settings without psychiatric-psychotherapeutic expertise.

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## Keywords

People with Intellectual Disabilities, Obsessive-Compulsive Disorder, Compulsive Behavior, Diagnostics, Differential Diagnosis

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## 1. Introduction

The global prevalence of people with intellectual disabilities (IDs) is estimated at 0.05% - 1.55% [1] [2]. Some reports cite a 1% - 3% prevalence [3]. In the 11<sup>th</sup> revision of *the International Statistical Classification of Diseases and Related Health Problems* (ICD-11), code 6A00 characterizes the group and support needs of persons with disorders of intellectual development as a group of disorders during the development of various etiologies characterized by significantly below average “intellectual functioning and adaptive behavior that is approximately two or more standard deviations below the mean” [4]. With regard to mental health, people with ID are three to four times more likely to have a mental disorder [5] and evidence of a need for psychiatric treatment [6] [7]. For obsessive-compulsive disorder (OCD), studies have shown a lifetime prevalence of 1% - 2.3% and a 12-month prevalence of 1.2% in the general population [8] [9], and 0.7% to 3.5% for people with ID [10] [11] [12].

Despite the comorbidity involving OCD, limited research attention has been paid to OCD in people with ID. This limited research focus may be due to the risk of prevalence data including both OCD and behaviors labeled as OCD in people with ID [13], stemming from the challenging classification of repetitive behaviors as OCD or ID [14]. In the context of people with ID and OCD, this study focused only on the observable behaviors of people with ID: compulsive actions.

The greatest diagnostic challenge when dealing with individuals with ID is that their symptoms of mental disorders may differ from those of the general population (*i.e.* become more undifferentiated and atypical as the severity of the ID increases) [5] [15]. That is, the diagnostic process is complicated by the symptom presentation of OCD, as ID and autism spectrum disorders (ASDs) are often associated with compulsive-like behaviors such as repetitive behaviors or rituals [16]. This also applies to ritualized behaviors, which are more common in people with “autistic traits” [5]. Diagnosis of OCD in the context of ID requires differentiation of true OCD symptoms from stereotypical and self-injurious behaviors, which are more common in people with ID [5]. With this in mind, the well-known challenges of diagnosing and differentiating mental disorders in people with ID (e.g. [17]) appear to be particularly amplified in the context of OCD. For that reason, adapted assessment tools, diagnostic manuals, and guidelines have been developed. Specifically, the Yale-brown obsessive compulsive scale (Y-BOCS) [18] is widely used for evaluating OCD [19], while the compulsive behavior checklist (CBC) [20] serves as an adapted assessment tool for care-

givers to assess compulsive behaviors specific to adults with moderate to severe ID.

Similarly, clinical guidelines specific to OCD (e.g. [21] [22] [23] [24]) are also not universally applicable to the assessment of OCD in people with ID. Therefore, overarching guidelines for the assessment of mental health problems in people with ID have been developed [25] [26] [27]. Beyond that, the adapted diagnostic manual-intellectual disability 2 (DM-ID-2) [28] and the recent European Guidelines for the Assessment and Diagnosis of Psychiatric Disorders in Adults with ID [5] provide an overview of the current knowledge regarding the diagnosis of OCD in people with all levels of ID severity. Despite these efforts, the breadth of topics related to OCD is still limited, even in existing guidelines and manuals.

The aim of this paper was to directly derive from the diagnostic problems described above and examine the following question: How does the compulsive behavior associated with OCD manifest itself at the behavioral level in people with ID? As such, the findings address the existing research gap by generating specific descriptions of obsessive-compulsive behaviors at the behavioral level in order to broaden the understanding of OCD in people with ID. In order to better support the mental health problems of people with ID and OCD through appropriate recognition and classification, the results are discussed in the context of existing diagnostic knowledge and summarized in empirically-based conclusions for research and practice.

## 2. Materials and Methods

### 2.1. Study Design

Case studies are common in qualitative research [29] and were considered helpful in answering the current research question. This qualitative research project followed an exploratory approach, mainly due to the clear research gaps in the context of ID and OCD. The people with ID participating in the study lived in institutionalized settings. In total, seven case studies (four males and three females) were conducted in order to provide a nuanced description of the compulsive behaviors of people with ID. The underlying research question was explored within the participants' natural environment through the following methods: non-participant observation of the individual with ID, group discussions with key informants from the support system ( $n = 28$ ), and semi-structured interviews with caregivers and legal representatives of the individual with ID ( $n = 20$ ). Additionally, caregiver scores on the compulsive behavior checklist [20] were included.

Upon completion of the seven case studies, all empirical data collected using qualitative research methods were transcribed verbatim into German and analyzed using qualitative content analysis as outlined by [30] and MaxQDA software. An inductive-deductive category system was developed for this purpose. By combining the same qualitative survey methods in the seven case studies as part of

the qualitative content analysis, it was possible to generate both case-specific and cross-case findings, with the cross-case findings presented in the paper.

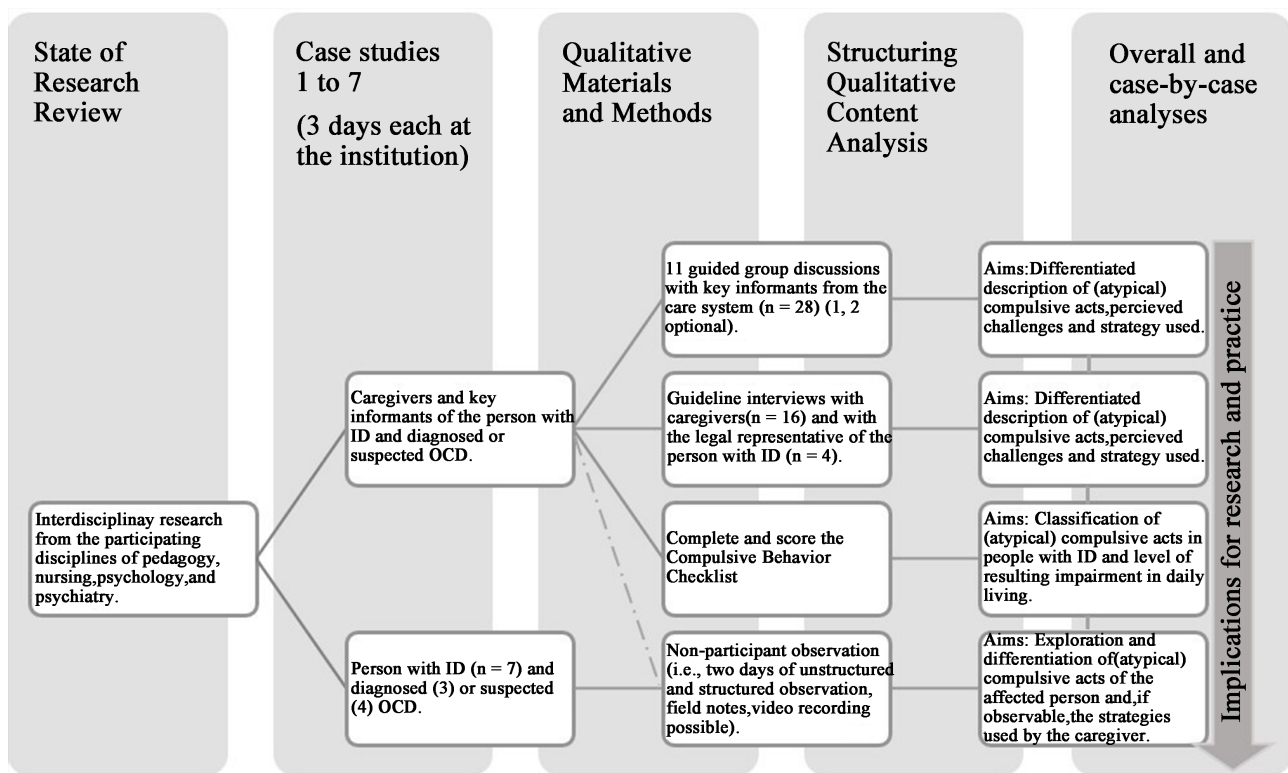
**Figure 1** illustrates the overarching research process to enhance the comprehensibility of this research. The findings presented in this paper are part of a larger study that seeks to generate specific knowledge about the description of compulsive behaviors at the behavioral level, thereby broadening an understanding of OCD in people with ID. In addition, the research sheds light on the a) perceived challenges and b) strategies practiced by caregivers in institutionalized settings, providing a comprehensive perspective in this particular area [31].

## 2.2. Recruitment, Description, Ethical Considerations and Consent of Case Study Participants

### 2.2.1. Recruitment and Description of Case Study Participants

To conduct the case studies, we sent letters and/or emails to 20 medium to large institutions in three German federal states where people with ID reside. The selection of these institutions was based on our contacts with people in key positions in these organizations. **Table 1** summarizes the criteria used to include and exclude cases.

If the inclusion criteria were met based on the descriptions of the institutions contacted in the first recruitment phase (consisting of 32 short descriptions from 20 institutions), a short questionnaire was completed by the institutions during the second recruitment phase, including a more detailed description of the



**Figure 1.** Visualization of the research process.

compulsive behavior (11 of the 32 short descriptions were selected). Eight individuals who met the criteria to participate were identified. Extensive interaction with an expert in OCD psychotherapy accompanied the recruitment phases. Case Study 8 could not take place due to illness, so a total of seven case studies were conducted. The age of the participants with ID ranged from 40 to 71 years. All ICD-11 severity levels of disorders of intellectual development (6A00) except for 6A00.3 (profound disorder of intellectual development) were represented (*i.e.* 6A00.0 Mild (2); 6A00.1 Moderate (4); 6A00.2 Severe (1)) [4]. Three of the individuals with ID were diagnosed with OCD, and four were suspected of having comorbid OCD.

All diagnoses listed refer to the 10<sup>th</sup> revision of the ICD, but they have been translated here in accordance with the 11<sup>th</sup> revision for the sake of the study results' connectivity.

**Table 2** summarizes the composition of participants in terms of the diagnoses present for those with ID and the professional affiliations of the other participants in the seven case studies.

**Table 1.** Summary of case study inclusion and exclusion criteria.

| Case Study Inclusion Criteria   | Case Study Exclusion Criteria  |
|---|--|
| <ul style="list-style-type: none"> <li>• Individuals with ID;</li> <li>• Diagnosis of OCD or massive compulsive behavior (<i>i.e.</i> engaging in compulsive activities 6 to 7 times per week that last more than one hour per day if not stopped);</li> <li>• High need for support due to additional OCD symptomatology;</li> <li>• OCD symptomatology to an unusual degree.</li> </ul> | <ul style="list-style-type: none"> <li>• Individuals without ID;</li> <li>• (Acute) somatic complaints;</li> <li>• Compulsive behavior as a phenotype of disability (e.g. Prader-Willi syndrome, Cornelia de Lange syndrome);</li> <li>• Disruptive behavior only limited to the environment (<i>i.e.</i> not categorized as pathological behavior);</li> <li>• Rarity of occurrence of the behavior.</li> </ul> |

**Table 2.** Summary of diagnoses and affiliations of participants in the seven case studies.

| Summary of ICD-11 Diagnoses of Persons with ID ( <i>n</i> = 7)   | Summary of First Group Discussion Composition ( <i>n</i> = 28)  | Summary of Individual Interview Composition of the ( <i>n</i> = 20)  |
|--|---|--|
| <ul style="list-style-type: none"> <li>• Disorders of intellectual development: 6A00.0 (2), 6A00.1 (4), 6A00.2 (1);</li> <li>• Obsessive-compulsive disorder: 6B20 (3);</li> <li>• Other diagnoses: 6A20.Y (1), 6A23 (1), 6A02.5 (1), 8A60.9 (1), LB18 (1), 2F34 (1).</li> </ul> | <ul style="list-style-type: none"> <li>• Institutional management (2);</li> <li>• Specialized service (4);</li> <li>• Nursing care management (3);</li> <li>• Pedagogue (4), curative education nurse (8);</li> <li>• Nurse (1), geriatric nurse (3), nursing assistant (3).</li> </ul> | <ul style="list-style-type: none"> <li>• Legal representation of the person with ID (4);</li> <li>• Specialized service (2);</li> <li>• Nursing care management (1);</li> <li>• Pedagogue (3), educator (1), curative education nurse (3);</li> <li>• Nurse (2), geriatric nurse (1), nursing assistant (2), medical assistant (1).</li> </ul> |

### 2.2.2. Consent of Case Study Participants

Prior to initiating each case study, we obtained informed consent [32] from the legal representative of the individual participating in the study. The selection of the individual with ID for the case study influenced the inclusion of other participants, *i.e.* caregivers and key informants of this person are included. The participating institutions decided independently of the researchers which key informants were important for additional individual interviews. Each participant, including the legal representative of the person with ID and key informants from the care system, provided written consent to participate in the research; it's worth noting that no participants withdrew from the study.

In accordance with the research ethics principles of informed and ongoing consent [33], before the non-participant observation began, the researcher provided the person with ID and received an explanation of the purpose of the observation, often with the assistance of caregivers, if circumstances permitted. With respect to ongoing consent, the researcher had experience and training in interpreting nonverbal signals from people with ID, and caregivers were instructed to report immediately any behavioral signals that might require cessation of observation. This principle of research ethics was applied to all participants.

### 2.2.3. Ethical Considerations

As outlined in the Statement of Ethical Considerations, according to local law and the institutional criteria of the University of Cologne, consulting ethics committees (e.g. an Institutional Review Board or Human Subjects Review Committee) is not legally mandatory for social or ethnographic research projects that do not require medical expertise for ethical evaluation. As a consequence, this study lacks ethical approval from a local, certified, independent ethics committee. However, recognizing the special importance of ethically reviewable research, we conducted the study in accordance with the two most recent research ethics guidelines to protect participants and ensure sound research practice as recommended in our field. Specifically, the study was conducted under strict adherence to the guidelines for ensuring sound research practice according to the Code of Conduct of the German Research Foundation (DFG) [34]. Further, as this part of the study also involved vulnerable people with ID in the broader sense (*i.e.* caregivers and key informants reported about people with ID, and their compulsive behaviors were observed by non-participants for a limited period of time), it was fundamentally important for us to use and strictly adhere to the research ethics guidelines of the German Interdisciplinary Society for the Promotion of Research on People with Intellectual Disabilities (DiFGB) [35] for the special protection of this population group.

Based on the aforementioned research ethics guidelines of the DFG and DiFGB, a specific self-reflection and research reflection framework was developed consisting of eight concrete procedural steps for clarifying ethical harmlessness. We adopted this approach to ensure an appropriate burden on all participants, particularly given the focus on caregivers and key informants rather than the vul-

nerable population of people with ID.

We also took great care to provide clear and transparent information to all participants through an information letter that covered the purpose of the study, study procedure, data protection, anonymity, retention obligation, voluntary participation, and publication. Informed and written consent was obtained from all subjects in the study and from the legal representative of the person with ID. Special attention was given to the vulnerability of people with ID, ensuring informed and ongoing consent as described by [33] for people with profound intellectual and multiple disabilities (PIMDs), and maintaining ethical standards and reflexivity throughout the research process. The study also adhered to the data protection regulations of the Data Protection Act of North Rhine-Westphalia (DGS NRW) in order to adapt the data protection law to the General Data Protection Regulation (DGSGV). Careful risk assessment ensured that the rights of research participants with and without ID were respected and that psychological or physical distress was avoided. For example, crisis intervention strategies were agreed upon, and crisis intervention plans were in place for six of the seven participants with ID with regard to careful risk assessment and respect for individual rights.

Each participating institution had a professional from specialized services trained in crisis prevention, intervention, and aftercare for people with ID. In order to avoid incidents during the study, close consultations were made with these individuals and the possibility of stopping the study if necessary was emphasized. The protection of the right to self-determination and privacy of all participants, as well as of the person with ID, was supported by excluding private situations from observation and by obtaining ongoing consent of the person with ID. For ethical reasons, situations essential for the psychiatric assessment of OCD, in which the person with ID was deliberately prevented from performing a compulsive act, were also avoided. Consequently, the results are based on caregiver reports.

All case studies were conducted without complications and with strict adherence to these research ethics principles. By thoroughly assessing the implications of the research and reflecting on and evaluating the relevant ethical aspects, the study was conducted in a highly ethical manner at all times, despite the lack of an ethics vote from a local, certified and independent ethics committee.

## **2.3. Description of the Survey Methods**

### **2.3.1. Group Discussions**

In each case study, a group discussion [36] was conducted with key informants at the beginning of the first day of research. The level of depth and intensity of discussion varied due to differences in time available and group sizes of the key informants. When possible, a concluding group discussion with the same or a similar set of participants was conducted on the third research day. This was feasible for Case Studies 1, 3, 6, and 7. The advantage of guideline-based group discussions is rooted in the potential for gathering and stimulating diverse opi-

nions and perspectives through collaborative deliberation of questions [36], resulting in nuanced descriptions of compulsive behaviors.

To ensure that the results would be relevant to the target group, the key informant groups were deliberately composed to maintain heterogeneity. The development of the guide was guided by the research question, with the aim of covering as many aspects as possible from different perspectives through discussion. The group discussions were pre-planned using a discussion guide that included open-ended questions, in this case focusing on identifying and understanding OCD in the context of ID.

### **2.3.2. Individual Interviews**

Guided individual interviews were conducted following a semi-structured interview format [37]. These interviews involved caregivers ( $n = 16$ ), some of whom had previously participated in group discussions, and legal representatives of individuals with ID ( $n = 4$ ).

The interview guides were designed based on the research question and prior studies on related subjects. According to [38], such guides should systematically capture the subjective perspectives and everyday knowledge of the interviewees while maintaining a high degree of openness. The interview guides encompassed both general and target group-specific areas. Each topic was introduced with a central question, and additional questions were asked as appropriate. This flexibility was motivated by the need to generate data that would reflect the diverse responsibilities and various forms of interaction that the target groups have with individuals with ID (e.g. legal representatives, specialized service).

### **2.3.3. Observation**

Additionally, non-participant observations in the natural environment as described in [39] were conducted to deepen the understanding gained from the interviews and group discussions with key informants. These observations involved two days of on-site observation within the institution with the collection of field notes, for a total of 102 hours of observation for the seven case studies. Situations in which the privacy of the individual with ID was a concern were excluded from observation. Due to the exploratory nature of the case studies, an initial unstructured observation phase was conducted before the structured observation began. The structured observation was based on pre-established observation categories and overarching observation questions, which were then used with the aim of capturing the symptomatology of the compulsive behavior of the person with ID and their responses at the behavioral level in as much detail as possible. Such an approach enables a more nuanced classification and interpretation of the empirical data collected on the background of the life realities of the persons studied. Observations were recorded in real time as field notes, and an observation protocol was developed based on these notes.

### **2.3.4. Compulsive Behavior Checklist**

Finally, we used Gedye's compulsive behavior checklist (CBC) [20], in consulta-



tion with the author of the German translation [40]. The CBC is designed to assess the severity of observable compulsive behaviors in adults with moderate to severe ID by the immediate environment (e.g. caregivers), as opposed to the Yale-brown obsessive compulsive scale (Y-BOCS) [18].

The scores of the CBC were used to classify (atypical) compulsive behaviors in people with ID and resulting impairments in daily life from the perspective of caregivers. The CBC lists 25 types of compulsive behaviors in adults with ID in the following five categories: ordering compulsions, control-an-touch compulsions, completeness and incompleteness compulsions, cleaning and cleanliness compulsions, and deviant personal hygiene compulsions. After the evaluation, the 25 types and the 5 categories result in a numerical value. In addition, caregivers are instructed to check applicable statements about the extent of impairment in the person's activities of daily living and rate the responses listed on the checklist (from 0 = *never* to 3 = *often*) when the compulsive behavior is interrupted. The caregivers completed the CBC after the second group discussion or after the case study survey.

### 3. Results

#### 3.1. Classification of Compulsive Behaviors in Accordance with the Compulsive Behavior Checklist

The purpose of this study was not to establish, confirm, or refute a diagnosis of OCD, as it was an exploratory pedagogical study. Rather the data were evaluated at the behavioral level in terms of behaviors associated with OCD.

Consistent with the CBC [20], all forms of compulsion occurred individually or in combination in the seven cases, especially compulsions concerning order, cleanliness, or control. Categorization of the data was based on the terminology of the CBC.

*Compulsion concerning order* was coded as behaviors that involved a rule-governed arrangement or sequence of selected objects or actions and indicated the restoration of an individual order principle of the person with ID. Compulsive ordering actions were predominant in Case Studies 1, 3, 4, and 6. These compulsive acts included, for example, arranging shoes or cups according to an individual pattern; precisely aligning clothes in a closet, pillows, wheelchairs, chairs, decorations, or bathroom fixtures; and positioning labels on food packages. Some orderings showed a tendency toward symmetry, while others showed an individual ordering principle. For example:

“Outside in the shoe room all shoes must be directed according to HIS order. Whether they belong there or whether they are right according to the name doesn't matter to him. But it must have HIS order. They must stand in a way that is acceptable to him. The window must be firmly closed. To be sure, he checks it five times. The same goes for the lock of the window or the tap in the bathroom; if he has washed his hands, the handle of the faucet must always be exactly in the middle, so he has to check five times back and

forth to be sure that it really is in the MIDDLE, yes. [Inhales deeply] So things simply MUST be in a certain way.” (Case Study 1, Interview Ms. B6, Nursing Assistant, pos. 38)

Only in Case Study 4 was another ordering phenomenon observed, the “double day”, as the caregivers called it, in which the person with ID always repeated a particular action twice:

“One double day, he repeats himself. He says to me twice, ‘good morning Mrs. B1, good morning Mrs. B1’ [...]. He just says everything twice.” (Case Study 4, Interview Ms. B3, Pedagogue, pos. 38)

Compulsive actions that were categorized as *compulsion to completeness and incompleteness* included completely emptying containers (e.g. pots, shampoo bottles), consistently closing fixtures (e.g. doors, cabinets, windows), and repeating an action an indeterminate number of times (e.g. dressing and undressing, putting away and taking away cabinets, turning light switches on and off). For example:

“[...] how he tidies up his laundry. He stands, then he kneels in front of the closet, he stands in front of the closet, pulls out some of the tops again, wants them to be folded again because they were apparently folded incorrectly; then he puts them back in, then he pulls them out again, because then ... because they got folded again when they were put in, or I don’t know what. That’s real. He sometimes needs a quarter of an hour.” (Case Study 1, Group Discussion, pos. 454, speaker B6, Nursing Assistant)

The compulsive behaviors coded as *cleaning and cleanliness compulsions* included adhering to hygiene routines according to a fixed procedure, intensive washing or scrubbing of selected body parts to the point of inflicting wounds (e.g. upper arms, hands), and checking and removing textile defects (e.g. loose textile threads). These behaviors occurred in Case Studies 1 and 2. For example:

“Yes, basically she prefers ice-cold water. So, when she starts, you just have to stick with it; she starts, first on the hair, that one with hair washing; then the washcloth is wet, which one hands her and then she puts it on and then one is allowed to put the soap on it, and then it starts. But first of all, first of all, here the upper arm forever long, so really. And in the past that was even often rubbed sore, yes.” (Case Study 2, Group Discussion, pos. 40, Speaker B2, Pedagogue)

Behaviors were coded as *compulsions to control or touch* constraints if they were associated with rule-guided control of rooms (e.g. be in other rooms), appliance functions (e.g. hallway motion detector, toilet flush), people (e.g. presence or absence), fixtures (e.g. windows, doors, closet doors, toilet lids), or touching objects according to a fixed pattern (e.g. pillows, light switches). For example:

“Then [the person with ID] goes to the toilet, waits a moment, closes the toilet lid, waits another moment, and flushes the toilet. After another brief moment of waiting, [the person with ID] opens the toilet lid, walks to the bathroom door, pauses briefly in the doorway, makes a sound similar to moaning, and then returns to the toilet. [The person with ID] repeats the described process in the same order, exits the bathroom, closes the bathroom door behind him, and returns to the dining area.” (Case Study 3, 2nd day of Observation of the person with ID, pos. 72)

According to the CBC caregiver assessment, the compulsive behavior “severely” to “very severely” *impaired the persons with ID in daily living*. The caregivers classified *the responses of the persons with ID to interruption of the compulsion* heterogeneously in terms of the occurrence ranging from “never” to “often”. Caregivers reported that the most common responses were the temporary interruption of the compulsive action, followed by resumption of the action immediately or after the caregiver left the situation.

### 3.2. Characteristics of Compulsive Behavior in People with ID at the Behavioral Level

One characteristic identified in the data was the heterogeneous form of compulsive acts in a less complex and more obvious way.

As shown in the categories of compulsions (e.g. compulsion to order, compulsion to control, or compulsion to touch), the compulsive behavior tended to be *more obvious and less complex at the behavioral level*. Specifically, the people with ID showed *heterogeneous forms of compulsions*; that is, not just one type (e.g. compulsive cleanliness), but different types of compulsion, with one type dominating. The data indicated that the compulsions manifest in different types, intensities, and relevance and never disappear completely. For example:

“Has got into it. The compulsions have become more and more different then. The one did not go away, the other only came in addition. That became more and more. And then he is again, yes, then he has stabilized again a little.” (Case Study 4, Interview Ms. B1, Specialized Service, pos. 16)

The empirical data showed that *waiting, observing, and reacting in compulsive contexts* was characteristic of individuals with ID; they adopted a wait-and-see attitude and focused on the objects relevant to the compulsive act. This resulted in the predominant radius of persons with ID being limited to the premises and the contexts in which the compulsive acts were performed. If a relevant object did not meet the individual’s expectations, they reacted immediately and immediately restored the principle (e.g. own arrangement, symmetry). In Case Study 3, a situation was observed in the living area in which the patio door in the living area was repeatedly watched and closed for 15 minutes during nap time (Case Study 3, 2<sup>nd</sup> day of Observation of the person with ID, pos. 83-84).

Behaviors such as tension, motor restlessness, and facial expression changes prior to performance, as well as self-injurious behaviors, were noted in people with ID prior to the performance of the compulsive act. These behaviors may be accompanied by nervousness and irritability or by rocking or twisting movements:

“And you also see, in most cases, unless you see correctly, there are just five hundred hooks actually still open in her head that are not yet set for the day [...] Then you see that she keeps jumping up and she keeps being restless and she keeps putting her hand in front of her mouth or pawing at her leg.” (Case Study 6, Interview Ms. B1, Curative Education Nurse, pos. 34)

In addition, the *uniformity, predictability, and repetition* of the same or similar sequences in each activity were found to be characteristic of OCD. It was the repetitive and similar sequences of actions at the behavioral level that caregivers associated with OCD in the person with ID. For example, caregivers used terms such as “her routine”, “makes her rounds”, or “he works off his plan” to describe such behaviors. The caregivers described the action sequences of the person with ID in detail, as the following description by the medical assistant shows:

“He often gets in his own way. For example, he wants to take a shower, BUT before that, he really has to work through his plan. I HAVE my window closed, I HAVE my light switched off, no matter what, and THEN I can continue. And if that has not happened, then he stands in his own way. Because he then goes back to the switch again and again and that can be TEN times, or [...] five times, depending on how he, here depending on the form of the day.” (Case Study 3, Interview Ms. B4, Medical Assistant, pos. 76)

From these characteristics, caregivers may be able to predict the compulsive behaviors of the person with ID. Interestingly, the recurring sequences of compulsive actions did not seem to follow an externally comprehensible logic but rather an action logic of the person with ID. For example, in Case Study 3, the order of checking the resident’s rooms is not based on their proximity to each other.

The data showed that *intense preoccupation with the act to the point of individual coherence* was also characteristic. The execution of the compulsive acts was described as intense execution (e.g. in terms of number of repetitions and increases). Individual compliance was not further differentiable in this regard, but an action was performed by the person with ID until everything fit. For example:

“He’s ... then we went to the neurologist, because we [the caregiver] said, it can’t go on like this. He has become so involved in the situation that he was no longer responsive.” (Case Study 4, Group Discussion, pos. 114, Speaker B3, Pedagogue)

“Only if something bothers him, then it has to be fixed immediately, and until it fits. And then it can be twenty times.” (Case Study 1, Interview Ms.

B6, Nursing Assistant, Pos. 34)

Another characteristic was the “high” to “very high” *time-consuming* nature of the acts. Compulsive acts, individually or in sequence, required a great deal of time—from several minutes to several hours—if the compulsive acts were not stopped. Thus, the person with ID needed sufficient time to carry out his or her compulsions, as illustrated by the following statement:

“Yes, because of [the person with ID], he already has real disorder, I say, OCD. And we try to take him OUT of this predicament. Otherwise, he can simply count for hours, simply count, stand and count. And we try to do that, of course.” (Case Study 4, Group Discussion, pos. 20, Speaker B2, Geriatric Nurse)

In the data, *concentration on the acts in the daily routine* showed that the entire daily routine of the person with ID was focused on performing the compulsive act or restoring order in the context of OCD. Caregivers reported that the person with ID had a daily routine that was consistently predetermined and shaped by the compulsive act. Caregivers descriptively used terms such as “compulsive daily routine”. The performance of the compulsive act took priority over other tasks (e.g. basic care, eating). In Case Study 3, the compulsions had increased to the point that the daily routine was focused almost exclusively on performing the compulsions (Case Study 3, Short Questionnaire, pos. 1). In this case study, the caregivers suspected that the person with ID was reducing or not performing basic care in order to have more time to perform the compulsions, as evidenced by, among other things, the following caregiver documentation: “*Goes after his compulsions very massively so that he didn't have time to shower*” (Case Study 3, Client-Related Documentation, pos. 1). The person with ID had to perform various compulsive acts (e.g. closing windows and doors in living rooms and hallways) before showering or going to the bathroom, which resulted in him urinating more frequently in compulsive contexts. Prioritizing compulsive actions resulted in little to no flexibility for the person with ID over the course of the day, as illustrated by the following quote:

“So now we just say [...] come on, we're going to take a shower. That's very difficult, for example, because he first has to check if the doors are closed, if the windows are closed, if the lights are off. That everything has HIS order for him. And then he comes to take a shower. So, we have to adjust very much to it, because he is very inflexible due to his compulsion, compulsion means, HE MUST DO IT [...] [H]e always wants the same daily routine. Precisely because everything is shaped by the FORCES and he has his own order. Yes, both in the daily routine and as far as the group is concerned.” (Case Study 3, Group Discussion, pos. 23, pos. 120, Speaker B3, Pedagogue)

From the caregiver interview data, it was determined that *aggressive reactions when stopping the compulsive actions* were expressed at the behavioral

level in the form of outbursts of anger, auto- or other-aggressive behaviors, and physical reactions (e.g. loud inhaling and exhaling, sweating). For ethical reasons, we refrained from staging an observation situation in which a caregiver would deliberately prevent the compulsive action of the person with ID. For example:

“As I said, she tends to be auto-aggressive and when she gets into it to an extreme, you notice that she gets into it. She then often runs to the toilet, she no longer finds time for anything, not for herself and not for anything else.” (Case Study 6, Interview Mr. B7, Curative Education Nurse, pos. 10)

At the action level, it was reported that the compulsive action was subsequently reperformed, pre- or post-processed, or shifted to other objects:

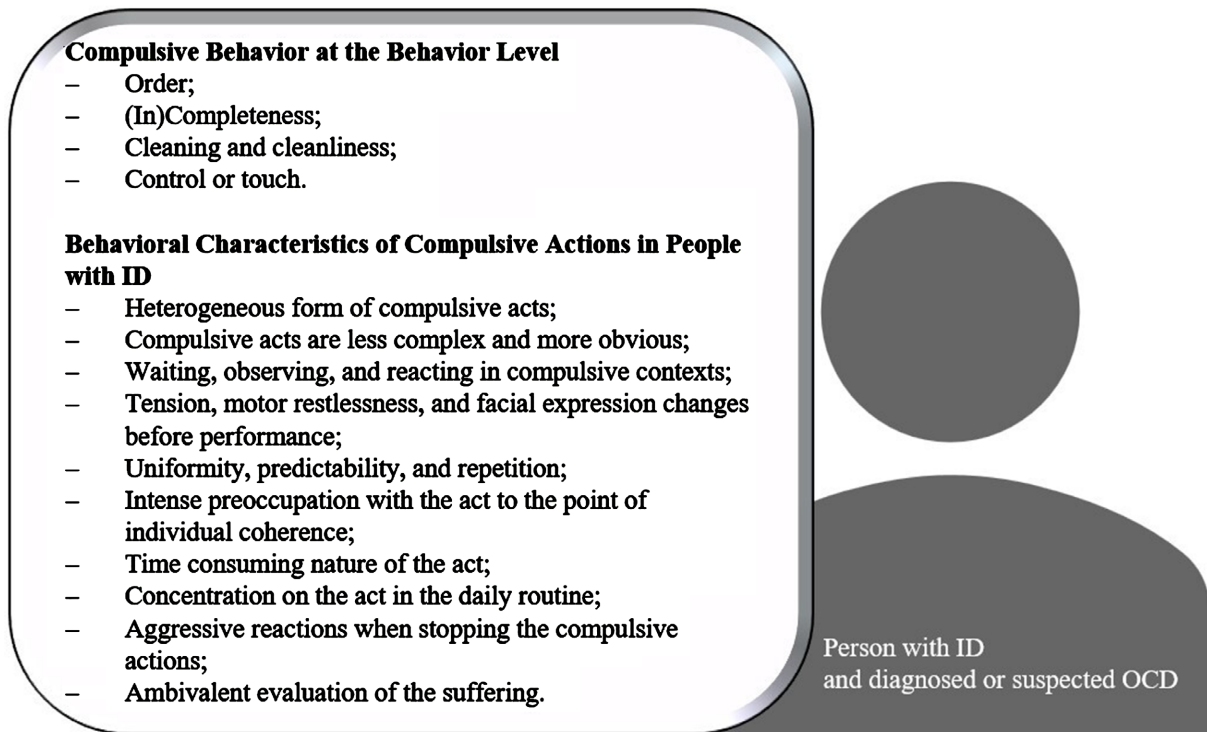
“B1: Because, if he makes there also still expression, and if he comes, he goes immediately after the compulsions. So, he shifts then, so he STOPS the things, then later when he comes, he goes again more intensively into the thing, so more intensively after. B2: Done it [laughs].” (Case Study 3, 2nd Group Discussion, pos. 130-131, Speaker B1 Specialized Service, B2 Nursing Care Management)

The *ambivalent evaluation of the suffering* due to the compulsive behavior could also be identified as characteristic in the data. Thus, caregivers made statements regarding the assessment of the present suffering due to the compulsive action, as well as regarding the assessment of the compulsive action as pleasure. The ambivalent assessment is attributed to a lack of biographical information about the person with ID and the person’s lack of verbal language capabilities. In addition, it is unclear at what point the distress exists—in the performance or non-performance of the compulsive act. For example:

“Limitations. HM. I think he needs it for himself. WE in the top view already have the feeling that he restricts himself with it, because he reduces himself to certain things and where I think to myself, if I always have to look there and that always has to be exactly SO, then, then that also falls away, so SPONTANITY and so, be flexible. That is then. Then it becomes more difficult again. There always come the things, which are actually beautiful. He voluntarily puts himself in a prison, so to speak. From the top view, it’s a prison, but I think in HIS eyes it creates some kind of relief for him.” (Case Study 1, Interview Mrs. B6, Nursing Assistant, pos. 62)

“It’s hard to say. I think it depends on the situation. So, there are situations where you just realize, she’s so tense, she HAS to do this now. Even if I tell her, LEAVE it. And there are situations where she doesn’t necessarily have to do it, but just wants to.” (Case Study 6, Interview Mrs. B2, Curative Education Nurse, pos. 62)

**Figure 2** illustrates the key findings regarding the behavioral manifestations of OCD in people with ID in institutionalized settings.



**Figure 2.** Key findings regarding the behavioral manifestations of OCD in people with ID in institutionalized settings.

## 4. Discussion

### 4.1. Summary and Discussion of Findings in Light of Current Research

There is a sound knowledge base with regard to the diagnostic and differential diagnostic requirements associated with the general classification of mental disorders and the classification of individual mental disorders (e.g. PTSD, depression, anxiety) in people with ID [28] [41] [42]. However, the comorbidity of OCD is understudied. One reason for the lack of scientific attention to this area may be information about the atypical symptomatology of OCD and doubts about the certainty of diagnosing OCD in people with ID. As described in the introduction, diagnosis of OCD in people with ID is difficult, so the findings are usually not only specific to OCD, but remain ambiguous even if, or especially because, the description is on the behavioral level. That is, the characteristics remain unspecific and may, therefore, indicate other causes of behavior in people with ID besides OCD.

Another key diagnostic problem associated with OCD is also evident in our empirical data—that is, the observed similarity of the occurrence of OCD to other known phenomena associated with ID through the characteristic features of “repetition [and] uniformity” [43]. Reference [13] notes that inadequate or lack of insight into the compulsions or thoughts as unreasonable cannot be adequately assessed as a differentiating criterion in persons with ID and, consequently, a definitive diagnosis of OCD in persons with ID is often not possible—“even though, regardless of this, in everyday life, people often talk about compulsions

and mistakenly about OCD” [13]. The presence of observable compulsive behaviors in people with ID without the concomitant knowledge about the presence of obsessive thoughts creates a situation in which symptoms become unclear and ambiguous. For this reason, [44] advocates describing the behavior of people with ID as compulsive behavior rather than OCD. To further differentiate, [44] suggests three types of compulsive behavior in people with ID in terms of the cause of the behavior: the organic type, the neurotic type, and the regulatory type. In situations where an organic brain or genetic cause is identified, such as Prader-Willi syndrome, it falls under the category of organic type, and drug treatment is recommended. Conversely, in cases related to the neurotic type associated with OCD, a psychotherapeutic approach is considered essential. Finally, in the case of the regulative type, it is necessary to identify the underlying psychological problem and adapt the environment to the basic needs of the person with ID. For example, when addressing issues related to insecurity, it is advisable to introduce interventions that address the security needs of the person with ID [44].

On the one hand, in people with ID, OCD occurs comorbidly [10] [11] [12], and these individuals have a corresponding need for disorder-specific treatment and care. On the other hand, diagnosing mental disorders in people with ID is generally difficult, especially for OCD [13] [45]. Not every behavior that is classified as compulsive is actually a manifestation of OCD [13]. The main diagnostic challenge is that the symptoms of common classification systems are largely applicable to very mild forms of ID and lose their validity as the severity of the ID increases, which is taken into account in the DM-ID-2 [28].

To identify OCD in people with ID, guidelines [5] [28] [45] have responded to the description of OCD by identifying commonalities and differences in the clinical symptom pattern for diagnostics in people with and without ID. For example, recognizing ego-dystonic compulsions in people with ID can be challenging, and the more severe the ID, the less likely they are to be recognized [5] [45]. These individuals may find it difficult to evaluate and communicate excessive or unreasonable compulsions or thoughts; therefore, resistance to compulsive thoughts or actions may not exist and is usually underreported [5] [13] [45].

However, the differentiation of insight capacity in the ICD-11 has limited applicability to people with ID [13]. Confirmation of impairment in social functioning or distress is not necessary for diagnosis, although problem behavior in people with ID may indicate such distress. Differential diagnoses with other mental disorders—especially affective and psychotic disorders [5] [45], as well as with tic disorders and other stereotypies—are necessary [13].

The symptom descriptions in the guidelines are helpful for diagnosis in the mental health care system. However, for caregivers with pedagogical or nursing expertise, existing diagnostic guidelines are too abstract, too clinical, too demanding, and not self-explanatory. To date, there are no empirically collected descriptions of OCD in people with ID at the behavioral level that can serve as an identification guide and red flag for caregivers to refer the person with ID to a



mental health professional.

To fill this gap, the present study aimed to identify symptoms of OCD at the behavioral level in a more nuanced way through differential acquisition and description of compulsive behaviors associated with OCD in people with ID. Notably, the study did not examine how obsessive thoughts may occur in people with ID but may not be very complex, necessarily intrusive, or fully captured or reported [45]. It is important to note that only three of the seven participants with ID had an OCD diagnosis.

The study shows that the diagnosed or suspected OCD of the seven persons with ID was manifested at the behavioral level in the form of compulsive acts according to the CBC. This, in turn, leads to the need to identify behaviors that may be indicative of OCD; that is, suggesting that atypical OCD manifesting in people with ID is only recognized by caregivers at the behavioral level through the differentiated description of compulsive acts. Following the CBC [20], compulsive behavior was divided into the following categories: order, (in)completeness, cleaning and cleanliness, and control and touch. Compulsions of deviant personal hygiene were underrepresented. The person with ID did not perform only one category of compulsions (e.g. ordering) but performed different types of compulsions, with one type being predominant.

As mentioned above, this study was able to identify specific variations of and possible clues about compulsive actions in people with ID through differentiated descriptions at the behavioral level: heterogeneous form of compulsive acts; compulsive acts are less complex and more obvious; waiting, observing, and reacting immediately in compulsive contexts; tension, motor restlessness, and facial expression changes before performance; repetition, uniformity, predictability; time-consuming concentration on actions in the daily routine; intense preoccupation with the act to the point of individual coherence; aggressive reactions when stopping the actions; and ambivalent evaluation of the suffering. Furthermore, the assessment of OCD is further complicated by the behavioural-level characteristics identified in this study (e.g. repetitive behavior, assessment of distress).

Among the identified behavioral characteristics, correspondences were found with OCD symptoms 6B20 of the ICD-11 (*i.e.* repetitive and excessive compulsive behaviors) and with compulsions as mental symptoms MB23.4 of the ICD-11 (*i.e.* rituals, repetitive behaviors, sense of completeness, preoccupation with the act until individual coherence, checking, washing). There was a high correspondence of identified behavioral characteristics at the behavioral level with atypical OCD symptoms according to the DM-ID-2 [45], which may be described in more detail in this study (e.g. presentation of compulsive behavior in situations) or be presented in a more differentiated way with regard to covert and atypical symptom presentation in people with ID (e.g. ambiguous behavior, aggressive behavior when stopping actions, repetitive behavior). The characteristics identified were not specific to OCD and were ambiguous; because of their

similarities, however, they suggest the classification of caregivers to be more common in the context of ID (e.g. stereotypies, ASD, rituals, habit).

## 4.2. Implications for Research

The strengths of this qualitative study relate to its generation of descriptions of compulsive behaviors at the behavioral level to broaden an understanding of OCD in people with ID.

The nature of the study means that it cannot be representative. That is, qualitative research relies on reflective interpretation of the empirical data by the researchers as an integral part of the evaluation process, which may be a limitation compared to quantitative research. Besides the small number of cases, another limitation of the study is that only three study participants with ID were diagnosed with OCD (6B20), while four were suspected of having a comorbid OCD. However, as highlighted in this paper, the diagnosis of OCD in people with ID presents diagnostic challenges. Therefore, inclusion and exclusion criteria were predefined, and case selection was supported by the assessment of a psychotherapist with expertise in the field of OCD.

It was already recognized in the design of the study that focusing on the behavioral level, while necessary, is challenging. This led to limitations of the results. That is, the identified behavioral characteristics remain ambiguous in terms of their cause and, without psychiatric evaluation, represent only indications of OCD in people with ID to be verified. For ethical reasons, important situations for psychiatric assessment in which the person with ID was deliberately prevented from performing a compulsive act were avoided, so that the results are based on caregiver reports.

In addition, since the focus of our study was on describing compulsive actions, no information could be generated about compulsive thoughts in people with ID, which is another important aspect of OCD.

Furthermore, research on OCD symptoms in people with ID is an interdisciplinary effort, involving psychiatry, psychology, and pedagogy. The present study deliberately approached a psychiatric issue from a pedagogical perspective. Participants were predominantly from the fields of pedagogy and nursing, with no psychiatric expertise. Therefore, it can be assumed that in addition to everyday experience, disciplinary aspects were also included in the description and classification of behavior. This raises the risk that the caregivers' classification and description of the behavior represent a misjudgment from a psychiatric perspective.

Self-reporting by patients is part of the psychiatric diagnosis, but it could not be included in this study due to the limited or total absence of verbal language of the individuals with ID, necessitating that reports be based on third-party reports instead (e.g. caregivers). Third-party reports carry the risk of misinterpretation compared to self-reports. Further, the study was not conducted in a clinical setting. The limitation here is that the participants involved in the natural environment of the person with ID did not have certified expertise in diagnosing

mental disorders; at the same time, the strength is that the people involved had expertise in the population of interest. Different professions were involved. However, in terms of the necessary interdisciplinarity, psychiatric and psychological specialists were missing, whose expertise is of great importance for this topic and should be considered for further research.

Throughout the study, it was recognized that some study participants were individuals with ID who were particularly vulnerable. For this reason, we focused on a research ethics framework. This was also necessary because the study was conducted with people without intellectual, mental, or physical disabilities.

### **4.3. Implications for Practice**

Disorder-specific guidelines for recognizing OCD in people with ID are needed for institutionalized settings without psychiatric-psychotherapeutic expertise. To meet the challenge of recognizing and classifying behaviors, such disorder-specific guidelines should provide information on (atypical) symptomatology by describing symptoms in everyday case studies at the behavioral level. Assessment of OCD is further complicated by the behavioral-level characteristics identified in this study (e.g. repetitive behavior, assessment of distress). Therefore, at the behavioral level, the guidelines should provide information that allows an initial distinction between OCD and behaviors associated with ID, ASD, stereotypes, and everyday habits. In this context, in both diagnostic and institutionalized practice, it should be evaluated to what extent the three types of compulsive behaviors in people with ID (organic, neurotic, or regulatory type) [44] prove valuable in classifying and distinguishing behaviors and diagnoses. Systematic observation, classification into the three types of OCD, and the CBC can support the process of initial assessment in an institutionalized setting in the form of team discussions and provide orientation for further diagnostic clarification and interdisciplinary support steps in collaboration between caregivers and the health care system.

## **5. Conclusion**

OCD may manifest atypically at the behavioral level in people with ID. Due to the ambiguity of symptoms, this poses a significant challenge for classification in the context of diagnosis and daily life in institutionalized settings. Caregivers are not sufficiently qualified to identify mental disorders and, therefore, need targeted support. Early identification of OCD in people with ID through differentiated description at the behavioral level can support needs-based psychiatric and/or therapeutic care, achieved through close collaboration with the health care system.

### **Data Availability**

The data presented in this study are available on request from the corresponding author. The data are not publicly available due to privacy.

## Authors' Contributions

Conceptualization: L.G.; methodology: L.G.; validation: L.G.; formal analysis: L.G.; investigation: L.G.; resources: L.G.; data curation: L.G.; writing and original draft preparation: L.G.; writing, review and editing: L.G. and M.G.; visualization: L.G.; supervision: M.G.; project administration: L.G. All authors have read and agreed to the published version of the manuscript.

## Informed Consent Statement

Informed and written consent was obtained from all subjects included in the study and from the legal representative of the person with ID, as described in Materials and Methods.

## Ethical Considerations Statement

This study is not medical research involving human subjects and is not a research project whose ethical evaluation requires medical expertise. According to local laws and institutional criteria of the University of Cologne, with which the researchers are affiliated, consultation with ethics committees (e.g. an Institutional Review Board or Human Subjects Review Committee) is not legally required for social or ethnographic research projects whose ethical evaluation does not require medical expertise. Because of these German regulations, this study did not receive the ethical approval of a locally certified independent ethics committee; moreover, it is not yet state of the art in Germany for these types of studies. Recognizing the special importance of ethically reviewable research, especially research involving human subjects and a vulnerable population (people with ID), this study was conducted in lieu of an official ethics vote under constant consideration and reflection of the two most recent ethical research guidelines recommended in our field. It is important to note that the study results were obtained primarily through interviews with caregivers about people with ID and secondarily through non-participant and time-limited observation of the person with ID, while respecting the rights of personality and self-determination. Informed consent was obtained from all participants involved in this study, with particular attention paid to ensuring the informed and ongoing consent from people with ID. To protect the participants and ensure good research practice, on the one hand, the entire research process was conducted in accordance with the guidelines for safeguarding good research practice as defined in the Code of Conduct of the German Research Foundation [34]. “The DFG Code of Conduct addresses both researchers and institutions (HEIs and non-HEI research institutions). It outlines the most important standards of good research practice and describes the procedure to be followed in the event of non-compliance with these standards” [34] (p. 9). On the other hand, especially for research involving human subjects and a vulnerable population, this study was additionally conducted under constant consideration and reflection of the ethical guideline on research ethical issues in the context of people with ID and people with profound intel-

lectual and multiple disabilities (PIMDs) of the German Interdisciplinary Society for the Promotion of Research on People with Intellectual Disabilities [35]. Based on a thorough assessment of research implications as well as reflection and evaluation of the relevant ethical aspects, the study was conducted in a highly ethical manner at all times, despite the lack of an ethics vote by a locally certified independent ethics committee.

## Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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