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Deutsche Interdisziplinäre Gesellschaft zur Förderung der Forschung für Menschen mit geistiger Behinderung e.V.

German Interdisciplinary Society for the Promotion of Research for People with Intellectual Disabilities e.V.

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## Research ethics issues in the context of intellectual and multiple disabilities

A reflection paper of the German Interdisciplinary Society for the Promotion of Research for People with Intellectual Disabilities e.V.

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# Research ethics issues and challenges – a stocktaking

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For human rights-based and subject-oriented action in research contexts, in-depth engagement with the discourses surrounding the topic area of research ethics is indispensable. The DEUTSCHE FORSCHUNGSGEMEINSCHAFT (DFG) [GERMAN RESEARCH ASSOCIATION] and the NATIONALE AKADEMIE DER WISSENSCHAFTEN LEOPOLDINA [NATIONAL ACADEMY OF SCIENCES LEOPOLDINA] therefore appeal to scientists not to be content with complying with legal regulations: Researchers have "a special ethical responsibility due to their knowledge, their experience and their freedom, which goes beyond the legal obligation [Trans.]" (DFG & LEOPOLDINA 2014, p. 8; see also BAUMGARTINGER, 2014, p. 100f.). So far, various professional associations have published statements, recommendations, guidelines and codes.<sup>1</sup> They offer an orientation framework for research ethics and thus express the self-image and understanding of the quality of their own work (cf. ETHIKDISURS, 2019). The history of human rights violations in the course of research practices, which is still relevant today, necessitates the writing of research ethics papers (cf. FACHBEREICHSTAG HEILPÄDAGOGIK, 2017). Although "(research methodological) specifications [...] exist in medical and nursing research [Trans.]" (FACHBEREICHSTAG HEILPÄDAGOGIK, 2017, p. 5), these are still largely lacking in the field of curative and inclusive education research. In relation to this, in November 2017, the FACHBEREICHSTAG HEILPÄDAGOGIK [SPECIALIZED SECTION CONFERENCE ON CURATIVE EDUCATION] drew up considerations on research ethics in curative education with specific reference to the phenomenon of disability. Likewise, in its draft research ethics code, the DEUTSCHE GESELLSCHAFT FÜR SOZIALE ARBEIT (DGSA) [GERMAN SOCIETY FOR SOCIAL WORK] takes into account "the reality of life of marginalized or stigmatized people or of people in vulnerable situations and situations characterized by dependencies [Trans.]" (DGSA, 2019, p. 4). Existing recommendations, guidelines and professional articles/publications (cf. among others ARN, 2017; COONS & WATSON, 2013; DEDERICH, 2017a,2017b,2018; GRAUMANN, 2013,2018; McDONALD. & KIDNEY, 2012; McDONALD et al., 2015; MIETOLA et al., 2017; VON UNGER, 2014a,b) show that the discussion of research ethics is accompanied by a multitude of tensions, contradictions and ambivalences.

This document<sup>2</sup> is intended as an orientation framework and attempts to identify and make visible a number of ethical problems and challenges, with particular reference to the group of people with so-called intellectual and/or multiple disabilities, using **critical reflection questions** as a **basis for self-reflection on one's own research activities** (from planning to implementation to dissemination of results). The aim is to anticipate possible risks (cf. DEUTSCHE GESELLSCHAFT FÜR PFLEGEWISSENSCHAFTEN E.V. 2016) and the associated

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<sup>1</sup> A selection of existing codes or guidelines is listed before the list of sources.

<sup>2</sup> This paper was written on the occasion of the DIFGB symposium 2019, "Who decides what for whom?" - Questions of research ethics in the context of intellectual and multiple disabilities. The paper was prepared in advance as a draft by the above-mentioned authors and intensively discussed in working groups and in the plenary session at the symposium in Leipzig on 22 November 2019. Subsequently, the results of the discussion at the conference were incorporated and a revised version is now available, which will be published for the first time in 2020 by the DIFGB board. The paper is explicitly understood as a *process document*, which should invite further comments, discussions and exchange. The genesis of the paper is a privileged humanities academic (research) framework. At this point, it is important to emphasize that due to this situatedness of the authors, only a certain perspective on research ethics in the context of research with people with so-called intellectual disabilities can be taken.

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ways of dealing with them in the research process by dealing with ethical dilemmas and against the background of (frequently) uncertain decision-making situations in the sense of weighing-up processes (cf. DGSA, 2019).

## Practical research challenges and fields of tension

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Fundamental to research processes in which people with so-called intellectual and/or multiple disabilities are to be included is the reflection of the "particularities of the respective research field [as well as] necessary negotiation processes with the [...] actors involved [Trans.]" (DGSA, 2019, p. 2). (Institutional) power structures and dependency relationships within living spaces and their influence on research action and the research process must be considered sensitively here (cf. among others DEDERICH, 2017a). In this context, the "protection, participation, information and freedom rights of the research participants [Trans.]" (DGSA 2019, p. 4) must be protected. Often these are in an ambivalent relationship with each other (cf. FACHBEREICHSTAG HEILPÄDAGOGIK, 2017). Phenomena caused by this will be examined in more detail below.

## Field of tension I: Genesis of research projects and interest in knowledge

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Advocating for change in social conditions (cf. PIEPER, 2008) is fundamentally seen as a constitutive element of research. Therefore, the *political dimension of research* must always be considered. Research does not take place in isolation from the public sphere, but on the contrary necessarily influences it (cf. BAUMGARTINGER, 2014). The supposedly suggested neutrality of scientific knowledge production is therefore rightly questioned (cf. DEDERICH, 2017a; VON UNGER, 2014a among others). Research efforts that explicitly consider the group of persons with so-called intellectual and/or multiple disabilities are based on a "historically [conditioned] social responsibility [Trans.]" (FACHBEREICHSTAG HEILPÄDAGOGIK, 2017, p. 1) (cf. among others GRAUMANN, 2018; SCHÄPER, 2018). Research is committed to "meeting the interests of the respective target group [Trans.]" (FACHBEREICHSTAG HEILPÄDAGOGIK, 2017, p. 5) and positively influencing the realities of life of the group of people (cf. among others DEDERICH, 2017a).

Currently, people with so-called mental and/or multiple disabilities live in (precarious) social conditions that are often characterized by "attribution practices and normalization techniques [Trans.]" (RÖSNER, 2014, p. 10) as well as "experiences of disability [Trans.]" (SCHUPPENER, 2006, p. 164). The ways of reacting, dealing and interacting with this group of people can be very different in the prevailing social system. The spectrum of possibilities ranges from appreciation, recognition, acceptance and social inclusion to rejection, exclusion and discrimination.

Research efforts are always situated in a *complex of knowledge and power*. The current conditions under which knowledge is produced are always embedded in hegemonic structures. Being embedded in the reproduction and leveling of these relations has a significant influence on the actions of researchers (cf. among others FRIETERS-REERMANN et al., 2019). Research approaches that are participatory in nature have the

potential to break down these structures (cf. ALDRIDGE, 2014; BERGOLD & THOMAS, 2012; BUCHNER et al. (2016); COONS & WATSON, 2013; FRIETERS-REERMANN et al., 2019; VON UNGER, 2014c).

It is therefore necessary to strengthen projects that are dedicated to *transformation processes*, which in turn show ways out of the exclusive mechanisms of an ableist<sup>3</sup> society, which can be characterized by dominance cultures, (institutional) special spaces (cf. DGSA, 2019; cf. FACHBEREICHSTAG HEILPÄDAGOGIK 2017; cf. SIERCK 2019) and the powerful construction of (pathological) otherness/deviation (cf. AKTIONSBÜNDNIS TEILHABEFORSCHUNG, 2019). In the course of this, a human rights-based, responsible and "institution-critical [Trans.]" (BAUMGARTINGER, 2014, p. 104; cf. among others ARN, 2017) research practice should be aimed at, which, among other things, addresses *societal power structures, discrimination and exclusion practices with regard to the phenomenon of so-called intellectual and/or multiple disabilities*, as well as the *creation of spaces for emancipation*, such as, for example, barrier-free access to social resources (e.g., education, work, housing) and the *realisation of inclusion in the community*, as well as the *implementation of the right to individual self-determination and participation* (cf. AKTIONSBÜNDNIS TEILHABEFORSCHUNG, 2019; MIETOLA et al., 2017).

These concerns must be reflected in the generation of research questions (cf. DGSA, 2019), the creation of research designs and the associated (interdisciplinary) practical implementation of research as well as the dissemination of results (cf. FACHBEREICHSTAG HEILPÄDAGOGIK, 2017). Qualitative social research that does not take these phenomena and conditions into account inevitably runs the risk of cementing categories of difference and stigmatizing notions of normality (cf. FINNERN & THIM, 2013). Taking these aspects into account, on the other hand, leads to research action that can be described as "critical reflexivity" **The DIFGB is committed to recognizing a critically reflective research attitude as a basic ethical principle.**

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<sup>3</sup> The term "able" refers to an ability orientation ("ability"). *Ableism* is associated with the hierarchization of (performance-related) abilities and an associated binary (privileged vs. nonprivileged) division of people into groups (e.g., people with and without disabilities) based on "the assessment (...) of their physical, mental and psychological abilities and functions [Trans.]" (cf. MASKOS, 2015, n.p.)

## Reflection questions:

- For whose benefit is the research intended? (cf. DEDERICH, 2017a)
- Does the research purpose justify the planned research procedure?
- What "exploitation interests" are embedded in the research process? On whose behalf is research being conducted? (cf. DEDERICH, 2017b)
- Who was involved in the brainstorming and conception of the research project?
- Which political and social contexts influence the desired goal of research?
- "What is the significance of individual-psychological, institutional, familial, socioeconomic, cultural and other factors in explaining research questions and the interpretation of research findings? [Trans.]" (DEDERICH, 2017b, p. 37)

## Field of tension II: Field access

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The often-existing involvement of people with so-called mental and/or multiple disabilities in the system of integration assistance and the simultaneous exclusion from publicly accessible living spaces must be taken into account by researchers with regard to the design of so-called field access. The reality of life of the aforementioned persons currently takes place in various special worlds. This involvement and the associated relationships among relatives, professional participants and the group of people themselves can make access to research projects possible, but also explicitly impossible.

Field access usually takes place through *gatekeepers*, who paradoxically can also act as *gateclosers*. These gatekeepers are obliged to guarantee the right to participation and to protect the well-being of the people they care for within caring relationship constellations. On the one hand, researchers have the opportunity to involve people in their projects via gatekeepers who otherwise have little or no opportunity to participate in research due to the exclusivity of their life reality. On the other hand, organizational cultures inevitably create *asymmetrical relationship structures*. Inherent in them is a power imbalance of pre-assumptions and -prejudgments about (anticipated) abilities and inabilities. This is connected to consciously chosen practices of inclusion and exclusion, which have an impact on the interest in knowledge as well as on the *reproduction of the (in)visibility of certain realities of the life of people with so-called intellectual and/or multiple disabilities* (cf. among others BUCHNER, 2008; McDONALD et al., 2012; REINDERS, 2016).

## Reflection questions:

1. "How is access to the research field established? [Trans.]" (VON UNGER, 2014a, p. 21)

- What possibilities are there for making direct contact with potential participants?
- What are the opportunities and challenges of involving gatekeepers in relation to the research concern?
- How can alternative field access be created, for example if the research concerns are closely related to institutional contexts?

2. Who is selected in the course of the acquisition of potential participants? (cf. DEUTSCHE GESELLSCHAFT FÜR PFLEGEWISSENSCHAFTEN, n.d.)

- What inclusions and exclusions are produced in the selection of research participants?  
What reasons are given for these?

## Field of tension III: Informed consent

In the course of the participation of people (with so-called intellectual and/or multiple disabilities) in research projects, the need for informed consent is *indispensable and essential* (cf. among others ARN, 2017; DEDERICH, 2017a; FUCHS et al., 2010; GRAUMANN, 2013,2018; RAUS & STERCKX, 2018; SCHÄPER, 2018; VON UNGER, 2014a). "Informed consent serves to ensure that a fundamental right, namely the right to self-determination [...] [in research contexts] is respected [Trans.]" (FUCHS et al., 2010, p. 71). Potential participants must be informed comprehensively and transparently about the content and objectives, duration, possible consequences and risks, as well as about the procedure, data protection regulations, possibilities of revocation and forms of publication of results in a form accessible to them (cf. among others DGPS & BDP, 2005; FACHBEREICHSTAG HEILPÄDAGOGIK, 2017; GRAUMANN, 2018; RAT FÜR SOZIAL- UND WIRTSCHAFTSDATEN, 2017; WMA, as of 2019). Education about the areas of information just mentioned serves as the basis for a conscious and voluntary decision<sup>4</sup> for or against participation in a research project (cf. among others DEUTSCHE GESELLSCHAFT FÜR PFLEGEWISSENSCHAFTEN 2016; RAT FÜR SOZIAL- UND WIRTSCHAFTSDATEN, 2017).<sup>5</sup> This is always done against the backdrop of the protection of personal rights and the associated preservation of personal integrity, and ties in with the maxim of *informational self-determination*<sup>6</sup> (cf. among others DEDERICH, 2017a; DGS & BDS, 2014; FUCHS et al., 2010; RAT FÜR SOZIAL- UND

<sup>4</sup> To ensure that participation is truly voluntary, critical thought must be given to "subtle [...] forms of pressure that can influence the decision [...] [Trans.]" (FUCHS et al., 2010, p. 70). GRAUMANN (2013) refers here to the danger of manipulation through existing dependency relationships. "Thus, under certain circumstances, people with so-called mental disabilities, when asked by staff of the institution caring for them regarding participation in a study, may declare their willingness to be interviewed due to social desirability, although they are actually reluctant to do so [Trans.]" (BUCHNER, 2008, p. 519).

<sup>5</sup> In the course of the decision-making process, it must also be made clear that nonparticipation does not entail any negative consequences for the potential participants (cf. among others DEUTSCHE GESELLSCHAFT FÜR PFLEGEWISSENSCHAFTEN E.V., 2016; FUCHS et al., 2010).

<sup>6</sup> "The right to informational self-determination means that personal data may only be collected, processed and stored on the basis of a law or with the consent of the person concerned [Trans.]" (POELCHAU et al., 2015, p. 157).

WIRTSCHAFTSDATEN, 2017; WMA, as of 2019). Suitable ways must be found to enable potential participants to *understand* (cf. among others COONS & WATSON, 2013; SCHÄPER, 2018). Given this, the question of which concept of understanding and related practices of action are assumed must be fundamentally considered and critically reflected upon.

A strongly cognition-oriented concept of understanding — within which the focus is primarily on the intellectual capacity that the potential participants must prove in the run-up to the survey situation — must be viewed critically (cf. BROSANAN & FLYNN, 2019). Against the background of the existing socialization and living conditions, it might be assumed that people with so-called mental and/or multiple disabilities cannot be able to make free and self-determined decisions with the same self-evidence as adults without so-called (intellectual/multiple) disabilities (cf. GRAUMANN, 2013). However, this is not primarily due to possible cognitive impairments, but rather conditioned by, among other things, existing social and structural framework conditions as well as pedagogical-educational convictions.<sup>7</sup>

In the course of the discourse on informed consent, the constructs of capacity or incapacity to consent and related practices as well as the distribution and attribution of decision-making power are also controversially discussed. Specific personal characteristics, such as the definition of a certain age and the attribution of a diagnosis of mental disability, can sometimes lead to the (blanket) attribution of incapacity to consent (cf. SCHÄPER, 2018). However, this does not take into account the "diversity of individual developmental trajectories [Trans.]" (cf. SCHÄPER, 2018, p. 136) or the fact that the development of the capacity to consent can ultimately also be fundamentally shaped by situational conditions (cf. SCHÄPER, 2018). Furthermore, the question arises as to when people's decision-making capacity may be doubted (cf. BHAILÍS & FLYNN, 2019; SCHÄPER, 2018): The "presence [...] [or] absence of certain (above all cognitive) abilities [Trans.]" (SCHÄPER, 2018, p. 127) as a starting point for capacity or incapacity to consent is mentioned in the course of this as an assessment variable (cf. SCHÄPER, 2018). It is problematic that here the "understanding [...] of traditional consciousness-theoretical conceptions of autonomy is followed [Trans.]" (SCHÄPER, 2018, p. 137) and thus "personhood is tied to cognitive competences [Trans.]" (SCHÄPER, 2018, p. 137).<sup>8</sup>

Such a basic understanding is based on status- and capacity-oriented ascertainment practices and is to be viewed highly critically because it values consent (in)capacity as a person characteristic (cf. SCHÄPER, 2018). In this context, it must also be critically reflected that persons with so-called mental and/or multiple disabilities have to prove their mental capacity disproportionately more often than people to whom such a disability is

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<sup>7</sup> Existing socialization conditions and living conditions in which people with so called intellectual disabilities do not have the opportunity to express their needs and wishes for a long time have an impact on self-determined actions and (future) decision-making processes (cf. among others GRAUMANN, 2016; NIEDIECK, 2016; RAMCHARAN et al., 2009). "A lifetime of recurrent restrictive practices is likely to significantly affect the person's self-perception, their self-esteem, their capacity for independent decision-making and choice, as well as to leave its mark" (RAMCHARAN et al., 2009, p. 53f.). Therefore, the dilemma that people with so-called mental and/or severe disabilities have to prove their capacity to consent against the background of hurdling contextual factors (non-)experiences as well as structural and formal barriers has to be reflected critically.

<sup>8</sup> This attribution dynamic can be considered highly critical with regard to the group of people with so-called mental and/or multiple disabilities (cf. SCHÄPER, 2018).



not attributed (cf. BROSAN & FLYNN, 2019).<sup>9</sup> From this criticism arises the claim to understand capacity or incapacity to consent as a *relational concept*<sup>10</sup> (cf. SCHÄPER, 2018). The relational claim here must be characterized by a reflection of the (research) relationship structure and decision-making power. Decision-making power – specifically, regarding the determination of consent (in)capacity and (non-)participation in research – is primarily held by persons without experiences of disability (cf. BROSAN & FLYNN, 2019, p. 33). In order to counteract this culture of dominance and substitutive decision-making (cf. BHAILÍS & FLYNN, 2019), the approach of *supported decision-making* is proposed here, which is based on Article 12 of the UN CRPD and states that persons with disabilities should be supported, if necessary, in exercising their "legal capacity and ability to act [Trans.]" (NIEDIECK, 2016, p. 78) (cf. GRAUMANN, 2013,2016; NIEDIECK, 2016). SCHÄPER (2018), with reference to GRAUMANN and her concept of assisted freedom, proposes thinking of *consent fundamentally as an empowerment and enabling process*. Participation or nonparticipation should be elicited in a *dialogue-based clarification process* (= *on-going consent*) (cf. among others SCHÄPER, 2018; SIOUTI, 2018; VON UNGER, 2014a). In concrete terms, this means that (framework) conditions are created through which potential participants are empowered to make decisions for participation or nonparticipation in a process-oriented manner<sup>11</sup> (cf. among others BUCHNER, 2008; COONS & WATSON, 2013; DEDERICH, 2017a; FACHBEREICHSTAG HEILPÄDAGOGIK, 2017; SCHÄPER, 2018; SIOUTI, 2018; VON UNGER, 2014a).

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<sup>9</sup> The explanations presented on the construct of capacity or incapacity to consent and the associated reduction to the phenomenon of mental capacity as an important criterion for inclusion in research projects should be viewed highly critically. Therefore understanding is measured by cognitive capacity and thus inevitably produces exclusions on the basis of discriminatory demands on the group of people who, as a rule, cannot fulfill these due to the contextual conditions just mentioned. There is a danger of categorically excluding people who are considered "difficult to interview" from research projects. As a result, their perspectives and lifeworlds remain unconsidered in theory building and certain obstructive practices are reproduced (cf. FACHBEREICHSTAG HEILPÄDAGOGIK, 2017; MIETOLA, et al., 2017; SCHÄPER, 2018). The question arises as to how far such exclusion mechanisms *really* meet ethical requirements for safeguarding consent. At the same time, however, ways must be found to safeguard understanding in order to prevent the danger of people being persuaded to participate without being fully informed about the research project (cf. DEDERICH, 2017a).

With regard to the legal situation of people with so-called mental and/or multiple disabilities, there is often a lack of clarity or uncertainty, which leads to the assumption "that legal guardians [...] are authorized to give proxy consent and [...] researchers are obliged to obtain their consent ("proxy consent," FUCHS et al., 2010, p. 71) [Trans.]" (SCHÄPER, 2018, p. 140). Although the term "proxy consent" is defined by law, it must be pointed out that this ultimately only applies to a small group of researchers and only comes into play if there is a considerable danger to the lives of the potential participants. In the context of social research, as SCHÄPER (2018) points out, the aspect of the reservation of consent plays a subordinate role and is hardly conceivable due to the basic principles of research ethics, such as freedom from harm. If research projects pose a danger to potential participants, they should generally not be carried out (cf. SCHÄPER, 2018).

<sup>10</sup> Consent as a relational concept means that every decision-making process is dependent on relational relationships, and accordingly, successful decision-making is only possible on the basis of mutual recognition.

<sup>11</sup> In the sense of empowering consent, on the one hand, very practical ideas of realization, such as the individual adaptation of information material to the needs of the target group, play a role (cf. among others COONS & WATSON, 2013; DEDERICH, 2017a; McDONALD et al., 2015). Likewise, the idea of seeing consent more as a *process* as opposed to a static state seems profitable in order to address the complexity of the wealth of information to be conveyed. In this respect, informed consent can rather take the form of *ongoing consent* (cf. DEDERICH, 2017a; SCHÄPER, 2018).

"If necessary, the researcher has the task of readjusting procedures in the ongoing research process and to ensure the continuity of consent in an appropriate manner [Trans.]" (FACHBEREICHSTAG HEILPÄDAGOGIK, 2017, p. 5). Furthermore, ongoing consent can be used (with references to the aspect of no harm) as a strategy to counter the pressure to tell the story (especially with sensitive topics) and to open up *active possibilities of contradiction*.

## Reflection questions:

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| <ul style="list-style-type: none"><li>• What concept of "understanding" is assumed within the research project? (cf. BROSAN &amp; FLYNN, 2019)</li></ul>  |
| <ul style="list-style-type: none"><li>○ What inclusions or exclusions does the research project's underlying concept of "understanding?" produce?</li><li>○ How is understanding secured? (cf. DEDERICH, 2017a)</li><li>○ What alternatives to "classical forms" of understanding can be identified and applied?</li></ul>  |
| <ul style="list-style-type: none"><li>• What concept of "voluntariness" is the research project based on?</li></ul>   |
| <ul style="list-style-type: none"><li>○ How can it be ensured that the decision to participate in a research project is made independently (if necessary, by means of supported decision-making) by the research participants themselves? (cf. DEDERICH, 2017a)</li><li>○ "Did suggestive formulations lead to agreement (or disagreement)? Does the individual in question want to behave in line with expectations, please the researchers and be recognised? [Trans.]" (DEDERICH, 2017a, p. 6)</li></ul> |
| <ul style="list-style-type: none"><li>• "How is informed consent obtained from participants (verbally, in written form)? What information is communicated? What information is not communicated? How is it communicated? [Trans.]" (VON UNGER, 2014a, p. 21)</li><li>• Which practical measures can researchers create to at entire research process to grant the possibility of revocation and objection?</li></ul>  |
| <ul style="list-style-type: none"><li>○ How is it ensured that the wish for nonparticipation/exit from the research project is possible at any time?</li><li>○ How can a space be created for active possibilities of contradiction in the research process?</li></ul>  |

## Field of tension IV: Harmlessness and experience of stress

Another essential component of research ethics principles is the principle of harmlessness (cf. among others DEDERICH, 2017a). "The generation of new knowledge must never be placed above the rights and interests of the individual. The risks that may arise from research must be minimized as far as possible [Trans.]" (POELCHAU et al., 2015, p. 154; cf. also RAT FÜR SOZIAL- UND WIRTSCHAFTSDATEN, 2017). The inadequate assessment of the impacts<sup>12</sup> of research actions can cause negative consequences for all persons affected by the research process (including the researchers themselves) (cf. among others VON UNGER, 2014a,b). Researchers must therefore be sensitive to potential problems that may arise from research activities and deal with them responsibly (cf. among others DEUTSCHE GESELLSCHAFT FÜR PFLEGEWISSENSCHAFTEN, 2016; DFG & LEOPOLDINA,

<sup>12</sup> Depending on the respective research topic, researchers must be given the opportunity to attend specific training courses in order to be able to recognize dilemmas, risks and burdens in advance (cf. POELCHAU et al., 2015).

2014)<sup>13</sup>. Research projects that violate personal rights, pose a "threat to the health, life or safety of the person [involved] [Trans.]" (VON UNGER, 2014a, p. 29) and must be refrained from (cf. among others FACHBEREICHSTAG HEILPÄDAGOGIK, 2017). Particularly in research contexts, where the focus is on vulnerable groups of people, it is of great importance to anticipate possible (re)traumatization risks in advance and to define targeted measures to prevent or reduce possible risks and burdens (cf. DGSA, 2019; FRIETERS-REERMANN et al., 2019; GRAUMANN, 2018; DEUTSCHE GESELLSCHAFT FÜR PFLEGEWISSENSCHAFTEN, 2016).<sup>14</sup> However, it should be noted that taking into account the principle of harm avoidance/minimization must by no means mean that it is impossible to research certain sensitive topics (cf. VON UNGER, 2014b). A reflective assessment of possible burdens and risks is needed to avoid blanket reductions based on presumed vulnerabilities and associated stereotypical presumptions, so that a situation is not reached where certain groups of people are categorically excluded from certain thematic discourses and are not trusted to share anything about certain life situations and experiences (cf. DGSA, 2019; GRAUMANN, 2018).<sup>15</sup>

In particular, within qualitative social research, it must be ensured that potential participants are comprehensively informed in advance about possible risks that may arise during their involvement in the research process and afterwards. The guiding principle can therefore always be the claim to make "damage-limiting decisions [Trans.]" (VON UNGER, 2014a, p. 43).<sup>16</sup>

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<sup>13</sup> Possible stresses and risks must be identified and minimized in advance, and ways of dealing with them must be explored (cf. among others POELCHAU et al., 2015). Possible stressful experiences can arise, among other things, at the level of data collection (cf. GRAUMANN, 2018). It must therefore be "checked in advance whether comparable data are already available and sufficiently public and thus a replication that is not absolutely necessary can be avoided [Trans.]" (POELCHAU et al., 2015, p. 154).

Furthermore, the participants' privacy may be violated due to a lack of data protection (cf. GRAUMANN, 2018; VON UNGER, 2014a). In order to counter project-related stress on the part of the researchers, supervision accompanying the research can be planned and several staff positions can be deliberately scheduled for the realization of the research objective in order to enable team exchange (cf. VON UNGER, 2014b).

<sup>14</sup> On the part of the potential participants, for example, so-called "vulnerability profile[s] [Trans.]" (FACHBEREICHSTAG HEILPÄDAGOGIK, 2017, p. 8) can be created. Support options can also be planned to counter stressful situations. For example, specific follow-up talks and psychological support can be organized (in advance). Ultimately, however, the question always arises as to how far the researcher's area of responsibility extends. It must be taken into account that potential research participants sometimes have limited opportunities to organize themselves and to access support services.

<sup>15</sup> This paper is based on an anthropologically universal understanding of vulnerability. Vulnerability is not seen as a problem of certain marginalized persons who are often confronted with paternalistic practices. Rather, the focus is on the fact that it is more a structurally conditioned vulnerability and that everyone is affected by it, albeit to varying degrees (cf. among others ALDRIDGE, 2014; STÖHR et al., 2019).

<sup>16</sup> Since researchers can ultimately only anticipate risks and burdens to a certain extent in advance, it also appears significant that they "can make decisions and/or moderate decision-making processes in ethical conflict situations [Trans.]" (FACHBEREICHSTAG HEILPÄDAGOGIK, 2017, p. 8).

## Reflection questions:

- What are the potential risks and burdens of the research project? (cf. among others DEUTSCHE GESELLSCHAFT FÜR PFLEGEWISSENSCHAFTEN, 2016)
- How can the risk of research participants being harmed be avoided? (cf. VON UNGER, 2014b)
- How can potential risks and burdens be responsibly countered? (cf. DEDERICH, 2017a; DEUTSCHE GESELLSCHAFT FÜR PFLEGEWISSENSCHAFTEN, n.d.; VON UNGER, 2014a)
- What precautions are taken to deal with unpredictability? (cf. among others FACHBEREICHSTAG HEILPÄDAGOGIK, 2017; FRIETERS-REERMANN et al., 2019; VON UNGER 2014a)
- How can all persons involved in the research project be informed transparently about possible risks and burdens?
- How can acute stressful experiences be dealt with in the course of survey situations?

## Field of tension V: Design of the survey situation

Every data collection situation in research projects is bound to the places and spaces corresponding to its concern, which have specific interaction events, relationship structures and power processes inherent in them. These in turn fundamentally influence findings that emerge in these contexts. Spaces and places are by nature not neutral, but always enriched with individual meanings and experiences, which in turn make (potential) statements possible or impossible. This not only affects the participants, but also the actions of the researchers. Researchers can adjust to the nature of the external and internal conditions of the survey situation. At the same time, however, there is a risk of bias, which can have a negative influence on the way encounters are organized. Assumptions that point to a possible/potential future research situation, necessarily shape attitudes, expectations and associated procedures in the process of discovery. An awareness of these connections is therefore indispensable.

Empirical social research always represents a *social interaction process*.<sup>17</sup> The establishment or termination of (research) relationships is an essential part of this (cf. DEDERICH, 2017a; KÜHNER 2018). On the one hand, researchers are obliged to maintain a professional distance; on the other, communication about highly personal topics requires an atmosphere of trust. The resulting relationships are always *temporary*. One challenge that arises in the course of this is the question of how to deal with prevailing biographies of relationship breakdowns and the high degree of involvement in professional relationship structures. In this context, researchers can quickly become a projection screen for unfulfilled relationship desires (cf. among others FRIETERS-REERMANN et al., 2019). To prevent these expectations, a closeness is needed that must be

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<sup>17</sup>In this context, DEDERICH (2017a) speaks of "act[s] of research as interventions [Trans.]" (p. 5). With reference to SCHNELL and HEINRITZ (2006), he mentions that "research [...] is more than a neutral observing, measuring or inquiring, [but rather an] "entry into a form of life [Trans.]" (p. 20) in which the researcher may encounter more "than he or she wants to know, should know and may [Trans.]" (SCHNELL & HEINRITZ, 2006, p. 20). Therefore, it is a central question of research ethics "how the researcher confronts the subject and takes a situational interest in him [Trans.]" (SCHNELL & HEINRITZ, 2006 cited in DEDERICH, 2017, p. 5).

professionally reflected. This requires honest and transparent communication about the researcher's concerns and role in the encounter with the participants (cf. among others BUCHNER, 2008).

Specific methodological approaches are always needed to realize research concerns. In the field of discourse around the group of people with so-called mental and/or multiple disabilities, pure access to classical methods of empirical social research can be considered critical. There is a danger of anticipating the illusion of a general research subject in the course of method development, which is transferable in its characteristics to all potential participants. However, this leaves out the *actual diversity* of the participants. Not taking these differences into account inevitably leads to the exclusion of certain people and their voices<sup>18</sup> in the discourse to be researched.<sup>19</sup> Therefore, in order to explore the research question(s), multimethod approaches must be chosen, which are oriented towards the respective individual needs of the participants. (cf. among others Aldridge, 2014; COONS & WATSON, 2013). This research ethics requirement also gives rise to the task of developing unconventional and innovative research methods and positioning oneself critically vis-à-vis traditional methodological discourses (cf. SCHUPPENER, 2019).

## Reflection questions:

- What (creative) research methods are needed to ensure that all potential participants have barrier-free access to the survey situation? (cf. SCHUPPENER, 2019)
- What prior information about potential participants is necessary (and why)?
- What is the relationship between research concerns and the places or spaces of the survey situation?
- How do we meet the challenges with regard to the organization of research relationships?
- What kind of encounter(s) are needed to build trust and allow participants a space to share?
- What (in)visibilities does the research methodology used (re)produce? (cf. DEDERICH, 2017b)

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<sup>18</sup> The relevance of the role of deputization and the associated problems will have to be discussed in more detail elsewhere.

<sup>19</sup> In their article on "research ethical and methodological challenges [...] [of] research in the context of education and migration [Trans.]" (p. 195), FRIETERS-REERMANN et al. (2019) refer to a "[s]ensible approach to language and expression barriers [Trans.]" (p. 202). They take a look at the problematic nature of language-focused survey methods and advocate the view that "language problem[s] are not [primarily] to be located with the respondents [...] [Trans.]" (p. 202), "but [rather] lie with the researchers [and their] often [...] poorly developed knowledge of foreign languages in relation to the first languages of immigrants and their forms of expression [Trans.]" (p. 202). Survey situations that are (exclusively) verbal-language can be very barrier-filled: For example, the interviewees can only inadequately present their views due to language and expression barriers (cf. FRIETERS-REERMANN et al., 2019). In addition, this reproduces, among other things, the "competence and dominance gap between researchers and interviewees [Trans.]" (FRIETERS-REERMANN et al., 2019, p. 202). The adaptation of survey methods to individual communication needs is fundamental. The "increased consideration of nonverbal forms of data collection [Trans.]" (FRIETERS-REERMANN et al., 2019, p. 202) enables access with fewer barriers (cf. MIETOLA et al., 2017).

## Field of tension VI: Data protection

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In the course of research processes, legal and institutional data protection regulations must be taken into account (cf. among others DEUTSCHE GESELLSCHAFT FÜR PFLEGEWISSENSCHAFTEN, 2016; RAT FÜR SOZIAL- UND WIRTSCHAFTSDATEN, 2017). In this context, the secure storage and processing of personal data and confidential information must be guaranteed (cf. among others DEDERICH, 2017a; RAT FÜR SOZIAL- UND WIRTSCHAFTSDATEN, 2017). An important dimension here is the process of anonymization, which should be understood as an act of masking the identities of the research participants in order to protect their personal rights and the associated integrity of the same (cf. among others BAUMGARTINGER, 2014; DEUTSCHE GESELLSCHAFT FÜR PFLEGEWISSENSCHAFTEN, n.d.; RAT FÜR SOZIAL- UND WIRTSCHAFTSDATEN 2017; VON UNGER, 2014a). "In qualitative social research, however, special challenges arise in anonymization due to the special nature of the data [Trans.]" (VON UNGER, 2014, p. 25). On the one hand, these challenges become apparent in the tension between granting (comprehensive) anonymity and the simultaneous significance of contextuality and contextualizations in the course of data evaluation (cf. VON UNGER, 2014). On the other, they become visible in the choice of research methodological design. "[...] When ethnographic field research involves in-depth descriptions or when experts are interviewed who have a special, possibly even unique expertise, deleting or replacing names of persons and places with pseudonyms is not sufficient to prevent inferences about places, institutions and persons [Trans.]" (VON UNGER, 2014, p. 25). In the case of biographical-narrative interview studies, there is a risk that "due to [the present] nature and context density [of the interviews], in spite of careful anonymization, inference about the person is possible [Trans.]" (VON UNGER, 2018 cited in SIOUTI, 2018, p. 7).

The demand for anonymization or pseudonymization is also made more difficult by the frequent field access via *gatekeepers* (see Field of Tension II). In addition, in the life contexts of people with so-called mental and/or multiple disabilities, there is often a degree of overbureaucratization. Biographical details are collected excessively and documented in files. They are accessible to various professionals. In the course of publishing research results, this aspect must be taken into account in order to avoid drawing conclusions about individuals and the possible consequences. In the case of the involvement of caregivers, it must also be explicitly pointed out that they are also subject to the obligation of confidentiality. Furthermore, it is important to critically reflect on possible *limits of the anonymization process* and to seek an open and transparent dialogue about this with the research participants (cf. DGSA, 2019). In addition, BAUMGARTINGER (2014) points out the aspect – about which, so far, there has been very little discussion – that transcription and anonymization processes can or should already be seen as initial analyses and interpretation steps (cf. BAUMGARTINGER, 2014). Deciding on a transcription and anonymization strategy always involves decisions for or against a certain procedure – for or against writing down certain aspects. For example, selection decisions (e.g. in the case of video data = the selection of video excerpts for an analysis) are always made "on the basis of contextualized, social knowledge, in which social evaluations and hierarchizations play an important role [Trans.]"

(BAUMGARTINGER, 2014, p. 107).<sup>20</sup> Anonymization and transcription as a "situated, social and political practice [Trans.]" (BAUMGARTINGER, 2014, p. 106) should therefore be consciously reflected upon.

## Reflection questions:

- Which sociodemographic data are relevant for research? Which are not?
- Which anonymization strategies are chosen? (cf. DEUTSCHE GESELLSCHAFT FÜR PFLLEGEWISSENSCHAFTEN n.d.; VON UNGER 2014a)
  - How should personal and biographical data relevant for the interpretation of the research results be handled? (cf. BAUMGARTINGER, 2014; SIOUTI, 2018)
  - "How are gendered, racialized, ethnicized connotations taken into account? [Trans.]" (Baumgartinger, 2014, p. 108)
  - How can anonymization be guaranteed when gatekeeping involves people whose identity and biographical details are known to third parties and this can lead to possible disadvantages for the persons involved in the research?
- How should information relevant to criminal law<sup>21</sup> be handled?
- How do researchers deal with the tension between duty of care and data protection? To whom do you feel obliged?

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<sup>20</sup> Language is consciously seen as a powerful instrument that can reproduce social (prestige) hierarchies in the form in which they are shaped (cf. BAUMGARTINGER, 2014). In light of this, the examination of anonymization strategies, which take into account the "social context in which [...] they take place [Trans.]" (BAUMGARTINGER, 2014), appears to be an important issue. "Anonymized text passages thus not only represent a linguistic event, but are above all an interpretation and can decisively change the analysis [Trans.]" (BAUMGARTINGER, 2014, n.p.).

<sup>21</sup> The disclosure of criminal offences that may have affected interviewees themselves may mean that the "anonymity/pseudonymization cannot be maintained [Trans.]" (POELCHAU et al., 2015, p. 156). It therefore seems important to deal with the legal provision and options for action in advance when conducting research in subject areas in which there is a foreseeable risk of being confronted with criminal offences (cf. POELCHAU et al., 2015). In this context, it must be considered at what point a law enforcement agency should be involved and how the procedure must be designed with regard to the person concerned (cf. POELCHAU et al., 2015). "Before possible interventions, the procedure should always be discussed and documented in the research group with the involvement of the leadership. The affected children or young people [as well as adults] should usually be included in these clarifications. If the situation cannot be clarified in this way, an expert counseling institution should be contacted at short notice. In case of imminent danger, action must be taken in accordance with the legal requirements [Trans.]" (POELCHAU et al., 2015, n.p.). Unless there is an acute danger for the potential participants of the study, it must always be critically weighed up to what extent it is "in the interest of the person concerned [...]" but also sensible not to inform the authorities or other agencies [Trans.]" (POELCHAU et al., 2015, p. 158). It makes sense to contact possible counseling centers or other specifically supporting institutions in advance of the study (cf. POELCHAU et al., 2015).

## Field of tension VII: Evaluation and results

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Both the processes of evaluation and the interpretation of research results in the context of qualitative social research can only take place in consideration of their specific context. This means that linguistic/non linguistic utterances, actions and their individual meaning are to be understood exclusively under the social, biographical and interactional circumstances in which they occur.

"The life situation of people with disabilities is always the result of the interaction between individual possibilities and social conditions. The complex set of conditions must be taken into account in research projects so that individual attribution and labeling effects are not repeated in research without reflection [Trans.]" (FACHBEREICHSTAG HEILPÄDAGOGIK, 2017, p. 7)

DEDERICH points out that it is part of the ethical responsibility of researchers to "ethically reflect on the potential consequences of the dissemination of specific knowledge and its application [Trans.]" (DEDERICH, 2017a, p. 5; cf. among others MIETOLA et al., 2017).

The position paper on the UNCRPD by the FACHBEREICHSTAG HEILPÄDAGOGIK (2017) also emphasizes: "No research is without preconditions. However, it is all the more necessary to reflect on the underlying assumptions of one's own research as well as the scope of the methods used in each case and to constantly question their appropriateness to the subject matter [Trans.]" (FACHBEREICHSTAG HEILPÄDAGOGIK, 2017, p. 2). It is also necessary that the participants in the research have access to the results. Results must be presented in such a way that the participants can understand them (cf. among others ALDRIDGE, 2014).

### Reflection questions:

- Who learns about the results? For whom are they processed and how? (cf. DEDERICH, 2017b)
- Who benefits from the results?
- What negative effects can the results trigger? Is there a risk of instrumentalization? (cf. RAT FÜR SOZIAL- UND WIRTSCHAFTSDATEN, 2017)
- "How do researchers behave towards the wishes and demands of participants with regard to the presentation of results?" (VON UNGER, 2014a, p. 22)
- "How do researchers respond when participants object to publication of results that show them in a negative light? [Trans.]" (VON UNGER, 2014a, p. 22)
- "Are there contextual factors that are considered particularly relevant and that lead to framing a research in terms of, for example, institutional theory, social psychology or social theory? If so: why exactly these? [Trans.]" (DEDERICH, 2017b, p. 37)
- "How should researchers deal with data that they have received 'in confidence' or after switching off the recording device were communicated? [Trans.]" (VON UNGER, 2014a, p. 22)



## Résumé: Research ethics self-conception

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In the current discourse of qualitative social research, representatives of various research attitudes/disciplines critically question the exaggeration of the quality criterion of *objectivity*. In this context, among others BREHM and KUHLMANN (2018), BREUER et al. (2019) and VON UNGER (2014a) point out that the subjectivity of researchers is not only unavoidable, but can also be of particular importance (VON UNGER, 2014a, p. 23). To realize this claim, a "critical, self-reflexive practice [Trans.]" (VON UNGER, 2014a, p. 21) is necessary (cf. among others BAUMGARTINGER, 2014; DEUTSCHE GESELLSCHAFT FÜR PFLEGEWISSENSCHAFTEN, 2016; FRIETERS-REERMANN et al., 2019).

In the methods literature, reflexivity is discussed in particular against the background of epistemological foundations of knowledge processes and with a view to the quality of the results. [...] However, practiced reflexivity can fulfil another function: It can contribute to reflecting on research ethical problems in the practical research process and to developing solutions [Trans.]. (VON UNGER, 2014a, p. 24)

The development of *reflexivity as a basic scientific attitude*, which does not deny the researchers' *involvement* in social structures of domination but consciously includes them, must be regarded as a *maxim for research ethics* (cf. among others BAUMGARTINGER, 2014; BREHM & KUHLMANN, 2018). For this, systematic reflection on the experience of researchers, their socialization and their subjectivity are indispensable (cf. BREUER, 2019). Insofar as researchers anticipate (critical) qualitative social research, they must make their specific self-understanding explicit in the sense of a *reflected subjectivity*. This is done primarily by making visible the constituent subjective role of researchers, their positioning and their individual perspective (cf. among others DEDERICH, 2017b). This process of reflection must become an essential part of the entire research process (cf. MIETOLA et al., 2017; SCHUPPENER, 2019).

Furthermore, insofar as their research is based on a process of social interaction, researchers constitute a specific counterpart relevant to their research project. In this relationship, the dichotomy between sameness and difference becomes clear and shapes the view of one's own and the respective "Other" (cf. BREUER et al., 2019). The associated assumptions about human nature determine every phase of the research process.

Often, a particular conception of the subject is set as universal and present. As a rule, this conception of the subject is characterized by qualities such as heteronormativity, rationality, self-determination, verbal communication skills, reflectivity and autonomy. Through this setting, hegemonies, hierarchies and exclusions are (re-)produced, as a result of which the overall social relations of inequality remain. However, these attribution practices are usually hidden (cf. BREUER et al., 2019; BUCHNER, 2008). In order to enable an active approach to them, they must be uncovered and made workable, so that a critical examination of one's own socialization-related imprints and scientific cognitive interests becomes possible.

In all of this, we consider the **(political) self-positioning** and the **critical reflection of individual assumptions about the human being** (cf. among others BREUER et al., 2019; DEDERICH, 2017a,b) vis-à-vis the group of people with so-called intellectual and/or multiple disabilities as an essential necessity in the design of research processes. This always takes place against the background of the cultural (re)production of normality and

difference, whereby "disability is not understood as a personal fate, but as a situation or social event, as the result of interactions between various environmental conditions and impairments [Trans.]" (AKTIONSBÜNDNIS TEILHABEFORSCHUNG, 2019, n.p.). In this context, research is faced with the task of producing insights from the point of view of the subject and critically reflecting on them,<sup>22</sup> placing them in the context of one's own involvement in the (re)production of relations of inequality and at the same time remaining capable of acting within these structures in order to oppose them with resistance and opposition.

Even the conscious decision for a specific research concern as well as the generation of concrete questions represents a fundamental ethical dimension, as every research context is shaped by specific value attitudes (cf. DEDERICH, 2017a; FACHBEREICHSTAG HEILPÄDAGOGIK, 2017).

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<sup>22</sup> This also involves continuous and critical self-reflection in the various phases of the research project (cf. among others MIETOLA et al., 2017; SIOUTI, 2018). "This reflection encompasses both one's own situatedness and activities as a researcher as well as the material, the results and their effects on a hierarchically structured social system [Trans.]" (BAUMGARTINGER, 2014, p. 101).

## Comprehensive reflection questions:

- "How can researchers continuously reflect on their own privileges and positions in relation to the research project? [Trans.]" (FRIETERS-REERMANN et al., 2019, p. 201)
  - "How can an open and transparent approach to existing dominance and power relations be made possible? [Trans.]" (FRIETERS-REERMANN et al., 2019, p. 201)
  - "How can the whole research setting be designed in such a way that existing dominance and power relations are reduced? [Trans.]" (FRIETERS-REERMANN et al., 2019, p. 201)
- What values underlie the research concern/question? (cf. DEDERICH, 2017a,b)
- What are the political implications of the research project? (cf. among others DEDERICH, 2017a)
- How do researchers define, communicate and negotiate their concern and role in the research field? (VON UNGER, 2014)
- What position<sup>23</sup> do researchers take on the phenomenon of 'disability'<sup>24</sup>? (cf. DEDERICH, 2017a,b)
- What significance is attributed to individual (medical or psychological) factors? (cf. DEDERICH, 2017b)
- How do the institutional context of the research work and the research itself contribute to the reification of disability? (cf. DEDERICH, 2017b, FINNERN & THIM, 2013)
- How are "research questions and [...] [research methodology] integrated into the constitution of the object, into the production, consolidation, questioning, critique and transformation of disability? [Trans.]" (DEDERICH, 2017b, p. 38)

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<sup>23</sup> Likewise, a "sensitive handling of [categories and terms relevant to the research process] [Trans.]" (FRIETERS-REERMANN et al., 2019, p. 197) is necessary. In this regard, FRIETERS-REERMANN et al. suggest the following further reflection questions: "Which terms and categories are used in the research process, by whom and how? How are the respective categories generated and how is the use of terms justified? How can a sensitive and reflexive approach to the categorization dilemma be continuously facilitated in the research process? How can the research partners be involved in the generation of categories? How can the research partners be taken into account as experts of their life realities in the critical reflection of attributions by others and self-descriptions? [Trans.]" (S. 198).

<sup>24</sup> FRIETERS-REERMANN et al. (2019) list the following supplementary questions in relation to a "sensitive handling of attributions and basic assumptions [Trans.]" (p. 200): "Which attributions and basic assumptions implicitly or explicitly underlie the research process? Which attributions and basic assumptions guide the actions of the actors involved in the research process? How can a critical reflection with attributions and basic assumptions in the research process be made possible on an ongoing basis? [Trans.]" (S. 200).

## Codes and guidelines

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# DIFGB

Deutsche Interdisziplinäre Gesellschaft zur Förderung der Forschung für  
Menschen mit geistiger Behinderung e.V.

German Interdisciplinary Society for the Promotion of Research for  
People with Intellectual Disabilities e.V.

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## Aims of the DIFGB

DIFGB's mission is to promote interdisciplinary research for the benefit of people with intellectual disabilities and to make research results useful for science and for living together in social integration. In doing so, it is committed to scientific standards and the preservation of human dignity.

## Priority tasks of the DIFGB

- Institutional anchoring of research for people with intellectual disabilities, especially in higher education.
- Enforcement of society's concerns in research policy and research funding
- Initiation, coordination and support of research projects
- Promotion of interdisciplinary cooperation
- Development and dissemination of positions on ethical issues
- Dissemination of research results into everyday areas of life, society and politics
- Cooperation with associations and organisations as well as institutions of education, further education and training
- Promoting international cooperation in the field of research for people with intellectual disabilities
- Organisation of scientific events
- Promotion of young scientists and scholars