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## **Characteristics of Studies in an Environment of Persons with Intellectual Disability—Ethical and Methodological Deliberations**

*Abstract:* The purpose of the article is to show the difficulties that are encountered by a researcher dealing with the problems of persons with intellectual disability. The article stresses some notions related to ontological and epistemological issues, the source of which are questions about the possibilities and manner of exploring mental handicap. They refer not only to the broadly-understood problems of handicap and the methodological consequences of identifications, but also the manner of diagnosis and analysis that are characteristic of particular fields of science. The article raises the notions related to a field researcher's workshop, difficulties in data acquisition, the emotional context of exploring the environment of persons with disabilities, as well as the ethical and moral dilemmas that provide an indispensable element of such a research undertaking.

*Keywords:* intellectual disability, field studies, methodological problems, ethical dilemmas.

### **Introduction**

A person interested in the problems of intellectual disability becomes forced to tackle various difficulties that appear at almost every stage of research work. Each research phase, including the field exploration related to the acquisition of empirical data, poses a kind of challenge. The environment of persons with intellectual disability is a specific field of research, requiring a flexible approach and an adjustment of the research strategy to the cognitive and perceptive abilities of those with intellectual disability. Therefore, a person who undertakes research on this group of people is expected to be especially sensitive, have cognitive skills and an appropriate methodological workshop, and must be technically prepared (having research skills and professional experience, but also “simple” preparation related to equipment, such as a good voice recorder). At the same time, such a researcher should be fully aware of the awaiting difficulties as well as the character and specificity of the environment of persons with disability. Only such an attitude and full thoughtfulness can bring fruits in the form of adequately and reliably performed studies. However, this specificity and uniqueness of this environment mean that a researcher can never be fully certain of the results of their undertaking. These difficulties, when combined with the uncertainty of the final result of the project, render research into persons with intellectual disability not only risky but also demanding.

Hence, the purpose of the article is to show some difficulties that are encountered by a researcher dealing with the problems of persons with intellectual disability. In the article,

I attempt to answer two main research questions: (1) what should be researched while taking into account the problems of defining the notion of intellectual disability?; (2) how can one carry out research, while designing and later performing the research in the environment of persons with an intellectual disability?

The presented notions result, on the one hand, from studies of the literature of the subject, and on the other, they derive from the author's personal experiences, the basis of which was research carried out on the order of interactions between the personnel and the wards in a social welfare home for individuals with intellectual disability.

### **What to Research, i.e. Some Problems in Defining the Notion of Intellectual Disability**

A researcher that plans to carry out a research project related to persons with intellectual disability encounters some significant difficulties regarding the notion of intellectual disability itself at the very beginning, i.e. at the conceptual stage. There are numerous definitions that vary in terms of law and content, which along with the assumed cognitive perspective focus on a different scope of meaning.

Currently, the manner of grasping intellectual disability is a result of the heritage left by researchers who dealt with the problems of intellectual disability in previous years. There has been a significant change in this scope, reflecting the significant evolution towards a social model of intellectual disability within which strong emphasis is put on the self-judgment, emancipation, and empowerment of people with various limitations in capability (Wiliński 2010: 56). It is also worth stressing that Polish sociologists have done a lot to change the scientific paradigm of intellectual disability, constructing and promoting a new and inclusive approach to this category of disabled individuals. They also advocated the social model of intellectual disability, at the same time recording an evolution of social attitudes towards people with disability. Here, it is worth mentioning such names as: Anna Firkowska-Mankiewicz (1993: 37–40), Krystyna Mrugalska (1995: 70–72), Elżbieta Zakrzewska-Manterys (2010: 181–184), Antonina Ostrowska (2013: 14–16, 82–88), Marian Anasz (2012: 23–24), Barbara Gąciarz (2014: 19–21), as well as many others distinguished researchers whose heritage contributes to the embedding of the emancipation disability model both in science and society.

In order to comprehend the specificity of defining and raising notions related to intellectual disability better, it is worth referring to the rich history and genesis of the shaping of researchers' views in this scope. The evolution of defining intellectual disability is connected with the gradual broadening of the description of notions that define intellectual disability.

Emil Kraepelin, one of the first researchers and creators of contemporary science on intellectual disability, used the term *oligophrenia*<sup>1</sup> to refer to the distortion of general mental

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<sup>1</sup> The notion of oligophrenia applied in this context is a classical definition, which currently has another, broader form. Nowadays, one department of special pedagogics which takes care of notions of intellectual disability is called oligophrenopedagogy (from Greek *oligos* = reduced, *phren* = mind, meaning reduced, decreased mind capability) (Wyczęsany 1998: 13).

development conditioned by organic factors. In terms of clinical image and morphology, this term combined various distortions whose common feature was specific qualities which differentiated them from retardation of general mental development arising as a result of sickness (Sękowska 1982: 146; Wyczęsany 1998: 19; Janiszewska-Nieścioruk 2006: 36). Gradually, under the influence of the comprehension of intelligence, a change in the manner of understanding oligophrenia took place. From defects of the brain structure, the stress was focused on pointing to various deficits of cognitive abilities, exacerbated to various degrees. This led to a revision of previous views on the phenomenon of intellectual disability, which formally resulted in replacing the term “oligophrenia” with “mental retardation” (Wyczęsany 1998: 21–22). Acceptance of the developmental approach supported the consideration of intellectual disability in a broader context, taking into account, apart from intelligence, the level of social adjustment and various personal features. This, in turn, influenced the spread of the concept combining disturbances in intellectual development with social and cultural conditions (cf. Barnes 1997; Albrecht, Seelman and Bury 2001; Brueggemann 2013). Broadening the spectrum of those reasons caused further transformations in how intellectual disability is perceived, and acceptance of its new terms — *mental handicap* (Janiszewska-Nieścioruk 2006: 39).

Currently, the classical manner of embracing intellectual disability is based on two central concepts. The first one, *etiologic*, suggests that intellectual disability is a condition characterized by an individual’s lowered developmental possibilities, especially in the scope of intellectual efficiency, caused by irreversible pathological changes emerging during the initial stages of the development of the central nervous system, or by factors of a social and cultural nature. The second concept, so-called *symptomatic*, treats the intellectual disability in a broader manner, referring to its symptoms, and not only to etiologically determined cases. Here, the stress is put on the character of retardation, pointing out that it is not necessarily a permanent condition, but one that can undergo changes in certain circumstances. This is a result of the accepted dualism of reasons, as apart from organic pathologies of the brain, there were also social and cultural reasons differentiated (educational deficiencies and shortcomings). It was also emphasized that ontogenic dysfunctions—intellectual disability—are decided by the level of adjustment to life, achieved through education and rehabilitation (Ferguson and Nusbaum 2012: 71–72).

There are various detailing criteria and classifications that group the definitions of intellectual disability, constructed on the basis of cause and symptomatic concepts. Therefore, there are biological-pathoneurological-medical (clinical-medical) definitions based on etiology and pathogenesis (Sękowska 1982: 146); and behavioral (psychological-social) definitions, characterizing the intellectual disability from the angle of psychiatric processes and the vulnerability of people suffering from it to revalidation and legal-administrative influence based on a practical criterion (Janiszewska-Nieścioruk 2006: 45–47).<sup>2</sup> Initially, the first group of definitions included such criteria as: type of etiological factors, time of in-

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<sup>2</sup> It is worth highlighting that Zofia Sękowska (1998: 215–217) introduces here a division into the following definitions: biological-pathoneurological-medical (medical), treating mental handicap as a symptom of the process of a medical condition, and psychological-pedagogical-social definitions, according to which the intellectual disability means a lack of, or worse ability in adjusting to social life as a result of the intellect functioning lower than average.

fluence of the harmful factors, symptomatic syndromes, treatment, or prognosis. Currently, the above-mentioned list is expanded with somatic, neurological, or biochemical issues.<sup>3</sup> The second group of definitions corresponds, first of all, with an evaluation of the depth of the disability, and it was initially based on three main criteria: an evaluation of results in school education, intelligence, and biological and sociological adjustment. Now, the scope of those criteria has been broadened and systematized, introducing a division into psychological, pedagogical, social, and evolutionary criteria (Barnes 1997: 11). The psychological criteria take the following processes into account: orientation-cognition, intellectual, emotional, motivational, as well as mechanisms of control and executive processes. In turn, the pedagogical criterion refers to the degree of ability to acquire knowledge and skills included in the curriculum. It also includes characteristics of difficulties in school education, as well as the pace of learning, at the same time dividing people into uneducated individuals, almost educated individuals, people who it is possible to educate but who are not teachable, and individuals that can be taught (Sękowska 1982, 1998). When it comes to social criteria, there is consideration of the general life resourcefulness of an individual, independence, responsibility and socialization. In the last example of the above-mentioned group of definitions, the evolutionary criterion, “an intellectually disabled child is compared with a child that develops properly in the scope of orientation-cognitive, intellectual, emotional, motivational and executive actions” (Kostrzewski, Wald 1981: 72). Generally, behavioral classifications are connected with a trial assessment of a disability, and the degree of disability is measured on the basis of IQ.

The third and last group, the legal and administrative grasp of intellectual disability, is strictly connected with the provisions of the law, both at a domestic and international level. Its practical dimension consists in the fact that it not only defines and specifies the notion of intellectual disability, but it also determines the scope of entitlements and duties of a person with dysfunctions and of the other subjects who take part in the education, care or nursing of such individuals.

Another division of intellectual disability, which recognizes all previously pointed out research approaches and theoretical angles, is introduced by Stanisław Kowalik (1989), who differentiates some basic paradigmatic perspectives: psycho-biological, psycho-developmental and psychosocial. Within the psycho-biological approach, the reason for an intellectual disability is damage of the brain structures, which may appear in the prenatal, perinatal or postnatal period, up to 3 years of age. It also includes the handing over of an irregular general-species pattern of development or, at the genetic level, errors in handing over this pattern in the fetal period. In turn, the psycho-developmental concept highlights that intellectual disability is a result of failures in the development of an individual, and the biological pattern of development for such a person may only be realized by the proper influence of the external environment. In the third, psycho-social approach, intellectual disability is understood as a social and cultural fact. Here, intellectual disability is a product of a mechanism that allows one to remove less competent people from socially significant tasks; it also involves social labeling or ascribing the role of an intellectually

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<sup>3</sup> An example of classification of intellectual disability based on these criteria may be provided by psychiatric classification, according to which there is a determination of detailed forms of intellectual disability, among others: microcephaly, Hurler syndrome, or water on the brain.

disabled person. According to this concept, biological, genetic, and developmental factors play a secondary role towards the social and cultural patterns of requirements put forward to an individual, mandatory in a given environment (Albrecht, Seelman and Bury 2001: 171 and further).<sup>4</sup>

There is also a need to mention the achievements of the World Health Organization, which introduced the following ways of understanding the notion of disability (both in the intellectual and physical dimension), at the same time considering a person's health condition. They distinguish: impairment, meaning each loss of capability, or disorder in structure, or functioning of a body in psychological, psycho-physical or anatomical terms; disability, i.e. each limitation or inability (resulting from impairment) to live an active life in a way or scope assumed to be typical for a human; as well as limitations in playing social roles, meaning the handicap of a specific person resulting from impairment or disability, limiting or rendering it impossible to fully play a social role corresponding to his age, sex as well as social and cultural conditions.

Taking into account all of the above perspectives, concepts and detailed comparisons referring to intellectual disability, it may be stated that this notion is understood very broadly, both with regard to the differentiated levels of intellectual disability, and distortions of motor efficiency, distortions of behavior, motivation, emotionality or other types of dysfunctions that accompany them. In other words, intellectual disability refers, on the one hand, to the cognitive sphere of humans, and on the other, it covers the whole personality of an individual and the character of social perception of such a dysfunction, as well as the people struck by it (Sękowska 1982: 145). Determining what intellectual disability is and how it should be defined, and first of all determining its boundaries (what state of mind may be qualified as underdevelopment and what degree of disability is represented by a given case), is a highly difficult issue, which previously was presented depending on the historical, social, and individual circumstances. Furthermore, measurement of mental disability on the basis of the applied and widely spread methodologies of IQ (intelligence quotient) is subject to criticism with regard to the lack of reliability of the measuring tools used for this purpose (cf. Clarke, Clarke 1969). Elżbieta Zakrzewska-Manterys is critical of the idea and the measurement of intelligence quotient (2010: 67), suggesting that “the idea to describe someone through a formula, which consists in dividing developmental age by the life age, could arise only in the head of someone who cares for people less than for a scientific method.” The adoption of a strict classification criterion of intellectual disability is not only of doubtful value, but it is also dangerous, in the sense that it can only lead to *an illusion of the feeling of fidelity* (Clarke, Clarke 1969: 73). It needs to be kept in mind that intellectual disability is a social concept to some extent, dependent on the changeable “threshold of social tolerance, and its classification is discretionary out of necessity, which suggests that there is no system of division that could be exhausting or permanent” (*ibidem*: 74). On the other hand, for practical and administrative purposes, there is an array of categorizations of intellectual disability encountered, which in turn causes that the discretionary

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<sup>4</sup> A social context of disability was discussed in the International Classification of Functioning, Disability and Health—ICF, adopted during the World Health Assembly in 2001. This document highlights that disability refers to the whole population, and problems related to disability cannot be displaced to social minorities—each person may experience some degradation of their health and thus become disabled.

boundaries of the division need to be defined as clearly and objectively as possible. At the same time, it is worth remembering that notions that classify social phenomena cannot fully reflect the social reality, which is continuously constructed by the actors. This reality is changeable and dynamic, with regard to contexts and situations, therefore, avoiding “strict” and unambiguous definitions (Kumaniecka-Wiśniewska 2006: 94). Regarding the relatively fluid and polysemic nature of the notion of intellectual disability, it seems that it may be treated as a “sensitizing notion,” which only provides instructions and suggestions that relate to the manner in which given classifications and boundaries that categorize the disabled are socially determined and constructed (*ibidem*: 94).<sup>5</sup> The notion of intellectual disability functioning in a social space is therefore

not just a term describing a certain state of affairs, but also a notion, whose understanding incorporates values and evaluations, hidden postulates, camouflaged labeling. In other words, the discussed notion is entangled in the world of senses and meanings that are polysemic, imprecise and changeable in their nature, regarding time and circumstances (Zakrzewska-Manterys 1997: 26).

The multitude and variability of definitions within the scope of comprehending the notion of intellectual disability itself constitute only an introduction to the problems of intellectual disability which are rich and, at the same time, full of ambiguities. These differences emerge in numerous points, and they provide a source for both research inspirations and scientific investigations, but also, or maybe, first of all, the difficulties while undertaking research issues focused on studying this environment.

### **How to Research, i.e. Designing and Performing Research in the Environment of Persons with Intellectual Disability**

While designing research, a researcher is forced to make numerous crucial decisions, the consequences of which will exert a significant influence on the course of the whole research process. Each subsequent step is a reflection of what was previously done by the researcher, and which actions they undertook. The process itself must be fully reflexive, preceded by deep considerations that should include, among other things, such crucial notions as the research problem, the subject of the research, or the character and specificity of the explored environment. At the same time, the researcher becomes somehow entangled within a whole series of issues of a methodological, ontological, epistemological as well as ethical and moral significance. With regard to research carried out in the environment of disabled individuals, these issues would include the ambiguity of the notion of intellectual disability itself, and the related definition difficulties, problems obtaining information from the disabled themselves, and also the emotions experienced by the researcher influenced by life situations of the observed individuals. It would also refer to the emerging attachment to members of the research community, and the changes in the researcher’s perception resulting therefrom, as well as the ethical aspects of research and the problem with the researcher’s field exploration boundaries.

<sup>5</sup> The World Programme of Action for Disabled Persons and The Standard Rules on the Equalization of Opportunities for Persons with Disabilities stress that disability is a social problem, and it is not limited to a particular person. While talking about a disability, we think about the relationship between human health (considering their age, sex and education) and society and the environment that surrounds them.

### Linguistic Competences and Perception Level of the Respondents

Each research undertaking should be based on a deeply thought out strategy and appropriate method and techniques for data collection adjusted to that strategy and the researched problems. Furthermore, to obtain the best possible picture of a specific social phenomenon, and to ensure the quality of the research, the researcher should use various tools and techniques for data collection. They should complement each other, to strengthen the reliability of the results.

In the research into the institutional order of interactions in social welfare homes for persons with intellectual disability, the researcher made use of techniques of data collection such as participant observation, unstructured interview, and analysis of the existing data (Niedbalski 2013). Application of the above-mentioned tools for collecting empirical material was, on the one hand, dictated by the specificity of the researched environment, and on the other, by exploiting qualitative data—grounded theory methodology and ethnography (Konecki 2000; Silverman 2007; Angrosino 2010). In the context of research into persons with intellectual disability, the greatest difficulties emerged in making use of the interview, thus, this issue is most focused on.

When it comes to research in the environment of persons with disability, unstructured interviews were employed. Thanks to their flexibility and the possibility to adjust the conversation to the course of the utterances of the respondents, it enabled recognition of particular notions from the perspective of the personnel who represent various positions and professions. At the same time, the mentioned features were very important, as they allowed the researcher to pose questions freely and adjust them to the intellectual level and communication capabilities of the residents of the social welfare home who had some intellectual disability.

A crucial notion for the success of the interview is to establish a good rapport with the interviewee (Fatyga 1999: 155). This can be done through adjusting the language to the requirements of the interaction and avoiding a formalized or a repetitive manner of asking questions. This does not encourage the interviewee to form extended narration and may impose the researcher's perspective on the respondent (Rubin, Rubin 1997: 214; Konecki 2000: 169 and further; Charmaz 2006: 33; Charmaz 2009: 44). In some cases, it may turn out that the researcher, who wants to "speak" with the subjects, needs to face a difficult, surprising or untypical situation, or one which is "technically" problematic, which can be a common occurrence when researching persons with intellectual disability (Cytowska 2012: 153). The process of collecting the empirical data itself becomes a challenge. However, it does not result from the unwillingness of respondents to take part in the research, or from the difficulties in reaching a given community. Also, these difficulties do not refer to the small number of people who may take part in the research, but they are directly connected with the psycho-physical limitations of the intellectually disabled (Żyta 2011: 24). Although it is not a problem regarding only this group of subjects, this particular group may provide an extreme form.

While the source of the problems lies in the psycho-physical limitations of persons with disability, the effect of these limitations, apart from perceptive difficulties, embraces communication barriers, understood here as being unable to establish contact with the en-

vironment, react to stimuli, or express one's needs and opinions, etc. (Dowse 2009: 145; Niedbalski 2009: 207). As emphasized by Coons & Watson (2013: 17) "researchers often encounter numerous practical or methodological challenges while accepting qualitative research projects regarding persons with intellectual disabilities." One of the problems that the above-mentioned authors pay special attention to is communicating with this category of people to a degree which assures freedom of speech and at the same time comprehension of the opinions that they express.

These challenges may be considered on several levels. The first one regards the "technical" difficulty of using verbal or non-verbal speech for physiological reasons, e.g. because of body deformations, distortions of the vocal cords, or damage to particular parts of the brain responsible for speech (Minczakiewicz 2000: 68).

A second reason for communication limitations is provided by a partial lack of ability to use and recognize the symbolic sense of written and spoken symbols, as well as gestures and body language (see Smyczek, Szwiec 2000: 22–23).

A third reason for difficulties in communication is a limitation in the competences in the scope of abstractive thinking, preventing a reflexive position towards their own actions and behaviors and those of other individuals from their environment (Piszczek 2001: 2–5).

A problem in understanding a person with intellectual disability also arises from difficulties in interpreting this individual's behavior, which may be both a kind of communication bearing particular content and an expression of unintentional and uncontrolled stereotypes (Reichmann 2006: 4).

The ability to communicate with persons with intellectual disability and the possibility to understand them requires individual treatment, appropriate to the linguistic and communicational competences of the speaker (cf. Frankfort-Nachmias, Nachmias 2001: 225).

Taking the above-mentioned difficulties and the need for an individual approach towards the speakers into account, it becomes impossible to use research tools of a high level of standardization. This, in turn, forces the researcher to adopt a specific attitude and a proper strategy for conducting the research and collecting empirical materials; it is characterized by significant flexibility (cf. Silverman 2007: 53). This is a feature of the qualitative methods and techniques that the author adopted in his research into the institutional order in a social welfare home for persons with intellectual disability (Niedbalski 2013). As observed by Lloyd and others (2006: 1388), "the only way to attempt to grasp the perspective of persons with intellectual disability is to ask them to express it directly." The same authors (Lloyd et al. 2006: 1388) while striving for information about experiences of those people, concluded that the best way is to use such data collection techniques that allow the broadest expression possible, despite any linguistic or communication difficulties. It seems that it is most important to be able to adjust the research tools and techniques to the subjects of the research, not the other way around. Therefore, structured research tools are not appropriate here as they make it harder for the researcher to look at disability as a multi-dimensional phenomenon (Winogrodzka 2013). In other words, a researcher should, first of all, care about the reliability of the collected information and not just strictly follow the technical "standards" of the interview. *Technicalities* cannot prevail over realities, including the communication or perceptive capabilities of the respondents, not to mention such issues as their ability to utter and verbalize thoughts, which proved to be crucial in



the research carried out in the environment of persons with intellectual disability (Niedbalski 2013).

At the same time, the already mentioned positive aspects of making use of unstructured interviews will not eliminate the difficulties related to acquiring empirical data completely. Hence, researchers must be flexible when carrying out qualitative research with intellectually disabled individuals. It may prove necessary to use agents, mainly the closest staff members, who will not only provide support when dealing with disabled individuals but who can also often “interpret” the messages of their wards (Irvine 2010: 26). In order to minimize the potential impact of particular members of staff, various people should be asked for such support, so several perspectives can be obtained, thus eliminating any potential subjectivism of views. Flexibility is also necessary to provide the maximum involvement of those whose linguistic skills are limited (Lloyd et al., 2006: 1389). Such flexibility may be related to carrying out the interviews in an unconventional manner to allow the participants to provide answers in various ways. For example, participants who have problems with verbalizing their statements can answer questions via sign language or appropriate tools (specialist cards or computer programs). Researchers should also consider the possibility to formulate their questions in such a way so that they are capable of adjusting them to each participant, regarding their individual communication possibilities (Coons & Watson 2013: 20).

### Emotional Context of the Research

A notion that emerges in the situation of field research is not only what is included in the broadly-understood “technical” area, but also everything that refers to the sphere of emotions and affective involvement of both the researchers themselves and the respondents. These are notions that are, on the one hand, directly related to persons with intellectual disability, and on the other, to the researcher themselves, “exposed” to the strong emotional impact and the need to undertake arbitrary decisions of often ambiguous moral provenance. It has significant consequences within the whole research process and provides a subject of further deliberations.

A researcher “(...) needs to start to ‘absorb with his all body’ the reality at the cost of breaking their internal barrier of high emotional expenses (...)—a researcher loses their shield, in the form of their status as a scientist, completely” (Miszewski 2007: 54). The emotional engagement of a researcher poses a challenge, and to some extent a trial of his mental toughness. A scientist, while carrying out field research, encounters ambivalent feelings and ethically unclear situations on morally doubtful choices, which he needs to face (cf. Kacperczyk 1999: 124).

Krzysztof Konecki (2000: 152) devotes significant attention to the matters of a researcher’s emotions, referring to his own experiences collected within the course of field work. He writes that

a researcher often feels strong emotions during field work. He also often feels a barrier, isolation from the group that he observes. What is more, he may be a witness to violence, or somehow engaged in its application. Their behaviors then depend not on their research problems, but they are also an issue of an ethical decision. A researcher is also often accompanied by unwillingness, anger or sympathy towards the participants of the group that he observes (ibidem 2000: 152; c.f. Kacperczyk 1999: 109; Ostrowska 1997: 22).

A researcher personifies the social and cultural values of the environment that he originates from, i.e. including the knowledge of a professional-scientist gathered during his academic education (Frankfort-Nachmias, Nachmias 2001: 100). At the same time, according to the requirement of maintaining objectivism, the habitus of the observer, his views, and beliefs ought to have no influence on the research process (*ibidem* 2001: 79). A researcher needs to reject or hide his personal beliefs, sympathies and antipathies, as far as possible (*ibidem* 2001: 100; c.f. Babbie 2006: 528) in relation to the observed individuals. On the other hand, contact with representatives of an environment, which constituted an exploration area for him, always triggers some reactions in the researcher. It may be concern, revulsion or disgust (Konecki 2000: 152; Kacperczyk 1999: 109).

While conducting research in the environment of persons with intellectual disability, the author had the feeling of constant emotional tension. On the one hand, it was directly connected with the disability of the members of a given community triggering natural empathy. On the other, there were constant feelings of uncertainty and anxiety about himself as a presence among unknown individuals, with unidentified intentions, uncontrolled motor activity, and with whom there was often no direct contact. He felt disoriented and, in extreme cases, even in danger. This belief of the researcher regarding the offensive attitude of the intellectually disabled residents of the social welfare home was justified by common knowledge and common sense (although it turned out later to be wrong). It was additionally intensified by stories told by the staff when they mentioned hazardous situations which had happened to them personally or to other people from their surroundings.<sup>6</sup> The atmosphere of the relationships between the researcher and the intellectually disabled subjects was initially dominated by difficulties with properly ascribing intentions to the actions of the charges of the welfare center. The researcher encountered problems with properly comprehending symbols, gestures and other forms of communication of the persons with intellectual disability numerous times. This created situations of misunderstanding, at the same time bringing concern about real intentions of the interviewees. This, in turn, triggered a feeling of threat within the researcher, which was initially made visible through limiting direct contact with the disabled, both in the form of physical spatial presence and a psychological barrier, hindering any development of interpersonal relationships with these people. Therefore, one may agree with Freedman (2001: 130–131) that performing research with intellectually disabled individuals is a specific challenge, as the researcher is involved not only in substantial terms, but also emotionally and mentally.

Apart from difficulties arising from the emotional entanglement of the researcher performing the field research, the literature of the subject (Konecki 2000: 125 and further) emphasizes the significance and meaning of emotions for comprehending any nuances and phenomena of the environment which the researcher is eager to discover. A researcher who deals closely with the subjects has an opportunity to “put” himself into the situation of others. This provides him with the basis for a deeper interpretation and more accurate understanding of the events that take place in a given environment, and to discover the mechanisms that rule the behaviors of its participants (Ślęzak 2009a: 39). Therefore, a re-

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<sup>6</sup> Such actions of personnel posed a kind of folklore of the personnel society of the welfare home, and they were a form of testing every new team member (and I was regarded as such to some extent), playing an initiation function towards reactions of an employee and his mental toughness. (cf. Konecki 1992).

searcher obtains a possibility to adopt their emotions to interpret the observed phenomena, assuming that they probably feel the same that the respondents. “The emotions of the researcher-participant may point to what is important in the reality that they observe” (Konecki 2000: 154). A scientist that does not allow himself to feel any emotions, automatically distancing himself mentally from the people that are researched. Therefore, he is wasting an opportunity provided by direct contact with the studied representatives of a given environment (Chomczyński 2006: 73; Janiszewski 1970: 309).

On the other hand, such a situation triggers a danger that the researcher might become excessively involved, resulting in a loss of objectivity and undue impact from the respondents on his perception of them. As suggested by Piotr Chomczyński (2006: 72) a researcher, “is only a co-creator of their image. Their shape depends to some extent on factors that are beyond the control of the researcher, and which result from the time-space context.” It means that the researcher and his actions are subject to the influence of the environment which is the subject of exploration. This is reflected in the words of Kamil Miszewski (2007: 54) “a researcher is forced to engage equally deeply or much deeper into the researched reality with their whole mind and body.”<sup>7</sup>

At the stage of preparing for a proper exploration of the area, the researcher is able to achieve neutrality of the experienced emotions without much effort (cf. *Doktor* 1964: 49). Over the course of time in the researched environment, the engagement of the observer increases, and he becomes an active participant in the events and actions of the individuals (or groups) that are being observed. A consequence of this is the emotions which appear, which form an indispensable part of every participant observation (Konecki 2000: 154; c.f. Kacperczyk 1999: 124). A difference between the observer and the observed does not consist in feeling emotional states differently, but in being aware of them and how they are exploited.

While establishing direct, close contact with the representatives of a specific group, the researcher becomes entangled in the world of interpersonal dependencies, often himself becoming a direct participant of events which initially only had an explorative dimension. They are impacted by the environment, which may also have consequences at the level of the researcher’s psyche.<sup>8</sup> Along with the process of growing into the researched environment, the researcher establishes increasingly more personal relationships with his surroundings (Niedbalski 2009: 211). He becomes an executor of actions resulting from the current interaction situation which he is an active actor of, but also a co-creator to some extent. He also becomes the subject of the activity of the social actors to an increasingly high degree, addressing particular contents and actions to them. While subordinating himself to them, the researcher obtains a role of a member of a specific group (Chomczyński 2006: 72). A consequence of the participant-observer situation which is shaped in this manner may be constituted by the danger of identifying with the researched group,

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<sup>7</sup> It refers to the applied “humanist” paradigm model of empirical research, a model whose constructive features comprise: the subjectivity of the researcher and of the subjects, directly experiencing the researched reality by the researcher, and the “commonness” of sharing the researched world by the person investigating and those who are investigated (Wyka 1993).

<sup>8</sup> Numerous authors raise this matter, warning against the deep emotional engagement of a researcher (Babie 2006: 315) and the danger of becoming excessively accustomed to the subjects (Frankfort-Nachmias, Nachmias 2001: 118).

as suggested by Frankfort-Nachmias (Nachmias 2001: 118), a process of the researcher becoming the native. The same authors (*ibidem* 2001: 307–308) suggest that to be able to counteract such circumstances, there is a need to “separate” oneself from the respondents, which may be achieved through the application of proper procedures and research tools. Krzysztof Konecki (2000: 151) believes that it is impossible to become fully distant from the observed objects. What is more, immersion in human affairs allows better and more adequate comprehension of the reality that the researcher is becoming familiar with. This author recommends that a researcher should make an attempt to keep his distance in the process of generating categories and writing theoretical notes (2000: 152), but during the field exploration he should penetrate the research area as deeply as possible, using introspection, his own emotions, and the accompanying feelings. What is more, Konecki suggests that the possibility of maintaining this methodological “neutrality” towards the researched phenomena, is provided by incorporating specific research procedures (*ibidem* 2000: 152).

When approaching the environment of the intellectually disabled charges of the social welfare home, the researcher was a total stranger, but at the same time, he was interesting for the residents. In the initial phase of exploration of the given field, the researcher treated himself as a professional observer, and the researched environment was just a rich source of empirical data for him. The definition of the situation was identical for the researcher and for the residents of the social welfare home in this respect, especially when the starting point was assumed to be a lack of knowledge on the interaction partners and their willingness to get to know each other (Niedbalski 2010: 52). Gradually, while identifying the environment of the social welfare home, a transformation in the residents’ perception of the observer took place, as they expressed their acceptance through their behaviors, therefore decreasing the distance between the individuals and the observer. At the same time, the researcher himself was becoming familiar with the customs of the residents and the atmosphere of the place of research. The periodicity and regularity of the researcher’s visits, hence the frequent contact with individuals residing in the social welfare home, meant they became, quoting an employee of one of the centers, “a constant element of the landscape.” Therefore, a devotion between the interaction partners started to emerge, and then I was treated as just one of the guys. On the other hand, it required increased self-control, as there were situations when the identity of the researcher clashed with that of a “friend” of the disabled individuals and the staff. In other words, they had become a familiar person, such as a priest, postman, sales representative (of companies that deliver hygienic materials or medical equipment to the centers) or a doctor, i.e. one of those people who was a permanent fixture in the reality of residents. The end of this period, and of the social identity of “the familiar person,” was the moment the researcher left the social welfare home. Every time was connected with emotions and loss he felt, and “betrayal” experienced by the charges. Withdrawal from the environment of the intellectually disabled residents did not cross the feeling of observer’s connection with the world of people remaining in the social welfare home. However, the inevitability of that fact meant that the feeling of regret and the mentioned loss was elevated (Niedbalski 2010: 59).

The transformation of status which took place in the environment of the researched individuals meant that the researcher gained a new perspective on the performed observations. And the temporary, but at the same time completely natural bond between the researcher

and his subjects, contributed to better and closer—from the respondents' perspective—understanding of the specificity of their lives.

Initially, the triggered emotions and feelings underwent a gradual transformation the longer the researcher stayed in the given environment. These changes related to how he perceived those he was researching and led to their redefinition. The gradual familiarization with the environment of the intellectually disabled charges of the social welfare home caused a change in the observer's perspective, and directly influenced his reinterpretation of how he had previously thought about the residents and the sense and meaning of intellectual disability as such. At the same time, the emotional consequences from the field exploration of this group of people, which provided an inseparable element of the researcher's experiences also left their mark, not just on his perception of this situation, but also his psyche in general. While it was possible to limit the first of the mentioned effects of the researcher's emotional involvement, and then to make use of it within the data analysis process (as previously mentioned), the "stigma" left by the researcher's experiences in his psyche required not only time to go through them, but also deep reflexion and the involvement of third persons (Arscott and others, 1998: 79). The strength of emotions and their accumulation meant that the most effective "safety valve" turned out to be talks carried out by the researcher with trusted individuals, mostly friends and close relatives. Preserving the anonymity of the respondents, and bearing in mind their well-being, the researcher tried to share their emotions and experiences with others, which was of twofold significance. Firstly, it gave the possibility to release and partially get rid of the load of accumulated emotions; secondly, it helped to better recognize the problems of both an analytical and a methodological nature, but it also helped to preserve distance and neutrality, necessary within the research process.

Nevertheless, both the transformations in the how persons with intellectual disability are perceived in the processual dimension as well as in the accompanying emotions, provided significant material for comparative analysis within the researched cases, from the angle of notions which were of interest to the author (cf. Borkowska-Beszta 2009).

### **Moral Boundaries of Field Exploration**

A researcher conducting field studies becomes a direct participant of events, thereby acquiring access to personal, private, or even intimate information (Ślęzak 2009: 194–195). The possession of such knowledge, and simply have access to it, obliges the researcher to follow the basic rights of each human being. This means that the researcher should absolutely comply with formally determined<sup>9</sup> guidelines, but also those arising from the principles of coexistence of an ethical nature, at each stage of designing, conducting and then presenting conclusions from the research (Flick 2010: 123). Therefore, it is assumed that those who are researched should have a right to privacy, intimacy, and independent decisions about the time, the circumstances and the scope in which they are willing to share their attitudes or behaviors (Frankfort-Nachmias, Nachmias 2001: 100).

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<sup>9</sup> One form of such assurance against breaking good scientific practice is ethical codes formulated by most sociological associations, and supervision from the part of monitoring institutions called on especially for this purpose (cf. Flick 2010: 122).

The literature of the subject points to several basic principles which should be followed by every researcher to fulfill the postulate of research ethics. They are: 1) informed consent, which means that nobody should take part in the research if they have not been informed about their participation; 2) avoiding the possibility to mislead the respondents; 3) the need to respect the privacy of the respondents and provide them with full confidentiality; 4) not allowing a situation of conscious omissions and manipulation during data collection and analysis; 5) subjective treatment of the respondents; 6) not harming the respondents in any way; 7) clear and precise information for the respondents about the benefits and burdens that may result from taking part in the research (Angrosino 2010: 155–157).

It may prove to be exceedingly difficult in practice for a field researcher to implement all of the above-mentioned assumptions and principles of conduct (cf. Kubinowski 2010: 338). A situation when a researcher is faced with the necessity to follow ethical principles may be combined with additional dilemmas regarding not simply the fact that they should follow the postulated research ethics, but the possibility that they might actually have to apply them (Ślęzak 2009: 195). This especially refers to the stage of collecting empirical materials and establishing direct contact with the participants of a given group, when there is a justified concern that group members will turn out to be incapable of understanding the essence of the research, the character and the role that they will be playing there, and expressing consent to take part in the research.<sup>10</sup> In such a situation, most problems are caused by what Dariusz Kubinowski (2010: 338) “calls negotiating consent on the principles of partnership,” as there is no possibility to meet requirements such as presenting all aspects of the research (taking into account their comprehension by the those being researched) and considering the wishes and propositions of members of the researched community.

Such a situation took place in research conducted with the participation of the intellectually disabled (c.f. Angrosino 2010: 82–84). A question on the permissible level of interference in the subjects’ lives constituted the basis of the ethical dilemmas in the case of the research<sup>11</sup> conducted in the environment of intellectually disabled residents of the social welfare home, as did the formal difficulties in obtaining consent for the researcher to take part in the everyday practices of the observed community (cf. Babbie 2006: 312–313).

Firstly, in the case of welfare institutions, such as the social welfare home, its residents spend their whole lives in one place, where there is no distinct division between the private and public spheres (c.f. Hammersley, Atkinson 2000: 272). A researcher who approaches the environment of intellectually disabled persons (the residents of the social welfare home) has an opportunity to observe the residents in almost every situation, even in the most intimate ones. The residents have no possibility to “hide” themselves, because their whole life takes place in the social welfare home, where they close themselves in<sup>12</sup> (Tarkowska 1997: 127; Tarkowska et al. 1994).

<sup>10</sup> In such situations, Uwe Flick (2010: 128) proposes determining the principles according to which the researcher will move towards obtaining expressed consent, and to what may possibly constitute an acceptable substitute. There is also a need to think about who may provide consent on behalf of those being researched.

<sup>11</sup> I applied participant observation in the research on the environment of the intellectually disabled, where the identity of the researcher was overt for the staff and residents of the social welfare home (cf. Frankfort-Nachmias, Nachmias 2001: 303).

<sup>12</sup> The situation is different in the case of investigating full-abled people, as usually the exploration of an area has a range limited to a certain fragment of reality, e.g. a workplace (Konecki 1992).

Secondly, an observer should obtain permission from the researched group to be able to take part in their everyday life and have the possibility to observe its members in their natural environment (Ślęzak 2009a: 39; Konecki 2000: 146; Frankfort-Nachmias, Nachmias 2001: 95). The principle of voluntary participation (Babbie 2006: 515) and *informed consent of the subjects* (Silverman 2007: 293; Flick 2010: 127; Angrosino 2010: 155) are often emphasized as being crucial in making decisions regarding the exploration of a given environment. Despite the open and undisguised attitude which the researcher attempts to maintain in the whole process of field work regarding persons with intellectual disability in a care home, the character of his participation in the group, like the purpose of actions taken and the reason for his presence, often remained “unidentified.” This was due to the limited perceptive abilities and difficulties with interpretation that persons with intellectual disability have. An occasional insufficient level of awareness of residents and psychophysical deficiencies meant that it was impossible to obtain official consent regarding their participation in the research.<sup>13</sup> Apart from author’s struggles to reveal his identity and apply a policy of “openness,” it proved to be impossible in practice to fulfill the condition of full disclosure towards all of the observed individuals (Niedbalski 2009: 210). Other researchers had similar dilemmas, which is especially visible in difficulties related to getting informed consent from the respondents, described by McCarthy (1998: 143). More generally, it refers to the intellectually disabled persons’ understanding of the questions, but also the researcher’s misinterpretation of the provided answers, as stressed by Heal & Sigelman (1995: 246). This is how such a situation is described by Matysiak (2001: 193): “It is good to talk about informed consent, and about the respondents signing adequate representations, but is it important for someone who does not read and has comprehension issues?” Therefore, the scientists must pay special attention to the matters of obtaining such consent from the respondents (Arscott et al., 1998: 82). It often means that they are forced to devote more time to implementing the research, which must be taken into account when planning the research project (Cameron & Murphy 2006: 117). Additionally, the information charters and consent procedures must be appropriately adjusted to the specific category of disabled individuals.

The above-mentioned notions related to research on intellectually disabled persons residing in social welfare homes have another significant aspect. Neither spatial (physical) limitations nor those arising from the necessity to obtain permission to conduct an observation constitute a “wall” against exploring the field of research as it is the researchers themselves who make decisions about the scale and scope of the exploration. At the same time, we cannot forget about the assumed ethics for social research. However, at the end of the day, the decision about respecting the rights of an individual and the permissible moral boundaries of cognitions should be made by the researcher (Frankfort-Nachmias, Nachmias 2001: 105–108).

The above-mentioned dilemmas may bring into question the moral adequacy of research in the environment of persons with intellectual disability in relation to the obtained benefits; however, this direct participation in the lives of the observed individuals allows

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<sup>13</sup> The decision makers, i.e. the people who expressed consent for the researcher-observer’s participation in the everyday practices of life in the social welfare home, were the employers, especially those working in managerial positions (cf. Hammersley, Atkinson 2000: 83).

the researcher to become familiar with various aspects of their everyday lives (*ibidem* 2001: 300). A proper attitude should be to maintain a balance between data acquisition and interference in people's private lives.

### Conclusions

A researcher interested in the problems of intellectual disability becomes forced to deal with various difficulties that appear at almost every stage of the research work. Even the initial stage of field exploration, regarding the obtained empirical data, constitutes a challenge. The environment of intellectually disabled persons is a specific object of research, requiring a flexible approach and adjustment of the research strategy to the cognitive and perceptive abilities of the intellectually disabled persons. Such a possibility is offered by qualitative research methods. I base my reflections on an analysis of applying the grounded theory (GT), which provided the base for my research carried out in the environment of intellectually disabled individuals. The selection of a specific method and techniques was governed by the specificity of researching intellectually disabled persons, considered in three dimensions: the purpose of the research—in-depth studies on selected cases; the research subject, i.e. interactions, meanings, their symbolic interpretation; as well as the type of the environment and the characteristics of the individuals who are being research—people with different levels of intellectual disability.

Taking those three dimensions into consideration, the following arguments supported the application of the mentioned methods: Firstly, the research regarded the sphere of a social reality which would be hard to measure through statistics, and the exploration of which with the use of quantitative methods seemed limited. Secondly, qualitative methods allow a deeper understanding of the researched phenomena, as they take into account their social and cultural context which, in the case of research on intellectual disability, is a road to interpretations, without imposing arbitrary explanations (*Silverman 2007: 56–58*). Thirdly, to understand all the interaction phenomena taking place in the environment of the mentally handicapped, the qualitative approach, which allows one to capture the essence of the researched phenomena, cannot be eliminated (*Kacperczyk 2006: 144*). Next, understanding the phenomena in their interactional perspective requires long-standing and direct contact with the subjects, which is offered by the exploited research methods, i.e. observation and interview (*Silverman 2007: 53*). Finally, qualitative methods offer flexibility at each stage of the procedure, required in the case of researching the environment of intellectually disabled persons (*ibidem: 53*).

Generally, the usefulness of qualitative methods in research on intellectual disability results broadly from the specificity of the explored environment, the representatives of which have limited possibilities to communicate. It also results from the researcher's contact with the surroundings and his interpretation skills. However, these difficulties should not impact the research quality or lead to its superficiality. Making use of qualitative methods allows the research to lean on his own experiences, while direct contact with the researched individuals provides a possibility to discover those social phenomena that would be practically impossible to discover with quantitative methods. At the same time, the qualitative pro-



cedures provide specific strategies of action, providing the researcher with the possibility to continuously verify and self-correct the performed analyses of the empirical materials. Therefore, we obtain a whole array of tools that allow the researcher to be flexible, at the same time giving him the possibility to perform continuous verification of the process for building hypotheses and theories. Hence, qualitative methods provide a possibility to get to the perspective of the social actors and grasp the processual dimension of the researched phenomena. Thanks to a liberal approach to the data sources, it provides the researcher with a possibility to make use of every kind of information. This is especially important when there are problems regarding phenomena that are difficult both with regard to collecting and analyzing empirical data, such as different spheres of social life or notions such as intellectual disability.

It must also be stressed that the direction of changes related to the introduction and distribution of the social model for disability is directly reflected in how the scientific research is performed. It seems that the main aspect of the changes that take place in this scope is definitely a greater stress on empowering the “research objects, and thus greater awareness related to ‘construing reality’ via performed research and its impact on the creation of reality,”<sup>14</sup> as well as a strong emphasis on responsibility, both while performing the research, and its scientific consequences for the perception of the problems of disability. Therefore, we can see increasing emphasis on undertaking the problems of disability in scientific research, which is no longer focused solely on the specificity of the incomplete capability of an individual as the main subject of the research, but it also considers the raised issues in a more holistic manner, related to a broader social, cultural, political, or economic context.

Undoubtedly, taking up some field research brings a series of consequences, not only of a methodological nature, but also psychological and ethical, which the researcher becomes entangled in. These matters become especially visible when the research is related to environments and individuals that are “problematic,” for various reasons. And people with disabilities can certainly be included in such a category. And it might be why we should discuss the nature of research performed in the environment of handicapped individuals. There are many issues that, despite the arguments of professionals, practitioners, and researchers, are not solved yet. It may be because of their specificity that they will never be clearly explained and evaluated. Such a situation may question the legitimacy and justifiability of research, especially when it is sensitive and interferes in lives of disabled individuals. On the other hand, the notions related to the existence and functioning of persons with intellectual disability, such as a welfare or aid system, and the issues of integration or standardization seem not only important but also embedded within the landscape of our social life. Furthermore, while we will still be dealing with various opinions expressed by average members of society, scientists, and practitioners of “helping,” when it comes to the

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<sup>14</sup> There is a certain significant fact emphasized in the literature of the subject regarding the influence of authority figures (scientists, specialists from a given field) on the manner in which a mentally disabled person is perceived by the environment (Barnes, Mercer 2008: 51). Usually, the categorization of such a person takes place based on “objective” indicators developed by science, which serve specialists as a gauge for evaluating the effectiveness or mental disability of an individual. As the author of research on the identity of mentally handicapped women, Kumaniecka-Wiśniewska (2006: 70) states that a specialist’s diagnosis exerts an enormous influence on almost all spheres of the person classified as intellectually disabled, including the fact that the system of social welfare takes control over the mentally handicapped, which results in the copying of biographical schemes (*ibidem*: 65).

“real” life conditions of disabled persons, the issues of the existence of an intellectually disabled individual will still be valid. Therefore, it seems that despite some complexities of a methodological, moral or ethical nature, it is justified to make an effort and undertake intensified actions towards the identification and better understanding of various life aspects of persons with intellectual disability.

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