

ANTHROPOLOGICAL RESEARCH ON AUTISM. REFLECTIONS FROM THE FIELD

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For a long time, people on the autistic spectrum were doomed to social marginalisation. They often spent their entire lives kept in homes or were sent to closed institutions where they were treated like passive objects of custodial care. Their developmental potential and creative possibilities were generally questioned. Since the 1950s, this has slowly been changing. Individuals with autistic syndrome and their relatives have obtained access to a variety of forms of aid. A network of specialist institutions supporting them through early diagnosis, therapy, care and education have been expanding as well. One such facility, located in Łódź, became for two years my research field. Stepping over the threshold of this institution I was not a novice since I had already met autistic people in the context of my private life. Still, I had never met such an abundant and diversified group of individuals on this spectrum (in terms of symptom level and age). During the course of my research, a number of issues needed to be addressed such as issues related to research method, my behaviour towards people with autism, some organisational matters as well as professional and ethical dilemmas, all of which will be written about in this article.

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Przez długi czas ludzie ze spektrum autyzmu skazani byli na społeczną marginalizację. Bardzo często spędzali swe życie uwięzieni w czterech ścianach własnego domu lub trafiali do ośrodków zamkniętych, gdzie byli traktowani jako bierny przedmiot dozoru i działań opiekuńczych. Na ogół wątpiono w ich potencjał rozwojowy i możliwości twórcze. Poczynając od lat pięćdziesiątych dwudziestego wieku, powoli się to zmienia. Osoby z syndromem autystycznym i ich bliscy uzyskują dostęp do rozmaitych form wsparcia. Rozrasta się również sieć placówek specjalistycznych, oferujących im możliwość wczesnej diagnozy, terapii, opieki i edukacji. Jedną z takich placówek, działającą na obszarze Łodzi, stała się dla mnie na dwa lata terenem badawczym. Przystępując do tej instytucji, nie byłam nowicjuską, ponieważ stykałam się wcześniej z autyzmem w życiu prywatnym. Mimo to, po raz pierwszy weszłam w kontakt z tak liczną i zróżnicowaną (pod względem objawowym oraz wiekowym) grupą osób z tego spektrum. Decydując się na aktywność w tym specyficznym i wrażliwym środowisku, musiałam także podjąć próbę odpowiedzi na wiele pytań dotyczących zagadnień badawczych, organizacyjnych oraz etycznych. O wszystkich tych kwestiach opowiadam w swym tekście.

Keywords: Autism Spectrum Disorders (ASD), disability, fieldwork, ethnographic observation, communication, empathy, ethics, research responsibility

INTRODUCTION

For a long time, all society could offer autistic persons¹ – just as to the people with many other disabilities – was not much more than a segregated education, rejection of them as individuals and confining them to standards of mediocrity and stereotypically established social roles. People with autism often spent their lives kept in homes or were sent to closed centres, so-called asylums, where they were treated like passive objects of custodial care (Goffman 1961; Woodill 1992; Barnes 1997; Barnes, Mercer 2003; Andreoli 2004; Zakrzewska-Manterys 2015, 2017). As was claimed by Ivan Brown and John P. Radford, particularly in the Western world

“It was widely agreed that, in a perfect society, all such people would be «put away», and it was often said of those who remained in the community that they «belonged in an asylum»” (2015, 13).

Also, they were usually seen as “incurable” and “defective”. Their developmental potential was questioned in general and their perceptions and experiences were not explored. Since the 1950s, this has slowly been changing. Attempts to understand these people and to connect them, in a friendly manner, with their socio-cultural environment have been made (Abberley 1987; Gałkowski 1997; Żuraw 2016). The foundation of these efforts is a belief that both disabled and able-bodied people have many more common characteristics than separate ones and that no person can live on his/her own and function in diverse society being isolated from it. In the case of ASD, the value of this strategy also consists in the fact that it contributes to engaging people from this circle with spontaneous social situations. Thus, it supports the development of creative and reflective thinking of these minority group members and equips them with the skills necessary to give their own opinions. As a result, they can learn to live based on their personal experiences and not under external control or pointless, automatic imitation.

Nowadays, the network of experts and specialist institutions supporting people with autism is expanding as well. Their aid programs include a variety of actions, but the priority is precise diagnosis, early intervention, (re)habilitation and personalised therapy. Time plays a key role in this context since an early diagnosis allows for early treatment and because the human nervous system decreases in plasticity with age, this results in better effects in the future, a higher quality of life and lower costs related to both social and medical care (Chojnicka and Płoski 2012, 250). The importance of early detection and treatment is indicated by the research data. This data shows that a wide group of autistic persons, estimated at even sixty per cent, have an intellectual

1 Being aware of all semantical differences, in this text I use interchangeably such terms as “autism”, “ASD (Autism Spectrum Disorders)”, “person(s) with autism”, “autist(s)” etc. I do it for stylistic reasons.

retardation lower than an IQ of fifty, but this percentage is less in the population of children with early clinical diagnosis (Goldberg Edelson 2006; Pużyński, Rybakowski, Wciórka 2010, 591–597; Dykens and Lense 2011; Kika 2014). Even if normalised intelligence tests are considered to be not an excellent tool to assess developmental potential and that this potential should be regarded individually, dimensionally and dynamically, it is beyond any doubt that the group of people most threatened with a lack of autonomy and permanent dependence on others is relatively wide among autists. The emerging network of specialist facilities which have sprung up have contributed to improved ASD prevention and, at least partially, counteracts the situation when the families of children with extensive developmental disorders are left on their own and not provided with even basic support or guidance. Unfortunately, such facilities exist mainly in big cities. One of them, located in Łódź, became for two years my research field. I entered this institution² in 2013, transgressing my own world and opening the risk of tensions related to exceeding the boundaries of other communities. Borys Cymbrowski and Dorota Rancew-Sikora both noted that leaving *orbis interior* and delving into the field usually entails researchers communicating with otherness, with unexpected social issues and launching a cascade of experiences to which they are not fully prepared but which they need to address (Cymbrowski and Rancew-Sikora 2016, 11, 14). This is exactly what happened in my case, although, it needs to be stressed that I was no ‘freshman’ entering the field since I had already met individuals with ASD in the contexts of my private life. Still, I had never met such an abundant and diversified group of people with this disorder (ranging from its severest forms to ambivalent manifestations defined as only containing autistic components)³. What is equally important, my field research was combined from the very beginning with voluntary service to the foundation. It was my way of thanking the local community for them consenting to my stay in the place and a way of more deeply exploring the environment (Męćfal 2016, 96). Doing voluntary service allowed me to have deeper contacts with the studied group and to accompany its members in different circumstances: during their studies, meals, play time, rest periods, sporting activities and therapy (both individual and group). Thus, I gained wide access to the so-called direct or embodiment channels of knowing the other person. The only limitations in this respect were situations during which my presence could disturb a person’s intimacy (nappy changing, or situations where physiological needs required satisfying) and also situations in which my presence could be unfavourable due to organisational or therapeutic reasons.

2 This was a foundation serving children and adults with disabilities.

3 It was a diversified group in terms of age ranging from children and youths from nursery schools to middle schools.

IN THE FIELD: MY AIMS, ASSUMPTIONS AND RESEARCH POSITION

As is well known, field projects never guarantee the certainty of gaining any interesting and satisfactory data. This happens not due to a lack of nimbleness or poor preparation on the researcher's part but simply because this is the logic of the research procedure and the nature of his/her activities. Fortunately, this state of affairs did not arise in my project. The period I spent in the field and the experiences I gained were very instructive. As has been previously mentioned, conducting this study involved several specific dilemmas and problems which I now wish to discuss.

I shall start from a primary issue, notably my mode of presence in the field. In general, it is assumed that in the case of traditional fieldwork there are at least two types of procedure. The first one consists in the participants of the research knowing the whole situation and fully cognisant of the researcher's intentions and often fully consenting to his/her plans. The other type of procedure involves people not being aware of what is being studied and conducted without their permission. This is not the rarity it might seem (Bielska 2016, 71–72). Much depends in these cases on the projected cognitive goals and the specificity of the penetrated environment. Important also are the individual characteristics of the researcher, his/her cognitive skills and axiological background (interiorised conceptual categories, thinking structures, hierarchies of importance, values as well as ethical and aesthetic standards). All of these factors define the frames in which the researcher operates and builds a basis for his/her assumptions. For my project, the deontological perspective, assumed as my reference point, turned out to be essential. According to this perspective, the well-being of the participants of the study is the priority, which means that no goals or arguments can be considered against this (Geisler 2007, 24; Jagiełło and Modnicka 2011, 106–107, 111). Adopting such a position meant that I decided to be fully open about my activities. I believed that concealing my own professional identity would disturb the fundamental rules of social relations (especially the human right of self-determination, personal freedom and control of information about oneself) and maybe would be close to “anthropophagy”. Consequently, my fieldwork was preceded by a direct conversation with the heads of the foundation during which I submitted a covering letter containing my personal data, institutional affiliation and a description of my study. Then, the heads turned to the legal guardians of the persons cared for by the institution and asked them for their consent to my research at the place as well as organising a meeting with me. The meeting was a way of informing people and of familiarising me with them and vice versa and it created a space for open dialogue. Only after gaining the acceptance of its members, did I take my first research steps.

An important cognitive doubt arises here. Did my self-disclosure affect the course and the results of the study? Did it limit my resources of observation? I believe this occurred to some extent. After all, the natural human reaction is to aim to build and

maintain a positive image of oneself and one's membership group. It leads, among others, to the staging of behaviour and the censoring of information considered inconvenient or damaging. Therefore, it can be presumed that if I had somehow camouflaged my professional identity, I would have found out more about the world I wished to explore and would have been allowed to know its secrets. As an ordinary volunteer, however I would be more transparent to my environment, which would weaken the embedded socio-cultural tendencies to self-creation and self-control. Being guided by the deontological perspective, I decided maintain standards of openness.

At the same time, I must admit that fulfilling this standard turned out to be impossible among all participants of the study. This resulted directly from the attributes of the group, especially the fact that a large part was represented by people with severe intellectual disabilities who were unable to communicate in a conventional or generally available way (including alternative and supporting methods of communication). Therefore, despite best intentions, I could not explain to them who I was and why I was staying with them.

Another important question I needed to answer entering the foundation was to choose the research method. For obvious reasons, the answer was not completely free but limited by three basic considerations: legal, ethical and practical. Taking them into account, I decided to choose ethnographic observation but excluded the use of audio-visual techniques for recording the research situations. I also gained the consent of my 'gatekeepers' to make field notes although not while communicating with those under care but, so to speak, after hours. Here I must point out that this self-imposed limitation to the ethnographic observation was not troublesome to me and that my research in the foundation was only one of my areas of activity and interests in the world of autism (concurrently, I studied written stories related to this theme). As such, my presence in the field was merely to support my already undertaken analytical work and enrich my empirical experiences. I must further mention that due to the specific nature of the reality I was studying, my observations were not fully participant but could be classified as so-called negotiated interactive observations (Wind 2004; Wierciński 2016, 89–90). As claimed by Hubert Wierciński, in this version of ethnographic fieldwork *in situ*

“(…) the researcher constantly absorbs the field, is present in it and experiences it with the whole self but does this without the imperative of experiencing what is felt by the «natives» and who they are since the access to their perspective is limited” (Wierciński 2016, 89–90).

Thus, emphasis is placed on the interactions, activities and practices in the field which are subjectively observed and analysed by the researcher. A consequence of this type of exploration may be the special awareness of the essence of the world he/she is interested in. This awareness is not equivalent to participating in this universe since no paths available to the ethnographer lead to it. The said theoretician uses in this context the metaphor of a wall which can be seen, tapped, identified through touch

but which retains the properties of a barrier – in that it rather suppresses and closes than opens (Wierciński 2016, 90). Such an understood formula of negotiated interactive observations relates to many field projects within which the observer finds it difficult to understand the rationale and feelings of the people under study (especially when this goes beyond the sphere of typical ethnic or social distance). It also applies to my actions as I was not a novice since I had already had dealings with autism in my private life. Also, what needs to be stressed, is that the experience turned out to be very important for my study in the foundation. It meant that in the initial stages (as well as the following) of my visits to the field, I was capable of preventing myself from what is defined as being in a state of being totally blinded and even traumatised by the sense of otherness. This state is often encountered by scientists during first contact with the explored completely new reality. The intensity of this experience is sometimes so strong that it distorts the researcher's perception and in extreme cases leads to a deep mental crisis that may last for years and dangerously transform the person⁴. My already gained empirical knowledge of ASD protected me from this effect and also permitted me to avoid some difficulties that might have occurred in my relations with persons on this spectrum. For example, being aware that autism is in general a permanent and strongly fixed condition, I was able to cope better with certain situations in the field that I encountered such as the lack of noticeable reaction of many children to my person, the non-establishment of eye contact by the children and their non-reciprocity or desire for isolation.

To continue in this vein, I would like to indicate another benefit I derived from having had private experience in dealing with ASD people. My research and voluntary activities in the foundation were not limited to passive ethnographic observation and typical service actions but also took the form of dialogue and partnership with the facility's employees. If I felt that I could help in solving any issue or sudden problems which arose, I immediately offered ideas, which, in many instances were acted upon. For example: one day, one of the people under study showed high irritability and increased level of psychomotor excitation as this person was incessantly running,

4 The situation is particularly distinctive of research studies conducted in difficult and vulnerable communities that pose special risks for researchers (Hart 1995; Harris 1996, 1997; Byrne 2005; Quina *et al.* 2007; Arditti *et al.* 2010; Kafar 2013). Examples include prisons, juvenile detention centres, shelters for people in crisis, hospital wards for seriously ill patients, hospices and other minority settings. It seems that trauma is almost inherent in these projects, especially if they are undertaken by a (highly) sensitive person and/or by a novice. Nevertheless, it is still comparatively rare that authors include descriptions and analyses of intense emotions experienced in the course of their fieldwork. It is a sorry state of affairs that this is the case, because feeling is a way of knowing. Consequently, emotions can be a powerful analytic tool which can provide worthy insights into a topic and relevantly enrich research reports and writings (Kleinman 1991; Kleinman, Copp 1993; Bourne 2005; Lalor, Begley, Devane 2006; Johnson 2009).

squeaking, crying and could not be calmed down. Members of the caring and tutoring staff were left largely confused by the child's behaviour. I looked closely at the child and noted that he would not permit anyone to make him wear shoes or socks which he took off right after entering the play area. I thought that perhaps the boy had had his nails clipped and as a sensory hypersensitive person felt much discomfort. I told his guardians about this presumption and they contacted his mother who confirmed my "theory" and informed all that she would be more careful next time to make sure that her son's nails were not cut too short since this irritates him.

Another similar incident happened in the dining room during dinner. One of those being cared for absolutely refused to eat. I thought that maybe his aversion was caused by the specific texture of a dish which made it difficult for him to put his food on the fork. It turned out to be true and the situation was quickly resolved.

In no way are these details provided to undermine the professional expertise at the institution of the foundation's staff. The point which I am trying to make is that even the temporary presence of the anthropologist within some social and/or institutional sub-world may be beneficial for its operation. With a willingness to adopt an adaptive fieldwork approach, an openness to others and sensitivity towards the local context, which are peculiar to anthropological approach, the researcher can bring a positive contribution to the communities being studied and described, on condition however, that the field preparation includes a versatile and deep reflection on the features of the analysed group. In the case of my exploration, especially important was undoubtedly the reflection I underwent on my behaviour towards the studied people. Most of all, I had to be aware that in spite of appearances, autists have a very fragile psyche and are very sensitive to the emotions, moods and the intents of people they interact with. This means that even if an individual with ASD does not show it, he/she may truly suffer in interactions with people whose behaviour concerns, hassles or distracts him/her. It is an important thing in terms of therapy. (It needs to be remarked upon that, according to contemporary standards, the main goal of treatment is not to break and reassemble the patient to match dominant norms and conventional expectations but to achieve his/her maximum self-reliance in his/her daily life, to achieve non-conflicting co-operation with the environment and to foster the ability to make conscious judgements. All roads behind these therapeutic activities is, or should be, to lead to as high an independence as possible of the person with autism⁵. It is indeed known that being in a nursing home, in isolation from the world, most often causes the psychophysical degradation of any human and a state of chronic, progressive dementia. Every coercive aim of making people with ASD become the same as the neuro-normative majority is an attempt to control them and thus an act of violence.)

5 Briefly, the primary aim is competence, not correction.

STAYING WITH AUTISTS: HOW TO BEHAVE AND WHY?

Today, there are different treatments for ASD but the truth is that therapeutic success is almost random. The reasons behind this are unknown. It seems, however, that two factors are favourable for positive results to be gained. Firstly, there are activities which contribute to the gaining of a higher trust of the patient in other people and secondly, activities which are used to strengthen the patient's belief in his/her own efficiency and self-agency (Mahrer and Nadler 1986). Of equal importance within a given therapeutic method are the so-called soft aspects of therapy such as the creation of a good atmosphere in a meeting and the manifestation of respect and support to the patient. Indeed, any spontaneous reaction and any contact with an autistic may trigger his/her potency which in turn will bolster the person and stimulate his/her development.

I tried to put these into practice in the field which translated into trying to be maximally calm, patient and predictable in my interactions with those under study. This was important because of any possible chaotic or expansionist effect on people with ASD which could engender a lot of fear and uncertainty which may lead further deterioration of the disease and intensify the existing mechanisms of it. Additionally, I had to bear in mind that individuals with an autistic syndrome usually choose different paths of communication than their neuro-typical counterparts. While the latter have high sensitivity to visual and auditory signals, the former are more skilled in using touch data, (micro)kinesthetic and proxemics (Wroniszewski 1993, 12; Kliś 1994). Therefore, during my fieldwork, I attempted to use the kinesthetic way of communication more than normal. I did this through keeping my body still, through a delicate and controlled touch, through the illustration of information conveyed verbally with motions and by the avoidance of any violent and invasive spatial behaviour. I endeavoured to pay attention to the body language of the children too. Their minds were mostly distant and "closed" to me, but their bodies became nearer and more "open". I had the opportunity to closely observe the children's faces, glances, postures and movements. Obviously, I do not know whether all these behaviours were significant but sometimes they were so suggestive that I recognised, personalised and remembered the child just by his/her intense or particular way of using his/her body as way of expression. Often, it was also the only tool available to create a kind of bond between us. I knew many of these young people not through their thoughts, dreams or views but through their physical contact with me: tapping, stroking, embracing, gazing, pinching and pushing etc⁶.

6 Body and bodily-sensual events are only one of the components of typical relationships. In the case of autism these spheres not infrequently take centre stage. It seems that sometimes we can speak about a kind of "hyper-embodied" contact in this context. This is a broad, compelling topic which requires separate elaboration.

Most authors agree that one of the defining features of ASD symptoms is occupied by failures in understanding and an inability to form statements, all of which occur in many patients. These problems negatively affect all spheres of personal development. There is a widely held view that linguistic processes form the basis of people's growth into the structures of society and culture – they help in intraception⁷ and are an important way of reaching others and influencing them⁸. During my study, I endeavoured to support all attempts at using language by those with autism but it was far from easy. I tried to speak slowly, calmly and articulate every syllable of every word clearly and expressively. Often, I kept uttering the same thing over and over again. Despite this, what I said was frequently not understood by the children and/or did not arouse any noticeable reaction and sometimes it was I who failed to grasp their messages. This is related to the specific character of verbal communication in autism which is composed of such features as: atypical pace of speech, echolalia, inversion, producing stereotypical sounds, repeated parts of words, shortcuts or sudden mental leaps (Vicker 2009; Eigsti *et al.* 2011; Boucher 2012; Ray-Subramanian, Ellis Weismer 2012; Kominek 2014). I need to say that this failure to comprehend on my part was one of the most

- 7 Intraception is a concept developed by H. A. Murray to describe those who process the world primarily through their feelings or emotions (<https://psychology.wikia.org/wiki/Intraception>, access: 10.11.2019).
- 8 Some people claim that with the development of language abilities other talents which may occur in ASD can be destroyed. They think that an autistic, as he/she makes progress in the process of verbalising, loses mastery in some areas and that he/she inevitably becomes an ordinary, handicapped person, although capable of speaking (a bit) but irrevocably robbed of his/her uniqueness. Sometimes, these people also believe that it is better for an autistic person to be incapable of saying anything, even his/her own name, asking for a glass of water or exchanging a few words with his/her parents than to be typical, or average. "Anything but ordinariness, it is so vulgar!" – they are strongly convinced. Quite apart from the fact that such elitist views are questionable, the opposite is true. Therapeutic and educational practice prove that an increase in language skills does not curtail an autistic's or an autistic savant's talents at all. Stephen Wiltshire is a spectacular example (<https://www.stephenwiltshire.co.uk/>, access: 10.06.2019). He is a brilliant urban artist who is capable of drawing almost the entire of London (after having only a cursory observation of its building). This man developed, both artistically and linguistically. At first, unable to speak a word of the language, he later communicated with the environment using his drawings. He was nonverbal during his early childhood and finally learned to talk only at the age of nine. Today Wiltshire is considered a great architectural innovator and was awarded The Most Excellent Order of the British Empire for services to the art world in 2006. His work is known and valued all over the globe, and his drawings are held in a number of important collections. Indeed, individuals with autism occasionally lose their aptitudes but it is often due to other factors. They become bored with some activities or certain biological changes in their bodies take place. At other times something happens to them – this can be a sudden loss of a significant loved one, the birth of siblings, moving to an unknown place, a change of school etc. (During the life cycle of every human a variety of unexpected events such as trauma, a trajectory process, epiphanies and life changing situations occur which can result in transformation.) In general, people on the autism spectrum will only benefit by improving their intellectual abilities in every field, especially in the field of language because it is an imperfect but powerful human instrument of cognition.

emotionally demanding moments of my fieldwork, being unable to respond to the initiative of the other side and accept that person's invitation to meet in the space created by the word – considered the main medium of meaning in human culture. In such situations, I tried to answer with a friendly gesture or smile but these were only substitutes. Encountering such language difficulties, I also tried to pay particular attention to their prevocalic or vocalic signals (squeals, shouts, peculiar exclamations and vocatives, etc.). All these behaviours may be an important means of communication, be a sign of the structure of social relations and may contain the characteristics of the performer, inform about his/her detachment and be a manifestation of pleasure or sympathy to the other person. On the contrary they may be a manifestation of displeasure, irritation and even of hostility. The literature has supported for a long time the view that many more negative and neutral emotional behaviours (such as: shouts, cries and a lack of interest) rather than positive ones (screams of happiness and murmurs of satisfaction and so on) are observable in autism. (Minczakiewicz 1994, 103). This fact may discourage some from interacting with people with ASD, organising activities for them or including them in social situations. However, it should be noted that the reaction of those with autism is dependent on many factors, such as their familiarisation with the people involved, the structure of the local space (many autists have a bad reaction to sensory complicated or crowd settings) and equally to weather. During the course of my study, it became apparent to me that even subtle changes in the environment (such as slightly turning up a ventilation in a room, or the darkening of a room), the playing of some music or a food break may affect the autistic people's mood, their willingness to interact and attitude to reality.

PENALTIES AND REWARDS. SOME ETHICAL DILEMMAS

Another issue is the use of penalties and rewards for sufferers of ASD. In general, it is assumed that in relation to these individuals no penalties should be administered. It is a very ethical assumption but in the light of what has already been said, it needs to be recognised that we do not always know what a penalty for a person with autism is and is not. In fact, physical and mentally felt displeasure-activities are still being carried out. These include making the cared one inactive and isolating him/her. These methods are especially practised in cases of (self)aggressive, destructive behaviours and tantrums. Most often these take the form of physical holding, relegating from a group activity or taking the sufferer to another room so that the individual may rest from excessive, overwhelming emotions and stimuli (sometimes, a specially equipped hall is used for this purpose where the person can release their tension by, for example, punching a mattress or throwing soft objects against walls). It needs to be noted that this exclusion may, paradoxically, be viewed as a reward since due to the act of aggression

and further isolation, the person may avoid stressful situations thanks to this exclusion. Being given a time-out, the person will avoid the activity he/she does not like but one which could inspire and strengthen him/her socially or mentally. In such cases, regular appliance of this technique may disturb or even inhibit the development of the individual. Questions arise as to how effective “punishment” is but also to its ethicalness. A definitive answer to this dilemma is, I believe, not available, since one is dependent on the concrete cultural context, diverse situations and individual aspects.

Another technique used in relation to those with ASD is hypercorrection. It is applied in particular in relation to children when they cause some damage. If, for example, a child soiled the floor, he/she would be required to clean it and in addition, wash something extra. Sometimes, hypercorrection goes hand in hand with a positive exercise. For example, if the sufferer draws on furniture, his/her drawing skill is tested on the board or on a sheet of paper. However, often it cannot be specified as to whether the damage caused by the child is a conscious act or is due to other reasons. It may happen that a child drops a plate with food and breaks it because he/she is incapable of tolerating the smell due to his/her neurophysiological condition. It is equally probable that he/she may do such an act on a completely unchecked impulse, such as becoming frightened of some sound which would remain unnoticed to a man from the circle of “normals”. When an individual with autism seems to be “absent” and does not communicate in the usual manner, it is very difficult to identify his/her motivations, intentions and current mental-emotional condition. Helpful tools here in the deciphering process are empathy, intuition, observation and an ability to think logically and strategically but sometimes these are not even enough. This is because no two human experiences are the same. Despite attempts to categorize them as so, they are still essentially indivisible and unique. That is why the other person always remains a kind of mystery – particularly if he/she differs in some way which is the case in autism.

CONCLUSION

Fieldwork is slowly losing importance in Polish ethnology and cultural anthropology (Kaczmarek 2016, 123). In spite of this, it remains a valuable method of collecting data. At the same time, the concept of field is understood in many ways (Buliński and Kairski eds. 2010), including the spheres of no “contact with a living human” (Buchowski 2012, 96): studies of artefacts apart from their creators and places of origin, some ethnohistorical and ethnolinguistic research, exploration of media spaces, textual and literary analysis etc. Some representatives of the discipline declare outright a farewell to the field (Żerkowski 2015) whilst others assess this idea to be premature and misleading (Sikora 2015).

In my study on autism, I have always employed a variety of sources and methods of analysis. By doing so, I consider my presence in this traditionally defined field to be an important way of acquiring knowledge and legitimising my conclusions. I have always assumed that the experiences I gained will help me to better understand the phenomena of my interest and will be helpful in the process of interpreting different research materials (such as written accounts, data, internet content and so on). This preliminary assumption has been positively verified during my field explorations which have largely expanded my cognitive horizons. Through contact with a wide and diversified group of sufferers I have encountered many faces of autism – in respect of individual characteristics and how these people function in their daily lives (from the people requiring total care, to those seemingly “absent” and to individuals capable of undertaking certain decisions and actions on their own). With my relatively long stay at the foundation, I could observe how a person with ASD may develop and change, improve in skills and gain more autonomy. I have also seen many opposite situations, where severely disabled people require permanent care and are incapable of achieving any high degree of independence⁹. Given the specific nature of the environment I entered, my field project was to some extent characterized by ambivalence. On one hand, I was very close to the studied individuals coming into contact within their sphere of intimacy. I held their hands, put their shoes on, passed them toys, helped them to eat, drink and reach the toilet; I was also the witness to many of their spontaneous behaviours and emotions. I was sincerely pleased with their achievements and worried about their failures. On the other hand, I could never bridge the distance – as a representative of the neuro-normative majority I could not become one of them and assimilate their points of view (Malinowski 1922, 25; Mead 1977, 6). I could attempt comprehension but I was not able to make myself similar in terms of mental and psychophysical condition. During my stay with them I sensed the clear distinction between “knowing” and “knowledge” which constitutes the distinction between “native experience” and “expert perspective”. For obvious reasons, it was also impossible for me to cross the border of closeness in the field, beyond which begins human (reciprocal) friendship or intimacy (Wax 1971, 373; Hendry 1999). I felt that many sufferers did not even recognise and notice me. Being physically present I was in a way somewhere else, far away, rather than next to or among them. Nevertheless, I consider the empirical sensation of this intensified quasi-closeness as a fundamental experience that has helped me to enrich my anthropological imagination and awareness of autism.

9 Such situations may be regarded as extremely negative and sad but this belief is not fully justified. Taking care of another person is indeed a natural human behaviour. Sometimes, we can give others nothing more than respectful, sympathetic care (Sośnicka and Dobrołowicz eds. 2011).

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