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Everyday Life of Intellectually Disabled Women. A Special Educator's Perspective

ABSTRACT The contemporary educational research methodology can boast of following the trends aimed at changing paradigms so as to create new research orientations. Traditionally, special education concentrates on researching the methods of influencing the disabled as individuals. Yet, at present, the recognition of philosophical, ethical and biological groundings of special education in the context of globalization seems a more tangible approach. Neither is disability a social taboo, nor its discussion can any longer ignore such topics as the quality of education for the disabled or the quality of their lives. This provides researchers with a broader cognitive perspective as regards the point of view of people with disabilities. One such point of view is everyday life.

KEYWORDS EVERYDAY LIFE,
WOMAN, DISABILITY

The late 20th century brought about significant changes as regards understanding the phenomenon of disability. The latter ceased to be perceived as a biological and medical category and began life as a socially-oriented term. Also, disability is no longer an individual attribute but rather a social property determined by the conditions and style of life of the disabled

such as dependence on the other people's help and necessity of dealing with architectural, economic and legal obstacles in particular. The disabled person thus lose their beneficiary – “patient” – status in favour of becoming the “client” and “consumer.”¹ They gain the right to decide about their own life and personal choices. Disability eventually comes in the open in the form of discourse on all sorts of topics starting from the quality of the education for the handicapped to the quality of their lives. (Ramik-Mażewska 2011) The third sociology paradigm according to which one is both whom s/he contacts and befriends and at the same time a record of all his/her past contacts, with „every [party on such a record] being an individualized synthesis of the society” (Ferrarotti in Sztompka, Bogunia-Borowska 2008: 22) prompts the researcher to ponder over the current life of the disabled, their social positioning and an ability to present it to the world. This article will take a look at the question of everyday life of women with intellectual disabilities.

Brief reflections on everyday life

The 20th-century sociology made use of three theoretical trends: phenomenology, ethnomethodology, and performance theory as a basis for the contemporary sociology of everyday life. These trends became the conceptual and theoretical apparatus for analysing and interpreting social occurrences. For example, A. Schutz representing the social phenomenology claims that life comprises “daily experiences, orientations and activities via which individuals conduct their affairs using objects, socializing, planning and realizing plans” (Wagner 1970: 14–15). Individuals construe their own lives shaped by situations, biographies and the scope of knowledge at disposal. These resources rest within the society, its culture in particular for an individual to subjectively transform and interpret them. A. Schutz highlights the role of observation allowing to discern the world as an intersubjective entity shared by people and experienced and interpreted as a common good.

Ethnomethodology demarcates everyday life on the basis of particular human practices. Its creator, H. Garfinkel (in Rawls 2002: 96) states that “there is order even in the most ordinary, concrete everyday activities, that is, in their continuously procedurally generated coherence of ordered details.” In such an order it is the society that creates the coherence of this order's details for the purpose of establishing a wider, unique social organisational. The latter in turn serves an area for ordinary people to perform their individual practices via which they establish the sense of their lives. According to this theory, the ordinary society seems to crop up as an all-embracing category working both on the macro- and micro-social levels (Sztompka, Bogunia-Borowska 2008: 38). Also, ethnomethodology sees everyday life as a peculiar, though discontinuous, order repetitively recreated by its participants via their permanent, transgenerational, collective and concrete practices. These are often experimental activities of ethnomethodology itself which, by creating disorder, aims at exploring its dis/orderly practices. Therefore, approached from the point of view of ethnomethodology, the phenomena such as anarchy, chaos, dissonance within social situations, or the phenomena of paradox, inappropriateness, deviancy of actions appear as particularly conclusive.

¹ A new approach to the problem of disability is related to theories of disability. Juxtaposing two dichotomous perspectives (materialism – nominalism, idealism – realism), Priestley speaks of four theory of disability types: an individualistic-materialistic model where disability appears to be a deviation in the psycho-physical development of an individual; an individualistic-idealistic model where disability is a special form of an individual's identity; a social-creative model, with disability as a material product of current socio-economic relations, and a constructivist model where disability is demarcated via a specific relation of an individual with his/her social environment.

E. Goffman's performance theory understands the cognition of everyday life in terms of "the most possible approximation and capturing of the social nature" (Willems 2001: 6300). An analysis of the simplest social situations becomes key to the understanding of more complex areas of social functioning. Goffman points out that daily life occurs in the presence of others and is thus socially anchored. The interactive order that Goffman studies (1997: 236) is defined by him as the "face to face" contact realized on the public arena. Interaction has two important characteristics particularly effective as regards the sociological analysis. Firstly, it is a common phenomenon to be encountered within all walks of social life. Secondly, interaction is universal, ergo, typical of every community regardless of time and place, with the meeting, understood as its participants' physical presence, constituting its ur-form. Only mutual closeness allows people to perceive and feel perceived (Goffman 1963: 17–18). We all are thus actors performing in the theatre of life. We perform "partly spontaneously and unconsciously, guided by our internalized, in the course of socialization, behaviours, and partly manipulatively and strategically modelling our demeanour so that it impresses others" (Sztompka, Bogunia-Borowska 2008: 43). The essence of performing is therefore to present the self marked by the consciousness of others' expectations and revelatory of the traditionally recognized social values.

This brief outline of the most tangible 20th century sociological trends demonstrates everyday life to be complex, multidirectional and he that I understand in terms that I understand in terms nce, ambiguous a phenomenon fit for being an arena where relations between very different aspects of human life can be studied. The sociological hybridity being a performance of the condition of the postmodern society marks searching for, so far reified, (parts of) structures in everyday life episodes *the* method of the social reality studies. The category of everyday life requires clarification as it can be misleading. First, everyday life does not constitute the reverse of the festal life; rather, it refers to the entirety of human activity. Second, neither does everyday life clash with elite life as it encompasses both mass and upper class practices, ergo, it is not synonymous with commonality but applicable across class divisions. Last but not least, everyday life is not tantamount to operating within the private sphere only as this category also functions with regard to the public events such as strikes and elections, rallies and political debates (Sztompka, Bogunia-Borowska 2008: 24–25).

In the past the everyday and "unwonted" life boundaries were clear-cut, religious systems constituting one good example of such a dichotomy. The sphere of the "unwonted" was a determinant of the "ordinary." At present, the latter determines the former, starting from time management and dress code to language and feelings. The unquenchable desire to experience the unwonted pushes people to seeking how to implicate it episodes of everyday life. Once "domesticated", the unwonted gets neutralized and loses its "freakish" quality. In effect, what used to be ordinary takes precedence over the unusual, obscuring its "unwonted" colour and meaning. The sociology of everyday life must therefore metamorphose into the sociology of the entirety of life, for contemporarily everything is slowly but surely becoming everyday life. One could almost say that the unwonted has taken the ordinary captive (Wojnar 2010: 10).

When analysing the theories of everyday life such as those of Watson, Felski, or Bevone, P. Sztompka (2008: 25) concluded that the ordinary:

- is always life with other people, in the presence of other people,
- means the repetitive, the cyclical, the rhythmic, the routine,
- often takes ritual, dramatized forms performed along the lines of inbred hence automated scenario,

- engages our biological characteristics both with all their limitations, weaknesses and imperfections and all their potential, strengths and possibilities as well as manifests a variety of emotions,
- is located in the space determining its content and character,
- is permanent and limited by strict timelines,
- has a non-contemplative, almost automatic character, yet is also spontaneous.

Contemporary perspective on Intellectual disability

With regard to intellectual disability, the transformations currently taking place in our reality concern branching off from educating children with disabilities in social isolation and into normalizing their life conditions. The latter attitude triggers the search for new rehabilitation methods. One manifestation of such changes is the increasing use of the term “intellectual disability,” both in the literature on the subject and in practice. Perennial terminological divergences eventually led to the creation in 2001 of the “International Classification for the Functioning, Disability and Health,” an approach to disability denoting the latter as the “multidimensional phenomenon resulting from human interactions with their physical and social environments.” So understood, disability translates into both a health damage effect and a process of “blocking” a person in his/her environment (Wapiennik, Piotrowicz 2002: 22). This demarcation of disability introduces scholars to the terms such as ability (capability), environment and functioning as key sociological concepts. Also, it calls for a reinvention of the phenomenon of disability itself. With reference to the intellectual disability, the general level of intellectual functioning, significantly lower than the average (two standard deviations below the mean, is highlighted. Significant limitations as regards adaptive functioning is also a valid factor constitutive of disability. The limitations must be visible within two of the following skills:

- communication,
- self-care,
- home life,
- social and interpersonal skills,
- use of social security funds,
- self-management,
- school abilities,
- performance at work,
- free time organisation,
- concern for health and safety.

The age limit for the reduced level of intellectual functioning to occur is 18, whereas the intelligence quotient obtained in an individual test should be 70 or less (Wyczesany 1998: 122). However, an examination of an individual with a presumed intellectual disability cannot focus solely on his/her characteristics but rather aim at understanding that person’s current functioning in everyday life (Luckasson et al. 1992, quoted after Kostrzewski 1997).

Gender and disability

Gender belongs into the group of the basic human description categories. Biomedically, it is determined with regard to anatomy and hormonal functioning. Gender identity is believed to be a “fundamental, existential sense of one’s masculinity or femininity and acceptance of one’s own sex on the psychological level” (Miluska 1996: 24). The anthropological studies on social divisions demarcate gender as a social roles- and tasks-identifier as well as a set of behaviours characteristic of femininity or masculinity (Goldman: 1992). Anthropological

interpretations emphasize the relation between gender roles played by representatives of each sex and based on the sex-specific biological potential and vital functions, decisive in the division of labour. From this vantage point, the motherhood-fatherhood dichotomy determines the specific social, care-oriented and family-stabilizing competence (conservative-utilitarian orientation) of the female gender and the material and cognitive protection – of what is known as “masculinity” (progressive-ideological orientation). In effect, each sex differently performs particular social and life activities (Kopciwicz 2003: 63).

Studies on women with physical disabilities and studies on significant persons demonstrate that the Occident attaches great importance to the functioning gender patterns thus expectations for disabled girls/women and disabled boys/men vary to the degree that these two groups have different life chances (Connel 1987; Renzetti, Curran 2008, Kopciwicz 2003). Intellectually incapacitated women have a different social status than their “healthy” peers, mostly because they are disabled to make important life decisions. Oftentimes, people do not admit that women with intellectual disabilities can have sexual lives at all and, by comparing them to children, deprive such women of their autonomy. Common opinion is that appearance of such women fall shorts of the accepted canons of feminine beauty. The infantilization of relations as above thus entails the impairment of gender role identification. One problem that both physically and mentally handicapped women share is of how to perform the mother role. Contrary to physically impaired women, females with mental disabilities do not identify themselves with their role, and, enjoying few social rights, they cannot effectively defend their interests. As a result, they do not shape the internal sense of self-reliance and independence, now associated with the woman (Kumaniecka-Wisniewska 2006: 83, Wołowicz-Ruszkowska 2013).

Disabled people need to function in gender roles, be fulfilled erotically or build emotional bonds to the same extent as “healthy” individuals. The institutions of marriage and family are significant both for the disabled and those without any impairments. Satisfying the need for creating one’s own family eventuates in breaking the ties with the original family, a step which requires maturity to overcome numerous psychological, social or economic difficulties. It can therefore appear to the disabled as too difficult due to these people’s reduced efficiency and because of different social stereotypes. Another very important aspect of disabled women’s lives is the possibility of finding professional fulfilment. The sense of self-fulfilment and social usefulness enrich these women’s participation in social life providing a chance to extend the scope of life experiences and to meet new people thus preventing social exclusion (Nowak 2012: 146–147).

The above analysis demonstrates that the question of women with disabilities encompasses the subjects of marriage, parenting, motherhood. There is a lack of research studies on a broader spectrum of these women’s lives (the emphasis is on women with intellectual disabilities). We must therefore approach the life of people with disabilities in general as well as its manifestations in a wide social perspective from a new angle, the latter being the scope of their everyday life.

Research analysis

Understanding everyday life of the three women under research requires applying an appropriate method of data collection. The author have used the narrative interview method aimed at obtaining stories of the studied women’s lives. The women in question have been interviewed at home. The participant observation (also in the homes of the studied women) have complemented the obtained material thus contributing to the fuller image of the disabled women themselves and their lives.

Woman One

Vocationally educated, she specializes in tailoring. She is 26 years old and her medical records confirm her as suffering from intellectual disability, with limited locomotive and seeing spectrum. The woman is single. Despite many efforts, she has never managed to find a job and is therefore a participant of the Therapy Workshops. She lives with her parents, has her own room with a large bed, a closet, a desk and the computer where she keeps her "diary." In it she jots down daily events and family and friends' anniversaries so as "never to forget about anybody." Every day the examinee gets up at 6:30 a.m., checks the weather, goes to the bathroom, gets dressed, and has breakfast made by her mother. All those activities are performed by turns at a set pace so that the woman is ready in time for the shuttle bus to come and take her to the workshop. She spends 7 hours at the therapy comprising scheduled classes set in specific time intervals; the examinee never remembers any radical change to that timetable. Twice a week she sees her rehabilitation consultant. She participates in the workshop on social and professional skills where she learns and develop social skills, and how to establish relationships with people and be assertive. Every day she is also rehabilitated so as to improve her manual skills. She gets acquainted with simple techniques of manufacturing artistic jewellery doing which she enjoys. In her free time the examinee occupies herself with poetry writing. The workshop is a predictable and safe context where she can openly discuss issues, usually popular TV series, with other participants.

The woman's home time is ritualized, too. After classes she has lunch prepared by her mother. The examinee can exactly tell what there is going for lunch each day as this knowledge results from the fact of home menu being planned for a whole week ahead. After lunch, she goes to her room to lie down only to spend the rest of her free time in front of the computer. She has no friends who would visit her and she rarely leaves the house. To the examinee's regret, her mother "will not let her go by herself." She believes she is old enough to go out for walks on her own, yet, her mother stays relentless in her decision. Occasionally, the examinee's elder married sister takes her out. Every day before going to sleep, her mother and herself select her clothes for the next day. She goes to bed at 8:00 p.m., watches in bed her favourite TV series and falls asleep.

The examinee does not like Saturday. She usually gets up later then, has breakfast, gets dressed, and cleans her room as much as she can leaving more difficult chores for her mother to do. She has a lot of free time with which sometimes does not know what to do and therefore ends up bored. Once in a – very rare – while, on monthly basis, she goes shopping with her parents. The first weekend day closes with the examinee listening to audio books before bedtime and going to sleep as usual. Sunday, on the other hand, is festive. The family gets up at 9:00 a.m. and go to church around 11:00 a.m. After church, the examinee prepares lunch with her mother and helps washing the dishes afterwards. At around 3:00 p.m. the examinee's grandmother comes to visit. The family treat themselves to coffee and a cake her mother usually bakes the previous day. Sunday is the examinee's favourite day for she spends a lot of time with her family and go to church, the activities she very much looks forward to. She would also like to participate in other church services but, as she says, she has nobody to go with. In the afternoon the examinee listens to audio books and watches TV. Asked whether she would change her life, the examinee insisted on her mother to treat her more seriously and let her go for walks or to church alone. She would also like to have her own family. If these dreams came true, then life, in her opinion, would be perfect.

Woman Two

She has received the vocational education of a seamstress. She is 41 and lives at her parents' house mother and a younger sister. She suffers from a mild intellectual disability and simple obesity. In 1998 the Family Welfare Centre directed her to the Therapy Workshops where she is passionately involved in the activities offered by the knitting studio. As she herself sees it, "embroidering is my life." This particular examinee gets up every day at 6:00 a.m., prays, makes her bed and gets dressed. She is not fond of the morning toilette and avoids it as much as possible. Neither she does have breakfast at home. She tries to leave the house as early as she can and goes to the workshop alone. The examinee enjoys breaks during classes, especially the coffee break during which she talks to her girlfriends. She likes it, for "it feels different than work conversations," one can "gossip freely."

She walks back home from the workshop along a fixed route where she passes by the pharmacies, the clinic, the church and her favourite shop. She visits these places every day greeting the shop assistants and reporting the details of her day to them as well as asking questions about theirs. For her these women are like close friends. She also go to church to pray every day and visits her siblings who live alone. She cherishes the company of her sister's children. During the interview, she often emphasises that "the family is very important and you need to see them every day." The examinee does not like staying at home and neither does she like doing house chores. She uses every occasion to slip out of the house. Her only responsibility is to clean her room on Saturday. She claims that she has no time for anything else as there are more important things to do for her such as the participation in the parish council. The examinee attends the council's meetings regularly. She usually does not take the floor but does the assigned tasks, e.g. church cleaning or decorating just the same.

It is hard to say whether the examinee belongs into any peer group as she does not go out with women from her workshop. She is unable to say which people outside her family are particularly close to her. Neither can she differentiate between quality and non-quality contacts with people. In her mind, as long as everyone is friendly, everyone is good. The only meal the examinee has at home is supper. She eats accompanied by her mother and sister. After supper, she watches TV series and goes to bed late, around 11:00 p.m. The examinee has oftentimes emphasized that she is an adult, whereas her mother treats her like a child by constantly asking her to report tell what she did or whom she met on a given day as well as never letting her shop for the family. The examinee feels she knows "what is needed at home..." Sundays, church services, events at the Therapy Workshop are her little celebrations.

Woman Three

This woman has the vocational training of the chef. She suffers from a mild intellectual disability. She is 28 and not even a one-year-old child. She is living in the Single Mothers' Home and is looking for a job. At first, she lived in the house of her partner's parents but she claims that, after a while, the relationship with them went sour and she and her baby had to leave. At present, at the Single Mothers' Home, she has a room with a private bathroom at her disposal. Her everyday life shows signs of permanence. She starts the day by changing and feeding the baby. She has her breakfast between 7.00 and 9.00 a.m. with the group or, and other times, depending on the child's behaviour, she eats in her own room. After breakfast the examinee airs the room, cleans it, and checks the laundry. She always does her make-up and hair. The examinee attaches great importance to her appearance for, as she says, it would be difficult for her to go out without her make-up on. Next, she usually

drinks coffee with other mothers in the living room, talks about children and takes her own baby for a walk. Most often, the examinee goes walking with another mother during which activity the two women talk.

On returning back home, the examinee changes and feeds the baby. If lunch is not ready yet, she reads to her child. If the latter is asleep, she reads for herself - teenagers' prose is her favourite book type. The examinee is a little ashamed of her reading preferences and remains convinced that other women make fun of her because of that. She is an eager participant of meetings organized by the management of the Single Mothers' Home. Trying not to miss any such meeting, she has already attended ones with a paediatrician, a stylist, a diet expert. The examinee says that she does not ask these people any questions yet is a careful listener and "watcher" of what is going on during each of such meetings. Twice a week, she cleans her room and cooks dinner. She finds great pleasure in preparing her favourite dishes, these being the tomato soup, spaghetti and potato casserole. She also likes baking cakes and does it in spare time.

Her afternoons proceed according to the repetitive agenda: watching TV series, playing with her child, taking a walk, or visiting her mother (rarely) with whom she has poor relationships. The woman's mother suffers from a profound intellectual disability. The examinee contacts her child's father only by phone. In the evening, when the child falls asleep, she calls him, sometimes crying. She would like to have a family and live with the father of the child on a permanent basis. Apart from the Single Mothers Home and her family, she has no friends to come and see. The examinee does not differentiate between special and ordinary events in her life. She associates festivity with church and Christmas, but, on the whole, festive are her memories rather than current experiences.

Conclusion

Depictions of everyday life such are not satisfying to a sociologist. As a special educator, I have focused on the examinees' daily activities, for I consider the latter significant in these women's social functioning. Such a functioning allows to address both the assumed (with regards to the definition of disability) and real potential of people with intellectual disabilities. Everyday lives of the examined women are all different due to their different life situations. Two examinees live in the family home and remain under a strong influence of the family. However, there are important differences between them. Woman One proceeds in her daily life by way of adapting to her family's demands, whereas Woman Two makes attempts at her independence and although her social contacts are not strong, she is nevertheless identified in her group and sticks to it by maintaining her relations with other women. Woman One does not make decisions about her own life and her everyday life oscillates solely around home and the workshop. The life of Woman Two appears as more complex – she has got the home, the workshop, and "friends" from various institutions. This is the life that takes place in the presence of others; the life which is sustained. Contrary to Woman One, Woman Two has little sense of living in isolation from the world; rather, she approaches it as creatively as she can.

Everyday life of Woman Three is completely different than that of the two women depicted above. It is the institution and the need to care for her baby that play the greatest role in her everyday life performance. She is a part of a group but hers is a quickly changing group, comprising women with life experience similar to that of Woman Three with whom the latter can share but not solve her problems constructively. The examinee observes the reality, wants to look good, and be like others. Still, her activity is of limited character and must be externally stimulated. One characteristic the three examinees share is the sense of festivity

associated with Sunday, attending church services, and belonging to a particular group. According to the examinees' observations and comments, the ritual of preparing herself to participate in social occasions, wearing festive clothes, experiencing the tension that accompanies these tasks is of significance to them.

The everyday life of the interviewed women is not particularly rich. Even though they watch the reality and participate in everyday events, monotony often sneaks into their lives. Women: One and Three have significantly subordinated their daily rituals to institutions. Regardless of a situation, all the examinees desire a change, in particular as regards close relations with another person from outside the family environment. Namely, the women in question would like to realize themselves in the classic female roles of wives and mothers. In their hearts, they are all convinced of their ability to cope well with these roles. However, this dream turns out to be difficult to come true for them, be it because of the past (Woman Three), or the family environment which, regardless of the examinees' age, does not give up on controlling their lives.

The long-termed education of people with intellectual disabilities aims at leading them towards their biggest autonomy possible. The above discussion allows us to conclude that, in the case of the said women, this education has proved successful. The examinees can communication and care for themselves as well as they want to make their own decisions. Unfortunately, in adult life, these skills do not always have a chance to be further developed. Why is that so? The answer cannot but be provided via pondering over the condition of the modern world and man. Is there space in such a world for the practices of normalisation, autonomy, self-dependence, or have these terms become empty? I hope that, researched, the question of everyday life will reveal the mechanisms that limit the autonomy of intellectually disabled adults and helps develop social forms of supporting them.

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CODZIENNOŚĆ Kobiet z NIEPEŁNOSPRAWNOŚCIĄ INTELEKTUALNĄ – PRÓBA SPOJRZENIA NA PROBLEM PRZEZ PEDAGOGA SPECJALNEGO

STRESZCZENIE W metodologii badań pedagogicznych dostrzec można istotne trendy prowadzące do zmiany paradygmatów i tworzenia nowych orientacji badawczych. Pedagogika specjalna w tradycyjnym ujęciu skłaniała się ku badaniom nad sposobami oddziaływania na jednostki dotknięte niepełnosprawnością. Obecnie ważniejsze wydaje się być zdążanie w kierunku rozpoznawania podstaw filozoficznych, etycznych i biologicznych pedagogiki specjalnej z uwzględnieniem szczególnych warunków jakie stwarza globalizacja. Niepełnosprawność przestała być społecznym tabu, zrodził się dyskurs na bardzo szerokim kontinuum od jakości edukacji osób niepełnosprawnych po jakość ich życia. Stwarza to badaczom coraz szersze pole do poznawania świata osób niepełnosprawnych z perspektywy osób niepełnosprawnych. Jedną z takich perspektyw jest niewątpliwie codzienność.

SŁOWA KLUCZOWE

ŻYCIE CODZIENNE, KOBIETA,
NIEPEŁNOSPRAWNOŚĆ

