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SCIENTIFIC STUDIES

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DISABLED IN THE WARSAW UPRISING

During the German occupation in Poland in 1939–1945, many disabled people were associated with the independence underground, fighting in the ranks along with non-disabled people. In Warsaw, the deaf and deaf-mute soldiers brought a significant contribution to the uprising that broke out on August 1, 1944 and in history is known as the Warsaw Uprising. Knowledge on this subject is extremely narrow and only occasionally little information in the form of memories appears in the journal *The world of the deaf*. It is worth recalling briefly some historically documented fragments and facts on where and when soldiers with disabilities, most often deaf and hard of hearing, took part directly in the fighting. It had to be important, because immediately after the war in the journal *Military Poland* (1946, No. 2) the first mentions of the participation of deaf people in the Warsaw Uprising appeared.

All the deaf and hard of hearing soldiers who fought in the uprising, in the interwar period were associated with the Institute of the Deaf Blind in Warsaw, which was located in the building at the Three Crosses Square. It is still in the same place today. They often used to meet in front of the nearby church of St. Alexander, carrying out tasks and commands of the authorities of the underground state, providing various types of information. The tradition of these meetings has survived to this day. The Institute had a very important meaning for them, because they managed to learn many specific professions in it, which helped them in their lives. They knew the area of the city well, and there, near the Square of the Three Crosses, they began their insurgent fights. I think it was a real miracle that no deaf soldier died.

An independent unit of deaf and hard of hearing soldiers became famous for insurgent fights. The branch's organization should be sought earlier, in the darkness of the German occupation. After thoroughly identifying the situation, several younger graduates of the Institute of the Deaf and the Blind made contact with their pre-war teacher Wiesław Jabłoński. It was in his apartment that the first underground group of the deaf in the number of 15 people was founded. After communicating with the Home Army Headquarters, all fifteen were sworn in and all joined the Home Army, becoming soldiers of the underground state. As one of them later recalled, it was a great experience for them, very important not only during the war, but also after its end.

During the occupation, all these soldiers had documents about disability, which made it easier for them to move around the city and to a large extent protected against round-ups or arrests. The underground authorities commissioned them very difficult tasks. They were connectors, they distributed leaflets, newspapers (Malinowski, 1998, p. 44). They performed these dangerous tasks as a soldier’s service. We can find some mention of it in *Life of Warsaw* in the numbers from 1945 and 1956. In other years, for political reasons, this subject was omitted, because if you could speak and write about the Home Army, you could do it only in a disadvantageous way. The slogan of this period is: “The Home Army wretched reaction dwarf.”

But the deaf and deaf-mute soldiers themselves undertook a series of actions to make the memory of them last. After the war they often met, because most of them lived in Warsaw. In 1975, the still-deaf soldiers wrote their own biographies and created an extremely interesting album-diary entitled *The participation of deaf soldiers in the Warsaw Uprising*. This initiative was led by a former deaf-mute soldier Henryk Konrad. This album is a unique source, a moving documentary about how these disabled soldiers were involved in the fight for freedom of the homeland. Those who wrote these words could use it thanks to the kindness of MSc. Tadeusz Konrad, whose father was a deaf soldier and fought until the end of the uprising under the pseudonym “Żbik”.

In the first part of this memoir album, we read: “In the thirtieth anniversary of the victory over fascism to commemorate our armed action in the Warsaw Uprising from 1 August 1944, we pass this album to the Main Board of the Polish Deaf Association” (*Participation*..., 1975, p. 1). Then there are the signatures of these soldiers who lived when the album was created, i.e. in 1975. It cannot be said that there were hundreds of them, twenty-nine were verified. Due to the special significance of an armed act, it is worth quoting their names, military rank and nicknames. Among them there were (ibid., pp. 1–2):

Corporal Włostowski Kazimierz	pseudonym „Igo”
Rifleman 1st class Anders Włodzimierz	pseudonym „Tezat”
Rifleman Bałdecki Wacław	pseudonym „Żubr”
Rifleman Bednarski Edward	pseudonym „Karabin”
Rifleman Bednarzewski Władysław	pseudonym „Orzeł”
Rifleman Bedyński Janusz	pseudonym „Sekund”
Rifleman Cepek Stanisław	no pseudonym
Rifleman Czerniecki Stefan	pseudonym „Omega”
Rifleman Chruściel Bolesław	no pseudonym
Rifleman Falencki Marian	pseudonym „Helmar”
Rifleman Gajda Stanisław	pseudonym „Gaj”

St. Rifleman Klimczewski Jan	pseudonym ,,Tajemniczy"
Rifleman Konrad Henryk	pseudonym ,,Żbik"
Rifleman Kozyrew Mikołaj	no pseudonym
Rifleman Lechman Zygmunt	no pseudonym
Rifleman Lubomski Mieczysław	pseudonym ,,Dzik"
Rifleman Maciejczyk Jan	pseudonym ,,Jastrząb"
St. Rifleman Obrycki Jerzy	pseudonym ,,Bim"
St. Rifleman Ostachiewicz Henryk	pseudonym ,,Zoryś"
Rifleman Purska-Goszczyńska Zofia	pseudonym ,,Zośka"
Rifleman Sawicki Witold	pseudonym ,,Kamień"
Rifleman Słojkowski Tadeusz	pseudonym ,,Tygrys"
Rifleman Sopyło Jan	pseudonym ,,Igła"
Rifleman Stec-Smoczkiewicz Jadwiga	pseudonym ,,Jaskółka"
Rifleman Sułkowski Kazimierz	pseudonym ,,Czuwaj"
Rifleman Szyszkowski Wacław	pseudonym ,,US"
Rifleman Wasiłowski Henryk	pseudonym ,,Czerwony"
Rifleman Zonenberg Franciszek	pseudonym ,,Olza"
Rifleman Zwierzchoniewski Zdzisław	pseudonym ,,As".

Perhaps there were more soldiers who fought in an independent unit, were included in other tactical relationships, performed guard duty or worked in sanitary services. To verify this, you need to conduct detailed source research. A characteristic example can be given to confirm this information. When in September 1944 heavy fighting continued in the Old Town, one of the insurgents did not escape despite orders and shouting, but only loaded ammunition into crates; he died from the explosion of the German shrapnel. Later, an insurgent said he was deaf and did not hear anything (Kirchmayer, 1959; Bartelski, 1981).

The organized troop, which consisted of soldiers who were deaf and hearing-impaired, structurally and militarily developed as follows. At the beginning of the outbreak of the uprising, it was an independent platoon commanded by the second lieutenant "Mundek" and was part of the third company, its commander was Captain "Reda", and the whole battalion was under the command of Major "Miłosz". The grouping occupying the area from the Vistula River to the Three Crosses Square and Jerusalemite Avenue was commanded by Colonel "Bogumił". So much information can be verified on the basis of *Military Poland* (1946, No. 2, Malinowski, 1998, pp. 44–45).

Probably fate would have it that the deaf soldiers began their battles in front of the Institute of the Deaf and Blind. Good knowledge of these areas greatly helped them in moving around, avoiding German ambushes, and achieving successes, especially in the initial period. From the surviving sources and the memoir album mentioned above, it appears that they defended Prince Street before the Germans broke out, which threatened the Downtown to be cut off from Powiśle (river-bank of Vistula district of Warsaw) They also fought on Frascati Street, Ujazdowskie Avenue and around the Parliament buildings. Together with able-bodied soldiers they showed great courage, sacrifice, heroism, friendship and other features so necessary in the battle. The young insurgent mentions it in the book "Wipe the battle dust off your hair" (Leżeński, 1997). He describes the courage and sacrifice of deaf soldiers to volunteer for outings, and carry reports to the most dangerous places. They defended important strategic circuits, for example the YMCA building. They also performed many tasks even before the outbreak of the uprising, engaging in underground fighting in various positions.

"How many times each of us moved calmly among the street crowd next to the gendarmerie posts, not showing by any twitching of the face or nervous, unnecessary movement that under the cloak or in a carelessly wrapped package we carried important documents, files of leaflets and the underground press, and even parts of radio and weapons" (*Participation*..., 1975, p. 4).

The gatherings took place in the building of a gardener at the Institute site, right next to the German station guarding the YMCA building (currently there is the Headquarters of the Polish Scouting Association). The Germans did not suspect anything. The soldiers kept strict secrets, no one knew about it, even the staff of the Institute. They were like social gatherings, and actually the soldiers learned about the use of weapons and the tactics of street fighting. It lasted almost two years until the outbreak of the uprising. It follows that the deaf and mute were well prepared for the armed struggle, which was particularly evident in August and September 1944 on very difficult sections of the battle with well-armed German armies, at the time when the Germans, breaking the resistance of the insurgents, cut off Powiśle. Many insurgents died in these fights. But none of the soldiers of the deaf died, even though this type of disability was a great threat to their lives. They moved among the ruins and the roar that they did not hear.

A platoon of deaf soldiers was ready to fight from the first day of the uprising, but not immediately did the soldiers get weapons, although they joined the active action. The first baptism of fire, already armed Home Army platoon of the deaf, passed on August 3, 1944, taking part in the winging of Germans occupying the Queen Jadwiga Middle School. From the side of Hoża and Mokotowska streets it was supported by regular Home Army units. This was important because the acquisition of the school building made it possible to establish contacts with the city centre where the main forces and command of the Home Army were located.

The Polish, despite the difficult conditions, did not resign. The Germans, on the other hand, achieved success on the section of Łazienkowska St., occupying the church. The insurgents suffered heavy losses during the attack. The recently appointed Major "Kryska" was severely wounded as well as lieutenant

“Leszek”, second lieutenants “Lazarus” and “Bekas”; Lieutenant “Jelito” died with a minor son. Fighting on the corner of Książęca, Ludna and Czerniakowska Streets, *Radosław* troops had to counter attacks by Dirlewanger’s criminals. The soldiers of “Czata” were supported by the company “Parasol”, its commander, 21-year-old lieutenant “Jeremi”, was wounded. In these heavy fights, deaf soldiers took part being an independent platoon and only two of them were slightly wounded. Despite the superhuman efforts, the insurgents failed to maintain a continuous frontline. The Germans broke the weak fortifications of the Poles in Powiśle, which – according to Jerzy Kirchmajer (1959) – largely determined the fate of the uprising. Upper Czerniaków was cut off from other districts of the city that defended themselves.

The situation was getting worse, there was a shortage of heavy equipment, ammunition was ending, civilians were dying or starving. The troop of the deaf soldiers was at the centre of these heavy fights. Difficulties intensified after the fall of the Old Town and Powiśle. It was already September and only isolated positions of the insurgents’ resistance remained on the Vistula. In Żoliborz, belonged to them Marymont adjacent to the river. In Mokotów, the fight for Sielce was not only of local significance. “Although insurgent troops were at least two kilometres away from the Vistula, they still defended the important coastal thoroughfare – Czerniakowska Street, and did not allow a blow to the Upper Czerniaków. Finally, the areas of Upper Czerniaków in this situation became the most important area of struggle, because they lay directly on the Vistula. As long as they had a connection with the southern city centre by Książęca Street, they could count on possible reinforcements” (Bartelski, 1981).

The Germans attacked with particular ferocity and fury, killed civilians along the way, taking everything they possessed. Within a few days they managed to oust the insurgents almost from all defensive units in Powiśle, by the escarpment and reach Książęca. Only Captain “Reda’s” (Zygmunt Miszczak) company survived in the YMCA building on Konopnicka Street, still being fiercely fired. Here, a troop of deaf soldiers was distinguished by valour, without any losses. It was them who took two Germans, from whom valuable information was obtained, as prisoners. Soon from the National Museum, Germans attacked St. Lazarus Hospital. After an hour’s battle of the “Eastern Muslims” battalion, supported by five assault guns, the enemy broke into the escarpment from the side of Smolna Street. On September 13 at midday, after an air raid by the divers and the decimation of Polish troops, the Germans reached Książęca Street. The Poles were still defending themselves at number 7 house, but then happened what influenced the later fall of Upper Czerniaków, it was cut off from Downtown.

After these heavy fights and heavy losses, the re-enactment took place and the new front was created, but now the danger threatened from two sides, that is from the side of the Vistula embankment and Jerusalemite Avenue. Soon after joining the main centre of the uprising, a platoon of deaf soldiers was incorporated into the third company of Captain “Reda”. After regrouping, the deaf were given the order to get the so-called Italian house, where the cinema “Napoleon” was located, at that time occupied by Germans. After installing themselves in the large, vaulted basement of this house, the deaf soldiers were ordered to move to an underground glazed garage, and the place abandoned by them was taken by command of the platoon. A few hours later, the bomb dropped from a German plane was so powerful that it pierced the roof and stairwell of the building, massacring everyone present there. This event is quite accurately described in the literature devoted to the Warsaw Uprising and memoirs.

A troop of deaf soldiers, this time well-armed, fought hard for the YMCA building. Although the object was quickly surrounded, due to large German forces the troop was not able to get it. The fight for this building was extremely fierce. Without hearing the shots, the deaf soldiers had to think twice, to keep their eyes wide open, not to be surprised by the Germans if they tried to attack their position. After these heavy fights, further regroupings took place. Shortly after the command of the unit was taken over by the energetic Lieutenant “Mundek” (Edward Malinowski) there was a further regrouping and new tasks were assigned to the unit. The command was not easy, because in the platoon only Kazimierz Włostowski had the rank of corporal, all others were riflemen.

It should also be noted that in the platoon of deaf soldiers there were two deaf-mute nurses: Jadwiga Stec and Zofia Purska – also a pupil of the Institute. During the fights, they were always at the station, bravely fulfilling their duties. They provided medical assistance to soldiers from other platoons. They boldly moved to the front line.

Both the deaf troop and other Home Army units attacked the YMCA building several times, as its control was to precede the acquisition of parliamentary buildings, in which strong German troops were fortified. Inside this building there were many well-armoured Germans. Despite surrounding and shouting in German through loudspeakers, in order for the Germans to give up, the battles continued and absorbed new victims. Finally, the German airmen helped the insurgents as they bombarded the building by mistake. And it happened because German soldiers removed a banner with a swastika from the roof, to wrap the body of a friend who died in battle. The airman thought that there were Poles in the building for which the battles were fought, so they bombarded it. Most of the Germans fled to the Parliament building, some gave up.

At the time the battles faded a little, the deaf soldiers set up a high-powered loudspeaker and their commander called on the Germans three times to surrender. They were given two-hour terms and were urged to hang out the white flag. The Germans were confused. Initially, they were willing to give up, but they were restrained from fear of ill-treatment on the part of the insurgents. Soon they took up the fight, and then saved themselves by escaping.

The headquarters of deaf insurgents has always been at the Institute of the Deaf and Blind. Its pupils defended this object. The building survived, but later the Germans burnt it. Deaf Home Army soldiers in the next days of the uprising performed guard function, often guarding very important objects. After the capitulation, they did not go into captivity. A certificate of disability gave them the opportunity to legally avoid it. According to corporal Włostowski, who before the war was the editor of *The world of the deaf* magazine, and later the actual organizer of the Home Army unit gathering deaf-mute soldiers, only eight insurgents were taken prisoner. Together with the crew of the entire post, they were led by their second lieutenant "Czółno". Their previous commander, injured in the Apollo cinema, was in an insurgent hospital.

To this day, many photographs have been preserved commemorating the participation of deaf-mute soldiers in insurgent fights, as well as depicting their stay in German captivity on the island of Sylt in the Baltic Sea in Germany, after the fall of the uprising. There are also photos and later memoirs written on the occasion of various meetings and anniversaries (*World of the Deaf*, 1969, No. 5).

BIbliography

Bartelski, L. (1981). *Powstanie Warszawskie*. Warszawa: Iskry.

Encyklopedia wojskowa (2007). Warszawa: Wydawnictwo Naukowe PWN, Bellona.

Kirchmayer, J. (1959). *Powstanie Warszawskie*. Warszawa: KiW.

Leżeński, C. (1997). *Zetrzyj z włosów pył bitewny*. Warszawa: Auditur.

Malinowski, L. (1998). Oddział żołnierzy głuchych w Powstaniu Warszawskim. *Roczniki Pedagogiki Specjalnej*, t. 9, 43–47.

Polska Zbrojna, 1946, 2.

Świat Głuchych, 1969, 5.

Udział żołnierzy głuchych w Powstaniu Warszawskim (1975). Warszawa [manuscript].

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PSYCHOSOCIAL ASPECTS OF SEXUALITY IN ADOLESCENTS WITH VISUAL IMPAIRMENTS

According to the ecological model, all sexual activity results from experiences gathered during the biologically based process of socialization. Therefore, analysis of the impact that visual impairment has on the psychosexual functioning of adolescents should consider not only the functional aspect but mainly the sociocultural aspect. Specific upbringing and education conditions in childhood and adolescence (e.g.: compulsory schooling in a special center – often in a live-in environment, parental overprotectiveness, lack of or unadapted sexual education curricula, etc.) may hinder learning of typical interpersonal interaction patterns and delay one's sexual identification process. The limited range of social experiences may result in a low mentalization of the need, and, in consequence, a lack of its stimulation, which manifests itself, for instance, in a lower frequency of autoerotic behaviors among blind adolescent boys as compared to their nondisabled peers. Moreover, a lowered self-esteem and sense of interpersonal attractiveness relating to the lack of acceptance of one's disability, awareness of being dependent on others, and negative reactions of people around which are based on false beliefs about blind people's sexuality can also make it difficult to build close relationships and form emotional and sexual bonds.

A review of studies on the sexuality of blind and visually impaired adolescents does not allow unambiguous conclusions to be drawn about the course of this group's development. The data collected are generally descriptive in nature and do not fully reflect the specificity of sexual functioning in the whole population of adolescents with visual impairments as, frequently, the studies were conducted with small samples and did not take into account different types and severity of visual impairment. Also, discrepancies in the findings relating to individual aspects of psychosexual development may be due to differences in instruments used by researchers as well as to the sociocultural nature of the approach to sexuality that is specific to the country where the study was carried out.

Keywords: sexuality, psychosexual development, adolescents, visual impairments

Introduction

Sexuality is a broad concept that integrates the physical, cognitive and emotional-social aspects of a person's personality expressing masculinity or femininity. In the perspective of all life, it is developed on the biological, intrapsychic, interpersonal and cultural level, so its analyses referring to a given person or social group should be holistic, take into account all aspects of psychosocial functioning and their interrelationships. At the level of general analysis, the phenomenon of human sexuality is often considered by the ecological model, which treats sexuality as an inalienable attribute of each person, describes it as an undifferentiated driving force with complex conditions expressed in the forms adopted in the systems in which the unit operates (Nowak, Gawęda, Janas-Kozik, 2010). According to this approach, sexual motivation is defined as the disposition, based upon innate and acquired elements, to react in a certain way to given stimuli. Among numerous innate elements including biophysiological properties, the state and way of functioning of receptors and senses are also mentioned. The group of acquired elements, in turn, includes all experience accumulated in the process of socialization. The ecological model enables the description of sexuality from a developmental perspective, as it attributes such features as constancy (though not stability) and variability. Stability means that every person, regardless of specific traits, such as age, race, gender or fitness, is a sexual unit permanently subject to the interactions of the two components listed in the model; and the variability is expressed in the fact that the impact of these individual factors is different at every stage of development (Beisert, 2006b). The ecological concept of sexuality corresponds to the assumptions of currently recommended models of disability, that is why it is used by researchers as theoretical background of empirical activities, the subject of which is the sexuality of people with various types of dysfunction (Kijak, 2010).

In the biopsychosocial view of disability, the experienced difficulties are manifested in such three levels of functioning as the dysfunction of the organism, limitations of individual activity and problems in social participation, with environmental and contextual factors having a significant impact on the situation of the person (Cepeda, 2012). Therefore, the functioning of a person with disability should be described and explained in the context of their living environments, because disability is a kind of interaction between the individual and the environment that is subject to constant change. In the description and interpretation of psychosocial activity, including sexual activity, people with disabilities, a human rights-based approach seems to be appropriate, which enables the analysis to take into account all individual and environmental characteristics constituting potential barriers to achieving a sense of well-being and high quality of life. In this concept, whose central conceptual category is the inalienable rights of every human being, the damage and dysfunctions of an individual organism are not negated, but the accent is primarily focused on adapting the environment to individual capabilities and needs of the individual and eliminating all barriers hindering participation in various forms of activity, fulfilling social roles, implementing educational and vocational plans, etc. Undoubtedly, the advantage is the interdisciplinary character of this model and the inclusion of the developmental situation of the person in a holistic perspective, in which apart from disability other factors that expose the individual to discrimination and/or social exclusion, e.g. sex, age, socio-economic status, negative attitudes of the environment are also taken into account (Garbat, 2013).

The adoption of an ecological model of sexuality and the social concept of disability referring to human rights allows us to look at the wider scope of functioning of people with disabilities in the intimate sphere, recognizing the significant role of cultural and educational factors in the psychosexual development of this group. Researchers (including Pilecka, 2004; Kef, Bos, 2006; Ostrowska, 2007; Parchomiuk, 2012; Szymańska, Compel, Lew-Starowicz, 2013) note that the difficulties of people with disabilities experienced in the area of sexuality, in particular in fulfilling sexual needs, playing gender roles, gaining the status of an attractive and full-fledged partner, are primarily a consequence of social attitudes, false beliefs and prejudices, specific educational conditions and segregationist educational path. The aspirations to build an inclusive society should, therefore, emphasize the rights of people with disabilities to education, participation, self-determination, self-fulfilment and the preservation of privacy and autonomy in every sphere of life, including in relation to sexuality.

The aim of the article is to present the current state of research on the psychosocial aspects of sexuality of blind and visually impaired youth, with special attention to factors that may disturb the trajectory of sexual development of this group.

Sexuality and visual impairments

Sexuality of people with visual disabilities is a problem that is relatively rarely subjected to research analysis, which is most probably caused by the fact that eye damage does not interfere with the physiological course of sexual activities (Radomski, 2010; Szymańska, Compel, Lew-Starowicz, 2013). However, the literature on the subject points to factors directly and indirectly related to eye disability, which can have a negative impact on the sexual development of a person. Among the direct consequences of eye damage, important for this developmental sphere, are: lack of eye contact, impossibility or difficulty in perceiving visual stimuli related to appearance and behaviour, problems in correct interpretation of other people's behaviour, limited possibilities of imitating accepted patterns of action in a given situation category and difficulties in spatial orientation and independent, safe movement (Kef, Bos, 2006).

Deficits of visual perception cause communication difficulties in the flirtation phase and during psychosexual stimulation in a partner relationship, but they can be minimized by developing mechanisms of substitute sexual communication and sensory compensation, especially tactile compensation (Radomski, 2010). In addition to the necessary reorganization of the perception of sexual stimuli, well-conducted sex education, fully taking into account the limitations of the reception of information flowing from the sense of sight, becomes particularly important.[1]

The visual impairments can also affect the child's sexual development through the mediation of specific social situations: the specific character of the education process related to the adaptation of parents to the fact of having a child with permanent, serious dysfunction; education at a special facility; reducing the possibility of using social stimulation, including participation in many forms of spending free time typical of able-bodied peers. Limitations of the possibility of full social functioning may have a negative impact both on the mentalization process and on the actualization of sexual needs. Overprotection of parents, often resulting from fear and desire to protect a blind child from suffering injury, hinders active exploration and learning about the environment, including free contact with peers, while growing up can significantly interfere with sexual development (King, Hauser, Isquith, 2006). According to Dutch research, adolescents with visual impairments more frequently than active adolescents undertake activities alone and spend a significant amount of time in a family environment, especially in the company of their parents, which is not conducive to establishing emotional relations. Although the parents provided visually handicapped teenagers with the necessary amount of knowledge in the field of sexual education, they insufficiently mobilized them to participate in activities with their peers outside the home, and did not provide social competences necessary during social events (Kef, Bos, 2006). Research conducted among German youth with this type of dysfunction showed that it exhibits the same desires of belonging to a group as non-disabled youth, however, it is less active in establishing emotional contacts (Pfeiffer, Pinquart, 2011). It should be remembered that when a blind teenager enters the phase of early adulthood, a small range of erotic experiences gained due to limitations in the current social functioning may lead to immaturity in sexual relations (Wild et al., 2014).

An important issue in the willingness and readiness to establish pre-intimate relationships in the adolescence phase is, moreover, self-esteem and the sense of interpersonal attractiveness, including sexual attraction, of one's own person, which in the youth with visual disability may be reduced. The conviction about the distance from the social pattern of attractiveness, and consequently the negative self-image and low self-esteem are factors conducive to the psychosexual distance of a visually impaired person towards a potential partner and avoiding entering a closer relationships. Experiencing negative attitudes of

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[1] A review of scientific research into sexual education of children and youth with visual disability has been made by the author of this text in: Czerwińska (in press).

a peer group, including emotional and social isolation and sexual rejection, can in turn significantly reduce self-esteem and lead to self-suppression of sexual needs. There are significant discrepancies in the results of self-assessment of the blind and visually impaired adolescents, which do not allow the adoption of unambiguous conclusions concerning the entire population, however a significant part of the analysis indicates the negative impact of sight damage on the image of their self (Datta, 2014).

Finnish questionnaire research on the psychosocial functioning of visually impaired youth, carried out in a group of 54 people (40 boys and 14 girls) attending public schools, showed that the respondents did not differ from able peers in terms of frequency of depression, emotional tension or relationships with parents and siblings. However, it was found that students with visual disabilities rarely had many friends and were less likely to date other young people. They also more often felt loneliness and had difficulties in establishing closer relationships, which could negatively affect their social self-recognition. An important variable turned out to be the sex of the respondents. Girls with visual disabilities had worse self-esteem, school achievements and social skills than able-bodied students from the control group (Huurre, Aro, 1998). These results partly correspond to data from studies on the existence of intersexual differences in the level of self-esteem of 23 adolescents aged 12 to 17 years (8 boys and 15 girls) with congenital near-sightedness who attended the second grade of secondary school or a university preparation course. Girls scored lower on the scale of social self-conception, attitudes towards family and moral attitude than male respondents, but achieved higher scores on the scale of physical self-conception (Lopez-Justicia, del Carmen Pichardo, 2001). The negative impact of eye damage on adolescence self-conception was also observed in studies of 160 Indian teenagers aged 15 to 18 years, among whom 100 were sighted and 60 blind. Visually impaired youth scored higher than blind in three of the six dimensions of self-conception (“physical appearance and characteristics”, “popularity” and “happiness and contentment”), which means that the overall result of self-conception was also higher (Halder, Datta , 2011). Dissatisfaction with the physical appearance, having a direct impact on the level of mental well-being, was also recorded in studies carried out among 177 German teenagers with visual disability compared to a control group of 531 seeing peers. The subjects with sight dysfunction were usually less satisfied with their body than the seeing teens, but the difference was mainly due to the girls’ opinions. In addition, subjects with visual disabilities, especially girls in this group, to a large extent combined the image of their own body with the experience of violence and mental well-being (Pinquart, Pfeiffer, 2012).

Summing up, current analyses indicate that the psychological conditions of sexual development of visually impaired adolescents have a complex character and affect all spheres of psychosocial functioning. The satisfaction of this group is largely dependent on physical well-being, strong ties with friends (Rosenblum, 2000) and activation of adults to demonstrate self-reliance (Kef, Deković, 2004). The positive perception of disability by peers and integration activities have a beneficial effect on the self-assessment of adolescents both blind and visually impaired.

The risk factor for certain abnormalities in the sexual development of a blind child is also education in a special educational centre for pupils with this type of dysfunction, which is often associated with the necessity of staying in a dormitory. Difficulties in adapting to such a situation experienced by children who are not ready for separation with the main caregivers may be secondary to such disorders in the area of sexuality as: lack of security in relationships with loved ones, difficulties in regulating emotional states and emerging as a result, substitutive forms of sexual behaviour (instrumental masturbation aimed at reducing anxiety, provocative behaviour aimed at obtaining peer group approval or attention from adults) (Zielona-Jenek, Chodecka, 2010). In analysing the problem of sexuality of children and youth with visual disability, the issue of emotional and social residence in the dormitory cannot be overlooked, as, according to national statistical data, despite the steady increase in the number of visually impaired students in inclusive and mainstream settings, the majority of blind students still fulfil their school duties in special centres. In the national literature on the subject there is no information on these problems, including data on boarding strategies adopted for dealing with this type of specific difficulties of the charges. A small exploration by researchers in this area may be considered as some kind of neglect, especially since individual reports from practice in the form of a case study (Szymańska, Compel, Lew-Starowicz, 2013) indicate a lack of sexual education in special centres.

Sexual activity of adolescents with visual impairments – a review of research

Adolescence is a phase in the development in which dynamic, radical changes occur at the biological and emotional-social level, preparing the person to undertake tasks typical of adulthood. In addition to the consequences of biosexual maturation, intense changes in the area of social relations are specific to this stage, especially the significant increase in the role of peer group, which provides teenagers with patterns of conduct and creates conditions for experimenting, shaping personal assessments, beliefs and attitudes. Contacts with peers and group functioning related to the search for one's own experiences are considered essential elements of proper sexual development, because learning sex behaviours, seeking and choosing a partner takes place among peers, not in a family environment (Beisert, 2006a).

In this phase of life there is an increase in the intensity of sexual need as a result of increased hormonal secretion; there is a process of concretization of this need, in which people undertake sexual activity, starting with less mature forms, to go to more and more sophisticated forms of erotic contacts (Radomski, 2010). The assessment of the course of this process in the group of adolescents with visual disability is difficult due to the small number of scientific studies devoted to this issue. On the basis of the few explorations concerning blind adults, some researchers claim that the sexual development of people with visual disabilities may, to some extent, run in a manner that differs from the typical, e.g. include other preferences of forms of sexual activity (Zielona-Jenek, Chodecka, 2010).

Interesting data in this area was provided by research in which participated 140 students with physical disability, visual or hearing impairment from special schools aged from 14 to 17. The results of the survey conducted in this group were compared with the answers of 306 non-disabled adolescents. The respondents were self-fulfilling the non-standardized questionnaire of the Federal Centre for Health Education. The research was aimed at determining whether adolescents with disabilities are less sexually active than their non-disabled peers. It turned out that 28% of people in the first group had sexual intercourse. Among them prevailed male persons and teenagers with hearing impairments. 39% of non-disabled respondents had sexual intercourse; girls prevailed in this group. Interestingly, despite the smaller sexual activity, disabled respondents experienced sexual contacts earlier than their peers from the control group. 36% of all adolescents examined were in permanent relationships, however, people with disabilities were less likely to have sexual intercourse. Among the predictors of sexual intercourse were: higher age, lack of disability and permanent relationship. The willingness to talk about sexuality played a minor role (Wienholz et al., 2016). The reference of these data to other studies involving only young adults with visual disabilities shows some discrepancies. Admittedly, subjects with visual dysfunction undertook sexual activities almost as often as their able-bodied peers and cohabited regularly, but sexual initiation took place about two or three years later, i.e. they started sexual activity more often in the early adulthood phase (Kelly, Kapperman, 2012).

Later initiation and a smaller range of sexual experiences were also found in Dutch studies devoted to the analysis of sexual knowledge, sexual behaviour and the psychological adaptation of blind teenagers. The results of a survey conducted in a group of 36 blind adolescents (16 boys and 20 girls) did not show any problems in the field of sexual knowledge or psychological adaptation. However, some difficulties have been revealed in the area of sexual activity. Almost all (94.4%) respondents stated that they were in love. Most of them (75%) also went on dates. Of the entire group, 86.1% had romantic relationships with less than two partners, and 13.9% had more partners. 57.7% of the whole group was less than 16.5 years old when it participated in the first date, and 42.3% were already older then. Twelve participants refused to provide information on whether they had had sexual intercourse. With regard to the variables studied in terms of sexual behaviour, one significant difference was found between the subgroups: the boys had sexual intercourse earlier than girls. No significant trend was found, however, with regard to the housing situation or the age of the respondents in which they survived the first date. In addition, a subgroup analysis showed that blind boys had higher self-esteem if they had already had sexual intercourse. If they saw their family as overprotective, their sexual experiences were less frequent. It was noticed that if the boys were dealing with the family's opposition, they co-habituated more often. These results did not concern girls from this sample. The research revealed not only that the able-bodied youth begin to go on dates and begin sexual intercourse earlier than the visually disabled, but also more often talk about it in the peer group. It was found that the information about the sightlessness and its consequences were relatively low both in the subjects with visual disability and in non-disabled youth. In the opinion of the authors of the research, the improvement of the relationship between sighted and blind adolescents, resulting in a more relaxed atmosphere conducive to conversations on difficult and intimate topics, is possible only when actions are taken to raise knowledge about the diversity of functioning in a situation of lack of eyesight. Important are also systematic therapeutic interactions that support blind people in the process of accepting limitations resulting from their dysfunction (Kef, Bos, 2006).

The perception of one's disability in the context of changes occurring during adolescence was the subject of research carried out in the quality strategy at the Pedagogical Support Centre. Participants in the study were five girls aged 12–17 years, one with visual impairment, the other blind. The questions in the in-depth interviews concerned knowledge about the causes of their vision problems, family functioning, emotional and sexual experiences, understanding of issues related to sexuality, including methods of contraception and sexually transmitted diseases. Analysis of the collected material has shown that girls with visual disabilities display characteristics of sexual development typical of their age group, however, some differences were also observed. The subjects showed interest in sex, their curiosity was significant – they declared their willingness to get to know their body and learn about its functioning. Young girls with visual disabilities expressed a desire to discover their own sexuality and find appropriate ways to express sex drive and to experience closer relationships. However, the inability to see was an obstacle that disrupted the sense of physical integrity, the image of the body of a sexually attractive person, and influenced the ability to choose a partner. The knowledge of the respondents on methods of contraception and venereal diseases was superficial and insufficient. Only one of the teenagers mentioned that her parents gave her advice on emotional and sexual life, but these were vague warnings about the possible risks associated with sexual activity. Sexuality issues were most often neglected in conversations with teenagers. Due to the fact that there was a lack of dialogue between girls and their parents, the respondents, wanting to satisfy their curiosity and explain their doubts, turned to friends. Interestingly, girls named television as one of the sources of knowledge about sexuality. Although due to sensory limitations they could not directly use the visual message, they tried to acquire the presented information and understand the main message of the program. Interesting was also the perception of various aspects of family life and social roles related to gender, which in the respondents differed somewhat from the traditional model. In the opinion of the respondents, taking the position of the head of the family was not only determined by the factor of being the main host, but equally important was the ability to advise other family members, support or set tasks and manage their implementation (Bezerra, Pagliuca, 2010).

Summary

In the population of people with disabilities, the highest percentage of partnerships is noted among people with sensory dysfunctions. These relationships function in a manner similar to those of non-disabled people, and the quality of psychosexual life is high in this group (Radomski, 2010). Obtaining such level of sexual well-being in adulthood requires, however, appropriate supporting actions during childhood and adolescence, which minimize the negative impact of congenital sense damage on the functional, mental and social area of functioning in this sphere and thus avoid possible irregularities or disturbances in the course of sexual development.

In the case of visual impairments, the key issues are: properly conducted sex education, activating adolescents to establish closer relationships with peers and activities outside the home environment, pro-dilution activities that prevent prejudices or overcome negative attitudes towards blind and visually impaired people as potential partners. Due to the strong feedback between the social and psychological aspect of the sexual life of people with visual disabilities, it is equally important to support adolescents in building a positive image of their own person, accepting their corporality, shaping the sense of interpersonal attractiveness while looking at the different functioning resulting from having a specific type of dysfunction.

Previous studies devoted to the issues of sexuality of blind and visually impaired youth are few and, due to the nature of the trials under review, do not give rise to unambiguous conclusions referring to the entire population in question. The almost complete lack of national research in this thematic area is noteworthy. The data obtained so far may be the basis for the design of broader research studies, taking into account the high internal diversity of the population of visually impaired people resulting, among others, from a different degree of eye damage and its functional consequences. A significant cognitive and application value would have been research in diagnosing particular types of facilities (special, inclusive, generally available) current status of sexual education among blind and visually impaired students, especially in the area of assessing the correctness of teaching methods. Undoubtedly, there is also a need to conduct research aimed at understanding, describing and analysing sexual activity of blind and visually impaired adolescents in the context of mentalization and concretization of sexual need and the role of environmental influences (family, school, peer group) on the normative course of development in this sphere. An interesting material, of great importance for the design of the upbringing process, could also be provided by research explaining the differentness of psychosexual development of people with visual disabilities in adolescence due to sex and the nature of dysfunction (congenital vs. acquired) in relation to sociocultural patterns of femininity – masculinity, beauty and attractiveness.

Bibliography

Beisert, M. (2006a). Trud dorastania seksualnego. In: M. Beisert (Ed.), *Seksualność w cyklu życia człowieka*. Warszawa: Wydawnictwo Naukowe PWN.

Beisert, M. (2006b). W poszukiwaniu modelu seksualności człowieka. In: M. Beisert (Ed.), *Seksualność w cyklu życia człowieka*. Warszawa: Wydawnictwo Naukowe PWN.

Bezerra, C.P., Pagliuca, L.M.F. (2010). The experience of sexuality by visually impaired adolescents. *Revista da Escola de Enfermagem da USP*, *44*(3), 577–582.

Cepeda, C. (2012). *Badanie psychiatryczne dzieci i młodzieży. Podręcznik kliniczny*. Wrocław: Elsevier Urban & Partner.

Czerwińska, K. (in print). Edukacja seksualna dzieci i młodzieży z niepełnosprawnością wzroku. *Niepełnosprawność – zagadnienia, problemy, rozwiązania.*

Datta, P. (2014). Self-concept and vision impairment: A review. *British Journal of Visual Impairment*, *32*(3), 200–210.

Garbat, M. (2013). Społeczne i ekonomiczne modele niepełnosprawności. *Niepełnosprawność i Rehabilitacja*, *1*, 15–29.

Halder, S., Datta, P. (2011). An exploration into self concept: A comparative analysis between the adolescents who are sighted and blind in India. *British Journal of Visual Impairment*, *30*, 31–41.

Huurre, T.M., Aro, H.M. (1998). Psychosocial development among adolescents with visual impairment. *European Child & Adolescent Psychiatry*, *7*(2), 73–78.

Kef, S., Bos, H. (2006). Is love blind? Sexual behavior and psychological adjustment of adolescents with blindness. *Sexuality and Disability*, *24*, 89–100.

Kef, S., Deković, M. (2004). The role of parental and peer support in adolescents well-being: A comparison of adolescents with and without a visual impairment. *Journal of Adolescence*, *27*, 453–466.

Kelly, S.M., Kapperman, G. (2012). Sexual activity of young adults who are visually impaired and the need for effective sex education. *Journal of Visual Impairment & Blindness*, *106*(*9*), 519–526.

Kijak, R.J. (2010). *Seks i niepełnosprawność. Doświadczenia seksualne osób z niepełnosprawnością intelektualną*. Kraków: Oficyna Wydawnicza Impuls.

King, B.H., Hauser, P.C., Isquith, P. (2006). Neuropsychiatric aspects of blindness and severe visual impairment and deafness and severe hearing loss in children. In: C.E. Coffey, R.A. Brumback (Eds.), *Pediatric neuropsychiatry*. Philadelphia: Lippincott Williams & Wilkins.

López-Justicia, D., del Carmen Pichardo, M. (2001). Self-concept and gender in Spanish low-vision adolescents. *Visual Impairment Research*, *3*(*1*), 7–16.

Nowak, M., Gawęda, A., Janas-Kozik, M. (2010). Fizjologiczny rozwój psychoseksualny dzieci i młodzieży. *Seksuologia Polska*, *8*(*2*), 64–70.

Ostrowska, A. (2007). Seksualność osób niepełnosprawnych. In: A. Ostrowska (Ed.), *O seksualności osób niepełnosprawnych*. Warszawa: Instytut Rozwoju Służb Społecznych.

Parchomiuk, M. (2012). Specialists and sexuality of individuals with disability. *Sexuality and Disability*, *30*, 407–419.

Pfeiffer, J.P., Pinquart, M. (2011). Control Strivings in attaining peer-group membership and forming romantic relationships among adolescents with and without visual impairment. *British Journal of Visual Impairment*, *29*(*2*), 113–129.

Pilecka, W. (2004). Wychowanie seksualne w systemowej rehabilitacji dziecka niepełnosprawnego. In: M. Kościelska, B. Aouila (Eds.), *Człowiek niepełnosprawny. Rodzina i praca*. Bydgoszcz: Wydawnictwo AB.

Pinquart, M., Pfeiffer, J.P. (2012). Body image in adolescents with and without visual impairment. *British Journal of Visual Impairment*, *30*(*3*), 122–131.

Radomski, D. (2010). Seksualność osób niepełnosprawnych. In: Z. Lew-Starowicz, V. Skrzypulec (Eds.), *Podstawy seksuologii*. Warszawa: Wydawnictwo Lekarskie PZWL.

Rosenblum, L.P. (2000). Perceptions of the impact of visual impairment on the lives of adolescents. *Journal of Visual Impairment & Blindness*, *94*, 434–445.

Szymańska, M., Compel, M., Lew-Starowicz, Z. (2013). Seksualność osób niewidomych. Studium przypadku. *Przegląd Seksuologiczny*, *34*, 27–33.

Wienholz, S., Seidel, A., Michell, M., Haeussler-Sczepan, M., Reidel-Heller, S.G. (2016). Sexual experiences of adolescents with and without disabilities: Results from a cross-sectional study. *Sexuality and Disability*, *34*, 171–182.

Wild, T.A., Kelly, S.M., Blackburn, M.V., Ryan, C.L. (2014). Adults with visual impairments report on their sex education experiences. *Journal of Blindness Innovation & Research*, *4*(*2*).

Zielona-Jenek, M., Chodecka, A. (2010). *Jestem dziewczynką, jestem chłopcem. Jak wspomagać rozwój seksualny dziecka*. Gdańsk: GWP.

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HOW FAST CHILDREN WITH INTELECTUAL DISABILITIES SPEAK

The article takes a position on speaking rates in people with intellectual disabilities, where speech tempo is a research category. It presents the findings of research on speech tempo in special school students with moderate and mild intellectual disabilities, which are compared to the results of a control group – nondisabled peers.
Students' utterances were analyzed in terms of selected quantitative and qualitative aspects of speech. They included: the number of sounds used in a 30-second-long speech segment, the number of pauses, and also the percentage share of pauses in an utterance. To test research hypotheses, statistical analyses of the linguistic material collected were made with the use of the Student's t-test, the non-parametric Mann-Whitney U test, and the Shapiro-Wilk test.

Keywords: speaking rate, speech tempo, moderate intellectual disability, mild intellectual disability, speech disorders

Introduction

In the characteristics of speech disorders (the speech of people with intellectual disabilities) the following phenomena, which are specific for the disorder, are mentioned: slower tempo of passive and active vocabulary development, difficulties in creating two – and more expressive statements, here: disruption of syntactic competence, use of incorrect grammatical forms, here: persistent inflectional problems, difficulties in creating coherent longer texts, here: reduction of narrative efficiency (Jęczeń, 2015, p. 268; Kaczorowska-Bray, 2017). At the same time, in the oligophrenologopedic literature, the statement – usually arbitrary and unambiguous – of the slow-motion rate of statements of people with intellectual disability is quite often found. If they do not fall directly, they are implied by negative linguistic phenomena indirectly influencing the speed with which representatives of this heterogeneous group make up statements. For example, Jacek Błeszyński (2013, p. 47) lists such phenomena as slowing down the rate of speech, growing disturbances in the fluency of speaking; Katarzyna Kaczorowska-Bray (2012, pp. 55–56) – decreased verbal activity, difficulties in remembering the right word, difficulties in updating names causing frequent breaks in the search for words; Urszula Jęczeń (2015, p. 268) – widely understood articulation disorders, and Tadeusz Gałkowski (1979, p. 192) and Zbigniew Tarkowski (2003, p. 209) – stuttering. Undoubtedly, the highlighted phenomena may in principle affect the rate of expression of people with intellectual disabilities, which – in addition to other prosodic disorders – we recognize after Stanisław Grabiasem (2012) as determinant of the formative deficiency of this group of language users. In order to verify judgments and hypotheses, research on specific speech parameters of persons affected by intellectual disability was carried out, which – thanks to the use of quantitative and statistical analysis – clearly answer the question of how quickly these people are saying.

Pace of speaking and the rate of utterance

In order to determine the speed of speaking, the rate of respondents' utterances, which is related to the fluency of speech defined by Tomasz Woźniak (2012, p. 550), should be analysed in terms of seamless building of the phonic sequence understood by the recipient: "Liquidity consists in the continuity of the following after each other of speech sounds that occur within regularly repeating rhythmic groups (phrases), lasting about 2–3 seconds, almost identically ordered in prosodic terms. The phrase can be filled with a different number of sounds (syllables) depending on the pace of speaking, with the average speaking rate in the colloquial speech 10–12 sounds (4–5 syllables) per second. There is a short pause between the phrases, the duration of which is not strictly defined. In the case of an uninterrupted speech, however, it should be shorter than 2 seconds, since there is no significant value" (ibid.). In connection with this, while indicating the pace of speaking, these regular repetitive rhythmic groups (phrases), lasting about 2–3 seconds (i.e. also Cholewiak, 2016) are used for analyses.

In real speech, except for phrases, there are pauses, or breaks in the phonetic sequence. Breaks – irrelevant when setting the pace of speaking – are crucial in the analysis of the rate of utterance, which includes both individuals in phrases (sounds or syllables), as well as pauses, and is calculated in longer than the phrase fragments of utterance. Pauses form a significant part of them, and also affect their shape, reception or understanding (Cholewiak, 2016; Michalik, Cholewiak, 2017). This rate of utterance is an important parameter in the communication process. During the speech it is modulated. This strategy prevents the effect of the monotony of speech, influences the level of attention of the listener, because the intended slowdown helps emphasize the most important point of utterance, in turn its acceleration - improves and strengthens the expression of the message (Milewski, 2017; Zyss, Zięba, 2015).

Putting the theoretical problem synthetically, one can assume that the pace of speech informs about the number of spoken words (or syllables) in the sentence phrase and unit of time, the rate of utterance in turn obliges to add to the previous data also the characteristics of pauses that are outside of the rhythmic groups, but co-creating a specific statement with the voices (Michalik, Cholewiak, Jagiełowicz, 2016, p. 86).[1] For the purposes of the studies on the rate of utterance of people with intellectual disabilities, we assumed that the rate of utterance would be a better research category because it is more closely correlated with real verbal messages created by subjects of research.

The rate of utterance of people with intellectual disabilities – own research

Assumptions

To explore the research problem, which is the speed of creation of utterances by people with intellectual disabilities, the rate of utterances of students with moderate intellectual disabilities was assessed and the rate of utterances of students with intellectual disabilities to a light extent, referring to the control group, i.e. children in intellectual norm . The research subjects were intellectually disa-

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[1] It is worth noting that Anglo-Saxon literature uses the term "rate of articulation", which is measured taking into account the syllables per second, words per minute and turnout pauses, while the term rate ('tempo'), after David Crystal (2008, pp. 427, 504), is used in phonetics and phonology in relation to the pace of speaking. The pace of speaking is the subject of contrastive research also on the level of suprasegmental phonology. Differences in the rate of utterance are analysed on the suprasegmental phonetics and phonology level, along with changes in the pitch and volume of speech sounds, as part of general speech rhythm research (ibidem). In turn, Anja Lowit (2014, p. 408) notes that the tempo of speech (speed of utterance) is important for the intelligibility of speech and is probably an aspect of the most commonly assessed prosody.
In the Russian-language literature of the subject, it is emphasized that the pate of speech (ros темп речи / движение речи) depends on the individual predispositions of the speaker, his emotional state, communication situation and pronunciation style (Светозарова, 1998, p. 508). In addition to the excessively accelerated and slow pace of speaking (темп речи быстрый, темп речи медленный), the pace of speech is still distinguished (темп речи прерывистый), in which the verbal communication is clearly divided into short sections (Ахманова, 1969). In speech therapy work it is emphasized that the disturbed rate of speech (темп речи нарушенный) is manifested in its excessive acceleration, slowdown or interruption/breaking. Speech disorder can be physiological or pathological (functional or organic); see. batarism, bradylalia, stuttering, physiological iterations, ticker, tachylalia (Šiliversov, 2004).

bled people to mild and moderate degree. The selection of study groups is due to the fact that among people with diagnosed intellectual disabilities as many as 85% are people with mild disability, with moderate intellectual disability there are 6% (Kaczorowska-Bray, 2017). People with profound and deep intellectual disabilities are not included because they constitute a relatively small percentage of the population and it is difficult to obtain a continuous statement as a material for analyses in the studied group due to the depth of speech disorders.

Research hypotheses

Before undertaking the research, the following research hypotheses were formulated:

1. There are significant differences in the average rate of utterance of children with moderate intellectual disabilities and children in developmental norms.
2. There are significant differences in the average rate of utterance of children with moderate intellectual disabilities and children with mild intellectual disabilities.
3. There are significant differences in the average pace of speech of children with moderate intellectual disabilities and children in developmental norms.
4. There are significant differences in the average pace of speech of children with moderate intellectual disabilities and children with mild intellectual disabilities.
5. There are significant differences in the average duration of pauses in the utterances of representatives of the three groups of respondents.
6. There are significant differences in the average speaking time in the utterances of representatives of the three groups of respondents.

Material and methods of research

The first stage of the research involved gathering recordings of children’s utterances. Each of the students previously knew the person conducting the research (student-teacher relationship). During individual meetings students were asked the following questions: What are you doing in the classroom/in the group? What are you playing in the group? What did you do in the common room? What have you done today? What did you do yesterday? What do you usually do at home? What will you do?

The material collected for research was audio recordings, and their multiple playback enabled measurements of significant phenomena to be made. For this purpose, the Audacity computer program was used.[2]

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[2] Audacity Team (2014). Audacity(R): Free Audio Editor and Recorder [Computer program]. Version 2.1.0 retrieved September 19th 2015 from http://audacity.sourceforge.net/.

The number of phones in the utterance and the duration of pauses (see Michalik, Cholewiak, Jagiełowicz, 2016) were considered indicators of the rate of utterance of a specific language user. From the whole of the utterance created by the sender, a continuous fragment was chosen, not interrupted by the recipient's reactions. The length of the fragment that has been analysed is 30 seconds.

The analysis of the selected recording began with its holistic hearing. Repeatedly listening to the statement made it possible to make a simplified record – allowing to indicate the number of phones.[3] The written statement also contains information about the pauses that appear during its creation, their duration and form. We present examples of statements of people with intellectual disabilities in mild and moderate degree, along with the results of partial quantitative analyses.

Fragment of the utterance of a student with intellectual disabilities to a mild degree: (-) [0.92 s] that he plays when there is a football player here [że on gra jak jest tu piłkarz] (-) [0.39 s] and here [a tutaj] (-y) [2.08 s] that he also helps a little [że pomaga też troche] (-) [0.29 s] must come back [musi sie wracać] (-y) [0.37 s] forward and backward [do przodu i do tył] (-) [0.36 s] because I still go to football [bo ja i tak chodze na piłke nożnom] (-) [0.2 s] yes [no] (-) [0.36 s] exercises then we play a moment [ćwiczy potem gramy chwile] (-) [0.55 s] and the end of the training because it the lasts only an hour [i już koniec treningu bo godzina tylko trwa] (-) [0.62 s] because, for example, in [bo na przykład w] (y-) [0.71 s] next Saturday we have a tournament [nastempnom sobote mamy turniej] (-) [0.39 s] I have already had [ja już miałem] (-) [0.48 s] on that Saturday [w tamtom sobote] (-od-) [2.31 s] since February [od lutego] (-) [0.34 s] already [już] (-) [0.35 s].

Number of phones – 223.
Rate of utterance: 7.43 phones/s (3 syllables/s).

Pauses	Number of pauses	Duration of pauses
In utterance	16	10.72
Proper	12	5.25
Filled	0	0
Partially filled	4	5.47

Percentage of pauses in speech: 35,73%.

Fragment of the utterance of a student with intellectual disabilities to a moderate degree: (-) [1.4 s] well I was going to England [no jechałem na anglii] (-)

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[3] Transcription has a form consistent with the rules of general spelling (the record includes grammatical errors).

[1.2 s] there was on the train [było w pociongu] (-yy) [1.9 s] there wasn't[nie było] (-po) [0.57 s] the weather on the sea [pogody na morzu] (u-) [2,85 s] no (-y) [0.72 s] I was playing walking with a dog [bawiłem sie chodziłem psem] (-) [1,78 s] outside [na dworze] (e-) [0.88 s] yes, it was great [no było ekstra] (-) [0.2 s] af [po] (-) [0.36 s] ter [tem] (-) [0.57 s] mother me [mama mi].

Number of phones – 98.
Rate of utterance: 3.26666667 phones/s (1,43333333 syllables/s).

Pauses	Number of pauses	Duration of pauses
In utterance	11	12.43
Proper	6	5.51
Filled	0	0
Partially filled	5	6.92

Percentage of pauses in speech: 41.4333333%.

After counting the phones in the speech, the student's rate of utterance could be indicated. At this stage, it was also possible to calculate the rate of utterance and indicate the percentage share of pauses. Additionally, by determining the difference between the duration of phones and the duration of pauses, the speaking pace was determined (see Michalik, Cholewiak, 2017).

Characteristics of the subjects

The language material obtained from sixteen children affected by intellectual disability to a mild degree, described and analysed in terms of accepted research criteria, was compared with analogous data obtained from sixteen children with moderate intellectual disability and data obtained from properly developing students (control group). The comparative characteristics of the studied groups are included in Table 1.

Findings

Quantitative data

The following parameters were analysed: speaking time (s), duration of pauses (s), participation of pauses in statements (%), average rate of speech (votes / s), average rate of expression (sounds/s + duration of pauses). Obtained results are collectively presented in Table 2.

Table 1

Comparative characteristics of the studied groups

Comparison criteria	Students in the intellectual norm	Students with mild intellectual disabilities	Students with moderate intellectual disabilities
Average age of respondents (in years)	9.1	9.3	15.3[4]
Average intelligence quotient	norm	60 II	46 II
Gender parameter – girls/boys	5/11	5/11	5/11

Table 2

Parameters of the rate of utterance of people with intellectual disabilities to a mild degree and moderate degree on the background of the parameters of the rate of utterance of people in the control group – quantitative data

Comparison criteria – research parameters	Students in the intellectual norm	Students with intellectual disabilities to a mild degree	Students with intellectual disabilities to a moderate degree
Average rate of utterance	7.1975 phones/s	6.60625 phones/s	3.2875 phones/s

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[4] When comparing data between intellectually disabled people to a mild degree and the norm, there was no so-called criterion of mental age. Although in the subject literature the skills of children with intellectual disability are often compared to the control group of younger students with register in the intellectual norm (both groups operate at the same level of mental age), this solution was abandoned mainly due to the relatively low record age of the intellectually disabled. Referring to the mental age criterion, it is assumed that people with intellectual disabilities to a mild extent function mentally at the level of 9- and 10-year-olds with typical development.

When examining 9-year-olds who are intellectually disabled to a mild degree, we do not know to what recordable age they should be referred. Therefore, the criterion of biological age (see Kaczorowska-Bray, 2017) was used as the comparison level. In turn, when comparing data between the intellectually disabled and moderate with the norm, the mental age criterion was adopted – it was assumed that moderately disabled people function mentally on the level of 6–9 year olds with typical development. According to the ICD-10 classification (1998, p. 128), people with intellectual disabilities reach the following mental age: significant intellectual disability – 3 to less than 6 years; moderate intellectual disability – 6 to less than 9 years; intellectual disability to a mild degree - within 9 to less than 12 years (see Kaczorowska-Bray, 2017).

Table 2

Average pace of speaking	11.226875 phones/s	10.990625 phones/s	7.7875 phones/s
Time of speaking	19.23 s	17.84 s	13.26 s
Duration of pauses	10.77 s	12.16 s	16.74 s
Average share of pauses in utterances	12.5625 (ok. 13 pauses) 35.895%	14.375 (ok.14 pauses) 40.52875%	10.1875 (ok. 10 pauses) 55.8%
Number of respondents	16	16	16
Age of respondents (in years)	9.1	9.3	15.3

Estimated assessment of the obtained results allows to note the differences between individual parameters in the three groups studied. With the degree of disability, the rate of utterance and the pace of speaking decrease and the time of speaking is also shortened in favour of the duration of pauses. The significance of these differences has been assessed using statistical tools.

Statistic data

Statistical analyses of the collected material covered the same data groups – parameters. In order to check the differences between the two groups, parametric Student’s t-test and Mann-Whitney non-parametric U test were performed. The first of them was used for variables whose distribution had the character of a normal distribution, the second – if the assumption was not met. The character of the distribution of variables was checked using the Shapiro-Wilk test. In all analyses, the significance level was assumed $p = 0.05$.

When comparing all the parameters that make up the rate of utterance in two groups, i.e. people in the intellectual norm and those with moderate intellectual disabilities, the following results were obtained (Table 3).

The data contained in Table 3 shows that a statistically significant result was recorded in relation to all parameters, i.e. duration of all pauses, speaking time, average pace of speaking, number of pauses, pauses in statements, and – most importantly – average rate of utterance.

Comparing, in turn, parameters that make up the rate of utterance in people with moderate intellectual disabilities and people with intellectual disabilities to a mild degree, the following results were obtained (Table 4).

Table 3

Parameters of the rate of utterance of people with intellectual disability to a moderate level in terms of parameters of the rate of expression of people in the control group – statistical data

Research parameters	Groups										Test results
	Norm					Moderate intellectual disability					
	$\bar{x}$	*s*	min.	max.	me	$\bar{x}$	*s*	min.	max.	me	
Duration of pauses	10.77	1.95	7.41	14.27	10.90	16.74	3.82	11.13	24,24	16.78	t = –5,574 df = 22 p < 0.001
Time of speaking	19.23	1.95	15.73	22.59	19.10	13.26	3.82	5.76	18.87	13.23	t = 5.574 df = 22 p < 0.001
Average pace of speaking: phones/s	11.23	1.50	8.69	13.72	11.52	7.79	1.77	5.60	12.30	7.35	t = 5.929 df = 30 p < 0.001
Number of pauses	12.56	2.76	7.00	18.00	12.00	10.19	1.80	7.00	13.00	10,00	t = 2.887 df = 30 p < 0.001
Share of pauses in utterances	35.90	6.50	24.70	47.56	36.33	55.80	12.74	37.10	80.80	55.90	t = –5.566 df = 22 p < 0.001
Average rate of utterance: phones/s	7.19	1.27	5.70	10.33	7.12	3.29	0.62	1.80	4.10	3.35	t = 11.031 df = 22 p < 0.001

Table 4

Parameters of the rate of utterance of people with intellectual disability to a moderate degree against the parameters of the rate of utterance of intellectually disabled people to a mild degree – statistical data

Research parameters	Groups										Test results
	Mild intellectual disability					Moderate intellectual disability					
	$\bar{x}$	*s*	min.	max	me	$\bar{x}$	*s*	min.	max	me	
Duration of pauses	12.16	3.66	6.67	17.35	11.52	16.74	3.82	11.13	24.24	16.78	t = –3.467 df = 30 p = 0.002
Time of speaking	17.84	3.66	12.65	23.33	18.49	13.26	3.82	5.76	18.87	13.23	t = 3.467 df = 30 p = 0.002

Table 4

Average pace of speaking: phones/s	10.99	2.35	8.10	15.13	10.12	7.79	1.77	5.60	12.30	7.35	t = 4.362 df = 30 p < 0.001
Number of pauses	14,38	2,42	9,00	20,00	15,00	10,19	1,80	7,00	13,00	10,00	t = 5,559 df = 30 p < 0.001
Share of pauses in utterances	40.53	12.20	22.23	57.83	38.38	55.80	12.74	37.10	80.80	55.90	t = –3.463 df = 30 p = 0.002
Average rate of utterance: phones/s	6.61	2.28	3.76	11.76	6.18	3.29	0.62	1.80	4.10	3.35	t = 5.614 df = 17 p < 0.001

A statistically significant result also in this case was noted for all the parameters listed.

The results of the comparison of parameters that make up the rate of utterance of people with intellectual disabilities to a mild degree and in the intellectual norm are included in table 5.

Table 5

Parameters of the rate of utterance of people with intellectual disabilities to a mild degree against the background of parameters of the rate of utterance of people in the intellectual norm – statistical data

Research parameters	**Groups**										**Test results**
	Norm					**Mild intellectual disability**					
	$\bar{x}$	*s*	min.	max.	me	$\bar{x}$	*s*	min.	max.	me	
Duration of pauses	10.77	1.95	7.41	14.27	10.90	12.16	3.66	6.67	17.35	11.52	t = –1.342 df = 23 p = 0.193
Time of speaking	19.23	1.95	15.73	22.59	19.10	17.84	3.66	12.65	23.33	18.49	t = 1.342 df = 23 p = 0.193
Average pace of speaking: phones/s	11.23	1.50	8.69	13.72	11.52	10.99	2.35	8.10	15.,13	10.12	*t* = 0.339 *df* = 26 *p* = 0.737

Table 5

Number of pauses	12.56	2.76	7.00	18.00	12.00	14.38	2.42	9.00	20.00	15.00	$t = -1.977$ $df = 30$ $p = 0.057$
Share of pauses in utterances	35.90	6.50	24.70	47.56	36.33	40.53	12.20	22.23	57.83	38.38	$t = -1.341$ $df = 23$ $p = 0.193$
Average rate of utterance: phones/s	7.19	1.27	5.70	10.33	7.12	6.61	2.28	3.76	11.76	6.18	$t = 0.905$ $df = 30$ $p = 0.372$

In this case, no statistical differences were found in any of the parameters analysed.

Summary

The analyses carried out showed that there are no statistically significant differences in the scope of these parameters between the utterances of children with intellectual disabilities to a mild degree and children in the developmental standard. However, there are significant differences in the average rate of utterance and the average pace of speaking of children affected by moderate intellectual disabilities and children in developmental norms. The same conclusions concern differences in the average rate of utterance, the average pace of speaking and the parameters of specific children affected by intellectual disabilities in moderate degree and those affected by intellectual disabilities in a mild degree. Therefore, it results from the calculations that the rate of utterance determining the speed with which messages are created clearly differentiates two groups of language users: people in intellectual norm and intellectually disabled to a mild and moderate degrees. It can therefore be assumed that people from the second group speak much slower, use more pauses, which in addition last longer than those of people from the first group.

Bibliography

Ахманова, О.. (1969). Словарь лингвистических терминов. Москва: Издательство «Советская Энциклопедия».

Błeszyński, J. (2013). *Niepełnosprawność intelektualna. Mowa – język – komunikacja. Czy iloraz inteligencji wyjaśnia wszystko?* Gdańsk: Wydawnictwo Harmonia.

Cholewiak, A. (2016). Tempo wypowiedzi gimnazjalistów – pilotażowe badania ilościowo-jakościowe. *Forum Logopedyczne*, *24*, 101–111.

Crystal, D. (2008). *A dictionary of linguistics and phonetics 6th edition*. Oxford.

Gałkowski, T. (1979). *Dzieci specjalnej troski. Psychologiczne podstawy rehabilitacji dzieci opóźnionych umysłowo*. Warszawa: Wiedza Powszechna.

Grabias, S. (2012). Teoria zaburzeń mowy. Perspektywy badań, typologie zaburzeń, procedury postępowania logopedycznego. In: S. Grabias, M. Kurkowski (Eds.), *Logopedia. Teoria zaburzeń mowy* (pp. 16–69). Lublin: Wydawnictwo UMCS.

Jęczeń, U. (2015). Postępowanie logopedyczne w przypadku oligofazji. In: S. Grabias, J. Panasiuk, T. Woźniak (Eds.), *Standardy postępowania logopedycznego. Podręcznik akademicki* (pp. 267–282). Lublin: Wydawnictwo UMCS.

Kaczorowska-Bray, K. (2012). Zaburzenia komunikacji językowej w grupie osób z niepełnosprawnością intelektualną. In: J. Błeszyński, K. Kaczorowska-Bray (Eds.), *Diagnoza i terapia logopedyczna osób z niepełnosprawnością intelektualną* (pp. 36–64). Gdańsk: Harmonia Universalis.

Kaczorowska-Bray, K. (2017). *Kompetencja i sprawność językowa dzieci z niepełnosprawnością intelektualną w stopniu znacznym, umiarkowanym i lekkim.* Gdańsk: Wydawnictwo UG.

Lovit, A. (2014). Acquired motor speech disorders. In: L. Cummings (Ed.), *The Cambridge handbook of communication disorders* (pp. 400–418). Cambridge.

Maulik, P.K., Harbour, C.K. (2011). Epidemiology of intellectual disability. In: J.H. Stone, M. Blouin (Eds.), *International encyclopedia of rehabilitation*, http://cirrie.buffalo.edu/encyclopedia/en/article/144/.

Michalik, M. (2011). *Kompetencja składniowa w normie i zaburzeniach. Ujęcie integrujące*. Kraków: Wydawnictwo UP.

Michalik, M., Cholewiak, A. (2017). Tempo wypowiedzi w oligofazji. *Logopedia*, *46*.

Michalik, M., Cholewiak, A., Jagiełowicz, W. (2016). Niemówienie, milczenie, przemilczenie, pauza, czyli wielkie nic w teorii i praktyce logopedycznej. In: I. Jaros, R. Gliwa (Eds.), *Problemy badawcze i diagnostyczne w logopedii* (pp. 79–93). Łódź: Wydawnictwo UŁ.

Milewski, S. (2017). *Tempo mówienia*, http://www.encyklopedialogopedii.pl/tiki-index.php?page=TEMPO+M%C3%93WIENIA (access: 21.11.2017).

Селиверстов, В.И. (ред.), (2004). Понятийно-терминологический словарь логопеда. Москва: Академический Проект.

Светозарова, Н.Д. (1998). Темп речи. W: *Языкознание. Большой энциклопедический словарь.* Гл. ред. В.Н. Ярцева. Москва: Научное издательство „Большая Российская энциклопедия".

Śniatkowski, S. (2002). *Milczenie i pauza w gramatyce nadawcy i odbiorcy. Ujęcie lingwoedukacyjne*. Kraków: Wydawnictwo Naukowe AP.

Tarkowski, Z. (2003). Zaburzenia mowy dzieci upośledzonych umysłowo. In: T. Gałkowski, G. Jastrzębowska (Eds.), *Logopedia. Pytania i odpowiedzi. Podręcznik akademicki*, t. 2 (pp. 203–209). Opole: Wydawnictwo UO.

Tarkowski, Z. (2005). Mowa osób upośledzonych umysłowo i jej zaburzenia. In: T. Gałkowski, E. Szeląg, G. Jastrzębowska (Eds.), *Podstawy neurologopedii. Podręcznik akademicki* (pp. 553–605). Opole: Wydawnictwo UO.

Woźniak, T. (2012). Niepłynność mówienia. In: S. Grabias, M. Kurkowski (Eds.), *Logopedia. Teoria zaburzeń mowy* (pp. 549–565). Lublin: Wydawnictwo UMCS.

Wysocka, M. (2012). Zaburzenia prozodii mowy. In: S. Grabias, M. Kurkowski (Eds.), *Logopedia. Teoria zaburzeń mowy* (pp. 165–184). Lublin: Wydawnictwo UMCS.

Zyss, T., Zięba, A. (2015). Tempo mówienia – kilka uwag z psychiatrycznego punktu widzenia. *Neurolingwistyka Praktyczna*, *1*, 15–26.

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> *As parents, we must always have wings large*
> *enough to surround with them our children*
> *and protect them from harm or pain.*
> *It appears in our contract with God,*
> *when we take responsibility for their lives.*
> Jonathan Carrol

FAMILY WITH A CHILD WITH MULTIPLE DISABILITIES AND A CHRONICAL ILLNESS – AN EXAMPLE OF NARRATIVE ANALYSIS

Parents of disabled children not only deal with raising a child but also with their disability. The whole family experiences various implications as their lives are strongly affected by the disability. Undeniably, the whole life depends on a disability, which forces parents to redefine the family life and give it a new meaning.

The conducted research was located in the stream of constructivist and interpretative research. The attempt of meeting and understanding the world the parents preserve in their memories allowed togain 'genuine' knowledge about a family with a chronically ill child. Told narrations present difficult parenthood and everyday problems that a family must deal with. Parents' biographies concern not only weaknesses which they have to face fighting for normal life for their children but also show determination in their constant struggle in everyday life. Everyday life is very complex for them. Thus, the reality that the separents create is full of both negative and positive emotions, moments of happiness, love and mutual respect

Keywords: difficult parenthood, chronic disease, functioning of a disabled child

Parents of children with disabilities

For most parents, the birth of a child is the moment of experiencing the greatest miracle and happiness. They are preparing for their roles beforehand so that after the birth of a child they can perform them the best as they can. Expectations of parents and all their plans are significantly modified when a child with disabilities and accompanying illnesses comes into the world. Then parents experience difficult situations related to the diagnosis and acceptance of disability and child's illness, there is also a change in mutual relations, reorganization of roles and a change in the hierarchy of values (Stelter, 2013, p. 49). Parents enter a "different world" that is foreign to them, unpredictable and hostile. Their hope regarding the health and functionality of the child – values that occupy the most important place among the desirable characteristics of children (Maciarz, 2004, p. 38) – gives way to concern for its decent life and normalization of conditions (Lipińska-Lokoś, 2010, p. 341).

Being the parent of a "different" child is undoubtedly a difficult parenthood. Maria Kościelska (2003, p. 27) writes: "It is difficult to be parents of a disabled child, because apart from internal and emotional problems, in such cases there are a lot of burdens related to the treatment of children and expenses, rehabilitation, extended care period [...]. In severe states of disability, parents have practically no leave during their whole life, because they are in need of a permanent experience of nursing and nursing services."

Parents of such a child very often act under the influence of strong emotions, stress, environmental pressure, often give up their own plans and dreams (Stelter, 2013, p. 50). This results in a conflict of parental identity, because from the perspective of the parent there is no good way out of the situation. Being a parent of a disabled child can lead to "social isolation, suffering, a sense of nonsense. The implementation of one's own life plans may in turn cause a sense of guilt and expose the parent to a negative assessment of the social environment" (ibid., pp. 65–66).

The situation related to bringing up a child with disability, which is additionally imposed on by a chronic illness, sometimes turns into a crisis that can be controlled through the bond between the spouses, their mutual respect, love and responsibility. Urszula Kazubowska (2010, p. 106) writes that "it is also very important that both parents feel fully responsible for the child's fate, and that in exercising parental authority over it there should be co-management, mutual support of parents in raising a child". Parents have dilemmas regarding being a good/good mother/father (Wojciechowski, 2007, p. 88). Undoubtedly, these parents are in a complex situation that forces them to be responsible for the child, expressing themselves in the ability to transform what is necessary into a compulsory duty. The responsibility is clearly exemplified, which "appears in the form of a multi-level and multi-stage causal relationship: man – parenthood as a value – possibility – consequences" (ibid., p. 89).

Concluding these brief reflections on the parents of a child with a disability, their role in upbringing, acceptance of the "otherness" of the child and themselves as responsible for his happiness, I will quote Kościelska (1995, p. 43): "[...] there are probably no feelings that children's parents would not survive [...], because even though there is a lot of space in their lives for pain, sadness, despair and other feelings that together constitute a sense of suffering, there is also room for joy and hope, pride and happiness. The scale of sensations that arise in contact with children with special developmental problems is overwhelming."

Research methodology

The research I undertook was embedded in the constructivist and interpretive studies. In my project I based on each of the three perspectives, because methodologists point out that there were strong three pillars for the qualitative paradigm: phenomenology, symbolic interactionism and hermeneutics (Pachociński, 1997; Sztompka, 2007; Ablewicz, 1994; Mead, 2000).

Phenomenology allowed me to focus on the unique experience of each individual in the world. This is very important, especially as the parental experiences lived in situations that are different from the expected, often difficult and being a kind of existential challenge, are the element of the human biography that evokes a kind of depth of experiencing one's own destiny.

Inspired by symbolic interactionism, I assumed that the child becomes "someone" in social interpretations, drawing from them the knowledge of who they are. These interactions, constructed by parents, become at the same time the basis of their construction. In other words, we are what other people see us. Thinking about a child diagnosed with disability and its relationship with parents is of phenomenal meaning.

Drawing knowledge from hermeneutics allowed me to perceive and later to expose the interpretive openness of experiencing parenthood of a child with a disability and a chronic disease. In this way, we succeed in overcoming the interpretive ambiguity of a specific triad: parents – their child – treatment. Disrupted disability ceases to be a disease entity, and it becomes an element of social life, subject to different interpretations, various solutions that can be questioned and considered. In other words, the assumption was made that there is only a cultural and biographical experience of parenthood in the world dominated by normalization, which is also very well problematized by Michel Foucault (Rzeźnicka-Krupa, 2011, p. 93).

The purpose of my research was to reconstruct the stories of people, not the reality behind their stories. So I researched how parents experienced their reality, not the reality itself. The main problem took the form of a question: How does a family with a child with a coupled disability and a chronic disease function? I was interested in how parents feel their being in a family with a disabled child, how they define their family, how they relate to a child, what meaning they give to a family in the context of a child's disability and what is most important in their perspective.

The adoption of an interpretative perspective in this study enabled the use of the biographical method, which serves to understand "how individuals participate in social contexts and how they understand them" (Kaźmierska, 2012, p. 659). It consisted in the analysis of the slice of reality – created by parents having a child with a coupled disability and chronical illness – which allows to know the problems of such a family. The use of narrative interviews has helped me gain insight into the meaning and sense that parents give to various manifestations of their lives.

Analysis of the story told by parents

The story told by the parents is sad, overwhelming, filled with negative emotions. It contains all the feelings that accompany people in difficult random situations. They make up the picture of a family with a child with coupled disability and chronical illness. The narrators also talk about positive experiences that are the result of love, great respect for each other, and special bonds in the family. They also show the everyday life of the family.

Parents' narratives can be divided into several thematic topics, such as: critical event, powerlessness, rebellion, loneliness, responsibility, duty, dedication, limitations, resignation, marital relations, family support, financial situation. They occur in the life of the family, show the palette of individual meanings and meanings given by parents to their own experience. The birth of a child is always a wonderful event for parents. Already during pregnancy, they write a scenario of life for a baby that will soon appear in the world. However, no life plan implies the disability of a child which will dominate the life of the whole family. Marcel's mother began her biography with the words:

> The pregnancy went well without any complications. [...] Nothing indicated that there would be something wrong with the child.

This allowed future parents to prepare for the arrival of their child and enjoy this fact. Unfortunately, their joy after the birth of the child did not last long. The mother, with tears in her eyes, mentions the moments she would like to forget:

> [...] two days after the birth a doctor came and said that I should not expect too much from a child [...] because he will have shortened limbs, that [...] he will not be able to function as well as healthy children function.

The moment of notification about the child's disability was a great shock for both parents. The father speaks as follows:

> The only feelings that I experienced were disbelief and rebellion. We could not understand why it happened to us [...]. Initially, our thoughts concerned only searching for the causes of the disease. However, it did not last long. After a moment, there were

> questions about how to help our child. [...] I had the impression that the doctors talk about another child, not ours, that they made a mistake and they would immediately say it was a mistake. [...] I could not believe it, nobody said anything before, and here it turns out that our son is disabled. I thought I would die there [...] I do not know, anger, anger, regret. I do not know what I was thinking then [...].

This part of the statement shows the complexity of the emotions accompanying the parents at the time of notification of their son's disability. This situation can be described as a critical event, because for parents the emergence of a disabled child is a turning point in their current life. There is a reappraisal of plans, change of roles, realization of new duties, change of the way of thinking about a child, re-acceptance of a child and constructive action:

> My husband and I tried to look for help with various doctors, but sometimes it came out the opposite, as if [...] they attacked us, and did not support us. [...] .we knew we had to seek help for our son, because there is no one but us here [...] it is our duty as parents [...].

Parents refer to their parental roles and their obligations. They give it a lot of importance because, in their opinion, responsibility for the child and his dignified life is their fundamental duty. In this narrative, the responsibility of parents for a child collided with a difficult reality. The biography shows that the boy's parents felt helpless, powerless in consideration to specialists who instead of willing to help their son were aggressive. They were aware that they had to fight for the boy's normality because, as parents, they were left alone, and they saw that their son had more and more health problems:

> We noticed that when we called Marcel, he would catch us by the ear, that is, he did not turn to us with his mouth in the direction we were calling, he just listened. [...] he often knocked over, did not hit the door, he began wearing glasses when he was a year and three months old, and it was then that Marcel was diagnosed with kidney problems. From that moment everything started to happen.

Seeking help for their son, they went to many specialist clinics, these visits became everyday life for the family. More and more dysfunctions were detected, which terrified parents and deprived them of the rest of their faith that their son would eventually function independently. During the conversation, the mother takes the boy's medical records and lists:

> Marcel is a child with a coupled disability. He is physically disabled and partially sighted. He was diagnosed with pathological kyphosis of the spine, irregularities in the skeletal system of the arms and legs and shortness of the feet. In addition, he suffers from chronic kidney disease, stage V in bilateral hypodisplasia, and is therefore peritoneally dialyzed.

This part of the narrative is particularly difficult for the mother. The shaking hands, the breaking of the voice and the streaming tears show how much pain was caused by further diagnoses. Whenever the mother returns to these memories, the emotions come alive again. The boy's situation is very overwhelming for parents, but they try to enjoy the present. This is proved by the words of the father:

> This is not one hundred percent acceptance. We enjoy the sight of Marcel, who is happy and smiling. We enjoy the moment here and now. We try not to think about what may happen in a few years or months.

The functioning of a family with a child with a disability and a chronic illness is very difficult. Parents call such a family "different" because the child's illness and the resulting duties for all household members come to the foreground. They attach great importance to being systematic and mandatory. This is especially visible in the mother's attitude. She has each day planned very precisely, and everything is subordinated to the needs of the child. Withdrawal from the established standard is not allowed. In the plethora of duties, however, the mother finds time for pleasure and fun with her son:

> Between dialysis, if we are not on rehabilitation, we try to do some art classes at home, something for him to paint, something to do. We have a lot of board games that he's interested in, so we play a lot. Marcel also likes to watch cartoons, so I do not forbid him. And when it is hot, I try to just take him to the playgrounds, to make him stay outside.

This part of the narrative shows concern for the correct, comprehensive development of the child. Parents attach great importance to the quality of free time, because they are aware of its positive impact on the child's development, socialization or acquiring competence to fulfil social roles. They strive to ensure that the boy's free time is filled with games appropriate to his age, as well as other activities that could holistically influence his development. They want the boy's life to look normal when possible. Unfortunately, the biography shows that it is not easy. Parents suffer, seeing the various limitations in the functioning of the son, as evidenced by the words of his father:

> [...] my heart aches, when I know that he wants to do something so badly and yet he cannot do it. When I look into the child's eyes and see the flash that goes out in a moment, I want to cry.

The parents feel helpless quite often. They are not always able to control their emotions. During the narrative, tears appear which are a sign of helplessness and a sense of child's being hurt by fate. However, there are also moments that bring joy to the whole family. They have a special meaning for parents, because they are a substitute for normality for them:

> Spending time together involves having fun, reading books, playing board games, playing in the yard. We like walking together to the forest or the lake, going to the theatre or the philharmonic. We sing together and arrange concerts. Marcel takes part in housework, such as baking cakes or backyard duties such as mowing the loan or helping grandpa repair the car.

Involvement in matters of a disabled son causes that parents have little time for themselves. The time that is at the parents' disposal is the time spent on "talking about what was going on during the day". Parents have great respect and understanding for themselves and their needs. It gives them strength so that they can survive difficult moments. They are a great support for each other, which may cause that such an important aspect of family life as social has been shifted to the margins. Perhaps the parents did not give much importance to this level of social life, because care for the son's health is the most important thing for them. They voluntarily limited this sphere to fully take care of the child. They emphasize that this is mainly related to the 24-hour dialysis requirement, but also to the risk that Marcel could catch some infection with such low immunity. From the narrative it can be concluded that parents do not regret much about limiting social contacts, but they experience some unpleasantness from some friends who do not understand the situation and consider them to be weirdos:

> Because of his illness, Marcel catches everything very quickly, so at the very beginning, as soon as he started to be dialyzed, we separated ourselves from everyone and half of the people understood us, half treated us as weirdos [...] [...] at the beginning it was like that – when someone called us, the first thing we asked about was if they were not sick. [...] And now we see each other from time to time. It is not that we broke off all contacts, but it is difficult to reconcile social life with the child's illness. In general, friends call, ask, transfer 1% tax, they also try to guide us, – for example, some kind of a therapist they know [...]. All life revolves around the son.

In a family with a child with a disability and chronic illness, the support of friends, acquaintances or family is very important and allows the element of normality to be introduced. Marcel's parents appreciate the support of grandparents, who often take over their duties, but also support them financially and – most importantly – mentally. The boy's mother had subordinated her entire life to taking care of him, it forced her to give up her job and limit her contacts with friends. She struggles with the hardships of everyday life, which sometimes become insurmountable problems. In this situation, her mother-in-law became her closest friend and supporter:

> The coolest thing is that if something happens to Marcel [...] I run right to my husband's mother and then I try to talk to her, so as not to go crazy.

The narrative shows that the family is also struggling with financial problems, because only the boy's father works, and one salary is not enough to meet all the family's needs:

> It's hard for us [...] the costs of treatment are high. If we do not have to buy drugs to lower phosphate, it is up to a thousand zlotys, and if we have to buy this medicine [...]. sometimes the monthly costs are greater, because we have to change Marcello's dressing with the catheter. [...] Well, but a thousand, sometimes more.

An important issue that was raised during the narrative is the boy's awareness of his illness. This topic is very important for parents, because thanks to his awareness, Marcel has a sense of safety and, in addition, he takes on the habit of taking care of his health:

> [...] probably because he knows, he is calmer [...] because he knows that he must do something for his own good. [...] He is aware of this. [...] It's all from the very beginning, so Marcel does not know another life. [...] Besides, it seems to me that he is a very clever child for his age [...].

Parents are aware that their child due to his illness matures much faster and understands much more than his peers. They interpret this fact negatively, because in their opinion the boy has no normal childhood. They also note that frequent stays in hospital and being only with adults adversely affect Marcel's relationship with other children. Undoubtedly, however, parents want their son to be happy in his own way. For this reason, they decided to carry out an experiment that would show them the feelings that he is experiencing:

> Once I heard that the best way to see how a child [...] experiences family life, is to buy him a teddy bear, which he will look after, and then he placed this teddy bear on a chair, as I do sometimes, as I give him food or medicine, and there was: «Bear, eat, eat, because your stomach will hurt» or: «Teddy, now there will be an injection, grit your teeth». Surely he is aware of what we are doing with him. [...] we also realized something about it [...]. It is Marcel's illness that comes to the fore in the functioning of our family [...], not that I did not know it, but when it was said loudly, I think I'm terrified.

The carried out experiment without a doubt confirmed that the child is aware of his illness. It also showed that he perceives his life as a process of continuous treatment. It was very difficult for parents because it made them aware that their son does not have a childhood like his peers, and their family life is dominated by illness. Parents are trying very hard to make the son have the opportunity to establish relationships with their peers and they are very important to them. They give these relations a very important meaning because they are aware of how important they are in shaping the right attitudes, respecting values, adopting norms and socially recognized principles:

> He was terribly afraid of going to kindergarten even before doing it [...]. It was obvious that this child is more aware of his strength, and he cried, he ran away, so I wanted this contact [...] for him to know what children are, because when he goes to school, he must somehow adjust to what will be there in the group, he must find some friends [...] well, this is the world, no human functions in it by themselves.

The mother's statement is very disturbing. It should be remembered that the boy was not able to shape correct relationships with his peers. The only contact with other children was in the playground or during walks, when he was looked after by his mother. Parents are aware of the limitations in the normal functioning of the child and experience frustration due to their consequences.

Ending

Analysis of the narrative presents constructions of meanings that show the functioning of a family with a child with coupled disability and chronic illness. During the story emerged the categories constructed by the parents, to which they gave subjective meaning and sense. Interpreting their own experience, parents presented the truth and it allows to understand the reality of the family with a chronically ill child.

Disability of a child is a big challenge for the whole family, especially for parents. It is them who have the greatest responsibility not only in the area of nursing and caring, but also in normalizing the living conditions of the child and the whole family. Everyday members of such a family face disability and its consequences, which are visible in every aspect of their lives. Care for the health and well-being of the child is paid for with the resignation of their own plans and dreams.

The story told shows not only a complex family reality dominated by disability and chronic illness, but also the needs of families with a disabled child. Support for them is required since the very beginning, since notifying parents about the child's disability by explaining the difficulties it involves. This should be psychological, financial and institutional support necessary for treating and normalizing the living conditions of the child and the whole family.

In the narrative, the parents did not mention the help obtained from any institution, which may mean the lack of such initiative from the institutions to support a family in a very difficult situation. However, they mentioned specialists, who instead of serving them and the child with help in the diagnosis and treatment accused them and left them alone with guilt. These parents showed a huge determination in the quest to normalize the life of a sick son and the whole family. It is worth noting, however, that not all parents have the strength and courage to fight for their child and themselves. Not everyone can say: "being the parent of a healthy child is not a philosophy, but being a parent of a disabled child – that is the distinction [...] it is a kind of contract with God to ensure the normality of the child".

The categories selected in the course of the narrative refer to numerous studies on the undertaken topic (Kościelska, 1995, 2003; Borzyszkowska, 1997; Minczakiewicz, 2003; Maciarz, 2004; Pisula, 2005; Lipińska-Lokoś, 2010; Żyta, 2010; Stelter, 2013, 2015). These and other studies show a great interest in the family with disabled children and various aspects of its functioning. The family phenomenon is still interesting for researchers and still leaves many unexplained issues. Therefore, the qualitative research strategy used in this study allows you to get to know a slice of reality from the perspective of parents' subjective experience.

Bibliography

Ablewicz, K. (1994). *Hermeneutyczno-fenomenologiczna perspektywa badań w pedagogice*. Kraków: WN PAT.

Borzyszkowska, H. (1997). *Izolacja społeczna rodzin mających dziecko upośledzone umysłowo w stopniu lekkim*. Gdańsk: Wydawnictwo UG.

Kazubowska, U. (ed.). (2010) *Odpowiedzialność rodzicielska jako wartość. Teoria i praktyka*. Toruń: Wydawnictwo Adam Marszałek.

Kaźmierska, K. (2012). *Metoda biograficzna w socjologii*. Kraków: Oficyna Wydawnicza NOMOS.

Kościelska, M. (1995). *Oblicza upośledzenia*. Warszawa: Wydawnictwo Naukowe PWN.

Kościelska, M. (2003). *Odpowiedzialni rodzice. Z doświadczeń psychologa*. Kraków: Oficyna Wydawnicza Impuls.

Lipińska-Lokoś, J. (2010). Niepełnosprawność dziecka jako czynnik konstruujący życie rodziny. In: J. Cichla, J. Herberger, B. Skwarek (Eds.), *Kultura pedagogiczna współczesnej rodziny*. Głogów: Wydawnictwo PWSZ.

Maciarz, A. (2004). *Macierzyństwo w kontekście zmian społecznych*. Warszawa: Wydawnictwo Akademickie Żak.

Mead, M. (2000). *Kultura i tożsamość. Studium dystansu międzypokoleniowego*. Warszawa: Wydawnictwo Naukowe PWN.

Minczakiewicz, E.M. (2003). Normalizacja życia rodziny nadzieją i szansą na pomyślny rozwój i przyszłość dziecka niepełnosprawnego. In: E.M. Minczakiewicz (Ed.), *Dziecko niepełnosprawne. Rozwój i wychowanie.* Kraków: Oficyna Wydawnicza Impuls.

Pachociński, R. (1997). Metody ilościowe i jakościowe w badaniach oświatowych. *Edukacja*, 3.

Pisula, E. (2005). Psychologiczne problemy rodziców dorastających i dorosłych z zaburzeniami rozwoju. In: A. Twardowski (Ed.), *Wspomaganie rozwoju dzieci ze złożonymi zespołami zaburzeń*. Poznań: Wydawnictwo Naukowe UAM.

Rzeźnicka-Krupa, J. (2011). *Niepełnosprawność i świat społeczny. Szkice metodologiczne*. Kraków: Oficyna Wydawnicza Impuls.

Stelter, Ż. (2013). *Pełnienie ról rodzicielskich wobec dziecka niepełnosprawnego intelektualnie*. Warszawa: Difin.

Stelter Ż. (2015). Poczucie sensu życia rodziców dzieci niepełnosprawnych intelektualnie. *Diametros*, *46*, 92–110.

Sztompka, P. (2007). *Zaufanie. Fundament społeczeństwa.* Kraków: Znak.

Wojciechowski, F. (2007). *Niepełnosprawność. Rodzina. Dorastanie.* Warszawa: Wydawnictwo Akademickie „Żak”.

Żyta, A. (Ed.). (2010). *Rodzina osób z niepełnosprawnością intelektualną wobec wyzwań współczesności. Heurystyczny wymiar ludzkiej egzystencji.* Toruń: Wydawnictwa Edukacyjne Akapit.

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INCLUSIVE EDUCATION POLICY AND ASSURANCE OF THE QUALITY OF LEARNING FOR CHILDREN WITH DISABILITIES

The article analyzes the educational situation of students with disabilities in Vietnam. The author reviews legal acts regarding inclusive education. He also presents research aiming to determine the preparation level of preschool and school teachers in four Vietnamese regions to work in inclusive education. The results of the survey were compared with data obtained through direct observation of teachers' work in inclusive settings. It turned out that the declared level of teachers' preparation for inclusive education did not coincide with their real competences. Teachers overstated their degree of preparation to work in inclusion with students with disabilities. The author formulates a number of recommendations that are intended to improve the quality of education for students with special educational needs in Vietnam.

Keywords: persons with disabilities, inclusive education, policy, quality, Vietnam

General education programs tend to focus on the dominant group (Blankenship, Lilly, 1981). This means that there is limited access to appropriate learning opportunities for persons with disabilities (PwD) in general education programs. The results of a survey on children's school non-attendance show that persons with disabilities account for one third of children excluded who do not have access to education.

Currently, Vietnam has about 1.3 million persons with disabilities (excluding the number of persons with developmental disabilities). Since the implementation of the policy of inclusive education in the past, the number of persons with disabilities attending preschools and general education settings has increased and we have been increasingly focusing on ensuring an appropriate quality of learning. As of the end of the school year 2015–2016, there were more than 600,000 students with disabilities, mostly at the primary level (over 400,000 children) and in preschools and junior high schools.

The contents of this article are as follows: (i) inclusive education is to ensure equal and appropriate learning opportunities for persons with disabilities; (ii) policy system and effective assessment of the current educational policy system for persons with disabilities in Vietnam; (iii) effectiveness of inclusive education policies for persons with disabilities in practice – an example of survey research in four districts of Thanh Hoa province, Vietnam, in 2017; (iv) discussion and recommendations to implement the policy of inclusive education effectively, ensuring learning quality for persons with disabilities in Vietnamese schools.

Inclusive education was chosen as the main educational mode to ensure equal and appropriate developmental opportunities for persons with disabilities in Vietnam

In the Law on Persons With Disabilities No. 51/2010/QH12 of June 17, 2010, Article 3 (Paragraphs 4, 5, and 6) mentions three forms of education for persons with disabilities, including: "4. Inclusive education is the main mode of education for persons with disabilities provided in general education settings;" "5. Special education is an educational mode for persons with disabilities provided in special institutions;" and "6. Semi-integrated education is a form of education that combines inclusive education and special education for persons with disabilities in general education settings" (National Assembly…, 2010).

Currently, persons with disabilities receive inclusive education mainly in preschools and general education settings and some of them study in special educational institutions.

Analyzing general education and special education, W. Stainback and S. Stainback (1992) stated that the existence of two modes of education easily leads to the phenomenon of separating learners into each education system, creating an imbalance of opportunity, integration, and development for learners because of their dependence on each system, and children are directly influenced by the intrinsic qualities of each mode of education. It is, therefore, necessary to have a functional interaction between the modes of education to ensure that persons with disabilities participate and enjoy equal educational opportunities. Inclusive education for persons with disabilities in general education institutions with individualized education programs that meet the physical, intellectual, and psychological characteristics of each child is an important solution for all children as it allows them to participate in an equal, inclusive, quality, and appropriate education. Implementing inclusive education not only creates the opportunity to benefit persons with disabilities, but first of all, it signifies a change in the approach to education for children with disabilities (Villa, Thousand, 2005; Stainback, Stainback, 1992).

Conducting research into the value of inclusive education and special education, Richard A. Villa and Jacqueline S. Thousand said that special education creates a sense of self-esteem that is not valued, and only fits into a special environment (Villa, Thousand, 2005). N. Kunc, R.A. Villa, and J.S. Thousand argued that there are many risks that children in special education settings face outside the school system, such as feeling embarrassed, alone, different, or inferior... In contrast, inclusive education helps learners in general, and persons with disabilities in particular, feel happy, proud, safe, comfortable, and accepted. They are active, important, and responsible, mature over time, etc. (after Kunc, 2000). S. Stainback and W. Stainback (1996) pointed out that persons with disabilities can participate fully in family and community life if they receive appropriate and effective support programs.

Along the way, Richard A. Villa and Jacqueline S. Thousand (2005) said that each child can learn and succeed, each child has different strengths and needs, and the variety of children will make school become rich. Children can overcome their barriers and limitations as a participant and learner, collaborating and sharing with other members. The authors also argue that high school should: be willing to accept all students with disabilities; implement educational programs that ensure the balance of cultural and social literacy benefits for children; ensure integrated facilities, services, and support systems for persons with disabilities; and organize all activities involving persons with disabilities (Villa, Thousand, 2005).

Thus, it can be said that inclusive education is a way to provide equal and effective learning opportunities for persons with disabilities. To ensure quality in inclusive education for persons with disabilities, schools need to make sure that educational and supportive conditions meet the needs and engagement of each child.

The current system of educational policies for persons with disabilities and their implementation in Vietnam (Kunc, 2000)

(i) Current education policy system for persons with disabilities

In recent decades, Vietnam has made commitments to implement international treaties on the education of persons with disabilities. These include: the International Convention on the Rights of the Child (1991); the World Declaration on Education for All (1990); the World Education Forum in Dakar (2000) with the Declaration on Education for All through the adoption of the Dakar Framework for Action; the United Nations Millennium Declaration; the International Convention on the Rights of Persons With Disabilities (signed by the National Assembly of the Socialist Republic of Vietnam in 2007 and ratified in November 2014).

On the basis of these commitments, Vietnam issued a series of legal documents on the implementation of education policy for persons with disabilities and directly related to the rights of persons with disabilities – mainly after the

Law on Persons With Disabilities (2010) was introduced. The most important documents are: Regulations on Inclusive Education for Persons With Disabilities No. 23/2006/QD-Moet; Law on Persons With Disabilities No. 51/2010/QH12; Decree 28/2012/ND-CP adopted by the government relating to details and guidelines for the implementation of the Law on Persons With Disabilities; Inter-Ministerial Circular No. 58/2012/TTLT-Moet-Molisa, which lists conditions and procedures for the establishment, operation, suspension of operation, reorganization, and dissolution of the Centers of Support Development for Inclusive Education; Inter-Ministerial Circular No. 42/2013/TTLT-Moet-Molisa-Mof, which regulates policies for persons with disabilities; Project aiming to support persons with disabilities in the period 2012-2020 No. 1019/QD-TTg, launched in 2012; Inter-Ministerial Circular No. 37/2012/ TTLT-Molisa-Moh-Moet on determination of severity of disability by the disability determination council; Inter-Ministerial Circular No. 19/TTLT-Moet-Moha, launched in 2016, which provides the code and criteria for the occupational title of Educational Support Worker for persons with disabilities in public educational institutions; Circular No. 03/2018/TT-Moet dated 29th of January 2018 on Inclusive Education; Decision No. 338/QD-Moet dated 30th of January 2018 promulgating the plan for educating persons with disabilities for the period 2018-2020; etc.

In particular, the Prime Minister issued Decision No. 1100/QD-TTg on June 21st, 2016, ratifying the United Nations Convention on the Rights of Persons With Disabilities.

Educational policy for people with disabilities specifies four areas of action:

1) Implementing inclusive education for persons with disabilities; developing curricula, materials, and research; providing materials, equipment, and teaching aids specifically for the education of persons with disabilities;
2) Developing training programs and materials and providing professional training for managers, teachers, and educational support workers for persons with disabilities participating in education for persons with disabilities;
3) Strengthening the capacity of the Centers of Support Development for Inclusive Education;
4) Researching into the development and dissemination of a common sign language to be used throughout the country; continuing to develop and refine the sign language for general education.

The Ministry of Education and Training (MOET) is also working to develop a plan for the implementation of the United Nations Convention on the Rights of Persons With Disabilities in accordance with the Prime Minister’s Decision.

(ii) Assessment of the implementation of education policy for persons with disabilities in Vietnam

The assessment of the implementation of education policy for persons with disabilities is based on the results of the annual support missions of the Steering Committee of Education for children with disabilities and children in disadvantaged areas (MOET) in localities, and refers to research results obtained by units, organizations, and individuals (Ministry of Education and Training…, 2013; Vietnam Association for…, 2016; Vietnamese Encyclopedia, 1995).

The assessment of the implementation of education policy for persons with disabilities recently yielded the following findings:

a) Positive points in the implementation of legal documents:
   - Some education and training departments have statistics on the number of persons with disabilities at school age (preschool and high school). However, this is the number of persons with disabilities who are provided with intervention and treatment and who attend schools in the area. For instance, according to Thai Nguyen Provincial Department of Education and Training, as of 30/10/2016, the province had 1,654 persons with disabilities, including 1,109 students in primary schools, i.e. 67.05 percent of the total number; Dak Lak Provincial Department of Education and Training annually produces statistics on each type of disability, and the total number of persons with disabilities in the province is 1,746, including preschool – 356 (pre-k: 93, kindergarten: 263) (Vietnam Association for…, 2016).
   - Local departments are trying to implement their policies for persons with disabilities and related beneficiaries in accordance with state regulations. The Ministry of Education and Training is demonstrating its efforts in promoting the development and organization of the Centers of Support Development for Inclusive Education (Inter-Ministerial Circular…, 2012); implementing Article 7, Clause 2 of Decree No. 28/2012/ND-CP dated 10/4/2012; guiding the implementation of school-year tasks for all levels; providing training and professional development for managers and teachers in inclusive education.
   - Departments cooperate in implementing activities to support persons with disabilities in general. For example, the Department of Education and Training cooperates with the Department of Labor, Invalids, and Social Affairs in implementing inclusive education, supporting special schools in cultural activities, recreation, or camps for persons with disabilities in Suoi Tien; it cooperates with the Department of Culture, Sports, and Tourism to organize events for persons with disabilities; it also cooperates with the health sector to provide medical check-ups for persons with disabilities; etc. (Vietnam Association for…, 2016). At the same time, the education and training sector is actively taking part in the adjustment and supplementation of Inter-Ministerial Circular No. 37/2012/TTLT-Molisa-Moh-Mof-Moet.

b) Some challenges to the implementation of legal documents:
   - The Law on Persons With Disabilities stipulates that there are six basic

forms of disability; however, there are some forms of developmental disabilities, such as autism spectrum disorders and learning disability, and these new forms of disability are not included in the legal documents. Therefore, people with autism spectrum disorders or with learning disability are not entitled to social and educational support. Local authorities can not provide support to persons with disabilities unless explicitly stated in legal documents.

- The coordination between departments is not very effective, each department concentrates only on the performance of tasks assigned vertically. In particular, there are differences in the decentralization of management and the organization, direction, and supervision of the implementation of legal documents in the sectors, which leads to difficulties and ineffective coordination. Besides, the understanding levels of commune officials are limited to implementing documents and confirming the disability; they are also unable to understand and determine what intellectual disability or developmental disability is.

Thus, due to the above constraints and challenges, the implementation of education policies for persons with disabilities is not sufficient. Although there are clear regulations on the rights of teachers and persons with disabilities, most of the localities have not yet implemented them, including some that are fit in terms of economic and social conditions to do this. The access to the rights of persons with disabilities has many barriers: a) parents of persons with disabilities are not fully aware of their right to education; b) teachers and schools have not been guided and provided with essential resources and services to support education for persons with disabilities; c) managers and leaders have not yet been guided in setting plans and supporting their implementation; d) the community and social organizations have not really taken the lead in monitoring the implementation of policies and helping to advocate for persons with disabilities and their families.

Effectiveness of inclusive education policies for persons with disabilities in practice – An example of survey research in four districts of Thanh Hoa province, Vietnam

(Nguyen Xuan Hai, Le Thi Thuy Hang, 2017)

A survey on the status of inclusive education for persons with disabilities was conducted from 31/10/2017 to 22/11/2017 in 30 communes of four districts (Tinh Gia, Thach Thanh, Ngoc Lac, and Nga Son) in Thanh Hoa province (each district has two preschools, two primary schools, two secondary schools, and one disability certification board to provide initial assessments of the effectiveness of inclusive education policies for persons with disabilities in practice).

The results of the survey

Regarding the number of persons with disabilities attending and not attending school – all levels

Table 1 shows the number of school-age children who attend and do not attend school in four districts (preschools, primary schools, and secondary schools).

Table 1

The number of people with disabilities (PwD) at preschool and school age in four districts

Level of education	Students with disabilities at preschool and school age		
	Do not attend school	Attend school	The rate of PwD who do not attend school (%)
Preschool	6	26	23.08
Primary school	15	66	22.73
Secondary school	27	48	56.25
Total	48	140	34.29

The results of the survey showed that the proportion of persons with disabilities who do not attend school in the total number of persons with disabilities in 30 communes in the four districts is 34.29 percent, which means 65.71 percent of persons with disabilities go to school. This proportion is similar to the proportion of persons with disabilities in the same age group at school age who are currently enrolled in educational institutions nationwide (about 58%).

The proportion of persons with disabilities who do not attend secondary school is the highest, accounting for 56.25 percent, followed by preschool with 23.08 percent, and primary school with 22.73 percent. The results are consistent with the reality in other schools where more persons with disabilities are unable to continue their education to higher levels. People with intellectual disabilities are the largest group of children with disabilities attending school, 27/140, approximately 19.28 percent. The number of children with hearing and visual impairments attending school is the lowest, no deaf children study in primary or secondary schools.

Teachers' knowledge and skills of inclusive education

Most of the teachers have a general knowledge of inclusive education acquired during general education courses of just a few hours per year; 100.0% of the teachers in the surveyed schools have not received training in inclusive education, which results in not enough knowledge and basic skills to organize the integration activities of teaching and learning for students with disabilities at school.

Table 2

The number of teachers that have received training in inclusive education (survey information from four districts)

Districts	Certificate (>3 months)		General knowledge of inclusive education		Untrained		Total
Tinh Gia	0	0.0	729	33.14	1471	66.86	2200
Thach Thanh	0	0.0	0	0.0	1539	100.0	1539
Ngoc Lac	0	0.0	1362	79.98	341	20.02	1703
Nga Son	0	0.0	15	100.0	0	0.0	15
Total	0	0.0	2106	38.59	3351	61.41	5457

Preschool teachers' knowledge and skills of early intervention

We conducted a survey on early intervention knowledge, skills, and education and teaching inclusive education among teachers at the preschool level and teachers at primary and secondary schools. The results are shown in the tables 3 and 4.

Table 3

Early intervention skills of preschool teacher

Types of skills	Numbers of teachers on each level										Total
	Very high		High		Average		Low		Very low		
	No.	%	No.	%	No.	%	No.	%	No.	%	
Identify the type of disability	5	4.95	65	64.36	20	19.8	11	10.89	0	0.0	101
Diagnosis and assessment of persons with disabilities	3	2.97	61	60.4	27	26.73	9	8.91	1	0.99	101
Set up early intervention goals for persons with disabilities	3	2.97	36	35.64	45	44.55	17	16.83	0	0.0	101
Identify early intervention activities	4	3.96	41	40.59	29	28.71	27	26.73	0	0.0	101

Table 3

Early intervention for persons with disabilities	4	3.96	42	41.58	33	32.67	22	21.78	0	0.0	101
Assess the progress of persons with disabilities	4	3.96	50	49.5	26	25.74	21	20.79	0	0.0	101
Use equipment and early intervention devices for persons with disabilities	4	3.96	35	34.65	34	33.66	15	14.85	13	12.87	101
Family counseling for early intervention	4	3.96	47	46.53	15	14.85	17	16.83	18	17.82	101

Table 4

Integrated teaching and learning skills of primary and secondary school teachers

Types of Skills	Numbers of teachers on each level										Total
	Very high		High		Average		Low		Very low		
	No.	%	No.	%	No.	%	No.	%	No.	%	
Determining the abilities and educational needs of persons with disabilities	1	0.53	42	22.22	72	38.1	65	34.39	9	4.76	189
Developing an individualized education plan	0	0.0	47	24.87	79	41.8	56	29.63	7	3.7	189
Adjusting educational activities and inclusive teaching	0	0.0	49	25.93	70	37.04	64	33.86	6	3.17	189
Organizing educational activities and inclusive teaching	0	0.0	50	26.46	78	41.27	59	31.22	2	1.06	189
Consultation on care and education of persons with disabilities for related subjects	2	1.06	58	30.69	68	35.98	60	31.75	1	0.53	189
Assessing the progress of persons with disabilities	2	1.06	87	46.03	51	26.98	49	25.93	0	0.0	189
Using means and equipment of inclusive teaching	0	0.0	9	4.76	88	46.56	81	42.86	11	5.82	189
Family counseling on education and inclusive teaching	2	1.06	72	38.1	75	39.68	37	19.58	3	1.59	189

Skills in early intervention, care, and education for persons with disabilities in preschool are listed based on the survey.

As many as 101 preschool teachers in 8 preschools were surveyed. The majority of teachers rated themselves at the 'high' level for two skills: the ability to recognize a child's disability (64.36%) and the ability to diagnose and assess disability (60.4%). The lowest item at the 'high' level was the ability to use the equipment for early intervention for persons with disabilities (34.65%). In addition, there were many teachers who self-evaluated their skills as 'low': the highest was the ability to identify early intervention activities for children with disabilities (26.73%), and the diagnosis and assessment of persons with disabilities (8.91%) was the lowest. Only a very small number of teachers evaluated these skills at the 'very high' or 'very low' level.

However, conducting research in preschools, we found out that many teachers were not aware of the concept of early intervention, what the purpose of early intervention is, its content, process, and steps.

In a survey of 202 primary and secondary school teachers into inclusive teaching and education skills, 13 teachers did not answer the questions, so the total number of questionnaires was 189/202.

The results of the survey showed that most of the primary and secondary teachers rated these skills at the 'average' level. Specifically, the ability to use means and equipment of inclusive teaching constituted 46.56 percent of the 'average' level and had the highest ratings compared to other skills. At this level, the ability to assess the progress of persons with disabilities constituted 26.98 percent and had the lowest ratings compared to other skills.

In addition, many teachers self-evaluated their skills at the 'high' level, in which the ability to assess the progress of persons with disabilities had the highest rate – 46.03%. The teachers said that this is their daily routine and also compulsory work within the teacher's teaching process. The ability to use means and equipment of inclusive teaching for primary and secondary school teachers was rated lowest at the 'high' level (4.76%).

The results of the survey assessing skills in teaching and integrating students with disabilities through observation of the teachers in inclusive classrooms show that the teachers' self-evaluation of their skills and the observation results do not match. Most of the teachers are not prepared for work in inclusive classrooms: they do not have knowledge of students with disabilities (do not understand them), they lack skills necessary to teach them, they do not know methodology of inclusive teaching. Persons with disabilities are not well positioned and comfortable in the classroom, so there is less opportunity to participate in learning activities. Most persons with disabilities do not have individual education plans. Teachers do not have inclusive teaching plans. Teachers do not know and do not use methods to adjust teaching content for persons with disabilities. Teachers sometimes pay excessive attention to their students with disabilities and sometimes ignore them. Also, teachers and other children in the class discriminate against persons with disabilities (when a student with disability speaks, the whole class laughs, but the teacher does not react, etc.).

It can be seen that although many persons with disabilities are currently attending the preschools, primary and secondary schools surveyed, the teachers are not prepared to work with them in inclusive settings.

Discussion and concluding suggestions

The results of the study on the effectiveness of inclusive education policies for persons with disabilities in preschools, primary schools, and junior secondary schools in four districts of Thanh Hoa province showed that: (i) most children with disabilities have been mobilized to attend school and are included in all levels of education. There is still a small number of children who do not attend school due to severe disability. The proportion of persons with disabilities who do not attend school at the secondary school level is the highest compared to the primary and preschool levels; (ii) all the schools have implemented inclusive education, but are not ready in terms of staff qualifications, facilities, equipment, and furniture to teach children with disabilities and the educational policies are still ineffective in practice, etc.; (iii) the teachers and schools have demonstrated professional responsibility, enthusiasm, love, and care for children with disabilities. There is a lack of knowledge and skills in inclusive education; therefore, children with disabilities do not really receive high quality intervention, support, care, and inclusive education that is adapted to their abilities and needs.

In order to ensure high quality education for children with disabilities, inclusive schools need to update legal documents and timely implement the quality education requirements of the Ministry of Education and Training for children with disabilities, according to which schools need to: (i) properly implement the goals of inclusive education; (ii) ensure that all children with disabilities are included in inclusive education in educational institutions; (iii) provide education that meets all the needs and abilities of individuals with disabilities; and (iv) develop support systems for inclusive education for persons with disabilities in and out of schools.

Specific solutions:

- Developing a plan for implementing inclusive education to ensure the achievement of the school's objectives and priorities for inclusive education for children with disabilities. Identifying and focusing on resources for the implementation of priorities relating to inclusive education for children with disabilities for each school year in accordance with the reality of the school and local situation, expressed in specific performance indicators, specifically: (i) identifying the number of school-age children with disabilities; (ii) identifying the educational needs of persons with disabilities, developing individual education plans and organizing intervention and educational support; (iii) identifying the capacity and professional needs of managers and teachers working with people with disabilities, developing plans/programs including persons with disabilities in the education process; (iv) identifying the conditions to ensure the implementation of inclusive education, developing a plan for mobilizing resources for investment in physical facilities, teaching aids, and effective resources for educational support workers for the implementation of inclusive education for persons with disabilities.

- Strengthening the capacity of the staff to meet the educational needs of persons with disabilities: (i) selecting and building a network of key teachers for inclusive education; (ii) organizing professional development for staff who meet the requirements of inclusive education for persons with disabilities; (iii) effectively using the network of professionals trained in inclusive education to re-train and hold consultations with all the staff at schools, they are also nuclear members in education and training for persons with disabilities; (iv) organizing inclusive teaching contests, making and using equipment and inclusive teaching equipment to enhance sharing and learning opportunities among school teachers and being respectful to persons who have enthusiasm and capacity in inclusive education for persons with disabilities.
- Improving the quality of education for persons with disabilities: (i) all students with disabilities are properly included in the education process, their potential is fully understood, individual educational plans are developed and effectively implemented; (ii) teachers who teach in inclusive classrooms focus on adapting the curriculum and teaching methods so that they are appropriate for persons with disabilities to ensure favorable opportunities and their participation in all activities; (iii) a friendly, barrier-free, and effective work and communication environment is created for persons with disabilities; (iv) equipment, facilities, and toys that are suitable for the learning needs of persons with disabilities are prepared and used; (v) children are assessed based on their individual education plans.
- Paying attention to the development of support for inclusive education for persons with disabilities and the coordination between schools and social services in inclusive education:

In the development of inclusive education support for persons with disabilities, it is necessary to: (i) identify the need for inclusive education for persons with disabilities; (ii) build and develop the operational capacity of the Inclusive Education Support Division at schools; (iii) build an inclusive education support network for persons with disabilities in schools with a professional link to the Centers of Support Development for Inclusive Education at the provincial level.

In the development of coordinated activities between schools and social services in inclusive education for persons with disabilities, it is necessary to: (i) strengthen the organization of inclusive education for persons with disabilities at schools and in the community; (ii) cooperate with local authorities, organizations, society, and community to organize community events and activities involving children and persons with disabilities; (iii) strengthen cooperation with organizations and individuals to mobilize resources in inclusive education for persons with disabilities.

Bibliography

Blankenship, C., & Lilly, M.S. (1981). *Mainstreaming Students with Learning and Behavior Problems: Techniques for the Classroom Teacher*. New York: Holt, Rinehart and Winston.

Decision No. 23/2006/QD-BGDDT dated 22 May 2006 of the Minister of Education and Training promulgating the Regulation on inclusive education for people with disabilities.

Inter-Ministerial Circular No. 58/2012/TTLT-BGDDT-BLDTBXH of 28/12/2012 issued by the Minister of the MOET and the Minister of the MOLISA regulating *The conditions and procedures for establishment, operation, and suspension of activities, reorganization and dissolution of the Centers of Support Development for Inclusive Education.*

Kunc, N. (2000). Rediscovering the right to belong. In R. A. Villa & J. S. Thousand (Eds.), *Restructuring for caring and effective education: Piecing the puzzle together* (2nd ed. pp. 77–92). Baltimore: Paul H. Brookes.

Ministry of Education and Training, UNICEF. (2013). *Study Report: Documenting the establishment and operation of the Centers of Support Development for Inclusive Education in Vietnam.* Hanoi.

National Assembly of the Socialist Republic of Vietnam. *Law on Persons with Disabilities*, Law No. 51/2010/QH12, June 17, 2010.

Nguyen Xuan Hai, Le Thi Thuy Hang. (2017). *Inclusive education survey report for persons with disabilities in Thanh Hoa Province*, CBM Australia.

Stainback, W., Stainback, S. (1984). A rationale for merger of special and regular education. *Exceptional children, 51*(2), 102–111.

Stainback, S., Stainback, W. (1992). *Controversial issues on confronting special education.* Boston: Allyn and Bacon.

Stainback, S., Stainback, W. (1996). *Curriculum considerations in inclusive classrooms: Facilitating learning for all students.* Baltimore, MD: Paul H. Brookes, pp. 65–84.

UNESCO. (2009). *Policy guidelines on inclusion in education.* Published by the United Nations Educational, Scientific and Cultural Organization, 7, place de Fontenoy, 75352 Paris 07 SP, France.

Vietnam Association for the Protection of Children's Rights and International Child Saving Organization. (2016). *Research Report: A Study on the Situation of Children with Autism Spectrum Disorders in Vietnam: Challenges and Solutions*. Hanoi.

Vietnamese Encyclopedia. (1995). Hanoi Polytechnic Publishers.

Villa, R.A., Thousand, J.S. (2005). *Creating an inclusive school, association for supervision and curriculum development.* USA.