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Early Neurological Speech Therapy Interventions as Inclusion of an Extreme Preterm Infant and her Family — a Case Study

Wczesne działania neurologopedyczne jako inkluzja skrajnego wcześniaka i jego rodziny – case study

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Abstract

Aim. In this article, I intend to show the impact of early neurological speech therapy intervention in the treatment of a preterm child from the perspective of feeding difficulties. Disorders in the intake of food by an infant born prematurely necessitate changes in the lifestyle of the child's mother as well as that of the entire family, and very often partially limit their normal functioning.

Methods and materials. I want this article to show early neurological speech therapy intervention as inclusion — an opportunity given to the premature child and the child's immediate family. I understand it as an opportunity to help the child (as the subject of inclusion) in harmony and respect for the child's individual dynamically changing needs and limitations.

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Results and conclusion. I will discuss here the ambiguous definitions of early intervention and diagnosis from the perspective of interdisciplinary speech therapy. I will also present the diagnostic and therapeutic steps in therapeutic feeding of an extreme preterm infant at risk of disability, taking into account the child's capabilities and limitations, as well as the opportunities provided by early neurological speech therapy intervention introducing the child and her family into life in the new reality.

***Keywords*:** early speech therapy intervention, diagnosis, preterm infant, therapy, feeding, inclusion, inclusive pedagogy

Abstrakt

Cel. W niniejszym artykule chciałabym ukazać wpływ wczesnej interwencji neurologopedycznej w terapii dziecka urodzonego przedwcześnie z perspektywy trudności w karmieniu. Zaburzenia w przyjmowaniu pokarmów przez wcześniaka powodują konieczność zmiany stylu życia matki, a także całej rodziny dziecka i są bardzo często powodem częściowego ograniczenia normatywnego funkcjonowania jego samego i rodziny. Chciałabym, aby niniejszy artykuł ukazał wczesną interwencję neurologopedyczną jako inkluzję – szansę daną wcześniakowi i jego najbliższym.

Metody i materiały. Rozumiem inkluzję jako możliwość pomocy dziecku (jako podmiotowi włączania) w zgodzie i szacunku dla jego indywidualnych, dynamicznie zmieniających się potrzeb i ograniczeń. Zastosowaną przeze mnie metodą jest case study oparte na wywiadzie z rodzicami dziecka, a także z jego dalszą rodziną włączoną w proces rehabilitacji neurologopedycznej. Nie bez znaczenia jest także szczegółowa analiza dokumentacji medycznej oraz badanie neurologopedyczne dziecka będące podstawą do rozpoczęcia działań realizowanych w ramach wczesnej interwencji logopedycznej z elementami inkluzji.

Wyniki i wnioski. W artykule omówię niejednoznaczne definicje wczesnej interwencji oraz diagnozy z perspektywy interdyscyplinarności logopedii. Przedstawię także kroki diagnostyczne i terapeutyczne w pracy nad karmieniem terapeutycznym skrajnego wcześniaka zagrożonego niepełnosprawnością, z uwzględnieniem możliwości i ograniczeń dziecka, a także szanse, jakie daje wczesna interwencja neurologopedyczna włączająca dziecko i jego rodzinę do życia w nowej rzeczywistości.

***Słowa kluczowe*:** wczesna interwencja logopedyczna, diagnoza, wcześniak, terapia, karmienie, inkluzja, pedagogika włączająca

Introduction

Surrounding prematurely born children with neurological speech therapy care is a challenge of modern speech therapy, medicine, as well as pedagogy. It seems justifiable to evoke the deployment of inclusion pedagogy as a sub-discipline of pedagogy, which deals with the study of the phenomenon of inclusion, understood as education for diversity without prejudice. Inclusion understood in this way introduces us to the important task of noticing and accepting diversity as a social phenomenon. It is not about its mere recognition, but about its coexistence without any kind of hostility (Kwieciński, 2015).

In this article, I would like to present the impact of early speech therapy intervention in the treatment of prematurely born children from the perspective of feeding difficulties. Feeding disorders in premature infants necessitate lifestyle changes for the mother and the entire family, and very often lead to a partial limitation in the normative functioning of the child and their family. I would like this article to present early speech therapy intervention as inclusion – an opportunity given to the premature infant and their loved ones.

Theoretical Background

I understand inclusion as the ability to help the child (as the subject of inclusion) with understanding and respect for their individual, dynamically changing needs and limitations. The method I used is a case study based on interviews with the child's parents and their extended family, who are involved in the process of speech therapy rehabilitation. A detailed analysis of medical records and a speech therapy examination of the child are also important, as they form the basis for initiating early speech therapy interventions with elements of inclusion.

Methodology

In this article, I will discuss the ambiguous definitions of early intervention and diagnosis from the perspective of the interdisciplinary nature of speech therapy. I will also present diagnostic and therapeutic steps in working on therapeutic feeding of an extremely premature baby at risk of disability, taking into account the child's capabilities and limitations, as well as the opportunities offered by early speech therapy intervention that includes the child and his family in life in a new reality.

In this article, I will discuss the difficulties of feeding an extreme preterm female infant (Ania) born in the 27th week of pregnancy. According to scientific reports, a newborn delivered prematurely is a child born prior to 37 weeks of gestation. With regard to the age at birth, the following are distinguished: 1) late preterm infants — born between 32 and 36 weeks of gestation, 2) moderate preterm infants — born between 28 and 31 weeks of gestation, 3) extreme preterm infants — born before 27 weeks of gestation (Zdzienicka-Chyła & Mitosek-Szewczyk, 2018). It should be noted that any children born prematurely, and especially extreme preterm infants, are at risk of disabilities and, consequently, of exclusion. This is why it is important to take early intervention measures aimed at their inclusion, understood on the one hand, as introducing the child's parents to a situation that is new to them and returning them to social functioning, and on the other as the inclusion of the child — creating a chance to function as normally as possible in the world and in society (despite the difficulties that premature birth may bring). In these considerations, I understand inclusion as an opportunity given to the premature baby and her immediate family. It refers on the one hand to the inclusion of the child (struggling with complications related to premature birth) into the family, and on the other, to the inclusion of the entire family into society — taking into account that the family of a preterm child will certainly function in a new reality, struggling with new difficulties — the child's illness, often entailing resignation from work, the multi-profile care of the child, the costs of rehabilitation, *etc*. The issues of inclusion and an inclusive society, whereby marginalised groups are given increased opportunities for social participation and the possibility of a dignified life, is not some imaginary idea, but also a vision of the practical possibilities for its implementation and legitimacy (Gray, 2000).

Each of the situations mentioned above was described repeatedly by Ania's family — in particular, her mother, who devotes most of her time to the child. Initially, she experienced fear and concern for Ania's life and health. This, in turn, caused mood swings and frequent lowering of her mood, which posed a challenge not only in parental care, but also in marital and family relationships. Currently, the mother is benefiting from professional support from specialists, as well as methods supporting pharmacotherapy of mood disorders — tDCS. In order to fully devote herself to her daughter, Ania's mother gave up professional work, and the financial maintenance of the family rested entirely with the child's father, which is also a new and difficult situation. The young parents are supported by the grandparents, who take care of Ania and, despite their age, take on many of the household chores, such as housework, ironing, and caring for the animals and the family farm.

Thus, the above preliminary considerations indicate that I will understand the child as well as her family as the subject of inclusive activities. This is because all of them are involved, be it passively or actively, in early intervention activities. The case study in question illustrates the thesis that early intervention is inclusion. I would like it to influence the perception of early therapeutic interventions as being inclusive for the child and the child's family, rather than being carried out only at the request of the family or on the order of the physician.

The article is based on research techniques such as an interview (with the parents), observation (of the child and family) and analysis of medical records (of the mother and the child). Following Sztumski, when talking about research techniques, we will mean a set of activities related to the various ways of preparing and conducting research (Sztumski, 2005). I also used statistical techniques, *i.e*., I compiled the collected material and presented it as a case study of the child and her family.

Due to medical advances and, consequently, increasing survival rates, the group of extreme preterm infants is growing year by year. The increase in the survival rate of newborns with low and very low body weights (the survival rate of newborns weighing less than 1000 g is 85%) results in an increase in the cohort of children whose further psychomotor development must be closely monitored and stimulated early (Pusz, 2018). Thus, there is also a growing need for education and further training of early intervention specialists from various fields, as children who were born before the 37th week of pregnancy usually require long-term, holistic and multi-specialty care and rehabilitation, including neurological therapy.

The premature birth of a child causes changes in the functioning of the entire family. After leaving the hospital, the child goes home and begins, most often, multispecialty rehabilitation, tailored to his or her specific needs. Due to multisystem immaturity, the child is under the care of many specialists, which is associated with the full availability of the parents (especially the mother), who very often needs to give up gainful employment, and the financial maintenance of the family rests exclusively on the father. Frequent visits to doctors and the rehabilitation sessions result in additional costs for the parents of the premature baby, if only related to traveling. All this results in changing the economic situation of the family, limiting professional work, as well as social and personal contacts.

Analysing premature birth from the position of a parent, one can see the need for inclusion — concerning the child's parents first. The term *inclusion* itself is derived from sociology. It is not a one-time action (act), but a long-term phenomenon (process). In the literal sense, it means the process of integrating individuals, groups, or social categories (for example, people with disabilities) into the functioning of wider society (Speck, 2013). Ziemen believes that inclusion is the overcoming of social inequalities, separation, and marginalisation (Ziemen, 2012). Feuser, on the other hand, argues that inclusion can happen in open societies, while in closed societies it will be hindered or merely apparent (Feuser, 2012).

Referring to the family and caregivers of a prematurely born child, we are dealing with social inclusion. The issue of social inclusion is much more frequently addressed in Western literature in terms of conceptual approaches to the problem (Simplican *et al.*, 2015), as well as analysis of research results (Wilson *et al.*, 2016).

Broda-Wysocki defines social inclusion as increasing the chances of marginalised groups for social participation, opportunities for a good life, and participation in social relations (Broda-Wysocki, 2012). Social inclusion is understood as the inclusion in society of people at risk of social marginalisation (exclusion), by creating opportunities and possibilities for them to obtain the resources they need to function in social life (Szatur-Jaworowska, 2005). Such an opportunity is provided by the child's parents, if only by belonging to associations, organizations, or support groups available online or offline.

The local community in which the parents and the child function is also important. Speaking of the local community, it should be emphasised that it is a community of people united by, among other things, the environment (immediate surroundings), culture, traditions, attachment, neighbourhood, local nature, and so-called *local patriotism*. It is in this collective that the identity of individuals and social groups is formed (Theiss, 2001). The relationship of the immediate environment thus determines the involvement (inclusion) of the premature child's family, as well as the child, in learning the new reality. In the local environment, direct contacts occur, through which interpersonal ties are formed and socio-professional activity of people, including those at risk of exclusion, takes place (Schindler, 2014).

Therapists working with the child can also come to the aid of early intervention efforts. This is because in the therapeutic team, in addition to specialists in different disciplines, there is always a parent, who is simultaneously involved (included) in the care and early intervention activities concerning the child. Early intervention programs are usually run by specialists in infant and toddler development (specially trained psychologists, educators, physiotherapists, and speech therapists). They are centred on the family, which means that their task is to support the child and the child's relatives by providing information, skills, and support (Bernatowicz-Łojko *et al.*, 2013).

Results

Today, the term *early intervention* is used increasingly in reference to many disciplines, including speech therapy. Early intervention involves such disciplines as medicine, psychology, neurological speech therapy, and special pedagogy, which classify it as preventive care (Błeszyński, 2015). I myself, however, favour the definition put forward by Cytowska (2013), who defines early intervention as early, multi-specialist, comprehensive, coordinated, and continuous assistance to a child at risk of disability or with a disability, as well as the child's family.

In this sense, early intervention (including neurological speech therapy intervention) can be counted as inclusion, in reference to the first, official manner of social inclusion of individuals at risk of disability (and extremely premature children constitute such a group) and their immediate families. This is evidenced by the following passage. Societies have developed two types of mechanisms for the social inclusion of people with disabilities and illnesses. The first comprises official measures, which are derived from the development of human rights, patient rights, normalisation ideology, the trend toward social inclusion and the theory of empowerment. The point here is preventing the marginalisation and discrimination of any group due to illness or the effects of dysfunction, widespread provision of rehabilitation services using all sorts of medical technologies and procedures designed to improve the quality of life and well-being of the individual affected by disability (Crane, 2005).

Timely introduction of early interventions — according to the principle "prevention is better than cure" — is very important in undertaking these procedures. All such interventions are preceded by a comprehensive medical diagnosis, *i.e.*, "the diagnosis of a disease based on the analysis of the changes it causes in the body"[1] (Diagnoza, n.d.). Due to its interdisciplinary nature, speech therapy as a science, this definition is acceptable, as the theory of speech therapy is based primarily on linguistics — the study of the mother tongue (in which speech therapy is created), pedagogy, psychology, and medicine. These can be considered the four pillars on which speech therapy is based. These pillars underlie the models of diagnosis (Jastrzębowska, 1998).

However, in the dimension of neurological speech therapy, it is worth recalling the definition of diagnosis proposed by Tarkowski, who understands it as the recognit ion of a state of affairs and its developmental tendencies on the basis of understanding general regularities (Tarkowski, 2017).

The first possibility of implementing this idea includes early intervention activities involving the child's parents, as well as the child, which are preceded by a multifaceted diagnosis. In the diagnosis, treatment and therapy of a child with a disability or at risk, cooperation plays an important role. Problems of the diagnosed children can manifest themselves in different spheres, overlapping and compounding adverse effects, which is why their proper recognition and subsequent elimination requires the actions of the entire treatment and therapy team (Gacka, 2016). This is particularly important in the case of a child born prematurely. This is because a preterm child differs significantly from a newborn who was born full term. The fetal age of such a child ranges from 26 to 37 weeks, with body weights ranging from 500 g to 2500 g (Grabowska, 2019).

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[1] Author's own translation.

Ania was born at 27 weeks of gestation, by caesarean section due to a threat of intrauterine hypoxia and hypotrophy, with a body weight of 550 g, in an average overall condition. On the first day of life, due to increasing oxygen requirements, she was intubated. Due to episodes of apnea and increased respiratory effort, on day four, the newborn was connected to mechanical ventilation. She was finally disconnected from mechanical ventilation on the 24th day of life, after several previously unsuccessful attempts to extubate her.

The first neurological evaluation of a child born prematurely takes place in the neonatal unit and is always a challenge. When comparing the behaviour of a healthy infant born full term with that of a baby born prematurely, physicians find significant differences. These differences include the neurological sphere and orofacial reflexes (Grabowska, 2019). Their examination is always based on touch. This is the most extensive of the senses, also called the primary sense, as it develops earliest of all the senses and is the first to become fully functional, providing the child, still in the womb, with the first impressions, *i.e.*, messages received from the external world (Lorens & Karwowska, 2015).

Ania also underwent her first diagnosis of orofacial reflexes while remaining in the neonatal intensive care unit. Her hospital discharge abstract says that at that time major problems in feeding and poor weight gain were observed. It is worth noting that early intervention in the speech therapy system is already a well-established approach, which primarily involves cooperation with neonatologists. Early speech therapy intervention, as a holistic approach, addresses the problem of improving the (initial) digestive and communicative functions, as well as compensating for deficits (Błeszyński, 2015). The role of the whole team, which includes the parents, physicians, nurses, physical therapists, psychologists, and speech therapists, is of paramount importance in this context. Neonatologists and paediatricians begin developmental observation with the assessment of basic vital functions, with particular attention being paid to the ability to eat (Pusz, 2018). The medical observation is complemented by a diagnosis carried out by a neurological speech therapist. The most common decision made by the team is to start feeding the infant, bypassing the immature digestive system — by means of intravenous feeding. Extremely premature children have problems with sucking, because they have not mastered the skill in fetal life (which typically happens between the 34th and 35th week of gestation — author's note), they also have problems with swallowing, hence feeding them is usually carried out intravenously (Pietrzak-Szymańska, 2013). Ania was fed entirely parenterally for 15 days. The subsequent stage is the insertion of a nasogastric tube and providing food directly into the child's stomach. However, it is worth noting that this is postponed in extremely premature babies. This is because some important functions mature later, for example, intestinal peristalsis does not work properly before 28–30 weeks of gestation. Premature babies also do not produce sufficient amounts of digestive enzymes (Pusz, 2018).

Summary

As already mentioned, in Ania's case the first neurological diagnosis took place in the Neonatology Department, and another one after discharge, at the age of 3.5 months.

At that time, the child was receiving food through a long-term gastric tube. Reddening of the nasal area was already evident at the first contact. Facial touch examination showed the presence of significant hypersensitivity of the oral region and increased muscle tone (of the whole body as well as the oral region). Examination of the primary functions showed reduced efficiency of the articulatory apparatus (during the examination of the oral reflexes: mouth opening/closing, and mandibular, snout, swallowing, and vomiting reflexes, *etc*.). The defensive reflexes of the orofacial region were exaggerated, especially the vomiting and biting reflexes. It is worth noting that in Ania's case, the pathological reflexes were caused by several factors. On the one hand, it is obvious that the shortened fetal period, in particular below 32–34 weeks from conception, means that the organs involved in these tasks are still very immature. Similarly, reflex reactions and their coordination are not fully functional (Amiel-Tison, 2008). On the other hand, prolonged use of an intranasal cannula to feed the child is also not without its influence, as it causes other side effects, in the form of mucosal swelling and oral hypersensitivity. The condition of the oral organs was also affected by the support of the girl with mechanical ventilation to secure her basic vital functions. Particularly traumatizing in this regard is the use of intubation, as well as the need for frequent evacuation of secretions from the oral and nasal cavities by suctioning them with a catheter (with the use of negative pressure; Bernatowicz-Łojko *et al*., 2013).

Due to Ania's extreme prematurity, her neurological speech therapy examination revealed no seeking and sucking reflexes. There were also respiratory difficulties (significantly shallow breathing) and rapid fatigability. The breathing pattern was normal — despite the child's limited ability to take in air through both nostrils.

The structure of the articulatory organs was abnormal — there were changes in the morphology of the articulatory apparatus, *i.e*., a high-vaulted palate. It should be noted that this is a characteristic of extreme premature children, as it is a consequence of too little time for the development of the palate in fetal life (Amiel-Tison, 2008). The examination also confirmed increased muscle tone in the baby's tongue, lips, cheeks, as well as her neck and shoulder girdle, which had already been identified in the hospital. This information was also confirmed by a medical rehabilitation physician and a physiotherapist.

The girl's auditory responses were normal. This conclusion confirmed the hospital discharge data from the Pediatric ENT Ward, where Ania underwent a comprehensive audiological evaluation (ASSR steady-state response test, otoacoustic emission [OAE] and impedance audiometry), which did not reveal hearing loss (despite initial abnormal screening test results).

Following the diagnosis, the child was subjected to systematic speech therapy. Her initial goal was to introduce touch therapy due to hypersensitivity. Its causes were complex. The main one was preterm birth, and thus, multisystem immaturity, also affecting the sense of touch. The entire torso of a premature baby is quite long, the arms and legs are thin, the buttocks are not fully developed, and the body is often covered with delicate hair called lanugo. Premature babies have no adipose tissue; hence, their skin is sometimes as thin as parchment (Helwich, 2002). The caesarean section that brought Ania into the world was also not without significance. Bypassing the genital tract, typical of physiological birth, prevents sufficient stimulation of sensory receptors in the skin. This results in hypersensitivity of the newborn to touch, especially in the head, neck and chest area (Bernatowicz-Łojko *et al.*, 2013).

It is worth noting that due to extreme prematurity, Ania was not subjected to kangaroo care, *i.e.*, the first skin-to-skin contact, which, according to the recommendations, should begin immediately after birth and end after the first feeding. This method has many advantages, including better adaptation to new conditions by minimising feelings of stress, or reducing the risk of cardiovascular, respiratory, and immune problems (Bajek *et al.*, 2014). Kangaroo care also has an impact on feeding and protects the child against the onset of various disorders. Many speech therapists encounter in their work children with feeding difficulties or articulatory disorders that are based on hypersensitivity of the orofacial area. Kangaroo care is one of the elements that protect the child from the onset of such hypersensitivity, thereby reducing the risk of the difficulties mentioned above (Charpak & Ruiz-Pelaez, 2006). This is one of the factors accounting for the occurrence of hypersensitivity of the orofacial area in Ania. Due to her unstable postnatal condition, the girl was immediately placed in an incubator, thus not having a chance to develop the seeking reflex and satisfy it. In babies placed in an incubator, if their efforts to seek the breast in the first hours of life are not rewarded and satisfied, the seeking reflex dies out. Thus, if suckling is not taken up during the critical period, the baby is likely to have trouble ingesting food (Odent, 1997).

Initially, Shantala touch massage was used. This is a traditional art of massage observed by French obstetrician Leboyer during a trip to Calcutta, which he described in a book entitled *Shantala: un art traditionnel, le massage des enfants* (Leboyer, 1976). Stimulation involves the entire body of the infant and is performed with bare hands lubricated with oil. The specific sequence of movements was aimed at relaxing, soothing and calming the child, but most importantly, lowering muscle tone and preparing the orofacial area, which was the main goal in working with Ania.

In addition, studies have shown that premature infants who were regularly massaged and who regularly listened to their parents' voices grew and developed much faster. Infants in the intensive care unit responded positively to massage; muscle tension and reflexes of retreating from touch disappeared. In many cases, massage also alleviated symptoms of breathing difficulties — episodes of apnea (Kaczara, 2005). Massage instructions were also given to Ania's mother. She was taught to weave gentle movements into the girl's daily care, thus establishing a close bond between the mother and the child.

The neurological speech therapy also included therapeutic massage used in order to desensitise the child's oral area and suppress defensive reflexes, which would prevent working on Ania's sucking reflex. Massage of the articulatory apparatus (digestive in its basic biological function) just like massage of other organs of locomotion is a stage of passive exercises aimed at training muscles by activating nerves that transmit information to the sensory cortex. The massage also activates the speech therapist's sense of touch, so that the therapist may assess by palpation the functional state of the muscles of the digestive-articulatory apparatus, *i.e.*, the face and the inside of the mouth (Stecko, 2012).

As Ania was responding better to the treatments, the next step was to induce the sucking reflex. Tactile stimulation was enriched by elements of the Castillo-Morales concept — in particular related to the oral complex of neuromotor points, where nerve endings are most shallowly located.

The Castillo-Morales concept consists of several parts: the sensorimotor component (the orofacial complex); communication (use of the body for communication, communicative situations, polysensory contact); eating activities (body position, use of the senses, time of eating, bodily reactions during feeding, movement within the orofacial complex, breathing); play (Błeszyński, 2015). In working with Ania, orofacial regulation therapy (ORT), which aims to build a normal movement pattern, proved to be particularly important (Brzozowska-Misiewicz, 2018).

After a month of guided stimulation, the girl developed the sucking reflex — first on her finger, then on a pacifier. The parents were recommended to conduct pacifier training at home. During subsequent training sessions, attempts were made to feed the child with her mother's frozen milk using a bottle. The therapeutic difficulty was the child's very high fatigability due to multisystem immaturity, along with respiratory difficulties and no coordination of sucking, swallowing, and breathing. The child's vital signs were monitored with a pulse oximeter.

At eight months of age, a percutaneous endoscopic gastrostomy (PEG) was administered in order to accelerate weight gain, due to very small amounts of food ingested through the mouth. The girl's enteral feeding takes place only at night, during sleep. During enteral feeding, a syringe filled with the appropriate amount of milk or formula is attached to the tube, which then flows down slowly thanks to the force of gravity (Pusz, 2018).

Currently, Ania has turned one year old. The goal of speech therapy is to increase food intake. The child is able to drink 400 ml of modified milk during one feeding session (the mother is no longer lactating). Her diet is enriched with pureed soups, blended fruit and vegetables.

The child continues to exhibit pathologies in the orofacial area, and the biting and seeking reflex is persistent. There is also increased muscle tension — bruxism. Along with the development of cognitive functions, neurotic disorders have appeared — the child coughs and sometimes vomits (especially prior to motor therapy using the Vojta method — as signalled by the child's mother). Her respiratory capacity has increased significantly, which translates into less fatigue when eating and drinking (from a bottle).

The child was diagnosed at the Genetic Clinic. A preliminary diagnosis of cerebral palsy has been made.

The child's difficulties, as diagnosed and described above, cause social exclusion for both the parents and the child. Ania's mother was forced to give up her employment, and her father took over the maintenance of the family. The family's social relations have been reduced, as the difficulties associated with feeding the child require a great deal of time and preparation. One feeding session takes approximately 40 minutes and must be followed by a digestion break of several hours, so that the child does not vomit the meal. It is not possible to feed the child while travelling or away from home, which limits the parents' ability to function socially. The parents are also helped in their care of the child by the grandparents — Ania's grandmother has mostly taken over the household duties, and her grandfather drives Ania several times a day to physical and neurological speech therapy and rehabilitation sessions in different parts of the city.

Also, due to eating disorders and the need for rehabilitation, Ania has limited time to play and function in a peer group (it is impossible to put the child in any kind of institution such as a nursery, toddler club, *etc*.), or explore the world. Every free moment between her trips to rehabilitation and doctors' appointments, the whole family devotes to Ania, allocating this time to exercises at home or feeding.

As the diagnosis and therapy of extreme prematurity described above show, it is possible to anticipate the appearance of further disorders burdening children with extremely low weight at birth. In such cases, early intervention is understood as a pre-emptive rather than preventive approach, as already mentioned by Kaczorowska-Bray, pointing to the need to identify a group of people whose development should be monitored and supported from the first moment after birth. An important part of it, in numerical terms, is children in high-risk groups — those born prematurely and with genetic defects (Kaczorowska-Bray & Błeszyński, 2012). Certainly Ania, who continues to benefit from early neurological speech therapy intervention — at the moment oriented no longer only toward feeding disorders but also to the development of the child's speech — will be included in this group. After all, prevention is better than cure.

Therapeutic activities understood here as inclusion — a chance given to the child and the child's family to reintegrate into the community (after taking on the new roles of parents and grandparents of a child at risk of disability) opens a space for the rearranging the social relations between people without disabilities and those with disabilities based on the principle of voluntary social relations, exchange, cooperation and coexistence (Bąbka & Korzeniowska, 2021). In the case of Ania's family, the local community is very much involved in supporting the child and her loved ones. Picnics and fairs are organised in connection with holiday celebrations, with the proceeds going toward the child's therapy. Ania's aunts and uncles organise aid collections online. The openness of the child's family and the local community translates into increased opportunities for rehabilitation of the child (also commercially available), the use of systematic follow-up visits to specialists throughout Poland, which is associated with considerable costs. These examples support the statement that social contacts are the foundation of social capital, which serves pro-inclusive functions (Bąbka, 2019).

The path of people with disabilities to "normal life," in full inclusion within the social environment, is not easy. The obstacles encountered every day in the form of many barriers disorganize their arrival at independence, and the start of a self-supporting and satisfying life (Kirenko, 2021). However, it is possible, thanks to the openness of the family, the local social group, as well as early interventions with the person at risk of disability and her immediate environment.

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