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Siblings of persons with hearing disabilities – a study of individual cases

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The article describes the functioning of hearing siblings of persons with hearing loss in different developmental stages: childhood, adolescence and adulthood. It describes the key factors to the formation of positive relationships between deaf and hearing siblings. These may influence the psychosocial functioning of hearing people in adulthood.

KEY WORDS: siblings, deafness, relationships

Motherhood, just like fatherhood of children that are ill and disabled had become the subject of many studies. However, it needs to be remembered that the issues of child development influence the well-being and quality of life of all the family members. The underestimated difficulties experienced by the siblings of a disabled child can be considered a grave omission¹. As I. Przybył notes, the relationship between the siblings is a particular one, as it is distin-

¹E. Pisula, *Rodzice i rodzeństwo dzieci z zaburzeniami rozwoju*, Wydawnictwo Uniwersytetu Warszawskiego, Warszawa 2007, p. 122.

guished by its duration – it runs for decisively much longer than any other social relation. In addition, it „is an assigned relation, and at the same time, an egalitarian relation, permeated by a long history of unique intimate experiences, not to be recreated in any other community”². It is noteworthy that according to Victor Cicirelli, siblings can be perceived from two perspectives: a formal-biological one and a psychological one. The former considers the fact that siblings are biologically related, with the latter stating that siblings constitute the sum of interactions between individuals having the same biological parents, in addition to common knowledge, opinions, a specific attitude towards perceiving each other³.

Importantly, available theoretical sources indicate that the issue of the functioning of siblings of (adult) disabled children is enjoying increasing interest among researchers. Driven by the will to study the indicated topics, I have made siblings of deaf persons the main subject of my graduate paper studies. My strivings to authentically understand human experiences was conducted through direct and indirect discussions (interviews) with hearing adults who have deaf siblings.

Siblings with hearing deficiencies

Considering the expectations and attitudes of parents with respect to a child with good hearing, key issues are: the age of the deaf siblings against that of the hearing child, their gender and the order of births. Studies conducted up to now indicate that elder

²I. Przybył, *Siostry i bracia dzisiaj. Gwarancja i niepewność w relacji- nowe hipotezy na podstawie badań ankietowych*, [in:] *Role rodzinne między przystosowaniem a kreacją*, ed. by I. Przybył, A. Żurek, Wydawnictwo Naukowe Wydziału Nauk Społecznych Uniwersytetu im. Adama Mickiewicza, Poznań 2016, p. 165.

³I. Przybył, *Siostry i bracia dzisiaj. Gwarancja i niepewność w relacji- nowe hipotezy na podstawie badań ankietowych*, [in:] *Role rodzinne między przystosowaniem a kreacją*, ed. by I. Przybył, A. Żurek, Wydawnictwo Naukowe Wydziału Nauk Społecznych Uniwersytetu im. Adama Mickiewicza, Poznań 2016, p. 166.

sisters of children with hearing deficiencies have behind them experiences different than elder brothers of such children, which is the effect of social expectations of girls with respect to taking care of their siblings. In a situation, „when the hearing sibling is younger than the deaf child, then it comes into the world in a „good moment”, when the world is already arranged in order, and when the family, even if to various extents, had arranged its mode of life, in which there exists, and which is co-created, by the elder deaf child”. However, if the deaf child comes into the world as a subsequent child in the family, we are dealing with a different situation – for well-hearing children, the arrival of a sibling with a hearing deficiency constitutes a change „for the worse”, a rearrangement of life, the appearance of negative emotions and tensions, an alteration of expectations with respect to them, lack of understanding as to why the hearing siblings behave differently than other children⁴. Research results indicate that sibling disability (irrespective of its kind and gravity) impacts most negatively the oldest of sisters, who compared to their peers with healthy siblings take on the roles of caretakers and teachers four times as often. Hearing sisters, among others, care for tidiness, arrange to the preparation of meals, bathe and feed the disabled sibling, walk it to school or preschool and bring it back, and go on walks with it. The imposed duties gravely reduce the possibility of attending to their own needs, developing their own interests or maintaining relations with their peers⁵. Older brothers with disabled siblings also significantly more often than their peers from the control group take care of their brother or sister, and do so as often as older sisters with properly-developing siblings. Both older brothers of disabled children, as well as brothers of children without health problems undertake often than elder

⁴J. Kobosko, J. Kosmalowa, *Słyszące rodzeństwo dzieci głuchych i słabosłyszących – spojrzenie z różnych stron*, „Słyszę. Dwumiesięcznik dla osób z problemami słuchu i mowy”, wrzesień – październik 2010, p. 29.

⁵A. Twardowski, *Sytuacja psychologiczna rodzeństwa dzieci z niepełnosprawnościami (część 1)*, „Szkoła Specjalna”, 2/2011, p. 96.

sisters work in the house garden, clean the yard or work in the garage. They do not take care of feeding and bathing the siblings. Moreover, older brothers of disabled siblings maintain relations with their peers and friends more often than older sisters do, both at home and outside of it⁶. „At times, the expectations [of parents] are not compatible with the individual developmental and emotional needs, and exceed the real abilities of the siblings. The situation becomes particularly difficult when the age difference between the well-hearing siblings and their disabled brother or sister is big. The assigned caretaker role may hinder the process of separation from the family to a young person entering adolescence. On the other hand, in certain situations, this process may paradoxically be sometimes made simpler for a young person who up to that point was part of the marriage dyad”⁷.

With certainty, parents with hearing and deaf offspring experience numerous difficulties in the area of nurturing. A challenge is preventing mutual damage to the siblings, learning to understand, accept and love one another. The fear of the parents about hindrances to the development of the „healthy” child or the takeover of unwanted behaviour of deaf siblings are odds with the need to strengthen the bond between the children⁸. It is not easy for parents to set out reasonable limits between duties and the fear of overburdening well-hearing children with the care for their hearing-deficient siblings. Parents (primarily mothers) entirely devoted to hearing education in general unconsciously and against the best intentions, in order to primarily help „the one in more need”, focus

⁶ A. Twardowski, *Sytuacja psychologiczna rodzeństwa dzieci z niepełnosprawnościami (część 1)*, „Szkoła Specjalna”, 2/2011, pp. 96-97.

⁷ A. Wzorek, *Rodzina z dzieckiem z zaburzeniem słuchu- spojrzenie systemowe*, „Psychoterapia”, 4 (151) 2009, p. 57.

⁸ A. Kucharczyk, *Kiedy w rodzinie nie wszystkie dzieci słyszą...*, [in:] *Młodzież głucha i słabo słysząca w rodzinie i otaczającym świecie dla terapeutów, nauczycieli, wychowawców i rodziców*, ed. by J. Kobosko, Stowarzyszenie Rodziców i Przyjaciół Dzieci i Młodzieży z Wadą Słuchu „Usłyszeć Świat”, Warszawa 2009, pp. 137-138.

on the deaf child, marginalising at the same time the needs of the other children, and weakening their potential⁹. In certain families, well-hearing siblings function as an intermediary between the deaf brother or sister and the parents, when, contrary to the caretakers, they spontaneously learn sign language from their deaf siblings. It also happens that the parents implement a separate system of punishments and rewards, thus favouring the hearing-deficient child or its siblings. Comparing children, e. g. akin to the rule that „the deaf child was burdened by fate”, or „one loves an ill child differently”, as well as strong differentiation is destructive on the sibling bond, and indicates flawed relations within such a family¹⁰.

Studies concerned with the situation of siblings of well-hearing children provide contradictory information: some suggest that hearing siblings is subject to stress and may experience difficulties adapting socially¹¹. As Joanna Kobosko and Joanna Kosmalowa note, „at times, hearing siblings become naughty, disturbing, rebellious, may even start to cause trouble: they have problems in school or become aggressive against friends, clearly or covertly showing behaviour competitive against the deaf brother or sister, all to bring back the unbalanced order, its place within the family”¹². Other authors stress that the siblings need not necessarily experience problems with adaptation and emotions. The fact of having a disabled brother or sister may contribute to the collection of positive experiences by the siblings – e. g. create the possibility of development of pro-social attitudes and tolerances for broadly understood

⁹J. Kobosko, J. Kosmalowa, *Nasze słyszące dzieci*, „Słyszę. Dwumiesięcznik dla osób z problemami słuchu i mowy”, październik 2002, p. 22.

¹⁰J. Kobosko, J. Kosmalowa, *Słyszące rodzeństwo dzieci głuchych i słabosłyszących-spojrzenie z różnych stron*, „Słyszę. Dwumiesięcznik dla osób z problemami słuchu i mowy”, wrzesień – październik 2010, p. 30.

¹¹U. Bartnikowska, *Sytuacja społeczna i rodzinna słyszących dzieci niesłyszących rodziców*, Wydawnictwo Edukacyjne Akapit, Toruń 2010, p. 53.

¹²J. Kobosko, J. Kosmalowa, *Słyszące rodzeństwo dzieci głuchych i słabosłyszących-spojrzenie z różnych stron*, „Słyszę. Dwumiesięcznik dla osób z problemami słuchu i mowy”, wrzesień – październik 2010, p. 29.

otherness¹³. Among the „gains” of siblings of deaf children, the following can be named: more independence, better developed empathy and the ability to cooperate. These divergent study results indicate a multi-factor basis for the situation of children in the family¹⁴.

The condition of the family, in which a deaf child had come into the world is of key importance to the shaping of relations between the child (and later, the adult) and their deaf siblings. How this family dealt with emerging difficult situations, until the birth of the child with the hearing deficiency, what is the atmosphere within the family, how does the family now cope with adapting to the child's deafness. In addition, relevant is the parenting style in the family, the way emerging conflicts are solved, can they exhibit common experiences related to deafness, can they make use of the aid and support of those closest to them and of others¹⁵. Of importance for the adaptation of siblings with disabled brothers or sisters is also the knowledge base on the disability itself – the better the knowledge, the more positive the attitude of the child towards the ill sibling, and the less negative their evaluation of the influence of the disability/ illness on the functioning of the family, and the more frequent its experiences of positive moods¹⁶. The quality of the relations between the siblings is significantly influenced by the possibility of communicating. Experienced difficulties in communication hinder the formation and care for psychological bonds between the siblings, and also the acceptance of a deaf brother or sister by a well-hearing child¹⁷.

¹³ Ż. Stelter, *Realizacja ról rodzinnych w rodzinie z dzieckiem niepełnosprawnym*, [in:] *Rodzina z dzieckiem niepełnosprawnym – możliwości i ograniczenia rozwoju*, ed. by H. Liberska, Difin, Warszawa 2011, p. 83.

¹⁴ U. Bartnikowska, *Sytuacja społeczna i rodzinna słyszących dzieci niesłyszących rodziców*, Wydawnictwo Edukacyjne Akapit, Toruń 2010, p. 53.

¹⁵ J. Kobosko, J. Kosmalowa, *Słyszące rodzeństwo dzieci głuchych i słabosłyszących – spojrzenie z różnych stron*, „Słyszę. Dwumiesięcznik dla osób z problemami słuchu i mowy”, wrzesień – październik 2010, p. 29.

¹⁶ E. Pisula, *Rodzice i rodzeństwo dzieci z zaburzeniami rozwoju*, Wydawnictwo Uniwersytetu Warszawskiego, Warszawa 2007, p. 126.

¹⁷ A. Kucharczyk, *Kiedy w rodzinie nie wszystkie dzieci słyszą...*, [in:] *Młodzież głucha i słabo słysząca w rodzinie i otaczającym świecie dla terapeutów, nauczycieli, wycho-*

The revalidation of a deaf child spans for the most part the formation of speech and language. Well-hearing siblings create a specific peer group around the brother or sister with a hearing disability, and in it they act as partners, companions during play. A disabled child, through contact with siblings, satisfies its needs, such as: the need for emotional closeness, for security, respect or movement¹⁸. Considering the good of all children in the family, parents should remember that hearing children have full right to their own childhood, and that they cannot be overburdened by duties over the deaf siblings¹⁹.

It is difficult to provide a clear reply to the question *how is it, to be the brother or sister of a deaf person?* Some adult, siblings experience the emergence of the need to seek support and understanding for their deaf brother or sister. One of the sources of information and aid for deaf siblings are portals and websites concerned with SODA (Siblings of Deaf Adults). Hearing children growing up alongside deaf siblings have unique experiences. Some of these people would like to reach other hearing people with deaf siblings to share their experiences²⁰. Hearing siblings often talk in on-line forums for the deaf, and participate in the affairs of the community of people with damaged hearing. In some cases, coping with difficulties occurs through the choice of surdopaedagogical studies or the writing of graduation papers centered around special education. Sometimes, the well-hearing brother or sister becomes a sign language interpreter or teacher to children with hearing deficiencies²¹.

wawców i rodziców, ed. by J. Kobosko, Stowarzyszenie Rodziców i Przyjaciół Dzieci i Młodzieży z Wadą Słuchu „Usłyszeć Świat”, Warszawa 2009, p. 140.

¹⁸ A. Twardowski, *Sytuacja psychologiczna rodzeństwa dzieci z niepełnosprawnościami* (część 2), „Szkoła Specjalna”, 3/2011, p. 191.

¹⁹ K. Bienkowska-Robak, *Udział rodziny w terapii dziecka z wadą słuchu prowadzonej metodą audytywnowербalną*, [in:] *Dziecko niepełnosprawne, jego rodzina i edukacja*, ed. by K. J. Zablocki, Wydawnictwo Akademickie „Żak”, Warszawa 1999, p. 183.

²⁰ J. Berke, *Sibling of Deaf Adult*, <http://deafness.about.com/od/hearingbasic1/g/sodadef.htm>, [accessed on: 17.01.2014].

²¹ J. Kobosko, J. Kosmalowa, *Słyszące rodzeństwo dzieci głuchych i słabosłyszących- spojrzenie z różnych stron*, „Słyszę. Dwumiesięcznik dla osób z problemami słuchu i mowy”, wrzesień – październik 2010, pp. 30-31.

Research methodology

The key problem in the undertaken study applied to *how and in what way does/did the fact of having siblings with hearing deficiencies influence the life situation of well-hearing siblings?* In order to provide an answer to this question, the method of individual cases was used. The studied population was selected with the use of the snowball method²². Six respondents participated – four women and two men (aged 20-50). These persons reside in various regions of Poland, differ by their education level and field, marital status and size of the locality, in which they reside. The interviews were based on a partially categorised interview questionnaire that permitted the adaptation of the content and order of the questions, as well as the introduction of additional questions. This choice was conditioned by the varied character of the functioning of persons with hearing deficiencies. The knowledge on the mode of communication of these people or the specific characteristics of the school they attended, among others, determined the mode, content and order of the questions posed during the interview with their well-hearing sibling. In order to faithfully record their statements during the conducted interview, recording hardware was used with the interviewees' consent.

Results of own research

Undertaking qualitative research, I needed to make the assumption that „limiting oneself to one or but a few cases may provide just the basis to formulate working hypotheses, and not one to make generalised conclusions”²³.

²² E. Babbie, *Badania społeczne w praktyce*, Wydawnictwo Naukowe PWN, Warszawa 2003, pp. 205-206.

²³ U. Bartnikowska, *Sytuacja społeczna i rodzinna słyszących dzieci niesłyszących rodziców*, Wydawnictwo Edukacyjne Akapit, Toruń 2010, p. 167.

A retrospect view of adult siblings on the issue of personal experiences from childhood beside a well-hearing brother or sister can be varied²⁴. Due to the limited volume of the present study, I present excerpts from statements of the interviewees. One of them – named Agnieszka, aged 24, a student of education science – had spontaneously learned (and continues to learn) sign language from her sister, something her parents did not do to that extent. Hence, in many situations she had become the „intermediary” in their mutual communication. Subject literature describes such cases, as I have mentioned in the introductory part of this article: *„It must have just happened like that. I knew she did not hear, that I cannot talk to her verbally, but that something else needs to be done; so there are gestures, so there is pointing, so there is something else. I think it must have been something like that. And I automatically, and she pointed to things for me, and when she learned sign language, she brought it home and I sort of happened to learn it along the way. I do not recall any item like „learn sign language already. Learn, you need to know it, you need to talk to me”. It came fluidly and we did it just between us, by ourselves”*.

In the opinion of one Marta, 24-year-old student of education science, having disabled siblings shapes personality traits in a certain way, and it makes one perceive themselves as being open to otherness. During her statement, she constituted that *„there’s something about it, we look differently (...). And it must be that if somebody else comes, e. g. with a different flaw, some disability, then to a certain extent I approach them more normally, because I experience it daily... and it is just like normal for me (...), a person like any other”*.

Tomasz, 24-year-old student at a post-secondary school in the field of computer science, had noticed the advantage of having deaf siblings in the form of development of his own independence: *„I was even satisfied by the fact that I could by myself... well, I couldn’t be that independent, (...). I just learned to be independent through this (...).*

²⁴ Cyran A., *Styszące rodzeństwo osób z zaburzeniem słuchu*, master’s thesis written under the guidance of Adam Mickiewicz University professor dr hab. H. Krauze-Sikorska, Adam Mickiewicz University of Poznań 2014.

The parents trusted me, and I trusted them. (...). And I never abused this trust."

During his statement, one Mirosław, 46-year-old sales manager, father to five well-hearing children, indicated the significance of the age difference between the siblings for the formation of the mutual relationship and the undertaking of care functions: *"I remember very well when my younger brother did not want to go to sleep, and when my friends would want to go play football and would call me, and I could not go out and I was very cross [laughs], but that was just this one time. We had a big age difference, after all (...), it was rather the older one who took care of me than me helping him in any way. As for the younger brother, as I said, well, it's clear, I was a bit older, at times he needed taking care of [laughs] be it to „lull” him or not to „lull him” (...), but in general everything was fine"*.

Anna, 23-year-old student of national security spoke in her statement of the feeling of responsibility for the deaf siblings that accompanied her: *"recently I have given it a lot of thought, because I am the oldest and I feel very much responsible for these siblings of mine, and I am certain, I am ready to help them in the future as well. I thought that I would like to have a good enough job so as to be able to help them in everything if need be. One never knows how life will go. I mean, I don't have any specific education or professional choices with respect to them, but I know that in the future I will certainly also be responsible for them in some way"*.

In case of Marzena, 48-year-old mother to three, the fact of having brothers with hearing deficiencies influenced the education, and then the professional choices, she made. Presently, the interviewee can prove long years of work at a school and education facility for deaf children. As she herself says: *"it really influenced how my life went"*. In the interviewee's opinion, having deaf siblings *"influences how one perceives people who can behave differently, whether I better understand certain situations and I have more distance to these situations. It must have had some influence, that I look at it differently, that I feel differently. Because I believe that if one does not experience certain things by themselves, then it is difficult to really accept all that just reading arti-*

cles or books, not having such experience, not keeping company with people generally disabled. Various people do in fact have some sort of acceptance at varied levels, and in case of further experiences one can have more acceptance than others, but I think that it also depends on the person.” In addition, in the interview, she indicated the social attitude towards the deaf and the need to support people with hearing deficiencies arising from it: *„in general, the problem is, as usual, with people. The problem is that some are open and want to do something, while others are closed and believe that „I know best anyway, and you have nothing to say to me”. In public offices everything depends on people, too (...).”*

Closing thoughts

The undertaken study was qualitative – the fate and thoughts of the interviewees can be treated but as an example constituting a point of reference. There must be noted, however, the motifs appearing in the interviewees’ statements, determining the formation of positive relations with deaf siblings. These include: coherent parental attitudes towards well-hearing and deaf children, the knowledge of methods of communication available to the siblings with hearing deficiencies, as well as a coherent family atmosphere, full of love and understanding. Of importance in this respect is also the mentioned moment of birth of the deaf child and the size of the family. Referring to the main problem of the presented research, one may conclude that in case of the described individual cases, the fact of having siblings with hearing deficiencies influenced the life situation of these people. It refers to the exhibited personality traits as well as the choices made in terms of education and work.

The present challenge is to seek answers to the questions: what to do for hearing siblings to get as much advantage from the family and social situation in which they have found themselves; what to do in order to minimise possible losses due to the fact of having siblings with hearing deficiencies? Doubtless, the key role in this

area is the emotional support provided to the well-hearing child (person) permitting the reduction of tensions and negative feelings²⁵ as well as broadly understood social support²⁶.

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²⁵ H. Sęk, R. Cieślak, *Wsparcie społeczne- sposoby definiowania, rodzaje i źródła wsparcia, wybrane koncepcje teoretyczne*, [in:] *Wsparcie społeczne, stres i zdrowie*, ed. by H. Sęk, R. Cieślak, Wydawnictwo Naukowe PWN, Warszawa 2004, p. 19.

²⁶ M. Winiarski, *Pedagogika społeczna humanistycznie zorientowana*, [in:] *Pedagogika społeczna: dokonania-aktualności-perspektywy. Podręcznik akademicki dla pedagogów*, ed. by S. Kawula, Wydawnictwo Adam Marszałek, Toruń 2001, pp. 72-73.

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