Thematic Article

Specific Needs of Families of Deaf Parents and Hearing Children

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Abstract

The aim of the paper is to describe specific aspects of deaf parenting of hearing children, based on an interpretation of research findings concerning the target group. Deaf parents, isolated from the verbally communicating majority by their sensory disability, face the challenge of raising and preparing hearing children for life. Our research based on semi-structured interviews with both deaf parents and hearing children demonstrates, however, that these parents do not primarily describe their parenthood as difficult or complicated. They are reconciled to their handicap and its consequences and use tools in the social environment to overcome the disadvantages of deaf parenting. Some "children" (all our respondents were adults reflecting on their childhood) describe, in contrast, their experience as a gradual reverse of natural family roles, with children eventually navigating their parents around the hearing world. These results indicate the need for further activities with these target groups in social work.

Keywords: childhood; children; CODA; deaf adults; parenting; social

Introduction

As contemporary society enjoys new levels of affluence, it has turned its attention to issues which there was no room for at a time when humans were grappling with existential problems or complex social transformations. One such issue is equality and equal opportunities for all. Equal rights and equal opportunities for all should not only be limited to the "big issues" of the prevention of discrimination on the grounds of sex, ethnicity, sexual orientation, religion or age. Society includes groups of people whose equal access to rights and opportunities is complicated by aspects, which are hard to see at first glance. All people need to have the opportunity to develop their competence and social relations freely. It is therefore the responsibility of science, particularly sciences related to the helping professions, to seek out and help break through or overcome barriers, which prevent some people or social groups from developing their potential. One of these at-risk but still often invisible groups is that of (hearing) children of deaf adults (CODA).

These families are exposed to multiple sources of debilitation in their development, which each member copes with independently in their own way. Deaf parents, isolated from the verbally communicating majority by their sensory disability, face the challenge of raising and preparing hearing children for life. The children are reared bilingual, with many interpreting for their parents from an early age and all growing up in two different cultures. The families experience a gradual reverse of natural family roles, with children eventually navigating their parents around the hearing world. All these can be interpreted as potential sources of social disadvantage for these families and their members.

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Theoretical background

The theoretical background for research on children of deaf adults is not particularly strong. Surveys and studies, apart from certain exceptions, (e.g. Bishop & Hicks, 2005, 2007, 2008; Preston, 1996; Redlich, 2008, Singleton & Tittle, 2000) do not deal with this issue. In these rare studies, children are more often the subjects of these research projects than their parents. Our theoretical basis relies on the description of CODA problematics presented by the authors mentioned above with a deeper focus on the theory of bilingualism and biculturalism and an analysis of the impact of parents' school segregation during the socialist era.

Bilingualism and biculturalism of CODA

The process of becoming bilingual is different for CODA compared to children living with two spoken languages. The majority of the communication partners had to be separated from deaf parents to learn spoken language. They had to experience separation and deprivation (Langmeier, & Matějček, 1968) as discussed further in the text. Spoken language was introduced by hearing grandparents or the communication partners were placed in pre-schools at an early age (earlier than their peers with healthy parents were). Sign language is visually motoric, non-vocal, based on the gestural mode of "reading" by sight. Prejudices about the limited vocabulary, "primitiveness" and "inadequacy" of sign language have been refuted by linguists (Armstrong & Wilcox 2007, Fox 2008, Macurová 2008). The problems the communication partners faced in childhood mostly stemmed from the fact that the deaf parents lacked sufficient knowledge of the spoken (lip-read) and written language. The limitation isolates deaf people from the information flow produced by the majority. This is in all probability one of the main reasons why deaf people (the deaf minority) are excluded from mainstream society. In this case, the situation of deaf adults and their children fits into the definition of exclusion and marginalisation provided by Mowat: "to be marginalised is to have a sense that one does not belong and (...) is neither a valued member of a community and able to make a valuable contribution within that community nor able to access the range of services and/or opportunities open to others" (Mowat, 2015, p. 457).

CODA grow up with deaf communication and culture, while navigating the world of hearing people at the same time. They learn two languages simultaneously: sign language from their parents, and spoken language from their grandparents, in pre-school and school, from healthy peers, etc. They are, as a result, naturally bilingual. In addition to language, children also acquire dual culture, the culture of hearing mainstream society and the culture of the Deaf community.[3] As Ross et al. (2002) claim, this bicultural identity can bring both benefits and insecurity which was one of the theoretical backgrounds for our research.

Impact of parents' school segregation

One of the key factors influencing the situation of CODA families (which was investigated through the survey) is school segregation of children with hearing impairment in the Czech Republic before 1989. Most deaf children[4] (the parents of the communication partners) attended weekly boarding schools from the age of three until the legal age. A communication gap developed over time between the children and their parents, as the children communicated chiefly in sign language with each other in the special school and dormitory while their parents relied on oral expression and lip reading. The weekly boarding school tore the children away from the emotional support of their family, from the daily life of the majority, leading to emotional deprivation. The literature has studied in detail deprivation induced by institutional care since the 1960s (Langmeier, & Matějček, 1968; Matějček, 1996). The younger the child was exposed to deprivation, the stronger and more permanent its adverse effects were (Matoušek, 2007). Deprivation may manifest itself as the unwillingness and inability to associate with people who have not had a similar impairment. The impaired person prefers the company of those with the same experience (Matoušek, 1999).

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[3] The terms "deaf" and "Deaf" serve as a terminological distinction between two psychologically and culturally distinct social groups (Napier, 2002). The term "deaf" refers to people who view their hearing loss (disorder) as a health or communication specificity. "Deaf" refers to those who, with regard to their native tongue, differ from the native language of the majority, and to the specific cultural traditions of the Deaf community, see themselves as an ethnic group (Holcomb, 2013). The "deaf" and the "Deaf" are separated mainly by the self-identification of the individual. Due to this self-identification we approach the Deaf community as an ethnic group.

[4] Prelingual deaf people are born with a hearing loss, or their hearing loss occurred prior to speech fixation, approximately by the age of six (Lejska, 2003; Browning, 2008; Hogan & Phillips, 2015). The time of hearing loss is important for constructing concepts and vocabulary, which influences the ability to communicate in oral – spoken language (Potměšil, 1999).

Research design and methods

The research area of the paper is the family situation of hearing children and deaf parents which splits up into two research topics - childhood of hearing children of deaf adults and parenthood of deaf parents of CODA. The aim of the paper is to describe specific aspects of deaf parenting and the childhood of hearing children, based on an interpretation of research findings concerning the target group. This paper presents an interpretation of two data sets gained in two separate surveys. Both of them were carried out as a qualitative explanatory (see Yin, 2002), collective (see Stake, 1995) case study. We find this setting appropriate considering the unexplored area. The unclear state of knowledge and its structure led us to use a qualitative research design. The character of the Deaf community suggested using a collective case study providing complex data and its interpretation.

The research aim of the first survey[5] was to explain how hearing children of deaf adults reflect on their past experience of childhood. The second research project was inspired by the results of the first survey. Its research aim was to explain how deaf adults reflect on their parenthood of their hearing children.

A total of fourteen communication partners were interviewed at the first stage and five at the second stage. The primary contact information of the potential respondents was retrieved from deaf and hearing-impaired support social services, while other communication partners were snowballed from the initial contact for the first survey. The second survey used only contact delivered from support social services. For the first survey following criteria applied to communication partners: (1) both the parents of the communication partner are prelingual deaf and the family uses sign language; (2) the communication partner is adult. For the second survey, (1) communication partners needed to be prelingual deaf and (2) at least one of their children needed to be over 15 years old.

We used semi-structured interviews, subjected to open coding followed by thematic content analysis (Flick, 2009), for both cases. In the first case, we used a general question about the childhood of respondents as a hearing child of deaf parents. The second survey began with a similar general question on the parenthood of deaf parents but was altered due to the reflection of the interview process to be more structured. For this structuration, we used the basic stages of ontogenetic development of a child (e.g. Piaget & Inhelder, 2008; Lambert & Johnson, 2011) as background for topics opened during the interview.

We followed the ethical rules designated for research in the humanities, as described in Flick (2009), in our surveys. We collected the informed consent of the communication partners and confirmation of confidentiality maintenance (from sign language interpreters). In the researchers' preparation for the interviews, we widely discussed the danger of harming our respondents (principle of non-maleficence) and adopted measures to lower this risk. Our interpretation process was led by the rule of justice in analysing data. Thus, our interpretation should have been descriptively based on the obtained data with an effort at lowering the chance of the embarrassment and dignity loss of our respondents. The principle of anonymity and confidentiality was ensured with our decision to quote specific utterances separately without matching them with anonymized names (e.g. Respondent 1, 2, 3…) in the text. Due to the rather intimate character of the target group, we considered this important for establishing a safer environment. The welfare of respondents was ensured with discussion and a process explaining to them both before the interview and during the entire process. Every respondent took part in the research voluntarily and always had the opportunity to terminate the cooperation.

Results

The Childhood of Hearing Children of Deaf Parents

The first theme of the first part of our research was interpreting for parents even where the children were too immature for the situation due to their age and lack of life experience. The respondents would begin interpreting for their deaf parents as early as aged five or six years. The interpreting children often found themselves in situations they were unable to comprehend fully given their age. The interpreting imposed varying degrees of responsibility on the interpreting child: in shops, at the doctor's office, at offices and agencies, interpreting television news and shows. One of the respondents said: *"Dad was looking for a job and so he took me with him for interviews ... ... The worst part was when I was told to fill in a questionnaire or take a test on Dad's behalf, he couldn't hear them, but I didn't listen either to what they wanted, and that was the worst and I would really stress out."* Another respondent complained: *"As a kid I dealt with my folks' issues even though*

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[5] The findings of the first phase of the empirical survey were published in the European Journal of Social Work (Klimentová, Dočekal, & Hynková, 2017).

I couldn't make heads or tails of it." Some children were never given the choice, as their parents automatically counted on their help and did not expect their children to refuse. A respondent recalled how she and her sister gradually refused to handle the problematic situations of their parents: *"It was annoying having to deal with things when we didn't feel like it, the worst was, and I remember clearly, it was the worst when we were teenagers, it was such a pain in the neck."*

The second topic was the lack of social support for interpreting children and their parents when dealing with social offices. The respondents recalled that some interpreting situations left the parents as helpless as their helpless children. Not having the support of readily available professional interpreters, the parents relied on the closest help, which they found in their children. When interpreting, the children were, however, forced to cope with situations for which they were clearly too immature. Neither of these parties knew where to seek help. They were left without any support, alone, within the social space of the majority. A respondent described one of the exceptions: *"I remember once, when my sis and I were little, there was a situation and the clerk asked our parents to come back with an interpreter. The clerks saw themselves as beyond our capacities."* Most offices did not object, however, to the presence of interpreting minors or offer an alternative aid as the offices saw the children as a readily available solution to the communication barrier between them and the deaf adults. One of the men recalled: *"My parents couldn't wait till I got a bit older and learnt to communicate, and then I'd accompany my Dad like four times a month to the office to request and demand regular housing. I wasn't even in school yet and about a year later, they were given a flat, likely just to get rid of them. I don't think it was normal for a five/six-year-old boy to help them get a place to live, but it all seemed pretty normal to everyone, I was never offered any help whatsoever, never."* Professional interpretation was strictly required only in one case – the legal procedures of divorce.

The third theme, suggested by the numerous responses, is the feeling of inadequate parental support in childhood. The hearing impairment made it impossible or difficult for parents to do activities with their children which are common in families but which require verbal communication. As children, the communication partners were not read fairy tales, were not helped with homework, did not receive support when making career choices or assistance with relationship problems. They could not share their joys and worries, inner world and everyday talk with anyone. One of the respondents stated: *"...my parents never read to me and I did the homework on my own, they just signed it, without going over it."* Another respondent added: *"I picked the school by myself, sent the application, basically all I've ever achieved since primary school has been my ambition only."* Yet another respondent summarized the impact of the absence of everyday family interactions: *"I missed the communication a lot, I felt so lonely, even when my folks were in, I was on my own."*

The interview sections, in which the communication partners grieved a lost part of their childhood, were accompanied by painful emotions. As stated above, many families experienced a change in the family roles, where the children felt responsible for their parents. *"I've felt all my life that I had to be the one looking after my parents"*. Another respondent stated: *"I reckon it stole the essence of childhood from me, the innocence, not a worry in the world that kids usually have, I got entangled in the world of adults way too soon for a young kid."*

The final frequently discussed theme was a childhood spent in the close community of the deaf. One of the research participants said: *"...they were always planning stuff to do, for kids as well, for example, Children's Day road safety workshop, skittles, we'd go on trips, to the mountains, they loved hiking and such, in short, there was a ton of things to do. There were loads of kids and we were all like one big family."* Some of the communication partners contemplated whether their parents felt more at home in the deaf community than with their children. "*... it was never just us four going for a trip, me and my brother and our parents; they always preferred other deaf people, they preferred hanging out with them than with us. They'd go for a trip with them and we stayed behind at home with Gran."* As another respondent said: "*...since they all had the same disability, it's a major thing that connects them, they stick together."*

The respondents largely agree on what the advantages and disadvantages of being a CODA are. The disadvantages, according to them, include the loss of childhood and a child's carefreeness, age-inappropriate feelings of responsibility for parents, early maturity, and the obligation to learn to understand adult problems. In retrospect, however, they appreciate the acquired abilities of empathy and patience, the willingness and ability to take responsibility, and the gained organizational skills.

Parenting of Deaf Parents

After finishing the first stage of our research, we focused on the point of view of parents of CODA. How do they perceive their parenthood with the hearing impairment? We used very similar research settings to obtain a similar character of gained data. The overall impression left by interviews with the deaf parents of hearing children is that of serenity. They do not consider their parenting role as problematic or aggravated. They all claim to have a very deep relationship with their children, who are clearly loved and welcomed. None of the communication partners had considered not having children. They all spontaneously stated that they did not mind whether their child would be hearing or deaf. *"We agreed that if we had hearing kids, it would be totally okay as they could speak, sign, all together, it would all work. If both our kids had a hearing impairment, they could also sign and speak at the same time. And if they were deaf, they'd be sort of part of the community as well, no problem."*

Parents spontaneously describe in the interviews the areas in which they are unable to exercise their parental competencies, mentioning the substitute strategies their children have used. Children were taught to speak by grandparents and one family hired a neighbour with children of a similar age to babysit their children, so the children had contact with spoken language. Children also attended specialized speech therapy classes. *"The kids went to pre-school at a younger age, because we were deaf."* Grandparents, children's friends or school helped with homework in the later stages of primary school as it usually became too challenging for parents. One of the respondents recalled the years her son went to school: *"And so a classmate would help him with school work. ... I was no use. ... He also took some extra classes at 7 a.m. before school. Yeah, he took extra classes in maths and Czech."* Communication partners ascribe their limitations in this area to their disability, to hearing loss. They by themselves do not seek alternatives, ways to expand or strengthen their competences. They do not study the impact it has on their children. They flexibly use the social environment to integrate their children, who can hear, into auditory society. The communication partners consider these strategies a utilitarian necessity, not a disadvantage. Instead of being discouraged, they observe and accept this as a fact.

In general, the interviews were mostly positive, with negative experiences presented rarely. The boarding facilities were also described as a positive experience of the communication partners. They felt to be "among their own" there, in a world free of communication barriers. One of the respondents, who has deaf parents, claimed to prefer the boarding facility to living with his family: *"I went to boarding school, I guess I was happier there. Friends, fun, sports. I didn't know what I'd do if I had to live with my parents in the village. I wasn't close to the other kids and so I preferred staying in the boarding school."* The problem was therefore not just intra-family communication, but also contact with hearing peers. The majority of respondents also met their mates in the deaf community, which was typically associated with a regional special school for children with hearing impairments.

Hearing impairments caused parents considerable complications notably when the children were young. One of the situations, mentioned by a communication partner, was losing track of his son in a forest. Calling his name was of no use, for, though the communication partner is able to speak, he would not have been able to hear his son's response. Unable to locate his son for some time, the father decided to call the emergency services. The intervention was successful – the boy returned from the forest, attracted by the sound of a siren. A similar experience was reported by a respondent who had lost her toddler daughter in a department store. After a long search, the child was located with the help of a camera system installed throughout the building. In addition to the mother's disability, the inability of the toddler to communicate with her social environment and seek help played a role in this case. The mother recalled how difficult it was for her to wait in the emergency room corridor while her son was undergoing a minor surgery. She had no idea how the child was coping, she could not hear whether or not he was crying.

Discussion

In the research, we noticed several factors that may have influenced the obtained data and their interpretation. Above all, we are aware that the nature of memories is influenced by the process of forgetting and the emotional settings of the respondent and cannot be considered an exact reflection of reality. Another limitation to the research was the need to involve the sign language translator in the second phase of the research. The fact that the translator was known, on the one hand, to all the communication partners was positive while, on the other hand, the statements could be distorted due to the stylization of the communication partners, the feeling of disruption of anonymity or the effort to meet the unspoken expectations of the community (which the

translator is part of). We tried to treat all these risks - by assuring discretion in information processing (from researchers and translators), by consistent communication and answering questions of communication partners before the interview, by signing confidentiality about the content and process with the translator and by attention paid to translation and communication during the conversation. As part of the reflections of the individual interviews, the procedure was adjusted and the translator was instructed to eliminate the influence of existing personal ties to the answers of the communication partners.

We are aware that we are affecting only part of the reality of the lives of families of deaf parents and hearing children. Although our research focused mainly on childhood and parenthood, other aspects of the life of the deaf community and their hearing children could certainly be examined. As part of (further) research, we considered creating case studies of entire families, which we consider to be extremely ethically demanding. Another option is to examine the current relationship between CODA and their parents, which would eliminate the risk of distorting respondents' memories. In the future, it will be relevant to conduct research on families in which parents no longer experienced boarding, which had a major impact on their adult parental life.

Conclusions

The conclusion of our survey pointed to the deficiencies of the deaf child care system and deaf adult social care services, which have a negative impact on both deaf adults and their hearing children. While the disadvantage of parents is visible (either due to the impairment itself or due to previous inadequate boarding school education) for children in these families, the disadvantage caused by the transfer of the impairment of their parents to them is difficult to see. Possible strategies for preventing and tackling these sources of social deprivation of deaf adults in their parental role involve, in general, support for the integration of CODA into the hearing world, and institutional support for the families concerned, mainly by training deaf parents to develop parental competences. The primary tool for preventing and addressing the situation is raising public awareness about and respect for the specific needs and specific form of deaf communication. This would reduce the pressure on involving hearing children in interpretation for their deaf parents. In addition, deaf people across all age groups should be trained as part of family education to make less use of their children as interpreters, particularly in situations for which the children are not mature enough, and to learn to be more flexible at using professional interpreting services and modern communication technologies. Additional proposed tools, to address the risky situation of the target group, are aimed at institutional support for the families in question. These are specifically the reinforcement of social activation services which facilitate the development of parental competences of deaf parents. The teachers and school counsellors of CODA also need to pay greater attention in order to enable the children to benefit from increased school support when they are unable to do so due to the hearing impairment of their parents. The goal is to better integrate CODA into the social networks of the community in which they live.

The results suggest the daily life of these specific families remains largely unknown to the majority. Both hearing children and deaf parents are forced to cope with obstacles generated by the hearing impairment but also by society as a whole. We assume and hope that the identification and description of said barriers can reduce the risk of social exclusion of these people and improve their access to equal rights and equal opportunities.

Conflicts of Interest: The authors declare no conflict of interest.

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