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**Abstract of the doctoral dissertation entitled:**

**The socio-economic situation  
of families with a hearing-impaired child in Poland**

**Discipline: public policy sciences**

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The issue of disability is an important social problem that affects a large proportion of the population, not only in Poland but also worldwide. For modern societies, in addition to the demographic problem of the increasing number of people with disabilities, the social and cultural dimension is also important. People with disabilities, can function on an equal footing in society and contribute to socio-economic development, changing social relations and transforming social consciousness, or they can remain as recipients of social benefits. To a large extent, this depends on whether the conditions in which they function contribute to their marginalisation or inclusion in mainstream society. In the dissertation, disability is understood through the prism of social and environmental barriers, thus in line with the social paradigm view. This issue is examined in detail in relation to hearing disability, where the sociocultural paradigm also becomes relevant.

The predominant problem for people with hearing disabilities is the communication barrier, with the group itself being highly diverse. On the one hand, this is due to the different degree and timing of hearing impairment, which further results in different levels of communication skills (Polish, Polish Sign Language, bilingualism). On the other hand, it is also the only group in which some people challenge the perception of them from a disability perspective, due to the formation of a specific community and culture in opposition to that of hearing people. This situation takes on added importance when dealing with families of a child with a hearing disability who may grow up and function in a hearing or g/deaf environment. In such a situation, families may perceive their child's disability differently and face other social, but also economic consequences.

A child's disability is also associated with numerous difficulties for the family. It can cause disruption to the basic functions of the family, accompanied by anxiety about the child's development and future, confusion due to lack of information, doubts about the validity of treatment and rehabilitation. It is also the need to adapt to a new situation, including the difficulty of reconciling work with the care, education and rehabilitation of the child. In addition, the additional costs that put a strain on the family budget are also important.

In this situation, the family requires additional non-financial and financial support, from state institutions.

The issue addressed in the dissertation concerning families of children with hearing impairment is a complex and interdisciplinary issue. This broad approach to the topic is made possible by analysis from the social sciences and, in particular, from the perspective of public policy, which, because of its many specific policies, covers almost all aspects related to the socio-economic conditions of this group in society.

Therefore, the planned main objective of the study was to determine what impact a child's hearing disability has on the socio-economic situation of the family, and to identify ways to counteract, reduce or eliminate the social exclusion of this group. An assertion was taken as the main thesis:

**Families with a child with a hearing disability are a group at risk of social and economic exclusion. Children with hearing impairment are given the opportunity to develop their speech through appropriate medical rehabilitation and educational support, which is an effective form of levelling the playing field and counteracting the exclusion of this group. Their systematic rehabilitation is a significant burden on the family budget.**

As numerous studies have shown, young people with various disabilities entering adulthood do not differ from their peers when it comes to aspirations and life goals. These differences are evident at the stage of achieving these objectives. Disability is therefore an important factor affecting readiness for future tasks and social roles.

The dissertation set out to analyse whether there is an opportunity to prevent or minimise the barriers that are the cause of exclusion and discrimination against people with hearing disabilities. The situation is particularly justified when the cause of the disability is congenital or appears at the childhood stage, when fundamental decisions are taken within the family regarding treatment, rehabilitation and, subsequently, the choice of school and the continuation of education, which will have an impact on, among other things, professional activity and, therefore, on the future material and social situation, as well as on the person's well-being and quality of life. On the other hand, at each stage, these decisions will be able to be made within the framework of the legal system in place in the country, the institutions implementing the support and the medical, technological and therapeutic options available. Here, it is worth emphasising the conclusions that it can be expected that children who are diagnosed with a hearing impairment at birth and given effective intervention in the form of hearing prostheses (hearing aids/implants) and hearing and speech rehabilitation can develop in the same way as their hearing peers, and therefore there is the possibility of significantly reducing the communication barrier that has so far been a reason for the professional, economic and social exclusion of people with hearing impairments.

In order to achieve the aim of the study and to verify its thesis, the following research questions were posed:

1. What are the economic and social impacts of a child's hearing disability?
2. What are the legal, institutional and material forms of support for the family of a child with hearing impairment and are they effective?



3. How does a child's hearing disability affect parents' work situation?
4. What costs does a child's hearing disability generate for the family?
5. How does the family raise funds to finance expenses related to the child's hearing disability?
6. What are the tools to counteract the social exclusion of people with hearing disabilities.

Among the research methods used in the prepared dissertation were: literature studies, analysis of legal acts and statistical data, a questionnaire survey among families, a partially categorised interview among NGOs and a case study of one and selected organisations dealing with the support of people with hearing disabilities, including the rehabilitation of children.

The structure of the work includes an introduction, five chapters, a conclusion, a bibliography, appendices and a list of tables, figures and diagrams.

#### **Key findings from the survey of families of children with hearing disabilities:**

No.	Part of the survey questionnaire	Summary of responses
1.	Metrics	The majority of respondents were aged 31-40 (54.4%), with tertiary education (76%), mostly living in Warsaw (34.40%). Typically, the questionnaire was completed by the mother (88.80%) and the hearing person (88%).
2.	Child with hearing impairment	Age - the proportion of different age groups was similar, with most children aged 0-14 years (28%). Degree of hearing loss - the group with severe and profound hearing loss totals 70.4%, i.e. children who would not be able to learn and understand speech without intervention. A coupled disability in a child was indicated by 26% of respondents. Mode of communication - 92% of children can use speech. At varying levels, PJM is spoken by 28.8% of the children surveyed.
3.	Financial situation	The majority of respondents are satisfied with their material situation, 58% overall rated it positively (very good and satisfactory). The deterioration of the situation due to the child's hearing loss was observed by 30.40 % of the respondents. Among those whose material situation had deteriorated, this was assessed to have occurred to a moderate degree (68.42%). Among those whose material situation did not deteriorate, it was assessed that this was due to the possibility of subsidising or refinancing the costs incurred, and therefore related to the support system in place in Poland.

No.	Part of the survey questionnaire	Summary of responses
4.	Parental labour force participation	<p>In the majority, both parents work (60%). Mothers are less likely (46.40% ) than fathers (77.60% ) to work full-time. In the family, the child's education and rehabilitation is mainly taken care of by the mother (63.20%).</p> <p>The child's rehabilitation often requires permanent or temporary resignation from work or a change in work organisation (86% in total).</p> <p>A change of industry or occupation occurred in one in four families of a child with a hearing disability. One in seven families decided to change their profession/industry to one related to the treatment, rehabilitation or support of people with disabilities.</p>
5.	Costs related to hearing and speech rehabilitation	<p>Among the costs, the purchase of hearing aids was considered to be the most burdensome, followed by private rehabilitation and commuting to classes.</p> <p>Families cover the largest share of costs related to their child's hearing impairment from their own resources (88%) and from funds accumulated in an individual account of 1.5% (61.6%).</p> <p>Most often, families manage to obtain at least partial funding or reimbursement for the purchase of hearing aids (57.6%) and additional rehabilitation (32%).</p>
6.	Social and institutional support	<p>Most families benefit from attendance allowance (93.6%) and attendance benefit (48.8%).</p> <p>A total of 68% of children from the families surveyed attend an inclusive and mainstream facility, and a total of 20.8% attend a special facility.</p> <p>Children mostly benefit from rehabilitation in educational institutions (79.6%) and NGOs (50.4%).</p>
7.	Identification of constraints and barriers	<p>A situation of exclusion or inferior treatment was experienced by (36%) children and, in the case of 16.8% of respondents, also experienced by another family member.</p> <p>Among those who experienced inferior treatment, the majority of these situations were rare and very rare (64.8%).</p> <p>The person treating them worse was usually a peer (40%), teachers or other staff at school (16.8% in total), and relatives (14.4%).</p> <p>According to the respondents, the greatest difficulty is balancing work with the care and rehabilitation of the</p>

No.	Part of the survey questionnaire	Summary of responses
		child, followed by the costs they incur due to the child's hearing disability.
8.	The development of children's speech, through medical rehabilitation and educational support, as a form of equalising opportunities and counteracting the exclusion of this group -question that relates directly to the thesis.	Among the families surveyed, the vast majority (88%) rated the development of children's speech through medical rehabilitation support and education as an effective way to counteract the exclusion of this group.
9.	Necessary actions to reduce and eliminate social exclusion of children with hearing loss	The first 5 of the 15 proposals, in order from highest to lowest rated by families: 1) Greater access to hearing and speech rehabilitation specialists, 2) Providing systemic care for the whole family from the moment of the child's diagnosis, through counselling and support, e.g. in choosing a place for rehabilitation, education and other difficult decisions related to the child's hearing loss, 3) raising public awareness of hearing loss issues 4) greater access to medical care specialists 5) additional support for the child at nursery/school.

#### Key findings from the interviews:

No.	Category	Summary of responses
1.	Support currently offered in Poland	In the organisation's view, the support currently offered in Poland is not sufficient, although the positive changes that have taken place over the past few years are also noticeable.
2.	Social exclusion of children with hearing impairment and their families	According to the organisation, the group surveyed is at risk of social exclusion, although not all to the same extent. Those most at risk of exclusion are individuals and families in smaller towns and in situations of abnormal or unclear child speech. The situation is particularly difficult for families where the parents also have a hearing disability, due to their difficulties in finding employment.



No.	Category	Summary of responses
3.	The development of children's speech, through medical rehabilitation and educational support, as a form of equalising opportunities and counteracting the exclusion of this group -question that relates directly to the thesis.	In the organisation's view, the development of children's speech through medical rehabilitation support and education is an effective way to counteract the exclusion of this group. However, it must also be taken into account here that not every family will be able or willing to undertake such an intervention.
4.	Main barriers and difficulties highlighted	<ul style="list-style-type: none"> <li>– Lack of family support immediately after diagnosis.</li> <li>– Difficulty in accessing information.</li> <li>– Lack of proper preparation of staff in schools, low level of teaching in g/Deaf schools, inadequacy of textbooks.</li> <li>– Limited access to PJM interpreters, resulting in exclusion from access to many services, culture and recreation, as well as the quality of these interpreters.</li> <li>– Fewer opportunities for families outside large urban centres.</li> <li>– Lack of sufficient hearing and speech rehabilitation within the National Health Service and the problem of distinguishing between medical and social rehabilitation for people with hearing disabilities.</li> <li>– Inconsistency and subjectivity of jurisprudence.</li> <li>– Funding to support organisations and families, an increase in the supply of private services where the price does not always match the quality.</li> <li>– Social pressure that the only, right choice is to pursue speech development.</li> <li>– Insufficient non-financial support for families e.g. lack of psychological support.</li> <li>– Mental barriers.</li> <li>– Other non-system factors related to contemporary social change.</li> </ul>
5.	Other observations	<ul style="list-style-type: none"> <li>– Changing attitudes of modern families towards previous generations.</li> <li>– Increasing internal integration of the hitherto divided g/Deaf community.</li> </ul>

No.	Category	Summary of responses
		<ul style="list-style-type: none"> <li>– Adverse impact of technology on family engagement (tablets, phones).</li> <li>– Greater openness of society to diversity, linked to the parallel activities of other groups hitherto at risk of exclusion, e.g. LGBTQ+</li> </ul>

### Key findings from the case study:

- The holistic support model is effective in counteracting the social exclusion of people with hearing disabilities.
- It is important to involve the family in the child's rehabilitation process.
- The possibility of psychological support for the child and his or her family is important.
- Interdisciplinary continuous, long-term and well-considered rehabilitation by specialised people (surdologopedist, surdopedagogue, etc.) is important.
- It is important for children with hearing impairment to also be around other children with a similar problem, especially for children from mainstream schools.
- The opportunity to integrate families of children with hearing impairments, provides support for this group.
- It is possible to unite the hitherto divided g/deaf community and develop a common position on the support needed.
- It is possible to integrate the hearing and g/deaf community with appropriate support tools, e.g. PJM interpreters, and by fostering an atmosphere of mutual openness between the two groups.

The dissertation develops and describes two contrasting models of support for people with hearing disabilities:

- The exclusionary model - where, due to insufficient state support during childhood, people with hearing disabilities have a low chance of social inclusion during adulthood.
- Supportive model - where, thanks to state support during childhood, the chance of full social inclusion during adulthood is significantly increased.

The paper presents detailed recommendations aimed at implementing a model in Poland that supports people with hearing disabilities. These include:



- changes to the Polish Sign Language regulations (recognition of sign language as a language and not as an alternative form of communication, certification of the level of use of PJM, requirements for interpreters on lists maintained by voivodes),
- introduction of a communication assistant service,
- providing systemic care for the family from the moment of diagnosis,
- establishment of family support teams (doctor, psychologist, social worker, g/deaf person),
- appointment of coordination centres and a consultant in surdologopaedics,
- changes to the assessment of disability for children (adjustments to the concepts and approach to OzN, harmonisation of the criteria for the award of both the assessment itself and the indications in the assessment of the point. 7 and para. 8),

