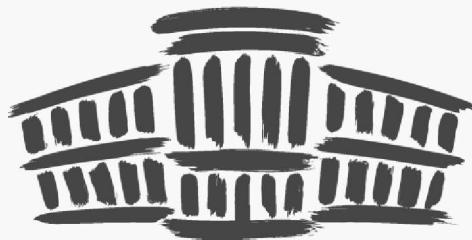


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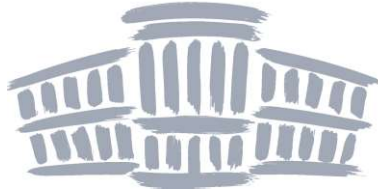
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## CHANCES AND OPPORTUNITIES FOR SOCIAL INTEGRATION OF A MINORITY GROUP

### *Abstract*

When examining an individual's social 'well-being' and integration, a number of factors can be identified that may make it difficult or hinder its success. One of these may be the fact of belonging to a minority group. The 'otherness' of people with speech impairments, cleft lip and cleft palate is also apparent in their external characteristics and can be the source of many stereotypes and prejudices. No large-scale, comprehensive research on their care, follow-up and mapping of the social context has yet been conducted in Hungary. We want to emphasise the importance of creating a fair society, with a theme in which we want to explore in the future an area of concern that highlights the strengths and possible weaknesses of the pedagogical, curative and health care sectors, highlighting the points where intervention may be necessary to make them work more effectively.

**Keywords:** *cleft lip and palate, social inclusion, equity*

### **1. Introduction**

In this paper, we would like to share our thoughts on a planned research project, underlining the urgent need for it, its niche nature and its scientific merit from an interdisciplinary perspective. In this paper, we would like to emphasise the pedagogical and speech-language pathology approach, because we consider it important to start from our practical experience in order to gain a deeper understanding of the topic, and to present it as a basis for further research. In addition to the special education/logopedagogical aspect, however, we also consider it extremely important to approach the topic from the sociological point of view of education, which can open up a number of new issues that have received little attention in academic life to date. Nowadays, the subject is mainly studied from an anatomical, medical point of view, while the educational aspects and the social context are mostly unexplored. Therefore, our aim is to carry out a comprehensive, complex research that examines the "everyday life" of clients with cleft lip and palate from multiple perspectives, thus representing a multidisciplinary approach.

### **2. Speech and language therapy and speech impairment**

Speech and language therapy is a very important part of the educational system and has been a service supporting education and training in Hungary for more than a century (Torda, 2015). The heterogeneity in symptoms, severity and age of the phenomena covered by speech and language disorders, as well as the diagnostic and therapeutic care issues related to these, are a constant challenge for one of the largest service systems in Hungarian special education, speech and language therapy. This system provides help to the affected persons in the framework of public education, both in an outpatient and in an institutional form (special speech therapy kindergarten/school) (Gerebenné et.al, 2012).

The development of speech requires an intact nervous system, perfectly developing speech organs, an excellent auditory system and an environment rich in verbal stimuli (Vinczéné et.al, 2013). If language acquisition, possession, knowledge and use, i.e. language competence itself, becomes

impaired, functions differently or inappropriately – i.e. differently from typical language users – this can result in a lifelong handicap (Fehérné, 2018).

Within the public education system, children with speech and language impairments occupy a somewhat special place, as the manifestation of their symptoms is often not as obvious as for a child with sensory, mobility or intellectual disabilities. Braun (2002) defines speech impairment as 'a primarily organic or psychological disorder of extensive, severe and long-lasting individual language impairment, which is also of pedagogical/logopedic relevance, if the intervention is provided within the educational framework of education' (Braun, 2002 in: Gereben et al., 2012: 9).

Speech impairment cannot be seen as a 'stand-alone' problem area, as it affects the process of thinking and cognition, and thus the level of intellectual development (Jenei, 2009). The quality of care, taking into account individual needs, is key not only for individual well-being but also for social integration.

### **3. Cleft lip and palate**

In the remainder of this article, we will focus on the specific area of speech impairment that is the focus of the planned research. Cleft lip and cleft palate is associated with the early stages of embryonic development (weeks 5 to 9), when the so-called lip and palate clefts do not fuse. Medical-genetic research suggests a multifactorial model, which means that several factors and their interactions may be involved in its development, above all heredity and toxic harm to the foetus in the prenatal period (Kivovics, 2019).

In Hungary, the incidence is 2.02 %, i.e. 1 in every 500 live-born babies, which means that approximately 300-320 newborns are affected each year (Hirschberg, 2004 in: Csák, 2007). In Hungarian colloquial language, the terms "rabbit mouth" and "cleft palate" are still used to describe clefts. Cleft lip and palate and insufficient function of the soft palate affect many areas indirectly. These areas include hearing, feeding, swallowing, but before all this, speech development is affected. It is most often characterised by delayed speech development, nasal tone, and defective articulation, which together lead to difficulty in comprehension (Vörös, 2006).

The term rhinophonia is used to describe a speech disorder resulting from cleft lip and palate. All forms of rhinophonia are pathological. The most common diagnostic category of congenital cause is facial clefting of various types and extent, i.e. developmental abnormalities of the lips and palate, which is the subject of this research.

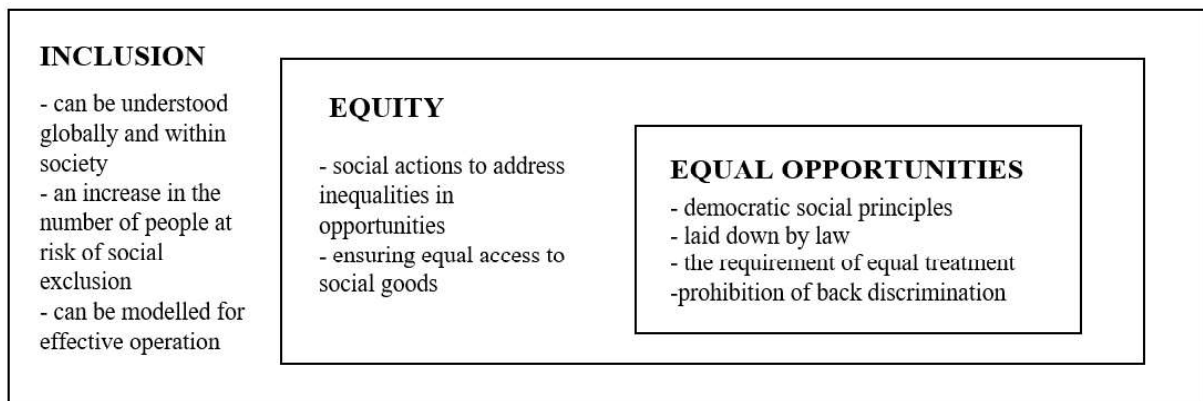
Mapping the mental health of the affected individuals can be a crucial area, but identifying the associated psychosocial factors can be challenging. One reason for this may be that participation in this type of research requires a high degree of self-reflection, making it difficult for people to open up about personal experiences and negative experiences. Self-perception, on the other hand, plays a key role in influencing an individual's self-evaluation and psychological adjustment (Hunt et al, 2005).

So it can be seen that the care of children with cleft palate requires an organised, multidisciplinary and close team approach from the moment of birth. The actors involved include the public education system (pedagogical service, specialised service, child health centre), the health care system (hospital, specialist clinic, paediatrician, network of defenders), interdisciplinary professionals (surgeon, orthodontist, ENT specialist, audiologist, phoniatrist, speech therapist, paediatrician, geneticist, family doctor, defender, coordinator) and the parent (Fehérné, Kas, and Pintye, 2018: 19). It is clear that the need for coordinated cooperation in this field can present many difficulties and problem areas.

### **3. Barriers and supports to successful social inclusion. Inclusion.**

Social acceptance often depends on physical appearance. The correlations between socially accepted physical beauty and social "thriving" can create frustration-laden situations that sharply predict the difficulties of social inclusion for individuals with cleft lip and cleft palate (Hunt et al, 2005). Examining the inclusion of children with cleft lip and cleft palate is an important focus of this research. And education is one of the most important areas for mainstreaming inclusion in society. And in discussing the quest for equality in education, the school mechanisms in which inequalities are rooted cannot be ignored. These are most evident in the form of latent selection mechanisms (Varga, 2015).

Children with cleft lip and palate are most likely to participate in education in integrated settings. However, this alone does not ensure equal access. Inclusive school environments can only be considered if they are complemented by equitable services (Figure 1.).



**Figure 1.:** *The context of inklusion (Varga, 2015).*

As children/students with cleft lip and palate may be affected in several areas of ability (speech, hearing, attention, cognitive skills) and are at risk of exclusion due to their impairment, creating an inclusive educational environment for them can be of paramount importance. "The basic principle of inclusive education is that pupils participate in education according to their own abilities, and it is the duty of the school to accept all pupils in this way" (Armstrong 2001, in: Varga, 2015: 50).

By constantly monitoring the special needs of the pupils concerned, using the right methods and tools in the right environment, possible exclusion can be avoided. The degree of 'preparedness' of majority teachers and the school environment, and the implementation of measures to address inequality, are fundamental to the extent to which we can talk about mutual inclusion for pupils with speech impairments (Varga, 2015).

Since education is seen as the main channel of mobility, the events of the years spent there are of particular importance for the later stages of the life course. It is undeniable that peer interactions play an important role in a child's life, and physical attractiveness has been shown to play a significant role in building the network of relationships that underpin these interactions. Research by De Sousa, Devare and Ghanshani (2009) has also confirmed that children with facial disorder are more likely to have reduced self-confidence, mostly due to the trauma, teasing and abuse they have experienced.

However, in addition to peers, a child's self-perception is also influenced by parents. Parents of children with clefts may often be more permissive and tolerant of their child's potentially inappropriate behaviour, and more likely to indulge their child in over-indulgent behaviour. However, the child may still experience this as negative discrimination, as it may make them feel different from the majority, and their feelings and thoughts about their physical appearance may constantly shape their attitudes towards their body image.

The results of the above-mentioned research suggest that a high percentage of children with cleft lip and palate underperform in various aspects of life, but there is no direct evidence that their disability has a real impact on their behaviour. Although the occurrence of psychosocial problems due to handicaps is likely, the ability to cope and integrate successfully in life is the result of a combination of many factors.

Through the presentation of resilient life paths, it is also important to shed light on the factors that, in the face of difficulties, have served successful social well-being and integration. -

By constantly monitoring the special needs of the pupils concerned, using the right methods and tools in the right environment, possible exclusion can be avoided (Figure 2.).

Problem: The kid	Problem: The school
Different from others	Not prepared to deal with differences
They have special needs	Lack of teaching tools and methodology
Not reacting, not learning	Not react, does not teach
The child is excluded from school	An inaccessible environment excludes children from school

**Figure 2.:** *Inclusion-focused approach to education. (UNESCO 2005:27; in Varga, 2015)*

#### 4. Relevance of the research

As speech and language therapists, we very often find that caring for children with speech disorders is very difficult and involves many problem areas. Unfortunately, there is a shortage of professionals and the number of speech/language therapy/pedagogy cases is increasing every year. Specialist Educational Services are very overloaded and in pre-school care there are many five year old children diagnosed with speech defects.

In Hungary, free speech therapy is provided from the age of five, starting earlier (at three) only in very justified cases (e.g. delayed speech development). In itinerant speech therapy, professionals mainly provide articulation (pausing) therapy. Therapy for speech fluency disorders (stuttering/stuttering), dysphonia (hoarse voice) and nasal speech is carried out in the Speech and Language Clinic.

In Győr, where we live, this means that although the sessions are free of charge, parents have to arrange for their child to be transported to the clinic during the morning hours on weekdays. In many cases, this makes it impossible for families to provide their child with regular free speech therapy.

And in our experience, newly qualified speech and language therapists are reluctant to take on the more "complex" cases because, although they could do so on the basis of their diploma, they do not feel competent in the field of organic/central speech disorders.

We believe that, despite the fact that the incidence of articulation disorders is much higher than that of organic speech disorders, the latter group should be given equal emphasis. It is primarily the difficulties outlined here, from a pedagogical point of view, which draw attention to other areas of care and to the examination of individual life paths.

##### 4.1. Research questions, hypotheses

Having outlined the theoretical and practical problem areas above, the research questions are therefore:

1. What is the prevalence of cleft lip and palate in children in our country? What are the main questions of the oral and maxillofacial syndrome and what are the main trends in the past years?
2. What social factors play a role in the school life of children with cleft lip and palate? Is their integrated education in an inclusive environment?
3. To what extent and in which areas does socio-economic status affect the life paths and opportunities of young people with cleft lip and palate?
4. Does the possibility and the fact of greater access to medical and educational services have a positive impact on the current and future (adult) quality of life of young people?
5. How effective is the cooperation between professionals in the provision of care? What do professionals in different fields see as the difficulties and what would they suggest as solutions?
6. Do mainstream teachers hear about children with special educational needs and speech impairments in their training and do they have enough information to promote their inclusion?
7. What courses are speech and language therapy students taking to learn about nasal phonation and methods of care for people with cleft lip and palate? What are the differences between training institutions in this area?

8. How prepared are graduates in speech and language therapy to care for children with cleft lip and palate (nasalization)? How can they implement the methods they have learned in their development?
9. What are the possible reasons why not all professionals provide therapy for speech disorders of organic origin?

After outlining my research questions, my initial hypotheses are as follows:

1. It is hypothesised that children with cleft lip and palate will face a number of barriers at different stages of their life course that will make their social integration more difficult.
2. We hypothesise that the socio-economic status of the families of children with cleft lip and palate draws significant differences in life course pathways, similar to those of the majority of pupils.
3. We believe that majority teachers do not receive enough information during their studies to promote the inclusion of children with special educational needs, including speech impairments.
4. We believe that the majority of newly qualified speech and language therapists have a fear of providing care for organic speech disorders.

#### *4.2. Research methods*

In addition to quantitative methods, qualitative methods will also be needed in the research to understand the whys (Szabolcs, 2001). It will be important to study the most recent figures, as statistical data can help to build a conceptual framework (Kontra, 2011). They can be considered as an objective source whose primary purpose is to obtain a realistic picture and real information about the main subject of the research (Kőfalvi, 2020). For this purpose, it will be necessary to visit Hungarian health "cleft care" sites, where different databases on the children served are available. In addition, studying the "Health, Accident" subsection of the National Statistical Office is also essential for collecting data on cleft lip and palate. The analysis of basic documents of health and educational institutions will also provide us with data. In order to reach the largest possible number of persons and professionals concerned nationwide, it will also be necessary to develop an online questionnaire, which will be complemented by semi-structured oral interviews. It would be interesting to carry out several case studies with relevant people from different social situations. We would like to present in a descriptive, exploratory, interpretive case study the life story of a young adult born with cleft lip and palate. Another exciting area for the realisation of this research could be the presentation of inclusive education processes from the perspective of learners with speech impairments.

### **5. Summary**

In our research, we would like to get an idea of the recent statistics on the number of children with cleft lip and cleft palate, their care, the problem areas, their position in the education system, their aftercare and their social integration. The aim of the research is therefore to examine the difficulties and social integration of children with cleft lip and palate in relation to the socialisation of their social environment, with particular emphasis on the field of education.

The concept of disability has undergone many changes over the last decades. The medical model has been replaced by the social model and its new approach, which now understands disability in the context of the individual and society. It also focuses attention on the social processes that can weaken the participation of people with disabilities in society (Koller, 2020).

In our planned research, the "voice" of the persons concerned will also play a particularly important role, since the difficulties and obstacles that emerge during the mapping of the life path of the target group cannot be examined in themselves. The individual's frame of reference can often nuance or even modify the emerging picture, helping a deeper understanding of the picture drawn by objective factors (Szabóné, 2021). Thus, it cannot be ignored that emerging risk factors can also become protective, as they teach coping in the context of possible negative life events and in different stress situations (Solymosi, 2017; in Szabóné 2021). We hope that our research, by focusing on the problem areas that are at the bottom of the agenda, can contribute to raising awareness, finding solutions, broadening the flow of information, reducing prejudice and shaping the social environment, and can contribute greatly to achieving a more inclusive and equitable society.

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