



# THE NURSING OPTIONS OF HEALTH VISITORS IN FAMILIES BRINGING UP CHILDREN WITH AUTISM

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## Summary

Present results are part of an overall exploratory research dealing with the quality of life in the families bringing up children with autism, which aims to support the effectiveness of health visitor nursing care.

**Objective.** Our goal is to reveal the demographic situation and health care of the families, which can be the basis of a professional guideline for health visitors and professional nurses.

**Method.** After finding the families bringing up children with autism part of the present research uses the data of the National Autism Research (OAK) made by the Jelen (Present) Institute, as well as its own focus group interviews. The tool of the written interview was applied by OAK, which could be implemented through a questionnaire sent by post. The qualitative data collection occurred in three focus groups (parents, autism specialists and health visitors), some elements of which are described in the study.

**Result.** There are several hundred families caring for autistic children/adults in Hungary. In our research 276 families caring for children between 3-18 were highlighted. No similar socio-demographic background can be recorded among them, all of them have to face many challenges with a very little help. They have different expectations towards the health care professionals caring for them.

**Deduction.** There is no comprehensive strategy for the problems of the families with autistic children neither on a national nor on a regional level. The regular operation of parents' groups is a task needing to be solved at a local level. Because of the lack of knowledge among health care professionals, our goal is to build a comprehensive training system.

Key words: Autism, health visitor, life quality of families, health care

*"In a perfect world, everyone is healthy and happy,  
people understand and care about each other.  
In a perfect world there are no ill people, no damaged ones.  
In a perfect world, everyone has equal opportunity  
to fulfill their latent talent.  
But our world is far from being perfect ..."  
a disabled youth*

## INTRODUCTION

The number of people living with deficiencies is increasing year by year in Hungary, due to the development of diagnostics there are more and more opportunities for early detection and to begin intervention as soon as possible. These developmental interventions, can support and improve the quality of life for families, increase the cohesion and the cooperation, of the family, and they can help solve the problems.

One of the major problems in connection with the families is the prejudices and stereotypes against the mentally handicapped, and autistic people which usu-

ally comes from ignorance and the fear of them. An important experience of social sciences is that negative attitudes prevent cooperation. It means that primarily the approach of helping professionals needs to be changed, which may affect the positive attitudes of the immediate and wider environment toward people with disabilities. The efforts of solving the problems have intensified over the past 10-15 years. Legislation has been defending the interests of people with disabilities, many advocacy organizations are working and more and more attention is being paid to integration. However people often avoid families with disabled children,

and an active attitude to help in the vast majority of the population has not been characterized yet.

#### THE DEMOGRAPHIC DATA OF THE FAMILIES LIVING WITH AUTISM IN THE LIGHT OF RESEARCH FINDINGS

##### Objectives

The present study aims to introduce the current situation of the 3-18 year-old autistic children living in our country, especially in light of demographic data. This way we are going to have an overview of the residential, age distribution, marital status, educational attainment, as well as the financial situation of the families. The results of focus group interviews can inform us about their daily lives and the problems that hinder them from social integration. We can also get an idea about how they feel about the work of professionals dealing with children.

##### Introducing Approaches

The quantitative analysis uses the data of the National Autism Research (OAK) prepared by the Jelen (Present) Institute. In the research the aimed and comprehensive sampling procedure covered all the people in the population living with autism, and members of an organization, or association in Hungary.

The written interview method that was applied by OAK, used two types of questionnaires. One detailed questionnaire covering several areas was filled out by interviewers, the other was a self-filled one sent by mail to the parents. In my own survey I used the data from the postal questionnaires, specifically the families who are raising children between the ages of 0-18. Due to the sampling procedure 276 valid questionnaires were returned.

The focus group study (qualitative) occurred in three groups, where I used the same questionnaire catalogue. Beside the parent group I asked health visitors and a group of heterogeneous professionals dealing with children with autism in their work. The SPSS version 15 was used for the data analysis.

##### Analysis

Among the qualitative results of the survey the present study covers only the presentation of the demographic variables.

The spatial distribution of the tested population can be considered as proportional but the region of Central Hungary is way ahead with 32.6%, where the number of queries in Budapest is 86, which is 31% of the sample. This is followed by the South Plains by 21%, and the Northern Plains by 16.3%. This regional distribution in my opinion, can be associated with the activity of the care organizations in the area.

The residence data obtained from the study is concordant with the average population in this area. 30.8% of the interviewed parents live in the capital. The number

of the families living in a county seat is 28%, more than 20% of them (22.5%) live in smaller towns. In addition, 18.5% of the families are bringing up their children with autism in villages.

In the present sample the ratio of men (boys) is more than four times that of women (girls), which confirms the results of other surveys, which also shows about 80% of males in the autistic population (Chakrabarti, Suniti and Fombonne, Eric, 2005).

The average age of parents surveyed is 38.5. In this study 87% of participants belong to the age group of 25-45 and only 13% of parents aged over 45. The proportion of parents under 30 (3%) is lower than the average proportion of women with children, according to CSO figures. 72% of the respondent parents are married and raise their children with their partners. The divorce rate is 15.6%, 7.6% of the respondents belong to the unmarried category. This latter ratio is higher than the average number of unmarried mothers with children, which is about 4-5%. The proportion of divorced women is 15.6%, which is about 2% higher than the same indicators in the population.

Considering the parents' highest level of education the highest proportion (55%) is represented by the ones with secondary education. Only 4.7% is the proportion of primary school education. Relatively high (30%) is the proportion of college and university graduates. From this it can be seen that the educational level of the parents included in the study is higher than the average population. The significant difference of the sample in the level of education compared to the average population is mainly due to the fact that these parents see different organizations in a much larger number of which operate in this case as an indicator for us. The reason for the significant difference can also be the fact that the people with higher education get to the appropriate specialist earlier so they are given the diagnosis on autism earlier as well. However these are only assumptions, they are not proven in the present study.

55% of the interviewed parents are out of a job, 45% of them are employed. This ratio is also likely to be in connection with age. If we compare the proportion of working women in the CSO data, we see that the number of employed women is lower among families with autistic children.

The income situation of the interviewed families were studied by two questions. Most of the interviewees fall into the category of between HUF 100-200 thousand in net income, which in case of an average 4-person household means HUF 40 thousand per capita (38%). 20% of the families live on an income of less than net 100 thousand, which is pretty high. Only 7% of the respondents have a higher than HUF 300 thousand income.

The assessment of their own financial situation was based on subjective opinion, but their comparison to the objective facts may be important. Nearly 50% of the families considered their income positions as moderate,

and only 11% as good or excellent. Around 30% is the number of those who graded it as sufficient, or bad. This means that the net income of less than HUF 200 thousand is not enough for the families to meet the needs of the family and the disabled children.

#### *The analysis of focus group interviews*

The aim of the interview was to reveal the opinion of parents and professionals to define shared goals and plans and to improve the quality of life for children with autism.

Three groups were studied during our research: concerned parents, health visitors, and professionals (psychiatrists, health visitors, special education teacher, teacher).

The results obtained during the research are the following.

The families of disabled children encounter the prejudices of society. It regularly occurred in the families surveyed that they got negative verbal opinions declaring that the parents could not discipline their children. The prejudices from outside affect the acceptance of the diagnosis as well. According to the opinions of the health visitors the parents who have already accepted the child's problem, they actually use the term autism, while those who have not identified with the status of their children yet use the word disabled in everyday conversations. "If they hear autism, two things occur to them: Oh my God, how serious it is, the other is what he is a genius in. Two extremes. Perhaps a talented genius, but he can not exist in this world." (A parent)

The prejudice and a general lack of knowledge make it more difficult and in some cases prevents, or even destroys the social relations of the children and families. They try to move to a place where the immediate environment is acceptant and tolerant to the contingent fuming and screaming of the child. Several people have said that the previous relations are worn, and the only really good friends remained. "The precious people who accept us, remain." (A parent)

The symptoms of autism, obvious to the experts interviewed, can be stated in general that while the parents mentioned positive and negative symptoms, the experts can only point out the negative characteristics. The experts particularly see the problems and their knowledge can be linked only to the difficulties. These are good foundations of transmitting the prejudices and explain their stability. Besides approaching this primarily emotional way, a wider range of knowledge can also be observed in the case of parents, since being concerned leads them on a constant learning endeavor.

The diagnosis of children often occurs only at the kindergarten age. The reason for this is that it is difficult, geographically limited, and slow to reach the health care system for diagnosis. Another reason may be that health visitors, as primary prevention professionals do not have sufficient knowledge so that they

could help in the early diagnosis and effective treatment, however according to parents and professionals early diagnosis has greater developmental efficiency. The opinion of the parents is that they are not satisfied with the nursing care of the health visitors can be supported by the facts mentioned above and that they except more help from their health visitors. The situation could be improved by the expansion of the nurses' knowledge, and development of the professional protocols.

Parents of autistic children are doing their best in order to help their child, assume all the burden, but they do not receive adequate social assistance. Less public assistance and support is given in Hungary to the families involved than in other EU countries. The financial burden of development is gradually increasing, but the subsidies are stagnating. In spite of this, parents are looking for opportunities to develop the children as much as possible. Each of the families surveyed participate in programs organized by the Autism Association, which help the integration of children.

The vision of families bringing up children with autism is uncertain due to the weaknesses in the Hungarian health care system. There is no adequate institutional care for autistic adults. All goes well, until they go to school, but after that there are only day-care institutions, which relieve the burden of the parents. There is no solution to the situation where the parents are no longer able to stand beside them. We can read a lot about well-functioning autistic farms abroad, but only a few attempts were made to implement them in our country. "The parents sacrifice themselves as long as they can but what happens after that... The parent would like to accustom their children to an institution where they would provide for the child." (A health visitor)

#### SUMMARY

The autistic children mainly live in the Central Region of Hungary, with a Budapest center. It can be said that they are brought up mainly in full families. The financial situation of families is more difficult due to the special needs of the children, and because of the fact that only 45% of parents are able to work besides taking care of the child. The presented results and the parents reactions show the actual problem we are facing with. It is necessary to speak of autism, to help in early detection, to support parents in child development and to lobby the government for the health care of adults with autism and to improve social conditions. Besides training professionals it should be mentioned as an important objective to expand the knowledge of lay people as well in order to prevent the discrimination of disabled people in society.

"We want it to be accepted as a special thing that is completely different than a mental disability. You can live with it, live together with it, and they can be adorable, but you can go insane because of them." (A parent) □

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