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AN EXAMINATION OF THE FACTORS AFFECTING THE QUALITY OF LIFE OF PEOPLE WITH DOWN'S SYNDROME

Doctoral (Ph.D.) Thesis Summary

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1. Introduction

The best-known and most common chromosomal abnormality is Down's syndrome which is the main cause (3-5%) of mental retardation. Its frequency is 1 in 700 live births. About 50-60 % of foetuses with trisomy are not diagnosed which means approximately a hundred neonates with Down's syndrome a year in our country. At the same time, parallel with the development of medicine, their life prospects have been continuously improving and as a result their age-specific prevalence is increasing, therefore older people with DS are not few.

The above facts direct attention to the issue of the quality of life, which means a long-range social responsibility for both health care and education. It is a relevant issue for the whole society to consider to what extent the handicapped people need care and provision, how they can be trained, how independent they are, if they are able to adapt themselves to the communities.

2. The definition of the aim of the research

The basic preconception of the research was that the life quality indicators of people with Down's syndrome looked after at home are better than those of the ones living in institutions, at the same time the mother's higher educational level has a positive influence on the developmental level of the child living in the family.

The study was mainly oriented towards the objective factors influencing the life quality which are related to education, training, development, health and adulthood. To prove my presuppositions I examined several factors influencing life quality, like speech, drawing/writing, counting, self-support, the developmental level of motion, the different indicators of the state of health, interpersonal relations, the role in the world of work, spare time activity and pair-relationship.

I had supposed that people suffering from more severe and several associated diseases were placed in institutions, but at the same time they have an advantage in the fields of development, work opportunities, spare time activities, friendly and pair-relationships.

As a resultant of the research, the subjective quality of life was examined by the determination of the level of happiness of the people concerned and the parents of those living in families. In the case of DS people an indirect inquiry of the immediate environment was carried out. It is typical of their behavioural phenotype that they have a generally positive personality, they are peaceful, calm individuals. I had supposed that their level of happiness was considerably influenced by their personality traits, their place of residence (the ones living in the family are happier), parental attitude and their interpersonal relationships.

With its interdisciplinary attitude the thesis fills a gap in the research of DS people's life quality. The studies focusing on a single field of science touch upon a partial issue only whereas the present research aimed at a holistic approach, comparing two groups in different life situations. The basic aim of the research was to determine and compare the relevant factors influencing the life quality of DS people, and to prove with numerical calculations which form of accommodation offers them an optimal life quality. In the mirror of all these, to draw conclusions and form messages utilizable in practice for the professionals.

3. The sample and applied methods

Issuing from the interdisciplinary character of the research, it touches upon several fields of science: pedagogy, special pedagogy for backward children, medical and health sciences, psychology and sociology. I carried out an assessment of state in the first place, which was complemented with the data of history. No intervention happened in the course of the

research. The cross-sectional quantitative examination contained retrospective elements as well, because it also covered certain data of the health documentation. With the help of the registry sheets constituting the basic documentation of the patients the events of the earlier periods may be outlined more precisely, which makes a deeper, more adequate view possible, preventing the distorting effect of memory. Within the target group the sampling was not random. Data collection started after authorization in April 2008 and finished in December 2010.

The sample included people with DS, between the ages of 3 and 35, living in the family or in an institution for the handicapped offering full provision, nursing and care. In every location the data collection was carried out by health professionals, health visitors and caretakers.

The criteria of sample selection were: the person must be diagnosed with Down's syndrome, be between the ages of 3 and 35, still alive. Concerning those living in an institution it was also a condition that they went to live there before the age of 15 at the latest and had been staying there for at least 3 years. The determination of the age group is justified by the fact that age 3 is the youngest age when certain factors determining the life quality can be examined. The time interval ends at 35 years. The reason for this age restriction is that the older generation was mostly living in institutions, and also I intended to exclude Alzheimer's disease, as a disturbing factor having a negative effect on the life quality. The criteria of the examination were met by 204 people with DS altogether, 118 were living at home, and 86 were living in institutions.

A modular questionnaire of my own make contained physical, psychical and social domains as well. The structure of the questionnaire followed a chronological order including the following main question groups: family, gestation, birth, infancy and childhood, adulthood, questions relating to the present.

For the analysis I used descriptive statistics (absolute and relative frequency), mathematical statistics, Chi square test, Fisher Exact test, binary logistical regression and Spearman rank-correlation measuring. The results were considered significant if $p \le 0.05$.

4. The presentation of the results

The fate of the neonate with DS is often sealed at the hospital after the doctor's information. The indifferent or negative information shakes, hinders the strengthening of the maternal bonds, already wounded. In the examined sample significantly more misinformation happened concerning the mothers who put their children into institutions.

There is a decided difference of parental behaviour in the two groups examined. The great majority of parents looking after their children in the family are supportive, acceptive, while with those living in institutions an indifferent, refusing behaviour was more characteristic. The formation of the child's personality traits is strongly affected by the parental attitude. The acceptive, supportive mothers looked after children with the most positive characteristics.

Contrary to the misconception, the number of divorces is not higher in the families concerned. More than half of the parents nursing children in the family judged their family as outstandingly favourable and harmonious. After the child's birth 18,7% of the relationships broke up, which is well below the national divorce rate, despite the fact that this index number includes the breaking up of life-partner relationships as well.

Education-and development-related factors determining the objective life quality

According to the physiological stage of development, the backwardness of DS people is grave in every skill/ability studied (speech, drawing/writing, reading, counting, self-support, motion). At the same time, marked differences may be noticed between people of the same age, as some of them totally lack some skills, while others can reach the level of their healthy peers. With the increase of age and learning time, the skills improved. The institution placement had such negative effects that the tendencies accompanying the growing age could not prevail in the field of drawing/writing, reading and speech.

My thesis as to the question whether the development of DS people is affected by their place of residence is that those living in a family milieu performed better. Without exception, the development of every examined skill and ability showed strong significant relation with the place of accommodation. The ones living in the family proved considerably better in every field. I succeeded in the numerical definition of the negative effect that the accommodation in the institution has on the quality of life.

Examining the *maternal qualification* and the developmental level of the skills and abilities of the people living in the family, the mother's educational level significantly affected the development of drawing/writing, reading, counting and self-support of the person with DS. The higher level of educational qualification usually implies a frequent writing, reading and counting activity. In such an environment the child can easily understand that the sounds of speech can be written down, the written texts can be transformed into sounds.

In the field of *speaking skill* and *motion*, however, the positive effect of the maternal qualification was not considerable, because the beneficial effect growing parallel with the higher maternal qualification showed a strong decline in the case of graduate mothers. The best results were achieved by the children of mothers having a G.C.E., but not only in the field of speaking skill and motion, but also in drawing/writing and self-support. The level of the speaking skill is related to the development of the other skills. I measured a considerable effect between the developmental level of speech and the obtained level in drawing/writing, reading and counting. A more developed speaking skill resulted in a higher level of development in the field of the skills listed above.

I had supposed that as for the start and contents of the early *development* and the number of professionals the inmates of the institution were in a more favourable position than those living in the family. The reason for this was that in the institution it is compulsory to provide systematic individual development. However, the research did not indicate any essential difference between the two types of accommodation regarding the time of the beginning and the contents of the development. Only the number of the specialists differred to the advantage of those looked after in the family. This may have a positive effect on the development of the DS person because this way a more complex development was made possible, but it does not explain the far better performance of the ones living in the family in every field examined. I identified the environmental support of the family as the factor which significantly influences the start of the early development of those nursed at home.

The results imply that the main reasons for the great differences in the skills that determine the life quality in the institutions and in the families are not to be searched for in the development, but in every case the place of residence is the decisive indipendent variable.

Health-related factors affecting the objective quality of life

The frequent occurrence of *low birth-weight* is typical of the people studied. In the sample I measured a value 2,5 times the frequency (22,1%) in the Hungarian average population. A birth-weight below 2500 grams has a disadvantageous effect on the individual's life quality,

both in the early and in later periods of their lives, and it involves the risk factors of several diseases.

In accordance with the technical literature data, the sample studied is also characterized by the accumulation of *associated diseases*, among them the great frequency of heart-developmental anomalies (43,7%). The significant relationship of the associated diseases with the level of motion was provable. 90% of those who were not able to walk also had heart-developmental disorder.

I gained a result inconsistent with my expectations as for the relation between the place of residence and the associated diseases. All of the associated diseases, within that the heart-developmental disorder, were more frequent with those living in the family. Therefore I had to exclude the important explanatory factor that the greater frequency of the associated diseases among the inmates of the institution is the cause of the worse performance of people living there. It is possible that people with DS living in the institutions who suffered from serious associated diseases were not included in the sample due to their early death.

Plenty of technical literature report on their being *overweight* or *obese*. In comparison with the data of the Hungarian population, the results of DS people are not worse, so the misconception according to which people with DS tend to grow fat to a greater extent than an average person, seems to be refutable. The reason for the results is not an improvement of the data of DS people, but the radical weight gain of the average population over the past decades. There are a lot more overweight/obese among the adults in the examined group than children. The place of the accommodation is related to the change in the BMI values. There are more overweight/obese people among the ones living in the family, but it is surprising to find 17,1% of the inmates pathologically thin. It would be worth searching for its reasons in the future. The atrophic conditions show significant relation to the low developmental level of the motion and self-supporting ability.

Subjective quality of life

84% of the DS people examined are characterized as often or always *happy* by the immediate environment. The number of the ones who are often or always happy is significantly higher in the families than in the institutions. The *personality traits* have a considerable connection with their level of happiness. In 81% of the sample I found positive personality traits, they are the ones who are significantly happier. Among those nursed in the family however, there are considerably more positive personalities than among their peers living in the institutions.

I had supposed that the inmates are richer in *interpersonal relations*, as the community provides plenty of opportunities for the formation of friendly relationships. In contrast with this the majority (67,4%) are lonely, while a remarkable majority of those nursed in the family cultivate friendly relations.

It was possible to measure *parental satisfaction* among those living in the family. The result is that the majority (72,1%) adapted themselves to their situation and listed themselves in the often or always happy category. The level of happiness of the DS person and the parent were correlated. The majority of the happier DS people were being brought up by more satisfied parents.

A part of the skills showed a significant relation with the level of happiness. Parental satisfaction was correlated with the level of the child's self-supporting and speaking skills. Having self-supporting and reading skills significantly increased the subjective life quality of the DS person.

The special factors of adulthood

The majority (72,3%) of DS people do not appear in the world of *work*. In that respect there is no considerable difference between those living in the insitution or in the family. Regarding work, in the sample I found more favourable data (27,7%) than the national 10% employment rate of the handicapped. Most of them were doing simple, monotonous work, but 42% were performing creative tasks requiring thinking. The ones who worked had significantly more friends.

Most of them (75,5%) had a concrete idea about how to spend their *spare time*. Significantly more of those living in the family could find some useful spare time activity. The majority of the ones living in the institutions did not do anything in their spare time or performed an activity that could not be named recreational activity.

According to technical litarature data nearly 50% showed interest in *sexuality* but those numbers are not supported by the present research, as 80,9% of the studied adults were not seeking a pair-relationship. The cause of the relative contradiction is that only people living in families were examined and the young ones were asked for their opinions as well. In my sample a significantly higher number of the ones living in the family showed interest in the opposite sex and were planning a joint life.

75,5% of the adults in the sample did not belong to any other *community* beside the family or the institution, indicating that handicapped people get easily isolated. The inmates of the institutions form a closed community, only 4,8% had any connection with communities outside the institution, while the same ratio is 64% with those living in the family.

Comparing the skills and abilities with the factors related to the adults examined, it was the spare time activity which showed relation with the self-supporting ability. Considerably more people at a better self-supporting level did some useful spare time activity.

I had supposed that the adults' subjective life quality was affected by special factors of adulthood, like work, spare time activity, pair-relationship, community life. Beside the place of accommodation (people in the family are happier) the adults' level of happiness was affected in a significantly positive direction by having some useful spare time activity, whereas the other factors had no significant effect.

5. Summary and suggestions

The results measured in the course of the research in the field of skills and abilities showed a considerable *backwardness among DS people living in institutions*. These results cannot be explained by either early development or the fact that DS people in a worse state of health were placed in the institutions. Happiness is the comprehensive perception of life quality. In the course of the subjective life quality research *those living in the family proved to be happier*.

A numerical proof of the negative effects of the life in the institution provides some important information for the Hungarian care system. The message of the research matches the efforts of the European Union which focuses on the closing down of the big institutions and instead prefers education aiming at an independent life and living in the family or in residential homes. In our country the proper steps are still to be waited for.

The message for the profession is that priority must be given to the family education of DS people. No institution can offer them the family patterns, its care, love and motivating effect. *In respect to both the objective and the subjective life quality DS people looked after in the family live a significantly better quality of life*. In the family it is further enhanced by the mother's higher educational qualification and her supportive attitude. Highly qualified parents

probably develop their children through greater expectation, more interactions and activities associated with it. The stimuli-rich home milieu effectively inhances the child's development.

For the interdisciplinary approach a discourse of the cognate professions is needed. The regular professional dialogue between the teacher, teacher for backward children, health visitor, doctor, conductor may help to reach a higher life quality. The Health Visitors' Service working in a unique way in Hungary contains unexploited potentials. Health visitors are graduate professionals who carry out intensive, direct and complex family care, voluntarily get involved in the intimate sphere of the families. They nurse a uniquely confidential relationship with the parents, they have manifold knowledge which should be extended in an expedient way to be able to offer effective help to the parents educating handicapped children. It is a serious deficiency that even the bases of the development of handicapped children are not included in their training, therefore it is urgent to complete the curriculum in that direction. The Hungarian professionals involved in the care of the handicapped work independently of each other, isolated, completing only their part of the work.

The great individual differences between the DS people direct attention to the importance of the place of accommodation and to the differences in education within the family as well. In a longer time they are able to learn to write, read and count at a level which effectively helps their orientation in everyday life and improves their quality of life. Children with DS may take part in education, trainings increasing their chance in the work-force market, aiding to realize a fuller life. The satisfactory developmental level of writing, reading, counting, self-support, speech, motion involve freedom and the possibility to get acquainted with the world. A low level of parental qualification implies an environment poor in stimuli, and its compensation needs a *more intensive family care*.

In the interest of a discourse between the cognate professions, a close cooperation, a continuous information of each other and thinking together it is an urgent task for every professional involved in the care of the handicapped to any extent to organize joint further trainings and conferences. The health visitors could convey the up-to-date common message of the professionals to the homes of the families. A complex handling of the problem may be the only serviceable, effective method by which the life quality of DS people could be improved.

6. Further research tasks

In connection with the research *several unanswered questions were left open* which raise the possibility of continuing the work. Some possible directions:

- The creditable exploration of the life in the institutions raises the need for field-work, but it can be realized only through time-consuming, participating observation.
- The questionnaire inquiry would be worth complementing with the interview method in the future which can well be extended to the handicapped people who cooperate well, and to parents who had not undertaken the education of their child in the family.
- It would be useful to follow up the DS people studied, as a longitudinal research could precisely record the temporal changes in skills, abilities, state of health, i.e. the quality of life.
- Drawing up professional protocols would supply a defect to perform "telling it" and for the cooperation of various professionals.
- By establishing an interdisciplinary research team it would open a possibility to form a holistic attitude, which would broaden and make the DS people's life quality research more precise and that would provide a possibility to compile a standard life quality questionnaire.

The research has explored the various factors affecting the DS people's quality of life, in two groups exposed to greatly different circumstances: in the family and in the institutions. I have succeeded in defining numerically some correlations that had previously been based on intuitions, beliefs and misconceptions. People with Down's syndrome living in the family have a higher level of development, they live a better objective and subjective quality of life, while life in the institution considerably worsens the DS people's well-being.

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