



## Development of Walking and Self-sufficiency Ability Related to Nutrition among People with Down Syndrome

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**Abstract:** *Development of the walking ability and self-care of patients with Down syndrome is affected by their body weight determining their lifestyle to a great extent. Objectives: The study aimed at the determination of body mass index for persons living in residential institutions and families, exploration its impact on walking and self-care as two, objective factors of life quality. Method: Data collection of persons aged 3-35 with Down syndrome living in families covered seven counties, while those of living in residential institutions covered thirteen counties in Hungary. In the 183 cases studied 76 people in residential institutions, 107 people lived in families. The cross-sectional study was processed by non-random sample selection. The questionnaires were filled out by health visitors and care takers edited by their own. Results: 50.6% of adults and 26.1% of children belonged to the overweight or obese category. Their residence showed a significant correlation with the body mass index ( $p < 0.001$ ). Overweight and obese persons in families, while thin ones were more prevalent in institutions. Regarding the walking ability and self-care of the persons living in families a significantly higher level of development was achieved ( $p < 0.001$ ). Walking ability ( $p = 0.001$ ) and self-care ( $p = 0,008$ ) were worsened by less body weight significantly, while overweight or obesity influenced it less negatively. Discussion: The claim is not further acceptable whereas persons with Down syndrome are more prone to obesity than average people. However unfavourable weight gain in adults draws attention to the necessity to a healthy diet and regular exercise. The people living in residential institutions with significantly lower body mass index and the associated low development of walking ability and self-care envisages an urgent reform of residential institutions. Life in the institutions negatively affects the walking ability and self-care, and thus significantly reduces the quality of life of persons with Down's syndrome.*

**Keywords:** Down syndrome, body mass index, walking and self-care development

According to WHO data, among the 120 million children born in a year 800,000 of them have chromosome disorders. Among these disorders the most well-known and frequent is Down syndrome. It is a serious chromosome abnormality resulting in the major cause (3-5%) of mental disability. According to literature, it occurs in every 700th newborn baby (Weaver & Hedrick, 2000).

Literature emphasizes the fact that people with Down syndrome are more likely to be obese compared to average people. Its causes are various, such as hypotony leading to inactive life, susceptibility to metabolic diseases or slower metabolism. Due to the positive correlation between the increased level of leptin and BMI, leptin resistance is hypothesized in the background (Blascovi-Assis, 2009; Magni et al., 2004).

Showing its importance, WHO declared obesity as a chronic, recurrent disease in 1998. It belongs to the ten most severe diseases and the second most important risk factor following smoking. WHO (World..., 2000) formulated obesity as a rapidly growing threat endangering not only health, but causing social prejudice. The organization calls attention on inactive lifestyle and inadequate nutrition (World..., 1997). A great many people suffer from its complications or the aesthetic and social disadvantages. The prevalence of cancer increases in direct proportion with that of obesity in the population. As a consequence, treatment of the complications due to obesity is a serious burden not only for the person, but also for the society (Figler, 2009).

## *Objective*

The study aims to map the BMI values of people with Down syndrome and examine the relationship between the two objective factors (walking maturity and self-sufficiency) influencing the quality of life. The study aims to decide if institution or family provides higher development for people with Down syndrome. Priority was given to the following issue: To what extent does the type of accommodation (institution, family) affect the nutritional status and in this context, the maturity of walking and self-sufficiency?

## *Material and method*

The study was performed by convenient sampling within the target group in a quantitative, cross-sectional examination. The sample comprised of people diagnosed with Down syndrome, aged 3-35 living either in institutes or in families. The inclusion criteria for those living in institutions involved the following requirements: 15-year-old-age as the starting age of inhabitation and the 3-year-long staying. The definition for age groups is supported by the fact that age of 3 is the earliest period when

skills can be observed and investigated. The end of age investigated was 35 years, because early Alzheimer disease and confounding factors affecting negatively the quality of life in early ageing were intended to be excluded. 76 persons out of the examined 183 cases lived in residential institutions, while 107 persons lived in family.

*Data collection of people living in families:* NRID (National Registration of Innate Disorders) provided data of registered people with Down syndrome in the Trans-Danubian region (Somogy, Tolna and Baranya counties) between 1975 and 2005. First, we used this register then it was expanded by the actual cases found by the health visitors. Data collection started on the basis of NRID, but the past decades caused untraceable changes in the field: Some people died, some parents refused cooperation. The inclusion criterion for those living in a family was if they stayed at the institutions on a daily basis requiring only daycare facilities (in Pest, Bács-Kiskun, Hajdú-Bihar, Győr-Moson-Sopron counties). The nurses providing day care at the departments of the institutions interviewed the compliant parents.

*Data collection of people living at institutions:* The study focused on the successors of children's homes providing full care, health care and nursing for disabled people at residential institutions. Data collection was performed in 22 institutions in Baranya-, Somogy-, Tolna-, Győr-Moson-Sopron-, Pest-, Zala-, Hajdú-Bihar-, Jász-Nagykun-Szolnok-, Bács-Kiskun-, Komárom-Esztergom, Csongrád-, Heves- és Borsod-Abaúj-Zemplén counties. Data recording was accomplished by nurses who knew the patients well. Ethical requirements and data security was guaranteed by the experts obliged by confidentiality in both locations (family and institution).

The structure of the modular questionnaire followed a chronological sequence. The two groups were assessed by mostly identical questions. The difference lied in the separate locations.

In both cases, the achievement of the studied persons was compared with that of the normal, healthy contemporaries. In the case of self-sufficiency the findings were classified into three categories, such as persons demanding full care, retarded persons, and people whose self-sufficiency was appropriate to their age.

Assessing walking maturity, three values were also established. The first category comprised of the persons who were unable to walk, the second consisted of those who walked but its character fell short of the expectation and the third group involved the persons with good movement coordination appropriate to their age.

The statistical analysis was performed by Spearman rank-correlation calculation with 95% probability ( $p \leq 0.05$ ), Khi<sup>2</sup>-test, Fisher Exact test and using SPSS 13.00 program.

## *Results*

The mean age for the people with Down syndrome was 18.1%. Gender distribution was characterized by the following rates: 54.6% of the participants accounted for boys and men; 45.4% of them accounted for girls and women. Lower qualification than GCE accounted for 57.9% in

mothers, GCE or higher qualification accounted for 42.1% in them. School qualification of both fathers and mothers correlated ( $r = 0.703$ ,  $p < 0.01$ ). 20.6% of the families lived in below-average, 72.2% of them lived in average, and 7.2% of them lived in above-average living conditions.

Parental mean age was 28.35 years at the birth of the child. Extremely high ages were observed both in mothers (44 years of age) and in fathers (62 years of age). The mean age for the mothers was 35 years (22.2%) and 62 years for the fathers (31.2%).

No teratogenic harm affected two third of the mothers during the expectancy period with the baby with Down syndrome. One third of them named such an effect of which smoking was in the first place, secondly, medicaments taken during pregnancy or the impact of chemicals.

Parallel with the BMI values calculated in adults, BMI percentiles were set up in children during the research. The calculated values were categorized by the categories given by WHO (World..., n.d.)

WHO categorization cannot be used with children directly as the body build changes continuously until puberty, therefore, percentiles tables were applied for them. After calculating BMI, the received value was compared with the percentiles appropriate with the gender and age of the child in the tabular row. Value smaller than three indicates significant weight deficit, values between 3 and 10 show leanness, and values between 10 to 75 percentiles indicate adequate nutrition. Values between 75 and 90 percentiles refer to excess weight, thus, those people are at risk of obesity, but are not overweight. Values between 90 and 97 show overweight, and values over 97 percentiles indicate obesity (Pintér, 2004).

Recommendation of the expert committee of the American Medical Society is different from that of the Hungarian practice. Children between 2 and 18 are considered to be obese if their BMI is or over 95 percentiles concerning age and sex, or those whose BMI value is over 30. Those people are considered to be overweight whose percentile values are between 85 and 95 (Barlow, 2007). As the Hungarian percentiles tables own no calibration mentioned above, this recommendation was out of importance. Table 1 shows the categories for both adults and children.

Table 1. Categories of BMI values for adults and children

Categories	BMI of adults	BMI percentiles of children
Lean	Under 18.49	10% and under
Normal	18.5–24.99	10% above until 90%
Overweight	25–29.99	90% above until 97%
Obese	Above 30	Above 97%

### *Distribution of persons with Down syndrome by BMI*

Half of the total participants belonged to the normal weight category, 38.3% of them were overweight or obese, 12.6% of the participants were lean (peculiarity). According to Horváth (1990), persons with Down syndrome were considered to be short and obese, but nowadays average or above average height is common. He considers that this change is due to healthy nutrition, exercising and sports. Besides inherited factors,

environment plays a crucial role in the development of body sizes. Horváth's report on the height above average was supported by no case in our study. Average body height for adults was 150.3 cm, with the highest value (176 cm) for a 20-year-old young man. This height cannot be considered as above average. Shorter than average upper arm and femur was characteristic of persons with Down syndrome resulting in peculiar body shape. Table 2 shows the distribution of BMI categories.

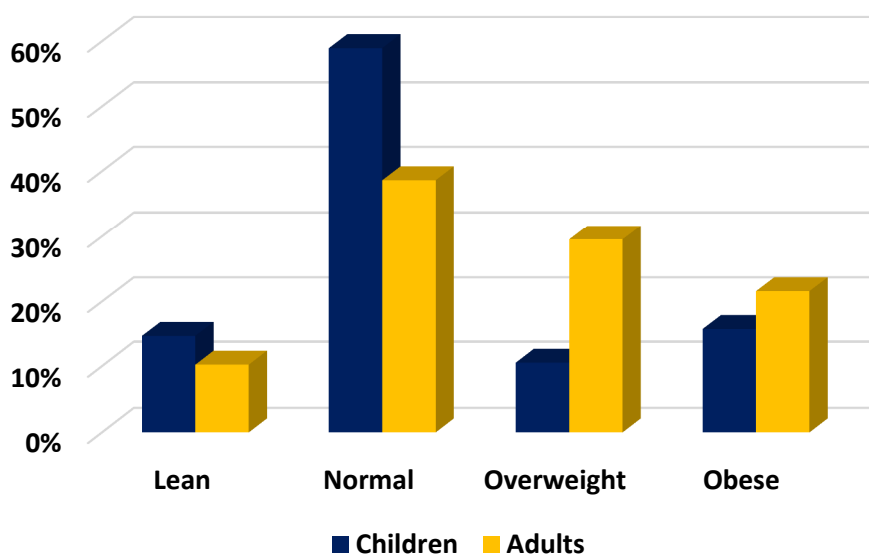
Table 2. Distribution of BMI categories in persons with Down syndrome (n = 183)

BMI categories	Persons	%
lean	23	12.6
normal	90	49.2
overweight	36	19.7
obese	34	18.6
Total	183	100.0

### *Distribution of BMI categories by age and sex*

50.3% (92 persons) of the participants were children and 49.7% (91 persons) of them were adults. 50.6% of the adults and 26.1% of the children belonged to the obese category (Fig. 1). On comparing children and adults an opposite trend was observed. A great number of children occurred in the lean and normal body weight category, but adults accounted for more overweight and obese cases. BMI values showed significant correlation ( $p = 0.002$ ) with age. Significantly more adults had excess weight.

Figure 1. Distribution of BMI categories by age in persons with Down syndrome (n=183)

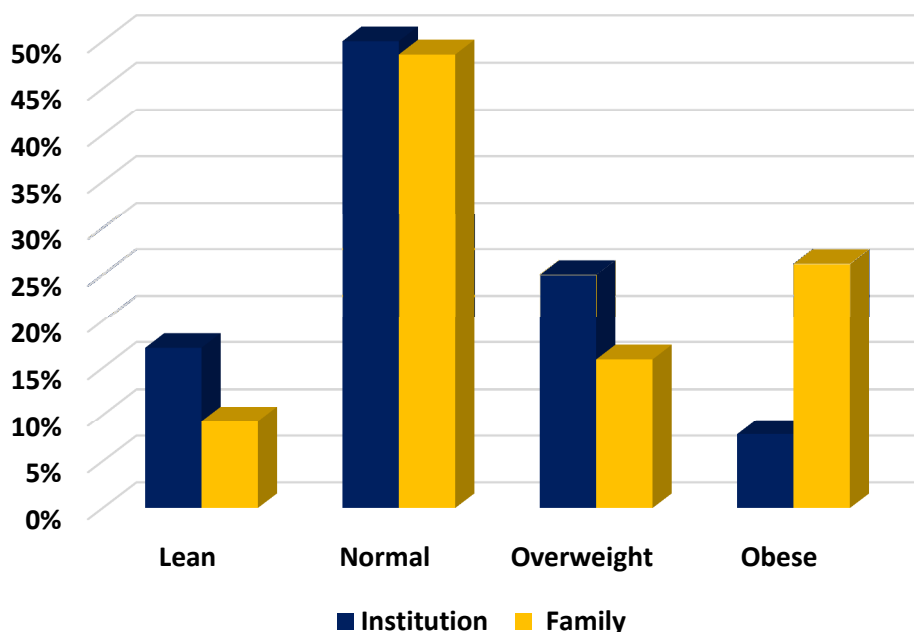


Difference between sexes could not be detected. Development of the BMI categories in both sexes moved parallel with each other.

### *Distribution of BMI categories by residence*

41.5% (76 persons) of persons with Down syndrome lived in institutions and 58.5% (107 persons) of them lived in families among the 183 persons studied. The residence showed significant correlation with the development of BMI ( $p < 0.001$ ). 41.4% of the persons living in families were overweight or obese, these figures accounted for 32.9% in persons living in institutions. On the contrary, significantly more people were lean (17.1%) in institutions, but this rate was 9.3% in persons living in families. The rate of normal body weight was almost the same in both residencies. 26.2% of the persons living in families were obese (see diagram). This data is alarmingly high, because we measured BMI values above 40 in six persons living in families. Such a high value was not observed in people living in institutions. However, in under normal weight category, alarmingly low value was found in four persons living in institutions as opposed to those living in families (Fig. 2).

Figure 2. Distribution of BMI values by residence in persons with Down syndrome (n=183)



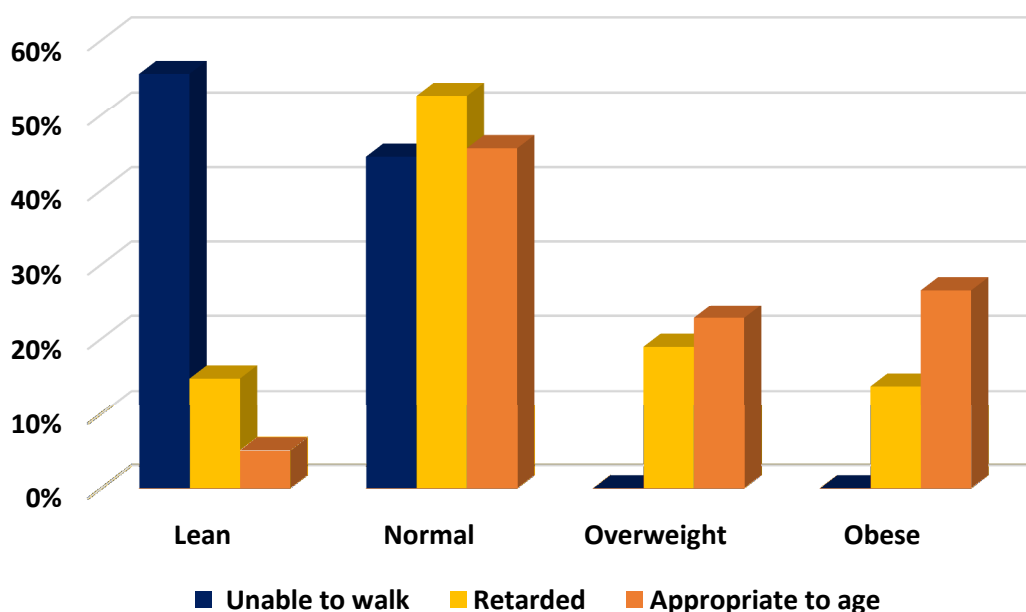
While obesity showed more beneficial values in institutions, the figures for leanness demonstrated worse values. A significant difference was identified in the development of the BMI values by the two types of residence.

## *BMI categories, walking maturity and self-sufficiency*

### *Walking maturity*

A significant difference was found in the walking maturity between persons living in families and institutions ( $p < 0.001$ ). Persons living in families achieved better results. A significant correlation was found between BMI categories and walking maturity ( $p = 0.001$ ). Persons unable to walk, or lean persons lagging behind age accounted for 55.6% of this category. Neither overweight nor obese person belonged to the group of people unable to walk (Fig. 3).

Figure 3. Development of walking ability regarding BMI (n=183)



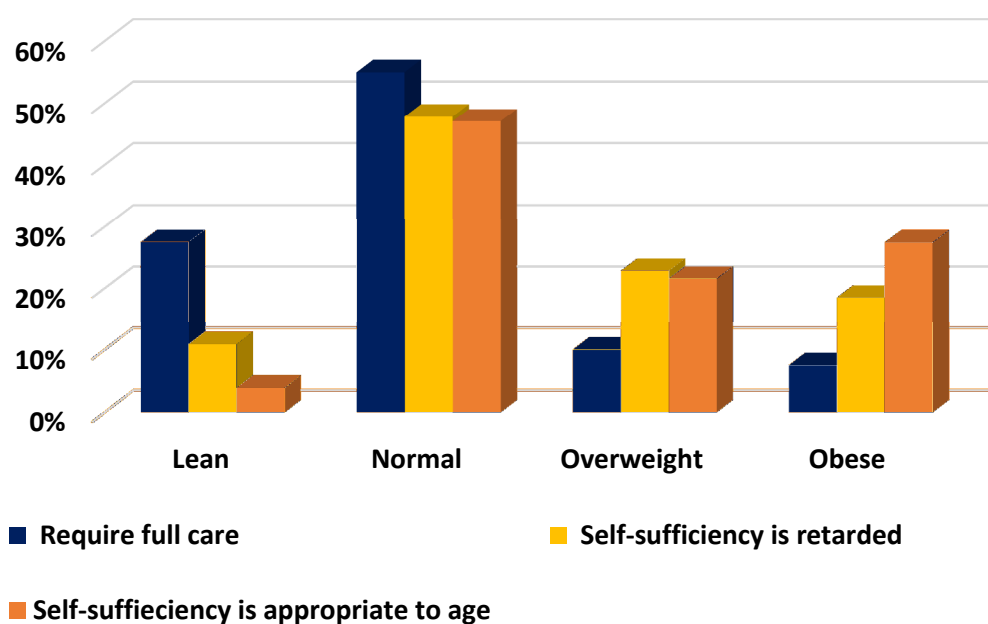
### *Self-sufficiency*

If lag in the fields of nutrition, dressing, toilet use and personal hygiene was observed, the participants were classified as retarded to their age. When the participant could attain one of the four self-sufficiency categories, he or she was categorized as a person requiring full care. It occurred in two persons demanding full care. However, they could eat on their own; pureed food with a spoon. The participants could receive self-sufficiency classification appropriate to their age if they attained the level of their age in all the four fields. If adolescents and adults were self-sufficient besides less control, the level was classified as appropriate self-sufficiency to their age. This could be explained by the fact that full self-sufficiency was not found in the participants.

A significant difference was observed in self-sufficiency related to the residence ( $p < 0.001$ ). Persons with Down syndrome living in families showed a significantly higher level of self-sufficiency than those living in institutions.

The same correlation could be found in the relationship between self-sufficiency and BMI than that in the walking ability. 27.5% of the persons requiring full care belonged to the lean and only 7.5% of them belonged to the obese categories. 3.9% of the participants fell behind the appropriate nutritional level of their age, 21.6% of them were overweight and 27.5% of the participants were obese (Fig. 4). Falling behind the normal body weight worsens the self-sufficiency of the persons with Down syndrome significantly. However, overweight and obesity affect self-sufficiency to a lesser extent ( $p = 0.008$ ).

Figure 4. Self-sufficiency of persons with Down syndrome related to BMI (n=183)



Qualification of the mother showed no significant correlation with the BMI values of those living in families ( $p = 0.594$ ).

Health status is adversely affected by overweight and obesity, accelerates the development of degenerative diseases worsening the quality of life and leading to a shorter lifespan. At the same time, leanness inhibits the motor development and self-sufficiency of people with Down syndrome. The BMI values different from normal ones affect the quality of life negatively.

## Discussion

High parental age in the study is in line with the data in literature. The number of women in labor over 35 years of age show a significant increase from the mid 80's. Examining the correlation between maternal age and the risk of Down syndrome, data of NRID emphasize that women over 35 provide only 7-8% of all mothers but they give birth to 42% of babies with Down syndrome. These rates show the significant effect of maternal age on Down syndrome (Szunyogh et al., 2006; Metneki et al., 2002). The system of non-invasive and invasive screenings is determined by a professional



protocol in Hungary. Screening, genetic counselling and invasive intervention were recommended for pregnant women over 35. From 2014 the care of pregnant women has changed, because screenings supported by Social Security have decreased. Thus, recommendation of genetic counselling has shifted to ages above 37 (26/2014. [IV.8.] EMMI rendelete..., 2014).

Following information provision, participation in the examination depends on the decision of the pregnant woman. The invasive procedures used in prenatal diagnostics carry fetal risks but detect the chromosome abnormalities safely. All the mothers in the study gave birth to babies with Down syndrome. One fifth of the mothers and one third of the fathers were or over the age of 35. Two third of the mothers could recall no teratogenic effect during the pregnancy (if they could, they mentioned smoking). The findings highlight the relevance of high maternal and paternal age and call attention on the increase in mutations of gametes parallel with the increase of age (Czeizel, 2001).

Comparing the nutritional status of adults and children with Down syndrome, the data demonstrated that adults had significantly more excess weight than children. The findings call attention on healthy nutrition and regular exercises. As children tend to be more active, adults' activity needs require more attention. Most adults do not work, have inactive lifestyle, therefore, their energy requirements are lower. Only 26.7% of the adults in the study had a regular job. It would be necessary to have tailored dietary needs and organization of regular exercises. In this way, excess weight increasing with age and the subsequent diseases could be prevented.

Children with Down syndrome grow with difficulties at the early age, and this growth is slow. Nevertheless they tend to be obese later. Several researches have supported the fact that they are less likely to be susceptible to environmental impacts than their normal contemporaries. Their growth is controlled by genetic factors primarily. This fact would mean that their physique is affected by environmental factors to a lesser extent (Hoshi et al., 1979). This finding was supported by the studies of Göllesz (1963), and Buday (1974) in Hungary. Despite, the overall research by Buday József (2001) showed that different environment also resulted in different growth and physique in people with Down syndrome. The difference was significant in both sexes. It has broken the line that genetic factors play an exclusive role in the development of physique.

In the present study, residence showed a significant correlation with the development of nutrition. The rate of persons with normal weight was almost the same in the two locations. More overweight and obese persons were found in those living in families. Significantly more lean people were found in institutions. These findings can be caused by the caring parental attitudes written by literature, because handicapped children trigger increased protective reaction from the parents (Büki et al., 2004).

In institutional context, only one social worker is in charge of several residents, therefore, he or she can meet their demands to a limited extent. Due to the integrated catering system, only a few institutions have own kitchen, therefore, the conditions cannot meet the individual demands. At the same time, stringent requirements determining the amount of energy intake must be met, and the limited financial framework affects the quality and quantity of food. People with Down syndrome seem to get used to

eating pieces of food with difficulties. Therefore, if food is not pureed for them, they can refuse it to eat. It depends on the social worker's personality much (patient, careful) if he or she can cooperate with the resident.

It is common in families that mothers compile diets to the children's liking, because weight gain is important for mothers. It is even more emphasized in the case of handicapped children, because mothers may have success in the field of nutrition. A well growing child can compensate her failure in reproduction.

The significantly lower BMI of persons living in institutions was remarkable, because they were mostly adults compared to the persons living in families who were children. Therefore, more overweight and obese persons were expected in institutions. Though institutional life had a negative effect, which fact did not justify the BMI leverage in age increase.

Maturity of walking and self-sufficiency are interrelated notions. Motor maturity has a transfer effect on the development of the other skills and abilities. Retarded motor development cannot be considered as a problem itself, but it determines the development of skills, attention and thinking. Besides retarded motor development, people with Down syndrome are characterized by muscle hypotension that is more expressed in infancy. From the point of view of motor development infant- and childhood can be regarded as a susceptible period when lag is already insurmountable. At the same time, the acquired motor skills are steady providing a solid base for the individual.

In the case of great movements, there is a significant difference between the two types of lifestyle. People living in families showed significantly better achievement. 55.6% of the people unable to walk were lean, at the same time, no overweight or obese people were found in those who could not walk. The motor development seemed to be affected by good stamina in a positive manner and be limited by overweight and to a lesser extent by obesity. Leanness significantly hindered motor development. This disadvantageous situation was characterized by those living in institutions.

Self-sufficiency was markedly affected by residence, because people living in families attained better level of self-sufficiency than those living in institutions. Comparing BMI and the self-sufficiency level, people requiring full care were among lean persons with Down syndrome. These people showed significant retardation in motor development, but overweight and obesity affected self-sufficiency to a lesser extent.

According to parents, their children would never attain full independency, because they handled unexpected situations poorly despite their efforts. Due to self-sufficiency people with Down syndrome enjoy such freedom that makes parents' work easier and promotes the quality of lifestyle in the family (Harjänné et al., 2010). Attention should be paid on revealing skills and options on determining the fields to be developed. Developing joyful skills handicapped persons may experience the sense of competencies (Falvai & Zolnai, 2007).

Several studies report the effect of the hormone called leptin on obesity. The increased level of this hormone is assumed in the background of the tendency of increased obesity in people with Down syndrome (Magge et al., 2008). Halmy (1999) claims in the study accomplished in adult

Hungarian people that obesity with the overweight group (40%) is affected by more than half of the population.

Nowadays obesity and overweight have an effect almost on the two-third (61.8%) of the adult Hungarian population (Országos..., 2010). Comparing these data and the nutritional status of the studied people with Down syndrome, these persons were not considered to be extremely overweight or obese, as it had been expected. Increased tendency towards obesity in people with Down syndrome was failed to prove. At the same time, significantly lower BMI was measured in people living in institutes.

The findings of the research highlights the fact that the care of people with Down syndrome living in institutions is deficient. Their nutritional level is below the required level resulting in an inadequate level of walking abilities and self-sufficiency. Significantly better skills were found in people living in families, despite their overweight and obesity. Higher BMI increases the risk of degenerative diseases leading to a shorter life span. Nutritional status different from the normal, such as leanness and obesity, affect the quality of life in a negative way.

The numerical evidence of the negative impact on institutional life provides an important fact for the domestic organizations. The message of the present study agrees with the efforts of the EU that targets the abolition of huge institutions, but prefers living in families or in residential homes independently. The findings of the study refer to the disadvantages of the environment that make people with Down syndrome handicapped.

Increased attention from healthcare should be paid on the development of healthy lifestyle among people living in families. Well-planned trainings improve stamina, physiological functions and maintenance of normal body weight with healthy nutrition (Mendonca et al., 2010). In this work, primarily health visitors are affected, who do intensive, direct and complex family care and are involved in family life voluntarily. They can turn parents' attention on the importance of healthy lifestyle by means of more intensive family care.

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