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# Warunki socjo-demograficzne rodzin dzieci z Zespołem Downa urodzonych w latach 1980-2010 diagnozowanych i leczonych według Wrocławskiego Modelu Usprawniania. Dwudziestoletnie obserwacje

*Sociodemographic conditions of families of children with Down syndrome born between 1980-2010 diagnosed and treated according to the Wroclaw Rehabilitation Model. Twenty years of observations*

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**Streszczenie:**

**Wstęp.** Istnieje szereg czynników socjo-demograficznych, wpływających na rozwój dzieci z Zespołem Downa (ZD). Poznanie ich dostarcza wiedzę terapeutom, dzięki której zwiększa się szansa pomocy osobom niepełnosprawnym i ich opiekunom.

**Cel.** Celem pracy jest retrospektywna ocena warunków socjo-demograficznych rodziny tj. określenie miejsca i warunków zamieszkania, charakter rodziny, dzietność, źródła utrzymania, zatrudnienie i wykształcenie rodziców, ich stan zdrowia, oraz sprawowania opieki nad dzieckiem.

**Materiał i metoda.** Analiza obejmuje dokumentację 200 dzieci z ZD leczonych w latach 1980-2010 w Samodzielnej Pracowni Rehabilitacji Rozwojowej (SPRR) w Katedrze Fizjoterapii Uniwersytetu Medycznego we Wrocławiu. Dzieci uczestniczyły w rehabilitacji wg Wrocławskiego Modelu Usprawniania (WMU). Materiał badań podzielono na 3 grupy, ze względu na dekadę, w której się urodzili. Grupa A obejmuje 50 dzieci urodzonych w latach 1980-1989 (28 dziewcząt i 22 chłopców), grupa B to 100 dzieci urodzonych w latach 1990-1999 (48 dziewcząt, 52 chłopców) oraz grupa C – 50 urodzonych w latach 2000-2010 (25 dziewcząt, 25 chłopców).

**Wyniki i wnioski.** Na przestrzeni lat zaobserwowano poprawę źródeł utrzymania rodzin dzieci z ZD, na które składa się wysoki poziom wykształcenia rodziców, zarówno matek jak i ojców, wzrost zatrudnienia w zakładach prywatnych, pełna rodzina, w większości przynajmniej dwoje, troje dzieci oraz udział obojga rodziców w opiece nad dzieckiem w dobrych i bardzo dobrych warunkach mieszkaniowych. Korzystny wpływ środowiska na warunki rozwoju i efekty rehabilitacji są widoczne w uzyskaniu dojrzałości społecznej i funkcjonowaniu dziecka z zespołem Downa.

**Słowa kluczowe:**
Zespół Downa, WMU, warunki socjodemograficzne

**Abstract**

**Introduction.** There is a number of socio-demographic factors, affecting development of children with the Down Syndrome (DS). Researching these factors provides therapists with knowledge, which increases their ability to help the people with disabilities and their caregivers.

**Aim.** The aim of this study is a retrospective assessment of the socio-demographic conditions of families, i.e. it specifies the location and conditions of their residence, characteristics of a given family, number of children, sources of income, employment and education of the parents, their health and the care they give their child.

**Materials and Methods.** The analysis includes documentation regarding 200 children with the DS, treated in the years 1980-2010 in the Independent Workshop for Development Rehabilitation (Samodzielna Pracownia Rehabilitacji Rozwojowej - SPRR) at the Department of Physical Therapy of the Medical University in Wrocław. The children participated in a rehabilitation program according to the Wrocław Rehabilitation Model (Wrocławski Model Usprawniania - WMU). Materials for the research have been divided into 3 groups, according to the decade, when the children were born. Group A has included 50 children born in the years 1980-1989 (28 girls and 22 boys), Group B - 100 children born in the years 1990-1999 (48 girls, 52 boys), and Group C - 50 children born in the years 2000-2010 (25 girls, 25 boys).

**Results and Conclusions.** Over the years, there have been observed an improvement in the sources of income of the families with the DS children, to which has contributed a higher education level of the parents, both mothers and fathers, growth among them of the employment rate in the private sector, full family status, in the majority of the families there have been at least two, three children and both parents have participated in the care of the child, in the good and very good residential conditions. The beneficial effect of the environment on the conditions for development, and the rehabilitation effects, are confirmed by obtaining by the children with Down Syndrome the social maturity and their functioning in the community.

**Key words:**
Down Syndrome, WMU, socio-demographic conditions

## Introduction

Down syndrome, formerly called mongolism, is generally a group of characteristic features and symptoms, caused by the genetic disorders. The Down Syndrome most often is diagnosed already during birth [1].

Early intervention within the medical treatment and childcare areas, according to the WMU rehabilitation program, shall include the assessment of the socio-economic conditions of the family, the pregnancy and labor processes, and the neonatal period. On the basis of the broad diagnostics, the rehabilitation program is being designed, including: evolution of the proper family relations, improvement of the family life quality, rehabilitation of movement disorders with the re-education in the correct posture patterns, sensory stimulation and stimulation of speech development. Designed in detail, the therapy program assumes an individual approach to each patient, which can be modified depending on the particular needs. The basis for the program is a thorough medical examination: cardiac, neurological, vision and hearing tests, and in the case of the Down Syndrome. Also the tests for the level of thyroid hormone in serum, in order to determine the degree of hypothyroidism. Further, the development profile is being established using the Munich Functional Development Diagnostics, and in older children using the Gunzburg Scale [2].

## Aim of the Study

The aim of the study is a retrospective assessment of the socio-demographic conditions of the families of the children with Down Syndrome, treated in the last 30 years, including risk factors during pregnancy, labor and neonatal period, on the basis of the analysis of medical records in the Independent Workshop for Development Rehabilitation and the Department of Paediatrics (in 2006 moved to the Department of Physical Therapy in the Faculty of Health Sciences of the Medical University in Wrocław). The assessment includes the status of the family with the children with Down Syndrome, their place of residence, age, education and employment place of the parents, number of children, source of income and housing conditions, the course of pregnancy, labor and neonatal period.

## Materials and Methods

The total of 200 children with the Down Syndrome (101 girls and 99 boys) have been examined. They were born between 1980 and 2010, and have come from all over Poland. The children have been systematically treated in the outpatient clinic, which has been a precondition to qualify for the study group and for the further scientific research.

According to the time of birth, the studied population has been divided into three groups. Group A has included 50 children born in the years 1980-1989 (28 girls and 22 boys), Group B - 100 children born in the years 1990-1999 (48 girls, 52 boys), and Group C – 50 children born in the years 2000-2010 (25 girls, 25 boys). Participation of boys and girls in the studied groups has been similar.

Data about the family and the child have been collected from the medical records (Book of Health, information cards from a stay in a hospital and the Disease Card from the Outpatient Clinic), according to the Survey Questionnaire, attached in the Appendix. Data

from the individual cards of the children have been transferred to the summary sheets in the IT system, built in the Microsoft Office Excel 2007 program, which has constituted the database for calculations of the arithmetic means, maximum and minimum values, standard deviation and for analyzes, in the Statistica Software, with the application of the Chi-square, Pearson and ANOVA tests.

## Research Results

The socio-demographic conditions of the examined families, in the three groups of children with the Down Syndrome, are shown in the diagrams, with the statistically significant (at $p<0.05$) differences highlighted.

### Place of Residence

The place of residence of the families with the children, by administrative criteria (villages and settlements, towns up 10 thousand inhabitants, medium towns – above 10-100 thousand, large cities of 100 thousand and above populations) illustrates the Figure 1.
Over the years, in the studied groups decreases the participation of families residing in large cities (in group A it is 52%, in group B – 37%, in group C – 32%), and increases the number of children living in villages and settlements, and small towns (respectively in the groups: A – 34%, B – 23%, C – 52%), but the differences are not statistically significant ($\chi^2=4,96$, $p>0.05$)

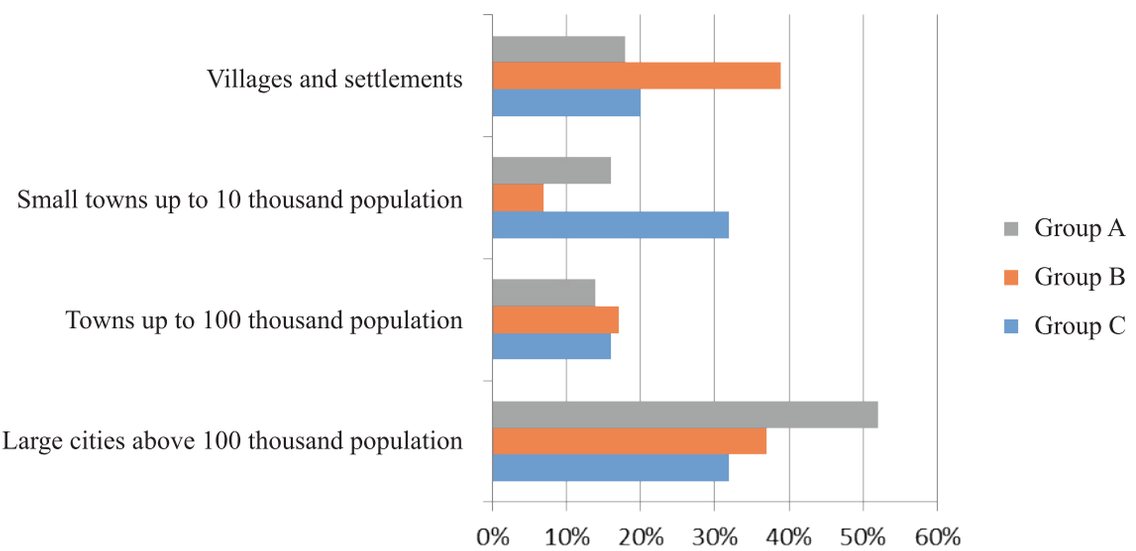


**Fig. 1. Place of residence families of the examined children, depending on the number of inhabitants**

### Age, Education and Place of Employment of the Parents

The age of parents at the time of birth of the child in the studied groups, over the last 30 years, illustrates the Figure 2. In the studied populations the average age of the mothers has been 34.05 years, and of the fathers 36.06 years. Comparative analysis with the use of the One-way ANOVA test did not reveal any statistically significant differences in neither fathers nor mothers ($p>0.05$).
In the studied groups of A, B and C both, fathers and mothers, most often possess a higher or medium level education. Comparative analysis of the educational level of fathers in the studied groups, indicates a significant increase in the number

of fathers with the higher education in group C. Test $\chi^2$=17.94, p<0.05, while comparison of the mothers has shown no significant differences between the groups ($\chi^2$=7,31, p>0.05).

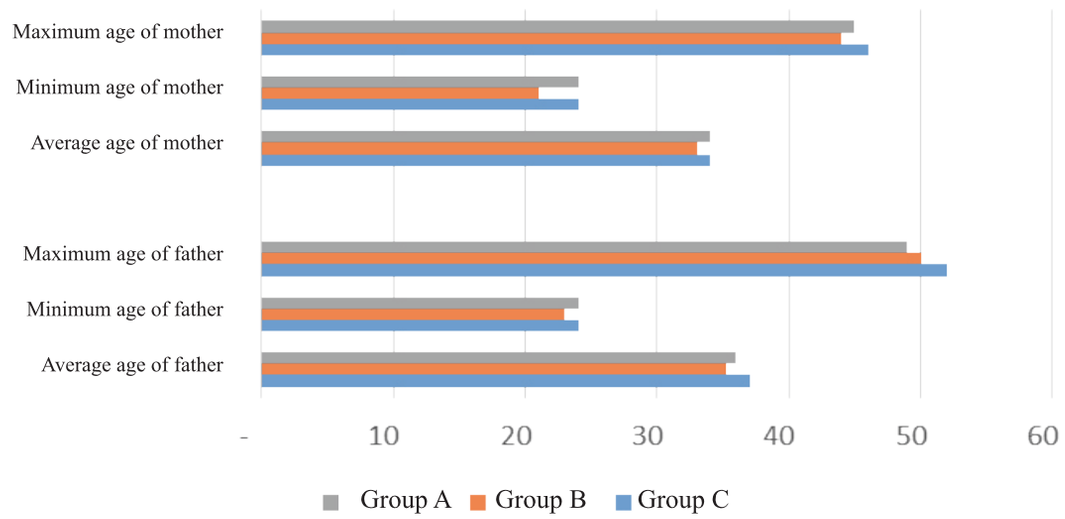


**Fig. 2. The age of parents at the moment of birth children in the studied groups**

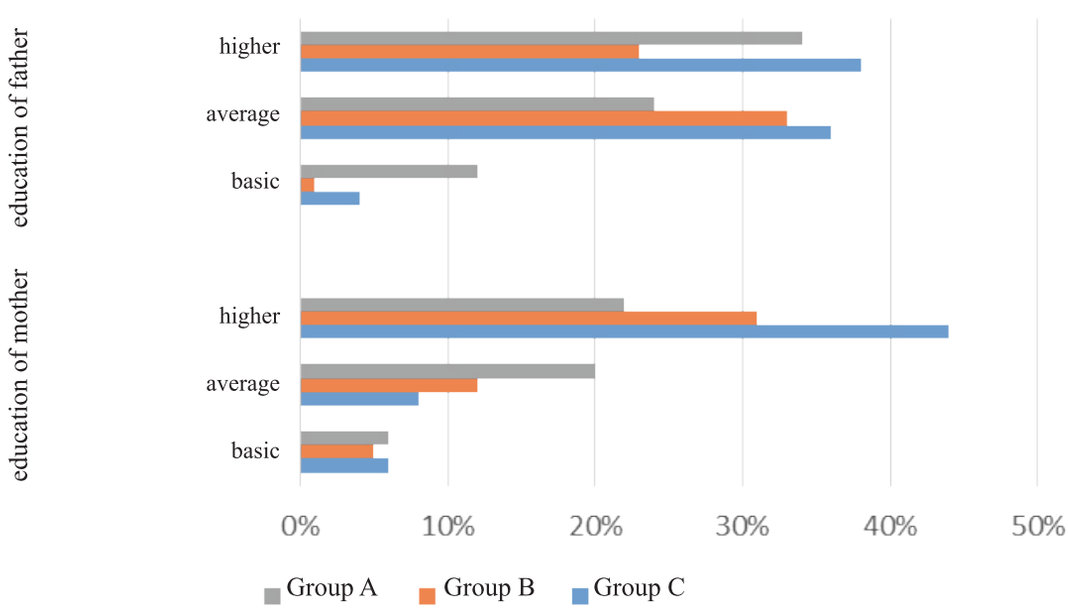


**Fig. 3. Level of education fathers and mothers of children in the study groups**

Figure 4 illustrates the employment pattern in the studied groups of parents.

In the treated groups of children, 46.6% of fathers worked in the private sector, 43% in the public sector, and 15.5% have been unemployed.

The study results show, that among the fathers in the treated groups of children, the number of unemployed has decreased. In Group A the unemployed have been 34%, in Group B - 11%, and in Group C - 6%. One may also notice the increase in the number of fathers employed in the private sector, respectively in the groups A, B, C: 38%, 48%, 52%. Comparison of the groups has shown statistically significant differences, $\chi^2$=10.03, p <0.05. A similar trend has been observed among the mothers, of whom 32.5% worked in the private sector, 42.5% in the public sector, and 25% have been unemployed $\chi^2$=13.29, p<0.05.

Also noted, has been the decline in the number of the unemployed mothers over the years, in Group A it has been 30%, in Group B - 26%, and in group C - 18%. Among the mothers of the treated groups of children, there has been noted, over the years, the increase of employment in the private sector, respectively in the Groups A, B, C – 22%, 31%, 46%, accompanied by the decrease of employment in the public sector (Group A – 48%, B – 43%, C – 36%).

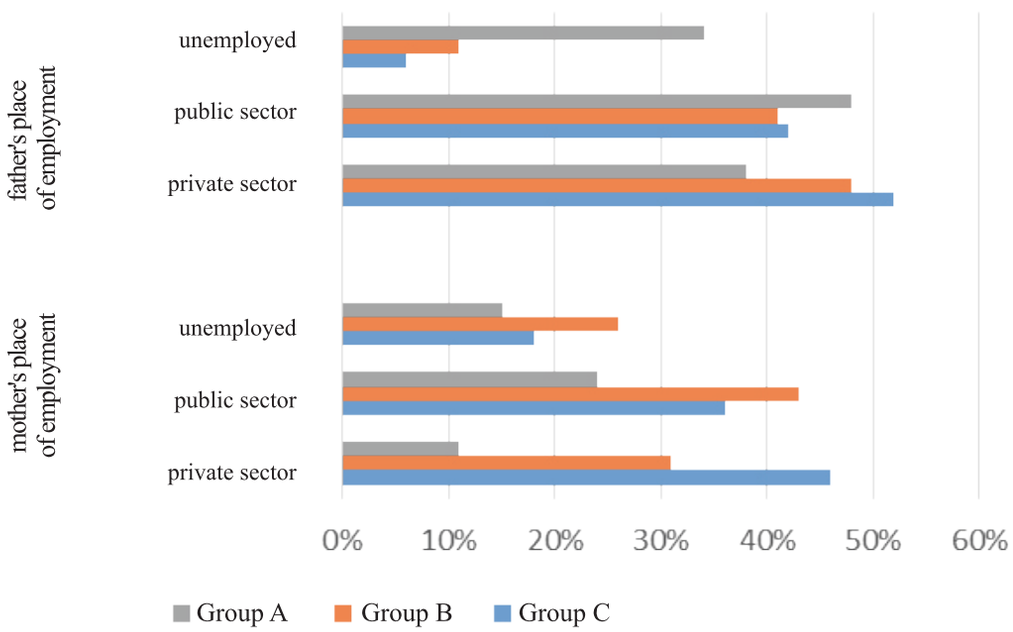


**Fig. 4. Employment characteristics of fathers and mothers in the study groups**

### Family Characteristics and the Number of Children

Characteristics of the families of the treated children illustrates Figure 5.

In all the treated groups of children 90% had a full family, 4% separated, 3% came from non-marital partners and 3% have been raised by a single mother. A detailed analysis of the studied groups has not shown differences occurring over time, which is not in line with the national trend of families' disintegration processes in Poland. In Group A the full families have been in 84%, in Group B - 92%, and in Group C - 92%. No statistically significant differences between the studied groups have been demonstrated $\chi^2$=6,57, p>0.05

Number of children in the families of the treated groups shows Figure 6 The number of children in the studied families is greater than the number found in national statistics, since our research has shown that only 30% of the treated children have been the only child. Similarly, some 30% of them has only one brother or sister. Of the remaining families, some 20% have three children, and 10.5% have four or more of them. Full families, and those with many children, have had positive impact on the level of care and the psychomotor development of the children with Down Syndrome. Differences between groups have not been statistically significant $\chi^2$=13,1, p>0.05.

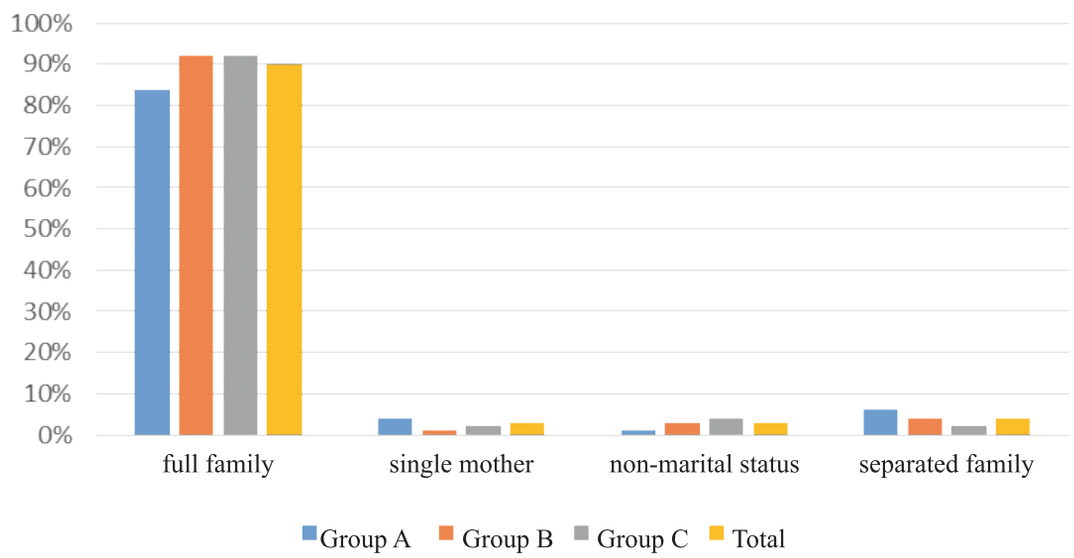


**Fig. 5. Character of the family in the examined groups of children**

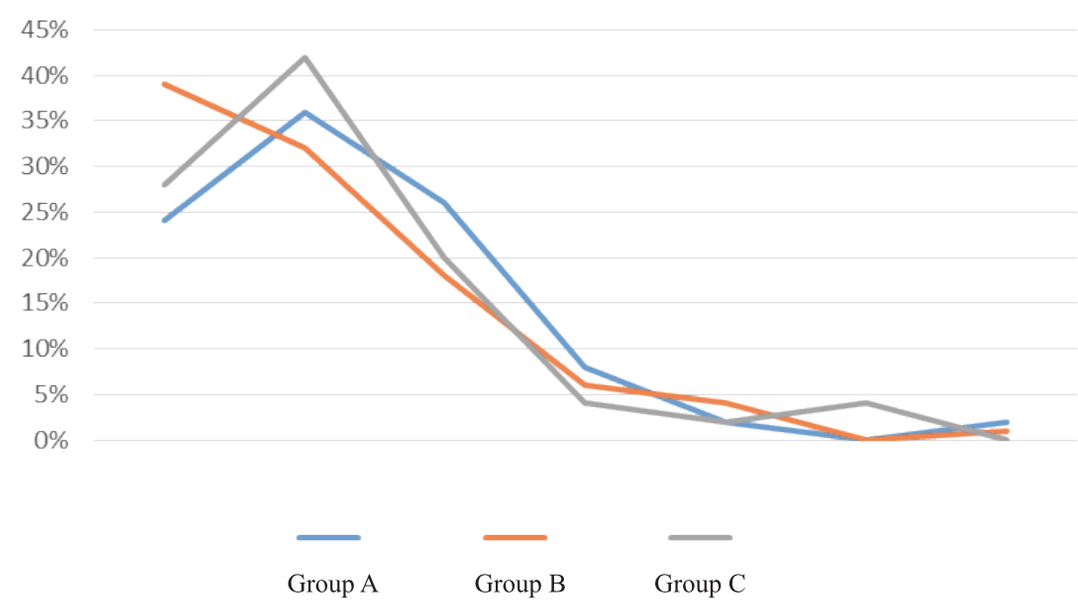


**Fig. 6. The fertility rate in families in examined groups**

**Care and Upbringing of the Child**

The basic source of income and the housing conditions illustrate Figures 7, 8 and 9.

Care and upbringing of the treated children have been provided by both parents in 88.5%, and in 4.5% it has been assisted by a grandmother. While only 6.5% of the children have been raised by a single mother, and 0.5% by a childcare facility. No statistically significant differences between the groups have been demonstrated $\chi^2$=8,13, p>0.05 The distribution of the analyzed feature illustrates Figure 7.

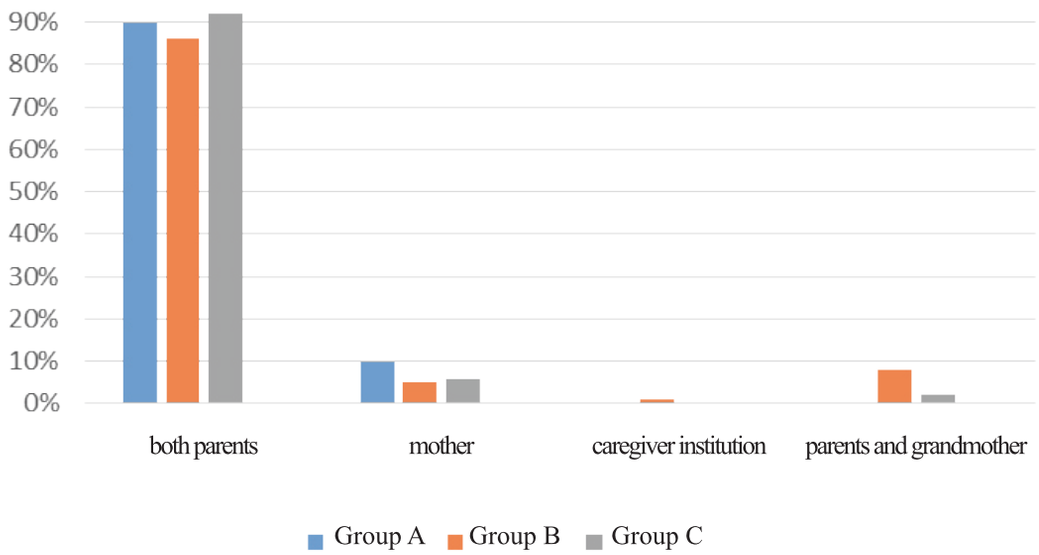


**Fig. 7. Taking care of a child in the study groups**

The source of family income is shown on Figure 8. It shall be noted, that the basis for the family economics has been the regular employment of at least one of the parents, some 75.5% in all of the studied groups, for some 5.5% it has been only social benefits and disability allowances, and for 19% of the families it has been mixed sources of income. Statistical analysis has shown no significant differences between the groups $\chi^2$=0.46, p>0.05.

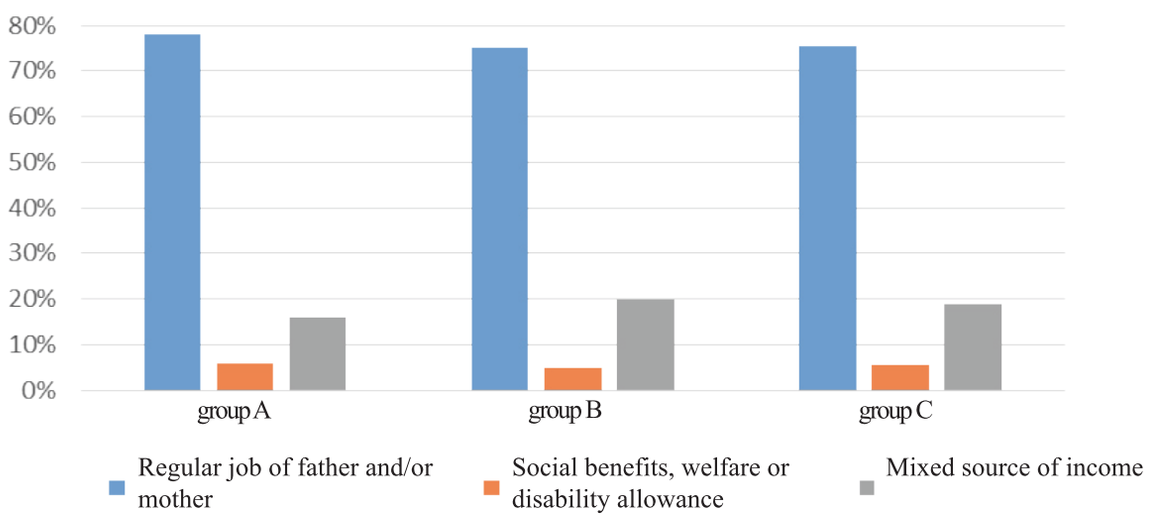


**Fig. 8. Source of income of the surveyed families**

Housing conditions are illustrated in Figure 9. Noteworthy is the improvement of the housing conditions of the studied families, over the 30 years. Majority of the families have lived in good and very good conditions, while significantly reduced has been the quantity of the sufficient an insufficient conditions. Comparison of the studied groups has confirmed the differences on the statistically significant level of $\chi^2$=8,9, p<0,05.

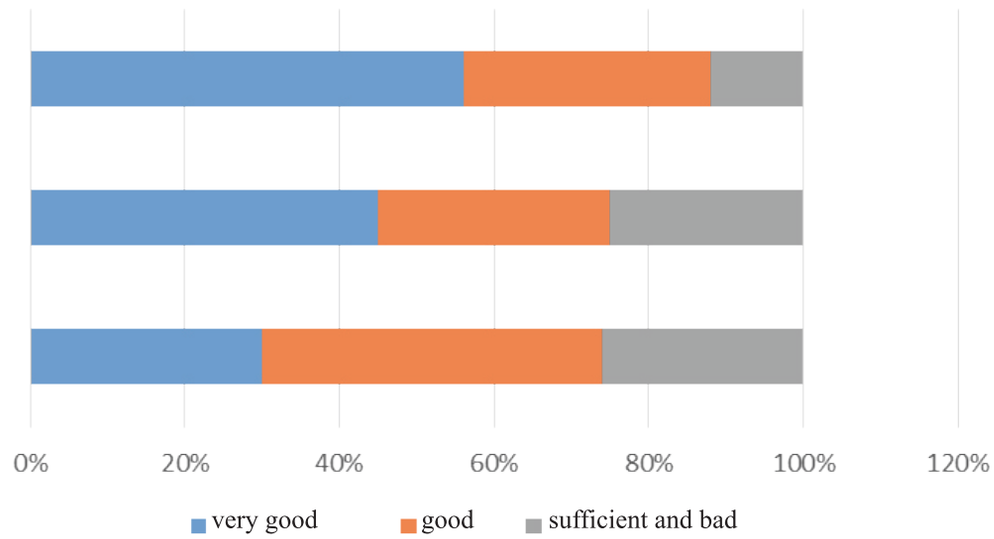


**Fig. 9. Housing conditions of families studied groups of children**

**Health Condition of the Parents**

In the questionnaires regarding the health condition of the fathers and mothers, attention is drawn by their answers, qualifying their health condition as good. The defined health condition, occurrence of chronic diseases and smoking of tobacco are shown in Figure 10. Among the fathers of the treated groups of children, their health condition as good have described: in Group A - 66%, in Group B - 71%, and in group C - 70%. Chronic diseases (most often hypertension, previous heart attack, ulcers of stomach and duodenum) declared respectively: 12%, 5% and 8%, acute 2%, 2% and 0%. In the questionnaires alcoholism has not been listed among the chronic diseases, and only two fathers have declared that they have had an alcohol problem. Similarly, the mothers have also declared a good health, by most part, in Group C - 86%, B - 79%, A - 72%. Very few of them declared chronic diseases, mainly stomach ulcers, anxiety, hypertension, varicose veins. The number of persons with chronic diseases has been declining: in Group C - 6%, in Group B - 9%, in group A - 14%. Over the years, the number of mothers smoking tobacco has also decreased: in Group A and B - 12% each, and in Group - C 6%. Attention draws the fact, that the majority of smoking mothers had also been smoking during the pregnancy. Comparative analysis of the health condition of the fathers has not revealed significant differences ($\chi^2$=3.39, p>0.05), and likewise in the group of mothers ($\chi^2$=5,64, p>0.05).

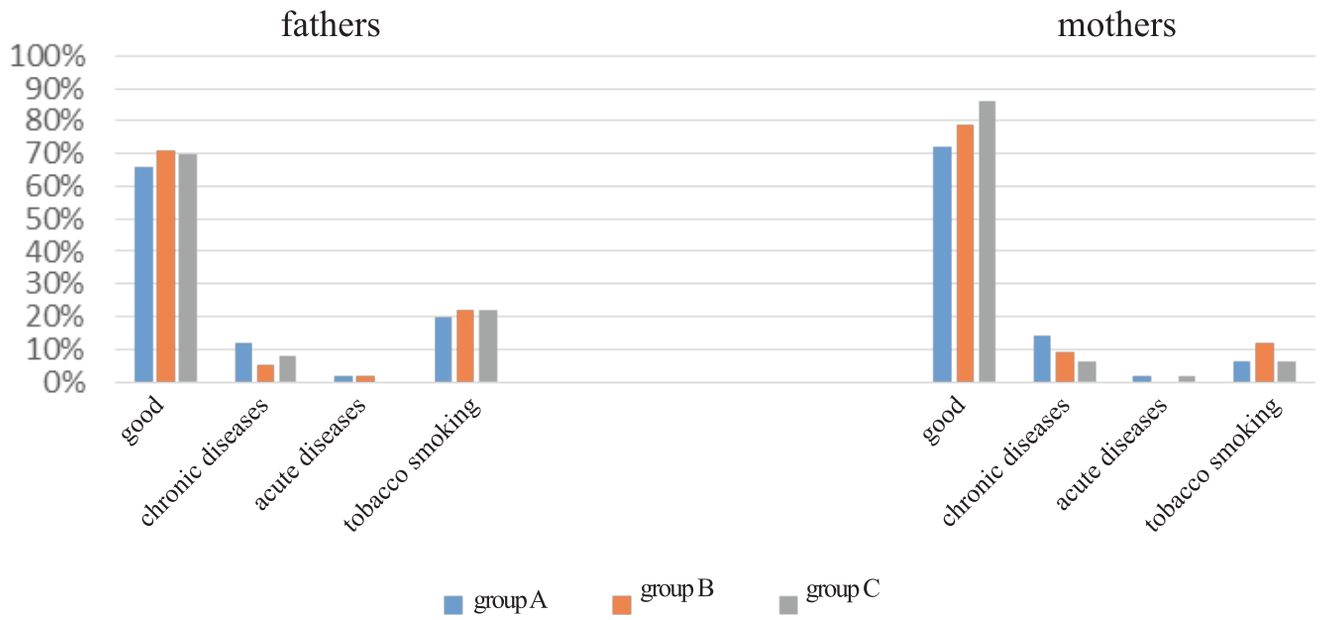


**Fig. 9. Housing conditions of families studied groups of children**

## Discussion

There are very few comprehensive studies regarding the social and living conditions of the families of children with the Down Syndrome. Noteworthy are the studies by Sadowska et al. on the group of children with the CNS dysfunction in Down Syndrome, compared with the control group of healthy children, which included 581 children and took place in the years 1995-1999 - from those come the Group B children in our study [3, 4]. In the above studies, notable is the high education level of the parents of children with the Down Syndrome, favorable status of full families with the larger number of children, higher than in the general population, and the greater awareness of the harmful impact of smoking and alcohol abuse by the parents, which is in line with the other study by the same authors, regarding smoking in children and junior high school youth [5].

Similar results concerning the characteristics and the number of children in the families with children with the Down Syndrome, also reports Skórczyńska in her PhD thesis entitled: "Early Childcare Intervention of the Parents of Children with the Psychomotor Development Disorders, in the Ages of 0 to 3 years". The author pays attention to the parental attitudes, against their living conditions, in the cases of 113 infants with the Down Syndrome and 187 infants with the central nervous system coordination disorders, in comparison to 50 healthy infants. She has shown, that 96% of children with the Down Syndrome have lived in full families, and in the control group of healthy children it has been - 90% [6]. Living in a full family affects the development of a child with the Down Syndrome, since the child feels the support and grows up in loving environment. Child being raised in a full family is developing better, since it has been shown the correct behavioral patterns, which is being stressed by many authors [7, 8, 9, 10, 11].

The total number of children in the families with a child with the Down Syndrome, in our research, similarly like in the other authors, stands at a higher level (three or more children) in every third family, in comparison to the average population in Poland, where the predominant is a family model with one or two children [12 , 13, 14, 15, 16].

Over the years, the statistically significant improvement of the housing conditions of the families with children with the Down Syn-

drome, have been higher according to our own research, in comparison with the studies published earlier, by other authors [17, 18, 19, 20].

## Conclusions

1. The socioeconomic conditions and status of the families with children with the Down Syndrome treated according to the Wrocław Rehabilitation Model (WMU), show statistically significant differences between the groups, depending on the period, when the treatment has started (calendar decades: 1980-1989, 1990-1999, 2000-2010).
2. A characteristic feature for all the children with the Down Syndrome treated according to the Wrocław Model is the full family with a large number of children, living in good and very good housing conditions.
3. At the time of birth of the child with the Down Syndrome, the mothers were generally above the age of 30., and the fathers above the age of 35, and by most part they had either the higher or medium level of education.
4. The source of income is a regular job of a father or mother, or both, and just 5% of the families live only on social benefits, welfare or disability allowances, while over 90% of the children are being raised by both parents, sometimes they are assisted by grandparents (4.5%), and only rarely it is a single mother (6.5%).

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