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INTERACTION BETWEEN THE NURSE AND FAMILIES OF CHILDREN WITH DISABILITIES IN PROVIDING INTEGRATED CARE

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Note: the figures' and tables' numeration in the abstract do not match the numeration in the dissertation.

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LIST OF ABBREVIATIONS

WHO - World Health Organisation

UN – United Nations

ECEC –education and care in early childhood

EU – European Union

EC – European Commission

RB – Republic of Bulgaria

MH – Ministry of Health

MLSP- Ministry of Labour and Social Policy

CRS – civil registration and status

CPA – Child Protection Act

HA – Health Act

HIA – Health Insurance Act

MTFA- Medical-Treatment Facilities Act

HCC- Health and Consultation Centres

LME- Medical-Treatment Facilities ActAct

SAA – Social Assistance Act

RICPA - Regulations on the implementation of the Child Protection Act

SSA – Social Services Act

PAA- Personal Assistance Act

CRC – Convention on the rights of the child

CM – Council of Ministers

SACP- State Agency For Child Protection

NGO – Non-governent Organisation

RHI- Regional Health Inspectorate

HMSCC – Home for the medical and social care of children

CCSCDCD - Centre for Comprehensive Services for children with disabilities and chronic diseases

DSA- Directorate of Social Assistance

SS - Social Services

SIP- Social Inclusion Project

MT- Multidisciplinary team

ECI–Early childhood intervention

FTAC - Family-type of accommodation centre

CSRI – Centre for social rehabilitation and integration

DCCD- Day-time centre for children with disabilities

INTRODUCTION

'*He is not like the others, she is like no one else. They differ from each other in thousands of ways. No, there have not been and there will never be two identical individuals, and even identical twins are physically and mentally different in some way or other. But there are also differences within the differences. One thing is different eye colour, another thing is a difference in height and physique, a third thing is a difference in mental ability, different characters, different ways of thinking and feeling. There are differences that in one way or another do not matter in life, and others that matter' are to one degree or another indifferent to life and differences that are not indifferent "(Vl. Levy," Non-standard children ")*

The attitude to children and people with disabilities is the most crucial criterion for the mechanism and maturity of a society.

Sources from ancient times show that attitudes to people with disabilities differed from the rest of society.

Homer wrote in his Iliad that the God Hephaestus was thrown from the peak of Mount Olympus by his mother Hera because of his disability.

In ancient Sparta, children with disabilities were left to die. Even today, despite progress in science and technology, our society treats children with disabilities through the prism of prejudice, stigma and branding [7,16,125].

From antiquity to this day, society has been trying to find the answer to two crucial questions: how should these children be taught? And how should they be accepted by other people? It has been a very difficult path, along which humanism and real achievements meet up with humiliating pity, rejection, indifference and demagoguery, to arrive at the modern perception that these children are like everyone else, regardless of the distinctive features of their development and the specific needs in their lives. These children are among us

and around us, which means that their problems cannot be resolved just by doctors, educators and psychologists but by a wide range of specialists [39].

The child with physical and mental disabilities should lead a full life in conditions that ensure its dignity, encourage its independence and facilitate its active participation in society. Under article 23 of the UN Convention on the rights of the child, each child with disabilities is entitled to special care and help ' each child '*aimed to provide effective access and education, training, health care, rehabilitation, preparation for work and the possibility of recreation, allowing the child the best possible social integration and individual development, including its cultural and spiritual development'* [46].

Early childhood is the period of human life from birth to reaching the mandatory age for school education. This period coincides with the most important stages in the person's development in every possible aspect. Regardless of the environment in which it happens, it requires optimal support for the child and its family from all society and all public institutions. Early childhood development is a process that determines the person's overall development [4,16,47].

That is why, the first years of its life provide a huge opportunity to fulfil the children's potential, to benefit them, society and the world. Early childhood development includes all necessary support for the child so that its right to survival, protection and care guarantees its best development. The development and implementation of early childhood policies are part of the values and policies of all EU citizens, including Bulgaria. The interventions comply with the child's needs and the situation in the family and approach each problem, associated with the child's development through the family-oriented approach to ensuring good health, physical and intellectual development, social skills and emotional well being [13,25].

Care of children and mothers is an investment in the future generations, which necessitates the introduction of an integrated approach by institutions and society towards opening services based on intersectoral cooperation [42,48]. These services support the families of children with disabilities and chronic diseases and can be regarded as an answer to the fragmented provision of health, social, educational and other services.

Care of children with disabilities requires the parents to take a patient psychological approach to a lasting and difficult battle with their challenges. The interrelationships between children and parents, medical and non-medical professionals, and the community are prerequisites for their individual development.

The nurse with her/his autonomous functions and responsibilities is a partner in child care as well as an active participant in the team that provides integrated services.

Analysis of the literature available shows various forms of integrated care of children with disabilities and their families. The problem's relevance and significance, as well as the need to bring out the nurse's role and functions in a team in providing integrated care, arouse our research interest and are a reason to develop the present dissertation.

1. AIM, TASKS, METHODOLOGY OF RESEARCH

1.1.Aim, tasks and research hypotheses

The present research aims to determine the nurse's role in the multidisciplinary team that provides integrated health and social services to children with disabilities and their families.

To achieve this aim, we have set ourselves the following **tasks:**

1. to study the core of the term 'integrated care' in scientific literature and research into the issue
2. to study the experience of some European countries and Bulgaria by providing integrated health and social services
3. to study and analyse the issues faced by the parents of children with disabilities regarding their awareness and ability to deal with the day-to-day care of them
4. to establish the degree of specialists' awareness regarding the introduction of integrated services
5. to bring out the nurse's function in integrated services by surveying the opinion of specialists who provide social services in the community
6. to examine the opinion of 4-th year student nurses regarding their readiness for professional development with the care of children with disabilities and their families
7. to develop and propose an Algorithm for providing services to children at a Centre for Comprehensive Services for children with disabilities and chronic diseases
8. to develop an information brochure for parents who take care of children with disabilities

Working Hypotheses:

- The nurse with her autonomous function as a member of the MDT can achieve the optimum of her aims when cooperating with the family, specialists from the team and other institutions working with children.
- The nurse as a member of the MDT does a smaller amount of activities than her qualifications and competence are supposed to do.
- A large part of the medical specialists will give a positive assessment of the introduction of criteria and standards for health care in integrated health and social services.
- Providing health care and social services to children with disabilities and their families would prevent their social exclusion and will ensure a life of dignity.

We developed the working hypotheses registering the results in the process of deinstitutionalisation and introducing integrated services for children with disabilities and their families.

1.2.Organisation and Methodology of Research

Subject

The nurse's activities associated with providing integrated health and social services for children with disabilities and their families

Object

- medical and non-medical specialists, working in social services for children with disabilities**;**
- parents of children with disabilities;
- fourth-year student nurses;
- experts from state and municipal administration and associate professors

Scope of Research

720 people have been included, distributed in four groups of respondents:

Group One - medical and non-medical specialists, working in social services for children with disabilities – nurses, doctors, social workers, psychologists, rehabilitators; speech therapists, etc. (n = **300) (**in table 1)

Table 1. distribution of respondents in group One (based on towns)

Town	Social services	Number of respondents(n)
Veliko Tarnovo	Day-time centre for children and young people with disabilities	12
	Tsarevgrad community centre	10
	Family-type of centres for accommodating children and young people with disabilities	14
	Centre for social rehabilitation and integration of children and young people with disabilities	8
Rousse	Milosurdie day-time centre for children and young people with disabilities	10
	Day-time centre for children and young people with disabilities	10
	Mecho Puh day-time centre for children with disabilities – weekly care	12
	Complex of social services for children and families – family-type Centre for accommodating children and young people with disabilities. (3)	20
	Slancho United services for children	15
	Centre for social rehabilitation and integration Children's Corner for development	12
	Family-type Centre for accommodating children and young people with disabilities requiring permanent medical care	10

Lovech	Day-time centre for children and young people with disabilities	12
	Family-type Centre for accommodating children and young people with disabilities	10
	Centre for social rehabilitation and integration	10
Gabrovo	Complex of health and social services for children and families	12
	Day-time centre for children with disabilities	10
	Centre for social rehabilitation and integration of autistic children	10
	Family-type Centre for accommodating children and young people with disabilities requiring permanent medical care	12
	Day-time centre for children with disabilities	12
Silistra	Day-time centre for children and young people with disabilities	10
	Family-type Centres for accommodating children and young people with disabilities	12
	Centre for social rehabilitation and integration	10
Svishtov	Day-time centre for children with disabilities	12
Debelets	Home for medical and social care	35

Group Two - parents of children with disabilities (n =240), (table 2);

Table 2. distribution of respondents in group Two One (based on towns)

Town	Social services	Number of respondents (n)
Veliko Tarnovo	Day-time centre for children and young people with disabilities	16
	Tsarevgrad community centre	12

	Family-type Centres for accommodating children and young people with disabilities	4
	Centre for social rehabilitation and integration of children and young people with disabilities	11
Rousse	Milosurdie day-time centre for children and young people with disabilities	10
	Day-time centre for children and young people with mental disabilities	12
	Mecho Puh day-time centre for children with disabilities – weekly care	10
	Complex of social services for children and families – family-type Centre for accommodating children and young people with disabilities (3)	15
	Slancho United services for children	19
	Centre for social rehabilitation and integration Children's Corner for development	10
	Family-type Centre for accommodating children and young people with disabilities requiring permanent medical care	4
Lovech	Day-time centre for children and young people with disabilities	12
	Family-type Centre for accommodating children and young people with disabilities	4
	Centre for social rehabilitation and integration	6
Gabrovo	Complex of health and social services for children and families	14
	Day-time centre for children with	7

	disabilities	
	Centre for social rehabilitation and integration	8
	Family-type Centre for accommodating children and young people with disabilities requiring permanent medical care	5
	Day-time centre for children with disabilities	10
Silistra	Day-time centre for children and young people with disabilities	8
	Day-time centre for children with disabilities	4
	Centre for social rehabilitation and integration	4
Svishtov	Day-time centre for children with disabilities	15
Debelets	Home for medical and social care	20

Group Three – fourth-year student nurses (n =150) in (table 3)

Table 3. distribution of respondents (based on structures of Varna Medical University

Town	**Varna Medical University**	**Number of respondents (n)**
Varna	Department of Health Care	69
Shumen	Subsidiary	42
Veliko Tarnovo	Subsidiary	23
Sliven	Subsidiary	16

Group Four – experts from state and municipal administration, Varna Medical University, 'St. Cyril and St. Methodius' University of Veliko Tarnovo and 'The Bishop Konstantin Preslavki' University of Shumen (n =30) in (table 4)

Table 4. distribution of experts based on institutions

Experts	Number of respondents (n)
Public administration	9

Municipal administration	13
Associate professors	8

Logical Units

➢**first logical unit – each medical and non-medical specialist**, practising social service for children with disabilities which provides integrated care to the child and the family.

➢ **Second logical unit - each parent** of a child with a disability, using integrated care.

➢ **Third logical unit – each 4-th-year undergraduate student nurse,** class of 2020, 2021 at Varna Medical University

➢ **Fourth logical unit – each expert**

Two groups:

- **Each director** of Directorate of Social activities and health, Director of Directorate of Social Assistance and head of the Department of Child Protection, an employee of Veliko Turnovo, Lovech, Gabrovo, Rousse and Silistra municipalities

Each Associate professor of the following departments:

- Department of Health Care, Varna Medical University and the subsidiaries in Shumen and Sliven conducting training in Nursing care in paediatrics, Nursing Care of children and adults with disabilities, Nursing care at home;

- Department of Organisation and Methodology of Social Work; Faculty of Economics, St. Cyril and St. Methodius University of Veliko Tarnovo;

- Department of Social Work, Bishop Konstantin Preslavski Shumen University.

Signs of logical units

Signs of the first and third logical units:

- Applying to the opinions of medical and non-medical specialists

regarding the core of the term ‘integrated care’.

- Associated with formulating the nurse’s functions in providing integrated care;
- Associated with the nurse’s opinion on providing integrated care of children with disabilities and their families at home;
- Associated with the nurse’s opinion on the need for further specialisation, aimed at providing integrated care of children with disabilities and their families;
- **Signs of the Second Logical Unit**
- Associated with the parents’ opinion on the difficulties they are facing in providing day-to-day care of their children;
- Associated with the parents’ opinion on using professional nursing care at home;
- Associated with the parents’ opinion on the support and consultations they receive;

Signs of the Fourth Logical Unit

Associated with the expert’s opinion on the need for the nurse’s inclusion as part of the team in providing integrated care for children with disabilities and their families;

- Associated with the expert’s opinion on the need for developing new standards and criteria for health care, in compliance with the needs of the children and their families;
- Associated with the expert’s opinion on the practical applicability of an Algorithm in providing services to children at the Centre for Comprehensive Service for Children with Disabilities and Chronic Diseases.

Venue of Research

The research was conducted in the territory of the **Central Northern Region:**

1. Social services to children with disabilities and their families to poll the opinions of specialists and parents:

- ✓ Day-time centre for children and young people with mental disabilities;
- ✓ Day-time centre for children and young people with disabilities;
- ✓ Complex of social services for children and families;
- ✓ 'Slancho' united child services;
- ✓ Centre for social rehabilitation and integration
- ✓ Home for medical and social care;
- ✓ Tsarevgrad community Centre;
- ✓ Family-type centre for accommodating children and young people with disabilities.

2. Directorate of Social Activities and Health, Directorate of Social Assistance, St. Cyril and St. Methodius University of Veliko Tarnovo, the Bishop Konstantin Preslavski University of Shumen for polling experts' opinions

3. Varna Medical University for polling the opinion of experts and student nurses

Research Organisation

The research took place during the June-October period, 2020 after receiving permission from the Committee on Research Ethics with Varna Medical University (*Resolution №92/02.04.2020г.).*

The main body of the research was conducted by the author. Managers of social services for children with disabilities and experts from the Directorate of Social Activities and Health of the selected Municipalities in the North Central Region have been recruited as associates, as almost all services offering

integrated care of children with disabilities and their families are managed by municipalities.

In polling the graduates' opinions, we were assisted by assistant professors at the Department of Health Care in Varna Medical University, and the subsidiaries in Shumen and Sliven.

All selected associates were familiarised with the aim and the methodology of the research in advance (Table 5)

Table 5. Research associates

Respondents' group	Associates
Group One (medical and non-medical specialists working at Sofia University for children with disabilities)	Sofia University managers and experts from the Directorate of Social Activities and health, the PhD student
Group Two (parents of children with disabilities)	Sofia University managers
Group Three (graduates)	The PhD student and course leaders
Group Four (experts)	The PhD student

The research is a complex empirical sociological investigation, using the inquiry method, standardised interview and a documentary method.

The research among specialists was conducted in a real-time environment, observing the requirement for voluntariness, anonymity and unpremeditated selection of the participants.

The parents have been questioned within the time set for taking the children to and from the social services (SS). Considering the situation, the poll was conducted in a setting of restricted access to SS, one part of the inquiry was filled in at the parents' homes as well. Their participation is anonymous and voluntary.

The research was conducted in four stages, the tools used, the venue and the time it took place, have been determined, presented in a table (Table 6).

Table 6. research stages

stagea II	Activities	Set of tools	Venue	Time frame
1.	Studying the problem's relevance; subject formulation; setting the aim, tasks, object and subject of research; development of hypotheses, the set of tools for conducting the research; preparation of literature overview	Literature sources on the subject, articles, reports, publications (including international regulations)	Veliko Tarnovo	September 2018 december 2019
2.	Conducting an anonymous survey of the opinions of medical and non-medical specialists from Sofia University, parents of children with disabilities, graduates, experts from the social sphere at the state and municipal administrations and university lecturers	**Questionnaire card №1** medical and non-medical specialists from Sofia University	Veliko Tarnovo Lovech Gabrovo Rousse Silistra	July September 2020
		Questionnaire card №2 graduates	Varna Veliko Tarnovo Shumen Sliven	July September 2020
		Questionnaire card №3 parents of children with	Veliko Tarnovo Lovech	July October 2020

		disabilities	Gabrovo Rousse Silistra	
		Questionnaire №1 experts	Veliko Tarnovo Lovech Gabrovo Rousse Silistra	September October 2020
3	Processing and analysis of the data obtained through the selected methods of analysis	SPSSv. 20.0	Veliko Tarnovo	November -2020 January -2021
4	Description of the results: The summarised data will be described in detail to reveal the core of the phenomena and the interdependencies observed.	SPSSv. 20.0 Microsoft Office Excel	Veliko Tarnovo	February April 2021г

1.3. Tools of Research

To achieve the research aims and tasks, a set of tools has been developed by the author:

- **Questionnaire card №1** – for polling the opinions of specialists from the social services for children with disabilities on the investigated signs. The card contains 25 questions (19 closed, 4 semi-closed and 2 open), grouped in the following manner into 4 groups (Table 7)

Table 7. distribution of the questions in questionnaire card 1.

Group One – associated with specialists' awareness about the core and importance of integrated care and the nurse's role as part of the multidisciplinary team in providing integrated care to children with disabilities and their families.
Group Two – associated with the nurse's competence and the need for further specialisation for work in services providing integrated care.

Group Three - indicates the opinion on the barriers to introducing integrated care in Bulgaria and the effect of developing an Algorithm for providing services at the Centre for Comprehensive Service of Children with Disabilities and Chronic Diseases
Group Four – studies the social and demographic characteristics

- **Questionnaire card №2** – for polling the graduates' opinion on the investigated signs. The card contains 23 questions (18 closed, 3 semi-closed and 2 open), grouped in the following manner into four groups:

Table 8. distribution of questions in Questionnaire card №2

Group One – associated with the students' awareness about the core and importance of integrated care and the nurse's role as part of the multidisciplinary team in providing integrated care to children with disabilities and their families.
Group Two- indicates the students' self-assessment of their training and motivation for work with children with disabilities and their families
Group Three – indicates their opinion on the need for further specialisation to work in integrated services
Group Four - studies the social and demographic characteristics

- **Questionnaire card № 3 –** for polling parents' opinions. The card contains 23 questions (17 closed, 4 semi-closed and 2 open), grouped in the following manner into 3 groups.

Table 9. distribution of questions in Questionnaire card №3

Group One – indicates the parents' opinions on the nurse's role as part of the multidisciplinary team in providing integrated care to children with disabilities and their families.
Group Two – indicates the parents' opinions on the difficulties they are facing with

the care of their children
Group Three – they present the social and demographic characteristics of the polled individuals

Questionnaire – for conducting a standardised interview with experts. It contains 13 questions (11 closed, 2 semi-closed), grouped into three groups in the following manner:

Table 10. Distribution of the questions in Questionnaire №1

Group One – indicates their opinion on the nurse's role in the team providing integrated care
Group Two indicates their opinion on the need for developing new standards and criteria for health care, in compliance with the need of the children and their families and an algorithm for providing services for children at the Centre for Comprehensive Service of Children with Disabilities and Chronic Diseases
Group three – studies the social and demographic characteristics

1.4. Sources of Information Collection

- Opinions of medical and non-medical specialists from social services on children with disabilities polled through a questionnaire card;
- Opinions of graduate nurses at Medical University – Varna Prof Dr Paraskev Stoyanov through a questionnaire card;
- Opinions of parents of children with disabilities through a questionnaire card;
- Experts' opinions through a questionnaire;
- Available national and international regulations associated with health care, social activities, nursing science and nursing practice, early childhood development (Health Act, Medical-Treatment Facilities ActAct, Social Services Act, Regulations on Implementing the Law on Social Assistance,

Child Protection Act, Personal Assistance Act);

- Legal framework, regulating the nurse's training and practice in Bulgaria;
- Available scientific literature – studies by Bulgarian and foreign authors on the issue of early childhood development and early intervention;
- Documents of the WHO and UNICEF

1.5. Research Methods

The aim of the present research necessitated the use of various *sociological methods:*

- ***Documentary method*** **–** studies national and international literature sources, documents and regulations, associated with providing integrated care to children with disabilities and their families
- ***Inquiry method*** **–** direct individual inquiries have been used. Three individual questionnaire cards have been made to poll the opinion of medical and non-medical specialists working in social services for children with disabilities and their families; parents of children with disabilities, nurse graduates;
- ***Standardised interview*** with experts from state and municipal administrations and university lecturers on a questionnaire prepared in advance

To reveal the core of the observed phenomena and their interdependencies, a set of *Statistical methods* was applied.

Descriptive analysis of present frequency distribution;

- ***parametric and non-parametric tests*** - to assess hypotheses – statistical comparison χ^2 analysis for checking out on hypotheses for a link between quality variables. The critical level of significance in the polls is $\alpha = 0,05$;

- ***variance analysis*** - measures the differences in the aggregate on a specific sign. Measuring the mean arithmetic value ($\bar{x}$), Mode and median of the statistical row and average quadratic deviation;
- ***correlation analysis*** – establishes the degree of connectivity between two variables. Measures Pearson's coefficient (r) to find out and determine the degree of rectilinear correlation dependence between quantitative variables and Student's coefficient of qualitative variables
- ***graphical analysis*** – indicates the inquiry data, processed graphically. MS Excel 2019 and IBM Statistics 19 have been used for the graphical analysis.

2. RESULTS AND DISCUSSION

2.1. Social and Demographic Characteristics of the Respondents

✓ **Medical and Non-medical Specialists**

the poll was conducted among medical and non-medical specialists (n=300) that provide integrated care to children with disabilities and their families in towns in the Northern Central Region - Veliko Tarnovo, Svishtov, Debelets, Rousse, Gabrovo, Lovech and Silistra regarding the nurse's role in the multidisciplinary team providing integrated care (Fig.1)

Fig. 1 image of the Central Northern Region

The specialists' social and demographic characteristics have been studied for this research

Table 11. specialists' social and demographic characteristics

Social and demographic characteristics	**n (number)**	**%**
Town	**n (number)**	**%**
Veliko Tarnovo	**44**	**14.67%**
Svishtov	**12**	**4%**
Debelets	**35**	**11.67%**
Rousse	**89**	**29.67%**
Gabrovo	**56**	**18.67%**
Lovech	**32**	**10.67%**
Silistra	**32**	**10.67%**
Basic education	**n (number)**	**%**
Medical specialists	**116**	**38.7%**
doctor	4	1,3%
nurse	57	19,0%
rehabilitator	23	7,7%
Kinesiotherapists	32	10,7%
Age	**n (number)**	**%**
25-35	8	6.8%
36-45	13	11. 2%
46 -55	35	30.17%
Over 55	55	47.4%
Age not indicated	5	4.3%
Professional experience	**n (number)**	**%**
1-5 years	5	4,3%
6- 10 years	25	21,5%
Over 10 years	83	71,5%
No answer	3	2,6%
Non-medical specialists	**184**	**61.33%**
psychologist	32	17,39%
Speech therapist	25	13,58%
Social worker	60	32, 6%
Special educator	47	25,5%
others	20	10,9%
Age	**n (number)**	**%**
25-35	53	28,8%
36-45	68	36,9%

46 -55.	33	17.9,7%
Over 55	26	14,13%
No age indicated	4	2,17%
Professional experience	**n (number)**	**%**
1-5 years	93	50.5%
6- 10 years	65	35,3%
Over 10 years	21	11.4%
No answer	5	2,7%

Based on the place of residence, the share of specialists from the Veliko Tarnovo district is the highest (30.33%). The poll was conducted also in Debelets and Svishtov because in Debelets is the Home for Medical and Social Care of Children, and the Day-time Centre for Children with Disabilities in Svishtov provides innovative practices in the care of children with disabilities.

Regarding basic education, 38.7% of respondents have a degree in medicine – doctor, nurse, rehabilitator, kinesiotherapist. Nurses' share is ½ of these medical specialists (19%). Non-medical specialists make up 61.33% of the respondents, the share of social workers is the highest (32.6%), followed by special educators (25.5%). A part of the specialists has more than one speciality. The assigned activities provided by social services for children with disabilities prioritise rehabilitation and integration of children, formation of skills for an independent lifestyle, informing and advising parents of children with disabilities on the specific character of their child's particular disabilities, which is why non-medical professionals prevail.

The age span of the polled respondents is within 25-55, ¾ of whom are aged 25-55. This is an active age that presupposes dealing with the multitude of their functions and possibilities of managing changes, taking up challenges and tackling difficulties.

83.6% of non-medical specialists fall within the 25-55 age group. These are psychologists, educators, social workers, speech therapists, etc.

(47,41%) of medical specialists are over 55 years, which coincides with the overall picture in the country regarding the average age of professionals working in health care.

¾ of medical specialists have over 10-year professional experience, whereas ½ of non-medical specialists have 1-5 years of professional experience. We can summarise that 82.9% of all specialists working in integrated services have over 10 years of professional experience. This can be explained by the fact that 10-15 years ago the process of deinstitutionalisation was launched successfully and services for children with disabilities were created to be raised in a family or an environment close to the family.

- ✓ **Experts**

The opinions of experts from state and municipal administrations and associate professors were polled for the aims of this research (Table 12)

Table 12. experts' social and demographic characteristics

Experts' social and demographic characteristics		
Workplace	**n**	**%**
University	8	26,7%
Public administration	9	30,0%
Municipal administration	13	43,3%
Length of service	**n**	**%**
5-10 years	2	6,7%
10-15 years	7	23,3%
Over 15 years	21	70,0%
Town	**n**	**%**
Veliko Tarnovo	7	23.3%
Silistra	4	13.3 %
Lovech	4	13.3%
Varna	3	10%
Shumen	4	13.3%
Gabrovo	4	13.3%
Rousse	4	13.3%

The share of the experts from the municipal administration is the highest (43.3%), followed by the state administration and associate professors. This is because all social services where the poll was conducted are state-regulated activities and are managed by the respective municipality. The experts' professional experience is another crucial factor that we were able to study. Almost ¾ of the experts have over 15 years (70%), and 23.3% of respondents have 10-15 years of professional experience. Regarding the distribution based on towns, the share of the experts from Veliko Tarnovo is the highest (23.3%). In the other towns, the share of the polled respondents is almost identical (13.3%).

✓ Parents

We included in the poll parents of children who attend social services in the community and residential-type services (n=240), (Table 13).

Table 13. parents' social and demographic characteristics

Parents' social and demographic characteristics		
Age	**n**	**%**
20- 25	10	4,2%
26- 30	32	13,3%
31- 35	71	29,6%
Over 35	127	52,9%
Education	**n**	**%**
High education	106	44,2%
College	19	7,9%
Secondary education	100	41,7%
Primary education	10	4,2%
No answer	5	2,1%
Град	n	%
Veliko Tarnovo	43	18.92%
Debelets	20	8.41%
Svishtov Свищов	15	6.28%
Rousse	80	33.33%
Silistra	16	6.81%
Gabrovo	44	18.36%
Lovech	22	9.17%

Parents' education is a key factor in the quality of the care provided to the child in the family. The share of people with university and college degrees is the highest (52,1%), followed by those with secondary education (41,7%), which presupposes good awareness, timely search for consultation and adequate support. A small share of respondents has primary education (4.2%). Almost ½ of parents are over 35 years, and only 4.2% of the polled respondents are aged between 20-25. Education and age are crucial to responsible parenthood.

✓ **Students**

To achieve the aims of this research, an inquiry among graduate nurses from the Department of Health Care, Varna Medical University and the Veliko Tarnovo, Shumen and Sliven subsidiaries was conducted (n=150), (Table 14).

Table 14. students' social and demographic characteristics

Students' social and demographic characteristics		
Age	n	%
18-20	3	2,0%
20-25	102	68,0%
25- 30	10	6,7%
Over 30	35	23,3%
Gender	n	%
Female	145	96,7%
Male	5	3,3%
Training venue	n	%
Varna	69	46,0%
Veliko Tarnovo	23	15,3%
Sliven	16	10,7%
Shumen	42	28,0%

The share of the students from the Department of Health Care at Varna Medical University was the highest (46%), followed by the students at the Shumen Subsidiary (28.%) The predominant part of the polled respondents are aged between 20-25 (68%) and almost ¼ of the respondents are aged over 35.

These data suggest that the choice of profession is a conscious and well-considered act, and above all, this profession is a vocation.

2.2. The Nurse's Role and Place in the Team for Providing Integrated Care

The birth of a child with disabilities changes the lifestyle and the relationships in the family. To keep and save its balance, it needs help from specialists and support from society. The specialists' professional knowledge and skills at working with children with disabilities and their families are vital to providing quality care. Adequate training and competence are an advantage when a new model of integrated services is introduced, and that would lower organisational resistance to realising the changes and ensure their adequate functioning. **The holistic approach** is a main principle of work in the multidisciplinary team, where decision making respects the child's personality and wishes, the parents and other figures important to the child are involved and specialists best suited to the child's needs and abilities are recruited. This type of model places the child's interests in the centre, and all-important institutions, services and organisations participate in the care.

It was important to us to poll the opinions of two groups of respondents - specialists and parents regarding the specialists who should be included in the teams for providing integrated care (Fig. 2)

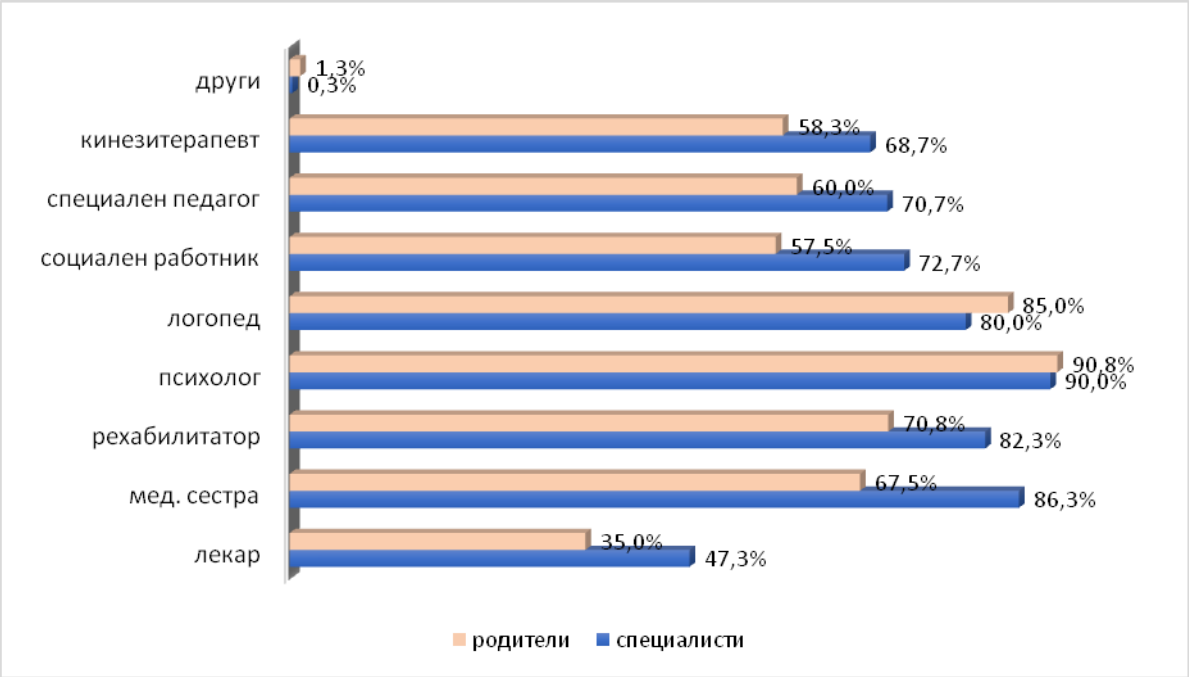


fig. *2 MDT members (comparative data)*

Of all specialists, the psychologist is the most important figure to parents and children with disabilities (90,8%), followed by the speech therapists with a relatively high share as a team member pointed by (85,0%) and the rehabilitator (70,8%). Only 1/3 of them believe that a doctor should be included, whereas 2/3 think that a nurse should also take care of the children (86.3%).

The regulatory framework has been changing in recent years (in health care, education and social services). Bulgaria is at the start of approving this integrating approach, and each model from the practice that accumulates professional experience contributes to developing efficient social policy.

Regarding the implementation of the integrated approach to the care for children with disabilities, it was important to us to study the parents' and specialists' degree of awareness (fig. 3).

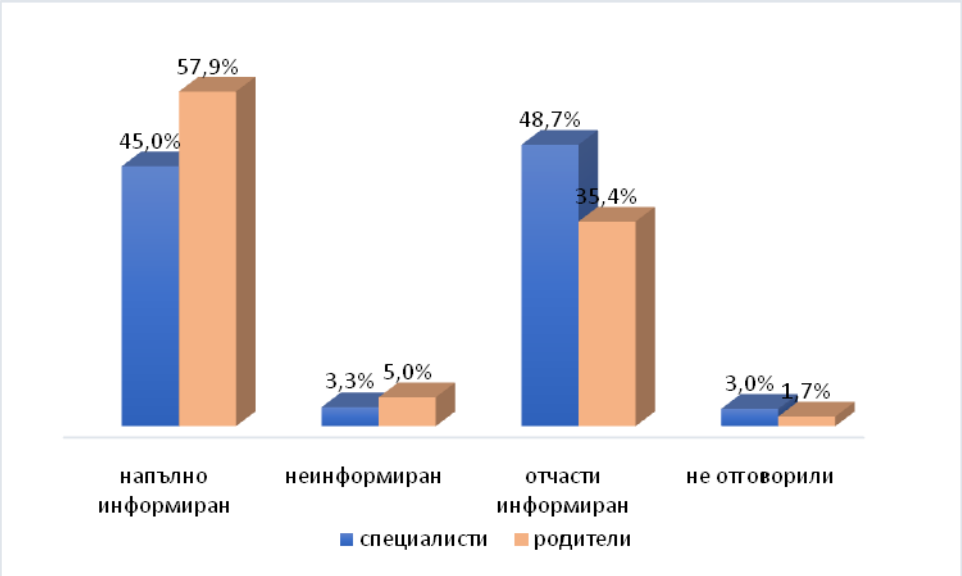


Fig. 3. Degree of awareness (comparative data)

The respondents' high degree of awareness results from the active deinstitutionalisation and the development of public and private partnerships in the field of social services for children at risk and their families. Nearly 1/2 of specialists believe that they are 'partly' informed about the need to implement the integrated approach (48.7%). We can attribute this to the fact that part of the respondents think they are familiar with integrated services as a chance for comprehensive care of children with disabilities and their families but not with the institutions that can provide them, the order and way of using them. Another factor that has an impact that we can register is that for many of them the terms 'health care, 'medical care, 'social care' and 'integrated health and social services' are almost identical.

More than ½ of parents and 45% of specialists are fully informed about the implementation of the integrated approach. The data analysis suggests that there is a statistically significant difference in the degree of awareness ($n=540$, $\chi^2 = 11.750$, $p < 0{,}001$, $r = -0.101$).

We think that the higher degree of awareness among parents results from the fact that they use many more sources, study our and the foreign experience.

The degree of parents' awareness depending on their education has been studied (Fig. 4).

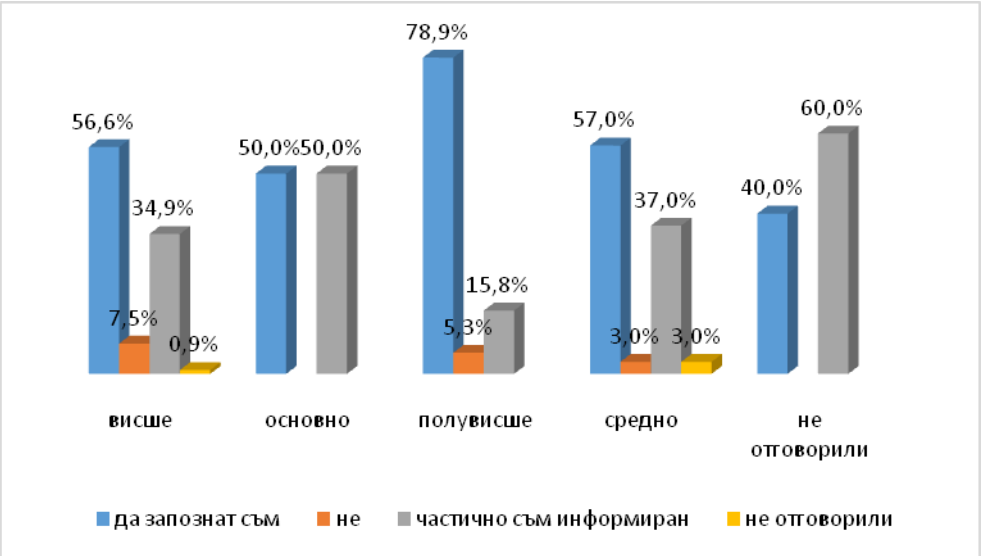


Fig. 4. Degree of parents awareness according to education

The analysis showed that there is no statistically significant difference in the answers. The polled respondents' education does not affect their opinions ($n=240$, $\chi^2 = 10{,}375$, $r=0.06$)

Children with disabilities and their families need the nurse but our society can not yet perceive her as a professional who can make independent decisions, provide care at home independently, which can only benefit the patient. During her training, the nurse masters knowledge and skills, which allows her to have professional competence in providing health care to both healthy and diseased individuals, independently or interacting with a doctor, to fulfil tasks in various sectors of health care, providing comprehensive care of the mental, physical and social health, as well as make decisions regarding marked or potential problems of the patient or the family.

We studied the nurse's role according to specialists working with children with disabilities and their families (table 15).

Table 15. nurse's role in providing integrated care (according to specialists)

Activities	Yes		No		I cannot say	
	n	%	n	%	n	%
Supporting the specialists	278	92.7	9	3,0%	13	4,3%
Training and consulting children and their families	212	70,7%	17	5,7%	71	23,7%
Fulfilling doctor's assignments	220	73,3%	13	4,3%	67	22,3%
Visits at home	145	48,3%	30	10,0%	125	41,7%

** % exceeds 100, as respondents have given more than one answer*

The experts' opinions on the nurse's role were important to us (fig. 5)

Fig. 5. The nurse's role in providing integrated care (according to experts)

**** % exceeds 100, as those who have been polled have been able to give more than one answer***

Specialists and experts perceive the nurse as a specialist who supports them. In Bulgaria, health care is still organised mainly by institutions, whereas in some European countries the nurse has more freedom to provide care in various forms, conforming to the individual needs of the child and the family.

To ¾ of specialists, the nurse trains the children and parents and fulfils the doctor's assignments. In terms of home visits, respondents have some hesitations

as the relative share of those who have given a positive answer, almost equals those who cannot answer. This is maybe because currently home visits are paid by the nurse who works with the GP.

Experts through their opinions have outlined the nurse's autonomous function. They point out what is expected from the nurse, that is, not just fulfilling the doctor's assignments but also conducting training, giving support to the children and their families, paying visits at home because they are familiar with the novelties in the training received by the nurse who has a Bachelor's degree.

We polled the parents' opinions on the possibility of using by-the-hour and mobile services provided by the nurse for this research (fig. 6)

Fig. 6. Mobile services used by the parents

2/3 of the parents would rely on training by the nurse, and 85.8 % of them would prefer the nurse to perform the treatment prescribed at home. Only 1/3 of the parents can trust substituting care. This type of service is not familiar to many of the polled respondents as currently it is provided only to children with disabilities at foster families.

We asked the parents for the aims of our research whether the nurse's inclusion in the team would improve the care of their child (fig. 7) Fig.

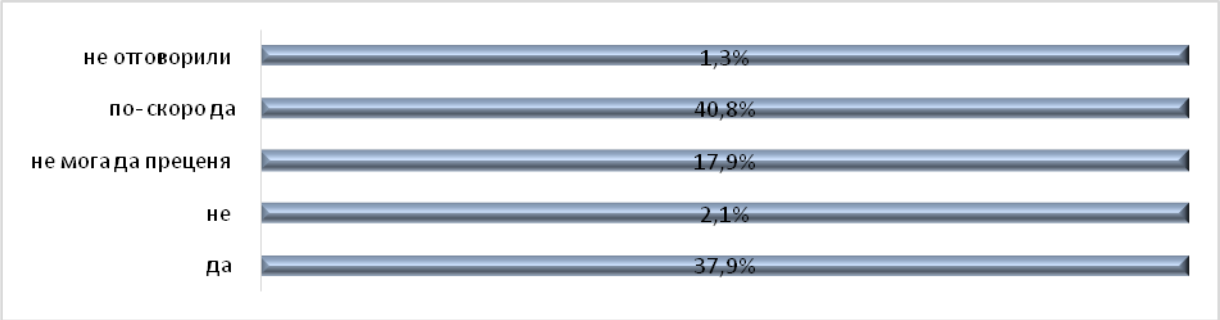


Fig. 7. Parents' opinions on the nurse's role in improving the quality of care of children with disabilities

Nearly 80% of parents believe that including the nurse would improve the care of their child.

We studied the link 'between parents' opinions and age and education (Fig. 8).

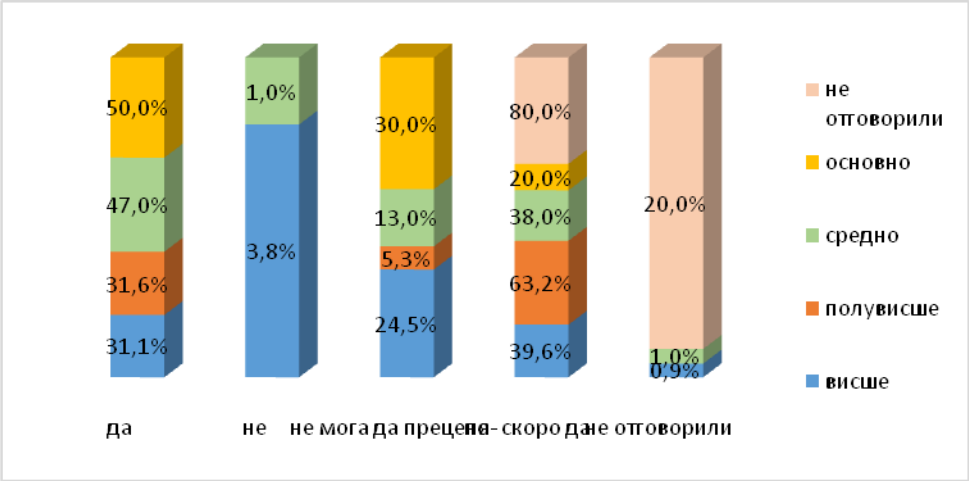


Fig. 8. Parents' opinions on the nurse's role in improving care quality (according to education)

The analysis shows that there is no statistically significant difference in answers. Respondents' education does not affect their opinions (n=240, χ^2 =36.064 , r= - 0.093).

We studied the link between parents' age and their opinions on the nurse's role in improving care quality (Fig. 9).

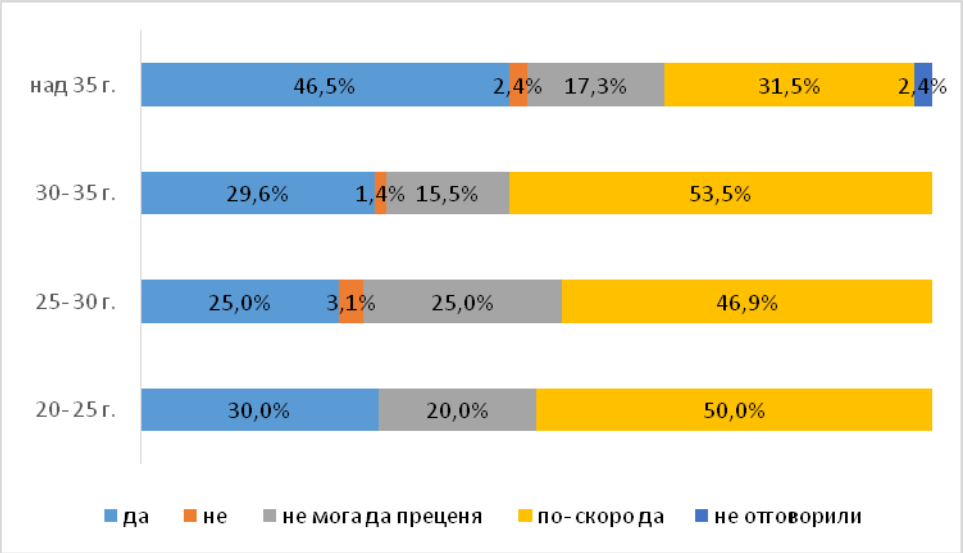


Fig. 9. Parents' opinions on the nurse's role in improving care quality (according to age)

Analysis results suggest that there is no statistically significant difference in answers. Respondents' age does not affect their opinions (n=240, χ^2 =15.746, r= - 0.134).

Nurses' training over the past years is based on conceptual models. As a result of the training they receive, they can evaluate each patient's individual needs – healthy, diseased or with disabilities, thus ensuring adequate care. Unfortunately, society still cannot perceive the nurse as a professional who can make independent decisions, and that they can only benefit the patient. In this way, the system of integrated care is deprived of a significant resource.

It was important for the research to compare the opinions of specialists, experts and students on the nurse's inclusion in the team for improving service quality (Fig. 10).

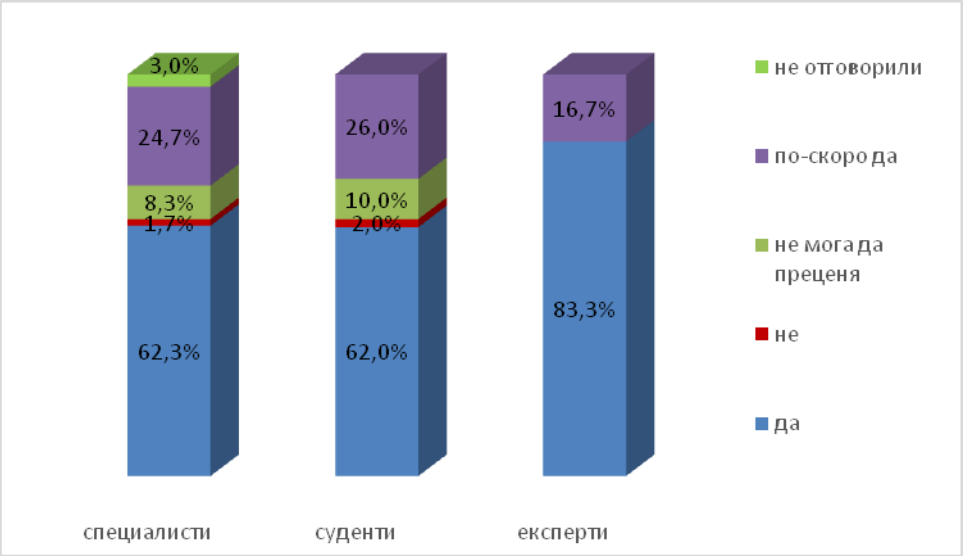


Fig. 10. The nurse's role in improving service quality (comparative data)

According to results, 83.3% of experts register the nurse's contribution to improving the care of children with disabilities. For 2/3 of specialists and students, the nurse's inclusion will have a positive impact on the team's work.

The specialists were able to describe what the nurse's help comes down to. They agree that the nurse's presence in the team would guarantee 'comfort for the parents' on the one hand, and on the other, ,will boost 'trust in them', ,will give 'security' to all. Respondents see in the nurse the specialist who will 'inform them about their child's diseases, complications, as well as the needs resulting from the disease'. They rely on the ,quick and adequate reaction in the event of deterioration of the child's condition or emergencies', and also 'to train the other team members how to behave in the event of emergencies.' The respondents say that they will rely on the nurse's competent opinion to draw up a plan for the child care, as well as discuss a case with other specialists. Besides training and support to specialists, the nurse is expected to 'consult parents' regarding the care of the children, the physiological changes which emerge with age, which in its turn is associated with behavioural reactions.

Specialists 'cannot think of integrated services without a nurse'. Her presence will 'improve the efficiency, and that will inevitably lead to 'better

quality, which is at the basis of integrated services. On the other hand, besides achieving better quality service, the aim is to achieve ‘a better quality of life’, as well as ‘quality change in the living conditions which will be felt both by the individual and community as a whole’. The positive evaluation that respondents give is a reason to believe that the nurse’s presence in the MDT guarantees the quality of the service provided (Table 16).

Table 16. importance of the nurse’s activity (comparative data)

Activities	**specialists**		**Students**		**Parents**		**Experts**	
	n	%	n	%	n	%	n	%
An important part of everyday life	**154**	**51%**	**91**	**60.7%**	**87**	**36.3%**	**15**	**50%**
Defining to the child care	144	48%	59	39.3%	108	44.6%	15	50%
Not important	1	0.3%						
Minor	1	0.3%			1	0.8%		
I cannot say					44	18.3%		

Only 10% of respondents cannot judge the nurse’s contribution. These are mainly superintendents and assistant superintendents whose activity is ancillary, aiming above all to organise the group’s work. According to 1/5 of parents, there is some hesitation regarding the nurse’s role in integrated services.

As a result of multiple activities, pointed out by respondents, and the reported significance of the nurse’s work in the care of children with disabilities and their families, it is necessary for the nurse to be included in the team providing integrated care. The nurse’s growing role in the patient’s comprehensive service and integrated teamwork has been appreciated evaluated [95].

The nurse with her training can provide the type of activities that can support the everyday life of the child and its family but currently, they are not yet applicable. This care is taken on by the family, one part of them being appointed as ‘personal assistants’ to the child.

This is why medical specialists are expected to give help and support to the children and families and help them overcome the feeling of being rejected by society.

2.3. The Nurse's Competence in Working in Integrated Care

Competence is defined as 'a set of knowledge, skills and habits which specialists acquire during their basic education, and which they can upgrade in the process of work.' [170]. Basic education is the basis on which the nurse upgrades her competence and improves over time. She has theoretical, practical and communication knowledge and skills, which is an advantage when introducing the new model for integrated services, which would reduce the organisational resistance to implementing the changes, and would ensure their adequate functioning.

We polled the opinions of specialists, experts and students on the skills and competence that the nurse working in integrated services should possess (Table 17).

Table 17. The nurse's competence and skills at working in integrated services (comparative data)

Skills and competence	**Специалисти**		**Експерти**		**Студенти**	
	n	**%**	**n**	**%**	**n**	**%**
Teamwork skills	**200**	**66,7%**	12	40,0%	**113**	**75,3%**
Good communication skills	157	52,7%	10	33,3%	128	**85,3%**
	224	**74,7%**	**22**	**73,3%**	**115**	**76,7%**
Knowledge of the specific character of social work with children with disabilities and their families	160	56,0%	**22**	**73,3%**	**110**	**73,3%**
Ability to make adequate decisions quickly under all kinds of situations quickly;	147	49,0%	9	30,0%	76	50,7%

To know and implement the current enactments in the field of health and social legislation	37	12,3%	8	26,7%	47	31,3%
A sense of responsibility	135	45,0%	6	20,0%	72	48,0%

**** % exceeds 100, as respondents have given more than one answer***

According to ¾ of respondents most important of all is for the nurse to be adaptable and be mentally prepared to work in the field of social services for children with disabilities. Adaptation is a process of workers' adapting to new working conditions. The time needed for adaptation is highly individual and is due to the interaction between multiple personality features, theoretical and practical knowledge.

Experts (73.7 %) and students (76.7%) say that the nurse should be familiar with the specific character of social work with children with disabilities. Almost ½ of specialists and experts believe that she should be able to make decisions quickly in all kinds of situations. The following are pointed out as the most important: skill at teamwork, adaptability, mental preparation to work in the field of social services for children with disabilities; knowledge of the specific character of social work with children with disabilities and their families.

85.3% of students think that communication skills combined with good theoretical training in general and special care, social legislation, child psychology and interaction between all team members are particularly important.

The nurse's main functions are dependent, interdependent and autonomous within the team providing care, regardless of whether it is a medical establishment, the patient's home or social service. According to the WHO, the nurse fulfils nursing care, trains patients and the nursing staff, and develops nursing practice with the help of research. [112,113].

No matter where the nurse works, she has a key role and accomplishes activities based on her competence. Expansion of her activities determines the

introduction of new forms of labour organisation. Terms such as 'nursing process', 'nursing diagnosis', 'clinical thinking' are becoming increasingly common. The modern concept of nursing is associated with creating habits and skills at clinical observation, analysis of the condition of the patient/user of a service, and applying an individual approach to nursing care. [10].

2.4. Need for Follow-up Training and the Nurse's Specialisation for Work in Integrated Care

According to 1/3 of specialists, the basic knowledge and skills that the nurse possesses are enough to work with children with disabilities and their families. We attribute the low share of respondents who have given a positive evaluation to the fact that many of them are not familiar with the activities that the nurse can provide. Currently, what she is doing in social services does not fit in with the new vision of integrated care.

With experts, the share of those who have expressed a positive opinion is higher (46.7%) as they are familiar with the curricula and plans in which the nurse is trained (Fig. 1).

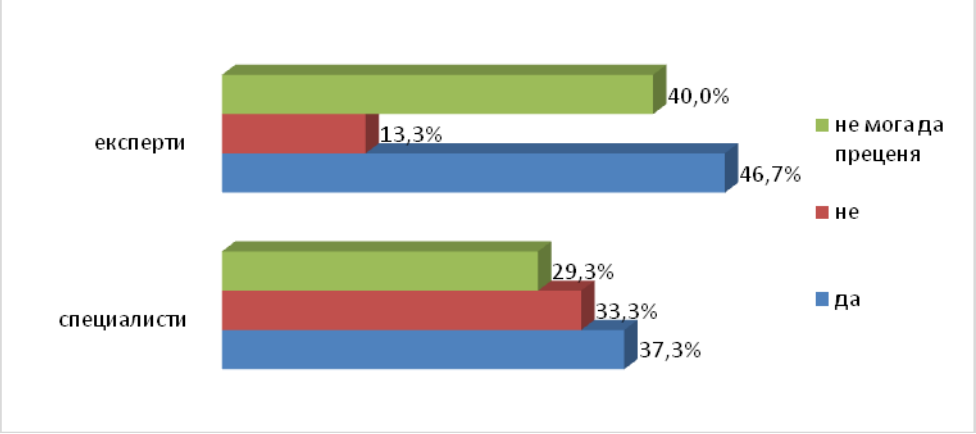
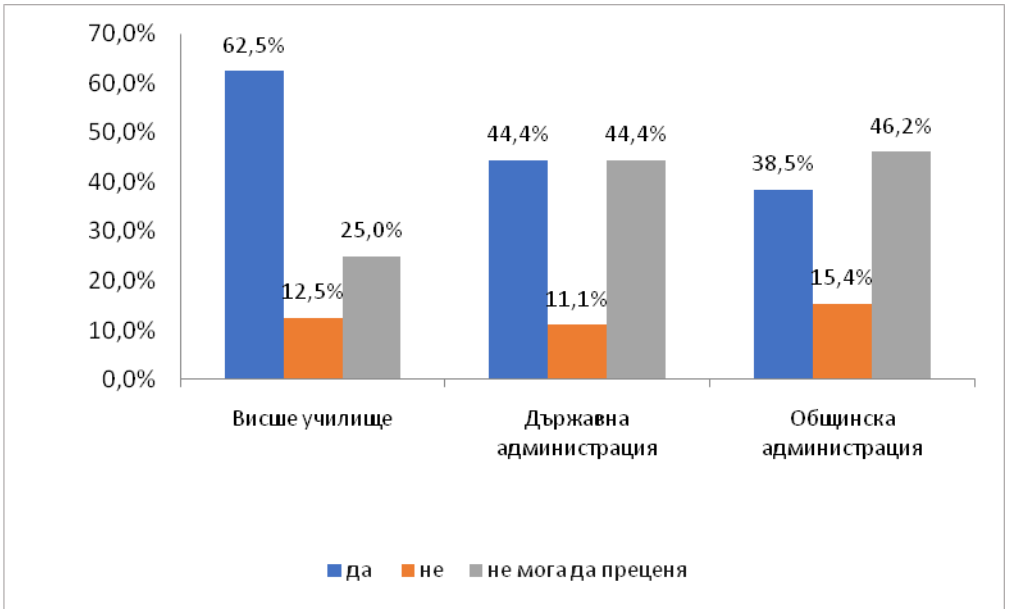


Fig. 11. Adequacy of the nurse's basic knowledge and skills (comparative data)

We studied to what extent experts' workplace affected their opinions on nurses' basic training (Fig. 12).



Фиг.12. Adequacy of the nurse's basic knowledge and skills (experts from Higher School, Social Assistance Directorate and Municipal Administration)

We found out that there were no statistically significant differences in the answers. Similar opinions on nurses' training was registered by representatives of various institutions (n=30, χ^2 =13213, r= 0.190).

Of interest are the opinions of the three groups of respondents – specialists, students and experts on the need for the nurse to have further specialisation in 'Nurse for social activities, to provide integrated services (Table 18).

T*able 18. A need for specialisation in 'Nurse for social activities'*

(comparative data)

answers	Specialists		Students		Experts	
	n	%	n	%	n	%
Yes	68	22,0%	43	28,7%	9	30,0%
Rather yes	112	36,7%	63	29,3%	15	20,0%
I cannot say	120	38,3%	44	42,0%	6	50,0%

Working with children with disabilities has a specific character, requires

extra knowledge, skills, not only regarding the care of these children but also regarding knowledge of regulations in social care. Acquiring a speciality is associated with mastering specific knowledge and skills needed to provide health care to certain groups of people. Half of the experts, 38.3% 42,0% of the students cannot decide whether further specialisation is needed for the nurse to work in integrated services. Specialisation is important to 1/3 of students and experts and 22,0% of specialists. As a result of mutual work, the specialists feel further specialisation is needed.

Acquiring a speciality is done under Decree 1/22.01.2015. Specialisation is done by the departments of Post Graduate Training with medical universities [69]. Speciality requirement is not regulated in Rules and regulations, applying to professional activities for which further qualifications are required.

Before the Decree on Specialisation was introduced in 2007, a change was made to the curriculum for the regulated profession "Nurse", according to the Unified State Requirements for higher education in "Nurse" and "Midwife" for Bachelor's degree [69]. Following the changes, the discipline ‘Practical Basics of Nursing Care’ was introduced, in which from the third to the sixth semester 14 subdisciplines are studied. Among them are:

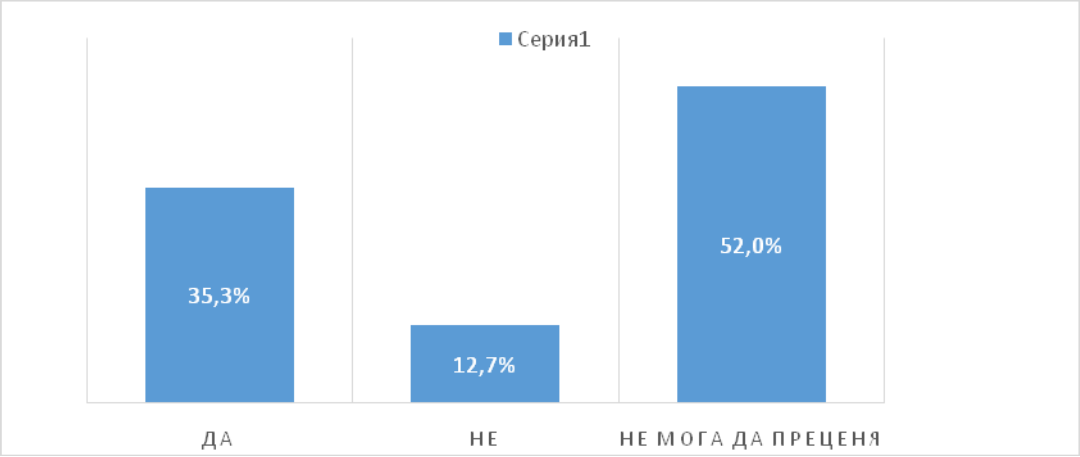
- ✓ **"Nursing care of children and adults with disabilities"**
- ✓ with a total workload of 60 academic periods (20 academic periods of theory and 40 academic periods of practice), which is studied within two semesters (third and fourth). The course aims to provide knowledge and skills in nursing, aimed at people with various types and degrees of disability.
- ✓ With a total workload of **60 academic periods** (20 academic periods of theory and 40 academic periods of practice) studied in two semesters (third and fourth). The discipline is aimed at teaching knowledge and formation of skills in nursing, aimed at people with various types and degrees of disability.

- ✓ **Nursing care at home**
- ✓ With a total workload of **60 academic periods** (20 academic periods of theory and 40 academic periods of practice) studied in two semesters (fifth and sixth). third and fourth).

When attending clinical practice sessions at Homes for Medical and Social Care of Children/Centres for Comprehensive Service of Children with Disabilities and Chronic Diseases, care homes, Daytime centre for children with disabilities, students can see the nurse's activities, comprehensive care provided to children.

Under the curriculum for Nurse, these two disciplines have one of the highest workloads; that is a prerequisite for good basic training in the care of children with disabilities and those provided at home. During their basic training through the disciplines studied, nurses acquire knowledge and practical skills about the specific character of working with children with different types of disabilities, their parents, implementation of communication techniques.

We studied for this research graduates' attitudes to professional development in the care of children with disabilities and their families based on acquired knowledge and skills during their training (fig. 13).



Фиг.13.readiness to work in integrated services

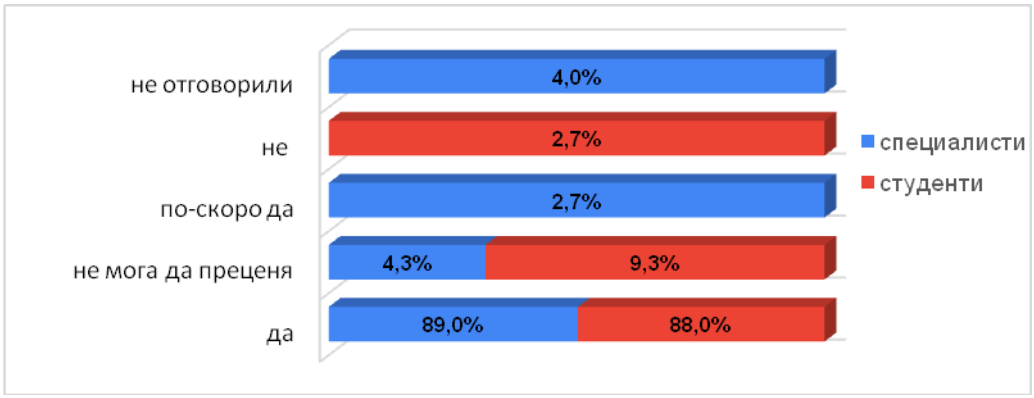
Despite the emotional burden and difficulties they are facing in communicating with the children and their parents during their practical training, 35.3% of the students say they are ready to begin working in integrated services.

Currently, more than half of the students do not have an opinion.

Working with children with disabilities is very specific and requires additional knowledge, and skills not only with regards to care of these children but also knowledge of regulations in social care. The adoption of Strategy for Equal Rights for People with Disabilities (2008-2015), is based on: „establishing a system for permanent training and enhancing qualifications of the staff at specialised institutions for children and people with disabilities to implement the modern standards for medical and social care' [75].

An important element of the nurse's professional practice is updating knowledge and skills and their constant expansion. According to M. Alexandrova 'the rapid development of all branches of science, in medicine and medical technologies as well, necessitates permanent training of health specialists' [2].

We sought the opinions of specialists and students on the need to sustain and improve the team's knowledge and skills to improve the quality of work (Fig. 14).



Фиг. 14. A need to update and improve the team's knowledge and skills (comparative data)

Training is key to the success of integrated services.

The relative share of positive answers is almost identical with both groups of respondents (89% with specialists and 88% with students). A very small share of specialists (4.3%) and 1/10 of students have no opinion on the need for sustaining knowledge and skills.

We studied for this research to what degree the professional experience affects specialists' attitude to sustaining training (fig. 15)

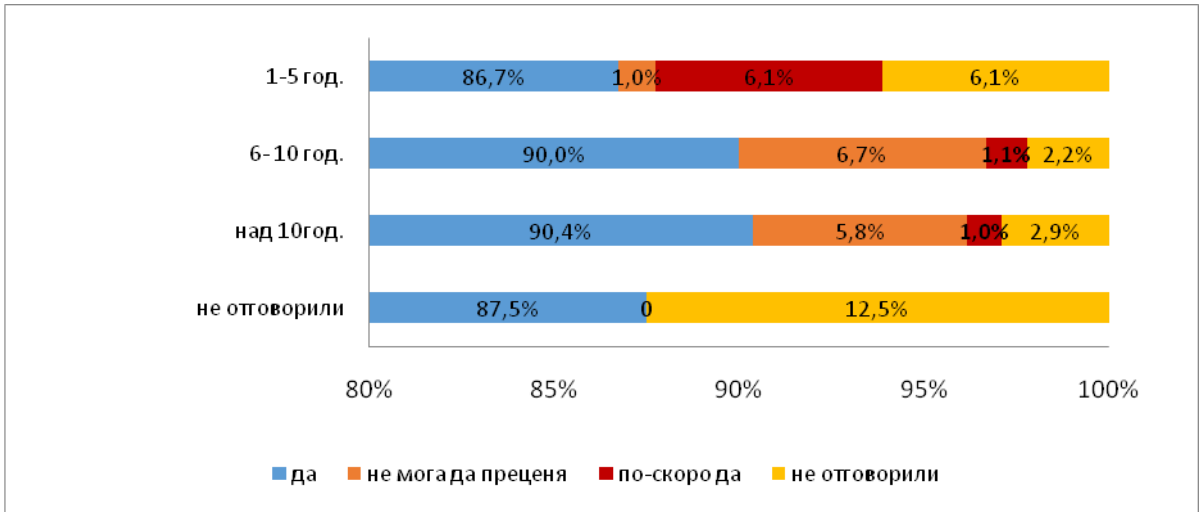


Fig. 15. A need to update and improve the team's knowledge and skills (according to specialists' length of experience)

We found out that there is no statistically significant difference in the answers. Respondents' opinion on sustaining nurses' training does not depend on the length of professional service (n=300, χ^2 =14.681, r= - 0.071).

It was important to us to find out whether education affects respondents' attitude to sustaining training (table 19).

Table 19. A need to update and improve the team's knowledge and skills (according to specialists' degrees)

Degree	yes	Rather yes	I cannot say	No answer
Bachelor **n= 194**	86.6%	3.6%	5.2%	4.6%
Master **n=56**	91.1%	0	3.6%	5.4%
Both **n=43**	97.7%	2.3%	0	0
No degree indicated **n=7**	88.7%	0	14.3%	0

The results show there is no statistically significant difference in the answers. Respondents' opinions on sustaining training does not depend on the

degree of education (n=300, χ^2 =9.165, r = - 0.103). The insignificant inverse correlation dependence means the answer of respondents whose education is lower or those who have not indicated their education is 'I cannot say'; their percentage is higher than those with higher education.

Of particular importance are the opinions of experts on the need to sustain the entire team's knowledge and skills. We see here an undeniable result – 97% of them have pointed out this is necessary. This opinion is shared by representatives of universities, municipal administration, Ministry of Labour and Social Policy, National Agency for Child Protection which organise a large part of training courses and scientific forums (Fig. 16).

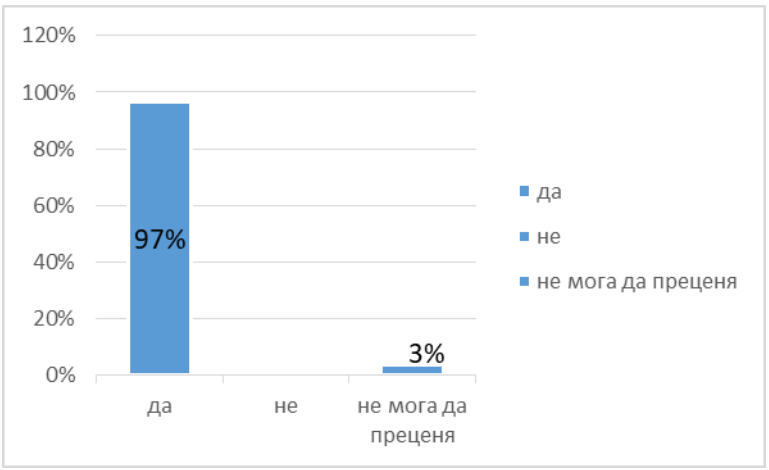


Fig. 16. A need for updating and improving the team's knowledge and skills (according to experts)

Specialists' opinion on the need to conduct sustaining training of teams can be perceived as the pursuit of self-improvement. The pursuit of personal self-improvement can be associated with the formation of attitudes to education and self-education. T. Popov (2006) points out that 'continuous education aims not only to master and expand knowledge and skills, needed for the new stages of the development of science and manufacture but also personal and cultural development' [2].

Post-graduation qualifications include various training forms which enable

knowledge update and efficient overcoming of difficulties that arise in the course of providing integrated care.

When discussing the possibilities of sustaining the knowledge and skills of the nurse in integrated services, we have to bear in mind that specialists from the social sphere and education participate in this process. This is why quite often training can be conducted in the form of team meetings for exchanging know-how and advice or sessions for feedback between cooperating partners. In this way, participants will be able to learn from one another by identifying the best practices and lapses.

We studied which form specialists prefer to sustain their knowledge and skills (Fig. 17).

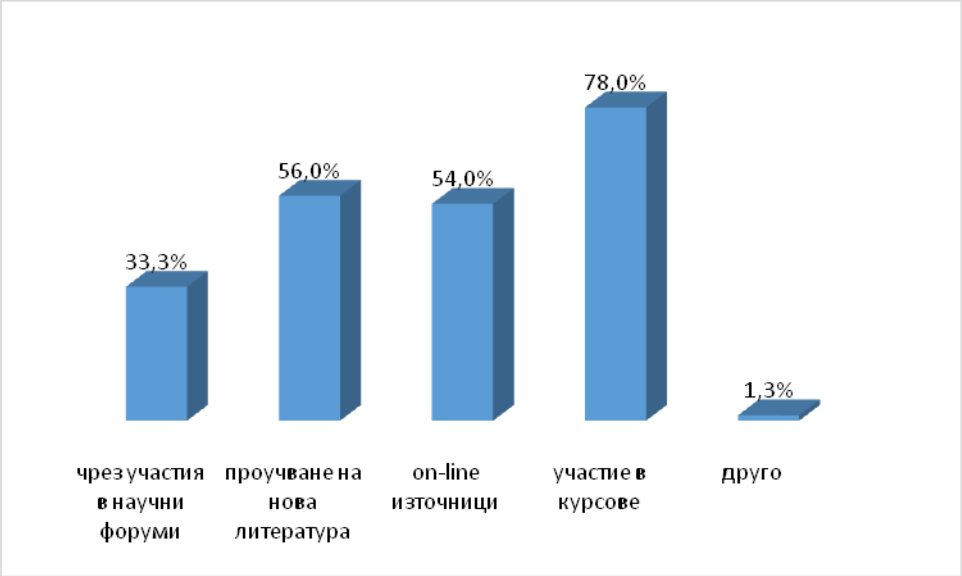


Fig. 17. *Methods of updating specialists' knowledge and skills*

* % exceeds 100, as respondents have given more than one answer

The design of the research allowed respondents to point out more than one answer. Course participation as a way of sustaining and improving knowledge have been preferred by almost 2/3 of specialists. Studying new literature and using online sources are preferred by over 50% of specialists. Distance training is gaining in popularity compared with traditional contact forms. Participation in scientific forums as a form of sustaining knowledge and skills is preferred by just 1/3 of the

people working in integrated services.

The need for permanent training and knowledge, skills and experience update cannot be denied. In most European countries follow-up medical education is obligatory. Nurses in most cases upgrade their knowledge and skills by their own will. Responsibility for medical specialists' professional development and adaptation under the Labour Code is with the employer who is supposed to introduce the principle of permanent training and development of all employees, and turn it into a standard for higher professional development.

2.5. The Parents - Part of the Team Providing Integrated Care

Nowadays more parents take on the care of their child with a disability. The changes overtaking them are quite important, and they need support to be able to accept these changes and deal with the difficulties, as well as credible and accessible information. Care of children with disabilities take a lot of patience and psychological attitudes from parents so they can save their health and take adequate care of the child. *"children are a battle of a different kind..a battle without flags or war horns, but no less furious' George Martin.*

The family is a constant value in the child's life, they are the most important factor in its life, which influences its development. In our work with families, it is crucial to emphasise their strengths which can be used as a resource to satisfy their needs. To ensure adequate support, specialists should be familiar with the processes the family are experiencing and show respect for their religion, language, customs, social and cultural level. Each child has its individuality as an overall condition and potential which predetermines its specific needs. When a child feels protected by the adult, this gives it a sense of support by the adult, it learns to cope with its everyday challenges. Stable and caring interrelationships in the family are vital to the child's right development.

The relationship between the professionals who have expert knowledge of child care and parents is a potential for implementing the family-oriented approach.

Having in mind the variety of families –in terms of family models, family relationships, material, spiritual and social capital, individualising the care as a means of efficient communication with the parents is key.

We sought information for our research from the Agency for Social Assistance about the number of children with disabilities during the 2018-2020 period in the districts included in the research (Table 20).

Table 20. number of children with disabilities assisted under article 8 of the Law on Social Assistance

Information about the number of children with disabilities assisted under article 8 of the Law on Social Assistance			
Districts	**2018 година**	**2019 година**	**2020 година**
Veliko Tarnovo	794	810	827
Gabrovo	586	611	610
Lovech	935	856	728
Rousse	712	705	694
Silistra	402	389	392
Districts	**3429**	**3371**	**3251**

((*the information has been provided by letter .№ 944-00-0108#1/ 25.05.2021 by the Agency for Social Assistance

We sought information for our research from the Agency for Social Assistance about the number of children in the districts we studied who are placed under protection under the Child Protection Act (Table 21).

Table 21. number of children with disabilities, placed under protection under the Law on Protection of Children

Information about the number of children with disabilities who have been placed under protection under the Child Protection Act			
Districts	2018	2019	2020
Veliko Tarnovo	29	41	26

Gabrovo	15	12	10
Lovech	13	12	4
Rousse	15	12	10
Silistra	16	9	13
Total	**88**	**86**	**63**

(*the information has been provided by letter .№ 944-00-0108#1/ 25.05.2021 by the Agency for Social Assistance

Unlike some other countries, in Bulgaria, there is no full statistical information base of indicators in child wellbeing. This is one of the major deficits preventing information justification on which the policies on children and families should be built.

It was important to us to find out the relative share of children with disabilities in the districts we studied. We checked data at the National Statistics Office on the child population in the Northern Central Region. The summary is made by the author based on data received from the Agency for Social Assistance and the National Statistics Office (Table 22).

Table 22. the relative share of children with disabilities in the investigated districts for 2020.

Districts	**The overall number of the child population**	**Children with disabilities n**	**Relative share %**
Veliko Tarnovo Търново	39 366	853	2.16%
Gabrovo	16 468	620	3.76%
Lovech	22 157	732	3.30%
Rousse	36 344	704	1.94%
Silistra	19 659	405	2,06%

According to the data, we can sum up that in 2020, the children with disabilities in the districts studied by us make up 2.52% of the child population in the Northern Central Region.

Part of the disabilities can be established right after birth. Others emerge later in the child's development and their manifestations may not be so visible

enough to point to a disability that necessitates intervention. The difficulties arise when these manifestations break into the parents' idealised world and hopes for their child. And here comes the question of how and who should test the child to find out whether specialised support is needed. The role of the system of health care is key to recognising and identifying and accompanying the problems of a child with special needs at an early age.

We studied the parents' opinions on the age at which the problem in the development has been established (Fig. 18).

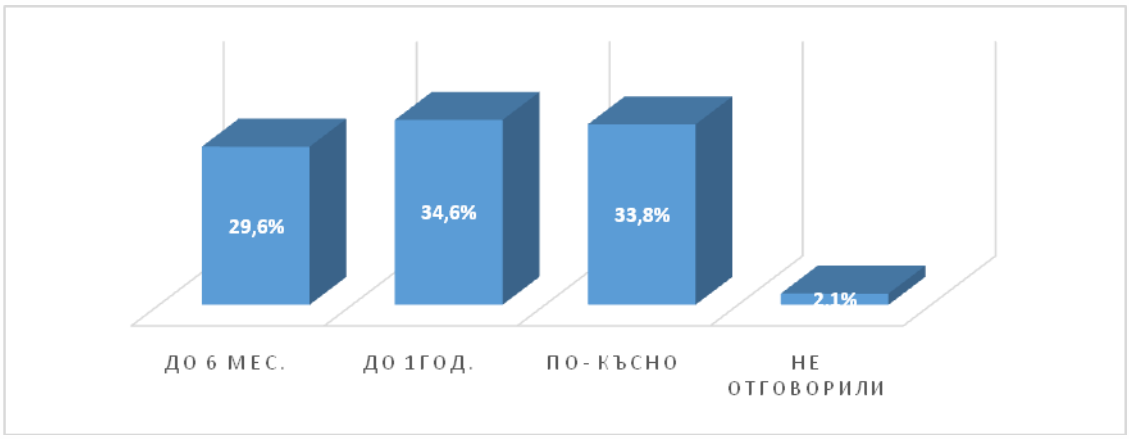


Fig. 18.age of the children when the parents established deviation from the development

Unfortunately, only 1/3 of parents discover a deviation from the development up to the sixth month. The share of families who have established a deviation to the first year. (34.6% and at a later stage, 33.8% of the respondents established this.

These results mean that the parents need to have preliminary knowledge of the indicators of the physical, neurological and mental development of the child during the first year.

Along with the disability, with a part of the children are observed other accompanying diseases and medical problems which have to be discovered in time, to plan adequate care.

This in its turn outlines the need to refer children to multidisciplinary teams. In Bulgaria, there are no such teams that familiarise themselves with the child's problem and draw up a plan to resolve it. To overcome the obstacles to accessing modern health care and the development of mobile services, the Ministry of Health made changes to the Medical-Treatment Facilities Act in 2015 by which a new type of medical establishment was set up. Centre for Comprehensive Services for Children with Disabilities and Chronic Diseases (CCSCDCD). This is a key moment because it brings to the fore the problem of 'the universality of the health service which guarantees unlimited access to it for each family of a child with special needs. These centres are opened in place of the former Homes for Medical and Social Care of Children, most of them are allocated in district cities.

A top priority for the families of children with disabilities is the need for accessible highly specialised help for diagnostics and treatment. We studied for this research the parents' opinions on the obstacles they are facing (Fig. 19).

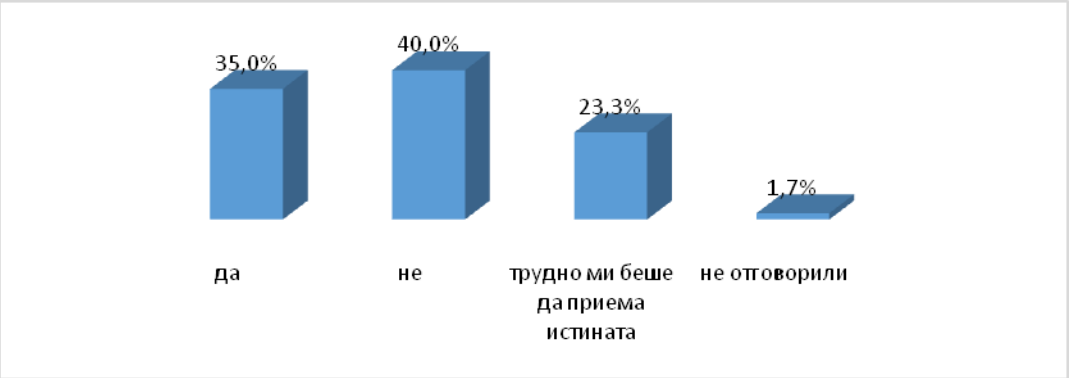


Fig. 19. Obstacles to parents accessing highly specialised help

The analysis of the results showed that the relative share of parents who have answered negatively is the highest (40.0%). Over 1/3 of respondents have had difficulties accessing highly specialised help. Accepting the truth has been a problem for almost 1/5 of the parents (23.3%).

The parents do not want to agree that their child has a problem, whether it is behavioural or medical. They are not always ready to realise the problem with the child because society perceives the disability as a stigma and deficit. Often they reject/deny the disability, citing that 'Specialists do not understand a thing'. The absence of cooperation on the part of the parents results from that same shame, hiding the problem from 'others' and isolating themselves in the family.

To reveal the problem of families with children with disability, it was important to us to find out whom they receive the most help and support from (Fig. 20).

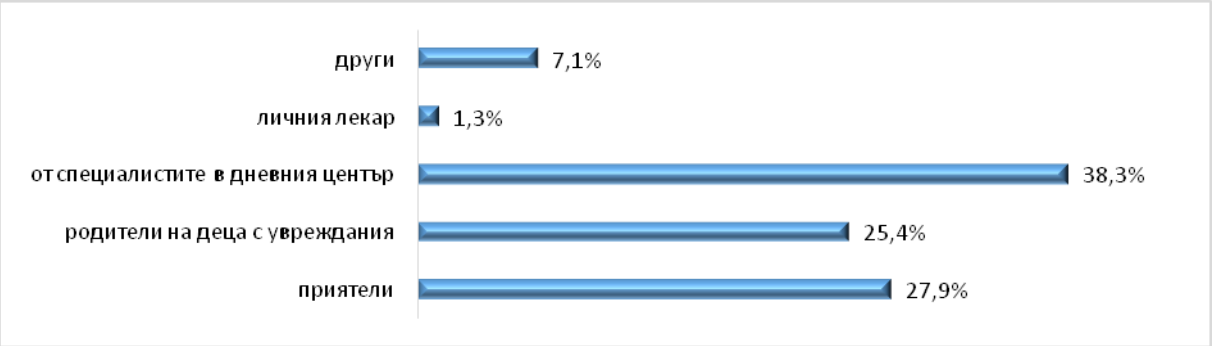


Fig. 20 Help and support for parents

Over 1/3 of parents (38.3%) rely on the daytime centre. We believe that this is due to the social services available for children with disabilities and the timely information and referral of parents to them. The share of parents of children with disabilities (25.4%) and friends (27.9%) who support them are almost equal. Curiously, 7.1% have pointed out other sources – *books, the Internet, family, and some say they will cope with the situation themselves.*

The share of parents who rely on help from the GP is considerably low (1.3%). The parents are convinced that the doctor's and nurse's role is just to cure the purely physical condition, and everything else should be left to other specialists.

We should note that the doctor has a key role in cooperation with other specialists. Very often doctors lack sensitivity and attention to the child's mental development to 3 years, which in itself results in lapses in discovering behavioural, linguistic and speech disorders which are hard to prevent at a later stage of the child's development.

In the course of the child's development, various age-related mental and physical changes happen and this requires information and advice on everyday care. Parents can obtain this kind of information from different specialists. We studied for this research the parents' preferences for specialists they would trust to train them to take care of the child (Table 23).

Table 23. parents' opinions on the MDT members that provide training.

MDT members	Parents n	%
Specialist doctor	143	59.6
Nurse	152	63.3
Day-time centre rehabilitator	146	60.8
Parents of children with disabilities	97	40.4
Do not need training	10	4.2

**** % exceeds 100, as respondents have given more than one answer***

Parents prefer to be trained by a doctor (59.6%), nurse (63.3%), rehabilitator (60.8%).

Preferences for the nurse as a partner in child care are due to her uniqueness which builds up in the process of mastering knowledge, acquiring skills and formation of specific behaviour [112]. The nurse is no longer considered to be just a medical performer but also an active participant in the team with her autonomous functions and responsibilities.

The transition to specialised knowledge of raising the child by specialists to parents goes through building trust and compassion. A very important moment in the process of interaction is for the parent to allow the specialist to be close to

them and the child and accept the fact that the child has a problem that they can resolve together.

The birth of a child with a disability is associated with negative emotions in the family and requires professional help and training. To do this, the parents' attitudes should change towards acquiring knowledge and skills. The first step the parent should achieve is to allow the specialist close to him/her and the child. The consequences of parents' unconscious roles can be seen today - parents who do not take their children to check-ups and conceal the children's problems until the situation spins out of control.

This is particularly important to health care when the parent's low health culture becomes a barrier to his/her child's timely treatment.

A child with a disability in the family requires the efforts of the parties involved to be directed towards help and support to the entire family. We studied in this connection to what extent the parents can work in their professional field (Fig. 21).

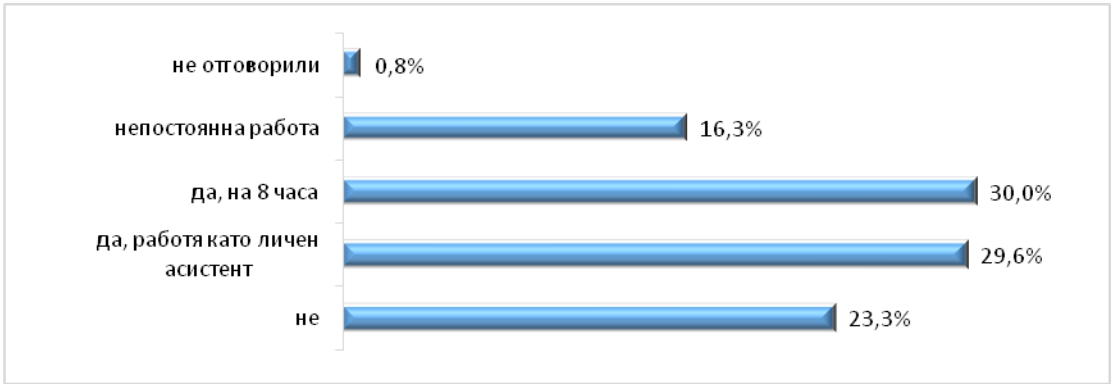


fig. 21. Parents' employment

The results show that ¼ of parents do not work, whereas more than half of them (60%) work. The fact that 30% of the respondents work 8 hours, almost as long as personal assistants is indicative enough.

We think these results are due to various factors, such as the type and degree of the child's disability, ability to attend school and accompanying services, supporting family environment. The care of a child with a disability is associated with financial means which is a major financial burden to some of the parents.

When we talk about the problems, we should have in mind that they are not just for the child and the parent but also the family as a whole. Raising a child with a disability is a physical, emotional and financial burden, and arguably causes serious negative emotions in each family [76,77]. To change their attitude and lifestyle, they need professional help and training.

One way for parents to cope is to organize sharing meetings in groups that they create.

Organising sessions for sharing in groups that they set up themselves is one of the ways for parents to deal with the situation. At their request, external lecturers can be invited - eminent medical specialists, representatives of organisations of parents of children with disabilities. MDT members too can suggest the organisation of these sessions. Important support to the family is if they are encouraged to communicate with other families who have children with disabilities, and in this way, they will understand that they are not alone, will learn how to share their problems and deal with difficulties more easily. It is advisable, with the help of a specialist, if there is another child in the family, to encourage and motivate it to get involved in the care.

It was important to poll the opinions of parents on the institutions that pose the most common difficulties with the service (Fig. 22).

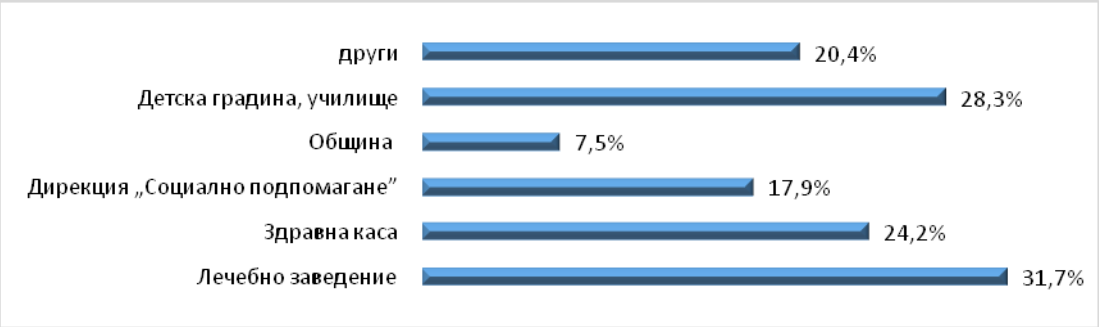


Fig. 22. work with institutions

**** % exceeds 100, as respondents have given more than one answer***

The results show that more than 1/3 of parents face problems with Medical-Treatment Facilities. The specific character of working with children with disabilities definitely requires further training of nurses to provide specific care and meet individual needs [106].

Despite efforts to regulate integrated services in the Health Act, there is virtually no shared concept between the three key ministries (Ministry of Health, Ministry of Education and Ministry of Labour and Social Care) on how they should be developed and regulated.

The health care system has a huge potential to help child development for all children in the community and through adequate sectoral services that realise an integrated approach, while integrated services are an important element regarding children with complex needs.

The care of people with various disabilities should not be considered a responsibility only for public institutions. The efforts should be directed towards establishing NGOs that aim to assist children and their families, and that is a prerequisite for more alternative solutions. The experience of many countries shows that parents feel more secure and stronger when they are within the structure of the organisation in question.

2.6. Barriers to Introducing Integrated Care

We looked at international practices and programs for integrated services and did not find a single and generally adopted concept model, practice or

program for them. Although the common aims are the same in the individual countries, the activities done for their achievement are different. Bulgaria is at the start of approving a similar integrated approach. The factors that encourage or hinder development have also been discussed by many authors and politicians. There are multiple microenvironmental factors such as legislative, financial and political that influence the organisation and development of integrated services. It appears that the number of unfavourable factors outweighs the favourable ones.

The factors discussed are taken into account when developing and introducing the services. There are various models of providing services but the common thing is connecting structures, financial and human resources, information and knowledge aiming to improve care and allocation of the economic resource. It was important to us to poll the opinions of specialists, students and parents on the existing barriers to introducing integrated services (Table 23).

Table 23. barriers to introducing integrated care

Barrier	**Specialists**		**Students**		**Parents**	
	n	**%**	**n**	**%**	**n**	**%**
Lagging behind the legislation on the actual development of care	**134**	44.7 %	**70**	46,7%	**121**	50.4%
Complicated and unwieldy rules and regulations	**168**	56%	**60**	40%	**157**	65.4%
Unclear sources of financing and mechanisms for paying for integrated care	**168**	56%	**55**	36.7%	**114**	47.5%
Absence of well-trained staff in integrated care	57	19%	52	34.7%	40	16.7%

Inadequate cross-sectoral cooperation initiatives	**135**	45%	29	19.3%	**89**	19.3%

**** % exceeds 100, as respondents have given more than one answer***

According to ½ of specialists, students and parents, one of the reasons for the barriers to the introduction of integrated care is because legislation is lagging from the actual development of care. A relatively high share of parents – 65.4% and almost half of specialists see complicated and unwieldy rules and regulations as the main barrier their children are facing. Unexplained sources of financing and the mechanisms of paying for integrated care according to ½ of parents and specialists impede the introduction of integrated care.

The link between social services, funded by the state and services funded from municipalities' revenues will be a key point in implementing the new legislation.

The partnership requires qualified talks, a clear purpose and sometimes compromises. With the adoption of the changes to the Medical-Treatment Facilities Act, non-profit legal entities registered at the Agency for Social Assistance will be able to do social work and provide health care, including home environment, in support of children, pregnant women, people with disabilities and chronic diseases who need support in doing their everyday activities.

Unlike the existing practice in the world, the Bulgarian sector of social services is dominated by public providers.

We believe that the challenges the government is facing, are associated with synchronising regulations as the Ministry of Labour and Social Policy, Ministry of Education and Science, Ministry of Health, Ministry of Finance are involved in providing integrated services. With the introduction of the new Social Services Act, changes are envisaged to the Health Act, Medical-Treatment-Facilities Act

and Health Insurance Act, which stem from the new regulation on social services and close down of Homes for Children, including Homes for Medical and Social Care of Children.

3.1 PROVIDING CARE TO A CHILD AT A CENTRE FOR COMPREHENSIVE SERVICES FOR CHILDREN WITH DISABILITIES AND CHRONIC DISEASES

Social policy, social services and institutions in Bulgaria are dynamic and developing systems that are transformed constantly. The course of the social policy carried out is directed towards effective deinstitutionalisation.

In Bulgaria, the care of children with disabilities and chronic diseases are provided partly by the health care system and the system of social assistance.

An addition to the Medical-treatment Facilities Act in 2015, *a new type of medical facility was regulated –a Centre For Comprehensive Services For Children With Disabilities And Chronic Diseases* [32].

Establishing this type of medical facility aims to meet the needs for comprehensive care of children with disabilities and chronic diseases, improve their health status, guarantee their access to all necessary medical care and social services, without institutionalising them.

The institutional organisation of life does not presuppose a confidential relationship with a permanent adult, individual care, attention and personal space for the child. It cannot satisfy the basic needs of children and harms their development and behaviour. This in its turn leads to extra-economic and social costs for the whole society.

For this reason, and in the child's best interest from 2009, following changes to the Child Protection Act, accommodation at an institution is undertaken only when all other measures have been exhausted.

The National Strategy 'Vision of Children's Deinstitutionalisation in the Republic of Bulgaria', adopted in 2010, envisages that all Homes for Medical and

Social Care for Children as institutions for raising children should be closed down, and create alternative services and forms of care in the community, helping to raise children in the family. In this connection, in 2019, the Social Services Act was adopted which regulated the close-down of all Homes for Medical and Social Care for Children as of January 1, 2021. An exception is allowed only to four institutions.

We prepared a report for our study on the number of children accommodated in the Homes for Medical and Social Care for Children during the 2010-2021 period (Table 24).

Table 4. movement of children at Home for medical and social services for children during the 2010-2021 period.

Year	Number of Homes for medical and social services for children	Capacity	Accommodated	Received
2010 г.	32	3854	2455	2209
2014 г.	29	2199	975	1041
2019 г.	13	809	454	650
2021 г.	4		277	0

Source: National Statistics Office – Homes for the medical and social care of children

During the period of deinstitutionalisation in 2010 to this moment, the following alternative forms for children with disabilities were established:

- Foster care - data from the Agency for Social Assistance show that the number of foster parents in Bulgaria as of 2021 is 2227.
- Centre For Comprehensive Services For Children With Disabilities And Chronic Diseases – it will eliminate the need to accommodate

children up to 3 years at institutions. The following activities will be done at the innovative medical facilities:

- Support to families of children with disabilities and chronic diseases for assigning and making early diagnostics, treatment and medical and psychological and social rehabilitation;
- Ensuring visits by medical specialists for the specific care of children with disabilities and severe chronic diseases, raised in the family and a residential type of service.

3.1. Multidisciplinary Team Care at a Centre for Comprehensive Services for Children with Disabilities and Chronic Diseases

Based on analysis of the current regulations and our clinical experience, we developed **the Model for Multidisciplinary Team Care of children with disabilities** at a Centre for Comprehensive Services for Children with Disabilities and Chronic Diseases, by applying multidisciplinary team care of children with disabilities and their families (Fig. 23).

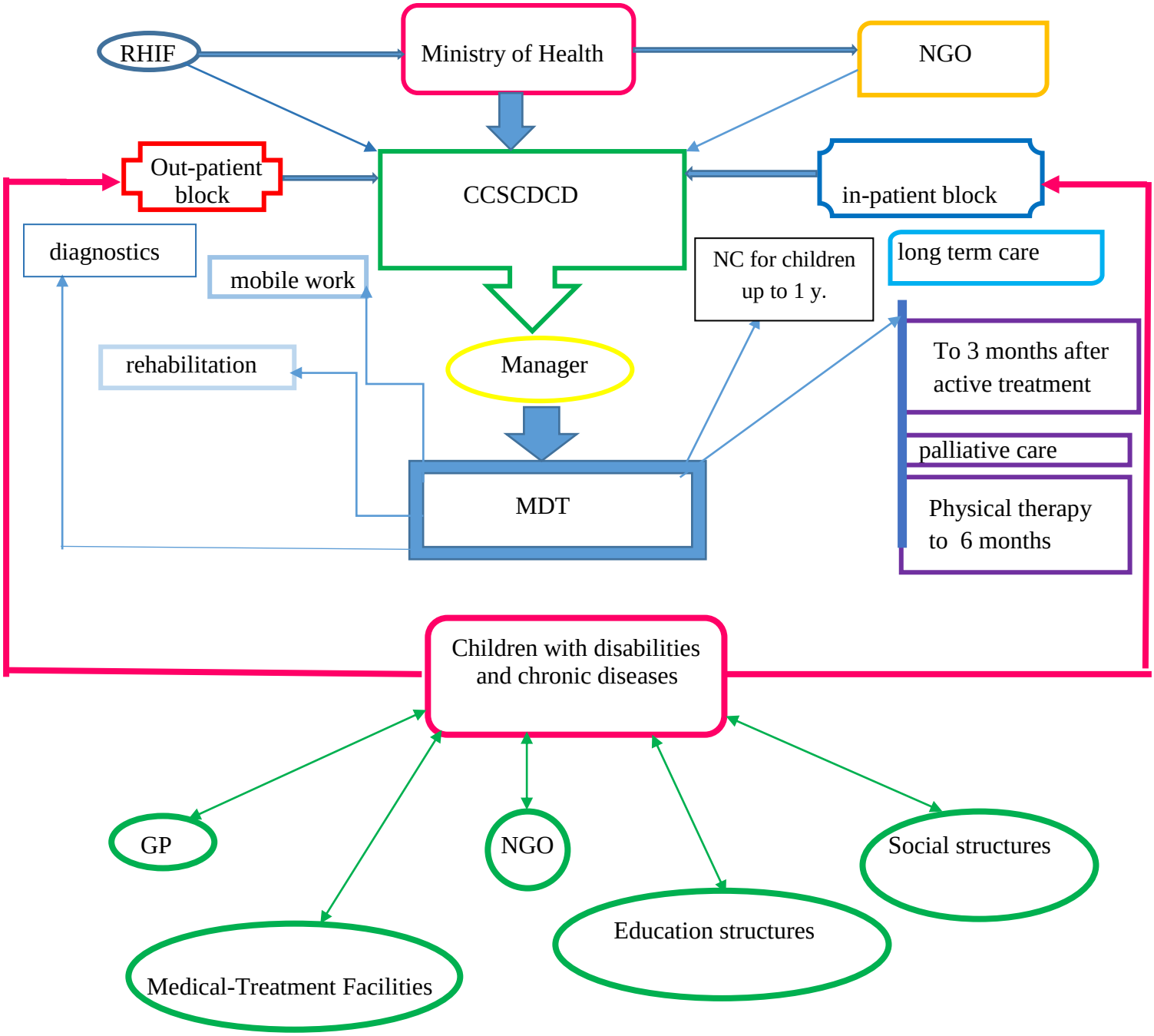


Fig. 23 Model for multidisciplinary team care of children with disabilities (structure and interaction) at a Centre for Comprehensive Services for Children with Disabilities and Chronic Diseases

The model we propose unifies structural, human and information flows aimed at providing integrated care of the children with severe disabilities, support to the parents and preventing institutionalisation. The model includes both a

clinical aspect – early diagnostics, diagnostics, treatment, medical and psycho-social rehabilitation and managerial, organisational and information aspects.

The MDT ensures diverse and complementary care, ensures an environment with clear roles, shared responsibility and a possibility of professional autonomy. Including various specialists in the team guarantees magnitude. The main team includes a doctor, psychologist and a social worker. Depending on the specific case, other specialists can be included (rehabilitator, kinesiotherapist, speech therapist, educator and musical educator).

To realise its activities, the team works in close cooperation with GPs, paediatricians, educational, social institutions and NGOs.

As nursing science and practice develop, the nurse's role and function change. The nurse's professional activity is regulated by delegated and sub-delegated acts for professional qualifications, legal capacity and membership of a professional organisation recognised by the state [33,67,68,69,70,82].

The nurse provides quality and comprehensive care by applying scientifically substantiated methods and approaches in all structures of the healthcare system. Decree 1 of the Ministry of Health, dated February 8, 2011, describes the professional activities that nurses, midwives and related medical professionals and health assistants can perform on assignment or independently. The requirements for the nurses' professional activity are updated constantly. To the traditional requirements are added: applying modern knowledge and scientific proof; clinical thinking and a critical analysis of activities and the results of their application in human health; care management; taking on responsibilities for professional actions and risk management; active communication; effective team interaction; pursuit of autonomy within capacity; pursuit of personal and professional development.

Our research has proven some more important skills (see table 17) and has outlined the competence the nurse should possess to work at a CCSCDCD (Table 24).

Table 24. *the nurse's skills and competence in providing integrated care at the CCSCDCD*

Nurse's skills in the MDT	Nurse's competence in providing integrated care at the CCSCDCD
✓ *clinical thinking;* ✓ *organisational skills*; ✓ *communications skills*; ✓ *skills in teamwork*; ✓ *adaptability and attitude to working with children with disabilities and their families*; ✓ *skills in analysing, synthesising information and submission of results;* ✓ *ability to make accurate decisions in various situations;* ✓ *to demonstrate initiative, tolerance and loyalty to the users of the services and team members;* ✓ *skills at forming an attitude, behaviour and values to the profession, themselves and the community*	✓ *to implement the family-oriented approach;* ✓ *to plan child care together with the parents;* ✓ *to work independently and with other team members;* ✓ *to participate in the multidisciplinary team in preparing the individual assessments of the need for support and the individual support plans* ✓ *to know the enactments associated with her activity and;* ✓ *to abide by the rules of good medical practice;* ✓ *to know the stages of physical and mental development of the children and young people, and in particular, in the event of a disability, associated with the mental health and intellectual development* ✓ *to conduct training of the child and parents on health subjects;* ✓ *to consult and refer the parents to specialists;* ✓ *to provide mobile services;* ✓ *to abide by the code of ethics for work with children;* ✓ *to participate in training sessions, supervision and team meetings.*

We offer meaningful aspects of the nurse's functions in the MDT in the CCSCDCD (Fig. 24).

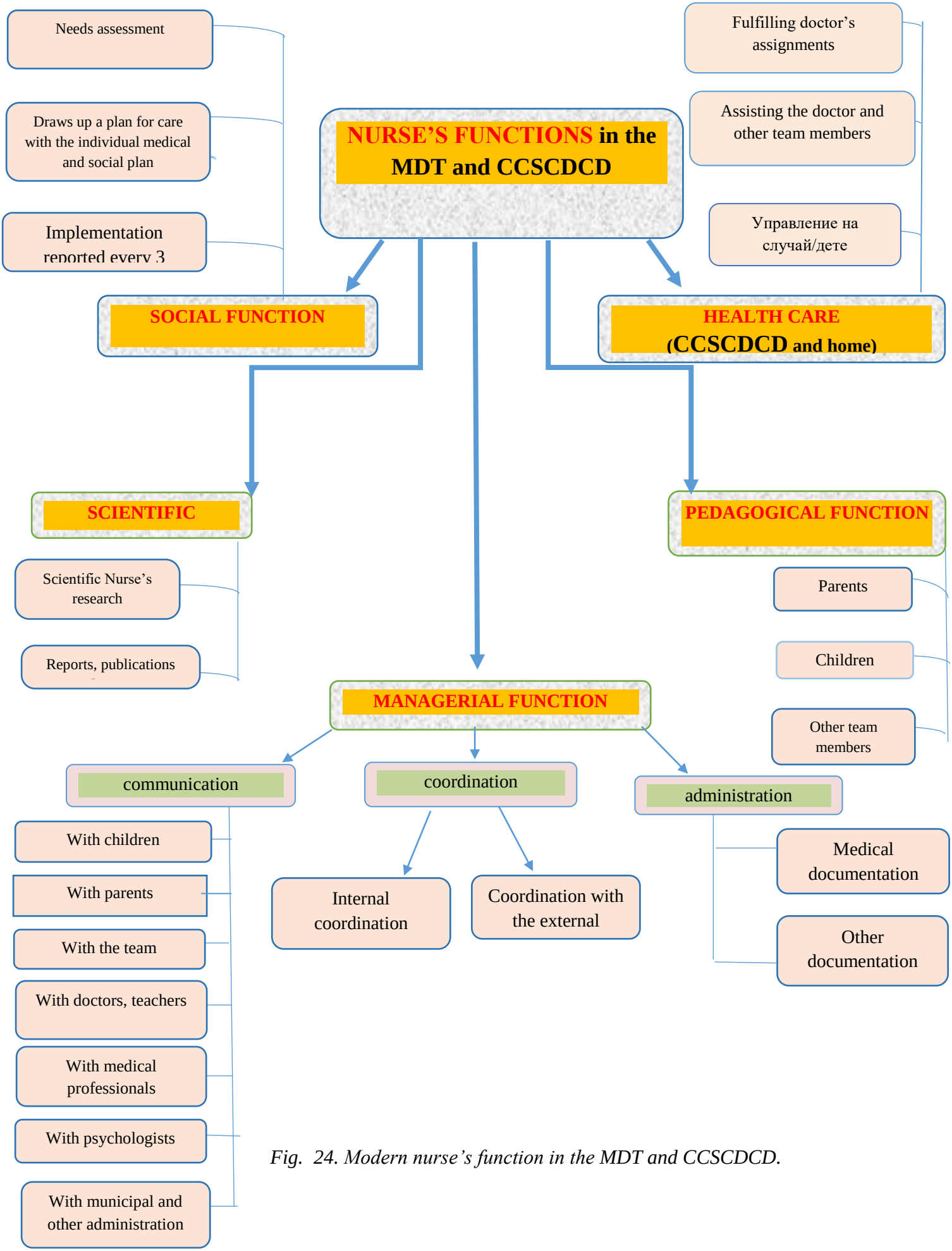
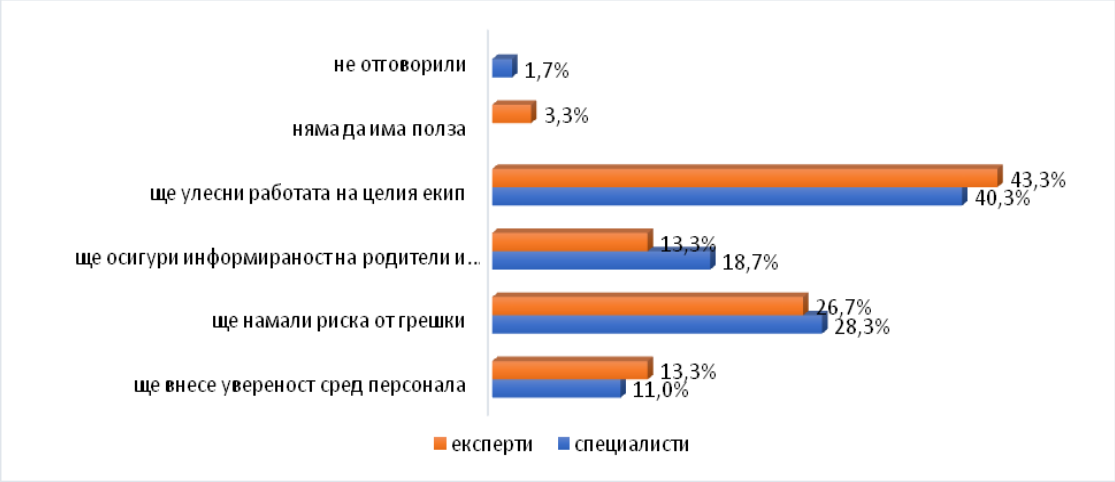


Fig. 24. Modern nurse's function in the MDT and CCSCDCD.

The determined competence adds new meaning and form a new attitude to the profession. To realise her unique professional role, the nurse can alone or in a team with a doctor provide comprehensive care (activities) for all aspects of human health.

Based on the existing regulations and our clinical experience, we developed and propose an Algorithm for the nurse's action at the CCSCDCD. We propose specific steps and interrelations which could facilitate the specialists' work in the individual units of the Centre, they will reduce the risk of mistakes and will ensure better awareness to parents. The proposed algorithm has been described in detail In the dissertation. We have specified the nurse's activities in the out-patient and in-patient block when providing mobile services.

We studied the opinions of experts and specialists working in integrated care regarding the effect of introducing an algorithm for the nurse's work in the individual units of the CCSCDCD (Fig. 25).



Fig, 25. The effect of introducing an algorithm for the nurse's work at the CCSCDCD (comparative data)

¾ of respondents believe that introducing the algorithm will facilitate the team's work and will reduce the risk of mistakes. According to the specialists (18.7%) and experts (13.3%), it will ensure parents' awareness and specialists, involved in the care of children with disabilities and chronic diseases. The statistical surveys suggest that there is no statistically significant difference in the answers of the two groups of respondents - χ^2 =11,046, n=330, p<0,05,r= 0,004.

For this research, and after a survey, we conducted of the regulations and an analysis of the poll, we propose **a model for the nurse's job description** who works in integrated care. It combines traditional values and modern aspects of the nursing profession. The model we propose streamlines the job description that existed so far as it does not take into account the possibility of the nurse's independent work. We pointed out the work characteristics, the nurse's main duties, skills and competence she should possess to work in integrated care, the main regulations she should be familiar with, interactions she performs with others working in integrated care, families of children, with various organisations – state, municipal – NGOs.

In the course of this research, the need for developing an information brochure for parents, specialists involved in the care of children with disabilities and their families became apparent. The information brochure we developed allows informed choice to the parents regarding the use of services from the Centre to specialists to consult and refer the children for diagnostics, treatment and rehabilitation.

The brochure describes **the main functions** of the Centre: support for parents to prevent children from being abandoned, assigning and making early diagnostics, treatment, medical and psycho-social rehabilitation.

Information has been provided on a **set of documents** that parents should prepare to use the services of the Centre – an out-patient form, medical expert

examinations, tests, decision by the Medical Disability Committee; child's tests – pathogenic gut flora, gut parasites, Wassermann test for one of the parents, full blood count, a medical certificate for the absence of contact with a person suffering from severe infectious disease, a copy of the birth certificate.

The brochure gives the parents **information on the team** that is going to work with them. It is designed to meet the child's individual needs, and including a doctor, psychologist and a social worker are mandatory; depending on the specific case, other medical and non-medical specialists may be included as well.

The brochure describes the various **forms of care** which are offered – daytime service, by-the-hour service – it is based on a timetable and mobile service – the specialists pay home visits and provide the service to the family at home.

4. CONCLUSIONS AND RECOMMENDATIONS

4.1. Conclusions

Based on the experience we studied, a poll and an interview among specialists, graduates, parents of children with disabilities and experts, we can **draw the following conclusions:**

1. the main difficulties the parents are facing are associated with access to highly specialised help (35%); medical facilities (31.7%); working with the Health Insurance Fund and the Directorate of Social Assistance (40%). In the process of getting information and support, almost 50% of the parents rely on their friends.

2. the level of parents' awareness about the implementation of the integrated approach is relatively high (57.9%), whereas with specialists the share of those who are fully informed (45%) and who are partly informed about its implementation is almost equal (48.7%). Analysis data suggest that the differences are statistically significant.

3. more than half of the parents prefer the nurse to carry out treatment (85.8%), to consult and refer them (76.3%) and last but not least, to train them in the care of their child (63.3%).

4. the activities a nurse can do in implementing in practice the **Model of MDT for children with** disabilities are: support to specialists (specialists - 92,7%, experts - 100%); training and consulting children and their families (specialists -70,7%), experts - 93.3%); fulfiling doctor's assigmnents (specialists - 73,3%, experts - 83.3%); home visit (specialists - 48,3%, experts -83.3%). In this way, conditions are created for expanding the nurse's functions and the team's efficient functioning.

5. the nurse's inclusion in integrated care will improve child care (parents - 80%, experts - 83.3% and students -75%).

6. a positive attitude has been established to participate in various forms of follow-up training for working with children with disabilities and their families (specialists - 89%, students -88% and experts - 97%)

7. readiness to begin working in integrated care for children with disabilities and their families is shared by 35% of graduates

8. integrated service is coordination between various sectors in health care, social activities and education, to improve care quality, quality of life, particularly of chronically ill children – patients with complex needs

9. each country realises its care model. differing in terms of the degree of integration and structures involved, financial, human resources and legal framework. Currently, in Bulgaria, there is no political document or a concept that coordinates and plans the development of integrated services and early intervention

10. the barriers to introducing integrated services are legislation lagging behind the actual development of care (specialists - 44.7%, students - 46.7% and parents -50.4%); unwieldy rules and regulations (parents – 65.4% and specialists - 56%); unexplained sources of financing and mechanisms of paying for integrated care (47.5% - parents and 56% - specialists).

11. the brochure will help to improve parents' and specialists' awareness about the services provided by the CCSCDCD

12. the nurse, following the algorithm for work at the CCSCDCD, will contribute to facilitating the team's work (experts - 43.3% and specialists- 40.3%); reducing the risk of mistakes (experts – 26.7% and specialists - 28.3%); providing awareness to parents and specialists involved in the care of children with disabilities and chronic diseases (experts – 13.3%and specialists – 18.7%).

The conclusions we arrived at after the research, cannot be full and exhaustive because of the complexity of the problem examined and its profound core but they are enough to prove that health care specialists have a place in

providing integrated health and social services to children with disabilities. The specific character of the work definitely requires further training to nurses in response to the specific care and individual needs of the children and their families.

4.2. Recommendations

In connection with the research, and based on the literature studied, we can make the following recommendations:

To the Ministry of Health, the Bulgarian Association of Healthcare Professionals, Bulgarian Medical Association and Medical Universities

- holding training and practice/internships of specialists regarding the core of integrated care, the role of the individual health professionals and organisation of providing health care;
- Training medical specialists, GPs, paediatricians etc. within the system of primary medical assistance for improving competence, regarding early identification of special needs at a child's early age and providing adequate integrated health and social services.
- the Bulgarian Association of Healthcare Professionals should propose Standards for providing health care by the nurse within the structures of social services

to the Ministry of Labour and Social Policy and the Agency for Social Assistance

- based on intersectoral cooperation to be regulated new standards and criteria, including health care, in compliance with the needs of the individual target groups
- synchronising the new legislative changes, referring to the functioning of integrated services to regulate the provision of mobile services by the nurse.

- To build an information base of indicators in the field of children's wellbeing on which to build the policies on children and families
- Developing programs for further qualifications 'Supervision in assisting professions'

CONCLUSION

Integrated services for children with disabilities are meaningful to the child, family and community. They help children to achieve better results, protect human rights, support families and save valuable resources for the community. The Bulgarian society, politicians, professional organisations, experts, specialists, as well as the families of children with disabilities should go all this way and realise that the differences between the individuals, the differences between children, including the presence of a disability or a chronic disease is part of life. Each child, regardless of its features, should have the opportunity to realise and develop its potential, to learn and participate in the life of society. This can happen best when it is in the family and gets the love it needs, help and support from parents, relatives and specialists depending on its individual needs.

Joining forces by all institutions from the health, social and education sectors is an important factor to the success and development of integrated services.

The nurse with her uniqueness which is built in the process of mastering knowledge and skills becomes a preferred partner for the families in the care of children with disabilities. To realise her unique professional role, the nurse can alone or in a team with a doctor provide comprehensive care (activities) for all aspects of human health.

CONTRIBUTIONS

The present research allows outlining the social and medical aspects of the nurse's activities and her contribution and interaction with the families of children with disabilities in providing integrated care.

Theoretical Contributions

- Possible activities have been suggested in theory that the nurse can do within the structures of the CCSCDCD.
- The modern nurse's functions in the MDT and the CCSCDCD have been successfully brought out
- The nurse's social role in the care of children with disabilities and their families breaks with the traditional understanding of her role as providing only health care
- Analysed are the main barriers to introducing integrated services
- The nurse's necessary skills and competence in providing integrated care in the CCSCDCD have been defined.
- **An Algorithm for providing services to a child has been developed at the Center for Comprehensive Services for Children with Disabilities and Chronic Diseases**, which logically determines the steps supposed to be taken by the nurse from the time of childbirth to follow-up care by MDT.

Contributions of an applied and practical character

• It has been proven that the introduction of the Algorithm will facilitate the work of the team and reduce the risk of mistakes, will provide information to parents and professionals involved in the care of children with disabilities and chronic diseases.

- A **Model for the nurse's job description in providing care of a child with disabilities and chronic diseases** has been created, whose implementation will improve the parents' satisfaction with health care.

- That author has developed **an Information brochure that allows the parents informed choice regarding the use of services from the Centre, the specialists to consult and refer the children for diagnostics, treatment and rehabilitation.**
- **A Model for Multidisciplinary care of children with disabilities with the nurse's participation has been presented;** it can be applied in the practice of the CCSCDCD.

ПУБЛИКАЦИИ СВЪРЗАНИ С ДИСЕРТАЦИОННИЯ ТРУД

PUBLIKATSII SVURZANI S DISERTATSIONNIYA TRUD

1. **Тасева, Д.,** И. Манолова, **Интегрирани здравно-социални услуги, предизвикателство пред медицинската сестра**, Македонско сестринство, Изд. Висока медицинска школа, Битола, 2019 г. бр.8, 6-13стр., **ISSN 1857-6605;**
   Taseva, D. I.Manolova, **Integrirani zdravno-sotsialni grizhi, predizvikatelstvo pred meditsinskata sestra,** Makedonsko sestrinstvo, Izd. Visoka Meditsinska shkola, Bitola, 2019, broi 8, 6-13 stranitsa, **ISSN 1857-6605**

2. **Тасева, Д.,** С.Тончева, **Ролята на медицинската сестра в интегрираните грижи през погледа на специалиста“** ,Здравни грижи“ изд. БАПЗГ, 2020 г., бр.3, 5- 11 стр. **ISSN 1312 -2592**
   Тасева, Д., S. Toncheva, **Rolyata na meditsinskata sestra v integriranite grizhi prez pogleda na spetsialista,** Zdravni grizhi, izd. BAPZG, 2020, br. 3, 5-11 str. **ISSN 1312 -2592**

3. **Тасева, Д.,** С.Тончева, **Центровете за комплексно обслужване на деца с увреждания и хронични заболявания - алтернатива на деинституционализацията**, сп. Обща медицина, 2021, 23(5), 57-61стр. **ISSN 1311-1817 УДК 611**

   Тасева, Д., С.Тончева, **Tsentrovete za komleksno obsluzhvane na detsa s uvrezhdania i hronichni zabolyavania – alternativa na deinstitutsionalizatsiata,** sp. Obshta Meditsina, 2021, 23(5), 57-61 str. **ISSN 1311-1817 УДК 611**

4. **Даниела Тасева, Проучване нагласите на студенти дипломанти за работа с деца с увреждания и техните семейства“** , Варненски медицински форум, 2021,10(2), 405-410 стр. **ISSN 1314- 8338**

   Daniela Taseva, Prouchvane naglasite na studenti diplomanti za rabota s detsa s uvrevdania i tehnite semejstva, Varnenski meditsinski forum, 2021, 10 (2), 405-410 str. **ISSN 1314- 8338**