



SOCIAL WORK WITH CHILDREN WITH CHRONIC DISEASES

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ABSTRACT

The present paper is dedicated to children with chronic diseases and their families.

An important place is given to the necessity for more information about the problems of children with chronic diseases and their overcoming through timely and adequate to their needs social work.

An accent is put in the material on the enhancement of the resources (social, pedagogical and psychological) and their direction towards a more successful help for children with chronic diseases and their families.

The enhancement of the resources is regarded not only from the point of view of its quantitative but also its qualitative aspect.

Key words: children with chronic diseases, integration, social work, pedagogic work.

The social work with children with chronic diseases is a topical problem from the point of view of the necessary and insufficient services which are offered within the community. The care for them concerns the competence of well prepared young staff carrying out the mission to address modern forms of social support for each of the categories in need.

The chosen topic is up-to-date owing to the lack of enough specialized literature on the problem and the insufficient information about children with chronic diseases.

Their problems have their specifics and importance and the present work aims at attracting the attention towards the problem of these children and their families.

A chronic disease is a disease going on throughout the whole life. Depending on the clinic picture of the disease itself, it can develop in different ways. It is not a temporary condition but a constant phenomenon which, during the different periods of human life, sharpens and progresses and during other periods weakens and goes away.

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The notion of chronic diseases includes a number of diseases which differ from each other in terms of their causes, clinical exhibits, development and outcome. These diseases have periods of activating and of remission. [1]

In the most general sense, social work is defined as “Particularly topical and necessary, basically assistance activity, directed towards the overcoming and alleviating of a number of risks which accompany the life of certain families, persons and social groups”. [2] Georgi Kolev (2002) defines social work as a science which “has to be regarded as a specific field of human activity, as a function which consists of the creation and the theoretical systemization of the objective knowledge about a definite reality – the social sphere and the specific social activity. This may be specified as the professional and social activity of the government, the social and the private organizations, the specialists and activists who have directed their potential towards the solving of the social problems of the individuals, the families, the groups and layers of society.”... “Social work is in its essence a social science which is, however, connected to the technical and, particularly, to the natural sciences.”[3]

Pedagogical work – education, upbringing and training are specific phenomena. The preparation of the adolescent generation for

life is a social necessity, a constant function of society [2].

On the basis of the used sources, children with chronic diseases are mentioned as a group only in Regulation № 1 from 23rd of January, 2009, concerning the education of children with special educational needs and/or chronic diseases and regulation № 6 from 19.08.2002 about the education of children with special educational needs and/or chronic diseases.

The research has been performed in the region of Stara Zagora and the Clinic for Rheumatic and Collagenic Diseases at the Infant Pediatrics of the Medical Academy in Sofia. It will be presented further down, proving that there is a deficiency in the supply and use of social services for children with chronic diseases. The methods used in the study are: research work in the Department for Child Protection at Stara Zagora Municipality, the Agency for Social Assistance in Stara Zagora, laws, regulations and rules, other sources of information, such as people working in the social field and children with chronic illnesses and their families. In the course of the research work, it was established that children with chronic diseases are mentioned as a group only in Regulation № 6 from 19.08.2002 about the education of children with special educational needs and/or chronic diseases. The regulation thus sets the requirements for education of children with special educational needs and/or chronic diseases, as well as the specifics in the structure and the activity of the special kindergartens and schools. The conclusions made are based on the sources used.

Part of the social work is performing social work for mutual help. But how is this done with children with chronic illnesses, on condition that most of the time these children are in the hospital? Is there a social worker or a pedagogue in the nursery units who can supply such help to these children and their parents? On the territory of Stara Zagora, no information about the existence of such a specialist in any of the nursery units was found. There are only a few institutions on the territory of Stara Zagora supplying such resources, and they are the following: the House of Mother and Child - Stara Zagora, the House for mentally retarded children – Sladuk Kladenets, the Day Home - Stara Zagora and in the Home for mentally retarded children in the village of Petrovo. On the territory of the

city there is also a kindergarten for children with asthma in the area of Dubrava.

According to regulation № 6, chronic illnesses include: the illnesses of the lungs, the cardiovascular, the digestive, the endocrine, the kidney, the neurotic illnesses and the ones of the bones and joints. These also include diseases such as systemic lupus erythematosus, myocarditis, chronic bronchitis, bronchial asthma, chronic pneumonia and others. Let us take as an example a child with systemic lupus, with an extremely weak immune system as a result of the treatment and the disease itself. This child spends from 6 to 7 months each year at home or in hospital, as it needs constant medical treatment and medical observation and because of its weak immune system, it is often ill. The only contacts of this child are the doctors, the nurses, its parents who visit it or are with it in the hospital ward and the teachers who are with it in the hospital under an individual programme, co-ordinated with the doctor in charge. These are the real contacts of any child, not only the one having systemic lupus but also the many other children spending most of their time in the hospital. All this shows that most of children with chronic diseases live in isolation. There are quite a few cases in which children with similar problems are not spending most of their time in the hospital but because of the peculiarities of their illness have to stay at their homes for home treatment. The fact is that most of these children do not attend school but are taught under an individual programme at home. Another fact is that most of the parents have not been provided with information about the opportunity for integrated education and the children of these people keep on staying at their homes, completely isolated from the outer world. In other cases, when the child, after staying in hospital under medical treatment for a long time, goes back to the normal school. In such situations, the child, and not only the child but also the parents, is in the biggest need of help. Because of the long isolation, the child needs to be prepared psychologically for getting back to school. At this point, it does need help. For years such help has not been provided. Now there are Resource centres whose purpose it is to help the integration of children and students with special educational needs in the environment of formal education. The Rules of Procedure of the Resource Centres for the activity and function of the centre is described in detail, the main approach

of work being the systematic one. What makes an impression is the fact that nowhere the children are with chronic diseases mentioned as a separate group. These centres gravitate around mentally retarded children or children with auditory or visual disturbances, but nothing specific is said about the children with chronic diseases.

In the The Rules of Procedure of the Law for integration of disabled people, again, nowhere the children with chronic diseases are mentioned as a separate group. The children with permanently decreased ability for social adaptation aged from 7 to 16 get 9.25 leva as help for transportation services. 13 leva are allowed to children up to 16 years of age with permanently decreased ability for use of information and telecommunication. Some children of up to 18 years of age receive 9.25 leva as a monthly allowance for education and this is only done if the child does not study in a special school or is included in some education under the Law for encouragement of the employment. In cases when medicines are taken, which are partly reimbursed by the Health Fund, the children are also entitled 9.25 leva for diet food and medicine. Under The Law on Family Benefits for Children (ZSPD), children with disability over 50% receive 170 leva a month, provided they have the decision of the Labour Expert Medical Commission (TELK). According to Art.7 al., under the same Law, these children are entitled to double the child benefits equal to 70 BGL, again, provided they have the decision of the Labour Expert Medical Commission (TELK). According to the social worker, children with disabilities come into the group of the disabled people and the sum granted by the government to a child with a chronic disease is at best 285.75 BGL a month, on condition that the family meets all the requirements and is eligible to that sum. This is the whole financial help that the state provides for these children.

Neither in the Rules of Procedure of the Resource Centres, nor in the Regulations of the Law for disabled people there is a mention of chronically ill children or adults. If we are guided by these, it will come out that no work is performed with such people. In the Agency for social support, the chronically ill are in the group of people with disabilities and enjoy preferences on this line, but not as a separate group.

In the Department for Child Protection in Stara Zagora, the children with chronic diseases are

not included as a group, too. When asked if there is any work done with such children, the answer given was that, in case of a signal for help needed, such cases are treated as individual ones. The social worker from Department for Child Protection we asked said that in practice no one is in charge of children with chronic illnesses and no special attention or care is given to them. The only approach applied is the medical one. It turns out that no one provides these children with the help they need and they do need help. The resource centre can be a solution to the problem but only on condition that the child attends formal school. But what happens to the children who are not integrated? They are in total isolation, in some cases the child is at home and undergoes an individual programme but there are cases in which that does not happen – those children are completely isolated from the outer world and their contacts are extremely limited. Of course, the integration of the child depends on its health condition, on its individual characteristics and on the parents. After it leaves the hospital, the child goes home to continue its treatment in home conditions. No one has explained to the parents that there is an alternative when it can be integrated in education and, because they are in a psychological stress from the health condition of their child, it does not learn about this. It is normal for them to be worried to let the child go to school for a number of reasons, but it is the role of the social worker or – in the better case – the social pedagogue – to explain to them that this would have a positive effect on the child and would provide it with the equal chance to develop in optimal conditions. There is not enough social work done with children with chronic illnesses. Of course, there are cases when children with chronic illnesses, with the initiative of their parents, are integrated in formal schooling. But for children in wheelchairs, at this stage of development of our country, this is in some cases impossible, as there is not the necessary material equipment. It is true, though, that the Directorate for Social Assistance provides some medical equipment: strollers, chairs, shoes, crutches, orthoses, walkers, prostheses, etc., depending on the disease, provided there is the necessary documentation from the Labour Expert Medical Commission (TELK).

When the child is chronically ill, it is not able to attend school. Then one of the parents, in most of the cases this is the mother, stays home

to take care of the child. The father works to get the average salary, with which he has to provide for a four-member family and let us not forget the 285.75 leva which the family receives as help from the government (while some of the medicines for these children cost 180 leva a month and if the family is lucky enough and meets the requirements help will be received to buy at least one of the medicines for the child). But there is one very important detail – children with chronic illnesses need systematic medical treatment and if the treatment is not included in the Regulation of health care the parents have to buy the medicines themselves to keep it alive. In many of the cases these medicines are very expensive. In such cases the economic factor is decisive because it is namely the means that are needed to these. In this situation, the mother may be assigned as a personal assistant to her child and thus receive the minimum salary but this, again, only if she meets the requirements and the income of the family is 45 leva for each member, which automatically decreases her chances to get the relief. This is the time to provide the social help and, if the government does not provide enough means for these families, the social worker should be able to provide alternative help for meeting the financial difficulties. For example, he or she may connect the family to some foundation which can provide the necessary sum to buy the needed medicines or the medicines themselves. In case the mother is unemployed, because she is taking care of the child, the social worker may provide her some outwork, so that some extra money comes into the family. There are many ways of helping such a family. Unfortunately, this is not done and, if it is done, it is in very rare cases and by the good voluntary will of the social worker. From February, 2010, there is a new European programme for social assistants which have not been well developed yet.

The problem with children with chronic illnesses is a very serious one and should be treated with great attention because otherwise these children would be destined to isolation. In order to achieve that, there should be social workers and pedagogues in the hospitals, giving the necessary help not only to the children but also to their parents. The social worker will be able to prepare them for what is going to after the children leave the hospital, will direct them to the institutions that can help

them, will inform them of their rights and of the help they can get from the government, in case they need a psychologist, a speech therapist or resource teacher. This will make things much easier for the parents and the child. The social worker and pedagogue will prepare the child for its getting back to its social life and will help it overcome the stress at entering and leaving the hospital. Those people will prepare the child for the eventual problems it might have when coming back to the formal school. This work can only be done by a pedagogue, not by a doctor or a nurse. That is why it is extremely necessary to have this resource in the health institutions. Unfortunately, this kind of policy of social work has still not been implemented in our country.

In conclusion, we have to point out the following: Chronically ill children, although not listed as a separate group in the regulations and codes, are a special group of children. They form a small socium with their specific needs. For children with chronic illnesses there is not sufficient care provided. Due to the characteristics of these children, arising from their health condition, they need psychological help and support. There is a shortage of resources (social, pedagogical and psychological) to engage and work with children with chronic illnesses and their families.

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