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ЗДОРОВ'Я ДІТЕЙ І МОЛОДІ: безпекові та психологопедагогічні аспекти

Колективна монографія за загальною редакцією професора Н. І. Коцур

Випуск 3

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У монографії розглянуто безпекові та психолого-педагогічні аспекти здоров'я дітей і молоді. Висвітлено теоретичні та практичні результати досліджень із питань формування, збереження та зміцнення здоров'я дітей і молоді у контексті безпекових проблем сучасності.

Колективну монографію адресовано викладачам вищих навчальних закладів, студентам, аспірантам, учителям шкіл різного типу і широкому колу науковців, які цікавляться сучасними питаннями безпекових проблем здоров'я дітей і молоді.

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ДІАГНОСТИКА ЯК КЛЮЧОВИЙ ЕТАП СОЦІАЛЬНО-ПЕДАГОГІЧНОЇ РОБОТИ З СІМ'ЯМИ, ЯКІ ВИХОВУЮТЬ ДІТЕЙ З ДЦП

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DIAGNOSING AS A KEY STAGE OF SOCIO-PEDAGOGICAL WORK WITH FAMILIES RAISING CHILDREN WITH CEREBRAL PALSY

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A pressing issue in our society today is creation of a special model of socio-pedagogical work with families raising children with disabilities in the inclusive and resource centres environment. These institutions ensure early adaptation, correction of communication skills; physical rehabilitation; medical, psychological, and speech correction; socio-pedagogical and psychological support to families raising a child with disabilities. The socio-pedagogical work with families may be expected to be effective, provided that: the study of the family structure and its pedagogical potential is made; the parents' readiness to participate in psychosocial rehabilitation of a sick child is formed; psycho-physiological characteristics and impact of the social environment on family are taken into account.

One of the key stages of socio-pedagogical work with the family is diagnosing, which means identification of abnormalities in the life of a family that lead to its dysfunction. Based on the results of diagnosing, types of families can be determined and a strategy can be developed for further socio-pedagogical work with them.

The main objective of this paper is to define the types of families raising children with disabilities, in the inclusive and resource centre environment, based on a comprehensive sociopedagogical diagnosing.

The research tasks:

- to substantiate the expediency and necessity of application of certain empirical and theoretical methods of socio-pedagogical diagnostics in work with families raising children with cerebral palsy;
- to define types of families raising such children, based on the proposed diagnostic methods;
- to describe the criteria and parameters for assessing the efficacy of socio-pedagogical work with families raising children with cerebral palsy in the inclusive and resource centre environment.

Typology of families and the key aspects of socio-pedagogical work with different types of families are sufficiently developed in pedagogical theory. Thus, the family typology using certain criteria was defined by D. Baumrind, L. Vakhovskyi, O. Karaman, M. Kratinov, V. Kratinova, D. Olson, O. Pesotska, S. Kharchenko.

Socio-pedagogical problems in working with families having children with disabilities were addressed by A. Maller, I. Mamaychuk, E. Mastyukova, Nancy R. Finnie. But, in our opinion, the typology of families raising children with disabilities is developed insufficiently.

Family with CP child is a special integrated social system having a complex internal structure, its own psychological structure and specific functions; it determines certain socio-psychological characteristics of constituting individuals, and is characterized by mutual influence of family members [14]. Besides, being a relatively autonomous system, such family is capable of self-regulating.

The theoretical basis of socio-pedagogical work with families raising children with CP is the awareness of a decisive role of the family as a socio-biological community that regulates the relations between husband and wife, parents and children, performs a variety of functions and directly influences the socialization of such child [15]. The role of parents in the rehabilitation of children with special needs is very important [16; 9].

It is important for a specialist to study the structure of the family, its life cycle, internal and external strategies of family life, emotional adaptation of the family to the child's disability issue, etc.

One of the main parameters of family life is a family climate that to a certain extent affects the process of child's socialization and personality becoming [4]. Negative factors of family education may lead to delay in mental and personality development of a child in general.

The peculiarity of mental development of children with CP can be clearly seen in their cognitive and motional activities, in their emotional expressions and volition actions, in their capability for self-care and acquiring of social skills, and in the personality formation in genera [5; 7; 8]. Improvement of family education conditions is the key countermeasure to negative emotional expressions and volition actions that are easily provoked by organic lesion and child's weak nervous system and affect the personality formation.

The research involved 180 families (322 adults and 180 children with cerebral palsy); 18 social workers, 12 psychologists of inclusive and resource centres.

The diagnostic work was based on the following principles: face-to-face work; professionalism; confidentiality and consistency.

To identify the psycho-pedagogical problems of families, the following methods were used: diagnostic and evaluation interviews, discussions, questionnaire surveys, tests, opinion polls, observations, expert assessments, creative tasks and self-analysis.

The main purpose of a *diagnostic interview* was to obtain data on family relationships and individual characteristics of the child, therefore it included the testing techniques. The results of diagnostic interviews were used afterwards for the development of programme of socio-pedagogical work with a family and became grounds on which the methods of influence on the family members were selected in order to overcome the negative perception of one another, to normalise the family relations and to improve their relations with the doctor for effective medical care of the child.

Conducting of assessment interviews using the communicative technology with an emphasis on finding the difference between the family members has enabled the family members to «open» a new reality in their relations and to launch the mechanism of change.

Diagnostics involved the following types of *conversation*: psychotherapeutic, standardized, free, controlled, uncontrolled etc. In order to communicate with parents in a trusting manner, the specialist should be able to use the method of empathic listening. This method, as defined by C. Rogers, consists in creating the atmosphere of an interesting conversation, joint problem solving [17]. In addition, a very important aspect in communication is the ability to see the world through another person's eyes while remaining professionally objective.

Using the *observation method*, we identified the special features of relations between adults and children, by which the degree of their emotional intimacy and characteristic aspects of communications can be estimated.

Keeping track and in-depth study of family relations is possible on condition that the specialist «lives» the child's life, therefore during the diagnosing the *projective techniques* were used (kinetic family drawing, commenting on pictures and unfinished sentences), which assist in studying the degree of perception of family relations by children [2; 3]. Study of the parents' attitude was facilitated by the parents writing an essay «My Child.»

The opportunity to learn about the family's value system, relationships between parents and children, consistency or inconsistency of adult family members' requirements to the child, was provided by the *game tasks*.

Along with projective techniques and game tasks, the specialists working with children evaluated the current level of development of children with CP by several functional areas: gross and fine motor skills, speech perception, social skills. By these parameters we determined the degree of social and psychological adaptation of children to their own problems and needs associated with disability.

In addition, in determining the type of family raising a child with CP, the following diagnostic methods were used:

- Methods of diagnosis of socio-psychological adaptation (SPA) by C. Rogers and R. Diamond. Based on the diagnosis results, we identified the parents' feelings in respect of their children's disabilities. The results were processed and interpreted by the following parameters: adaptation, self-perception, acceptance of others, internality, emotional comfort, the desire to dominate.
- Express-method for diagnostics of psychoemotional strain (PES) and its sources (O. Kopina, E. Suslova, E. Zaikin) allows us to evaluate the level of psychoemotional strain of a person, and reveals the particularities of each parent's awareness of what is happening in their lives and how they evaluate the satisfaction of their needs. This method was used for studying of the parents' emotional state.
- «Locus of control» method (O. Ksenofontova) enabled us to identify the parents' opinion regarding the localisation of the factors that influence, manage and control their lives. Using this method, we identified the parents' state by activity indicator and its orientation in a difficult situation.
- K. Thomas test measures the productive and unproductive behaviours of the family members, identifies personal tendency to

conflict behaviour, and detects the following conflict-handling modes: competing; adapting; compromising; avoiding; cooperating. The score on each of the five modes gives us an idea of the prevailing parents' behaviour in conflict situations, which affects the family climate, emotional development and socio-psychological adaptation of the child.

- PAQ parental attitude questionnaire (A. Varga, V. Stolin) measures the whole range of feelings that adults experience towards their children, their behavioural patterns, learning styles, and understanding of the child's character and actions. This method was used for measuring the parents' attitude to children with CP.
- The «Analysis of family relationships» method identifies the parenting styles: authoritarian, democratic, permissive.

Based on the results of socio-pedagogical diagnosis, we defined the *parameters*, which characterise the families raising the children with CP:

- pedagogical culture of parents, their readiness to raise a sick child;
- emotional adaptation of parents (productive/unproductive) to the child's disability;
- family climate, which creates favourable/unfavourable atmosphere for emotional development of a child with CP;
- parents' readiness (active/passive attitudes) to work with a specialist;
- socio-psychological adaptation of the child to his/her own problems and needs associated with disability.

Based on the existing research [1], the parents' *pedagogical culture* is determined by the following factors: possession and quality of psycho-pedagogical knowledge, attitudes and beliefs; the degree of formation of parenting skills; value-laden attitude towards a sick child; consistency of interest in the parenting process in general.

In families with high pedagogical culture the parents have sufficient psycho-pedagogical knowledge and use it in the family communication; they are involved in systematic education of children with emphasis on their age and individual characteristics. This type of families is characterised by high degree of parents' responsibility for positive socialisation of a sick child, as well as their active attitude.

In families with average pedagogical culture the parents do not have enough systematic knowledge of pedagogy and psychology; they have no clear ideas about parenting methods and techniques; their basic approach to solving the life problems of a child with disabilities is intuitive. The parents are involved in raising of their children sporadically, and the educational function is substituted by care and unsystematic supervision.

In families with low pedagogical culture the parents do not have knowledge of family pedagogy, they are passive in performing parental functions. In such families, typical parenting mistakes are often observed such as no uniform requirements, harshness and authoritarian style of communication, bodily punishment and manipulation.

The level of emotional adaptation of parents to the child's disability was measured for each type of families by the following characteristics: productive - marginal - unproductive adaptation to disability of the child.

Families with productive adaptation to the child's disability are characterised by creation of a new circle of contacts or selective resumption of old friendly ties; positive attitude to people; ability to openly discuss their problems; willingness to share experiences and to come to assistance; interest in the surrounding world; opening of new opportunities for self-fulfilment; realistic evaluation of constraints and opportunities of child's development, possibilities for child's adaptation and readiness to translate them into action; recognition that they can be happy.

The families with marginal adaptation to the child's disability are those where parents lack contact with other people; family members are not ready to communicate openly and to discuss their family problems; the adult family members do not have clear ideas about possibilities of children's self-realisation and development, the basic approach to solving of family problems is intuitive. These families follow a strategy which consists in accepting whatever happens - «Everything is God's will.» They exclude any possibility of changes for better and keep the existing situation alive, thus not solving any problems and deepening the stress.

Families with destructive emotional state, which makes them live in isolation and confrontation with society, are families with

unproductive adaptation to the child's disability. They complain about the heavy burden and permanent frustration, which leads to conflicts in the family. If not duly corrected, this condition will deepen, becoming dominant and taking control of the parents' behaviour. They develop self-centeredness that leads to estrangement and social exclusion.

Parental egocentrism has an affect on the character of children, who also become unable to feel compassion and to help the others. This progressively prevents the children from establishing the relationships, communication and cooperation with their peers, and makes them feel lonely and isolated.

Too high expectations the parents had of the child's outstanding achievements in future do not allow them to overcome frustration, shame and humiliation of having a child with CP, who «just won't make it». They try to forget about the existence of this child, although he/she stays at home; the child is never spoken about nor shown to anybody, and, if possible, is left to baby-sitters, caregivers or grandparents. Such emotional coldness and alienation of parents make the child actually suffer from neglect.

Some parents develop this kind of attitude due to the child's communicative peculiarities in early childhood: no smile, weak 'animation complex', which prevents the parents from forming an appropriate emotional response. In these conditions some families manage to achieve a stable life, the parents self-actualise and appear to be successful; however, the psychological stress, associated with the fear that their friends may find out about their sick child and this will affect their relations, still remains. These families are emotionally unstable, they are incapable of finding positive solutions to their vital problems.

The family climate was measured by factors: 'favourable - unstable – unfavourable' in relation to emotional development of a child with CP.

Families characterized by the family climate favourable to the emotional development of the child are those where authoritative style of parental behaviour prevails ensuring equal participation of all family members in organization and management of the family's daily life. By the type of family relationship they are structured or flexible [12]. Such families have a collegial atmosphere. Here, the

democratic leadership dominates, when the opinions of all family members, including children, are taken into account, the roles and interfamilial rules are stable, but with a possibility of change; the roles are distributed among all the family members who easily communicate with each other (roles may change when necessary). The type of parental behaviour is «acceptance and love» that generates a feeling of safety in a child and contributes to normal development of personality. These are families with open communication [4], when family members are able to actively listen to each other, being able to freely express their opinions and give emotional support to the conversation partner.

Families characterized by unstable psychological climate employ a permissive parenting style, when parents make certain decisions depending on the situation, having no universal parenting strategy, their system of requirements for the child being unstable and flexible. In such families relationships are chaotic, family members live without clearly defined rules and principles, often shifting from emotional closeness and connection to hostility and separation, and a child with CP feels like a burden on the parents. These are families with sporadic interaction, when all problems without exception are hotly debated, although family relationship may seem smooth and balanced to an outside observer.

Families with unstable psychological climate for the development of children are characterised by authoritarian parenting style, where the leadership and organization of all functions are carried out by one of the family members, where unconditional and totalitarian relations are established among adults, as well as between adults and children; where cruelty, aggression and coldness predominate in the family. Family relationships are rigid: the father is engaged only in financial support, and the mother spends all her time taking care of the child, leaving other family members out in the cold. These are families with closed communication, lack of interaction between themselves and emotional coldness. Disharmony in marital relationships creates an unfavourable environment for emotional development of a sick child and may become a source of neuropsychiatric conditions of this child.

Such families are reported to have numerous cases of unreasonable and inefficient use of compulsion methods; however

certain cases of helicopter parenting, when parents try to indulge their children in every possible way, thus causing irreparable damage to them. One of the most serious consequences of helicopter parenting of a sick child is the hostile attitude of brothers and sisters who are deprived of maternal care and affection. In the course of time, while the child grows up, the conflict between the child and parents also grows because of the child's desire for independence and the inability of adults satisfy it.

The socio-psychological adaptation of children to their own problems and needs associated with disability is defined as relatively high, medium and low.

The children with high socio-psychological adaptation to their own problems and needs associated with disability to develop most skill groups corresponding to their age. The children perceive speech and understand what they are told, they are more active in forming categories and combinations, understanding symbolic meanings, acquiring social skills (they take food, use the toilet, dress and undress, are able to establish contacts (visual, tactile, verbal), freely communicate with peers, parents and other adults). They are able to behave quite adequately and make logic assertions; they have positive and easy attitude to themselves and their handicaps; they perceive the world with interest, their attention being attracted by various objects and phenomena. The sensory, emotional, physical and intellectual development indicators of such children have high positive dynamics.

Children with medium socio-psychological adaptation to their problems and needs associated with disability are characterized by insufficient level of development of learning skills and group skills corresponding to their age; the process of cognitive activity and acquiring social skills is slower. These children are not able to establish contacts and communicate with their peers and others without the adults' assistance. Diffidence, shame, unsociability and depression are often observed in these children; their different knowledge and ideas of themselves, as well as of interrelations between objects and phenomena of the world, and of the relationship between humans, are not systemised. The sensory, emotional, physical and intellectual development indicators of such children change more slowly.

Children from low socio-psychological adaptation to their problems and needs associated with disability are not capable to fulfil practical and cognitive tasks; they have poorly developed learning skills and abilities corresponding to their age. Unsteadiness of attention and small amount of operating memory caused by nervous exhaustion and low labour ability, are key obstacles to the use of available knowledge and skills by such children. Emotional responses to parents and other adults are poor or absent. The children have low response to communication, they can hardly imitate facial expressions and sounds, and show little interest in toys. While communicating with relatives or strangers, negative emotional responses prevail - screaming, crying and fear. These children are characterized by irritability, capricious behaviour, features of anxiety and negativity that contribute to low ability to use even the simplest forms of self-regulation. They take other people's attitude heavily; they are passive, inert, having poor communicative motivation that prevents them from social inclusion and becomes an obstacle on the way to self-fulfilment. The sensory, emotional, physical and intellectual development indicators of such children have unstable dynamics.

So, according to the objectives of the research, we developed and applied performance criteria of socio-pedagogical work with families raising children with CP and their indicators: cognitive (parents' psycho-pedagogical and socio-pedagogical knowledge of child's socialization issues, their prevention and elimination; knowledge of special physiological features of children with CP); emotional and adaptive (indicator of confidence/uncertainty, emotional adaptation to the child's disability issue; expectations of the people and attitude to others in a difficult situation, activity and orientation in a difficult situation, parents' readiness to cooperate with a social teacher); practical (family relationships between adult family members, parents' attitude toward their child, creating a success situation in communicating and learning); sociopsychological adaptability of a child with CP (indicators of social, intellectual, emotional, sensory and physical development). Based on the totality of the above indicators, we developed an integrating indicator - psycho-pedagogical adaptation of the family to disability of the child, which we took as a basis for setting-up a typology of families having children with CP, by the degree of its well-formedness.

Type I included families with high pedagogical culture, productive level of emotional adaptation of parents to disability of the child, favourable family climate; active attitude to addressing the child's disability; relatively high degree of socio-psychological adaptability of children to their own problems and needs.

Type II included families with medium pedagogical culture, marginal level of emotional adaptation to disability of the child, unstable family climate; neutral attitude, medium degree of socio-psychological adaptability of children to their own problems and needs.

Type III included families with low pedagogical culture, unproductive emotional level of adaptation to disability of the child, unfavourable family climate; passive attitude, low sociopsychological adaptability of children to their own problems and needs.

The family typology that has been developed makes it possible to ensure more targeted work of teams in inclusive and resource centres with the families of each type, to successfully influence the family situation in order to create favourable conditions for psycho-pedagogical adaptation of the family to disability of the child, to carry out individual rehabilitation programmes, to take a balanced approach to solution of family problems.

Socio-pedagogical work with families raising children with CP should be organised with account being taken of types of families by degree of psycho-pedagogical adaptation to disability of the child, which subsequently determines the choice and use of appropriate forms and methods of work with them, thereby improving its efficacy.

The implementation of research results in the inclusive and resource centres activities has produced the following results: positive changes were reported in the emotional state of children with CP; solving the problems of families, taking into account their social, psycho-pedagogical features, encouraging the parents to cooperate, their high pedagogical culture and productive emotional adaptation – all this contributes to socialisation of children with CP,

development of their inborn aptitudes, improves psychopedagogical adaptation of family to disability of the child, creates conditions for the social inclusion of the family.

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