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PSYCHOLOGICAL DETERMINANTS OF ACCOMPANYING A FAMILY RAISING A CHILD WITH INTELLECTUAL DISABILITIES

ПСИХОЛОГІЧНІ ДЕТЕРМІНАНТИ СУПРОВОДУ РОДИНИ, ЯКА ВИХОВУЄ ДИТИНУ З ІНТЕЛЕКТУАЛЬНИМИ ПОРУШЕННЯМИ

A scientific article that analyses the support system of a family raising a child with intellectual disabilities. This article examines modern foreign studies of a family that is raising a child with intellectual developmental disabilities through an analysis. The authors have identified the criteria that determine whether a family is functional or dysfunctional in this category. The chosen criteria describe the typical problems that arise for the family of a child with intellectual disabilities. Taking into account the "problem fields" of a family raising a child with an intellectual disability, its complex psychological support should be aimed at parents' awareness of the specifics of raising a special child, the formation of an adequate attitude towards his personality and illness, the harmonization of intra-family relations, which will ensure optimal functioning family. The development and upbringing of a child with an intellectual disability require greater awareness of the parents about the disease, the causes of the disease, its consequences, and the child's potential. Social and psychological support for the family should be provided simultaneously in multiple directions. Psychological and pedagogical support of a family raising a child with an intellectual disability should include three levels: macro level (level of collective interaction) – "school of responsible parenting" (parental lectures); meso level (level of group psychocorrective work) – psychocorrective trainings aimed at solving parents' psychological problems; micro level (level of individual work) – psychological consultations of parents. The scientific novelty of the article consists in the development of ideas for ensuring positive socialization of families, analysis and systematization of factors affecting the psychological well-being and educational potential of families raising children with intellectual disabilities. The practical significance of the results of the implementation of a complex three-level support program can be used in the system of inclusive practice and special education when implementing social and psychological support for students with intellectual disabilities and providing assistance to their family members.

Key words: psychological support, children with intellectual disabilities, parents of a child with intellectual disability, parental relationship, psycho-emotional state, frustration, subdepression.

Наукова стаття присвячена аналізу системи супроводу родини, яка виховує дитину з інтелектуальними порушеннями. У статті подано аналіз сучасних зарубіжних досліджень сім'ї, яка виховує дитину з відхиленнями в інтелектуальному розвитку. Авторами виокремлено критерії, що визначають функціональність чи дисфункційність сім'ї даної категорії. Відповідно до виділених критеріїв охарактеризовано проблеми, типові для сім'ї дитини з інтелектуальними порушеннями. Враховуючи «проблемні поля» сім'ї, яка виховує дитину з інтелектуальною недостатністю, її комплексний психологічний супровід має бути спрямований на усвідомлення батьками специфіки виховання особливої дитини, формування адекватного ставлення до її особистості та захворювання, гармонізацію внутрішньосімейних відносин, що забезпечить оптимальне функціонування сім'ї. Розвиток і виховання дитини з інтелектуальною недостатністю вимагають більшої поінформованості батьків про захворювання, причини хвороби, її наслідки та потенційні можливості дитини. Сім'ї необхідна соціальна та психологічна допомога, яка має здійснюватися одночасно в кількох напрямках. Психолого-педагогічний супровід родини, яка виховує дитину з інтелектуальною недостатністю, має включати три рівні: макрорівень (рівень колективного взаємодії) – "школа відповідального батьківства" (батьківські лекції); мезорівень (рівень групової психокорекційної роботи) – психокорекційні тренінги, спрямовані на вирішення психологічних проблем батьків; мікрорівень (рівень індивідуальної роботи) – психологічні консультації батьків. Наукова новизна статті полягає у розвитку ідей забезпечення позитивної соціалізації сімей, аналізу та систематизації чинників, що впливають на психологічне благополуччя та виховний потенціал сімей, які виховують дітей з інтелектуальними порушеннями. Практична значимість результатів імплементації комплексної тривірневої програми супроводу може бути використана в системі інклюзивної практики й спеціальної освіти при реалізації соціально-психологічного супроводу учнів з порушеннями інтелекту та надання допомоги членам їх сімей.

Ключові слова: психологічний супровід, діти з інтелектуальними порушеннями, батьки дитини з інтелектуальною недостатністю, батьківське відношення, психоемоційний стан, фрустрованість, субдепресія.

Formulation of the problem. Building an inclusive space emphasizes the family's crucial role in raising and correcting the development of children with special psychophysical needs. Special and clinical psychology is currently in the process of developing new ways to adapt socially for children with intellectual disabilities. In this connection, the issue of the participation of a family raising a child with an intellectual disability and its psychological and pedagogical support in this process are becoming more and more relevant and in demand. Without the involvement of parents, socialization of a child with an intellectual disability cannot be achieved. The family is where a child develops his initial understanding of human values, the nature of relationships between people, and moral qualities. The family is playing a greater role in raising a child with an intellectual disability in this context. Scientists note that, in connection with the birth of a child with an intellectual disability, the parents' view of the world, their attitude towards themselves, their child, other people and life in general changes. It's crucial to study both children with intellectual disabilities and their families, who require complex pedagogical, social, and psychological assistance. Children with intellectual disabilities can only be rehabilitated and integrated into society if this problem is solved. Psychological support is a form of psychological assistance for this population category. Ideology and technologies of psychological support were developed by such specialists as I. Baeva, M. Bityanova, H. Bardier, O. Volosnikov, O. Kazakova, O. Kozyreva, V. Mukhivna, Yu. Slyusarev and others [1]. In the scientific literature, a number of directions are distinguished in the work with a family that raises a child with an intellectual disability: pedagogical, socio-legal, medical, psychological. In the last decade, psychological and pedagogical support began to be considered as a separate and independent type of assistance to a family raising a child with an intellectual disability [3].

In the last decade, leading Ukrainian scientists (I. Bobrenko, V. Bondar, L. Vavina, A. Vysotska, I. Gudym, O. Havrilov, O. Garmash, V. Zesenko, V. Zolotoverh, V. Kobylchenko, A. Kolupaeva, S. Kulbida, T. Sak, I. Sukhina, O. Taranchenko, V. Tarasun, O. Khokhlina, etc.) [4].

The Institute of Special Pedagogy of the National Academy of Sciences of Ukraine has published scientific works on the psychological support of school-age children with moderate mental retardation, children with visual and intellectual disabilities, and children with hearing and intellectual disabilities. This

emphasizes the importance of psychological support and timely provision of psychological support [2].

Almost no research has been done on special psychology and psychological support for families of children with special intellectual development in Ukraine. In connection with the socially important task of developing technologies for psychological support of parents who raise children with intellectual disabilities, there is a need to study issues related to the problems of parents who raise children with intellectual disabilities, parental attitudes in these families, and create a program comprehensive psychological support.

The purpose of the article is a theoretical-empirical analysis of the "problem field" and the characteristics of families raising children with intellectual disabilities, systematization of approaches to comprehensive support of a family with a child with intellectual disabilities

Research results. Modern foreign studies present various approaches to understanding the problems of families with children with intellectual disabilities, as well as the causes of their dysfunction (M. Dowling, L. Dolan, V. Hemsley, S. Balandin, L. Togher, K. Hemming, J. Hutton, P. Pharoah, A. Dew, S. Balandin, G. Llewellyn and others) [5; 6; 8]. Families that raise children with intellectual disabilities often experience the following psychological problems:

- negative emotional experiences of parents (nervous tension, worry, anxiety, fatigue, despair, insecurity, stress) due to the lack of prospects for their child's future;
- irritation, dissatisfaction caused by the contradiction between parents' expectations of their own child and the peculiarities of its development;
- problems of self-actualization and self-realization of parents;
- destruction of family relationships due to conflicts related to raising a special child;
- limited contacts with the surrounding borders of one's own family;
- the risk of the development of persistent psychotraumatic situations in the family in connection with the economic costs of treatment and rehabilitation of a child with an intellectual disability;
- tendency of parents of a child with intellectual disability to form aggressive forms of behavior and interaction due to constant internal stress, lack of opportunity to share their own experiences [9].

Qualitative changes in such families are manifested at the following levels: psychological, social and somatic.

Psychological level: the birth of a child with an intellectual disability is perceived by its parents as the

greatest tragedy. The fact of the birth of a child "not like everyone else's" is the cause of great stress felt by parents, first of all mothers. Stress, which has a prolonged character, has a strong deforming effect on the parents' psyche and becomes the initial condition for a sharp traumatic change in the way of life that has formed in the family. In the family structure, the following are deformed: the style of intra-family relations; the system of relations between family members and the surrounding society; peculiarities of the worldview and value orientations of each parent of a child with an intellectual disability. All the hopes and expectations of the family members regarding the child's future turn out to be useless and are destroyed in an instant, and the understanding of what happened and the acquisition of new life values is stretched over a long period of time [11].

Social level: after the birth of a child with developmental problems, family, due to numerous difficulties that arise, becomes unsociable and selective in contacts. It narrows the circle of acquaintances and even relatives due to the characteristic features of the condition and development of the sick child, as well as due to the personal attitudes of the parents themselves (fear, shame). Another feature that characterizes the social position of a significant part of parents regarding upbringing, development and overcoming the problems of a child with an intellectual disability is a dependent or lack of initiative position. The lability of the structure of the family of a child with intellectual disabilities, as confirmed by the conducted studies (M. Dowling, L. Dolan; S. Hatton, E. Emerson, N. Graham, J. Blacher, G. Llewellyn, etc.), is due primarily to, unfavorable socio-economic circumstances determining the complexity of life for this category of families. Such difficulties include the limited opportunities of parents of special children in building a successful career, achieving material well-being, spending leisure time and, as a result, a high quality of life [6; 7].

Somatic level: the stress that arose as a result of a complex of irreversible mental disorders in a child can cause various diseases in his mother, being as if the trigger of this process. A pathological chain arises: the child's illness causes psychogenic stress in his mother, which to one degree or another provokes the emergence of somatic or mental diseases in her [3]. Thus, a child's illness and mental state can be psychogenic for parents, especially mothers. A study of the psychological distress of mothers of children with intellectual disabilities, conducted by scientists from the universities of Great Britain, Australia, and the United States: Lancaster University, Lancaster, UK; University of Sydney, Australia; University

California in Riverside, Riverside, CA USA; University of York, UK (E. Emerson, C. Hatton, G. Llewellyn, J. Blacher & H. Graham), showed a significant difference according to the indicators of well-being selected by the authors (a sense of happiness, self-esteem, self-confidence) between mothers of disabled children and mothers of develop normally. 6,954 mothers of children under 17 took part in the survey, including 514 mothers who are raising disabled children living in England. Mothers of children with intellectual disabilities noted a lower level of manifestation of these indicators than mothers of children without disabilities. Statistical indicators of the difference in socio-economic status, home conditions and the state of health of mothers show a difference between groups in indicators of maternal happiness and account for about a 50% increase in the risk of self-esteem and self-efficacy [7].

Different theories and concepts have different criteria for determining the functionality or dysfunctionality of the family of a child with severe developmental disabilities. However, theorists and practitioners emphasize the special importance of such criteria as the social status of the family, the nature of the relationships of family members with each other, the attitude of family members towards a child with intellectual disabilities, and the awareness of family members of the need for psychological help and support [10]. The problem area related to the social status of the family of a child with severe developmental disorders has been sufficiently studied by foreign scientists (Winslow, Wolchik, Sander; Clarke & McKay, etc.), and the following trends were identified:

- children with disabilities in intellectual development are less likely than normal children to be brought up in a full family with both biological parents or in a family where the mother is married from the moment the child is born to the age of 5;
- there is a sharp increase in the number of single parents with disabled children from newborn to 2 years old;
- there is a significant increase in the separation of parents of a child with an intellectual disability;
- recently, a significant increase in the number of cases where a child with intellectual disabilities lives in a foster family has been recorded [12].

The attitude of family members towards a child with mental retardation is not always adequate, psychologists often state a lack of understanding of the diagnosis and condition, emotional rejection of the child or another extreme – symbiotic relationship with him, lack of realism in assessing his capabilities, etc. In overcoming these problems, a formed parental

position, characterized by adequacy, flexibility, and predictability, plays a major role. Research proves that parents who feel a personal responsibility for stimulating the social development of their children usually raise competent children with developed social skills, while children of those who are not involved in education and transfer responsibility completely to professionals, are characterized by low adaptability.

It is known that children with impaired intellectual development have a high degree of risk in the appearance of behavioral problems, which increases stress for parents, actualizes protective mechanisms, such as denial of the diagnosis or distortion of reality, depression, maladjustment, passive attitude to the existing difficult life situation, negative affects marital relations (joint research Department of Psychology of California, Los Angeles, CA, USA, School of Education, University of California, Riverside, CA, USA and Department of Psychology, Gothenburg University, Sweden. The above facts indicate the need to develop a comprehensive model of psychological support for a family raising a child with limited health opportunities, oriented to its actual needs.

As part of the empirical study, which was conducted on the basis of the Laboratory of Health Psychology of Bogdan Khmelnytsky Melitopol State Pedagogical University, the characteristics of families raising children with intellectual disabilities were analyzed, and a comprehensive support system for such families was implemented 30 families raising children with intellectual disabilities took part in the study. As research methods, the following were chosen: a parental relationship questionnaire (A. Varga, V. Stolin), a scale of low mood – subdepression (V. Zunga – T. Balashova), a technique for determining the state of frustration (V. Boyko) and a questionnaire aimed at identifying the state of emotional tension (T. Nemchyn). The developed and tested program of psychological support for parents raising children with intellectual disabilities is based on a three-level structure of interaction of all participants in educational influence:

1. Macro level (level of collective interaction) – "school of responsible parenting" (parental lectures). The purpose of this work was, first of all, to increase the awareness of parents in the field of the supporting and educational potential of the family. Classes at the parent's school were held twice a month of the year (18 classes in total).

2. Mesolevel (level of group psychocorrective work) – psychocorrective trainings aimed at solving psychological problems of parents. The tasks of psychocorrective training were:

- formation of positive self-esteem of parents, relief of anxiety;
- development of self-analysis skills and overcoming psychological barriers that prevent full self-expression,
- formation of positive attitudes in the perception of the child and life situation;
- improvement of communicative behavior;
- formation of skills of adequate communication with the surrounding world.

The main technologies of psychocorrective work were group discussions, role-playing games, musical visualizations, art therapy.

The program consists of four meaningful blocks:

1. Organizational. Acquaintance with a group of parents and children, motivation, formation of a positive mood for further work.
2. Informational and educational (educational). Activities of an educational nature.
3. Practical (activity). Measures aimed at individual and group work with families regarding the implementation of psychological and pedagogical support technology.
4. Analytical (reflective). Measures of a reflective nature. Carrying out secondary diagnostics to monitor the effectiveness of the program.

Classes were held once a week for 4 academic hours. The program included 15 classes.

3. Micro level (level of individual work) – psychological consultations of parents.

The main principles of the organization of psychological and pedagogical support for families raising children with intellectual disabilities:

- Facilitation. Creating conditions for the child/family to solve problems, the facilitator only accompanies. Reliance is placed on the potential of each family member's personality and support for their self-realization in the process of family life.
- Creativity and creative beginnings in the organization of joint activities.
- Complexity – involves work on adjustment of all components of socio-pedagogical and psychological-pedagogical support; as well as comprehensive work with both parents;
- Voluntary – based on parents' free choice of attending classes;
- Dialogicality – assumes that psychological and pedagogical support for families takes place most effectively in the process of interaction between parents and a student-intern who possesses professional competences, parents and teachers, parents and children.
- Support of family self-organization (activity of parents and children themselves in building an

educational and rehabilitation route).

- Pedagogical optimism (belief in the possibilities of parents and children).
- Problematization (analysis of specific family problems, development of an educational route taking into account the problems of the families themselves);
- Account of the characteristics of modern parents.
- Axiological orientation of content.
- Reflections – involves parents reflecting their thoughts, feelings, and opinions at various stages of the lesson.

Evaluation of the effectiveness of the psychological support program included: analysis of changes in the emotional and personal sphere of the parents of the experimental group (before and after the implementation of the support program); comparing the indicators of the experimental group (after completing the program) and the control group that did not participate in the program. Following the implementation of the psychological support program, the analysis of the changes in indicators studied in the experimental group showed the following. There have been changes to all styles of parental relations. The child's emotional rejection was unconditional before the program was implemented, but it decreased to 49.93 points after the experiment. Parents began to accept their child as they are, realized the true level of their capabilities, and reconciled with them, and this is evidence. It was found that there was a decrease in indicators for a disharmonious parental relationship, such as symbiosis, which was revealed. Parents no longer seek to establish a symbiotic relationship with their child, having realized, on the one hand, the need to live their own life, and on the other hand, the importance of not only giving the child independence, but also teaching him independence.

The decrease in indicators of hypersocialization indicates that the child's successes and failures

began to be perceived not as indicators of the ability of the parents themselves, but as indicators of the child's development. This change in the parents' consciousness led to a decrease in their frustration .

Changes in the indicators of violent invalidization (infantilization) are explained as follows: when evaluating their child, parents stopped comparing them with normative children, and began to take as a basis the dynamics of the development of the special child. Moreover, at this level, his own child ceased to seem as incapable as before. Indicators also decreased for such a style of parental relationship as cooperation (the image of a socially desirable parental relationship), that is, parents realized the fact that it is possible to become "good" only after solving their own problems, so the child's problems ceased to be the center of their attention for a while. The psycho-emotional state of parents who participated in the psychological support program has significantly changed.

It can be stated that in the process of implementation of the psychological support program, the indicator on the frustration scale of parents decreased: if before the experiment, the average value of the respondents corresponded to the state of frustration, then the control study showed only a tendency to frustration. This fact is connected with the fact that parents raising a child with an intellectual disability stopped perceiving their life situation and the child as a frustrator, a barrier to self-realization.

Subdepression also changed: if the data of the ascertaining study showed a significant decrease in mood, the control study, which was conducted after the completion of the psychological support program, revealed only a slight decrease in mood. The experiment's participants' realization of their life prospects and change in attitude from 'I can't' to 'I will succeed' is related to this.

Table 1

Reliably significant differences in the average indicators characterizing the styles of the parental relationship

No n/n	Indexes	The average value of the indicator in the experimental group (before the implementation of the program)	The average value of the indicator in the experimental group (after the implementation of the program)
1	Emotional denial	82.96	49.93***
2	Cooperation (an image of a socially desirable parental relationship)	10.61	9.26**
3	Symbiosis	73.21	57.82***
4	Hypersocialization	66,67	47.89***
5	Violent disability	62,69	50.94**

* $p \leq 0.05$; ** $p \leq 0.01$; *** $p \leq 0.001$

Table 2

Significant differences in average indicators characterizing the emotional state of parents

No n/n	Gel show	The average value of the indicator in the experimental group (before the implementation of the program)	The average value of the indicator in the experimental group (after the implementation of the program)
1	Frustration	7.36	3.45***
2	Subdepression	57.86	38.83***
3	Neuropsychological condition voltage	75,26	45.7***

* $p \leq 0.05$; ** $p \leq 0.01$; *** $p \leq 0.001$.

A change in the level of mood in a positive direction also led to a decrease in the neuropsychological stress of the parents who participated in the experiment: a control study showed that they noted the second degree of neuropsychological stress in themselves, in which minor stress is associated with intensive productive activity.

A comparative analysis of the data of the tested control and experimental groups allows us to conclude that all the studied areas in the participants of the psychological support program have undergone certain changes.

First, reliably significant differences were recorded in the indicators characterizing the psycho-emotional state of the parents of the two groups:

– according to the "low mood – subdepression" scale, the differences were 14.47. In the participants of the experimental group, this indicator decreased from the third level – a significant decrease in mood (61.73 points) to the first level (41.83 points) – the absence of psychological support for low mood at the end of the program.

– according to the "frustration" scale, the indicators also differ. If the parents of the control group had indicators remaining at a level that characterizes a persistent tendency to frustration (6.73 points), the parents of the experimental group who participated in the psychological support program had no frustration at all (3.43 points). Thus, based on the analysis of the obtained data, we can claim that in the process of passing the psychological support program, parents became aware of their capabilities, revealed their own reserves, which can be aimed at taking responsibility for themselves and their child.

Secondly, differences in parental relationship styles were found among the respondents of the control and experimental groups. Thus, according to the "acceptance – rejection" scale, the differences in the data obtained by the subjects of the control and experimental groups amount to 42.57 points.

According to the results of the formative stage, there is a tendency to replace children's unequivocal

emotional objection with their parents' relative acceptance.

According to the scale "authoritarian hypersocialization" the difference in indicators is equal to 18.55 points. This difference demonstrates a decrease after the implementation of the program of psychological support of parents' authoritarianism, the development of their desire to listen to their children.

On the "small" scale loser" indicators also differ (the difference in value reaches 24.55 points). This indicates a more realistic assessment by parents of their children's capabilities, a decrease in control over children, a perception of the child as a given that cannot be changed, but it is simply necessary to learn to live with it.

In order to assess the dynamics of the indicators of the emotional state of parents in the experimental group towards normativity, a control ascertaining study of personal qualities, emotional state and styles of parental attitude in the subjects of the normative group and experimental groups (after completing the psychological support program) was conducted. It was found that the differences in the emotional state of parents who went through the support program were leveled on two scales: the state of frustration and the state of subdepression caused by the problems associated with raising a child with intellectual disabilities. The conducted assessment made it possible to state that the proposed model of support stabilizes the emotional state of parents and brings it closer to normality.

Conclusions and prospects for further research.

As part of the empirical study, a category of parents was found who broadcast one of the following styles of parental attitude: sub-depressive parents tend to disable their child and establish symbiotic relationships with him, the second group consists of frustrated parents who broadcast either emotional rejection of their child or hypersocialization. We can state with confidence the fact that during the implementation of the support program we managed

to overcome the intrapersonal conflict of parents raising children with intellectual disabilities and bring the structure of relationships closer to the structure we observed in parents raising normal children. As part of the research, it was found that the emotional state is determined not so much by problems related to

the upbringing of a problem child, as by the personal characteristics of the parents themselves.

Prospects for further research include the development of a system support for parents aimed at developing the educational potential of families raising children with intellectual disabilities.

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