

**THEORETICAL ANALYSIS OF THE LIFESTYLE OF  
FAMILIES WITH DISABLED CHILDREN IN PSYCHOLOGY  
IN THE MID-TWENTIETH CENTURY**

**L. V. Kalinnikova,**

PhD, Associate Professor in psychology of the Department of  
Social Work of Pomorskyi State University named after  
M. V. Lomonosov (Arkhangelsk, Russia)

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*This article describes the evolution of systematic research into the social-psychological characteristics of families with disabled children in psychology. The concept of “family lifestyle” is the theoretical platform for the research. Psychodynamic, behavioural and social-psychological approaches are the focus of theoretical methodological analysis of parental characteristics as one of the components in the overall structure of a “family lifestyle”. The psychodynamic approach is considered through the prism of inner maternal conflict. The social-psychological historical perspective is represented through the social-cultural parent conflict in accepting a child with a disability. The behavioural approach considers parental characteristics through mental and behavioural analysis. All together, three dominant psychological traditions focus on the negative influences of a child with a disability on the “family lifestyle”.*

The term “lifestyle” is widely understood as “the way people really live”, how they organise their lives [1, p. 11]. Although “lifestyle” has traditionally been a philosophical phenomenon, its content is mainly unpacked using psychological categories, such as feelings, needs, attitudes, interpersonal relationships, the meaning of life, etc. [2]. According to V. I. Tolstykh, lifestyle “covers and characterises typical things in the life” of people and is determined by conditions of both an objective and subjective nature [1, p. 14]. These conditions influence both the lifestyle of an individual and social groups as a whole. The family, which is a small social group, is also influenced by these conditions.

Family lifestyle, on the one hand, is hidden in its own nature and, on the other hand,

within the social and economic order. The family's own nature, its inner life, can be understood on the basis of an analysis of the complex socio-psychological characteristics that determine the life of each of its members. Such characteristics include emotional, cognitive and behavioural components [2].

The family's lifestyle influences the development of the future personality. Arising as a result of the operation of objective and subjective factors, family lifestyle becomes a background against which the unique social situation of a child's development unfolds [2].

In this publication, we analyse theoretical approaches to studying the lifestyle of families with disabled children. In an attempt to present theoretical approaches, we rely on several provisions.

- We began with an initial provision based on the understanding that the lifestyles of the families we are interested in has not yet been a focus of systematic psychological research and turned to a rather wide group of foreign and domestic psychological works representing various scientific schools and tracked the dominant trends that appear within them.

- The second provision was built on the principle of causation, which allowed us to retrace the evolution of scientific views.

- And, finally, studying the subjects of scientific studies, their contents and contexts using elements of methodological analysis [3] allowed us to interpret the "lifestyle" of families with disabled children in various scientific approaches.

The emergence of interest in socio-psychological research on families with disabled children was preceded by an awareness of the importance of the family environment in rendering help to people with mental disabilities and the beginning of providing such help. Interest in such families developed in the 17th century due to the spread of clinical observations in the field of "child defectiveness", the practice of psychiatry, as well as the successful experience of training of deeply "mentally challenged" individuals by humanist teachers [4]. Still, it took almost two centuries before isolated mentions of the importance of family environment turned into systematic research, becoming a subject of study in various scientific approaches. Dominant social and political, cultural and scientific ideas of that time rejected the worth of such children living with their families, and parents were not allowed to bring up these children.

Since the end of the 19th century and beginning of the 20th century, under the influence of the development of scientific and practical psychiatry, and the opening of the first homes and public institutions for the "mentally challenged", a shift in research interest from primary study of the problems of the "patients" to the problems of their families took place. The first to examine problems of family environment were psychiatrists. They put forth the idea of

the psychological impact of a family on the "patient" and initiated educational conversations with the parents about understanding their children's condition [5; 6]. They substantiated the need to diagnose family relationships and providing patronage for such families in "home care" situations [4, p. 16], as well as organising counselling for parents, [5; 6] etc. These ideas started to gradually penetrate assistance practices for such children and establish the "tradition of using family influence to solve problems related to the treatment and upbringing of a sick child" [4, p. 19].

In the beginning of the 20th century, the first scientific discussions about the traumatic impact of the "mentally ill" on a family appeared. In her scientific monograph, V. V. Tkachiova [4], while undertaking a historical examination of the problems of researching such families, cites one of the most popular psychiatrists of that time, E. Krepelin: "...most of them live for decades in a state of mental disability and complete helplessness and are a heavy burden for their families and community that grows heavier every year" [4, p. 6; 7]. By the middle of the 20th century, these very scientific discussions began to dominate the research papers of psychologists. By summarising the experience of those studies we will try to find key values in understanding and interpreting the dominant ideas about lifestyle of such families.

**The psychodynamic approach** is was one of the first scientific approaches that paid attention to the families of disabled children. This approach is rooted in the classical psychoanalysis of S. Freud. Analysis of internal processes of personality that are outside the threshold of consciousness is traditional for this school. Consequently, it was believed that the birth of a disabled child created an unconscious conflict between the parents' conscious intentions and their behaviour towards that child. The psychodynamic model helps to understand the lifestyle of such a family by analysing the emotional states of the parents, the psychological

defence mechanisms and attitudes towards the child and specialists.

*Understanding the psychological nature of family lifestyle.* While exploring primarily the unconscious maternal experience, the psychodynamic model focuses analysing the universal conflict experienced by each mother in connection with the birth of a child. The essence of the conflict lies in experiencing the inconsistency between the child imagined by the mother and the child she gives birth to. The basis of this phenomenon is the mother's need to perpetuate herself and the fantasy of giving birth to a "perfect" child (embodying all of the mother's best traits), which fills the mother with feelings of joy and pride. Because a child is perceived by a mother as her "own product", he/she is viewed by as the mother's "personal accomplishment".

If the child has disabilities, this inconsistency is too great and the parents suffer from severe psychological trauma. The mother's own significance becomes threatened. The solution to this inconsistency is acceptance of reality and the loss of a "perfect" child. This process is similar to the process of inevitable suffering or regret we experience when someone we love dies. Accepting and resolving the inconsistency between expectations and reality becomes a development task of motherhood or one of the aspects in the development of healthy mother-child and child-parent relationships.

*Parents' emotional experience.* Researchers focus the most attention on maternal feelings of guilt and grief. An analysis of scientific publications reveals a wide range of interpretations in understanding the nature of these phenomena: from their broad generalisation in initial studies to a deeper understanding of their qualitative differences in the individual emotional experience of parents in subsequent ones.

Thus, the appearance of feelings of guilt was first explained through the perception of parents that they were responsible for what happened. A number of studies have noted that guilt experienced by parents play the role of a triggering mechanism for other feelings, such as grief, sadness, aggression and suffering,

etc. Later feelings of guilt can become a "guilt complex", or deep desire on the part of parents to overcome what has happened and compensate for its consequences [8]. The experience of guilt was viewed as a continuous process of self-blame, which influenced mother-child attachment, the psychological state of mothers, close relationships between the spouses and their ability to take care of their own needs [9].

Later, with the development of qualitative research methodology, it was shown that the guilt experienced by parents in connection with the birth of a disabled child remains an invisible phenomenon that is hidden from researchers and a number of unique meanings of this feeling in the individual experiences of parents were described. In the study carried out by C. Nixon and G. Singer [10], feelings of guilt appear as an indication of *cause* (the parents as the cause behind the birth of a disabled child), *morality* (the birth of such a child is a punishment for breaking religious, ethical, or moral social standards), *inconsistencies in the parental role* (an inability to meet the expectations of one's ego and society when bringing up such a child), etc.

The experience of grief for parents of disabled children is a less studied phenomenon. In this connection, the most often cited studies concern *chronic sadness* [11] and *bereavement* [12]. These studies are based on clinical observations of how parents behaved when confronted with their child's diagnosis, as well as subsequent emotional states of parents in the process of treating and caring for their child. The experience of grief was perceived as the universal inevitability of loss. L. Powers [13] noted that for a family the experience of grief was perceived as distress for a child, who has "changed" forever. Moreover, the inevitability of grief was perceived as a necessity in resolving the psychological trauma of parents [14]. These studies thereafter created widespread concern

that the experience of grief by parents is an inevitable consequence of a child's condition, i.e. disability. Based on these studies, the overwhelming majority of psychotherapeutic practices focused on working with *the feeling of grief*.

At the same time, while studying the phenomenon of grief, scientists failed to avoid certain contradictions in understanding it and establish clearer boundaries in its definition. The problematic study of *grief* has given rise to imprecise information concerning its duration, high sensitivity and qualitative manifestations. As a result, the condition of parents who experienced feelings close to grief, such as long-term sorrow or suffering, was also analysed in line with the experience of grief.

*Parental psychological defence mechanisms.* By their nature, according to the traditional Freudian understanding, psychological defences are seen as negative and unhealthy psychic manifestations. This tradition has been also preserved in the psychodynamic approach.

Repression and denial are among the most studied psychological defences inherent in mothers who are faced with the problem of having a child with developmental disorders [15]. Researchers who have studied the attitudes of parents whose children have mental and emotional disabilities describe, first and foremost, states of repressed aggression, passivity and hostility. The emergence of psychological defences, as mentioned above, is facilitated by feelings of guilt experienced by parents and, as a consequence, denial of what has happened. Parental dissatisfaction with the system of professional assistance and services and refusal to accept a child's diagnosis and acknowledge that "there is something wrong with him, in contrast to normal children" were also perceived as causes of psychological defences [16; 17].

Subsequent narrative research revealed a lack of interpretations in the analysis of psychological defence mechanisms. It was shown that social definitions and the linguistic representation of the actual birth of a child in the parents' experience were no less dangerous. The social stigma hidden behind clinical conclusions of

physicians could reinforce negative attitudes of parents and be a separate source of psychological protection [18].

*Attitudes.* The psychodynamic profile of parental attitudes is characterised by neuroticism towards the child and professional community. These attitudes were, as a rule, the result of a process of experiencing psychological trauma and reflected parents' desire to influence the help offered to them. One of the studies, conducted based on analyses of parenting histories, notes that parents had no opportunity to change anything in existing care practices. Any attempts to draw attention to their child's abilities and see him/her as a whole person conflicted with standards that viewed the child either as disabled or deficient [19].

Parents themselves are often on the receiving end of disapproval from medical personnel and teachers. It was believed that parents were passive, that they were not attentive enough to their child's treatment and did not follow the specialists' recommendations. Often the inactivity of parents was perceived as a cause of a child's worsening condition [12]. The negative attitudes of service personnel toward parental participation in helping their child only strengthened their psychological defences and feelings of guilt. A. Solnit and M. Stark, when studying the texts of interviews with specialists, noticed that even parents who were rather committed to the process of helping their child were negatively perceived (for example, as parents experiencing latent feelings of guilt who wanted to compensate for it). Essentially, no matter how the parent responded to the assistance, the family was perceived as unsatisfactory in all of its roles [8].

Thus, the parents were "typified" just like their children. They were pegged as "parents fixated on the problem". As a result, different types of parents were described within the framework of this approach: "committed", "apathetic/passive", "aggressive/hostile" etc. [8].

*Conclusions.* According to psychodynamic tradition, the typical lifestyle of families with disabled children was

understood through an analysis of the internal unconscious reality of the parents, mostly within the context of mother-child relationships. The family's lifestyle in this model was perceived through the prism of "maternal conflict" originating from the moment of birth, which basically gives rise to a "neurotic family lifestyle model". The researchers focused on shattered maternal fantasies and negative feelings in response to the event and planning for the future. In this scientific view of the family, there are strong pathogenetic traditions that doom the family to disease and deny it health [20].

**Social-psychological approach.** The social-psychological approach to the problem we are interested in was inspired, first of all, by the development of structural functionalism and social constructivism. These theories helped in understanding a number of social phenomena that influence the family in the real flow of social interaction [21; 22]. In this scientific paradigm, there is a shift in emphasis to understanding the family lifestyle instead of analysing the internal unconscious reality of the parents (mostly mothers) and what impact these circumstances have on a family. The phenomenological language of this approach includes notions of social and psychological nature, such as values, role expectations, social conflict, adaptation, social deviations and norms, social stereotypes, communication, etc.

*Understanding the psychological nature of a family lifestyle.* In contrast to the psychodynamic approach, which focuses mostly on the nature of internal dynamics to understand a family's lifestyle, the social-psychological approach concentrates its attention on external circumstances (social, economic, cultural, etc.), supporting the view that a family's lifestyle develops under the influence of a certain social reality. When studying these theories, researchers trying to understand why a family lives in this way and not another, creates certain relationships and ties, analyse "social facts"

(values, standards, social institutes, etc.) [23] and "social acts" (social roles, attitudes, etc.) [22].

When integrating some of the provisions of structural functionalism and social constructivism, let us note two most important facts. *The first fact* indicates that any element of social interaction, when performing its particular functions, exists within a social structure or system, which in turn consists of a number of subsystems. Culture plays a central role in ensuring balance and internal homeostasis within a system or the real flow of social interaction [22]. If a deviation occurs in one of the subsystems, a mechanism is triggered to restore the balance, which is analogous to the defence mechanisms in the psychodynamic model. Activation of the balance restoration mechanism shifts the system towards the initial imbalance. External influences and discrepancies within the system require its adaptation and, consequently, a certain level of changes. Equilibrium may be reached, for instance, as a result of changes in the normative structures that regulate social relations [24]. *The second fact* emphasises the idea that social interactions are connected to the beliefs and stereotypes of individuals and represent social constructs that comprise a certain version of social reality.

Therefore, understanding the nature of a family's lifestyle using the social-psychological approach was perceived through the social nature of society itself.

With the involvement of social-psychological strategy, evolutionary tendencies in changing attitudes toward people with disabilities, their immediate environment and the family as a whole are explained and described. The basis for these changes was seen in the need for a so-called paradigmatic shift in the concept of "deviation/disability" in normative and value imperatives of the culture of a certain community [25].

The most striking and truly revolutionary example of such social a shift

is the concept of normalisation. Appearing at the end of the 1950s and beginning of the 1960s in Sweden and Denmark [26] as a response to “discriminatory living conditions in society” for people with disabilities, the concept of normalisation became the main ideological tool of the paradigmatic shift in ideas about norms and values in mid-twentieth century culture within the developed countries of the world. Perceptions of the issue of abnormality shifted from the individual with disabilities to society. As a result, understanding the social and psychological problems of the personality and its value, or a strengthening of the humanistic view of an individual, prevailed over a narrower biological view.

The lifestyle of a family into which a child with disabilities was born, in the social-psychological interpretation, was understood through the experience of novelty shock. This term was coined by W. Wilfensberger [27] and differs from the psychodynamic experience of grief connected with the “loss of an expected ‘perfect’ child”. Novelty shock emphasised the “unexpectedness of the occurred event” and the states of anxiety, confusion and perplexity that parents experience as a result. Instead of the “child’s disability”, the key factor that determined the family’s lifestyle was a result of social communication, social attitudes and the standpoints of professionals and other family members in interpreting what had happened. The researchers saw the lifestyle of such a family as an attempt to resolve the social conflict that occurs in response to an unexpected and undesired event that manifests in chronic suffering. Although a chronic emotional experience is understood as a normal process, this view was not free from the bias that suffering and sorrow represent the dominant

psychological contexts that determine the lifestyle of such a family.

We know that *social stereotypes and deviations* gain their significance in the context of social norms. In modern scientific research, we can distinguish several tendencies in social stereotyping that are not only rooted in perceptions of “developmental disability”<sup>1</sup>, but also in perceptions of “a parent of a child with disabilities”. The first tendency is connected with ideas about disability in various cultures in general and is a rather well-studied phenomenon<sup>2</sup> [11].

The second tendency gained traction thanks to dominant scientific trends and interpretations in academic research. The problem of stereotypes in scientific thinking became the focus in many scientific papers. For instance, S. Ryan and K. Runchwick-Cole [28], after addressing the problem of how to interpret the experience of mothers bringing up children with disabilities, concluded that the vast majority of scientific literature either refers to such mothers as parents “fixated on their problem” or describes them in terms of grief, loss or denial and egoism. In the authors’ opinion, this was not unfounded. First, the problems of parents are most often complex and the possibilities of assistance are rather limited. In practice, as a rule, the family and child support system itself is “rigid”. Secondly, research and practical interest was concentrated mainly on the phenomenon of “incapacity”, within the exclusive borders of which not only children with disabilities, but also their mothers gradually begin to be considered.

The general tendency to analyse parents within the framework of the social deviation phenomenon was also explored by R. Darling [29], N. Breslau, K. Staruch and J. Mortimer [30], etc.

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<sup>1</sup> The social stereotype of this social phenomenon is closest to the notion of “illness”, which has its own interpretation in structural functionalism. For instance, in T. Parson’s theory an “illness” is a form of social deviation or an abnormality, which must be overcome. T. Parson endows the patient with a specific social role – the role of the patient, in which this individual is exempted from the usual social obligations, attempts to recover as soon as possible, seeks competent help and follows physician orders. This interpretation is far from indisputable and is one example of the medical view of “illness” versus “health”.

<sup>2</sup> This scientific analysis is rather widely represented in humanitarian studies, e.g. in a scientific monograph by E. Yarskaya-Smirnova titled “Sociocultural Analysis Atypical (Социокультурный анализ нетипичное™) (Saratov, 1997).

In these studies, the characteristics of family members based on the example of interpretations of high interest by parents in precise diagnostic information about their child fell under a wide range of those deviating from the norm. Such parents were viewed as constructing a pathological/medical image of their child. It was believed that an interest in the diagnosis served the interests of the parents rather than the child. Scientific discussions of this kind had an accusing nature. As the following analysis of such interpretations showed, these accusations were dominated by medical and rehabilitation dominants dictated by political and practical decisions concerning disabled children and adults in society. Social circumstances encouraged parents to use diagnostic labels of their children to address the problems of both the child and the family as a whole. The desire of parents to operate with the most precise diagnoses for their children as possible, firstly, allowed them to protect themselves from being labelled as inadequate/incompetent parents and, secondly, gave parents access to information, resources and support [31].

The cultural value system is reflected in discussions about *parenting' role expectations* and *communication*. In this regard, the phenomena by which parents devalue their main purpose, to raise their child [3; 13] in favour of "interdependence and sacrificing oneself for the sake of others" [33] and helplessness and tension in communication [34], are of special interest.

The devaluation by parents of their role in relation to the child is seen as a result of society's rejection of the child. Despite the fact that self-depreciation is a consequence of peculiarities of intergroup and interpersonal perception, cultural values and normative imperatives play a significant role in the occurrence of this phenomenon. D. Nixon emphasised that, in a society where a child with disabilities is perceived as inferior, his/her parents are rejected and depreciated, deprived of

their main purpose – raising and educating their child [13].

In the research by N. Hampton and F. Xiao, who studied the values of individualistic and collectivist-oriented societies, differences in the level of social stigmatisation of disability were identified. For instance, a high level of social stigmatisation is characteristic for collectivist societies, as dominant values of interdependence and sacrifice for others in these societies are combined with a fear of not being able to do so. An individual in a collectivist society is part of a group in which all its members are equal. In an individualist society, central values are based on the concept of personal goals, as well as the uniqueness and autonomy of each person, which create conditions for independent existence in the context of "uniqueness" despite equal status with others. These studies show that the value system of collectivist societies results in negative attitudes towards people with disabilities and confirms the above-mentioned idea that rejection and depreciation of a person/child with disabilities rejects and devalues his/her loved ones. The lifestyle of families with disabled children in this culture resembles "complete helplessness" or "constant struggle" for the right of the family and child to a dignified life [35].

Researchers consider helplessness and tension in family communication as a complex problem. The absence of relevant support services, especially during the early period of child development, on one hand, and the lack of sensitivity for family culture among specialists, on the other, led to misunderstandings about the context within which the family lives, its values and needs, which resulted in inadequate strategies of help and support. At the same time, researchers believe that the family has certain potential communication aspects that allow it to adapt to family roles and create optimal conditions for child development.

So, in the socio-psychological approach, understanding the lifestyle of a family with a disabled child occurs as part of analysis of the social conflict experienced by a family. The nature of social conflict was perceived as a collision between the family and a certain version of social reality, the cultural imperatives of which pushed the family to the edge of the social norm while devaluating its main purpose – raising a child.

Attempts by the family to “restore balance” conflicted with social beliefs and stereotypes of disability existing in the society. The degree to which a family adapted to a child’s disability depended on its social context. The classic description of the typical lifestyle of such a family in this psychological approach was seen in chronic suffering as the only “response” of parents in these circumstances.

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*(To be continued in our next issue)*

## THEORETICAL JUSTIFICATION OF RUSSIAN LANGUAGE TRAINING METHODS FOR STUDENTS WITH SEVERE SPEECH DISORDERS IN THE CONTEXT OF FORMATION OF KEY COMPETENCES

**L. A. Zaitseva,**

**Senior Research Scientist at the Laboratory of Special  
Education of the National Institute of Education,  
Candidate of Pedagogical Sciences, Assistant Professor**

In connection with new trends in the development and renewal of education in general and language training in particular, the objective of education is shifting to formation and development of competence in graduates of educational institutions. The shift in emphasis from a “knowledge” to a “competence-based” approach to education involves the search for training approaches and methods which ensure that

students are able to use the knowledge they have obtained in various life situations and is reflected in works by A. L. Andreeva, V. A. Bolotov, I. A. Zimniaya, O. E. Lebedev, A. V. Khutorskoy, etc.

The concept of “Russian Language” as an academic area of study, approved by the order of the Ministry of Education of Republic of Belarus on 29.05.2009, notes that the system of teaching the Russian language in general education