



Psychological and Pedagogical Support for the Quality of Life of Persons with Disabilities



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Abstract

The current sociopolitical, socioeconomic, and sociocultural situation in Ukraine is complicated because of the continuing aggression of the Russian Federation and because of significant structural changes associated with global transformation processes of a long-term nature. Under these conditions, the society is looking for ways out of the situation to overcome the consequences of destruction, the decline in living standards, the disintegration of the system of values, social inequality that emerged, and deterioration of the quality of social institutions that implement its full-fledged activities. At the same time, the situation of socially disadvantaged groups of the population, among which the person with disabilities (hereinafter - the disabled) occupies a leading place, as the former mechanisms of solving problems do not work, and the new ones have not yet been formed, is worsening. Such people constantly have feelings of unsettlement, helplessness, and impasse, which cause the emergence of aggressive reactions, and sometimes complete indifference. As a result, social tension develops in relationships in society, which becomes a source of threat to social security, especially during the COVID-19 pandemic and military operations, which leads to overloaded health care systems with high level registered cases of hospitalizations of wounded troops and deaths. This situation causes a rapid increase in the number of people with disabilities in Ukraine and beyond, which poses a threat to social well-being.

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1 Introduction

As of the beginning of 2020, 2.7 million people in Ukraine had disabilities, including 222.3 thousand people with group I disabilities, 900.8 thousand people with group II disabilities, 1416.0 thousand people with group III disabilities, and 163.9 thousand children with disabilities. In the conditions of full-scale war, the situation with the disability of Ukrainians worsened. In the early 90's the problem of rehabilitation of persons with OMH acquires a new urgency, scientific interest in this problem arises, and the need to develop a new theoretical and methodological basis for the study of the problem of rehabilitation arises. At the same time:

- first, a worldwide trend of increasing attention to the socialization and adaptation of such people was developing;
- secondly, there was a sharp increase in the number of people in this category

A characterization reflecting current trends in human development would be incomplete if it did not include the concepts of “persons with disabilities” and “disability”. To adapt to the new conditions of life, each person with disabilities needs such an important social capital, a major resource, as health. At the same time, it must be borne in mind that in the interaction of society with citizens who are experiencing problems with disabilities, problems arise that reflect negative attitudes in dealing with a set of issues and situations ([Okhabska et al., 2022](#)). Therefore, the rehabilitative approach to solving this problem is the most successful because it means that this society is aware of the existing reality.

Considering social, pedagogical, and psychological rehabilitation as a social phenomenon, the main content of which is the process of realization, as well as the discovery and potential of such people, it should be emphasized that society needs to create conditions that promote equal interaction with people with disabilities ([Saitta et al., 2019](#); [Annaswamy et al., 2020](#); [Freeman et al., 2015](#)). In clinical practice, the rehabilitation specialist is predominantly interested in those aspects that change in connection with the illness and treatment situation, primarily patients' satisfaction with their physical functioning, and the focus is on the restoration of the person's somatic state, while the social and psychological aspects of the illness are often left out.

In this situation, the specialist rehabilitator has to inspire his or her patients, instilling faith in their strength and the potential and reserve capabilities of the body. At the same time, he performs the functions of a psychologist and educator, which help to overcome the client's lack of confidence in his abilities, inferiority, and insufficiency.

The goal of rehabilitation influences, as a system of socio-economic, medical, pedagogical, and psychological measures aimed at the fullest possible compensation of restrictions in the vital activity of a citizen, caused by a stable disorder of body functions, is the social adaptation of the suffering citizen of society, restoration of his social status, strengthening the material base, and in general, optimizing all parameters of quality of life ([Herasyenko et al., 2019](#)).

According to the definition of the World Health Organization, quality of life (QOL) is individuals' perception of their position in life, in the culture and system of values in which they live, following their goals, expectations, norms, and needs. Quality of life is determined by physical, social, and emotional factors of human life activity, the influence, and significance of which are beyond doubt. Quality of life is a person's level of comfort both within oneself and within one's society. According to the UN, the social category of QOL includes twelve

parameters, with health in the first place. The European Economic Commission has systematized eight groups of social indicators of QL, with health also in the first place. Consequently, health-related QOL can be considered an integral characteristic of the physical, mental, and social functioning of a healthy and sick person, based on his subjective perception of all spheres of life activity (Horetska, 2013).

Today more and more scientists are inclined to consider the category “quality of life” as a psychological and pedagogical one. Pedagogical context of the quality of life according to their research is understood as: a form of the socio-pedagogical system; a set of indicators of the degree of personal vitality; subjective and objective characteristics of the individual, in our case with HIA, and conditions of its existence. This allows us to consider the “quality of life” in a pedagogical context as an evaluative category, generally characterizing the state of the relationship between the environment and persons with disabilities in general. This concept includes components: breadth, intensity, awareness, generalizability, emotionality, social activity, and mobility, aimed at meeting the basic needs of the individual and affecting its development and the formation of subjective satisfaction with the conditions of life activity (Miliutina & Ivashova, 2017).

In this context, such a search for a solution to the problem of the development of persons with disabilities is advisably conducted based on the synergetic paradigm as a methodology for developing innovative problems in the field of psychological and pedagogical support of personality. In our study, we focus on children with disabilities as the most vulnerable and unprotected category of the population, which requires special attention (Sofija & Ivan, 2018).

2 Materials and Methods

The theoretical and methodological basis of the study consisted of:

- at the philosophical level study QOL, according to many scientists, there are factors influencing the satisfaction of personal desires, the ability to improve and spend life forces, and the social well-being of the individual and his family; the concept of QOL is substantiated by the integral approach (R. Inglehart, S.A. Aivazian, P.S. Mstyslavskiy, A. Campbell, A.I. Subetto, etc.);
- In the general scientific - the theory of personality self-realization (C. Rogers, etc.); methodology of pedagogical research;
- at the specific scientific level - real approach to defining QOL, based on statistical report data, objective information (E. Wiener, G. Kahn, D. Bell, O. Toffler, Z. Bzhezinskiy, etc.); theories of the social and historical development of the category “quality of life”; the concept of the patient role by T. Parson; social interaction theory by E. In our opinion, the innovative nature of the synergetic approach in psycho-pedagogical science and practice lies in the possibility of implementing ideas about the mechanisms of deployed formation of the full-fledged structure of the personality's life activity. This allows us to consider the synergistic approach as a methodologically effective means of psychological and pedagogical support for the development of persons with disabilities. Personality-activity, individual-creative synergetic approaches that consider personal development as a holistic, multifaceted, multi-level reality. Developed in modern psychology and pedagogy concepts of personality as a system of relationships, the relationship between the social environment and the individual, about “independent living” in social work with people with disabilities; principles of social rehabilitation of people with disabilities: equal social rights and opportunities for individuals;

The theoretical and methodological basis of the study also consists of the psychology of abnormal child development, psychology of child-parent relationships, modern ideas about the peculiarities of child-parent relationships in families raising children with developmental disorders, theory and practice of group correction and parental counselling (R.M. Hodapp, G.S. Singer, K. Scorgie, D. Sobsey). E. Schaefer's PARI technique was used in the research to study general parental attitudes, to study the style of parental attitude towards the child the corresponding questionnaire of V.V. Stolin and A.Ia. Varha was used. Reliability and trustworthiness of the research results were achieved by the representativeness of the study sample and the application of the Student's test.

3 Results and Discussions

The paradigm of psycho-pedagogical support has gained particular popularity in the development of models of personality formation and development. Psychological and pedagogical support is based on the concepts and pedagogical ideas of the personality formation process, education, development, and socio-pedagogical work. Psychological support and provision is a holistic process over the subject of education, including the study, formation, development, and correction. Scientific substantiation of the theory and practice of socio-pedagogical basis of personal support is considered in the theoretical developments of foreign psychologists and educators: R. Burns, S. Freud, E. Erikson, K. Jung, E. Berne, Abbey A., Andrews F., Glasser W., etc. The problem of psychological and pedagogical support and accompaniment is considered a paradigm that combines the pedagogical, and professional activities of a specialist to implement the conditions for achieving optimal full learning and harmonious development of personality.

In fundamental studies of domestic pedagogy, social pedagogy, psychology, social psychology, developmental psychology theories of communication and personality relations; the position on the role of activity in personality development; provisions on types of activities and their interrelation with personality development are of significant, conceptual importance.

However, despite a sufficiently large number of publications on the problem of psychological and pedagogical support of the process of personal development and formation, the specifics of psychological and pedagogical accompanying activity in inpatient medical institutions regarding the categories accompanied by disabilities due to health conditions are insufficiently studied (Sukmana et al., 2021). Therefore, the problem of psychological and pedagogical support for this process belongs to the category of understudy.

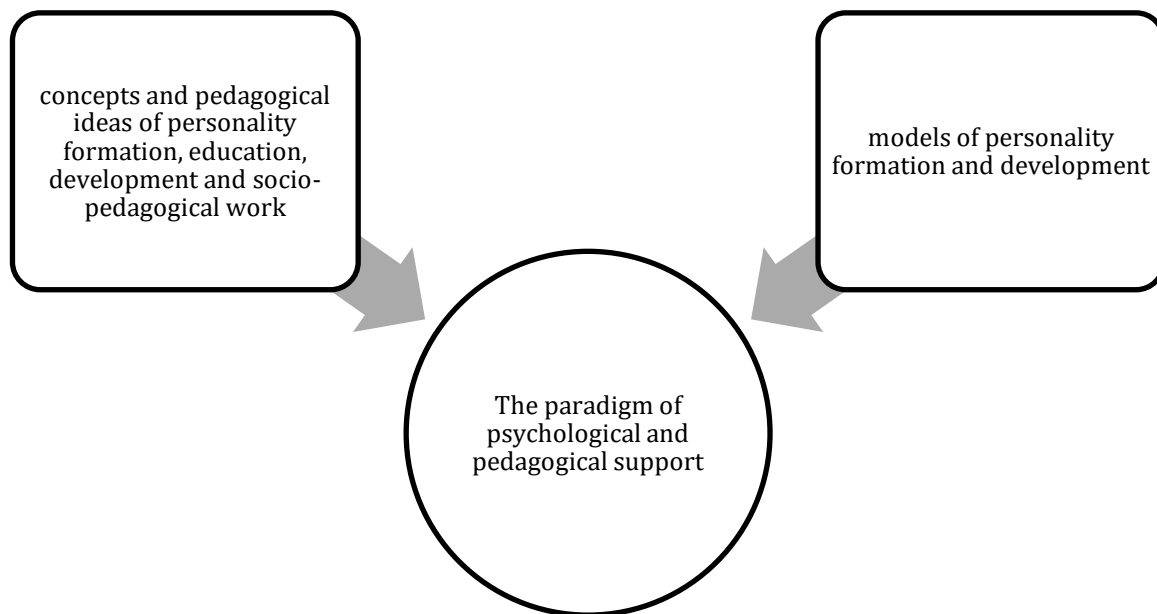


Figure 1. Elements of the paradigm of psychological and pedagogical support

In addition, despite the impressive figures of research on QOL of healthy people, the problem of optimization of QOL of persons with disabilities remains problematic. Psycho-pedagogical and scientific-methodological sources practically lack information about subjects of the process of optimization of disabled people's life with disabilities, approaches, and principles of their organization, implementation of consistency, and objective and subjective assessment of its results. Therefore, quite a large number of people with disabilities, both adults and children, are actually "left out" of life, becoming, at worst, patients of special medical institutions, and at best, isolated in the narrow circle of relatives and loved ones and feeling like an eternal "burden" to others.

The extensive character of development of the analyzed scientific direction, a variety of theoretical approaches to the definition of QOL, and its measurement in many respects have defined the contradictory condition in recent years. During the introduction of the term “persons with disabilities” into the active professional and terminological field, the necessary analytical study of existing not only in Ukraine but also abroad most often used, neutral, correct terms used in pedagogical science has not been conducted. It is known that the term “therapeutic pedagogy” means the treatment of persons with disabilities by pedagogical methods. It is not correct for pedagogy to take uncharacteristic actions and introduce itself into the path of medical professional activities. At the same time, persons with disabilities quite often need not only medical care but also corrective pedagogy of medical support.

Pedagogical science has never abandoned this term, the more so the term “remedial pedagogy” is generally known and widely used among foreign and domestic specialists

In our opinion, the requirements of modern society for the development of human social attitudes, allowing to adapt to new social conditions, a contradiction with the traditional system of attitude to the individual with disabilities, as unable to independently improve the quality of his life. On the other hand, the modern requirement of society in the development of flexible thinking rationally acting individual with a focus on creativity and self-realization encounters the lack of innovative, technological, and methodological approaches, mobile modelling complexes of its formation in conditions of limited opportunities for life activity due to health conditions. Another problem is the growing requirements stated from the state level to improve the quality of life of persons with disabilities, while there is an obvious lack of theoretical and methodological foundations and conditions of pedagogical support for this process. The objective need of today is to create a system to optimize the quality of life of persons with disabilities based on psychological and pedagogical support and innovative methodological approaches to this process (Augustsson, 2010).

The effectiveness of psychological and pedagogical support of the system of optimization of the quality of life of people with disabilities is provided by the development and implementation of an integrative personal and social concept of psychological and pedagogical support of the system of optimization of the quality of life of people with disabilities, the following ideas are a priority:

- the category of QOL is considered by the subjects of psychological and pedagogical support in the pedagogical field as the optimization of subjective positive perception of persons with disabilities in their life activities;
- psycho-pedagogical support is based on the principles consistent with the synergistic approach that promotes holistic rehabilitation and socialization of persons with disabilities through the introduction of innovative, health-saving, psycho-pedagogical technology, relevant forming and teaching her a new, positive stereotype in life ensures her successful entry into macro and micro-society, which in turn leads to a significant improvement in QOL of persons with disabilities;
- the process of psychological and pedagogical support of the system to optimize the quality of life of persons with disabilities is carried out with the following psychological and pedagogical and medical-organizational conditions;
 - a) development of individual psychological, pedagogical and medical rehabilitation programs to optimize the quality of life of persons with disabilities;
 - b) implementation of modern innovative technologies of psychological and pedagogical support of the system to optimize the quality of life of persons with disabilities;
 - c) organization of training and retraining of rehabilitation specialists capable of carrying out consistent, step-by-step psychological and pedagogical support for the system of optimizing the quality of life of persons with disabilities in inpatient care facilities.

The most demanded sphere of psychological and pedagogical maintenance of the quality of life is child-parent relations. It is caused by the influence of microsocial conditions on the formation of the child's personality and his or her socialization. The nature of parent-child relationships in families determines a person's personal development and further determines the success of socialization of a child's personality (Papakostas et al., 2004). The social adaptation of children with complex developmental disorders directly depends on parental

behaviour. Deficiencies in a child's cognitive activity impede the formation of his or her full-fledged interaction with parents, which hinders the assimilation of social experience, the formation of ways of interpersonal communication, and inhibits emotional development. The features of a child with developmental disorders' relationships with others are secondary complications of the underlying defect and are more amenable to correction than primary disorders. Moreover, the relationship of the developmentally disabled child with others is the most important factor in his or her personal development. Psycholinguistic characteristics of personal interaction of subjects in the educational space in the conditions of the COVID-19 pandemic and military aggression are also important (Truba et al., 2022). Many legal issues in the formation of child-parent relationships between themselves and with the outside world (Zaika, 2018). Consequently, the role of the family in the social adaptation of the child is huge. The analysis of the psychological and pedagogical provision of children's quality of life through the prism of specificity of child-parent relationships in families with children with complex developmental disorders is relevant and significant both in theoretical terms, because of the raw nature of this topic, and from the practical point of view (Cooke et al., 2020; Sonuga-Barke, 2002).

The need for psychological support for families bringing up children with complex developmental disorders is confirmed by the following research results: 80% of mothers and 60% of parents are characterized by an emotionally negative self-assessment; only 19% of parents experience emotional acceptance of the child, and 28.6% experience emotional rejection of the child (Shevchuk, 2021). This tendency is even more characteristic of families with children who have disorders of psychophysical development. More than half of the families have a negative impact on the development of, for example, a mentally retarded child, and only about 40% of families have a positive impact. These statistics point to the need to organize psychological and pedagogical support and accompaniment for families raising children with complex developmental disorders. There is little research into the specifics of child-parent relationships in families of "special" children. In the works of many researchers the idea of the mutual influence of parents and children on each other is underlined (Shevchuk, 2021). On the one hand, parental attitudes can cause secondary disorders in the child, and on the other hand, child psychopathology leads to various distortions of parental relations. Parents raising a child with psychophysical disabilities are in a situation of so-called parental stress, the stages and content of which have been fairly extensively studied in psychology (Hodapp, 2007; Scorgie & Sobsey, 2000; Singer, 2006; Chebotar'ova et al., 2019). In particular, sources have described processes of personal transformation when experiencing a crisis (Zaika, 2014, Zaika & Morhun, 2021). Research shows that mothers of such children are more depressed, more preoccupied with their children, and have more difficulty with self-control of negative emotions about their children than mothers of normal children (Hodapp, 2007). There is a dearth of research in domestic psychology on the influence of the nature and degree of pathology on parental attitudes toward children with complex developmental disabilities. Therefore, it is important to conduct comparative studies of parents who have children with different types of dysontogenesis.

The author's study involved 472 families, of which 152 had children with complex speech impairments combined with intellectual disability, 136 were raising children with musculoskeletal disorders combined with intellectual disability, and 184 were families with children with normal development. When comparing parents of children with musculoskeletal disorders combined with intellectual disability and parents of children with complex speech and intellectual disabilities, it was found that the first group of parents had significantly higher scores on the parent-child relationship test rejection scale ($t_s = 2.04$, $p = 0.045$) than the second group of children. Consequently, parents emotionally reject their mentally retarded children with a musculoskeletal disability to a greater extent than parents of children with speech and intellectual disabilities. This is because parents of children with speech and intellectual disabilities have a more positive pedagogical prognosis for bringing up and teaching children with such disabilities, and, consequently, a more successful social adaptation of such a child in the future is possible. The difference on the infantilization scale of the questionnaire by V.V. Stolin and A.Ia. Varha ($t_s = 3.05$, $p = 0.0032$), that is, parents of the first group perceive their children as more infantile, incapable of socialization, failing, losers. This parental attitude is one of the most serious factors hindering the social development of a child with mental retardation and locomotor disorders, unlike parents of children from the second group whose scores on this scale are not critically different from those of parents of children without developmental defects. No more statistical differences were found in the groups of parents under study according to the results of the Varha-Stolin test, and no statistically significant differences were found on the PARI questionnaire. Thus, the only difference in parental attitudes toward mentally retarded children with locomotor disorders and children with complex speech and intellectual disabilities lies in a

combination of the former having a higher level of emotional rejection and infantilization of the child at the same time. Such attitudes can be caused by the presence or absence of hope for improvement of the child's condition. If there is no likelihood of a sharp leap in the child's intellectual development, parents are disinclined to notice and support signs of the child's successful mental development. Even more, differences were found between each of the groups considered and parents of children with normal development. A number of these differences coincide. Consequently, the PARI scale's "Keeping Children Out of Difficulties" expression is higher than that of parents of children with normal development in both the group of parents of mentally retarded children with locomotor disorders ($t_s = 2.16$, $p = 0.033$) and the group of parents of children with speech and intellectual disabilities ($t_s = 2,51$, $p = 0,014$).

Table 1
Peculiarities of attitudes of parents of mentally retarded children with locomotor disorders and parents of children with normal development (based on the results of the PARI survey)

PARI questionnaire scales	Parents of mentally retarded children with locomotor disorders		Parents of children with normal development		Student's t-test value	The significance level of the Student's t-test
	Arithmetic mean	Standard deviation	Arithmetic mean	Standard deviation		
Keeping your child from hardship	63,648	2,88	58,784	2,16	2,162	0,033*
Parental irritation	63,648	2,07	59,044	2,37	2,2667	0,026*
"Parents" suffering	62,352	2,56	55,912	3,19	2,4231	0,017*
Approval of the child's activity	56,352	2,3	61,48	2,05	2,6246	0,01*
PARI Factor Democratism	236,588	6,31	247,564	4,3	2,3118	0,023*

Table 2
Peculiarities of attitudes of parents of children with complex speech defects and mental development disorders and parents of children with normal development (according to the PARI questionnaire)

PARI questionnaire scales	Parents of mentally retarded children with locomotor disorders		Parents of children with normal development		Student's t-test value	The significance level of the Student's t-test
	Arithmetic mean	Standard deviation	Arithmetic mean	Standard deviation		
Keeping your child from hardship	63,842	1,98	58,78	2,16	2,514	0,014*
Parental irritation	62,844	1,31	50,04	2,37	2,206	0,03*
"Parents" suffering	53,684	2,74	48,36	3,16	2,044	0,044*
Approval of the child's activity	14,395	2,57	62,68	2,64	2,235	0,028*
PARI Factor Democratism	57,58	2,65	61,48	2,05	2,515	0,014*
Keeping your child from hardship	237,368	5,19	247,56	4,3	2,462	0,016*

Consequently, child protection is a similar trend in parental attitudes toward children with intellectual developmental problems. Similarly, the PARI Parents' Annoyance scale of the PARI test differed from the scores of parents of mentally retarded children with cerebral palsy ($t_s = 2.27, p = 0.026$) and the group of parents raising children with speech and intellectual disabilities ($t_s = 2.21, p = 0.03$). Consequently, parents of children with intellectual disabilities try to protect their children from the difficulties, and difficulties of the world around them, at the same time it is one of the frustrating factors manifested in increased irritability of parents. Also, statistically significant differences were found between the group of parents raising children with normal development and the groups of parents of children with complex developmental problems, on the PARI Parent-Child Equality scale. Differences in the group of parents of mentally retarded children with cerebral palsy ($t_s = 2.28, p = 0.025$) and the group of parents of children with speech and intellectual disabilities ($t_s = 2.23, p = 0.028$) indicate that these parent groups do not perceive their children as equal partners in family communication. Children do not have equal rights with their parents in intrafamily interaction. At the same time, differences were observed on the "Encouragement of child activity" scale between the groups of parents raising normal children, the group of parents of children with mental retardation and locomotor disorders ($t_s = 2.62, p = 0.01$), and the group of parents of children with speech and intellectual disabilities ($t_s = 2.51, p = 0.013$). That is, parents of children with intellectual developmental problems do not show encouragement for their child's independence and activity. So, we assume that parents do not give the child the opportunity to express his/her opinion, do not take it into account, do not communicate with him/her as equals, do not share, and do not encourage his/her interests. All these features of parental guidance indicate a lower level of democracy in families raising children with intellectual disabilities compared to families with normal children. This is confirmed by the differences in the factor "Lack of Democracy in Relationships with the Child – Democracy" of the PARI questionnaire. The differences in the scores of the corresponding factor between the parents of children without handicaps and the parents of mentally retarded children with locomotor disorders ($t_s = 2.31, p = 0.023$), and between the parents of children with speech and intellectual disabilities ($t_s = 2.46, p = 0.016$) are statistically significant.

The results we obtained on the PARI questionnaire are confirmed by the results of the methodology of V.V. Stolin and A.Ia. Varha. The scores on the "Authoritarian Hypersocialization" scale in the group of parents of children with intellectual problems are significantly higher than in the group of parents of children with normal development. The differences between the scores of the parents of normal children and the group of parents of children with intellectual and locomotor disorders ($t_s = 3.42, p = 0.0009$) as well as the group of parents of children with speech and intellectual disabilities ($t_s = 2.14, p = 0.035$) are statistically significant. So, parents of children with intellectual disabilities are more irritable, do not perceive their children as equal communication partners, do not encourage their activity, are less democratic in their interaction with the child, and are prone to harsh disciplinary requirements. Such parental instructions and attitudes toward children can be caused by a psychological factor, since parents perceive their children as sick, needing special care, indulgence, or pity, while at the same time the child is irritating because he or she is different from others, slow in development; a social factor - rather strict social requirements for the child's behaviour make parents strictly control their "special" children, most often they choose the authoritarian style of education as the easiest for themselves and the most "understandable".

By comparing the results of the parenting groups in our study, we found some differences between them. The PARI survey results on the scale "Encouragement of child's dependence on parents" differ significantly in the group of parents of children with speech and intellectual disabilities and the group of parents of children with normal development ($t_s = 2.044, p = 0.044$). That is, parents of children with developmental disabilities are more inclined to encourage their child's dependence and consider him or her to be non-self-sufficient and infantile. Such character of the parental case can interfere with the formation of independence and slow down the rate of mental development of the child. The scores of the group of parents of children with motor and intellectual disabilities on the "Suffering" scale of the PARI questionnaire differ significantly from the scores of normally developing parents of children ($t_s = 2.42, p = 0.017$). That is, parents of children with motor and intellectual disabilities are more likely to perceive their role as a father as requiring sacrifice and a lot of restrictions. This may be because a developmentally disabled child requires more attention, care, and effort during parenting. Parents of a developmentally disabled child often have to make drastic changes in their lifestyle, so they tend to perceive the parental role as "suffering". The most significant are the differences in the indicators of the rejection scale of the V.V. Stolin and A.Ia. Varha in the group of parents of children with motor

and intellectual disabilities and the group of parents of children without malformations ($t_s = 4.73$, $p = 0.00001$). Parents of children with motor and intellectual disorders are more inclined to perceive their child as unfit and a loser, and often experience irritation, and resentment against their children, they are less likely than parents of children with normal development and parents of children with speech and intellectual disorders to trust their child. shy about their children and try to limit their contact with others. The difference on the infantilization scale of the V.V. Stolin and A.Ia. Varha between the indicators of the group of parents of children with normal development and parents of children with motor and intellectual disorders ($t_s = 2.87$, $p = 0.005$), who perceive their children's interests and judgments as not serious or meaningless, therefore they try to shield them from the difficulties of life and strictly control their actions. This is due primarily to the fact that the child is developing slowly, it is difficult to adapt to society, and parents try to help him or her, while often perceiving him or her as a failure. So, parents of mentally retarded children more often than parents of normal children perceive their role as "martyrdom". And more than parents of children with speech and intellectual disabilities and parents of children with no developmental disabilities are prone to emotional rejection of their child, his infantilization.

The study described above has demonstrated one way of psycho-pedagogical quality of life for children with disabilities. In the scientific discussion, scientists try to influence the quality of life of children with disabilities in different ways. Below we look at the most relevant applied research on this issue. Thus [Jaramillo-Alcázar et al. \(2022\)](#), investigating autism spectrum disorder (ASD) argue that encompasses some neurodevelopmental disorders that begin in early childhood and affect development. This condition can have a negative impact on the acquisition of knowledge, skills, and abilities, such as communication. Over time, different techniques and methods of teaching and communicating with children with ASD have been put into practice. With rapid advances in technology, particularly in smartphones, researchers have created creative programs such as mobile serious games to help children with ASD. However, usability and accessibility have not often been considered in the development of this type of program. For this reason, in their work, the researchers believed that usability and especially accessibility were very important factors in the quality and effectiveness of serious mobile games. Their approach has two important components: including accessibility as a fundamental requirement for the development of a serious mobile game and proposing a method for developing this type of program for children with ASD, a method that other developers can use.

[Russell & McCloskey \(2016\)](#), conducted a study that made significant contributions to the identification of medical, genetic, and environmental factors associated with autism spectrum disorder (ASD). The specific aetiology associated with the diagnosis remains unclear, although prevalence statistics continue to rise, with profound implications for families and their primary care providers. Support service professionals face significant challenges in the complex treatment of this complex neurobehavioral and developmental disorder. Children with ASD have a significantly higher risk of unmet health care needs, and parents report less satisfaction with their care, although the current literature does not fully explain why this problem remains. In this study, parents were looking for the missing answers needed to inform practitioners. Eleven parents of children with ASD participated in the study. Parents' perceptions of care were examined using the Interpretive Phenomenological Analysis (IPA) and Measure of Care (MPOC-20) to illuminate and describe their lived experiences of raising children with ASD and interacting with their primary care providers. Most parents used their child's primary care providers for general health support, and many felt that their primary care providers were unable to cope specifically with their child's ASD. Most did not rely on behavioural management support at home and school or identification of community and mental health resources, although many struggled with unresolved needs in both areas. Using parental perceptions to emphasize deficits in practice can provide the basis for more comprehensive, family-centred models of care.

[Carey \(2021\)](#), conducted a study with a focus on psycho-educational support for health professionals, including medical geneticists and genetic counsellors, who have much to learn about the experiences of parents raising and caring for a child with a rare disease or developmental disability. Knowing and understanding the challenges of caring for a child with conditions such as Down syndrome and Wolff-Hirschhorn syndrome is at the core of the practice of genetic medicine. Understanding these experiences can come from actively listening to stories and deeply reading memoirs and stories authored by parents of children with these problems. A recent book, *Raising a Rare Girl: A Memoir*, by writer, poet, and teacher Heather Lanier, is relevant and prototypical of this genre. Spending effort contemplating parenting stories provides a valuable lesson in narrative medicine and the experience of compassion for a family's plight.

Downes et al. (2022), in their study, investigated how parenting couples use their relationships to support each other after their child's autism diagnosis, assessing the role of dyadic coping and sense of parenting competence as predictors of quality co-parenting. Mothers and parents raising a child on the spectrum (N = 70 pairs) individually completed self-assessment questionnaires measuring stress ratings, dyadic coping, sense of parenting competence, and shared paternalism. Parents were recruited 1-36 months after their children's autism diagnosis, and data were analyzed using an actor-partner interdependence model. Dyadic coping and parents' sense of competence were related to their level of shared parenting. The influence of a partner was found to be significant because dyadic coping was positively related to shared parenting, and a higher sense of competence among parents suggested shared parenting with mothers. Further research is needed to understand how these effects develop over the stages of child development. Both partners were asked to complete identical questionnaires to assess how they perceived the experience of having a child on the autism spectrum, how they used their relationship to support each other during stressful situations, how competent they felt they were in performing their paternal tasks, and the paternal relationship . to explore how they worked together as a team when raising their child. Statistical methods were used to see the influence of the mother and father on each other. In general, parents who felt more competent and supported by a partner worked better as a team to raise their children on the spectrum. Parents were more invested in the shared paternal relationship when mothers felt more supportive parents. Mothers were more invested in a shared parenthood relationship when parents felt more competent in raising their children.

Green et al (2021), conducted a comprehensive study that found that parents of children with autism have greater mental health problems compared to other parents. Although several studies have examined factors related to the mental health of parents of children with autism, factors affecting and contributing to well-being remain poorly characterized. Parents of young children with newly diagnosed autism may also be particularly vulnerable to stressors affecting mental health and well-being. Raising a child with autism is associated with mental health issues. Various factors, particularly child, parent, and family/socioeconomic characteristics, are likely to influence poor parental mental health. However, little is known about what influences well-being (as opposed to mental health) among parents of young children recently diagnosed with autism, who may be particularly vulnerable. The authors examined childhood, parenting, and family/socioeconomic factors associated with mental health and well-being in a sample of 136 parents of preschool-aged children. Parent mental health was associated with both child-related factors (i.e., the severity of autism symptoms) and parent-related factors (i.e., personality traits reflecting a tendency to experience negative emotions). In contrast, other than mental health problems associated with well-being, only other parent-related characteristics (rather than child characteristics) were associated with well-being. These included personality traits reflecting a tendency to be more extroverted/communicative as well as mindfulness. Other factors related to the child and family/socioeconomic context (including household income, and parental education level) were not associated with mental health or parental well-being in this sample. These results support the idea that poorer mental health and well-being are not simply the opposite of each other. That is, while the two factors were related, they were related to different personal characteristics. Perhaps most importantly, the relationship between well-being and mindfulness, a personality characteristic that parents can improve, suggests that mindfulness-based interventions may be useful in directly supporting parental well-being in the context of raising a young child with autism.

Meleady et al. (2020), summarized the conceptualization and measurement of positive contribution in the literature and found related child, parent, family, and contextual factors based on a systematic review of the experiences of studies measuring positive contribution among parents of children with ASD (<18 years). The electronic database was searched using Medline, PsycINFO, CINAHL, ERIC, and Embase: 94 articles were identified for full-text review and 26 studies were selected. The quality of the studies was assessed, and the data were summarized according to the review objectives. Results showed that the selected studies conceptualized positive contributions in nine different ways. Ten standardized self-assessment questionnaires, one non-standardized questionnaire, and one closed-ended question were used to measure these constructs. Variables associated with higher positive contributions in this group included older child age, ethnic minority status, maternal status, higher psychological well-being, personal resources, relationship satisfaction, social support, and story writing. This review verified prior reports of positive contributions from parents of children with ASD and highlighted potential areas of support.

Hill et al. (2020), conducted a study to examine the possible outcomes of an intervention on the offspring of individuals (now parents) who participated in the “Raising Healthy Kids” prevention intervention in elementary schools. This non-randomized controlled trial was conducted in public elementary schools serving high-crime areas in Seattle, Washington. The panel originated in Seattle, but over time it has been investigated locally and out of state. The data analyzed in this study were collected from September 1980 to June 2011 with follow-up on firstborns (ages 1 to 22) of 182 parents who were in a total intervention vs. control childhood setting. Their children were evaluated in 7 waves in 2 blocks (2002-2006 and 2009-2011). Data were analyzed from September 2018 to January 2019. Intervention: in grades 1-6, the Raising Healthy Kids intervention provided elementary school teachers with classroom management and learning techniques, and first-generation (G1) parents with skills to facilitate opportunities for active participation in the classroom and family, and second-generation (G2) children with social and emotional skills training. Outcomes examined in third-generation offspring (G3) were self-regulation (regulating emotions, attention, and behaviour), cognitive abilities, and social abilities. Risky behaviours, including substance use and delinquency, were examined between the ages of 6 and the completion of the study. The early onset of sexual activity was investigated from age 13 to completion of the study. Intention-to-treat analyses were monitored for potential misleading factors. A total of 182 G3 children were included in this analysis (72 in the full intervention and 110 in the control condition; the mean age at the first wave of data collection was 7 [range, 1-13] years). Significant differences in the offspring of parents who participated in the intervention were observed in 4 domains: Improved early child developmental functioning (age 1-5 years; significant standardized range β , 0.45-0.56), less teacher-rated behavioural problems (age 6-18 years, significant standardized range β , -0.39 to -0.46), higher academic ability and teacher-rated performance (age 6-18 years; significant standardized range β , 0.34-0.49), and children's lowest risk behaviour (age 6-18 years; the odds ratio for any drug use [alcohol, cigarettes, or marijuana], 0.27 [95% CI, 0.10-0.73]) Benefits explored the benefits of the intervention in childhood for the target generation, showing that additional benefits could be realized in the next generation.

Tekola et al. (2020), examined perceptions and experiences of stigma among parents of children with developmental disabilities in Ethiopia and elucidated predisposing and protective factors of internalized stigma from the perspective of the parents themselves. The authors conducted in-depth interviews with eighteen parents and analyzed the data using thematic analysis. Parents experienced different forms of stigma directed at their child (public stigma) and themselves (courtesy stigma). Some parents also described how they isolated themselves and their children from social life (partnership stigma). Parents felt the negative effects of stigma on their child's life with sibling developmental disabilities and themselves. Most parents also described examples of positive responses and support from their own family and community. Participants' accounts indicated contributions of support, and positive feedback from the general public came mostly from those who were more aware of the developmental disorder. Not all parents in our study perceived the stigma directed at them. While the family's perceived support and acceptance and increased awareness of developmental disorders helped some parents not internalize stigma, the perceived lack of social support and acceptance made some parents vulnerable to internal stigma. These findings may prioritize anti-stigma interventions. Awareness-raising interventions targeting the community as a whole, as well as interventions targeting the parents themselves, can be helpful. Interventions should consider the well-being of the entire family, rather than focusing only on individuals.

4 Conclusion

The results of the study indicate a high severity of emotional rejection and infantilization of the child in the group of parents of children with motor and intellectual disabilities. Therefore, we can assume that the irreversibility of these defects affects the nature of parental attitudes. Narrower compensatory abilities of the child and less positive pedagogical prognosis cause parents to have a complex set of negative emotions reflected in the specifics of the attitude toward the child with intellectual underdevelopment and locomotor impairment. If we summarize the results of the comparative analysis of the three groups of parents, we can say that the most unfavourable child attitudes and nature of attitudes are demonstrated by parents raising children with motor disabilities and mental retardation. Parents of children with intellectual disabilities feel an acute need for qualified psychological aid. They are often depressed and feel guilty because of the birth of an abnormal child;

they experience social isolation and frustration with their basic needs. Systematic corrective work promotes a decrease in the emotional tension of parents and a change of attitude toward the child, as well as an increase in their level of competence in educational questions; however, programs of psychological and pedagogical support and supervision of families with children with complex developmental disorders are in their formative stages. Having read the experience of other researchers, we can state that the fragmented nature of sample research does not allow us to extend the experience of psychological and pedagogical support to the broader population in different countries. In the future, there is a need for closer cooperation with researchers from other countries to universalize psychological and pedagogical support and accompaniment of children with disabilities.

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