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THE QUALITY OF LIFE OF LIFE OF THE DISABLED CHILDREN: FUNCTIONING WITHIN THE FAMILY

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SUMMARY

The functioning of a disabled child is linked to multiple difficulties and problems unexperienced by fully able children. The life opportunities of these children will to a large extent depend on what social competence, predisposition and potential they develop at an early stage of life. Therefore, the quality of life of the disabled child depends greatly on the living conditions of their family. That is why the role of the disabled child's family is so important in the process of preparing the child for as independent a life, as possible. Poor health conditions and disability are among the reasons for adults' limited professional activity and the poor material conditions of the entire family. Limited family potential may lead to farreaching consequences for a child's current development and his or her future life situation. Disability in childhood carries risks of social exclusion from education and peer groups as well as from the labour market in future adult life, especially if the child grows up in privation. In order to prevent these risks, intervention to support children, youth as well as their families is necessary. Lack of family resources and the capability to invest in the child means that only external support (mainly adequate social care and educational system) may stop this negative life trajectory and prevent the disabled child from being a dependent disabled adult in future. The article takes up the problem of the quality of the disabled children's lives. characterising the capabilities, opportunities and limitations of these children's functioning within the family.

Key words: disabled child, quality of life, family

INTRODUCTION

Lack of protection and abandoning efforts to provide children with proper conditions and life quality carries a high risk of far-reaching consequences for the future life of these children. In the case of children with an irreversible disability, although the degree of health deficit may change, on average the course of future life will depend on how the family and the child alone cope with the disability. Disabled children may experience matters more painfully and to a larger degree internalise the social pressure put on them, because their weaker position means a higher sensitivity to the opinions of mainstream society. Moreover, their parents/ guardians may also unwillingly contribute to that oppression as their beliefs and expectations are in many aspects affected by professionals' opinions (French, 2004). This may lead to low the self-esteem of these children and consequently to a higher susceptibility to abuse. Negative social values instilled in children with disabilities lead to the situation where abuse is accepted and legit-imised. The child who is made to believe that they are "useless" may fully accept their worse life situation and life quality.

This may have a particular meaning in the childhood years when young people pass through a number of important stages in the identity formation process which defines the foundations of their self-assurance or lack of it and their self-value in future adult life (Connors, Stalker, 2007; Thomas, 2007).

The life opportunities of these children will depend, to a large extent, on what they achieve at an early stage of life, what social competence, predisposition and potential they develop. Therefore, the quality of life of the disabled child depends greatly on the living conditions of the family.

The problem of disability affects family life in a twofold way: firstly, the family as the social environment gives psychological, material and emotional support to the disabled person. Secondly, the family as the closest social setting for the disabled person experiences the direct consequences of their member's dysfunctionality (Ogryzko-Wiewiórkowska, 2008). That is why the role of the disabled child's family is so important in terms of preparing the child to an independent life in society, as much as it is possible. Poor health condition and disability are one of the reasons for the limited professional activity of adults and the poor material conditions of the whole family. A family's limited opportunities may cause far-reaching consequences for the current development of the child and his or her future functioning. Disability in childhood carries the risk of social and educational exclusion as well as exclusion from the labour market in the future, especially if the child grows up in poverty. In order to prevent those risks from occurring, interventions supporting children, youth as well as their families are required.

The presented analysis covers the living conditions of a disabled child in the family, primarily a child's health, material and housing conditions, relationships in the family, the attitude of the parents and other family members to the disabled child, contacts and relationships with the non-family environment.

The assumption guiding this article is that the factors differentiating the quality of life of the disabled child in the family are primarily: family status determined by the level of the parents' schooling level and the material situation of the household (poor – not poor), family structure (compete – incomplete), the child's age and the type of disability and related prognostication, as well as the family's capabilities in the process of the child's rehabilitation.

It is generally assumed that the experience of disability depends on the type of the child's disability. Referring to the subject literature, we have to note that usually persons with mental disabilities are in a worse situation.

Moreover, the experience of loneliness in the period of growing up, especially in the case of children with disabilities, may determine their future functioning on the margin of social life, thus preserving the system of social and economic inequalities.

The results of studies presented in the article are based on analyses of material collected during the project "Disabled students in the education system; Forms and effectiveness of social work for the disabled or their guardians" under the research project granted by the President of the City of Lodz City for the years 2009-2010. As many as 601 questionnaires were collected from parents/guardians of disabled children of school age along with focus interviews with the mothers of disabled children. Most of the studied families, 91.4%, had one disabled child while 6.8% of families had two disabled children and in 1.8% of cases families had three or more disabled children.

In the studied sample there were children with various degrees of hearing and vision disabilities, with low, medium and high degrees of physical disability and those chronically ill. Among the coexisting chronic diseases or single diseases that the children suffered from were: bronchial asthma, allergy, diabetes, epilepsy, hepatitis B and C, kidney diseases, heart diseases, inborn spine disorders, first-degree curvature of the spine, scoliosis, cancers, hypertension, digestive system diseases (varicose veins in the digestive system, enlarged spleen, coeliac disease, poor absorption syndrome), bladder diseases, cerebral palsy, autism, glaucoma, paranoid schizophrenia, psoriasis, ADHD, Asperger's syndrome and Down's syndrome.

The first three disorders (bronchial asthma, allergy, diabetes, epilepsy) were the most common among the studied children. Nearly 30% of the children had psychologically documented intellectual deficits.

RESULTS

Economic dimension of the disabled child's family life and social support

Capabilities of providing a child with decent social conditions are related to the economic situation of the family. Although in all families bringing up the child with a disability is linked to greater expenditures, poor families face challenges with satisfying even basic needs. The studies conducted clearly show that disabled children and youth have little chance of becoming independent adults in future due to their families' financial problems (underinvestment) and the limited educational offer for the disabled. The studies revealed that families with a disabled child, even if not on social benefit, are at the threshold of poverty. Mainly, due to the fact that one or both of the parents have to remain at the disposal of the disabled child who needs to be driven to school or at least prepared to be taken by special transportation, picked up from school, helped with doing lessons, taken to rehabilitation, accompanied at hospital when there is a need for another operation, etc. One food provider is not able to secure the family with decent lifving conditions, in a situation where expenditures are multiplied by the needs of the disabled child. The material situation is even more difficult when the mother brings up a disabled child on her own. Thus, disabled persons' childhoods are often threatened by poverty, difficult living and housing conditions and the absence or significant limitation of institutional support.

Therefore, it is of particular importance to determine the percentage of poor families among all families with a disabled child and to identify the correlates of poverty resulting from the need to care for a child. The analysis of the economic situation took into account the material and housing conditions in which the child and the family live.

A disabled child in a poor family is an excluded child at the start. His or her illness is a huge financial and organisational burden for the family, often one impossible to cope with. The lack of an ability to invest in the child reduces his or her chances of obtaining education and a profession and in the future - an adequate job.

In the studied sample, over one-third of the families with a disabled child (39.1%) meet the criterion of poverty. Families living in poverty (poor) were considered to be those that received care benefit and / or a supplement to family benefits (child benefit supplement) for education and rehabilitation. The proportion of children with disabilities living in economic conditions that do not guarantee development opportunities is greater, as in a part of the studied households there was more than one disabled child.

The correlates of poverty are the low level of economic activity and the low schooling level of the parents, the same circumstances that push also into privation families that do not experience disability. However, the extent of professional deactivation seems to be particularly high in poor families. As our data indicate, almost two-thirds (62%) of mothers (they were the vast majority of the respondents) from poor families remain outside the labour market.

Households with disabled persons are at a greater risk of material poverty (regardless of any assumed poverty threshold) than households in general. This risk applies in particular to households with at least one child under the age of 16, having a disability record, as a result of the resignation of one parent, usually the mother, from professional employment (Kołaczek, 2010).

The resulting research findings show, among other things, that the professional deactivation of the parent (often single mothers) and insufficient social support as well as restricted access to information on assistance opportunities, formalities and support in caring for a disabled child often condemn the child with disability and his or her family to a standard of living below basic standards.

Unlike the surveyed non-poor households, poor households are those where parents have lower education levels, lower economic activity and often remain single parents.

A subjective assessment of the family's situation is differentiated primarily by family structure, which confirms the fact that in biologically-incomplete families combining care and economic functions is particularly difficult. Hence the importance of the family type for the process of eliminating the threat of disabled children's exclusion (Balcerzak-Paradowska, 2008).

Poor housing conditions cause additional restrictions for a disabled child's development opportunities. However, in a situation where there is more than one child with a disability in the family, difficult living conditions become even more severe for the whole family, while this situation intensifies already acute problems.

Therefore, the family with a disabled child needs comprehensive assistance in dealing with the difficult situation that is the child's disability or even the threat of incorrect development. Social assistance assumes primarily equalizing the life chances of people who are in a disadvantaged health or social position. It is of great importance for people who need support in two aspects: poverty and disability. The simultaneous occurrence of these particular issues makes social support for poor families with a disabled child particularly important, certainly one of the areas for necessary assistance.

With regard to the assessment of the received support, undoubtedly opinions vary depending on the child's intellectual condition and even more so on the medical record of the degree of disability. The situation is worst assessed by parents of children with an intellectual disability and the parents of children with severe physical disability.

In view of the above data, it can be concluded that the most underinvested in and discriminated against are those vulnerable children who are most deprived in terms of health and have the worst functioning conditions. This is mainly due, of course, to the need to spend more money on the treatment and rehabilitation of these children.

Despite the large variety of forms of assistance offered by the social care system, their effectiveness in tackling the problems of families is limited by:

- too low amounts of financial benefits.
- too long periods of waiting for due benefits, services or funding,
- lack of commonly available information on the available forms of support and the simultaneous complexity of the assistance system,
- excessive bureaucratization of the social care system and the need for regular submission of the same documents (even in the case of those whose condition is not expected to improve).

Regarding support for families raising a disabled child, it is clear that for almost 60% of respondents this help is not enough. The opinions collected allow one to conclude that disabled children often live in poverty since institutional support is insufficient to meet the special needs of the child and their family.

The selected problems of families bringing up a child / children with disabilities are merely illustrative of the difficulties and problems of daily life faced by families with a disabled child. The main concerns of parents relate to discrimination against families of children with disabilities in the form of low financial security, the difficult professional situation of parents / guardians, difficulties and formal requirements in obtaining assistance, problems with access to health services, difficulties in access to schools and problems in the school system, limited access to information for parents, carers and people with disabilities about the possibilities of using assistance, a lack of knowledge about the location and types of foundations or other institutions providing assistance.

In the light of these studies, it seems to be most important that the experience of poverty and loneliness in childhood and adolescence, especially for children with disabilities, may cause their future functioning on the margins of social life, contributing to discrimination, to consolidating social inequality, and often the inheritance of this status on the part of the poor and disabled person.

Disabled child and relationships and conflicts in the family

Circumstances such as cases of giving birth to chronically ill or disabled children confront parents with a difficult dilemma: the acceptance (or rejection) of one's own child and destiny, one so dramatically altered (Sobczyńska, 1995). From birth, children with disabilities receive a lot of negative messages about the value of their lives and how they are perceived by parents, peers and professionals.

M. Mason (1990) notes that the reaction of shock and disappointment expressed by a mother who gave birth to a disabled child may affect the construction of the child's own negative image. Disabled children and young people are educated in a social climate of discrimination against persons with disabilities, dominated by the medical model of disability, characterised by constant efforts for achieving a social status considered to be "normal". This leads to various emotional and mental reactions in young people with disabilities, but often does not enhance their sense of self-value, on the contrary, it weakens their motivation to act due to a fear of failure to meet the expectations of parents, professionals and non-disabled peers.

A significant factor has also turned out to be the mothers' life situation, in particular whether they receive social assistance in child rearing and care activities or support from the fathers and other family members. In most of the surveyed families (over 80%), the mother spends most time with the disabled child, in 21.3% of the families father the joined in the care for the child (depending on whether the mother worked or not – it was smaller or larger involvement). In every 10th family the siblings of the child were involved in caring for the disabled child, and in 13.8% of the families – also other persons available (most often

grandparents, extended family members and neighbours, this involvement was proportional to the mother's work load).

Limited support and simultaneously the complex needs related to the education and rehabilitation of the disabled child often result in the need for support from those close and relatives, and this help often turns out to be the most important or even the only one of its kind. In the case of limited institutional support, the support from close and distant family seems to be strongly desirable.

Single mothers caring for children, either alone, or without the assistance and psychological support from family members most commonly revealed intensive symptoms of psychological "burn-out" (Macierz, 2004).

In summary, it can be concluded that the problems and difficulties of everyday life affect the majority of families who have a child with a disability. The specific role of women as mothers and carers of the children with disability often causes the state of burnout and resignation, even reluctance to undertake further action. Mothers of disabled children are exposed to physical and mental burdens that can be minimized through interactions within the family and non-family support networks. The scarcity of professional support for mothers of disabled children often limits the effective rehabilitation of the child in his or her natural environment.

In addition to the failure to meet the needs and expectations of mothers regarding the child's health and everyday functioning, it is common that people from the immediate surroundings (sometimes even husbands) blame the mothers for the children's disability, demean them as defective birth-givers or accuse them of a misdemeanour – in their opinion – the cause of the children's disability (Maciarz, 2004).

Conflicts and misunderstandings may occur in the family due to the child's disability. Among the respondents, 18.1% pointed to conflicts between spouses / partners, 11.9% pointed to conflicts between the disabled children and siblings (more often in families with only primary education, 6.9% to conflicts between the mother and the healthy sibling usually because of the less demanding treatment of the disabled child and devoting more attention to him or her. Exactly the same number of respondents indicated conflicts between the father and child with disabilities, and more than 8% pointed to conflicts with other family members (e.g. grandparents). These conflicts typically regard: allocation of duties (17.1%), expenditures on disabled children (7.7%), as well as ways of bringing up the child with disabilities (14.4%)).

The respondents' answers also illustrated siblings' care overload in relation to a child with disability (1.6%). According to researchers siblings are often "condemned to accompanying their brother or sister in disability", peers who have to share with their parents the misery of caring for the disabled child (Burke, 2009).

This confirms the thesis that *disablism*, the term used to describe discrimination against people because of their disability (Thomas, 2007), may also occur in relationships with one's immediate family, as reservations with regard to the child's disability may translate themselves into the level of acceptance and treatment of the child in terms of "improving" his or her life. Especially children below

the intellectual norm are exposed to intra-family *disablism*, their "otherness" is definitely less socially acceptable in comparison to other forms of disability.

Among the most important current problems mentioned in respondents' households seem to be such challenges as: lack of money for major expenses (57.6%), the educational problems of a disabled child (35.7%), poor housing conditions (24.0%), lack of money for daily functioning (23.9%), illness of relatives (21.5%), unemployment (16.6%), marital problems (6.7%), poor neighbourly relationships (4.2%) and the problem of alcohol abuse in the family (3.6%).

In summary, it can be said that the difficulties in the daily life of a family with a disabled child apply to all spheres of marital life and of course to all family members – both the family of procreation and of origin, because in a sense, the whole family is affected by the disability (illness) of the child.

By asking the respondents the hypothetical question of what their life would be like if the child was healthy, we intended to conclude in which aspects having a disabled child is particularly burdensome and brings the least benefits, and which can negatively influence building relationships with a disabled child.

In general, respondents most often indicated in all spheres of life the category "it would be the same," but it is clear that having a disabled child particularly affects the diversity of missed opportunities and benefits in areas such as:

- The material level would be "better" or "much better" indicated 46.6% of respondents,
- Personal satisfaction would be "better" or "much better" 40.4% of respondents,
- The opportunities for a professional career would be "better" or "much better"
 39.7% of respondents,
- Social contacts would be "better" or "much better" 28.7% of respondents,
- Contacts with other children would be "better" or "much better" 28.4% of respondents,
- Contacts with husband / partner would be "better" or "much better" 22.8% of respondents.

Yet sometimes, with all the effort involved in functioning as a parent with a disabled child, one can see the positive elements of life that often give them hope and strength to continue the fight against adversities (More than three-quarters of the respondents frequently thought: "My child is someone special and wonderful").

Conditions of rehabilitation of the disabled child

The rehabilitation of the disabled child often takes up most of the family's time. Usually it must be conducted primarily in order to increase the chances of the child achieving self-reliance in the future, as far as it is possible.

Many experts postulate that parents should take an active part in rehabilitation – when the child's need for security is fulfilled, the whole therapy brings about the desired results (Kornaś, 2010).

The material situation of the family is undoubtedly of great importance, both for the process of the child's treatment and rehabilitation and for meeting all his or her needs resulting from disability.

Discrimination in access to rehabilitation primarily refers to three aspects. The difficulties faced by parents of children with disabilities in the field of rehabilitation are mainly related to difficult access to specialists, a lack of systematic therapy and the necessity to pay for rehabilitation services. Even in those cases the person primarily engaged in improving the child's psycho-physical being is the mother.

It is often difficult for parents, directed by concern and anxiety at the same time, to take action leading to an empowerment of the disabled child.

There is also a relationship between the parents' education and rehabilitation of the child outside of school (paid-for or free). The higher the education level of the parent, the more frequent are decisions about "investing in the child" through additional paid rehabilitation activities. Parents with higher education are more than twice as likely than those with primary and vocational secondary education to rehabilitate the child free of charge, and three times as likely to pay for it outside of schools.

However, in poor households twice as many respondents declared that they had no money to pay for rehabilitation outside of school. The differentiating factor in this regard is also the child's age: in general younger children more often (by almost 10 percentage) than older children benefit from free rehabilitation, and more than twice as often from paid activities - an additional form of rehabilitation outside of school.

It has also been confirmed that generally parents of older children are more critical of rehabilitation services than the parents of younger children (Arnadottir, Egilson 2012). This may be due to two reasons. Firstly, in the case of an older child, parents have for a longer period been involved in the process of rehabilitation and already have experience and opinions in this area (including negative ones), and secondly, these services may, in fact, be perceived by parents as inferior/ worse, because they are scarce (younger children are prioritised in access to services) and can be of an "inferior quality", that is not generating visible, or spectacular effects. Problems with the rehabilitation of young people with disabilities are often associated with the question of "whether or not it is worth continuing to invest in the child; whether there will be a vast improvement"?

Disablism toward children with disabilities in the field of rehabilitation involves limited access to specialists and services. This is particularly true of poor households, which in our sample are populated with older, severely handicapped children.

It should be emphasized that a significant, very important form of support and help for the parents of children with disabilities are other parents in a similar life situation. When they find out about their child's disability, they can count on information about how to take care of the child (14.9%), and even information on further specialist treatment (9.7%). Contact with other parents of children with disabilities encourages them to share similar, often difficult, experiences and makes the struggle with daily difficulties easier. The fact that others have managed to overcome certain problems gives extra motivation to act and allows them to look optimistically into the future. Such relationships also give a real knowledge about specialist facilities and opportunities to support the development of disabled children.

At the same time, however, this increases the tendency to maintain contacts only with that circle of people having the same problems, and limits the opportunities for children with disabilities to integrate with non-disabled peers.

Such activities can also contribute to the formation and consolidation of the phenomenon of the self-exclusion of families with a disabled child and generally limited relationships with others.

Ż. Leszkowicz-Baczyńska (2001), in analysing the manifestations of the phenomenon states that in the case of families with a disabled child, self-stigmatisation mechanisms are released not at the level of the individual patient's activities, but at the level of the functioning of healthy family members. This specific situation is firstly related to the child's lack of dependence and secondly it is especially severe in the case of a child with mental retardation.

In line with previous findings, a family having a child with disabilities (especially one mentally disabled) is forced to take an active role in the illness. Any phenomena and the accompanying consequences which typically involve a disabled person, in this case are also taken over by the parent or parents. Situations of this kind are accompanied at the same time by the sense of a "deficient parent," related to the specific character of the illness. The result is the occurrence of the mechanism of stigmatisation and auto-stigmatisation, and its inevitable consequence will be the withdrawing of the family from social life. In such a situation, parents tend to burden both the child's peers and other adults with a reluctant attitude to the disabled child. It is, however, difficult to clearly judge whether the cause of isolation is a real lack of acceptance on the part of the environment, or the withdrawal of families with a disabled child from full participation in social life, as a result of the parents' interpretation of the social context in which they have found themselves due to the child's illness (Leszkowicz-Baczyńska, 2001: 83).

Family activity can be observed in that case only in the sphere of family life, obviously people with disabled children feel safest among those closest. It is much more rare that they look for social contacts or contacts with neighbours. Also cultural activities, or any kind of recreational activities by families with disabled children are significantly limited. Parents occasionally attempt to mediate in establishing peer contacts with the child. Withdrawal of the parents (especially mothers) from professional activity promotes marginalization, thus closing another chance for establishing social contacts.

As a result, one of the forms of activity of families with a disabled child is the creation of support, self-help groups. Their role lies in the fact that parents have the opportunity to share with others their experiences, externalize problems, decompress in positive interactions with people that have a similar problem. This can cause a deepening of social isolation by creating groups in which references to protective communities can be found (Leszkowicz-Baczyńska, 2001).

The specific character of conditions and the quality of life of an intellectually disabled child

In the light of the research the thesis that people with intellectual disabilities are in a more disadvantaged position in every respect has been confirmed, as the following results indicate:

- Treatment of a disabled child below the intellectual norm (realization of their rights to equal treatment) as opposed to a healthy child, is often assessed to be much worse;
- Reduced intellectual norm of the child leads to it being the target/ victim of unpleasant remarks, malicious comments from strangers in the street as well as from friends and neighbours. This type of behaviour often occurs in relationship to children below the norm;
- Discriminatory practices in access to state schools (non-fee paying schools) and integration schools mainly relate to children with a low intellectual norm, mental disability;
- Reduced intellectual norm decidedly affects the reduction of contacts of a disabled child with healthy peers at school and relationships with peers outside of school;
- Acceptance by the parents of a disabled child, to a large extent varies and depends mainly on the intellectual norm of the child.

Single mothers, having no support, suffer from a greatest emotional burden with negative emotional states. The mother's long lasting psychological stress usually coexists with physical exhaustion and threatens to cause a distress syndrome called "burnout of strengths." This syndrome is a specific psycho-physical state of exhaustion with multiple intensifying symptoms. Studies point out (Maciarz, 2004) that the severity of the threat with distress syndromes correlate, among other things, with the child's degree of disability – the high severity of symptoms among the mothers of the children correlate with the high degree of disability, often mental disabilities.

In the presented studies mothers with children below the intellectual norm are three times more likely than mothers of intellectually non-disabled children to think thus about their child: "Whatever I do, my child is still going to face difficulties in their life" and more than twice as likely to think "My child has been born such and there is little that can help them."

The above analyses confirm the thesis that the isolation of children with disabilities is greater for children with mental disability, and in peer relationships it can contribute to the reduction of psycho-emotional well-being and affect the current and future family, school, post-school and integration relationships of children with disabilities (particularly mental).

In cognitive terms, the study proved particularly valuable in finding evidence for the diversity of situations in families with disabled children, depending on their socio-economic status. We have shown that in a poor family the illness of a child is a huge financial and organizational burden, which the family is often unable

to cope with. Disabled children from poor families have little chance of obtaining an education and profession as well as an adequate job in the future.

The research findings also indicate that the possibility of regular treatment and rehabilitation are often dependent on the material resources of families, while their absence will automatically limit the opportunity of the child's development and reduce his or her chances of achieving self-dependence in the future. *Disablism* toward children in the field of rehabilitation involves limited access to specialists and services. This is particularly true of the poor households in our sample, in which there live older and more severely disabled children.

The described study has expanded our knowledge about the extent to which disabled children are an excluded category, in which areas they are excluded and in which areas of life they are socially marginalized. The research shows that disabled children and their families experience a multidimensional, cumulative exclusion (in family, educational and social dimensions). Mothers of children with disabilities are excluded from the labour market, which leads to restrictions in consumption, culture, education, health and rehabilitation. Experiencing multidimensional exclusion because of poverty and disability in childhood results in the further perpetuation of this unfavourable state equally in adulthood .

CONCLUSIONS

The main problem for families raising children with health problems are the financial difficulties and problems with execution of the right to financial support, something definitely negatively evaluated. The study documents that the disabled child is underinvested in and often lives in poverty (the difficult financial living and housing conditions of the family). This situation causes a risk of poverty and life chances depreciation currently and in the future. In such conditions it is difficult to appropriately implement the right of children to decent living conditions.

The care for a disabled child determines the framework for the functioning of the "disabled family," causing numerous conflicts and disturbances in the intrafamily relationships. In connection with this, rehabilitation and treatment providers, both in individual and systemic terms, should take into account the family situation of children with disabilities. Very often, psychological support is also necessary for all family members.

The experience of disability in childhood is mainly dependent on the child's intellectual condition. The specificity of the child's disability (especially mental disability) often excludes them from access to educational institutions and limits social relationships, as well as distorts the functioning of the family.

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