

ANALYSIS OF THE NEEDS OF FAMILIES WITH CHILDREN WITH DISABILITIES

Qualitative study

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INTRODUCTION

BACKGROUND

One of the most important changes that happened in the world, in the last decade is a paradigm's change in the disability area: from a medical model of assistance (protection) in approaching disability, towards a model based on social inclusion, the rights, equal opportunities and full participation of people with disabilities in the economic and social life of the community.

UN Convention on the Rights of People with Disabilities – a fundamental and without a precedent document in promoting the rights of people with disabilities, adopted on the 13th of December 2006, by the UN General Assembly – is part of these changes. The Parliament of the Republic of Moldova ratified this document on the 9th of July 2010, thus committing to promote, protect and ensure the fulfillment of the rights and fundamental freedoms of all people with disabilities, as well as to respect the inherent dignity of these people.

This great shift in approaching people with disabilities from simple recipients of social services and social benefits, towards people with full rights and capacities still has a long way to go in the Republic of Moldova. The system of social services in the Republic of Moldova is poorly developed and continues to be centralised, thus diminishing the participation of local authorities and local communities in the assessment and setting up of priorities regarding community needs. The access of people with disabilities to social services is still very limited in the country. This is due to a reduced number of social services, comparing to the number of people with disabilities, needing these services, but also due to poor quality of these services, that are focused around meeting the basic needs of people with disabilities and less or at all on their rehabilitation and abilitation.

Children are the most affected in the current system. In the Republic of Moldova there are over 17.000 children with disabilities; out of them, about 3500 are less than 7 years of age. Out of them, almost 6000 children are institutionalised and are considered to have some sort of disability. The vast majority of these children living at home or in an institution do not benefit from an early interventions aiming at abilitation and rehabilitation.

Early interventions can contribute significantly to the prevention of severe disabilities, through stimulation of the child development, prevention of consequences and minimisation of the negative psychological impact on parents, siblings, relatives. The attitude of people caring for children with disabilities (or indirectly involved in this process), the shift in general public attitudes towards people with disabilities are of a great importance within this change process as well. At the same time, this constitutes an efficient measure to prevent child abandonment and institutionalisation and to promote and implement social inclusion of people with disabilities.

According to the Universal Declaration on Human Rights (art.16), the family is the natural and fundamental element of the society and has the right to be protected by the society and state. The State should do everything possible to support parents' efforts to raise their child with disability within their family. In doing this, it has to be taken into consideration that the child's disability has a triple experience, involving interaction among the child living with a disability, the family that is affected by the child's problem and the external environment where the disability is manifested (Falik, 1995 and Heiman, 2002). Sometimes the chronic distress caused by the disability has severe implications over the general functioning of the family. As a system, the family could experience periods of intense distress, it can learn from these experiences and can learn to become stronger (Singer and Powers, 1993). That

is why, in order to prevent family breakdown, family separation and institutionalisation, it is necessary to develop services that would better respond to the needs of this group.

Scope and methodology

This study was conducted within the period between September 2011 and January 2012 and had as an aim the setting out of a baseline for the development of the short-break foster care for children with disabilities. The study has covered 2 regions – Chisinau municipality and Orhei raion. *The study focused on three main objectives:*

- Analysis of socio-economic and socio-demographic peculiarities of families with children with disabilities, from the prospective of their needs, difficulties and barriers, but also from the point of view of their functioning, access to services, support networks and development of coping strategies;
- Analysis of support strategies, of existing social services accessed by these families, as well as their level of information with regards to the rights of children with disabilities and their families and the availability of appropriate services for them in Chisinau and Orhei;
- Understanding the vision of parents, children and specialists regarding the concept of short-break foster care for families with children with disabilities.

The study applied a complex qualitative research methodology, implemented in three stages and included interviews and focus groups discussions with parents of children with disabilities, focus groups with children and observation of interactions between parents and children in their homes.

During the first stage, visits were undertaken to family homes and semi-structured interviews were conducted with family members. During these visits the research team observed the children’s living conditions, as well as the relationships between children and their family members. The visits’ duration was between 120 and 180 minutes.

Later on, a number of families with children with disabilities that are registered with Chisinau Child Protection Directorate and Orhei Social Assistance and family Protection Directorate were selected: in Chisinau **105** out of 946 families¹ registered, were selected, and in Orhei **176** out of 611 families were selected. The study covered a total number of **281** families.

During the second stage of the research, 8 focus groups discussions were organised with the following stakeholders: parents with children with disabilities, professionals, community social workers, foster carers, with a total number of **91** participants. Discussions in focus groups were based on a guide, developed in accordance with the objectives of the study. Initially, the parents were told about the short-break foster care service. A warm and friendly atmosphere was ensured, so that everyone had an opportunity to express their opinions and ideas. The length of the focus group discussions was between 60 and 90 minutes.

Nr.	Nr. of participants	Group	Location
F.G.1	9	specialists	Orhei
F.G.2	12	specialists	Chişinău
F.G.3	11	social workers	Orhei
F.G.4	12	Foster carers	Orhei

¹ According to the national Bureau of statistics there are 2232 children with disabilities registered in Chisinau municipality.

Nr.	Nr. of participants	Group	Location
F.G.5	11	Parents	Orhei
F.G.6	11	Parents	Chişinău
F.G.7	13	Parents	Chişinău
F.G.8	12	Foster carers	Chişinău

The third stage of the study included 3 focus group discussions with children and young people that live with families, a total number of **24** participants. At this stage the research team studied the children's understanding and vision with regard to the concept of short-break foster care. A warm and friendly atmosphere was ensured, so that everyone had an opportunity to express their opinions and ideas. The duration of the focus group discussions was between 60 and 90 minutes.

Nr.	Nr. Of participants	stakeholders	Location
F.G.1	12	Children with disabilities	Orhei
F.G.2	6	Children with disabilities	Chişinău
F.G.3	6	Children with disabilities	Chişinău

Difficulties and limitations

We have to mention that the data of the research is qualitative and is not representative for all families with children with disabilities in the Republic of Moldova. The findings and conclusions are based only on the opinions of the participants, and the data can be interpreted as trends, but could not be extrapolated at the level of all families, children and professionals in the Republic of Moldova.

There were a range of difficulties that were experienced by the research team during the course of the study. Some of the visits to family homes and some of the individual interviews were very difficult due to strong emotions of the parents. There were families that refused to meet the members of the research teams. Other families were closed and didn't wish to discuss about their children. There were families that could not believe that there was someone interested in them. They declared that they lost any hope and trust in people working for the state, as they used to mainly get refused when requesting help in the past.

In the focus groups with children and young people there were situations when the research team could not communicate with them. There were children that reintegrated from residential institutions who had some fears that they would return to institution and answered the questions of strangers reluctantly, although the team provided extensive information regarding their visit.

MAIN CONCLUSION

The study, in contrast with existing general perception, has shown that the majority of families with children with disabilities are complete families, where the main caregiver is the mother.

The isolation of parents with children with disabilities, their lack of trust in people can lead to the unmet needs of children with disabilities. Parents refuse external help; they do not entrust anybody else with the care for their child with disabilities. As a result the support network of these families is very underdeveloped and as a rule it is made of members of extended family exclusively. As a result of the lack of support offered to these families, children may experience neglect and abuse within the family. At the same time the risk of psychological burnout of the parents and family breakdown and separation is great. In the case of children with severe disabilities the parents become „life-long personal carers”.

The siblings of children with disabilities may also be at risk of neglect and abuse due to the parents' exclusive preoccupation with the children with disabilities, but also due to the psychological burnout.

Employment opportunities for parents with children with disabilities are also very limited, as there is a lack of jobs with flexible working hours, as well as day care services for children. Many parents (usually fathers) are forced to migrate to seek work. As a result the children are left to live with their mothers or grandmothers.

The educational level of parents can be directly linked to the family capacity to offer support, care, education, rehabilitation to their children with disabilities. Respectively, families with a lower level of education need more support and investments from the behalf of professionals and social services. The data indicates that the vast majority of parents have secondary education level.

Some of the families have no stable income that would permit budget planning. The financial difficulties have an impact on the psychological climate within the family; the family copes worse with difficulties related to disability of their child and this can conduct to child's abandonment. The situation is also severe when the family does not have an appropriate place to live that would fulfill the special needs of the child. This situation is more serious in Orhei, where half of the families do not own a space to live and rent have to rent one. In rural communities the majority of families do not have commodities that would make the care for a child with disability easier.

For many families the medical examination and care of children with disabilities is quite difficult as it involves transportation. Rehabilitation services cannot cover a great number of beneficiaries. The parents point out that doctors do not show interest in these children; parents receive some medical advice, only upon their request. Many parent gave up and do not believe in the possibility for their child's rehabilitation.

The majority of children do not have access to qualitative education; the school curriculum is not adapted to the child's needs. These children tend to be neglected by the teachers, their classmates and the parents of their mates. The school itself is not physically adapted to the needs of children with disabilities.

Families are not aware of the whole range of services that they can access. The services are mainly concentrated in Chisinau municipality or Orhei town and cannot be accessed by all families. Social services' professionals do not have appropriate capacities, skills and knowledge to work with children with disabilities. Social services for children with disabilities and their families are not able to cover a whole range of needs. These services are mainly focused on care and less on rehabilitation and abilitation. Moreover, staff working in services for children with disabilities is not qualified to provide effective rehabilitation,

children often benefiting just from care and there is little rehabilitation provided. In this way the time is wasted and the rehabilitation gets more problematic. The lack of day care services is not giving parents the opportunity to combine work with providing care to their child.

The persisting psychological climate within the family leads to psychological burnout. Thus parents need psychological counselling and the support from the extended social network. Some parent couples cannot face long-term stress and as a result the family breaks down and children end up in an institution.

The study has also shown that the permanent stress in the family can lead either to strong attachment or aggressiveness towards the child with special needs.

Children of preschool age need more care from their parents, later on the child's level of independence increases with age. In some cases the children are overly protected, as parents do not trust the child's capacities or have „I-can-do-it-quicker” attitude.

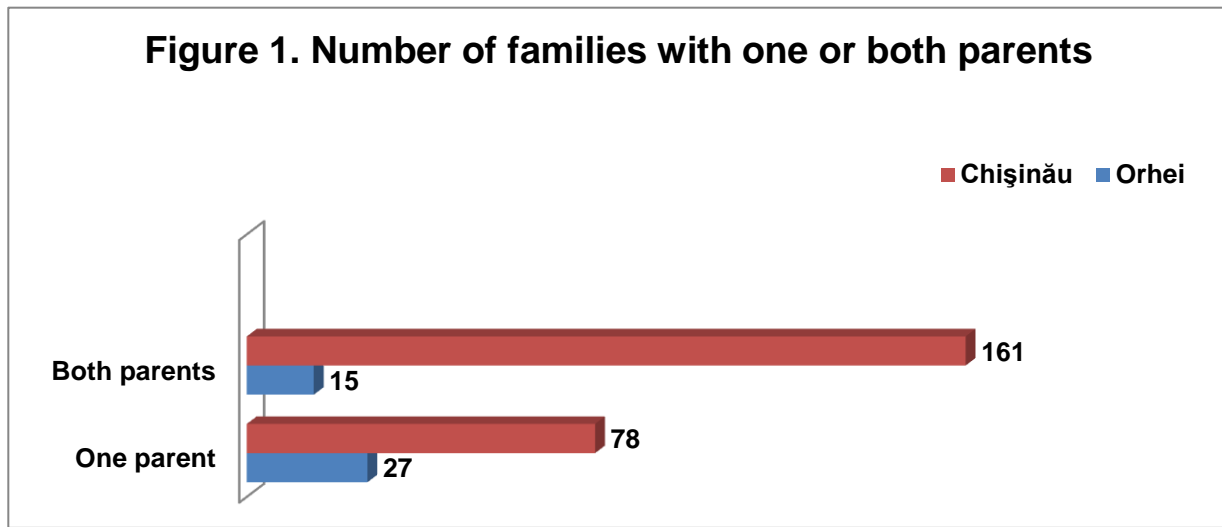
Most of the children with disabilities are isolated and their communication often is limited just to the members of the family.

FAMILIES WITH CHILDREN WITH DISABILITIES

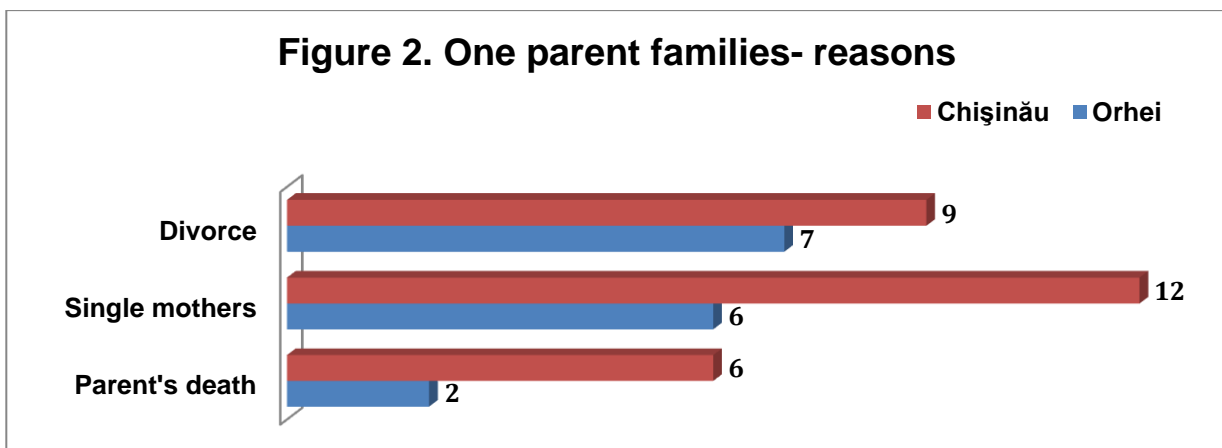
Amongst the factors that can influence the functionality of the family with children with disabilities are the demographical and socio-economical characteristics of the household, the quality of the relationships between parents and between parents and children, as well as the support of the social network.

Demographical characteristics of families with children with disabilities

Against general perceptions, the data shows that many children with disabilities (81%) live in complete and only 19% live in one-parent household. The study confirmed that with the exception of one child, the main caregiver is the mother.



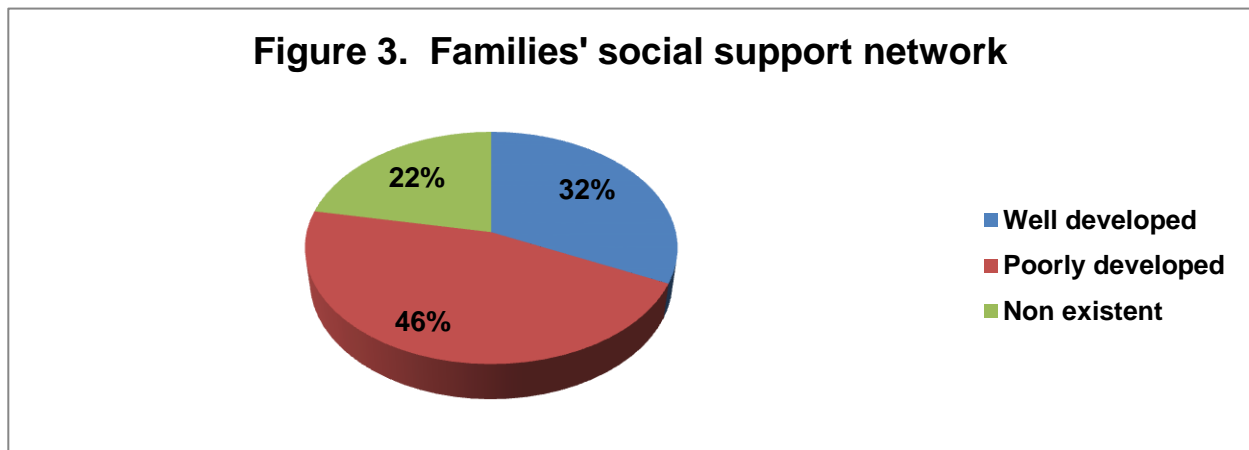
In 9,6% of complete families, parents were not married. The main causes of one-parent household in 42 families were: single mother (43%), parents' divorce (38%), death of a parent (19%).



The family structure in the case of children with disability influences the life style of the family, the way in which difficult problems are settled, as well as the style of child care. Incomplete families seem to be subject to greater risk as the lack of one parent leads to a faster burnout of the main caregiver, which has a serious impact on the care and education of the child, often resulting in child abuse and neglect. These families need more support from out-side.

„...our husbands forgot about our children and us, as it is difficult...” (a mother, Chişinău).

The families' support networks represent an important resource for the family that cares for a child with a disability. The study demonstrated that the social network of these families usually consists of family members: children who can offer support to parents looking after disabled siblings, grandparents, aunts, family friends or neighbours. The vast majority of respondents mentioned that this support is very important, but in most of the cases they cannot count on it as it is not offered with regularity. Not everyone has necessary set of skills to be able to care for a child with disability. The person needs patience, tolerance towards many unwanted or unpleasant manifestations of the child's behaviour that are usually linked to their disability, dependency and difficult communication.



The data shows that only 32% of families have a well-developed social network, 46% of the families have a poorly-developed network and for 22% families the social support network is non-existent. In many of the cases the parents themselves are the cause of the lack of the social network, as they do not want anyone outside of their family to interfere. In many cases, the parents are strongly attached to their children and they do not trust anyone to care or even to communicate with their child.

„I cannot entrust my son, Ion, to anyone. He cannot walk. Who is going to feed him? Who is going to take him to the toilet? I also had a daughter with disability and when she was 14 she died. After she died I gave birth to my boy. He is now 17. For the last 30 years I have been knocking at different doors. Anywhere I go, I am told that everything is going to be alright, that the situation will get settled and that's it”. (a mother, Chişinău).

In many cases, even the father of the child refuses to stay with his child for a couple of hours; he thinks that only the mother is responsible for the care of the child, as well as for other things in the household.

Families with a weak social network have a greater risk for breakdown with the child being separated from the family and even placed in residential care. In families like this the child's needs for care and education are not met in a holistic way, the risk for psychological burnout, child abuse and neglect, and institutionalisation is great, as parents do not have appropriate resources in order to face the emerging difficulties.

Families with children with disabilities need to communicate with families that face similar problems; they need meeting together in support group meetings. „We feel the need to communicate; we lost this skill. For example, I feel ashamed to have a discussion; I am not able to hold a discussion any more. Practically, we are all locked in our houses. ” (a mother with 2 children with disabilities, Chişinău)

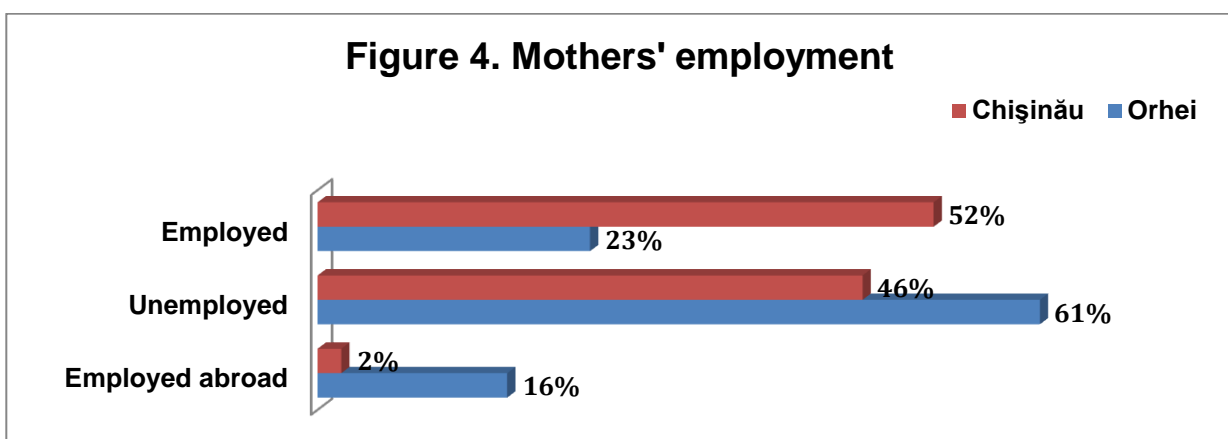
Socio-economical characteristics of the families with children with disabilities

Parents' engagement in the labour market is an important factor for a healthy family dynamics and for family cohesion. Under current socio-economic conditions in the Republic of Moldova, as well as due to lack of support from the behalf of the authorities to families with children with disabilities, it is vital that at least one of the parents is employed so that the family could cover basic needs of their children. Difficult economic conditions of the family have a dire impact on the family's psychological climate and cohesion and determine their coping and survival strategies and resilience.

A child with disabilities needs more attention and usually requires more care time. Often, the parents are forced to give up their jobs. These are usually the mothers. If the parents want to go back to work after some time, often their job position are not available anymore or the parents are not granted a flexible working time to be able to meet their child's needs in care, frequent medical treatments and rehabilitation. Women, under these conditions, usually stop their professional live forever. In the case of mothers with children with severe disabilities they call themselves „a nurse forever”, as their existence is built around their child.

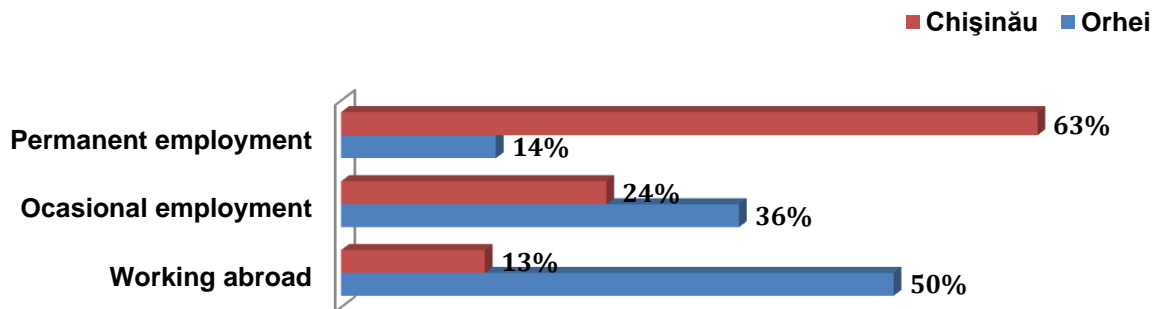
„I wish I could get out of my house, to stop being a prisoner 24/24, to be able to get enough sleep, as practically we do not sleep at all. As we have already talked about (she sighs), young children are seen more often by the social worker, by the Directorates, while young people of 17-18 years of age are completely forgotten. If I call someone to ask for some help, I often hear: „You look well; you can cope with your family”. I do look well, but should I split into two parts as an apple for people to see the way I look inside. If I only had a chance to get out my house, I could do much more.”

More mothers of children with disabilities are employed in Chisinau (52%) in comparison to Orhei (23%). This is mainly caused by the peculiarities of the labour market that is larger and more diverse and as a result more accessible by parents of children with disabilities in Chisinau. According to the parents, lack of job opportunities and salaries that would allow them to cover the care needs of their children, have influenced the decision of many parents to migrate for jobs. In Orhei raion 16% of mothers with children with disabilities are abroad comparing with only 2% of mothers from Chişinău municipality.



Fathers from Orhei have more difficulties to find employment; only 14% of them are employed, while in Chisinau 63% of fathers have permanent or temporary jobs. In many cases fathers had to give up their preferred job and accept a job that would provide a better salary. The situation is noted to be more difficult in Orhei raion, where 50% of fathers of children with disabilities work abroad, comparing to only 13% of fathers working abroad in the Chisinau Municipality.

Figure 5. Father's employment

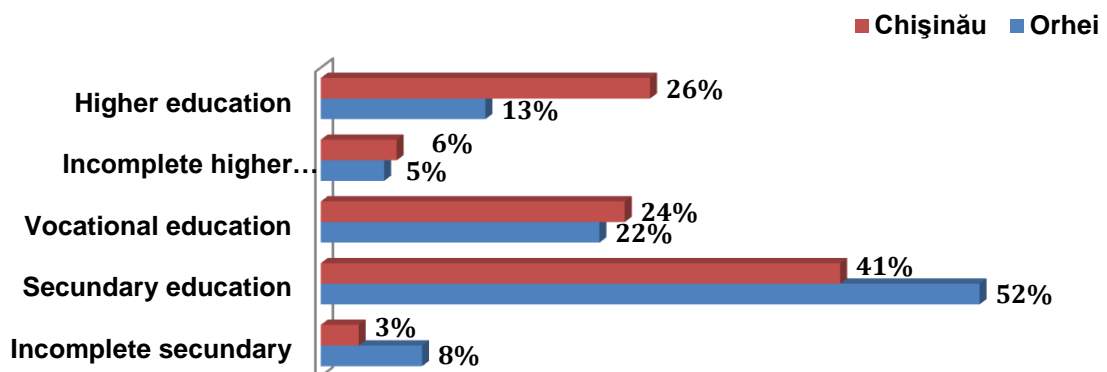


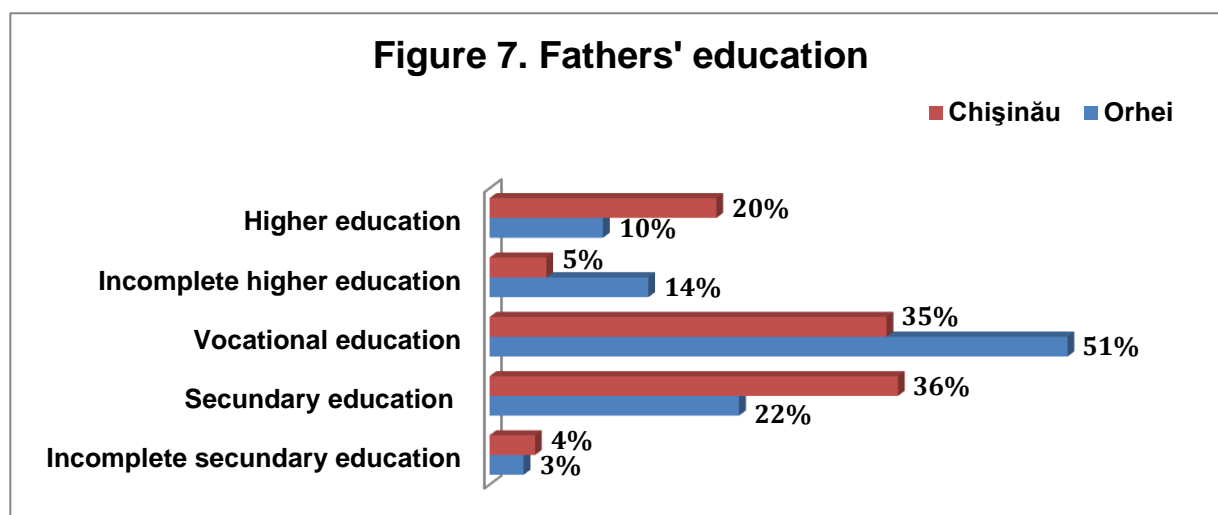
When fathers work abroad, mothers are forced to settle by themselves all the issues linked to the care of the disabled child and of the rest of the family as well as to all the other household issues. This situation leads to a high risk of psychological burnout, depression and other health related issues. This risk is even higher when the mother doesn't have any support network, made of family friends and relatives.

Parents' education is a factor that determines the family capacity to offer education and care to children with disabilities, including understanding the need for their child rehabilitation. Parents with better education seem to understand and provide better care to their children. Families with lower educational level need more support and training in order to better understand the needs of children with disabilities and to offer an improved quality care according to the needs.

The study has stated that the vast majority of parents have secondary or vocational education.

Figure 6. Mothers' education





From the discussions with parents of children with disabilities, the team has found out that many of them, especially the mothers, have not finished their education, as they lacked support when their child with disabilities was born. High costs of child with disability care, the need to be all the time with their child determined the parents to give up their education.

Financial situation of the family determines the family capacity to meet the needs of their child in care, rehabilitation, education and has a significant impact on the psycho-emotional state of the parents. The study had some limitations in assessing the real family income. The team has based their findings more on the verbal declarations of the parents, who indicated the following income sources: salaries, state indemnities, social aid, remittances, pensions, etc. 85 % of respondents consider their budget insufficient, and unable to cover their expenditures, as long as 15 % of the respondents described their family budget as satisfactory. Many of these families have both parents working or at least one of them has a competitive salary that allows the family to plan the budget according to the needs of their child. In the same time, many of the families with children with disabilities live in severe poverty conditions. In families where none of the parents is working the family budget originates from occasional works or remittances.

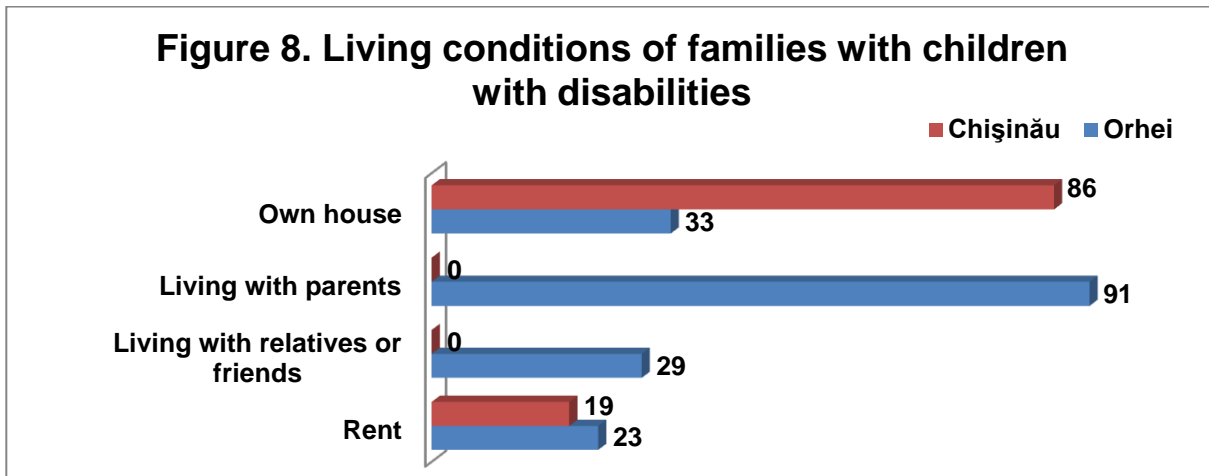
All children – participants in the study have a determined disability level and receive a disability pension that is quite small and doesn't cover at least partially the costs of the child's treatment, care and rehabilitation. Families usually prioritise costs for medication, food, hygiene, clothing and utility costs. The situation gets more serious if the family rents a place; in this case the family pays the rent and then plans the rest of the expenditures. „Medicines... there are no discounts on basic medicines that relax the muscles, in order for a simple body massage to be applied to the child. The prices for the medicines are crazy. My pension is not enough. And utilities costs need to be paid. I live in a house that is warmed with coal and wood. Where do I get them from? We live with no money and the situation is very serious. (a mother, Chişinău municipality).

Family living conditions often do not match with the children's development needs. The study revealed that the living conditions are better in case of families living in Chişinău: 86 families (out of 105 families) have their own house, compared to Orhei, where only 33 families (out of 176 families) have their own house. In Orhei 120 families live with their parents or with other relatives, like aunts, sisters or brothers.

„I blame myself for not being able to secure a normal place to live, so that I could have provided appropriate care to my child. In a room of 14 square metres, we cannot move. We have no bar that my child could use to learn to move to the toilet. His bed is small; he wants to stand up, but then he falls down. If I had had a spare room, I would have played with the child. If I had had normal living conditions for my child before the age of 12, he would have

been able to walk. Bad living conditions are the cause of his immobility.” (a mother, Chişinău).

„My main problem is that I rent the house. We are 5 people living in one room, and after the New Year we need to move out.” (a mother, Chişinău).



The majority of families living in Chisinau have necessary utilities (hot water, heating, gas, and telephone). The situation is completely different for families living in Orhei raion, especially in rural area. 174 families (out of 176) from Orhei do not have water, the distance to the nearest well being of over 500m; 162 families have non-adapted outside toilets. All respondents that have no place to live of their own mentioned that they could not see any possible improvements in the future.

The data indicates that the most important issues faced by the families with children with disabilities are:

Financial difficulties: allocations and indemnities for the care of the children with disabilities are very small; the social aid is also small (often due to the fact that these families share the same house with extended family members); material aid from the Fund for the Social Support of the Population is granted to the family only once per year and the family needs to invest much efforts in order to obtain it; many families have big debts for utility bills.

„Wherever we go, we need to bribe; everyone expects something from us. But I have nothing to give them; we could hardly survive on the pension we receive. We are waiting for a centre to be open so that the child could spend time there together with other children.” (a mother, Orhei).

„We need money and again money. Although I would want someone to give us some toys, orthopaedic shoes, diapers. The child has a problem with his feet, and we need orthopaedic shoes. My child likes yogurt, bananas, but I cannot afford to buy these things for him. I would appreciate if someone could call us at least once per month to ask us if we need any help at all, to support us at least emotionally.” (a mother, Chişinău).

“Our country doesn’t have the possibility to ensure opportunities for both parents to work and to guarantee appropriate care that would meet all the needs of our child with disabilities.”

Health issues: the list of medicines compensated by the state for the care of children with disabilities is incomplete; the medication is very expensive; rehabilitation services are not sufficient to cover a great number of beneficiaries; orthopaedic shoes are lacking or do not match the child’s needs (often the orthopaedic shoes do not corresponds the child’s needs and are delivered long after the feet measurements were taken); lack of access to medical

care; the family doctor has only 2 days per week for home visits (in rural areas), this fact creates long queues or the time allocated for one patient is very limited; the continuous stress that exists in these families leads to different health issues in parents, such as somatic illnesses, spine problems (due to the physical efforts of the parents to move their children position).

„In our case, we need in-home medical investigation to confirm the level of disability. We need to pass the Commission, and the doctors do not like to come to our home. It is very hard to take the child to each of the specialist. We cannot find a dentist that would want to treat our child. We have addressed a number of policlinics in the capital, but nobody wanted to accept us. We have gone to the republican dentist clinic that agreed to treat us but only if the child is given general anaesthesia and against a big payment and not through their accountancy office. I had to bribe them as officially they did not have to treat my child. They also made us to sign a document that if something wrong happens to the child, we, as parents, assume all the risks. We need a clinic which would provide services to children with disabilities and would provide services in our homes. The existing services do not fulfil their duties, although they have to come to our homes. The health system should come closer to the children with disabilities.” (a mother, Chişinău).

„It is necessary that the policlinic work differently with these children. In our case, for example, when we need to establish the child's disability level, we need to take the child to all specialists, to stay in long queues. Although there have been some rumors about this, but why shouldn't doctors like the neurologist, the psychiatrist be coming to see our children at home? With medical tests, some of the nurses know us and they would come home to take the tests. There should be a mobile medical team. The Minister Buliga said on TV that there is a mobile team which together with the social workers come to family homes to provide support. But I haven't seen it, I haven't heard about this”. (a mother, Chişinău).

In some of the cases the research team has observed lack of desire from parents to get involved in the process of their child's rehabilitation (actions foreseen in the child individual assistance plan as activities with parents in the family home); they consider that nothing could be changes in the child's situation.

Issues related to the living space: the living space is poor, inadequate, many families live at upper floors, without an elevator or with a damaged one; many families live with the extended families, where there is a certain level of nervousness and the right to personal intimacy could not be respected.

Educational issues: the domiciliary education is not qualitative and does not ensure the children's access to qualitative education; often children are not accepted in the community schools; most of the times the Medico-psycho-pedagogical Commission recommends children's separation from their families and placement in residential care.

At school, the parents are pressed to place their children in the residential institutions; they are disappointed as they are charged different payments for the school fund, sums that they cannot afford; in the rural area a lack of adapted bathrooms was observed; in some schools they are outside, often at long distance from the educational building.

„I am sceptical regarding the school, the school teacher comes to us twice a week, and this is not enough. There is a need of classes at least 3-4 times a week, as the children with disabilities need more time to learn. My son has a difficulty in speaking, hence the need of more learning hours. It would be beneficial for him to go to school, as he will learn more there, but the problem is the lack of help when he needs to use the restroom. I got in touch with people from a special school in Ialoveni, but I was told that he has to go to the restroom on his own. If he would be able to do it by himself, why would I give him away? If it was possible for him to do it alone, I would handle him on my own.” (a mother, Chişinău).

The parents confirmed that if the kindergarten or school administration accepts the child for training, often the teachers, the people in direct contact with the child (educators, professors) do not accept the children, with the excuse of not having special programs and not being paid for the additional individual work.

Social issues: the lack of a stable job and respectively of a stable income and appropriate to the family's needs; the lack of support groups for parent; the insufficient number of social services for children with disabilities and for their parents at the community level; families do not have information regarding the social services they could benefit from; families encounter difficulties in understanding the information communicated by the specialists; the society is not ready to receive children with disabilities; the children and families from the rural environment have difficulties in accessing the specialized services (specific therapy sessions, rehabilitation and medical services etc.); issues related to the child's transportation; the indifferent attitude of some specialists.

„A doctor asked me once: “Who asked you to give birth to a disabled child?”” (a mother, Chisinau

„We don't meet for the sake of enjoying the food and drinks, but to find a relief for our souls, to tell each other the things as they are, to communicate among us as parents, to find a relief in life” (a mother, Chişinău).

„Our children seem to become “wild”. They need communication and would love to meet other children. When we go outside in the yard, we are told that “ You took your stupid child for a walk again”. Even if I am bad at computers, my child is very good at it and learned fast” (a mother, Chişinău).

Emotional issues: In the families with children with disabilities there is a tensed psychological climate predominating; often there are issues in interpersonal relationships among family members; the family being rejected by some family friends.

The crisis generated by the diagnosis that established the child has problems is probably the most difficult and paralyzing for the parents of the disabled children. In most of the cases, the parents' reactions are negative, similar to the ones after irreparable losses. The families either flexibly adapt and mobilize in an effective action, or get stuck in some reactions with different degrees of rigidity and inefficiency. There are situations when the parents refuse to acknowledge the situation and deny the diagnosis.

The main problem faced by the family is that they do not want to admit that nobody is guilty for the birth of a child with disabilities. Most of them always look for the “guilty one” and always complain about the economic and financial situation. Families with children expect more support from outside, but do not see their own roles, which is very important in their situation. More often they see the negative side in their children. The child is compared to other children of their age, with better performances, etc. The parents need counselling. They have to acknowledge that all children are children, each of them with their own individualities, no matter if the child is disabled or not. The parent has to learn first of all to see the positive side of the things and work hand in hand with the professionals on the shortcomings.

Another important aspect mentioned by the parents was the psychological climate in the family based on the relationships between the spouses and other family members. The psychological climate is influenced by different factors, one of them being the attitude towards the disabled child. Once a disabled child is born in the family, the spouses face different challenges. The study has proven that in some families the husband left because of the birth of a disabled child, while in other families the birth of the child made the spouses' relationships even stronger.

„I have two disabled children and most of the time I don't go outside. I completely degrade and I need at least an hour per day to go outside and communicate with someone” (a mother, Chisinau).

Every family with a disabled child has their own specific features, their own psychological climate – this could either positively influence on the recuperation and rehabilitation process of the child or would block the specific process.

For a disabled child the parent is a professional who has to have knowledge in different areas; the parents should be a doctor, speech therapist, teacher, and nanny and also to know the laws.

The family where there is a positive psychological environment and a good understanding of the needs of their children with disabilities can provide an appropriate care, upbringing and education.

The psychological profile of the family with a disabled child

At the birth of a disabled child, the family goes through a series of emotions that affect their lifestyle as a whole. Shock is the first emotional reaction that blocks, for a reduced period of time, the normal functioning of the family. Then the parents start to deny the diagnosis: „No, it is not possible”, they try to verify the diagnosis, going to different doctors. This is followed by a reaction of anger, which usually is family oriented, "Why that happens to us?" This reaction is described as a way of externalizing the strong emotions arising when a baby with disabilities is born. And finally, after going through this succession of emotions, parents of children with disabilities are able to accept the diagnosis, and the situation changes, which is manifested in the establishment of a certain family lifestyle.

The care for a disabled child in the family inevitably leads to physical and emotional burden on all family members; there are many activities that need to be undertaken with the child such as medical consultations and treatments, rehabilitation and abilitation. All this is accompanied by strong emotional tension, subject to the increased responsibilities, changing attitudes of the extended family (blaming, especially in mother's address), former family friends, colleagues, neighbours etc.

The continuous stress with which the family lives can cause double reactions towards children with disabilities: starting with the appearance of a strong attachment to the child and their over tutorship and overprotection and up to aggressive manifestations towards the child with disabilities that could result in various forms of neglect and abuse. All these cause chronic suffering for all the family members.

What is specific for families with children with disabilities is that all emotional experiences are limited by family boundaries, they are not externalized and discussed outside the family, and they also include mutual accusations and blaming, which can lead to family disruption.

Accumulation of the tension within the family, and then externalizing it may lead to the situation when the child becomes a family "scapegoat", being the target of a discharge of the accumulated tension.

The social environment of the family with disabled children

The birth of a child with disabilities significantly reduces the parents' ability to engage in the labour market which leads to financial problems that diminish the possibilities of the families to create appropriate conditions for children care, development and education. The change in the lifestyle of the family with a disabled child reduces the contact circle; it has fewer possibilities of maintaining extra-familial relationships, and to participate in activities outside the family. As a result, there are serious problems related to social integration for disabled children and their parents.

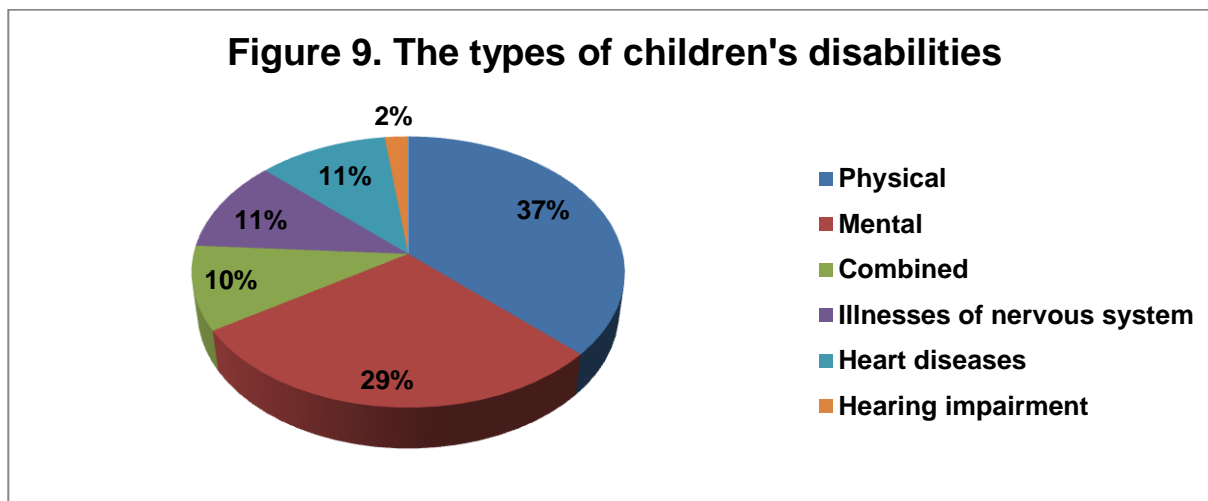
Individual needs of children with disabilities dictate the need to diversify and increase the diversity and the quality of medical, social, educational services which often do not correspond to the family expectations thus increasing the risk of abandonment and institutionalization of children with disabilities.

Another type of problem that the family with a disabled child may face is the relationship with the other non-disabled children in the family. After the birth of a disabled child, the family may change their attitude towards the healthy child, meaning that they will provide less attention, care and support to them. The non-disabled child may face some problems related to the change in attitudes of his/her school mates and friends, being ashamed to invite other children to the family home.

Consequently, the appearance of a disabled child in the family totally disorganizes the established lifestyle, relationships within the family and outside it. It may produce changes of values, interests, and needs. In such situations these families need specialized support, focused on a good knowledge of the peculiarities and needs of each family member.

THE DISABLED CHILDREN

There were 284 disabled children involved in the study. Out of them 176 come from 176 families from Chisinau and 108 come from 105 families (3 families have 2 children with disabilities each) from Orhei raion. The children involved in the study have different diagnoses: mental disability – 82 children, physical and mental disability – 30 children, dysfunctions of the nervous system – 32 children, heart defect – 32 children, deafness – 5 children. 19 of the assessed children are in a severe state and are bedridden. These children were visited at home. 24 children and young people participated in the focus groups.



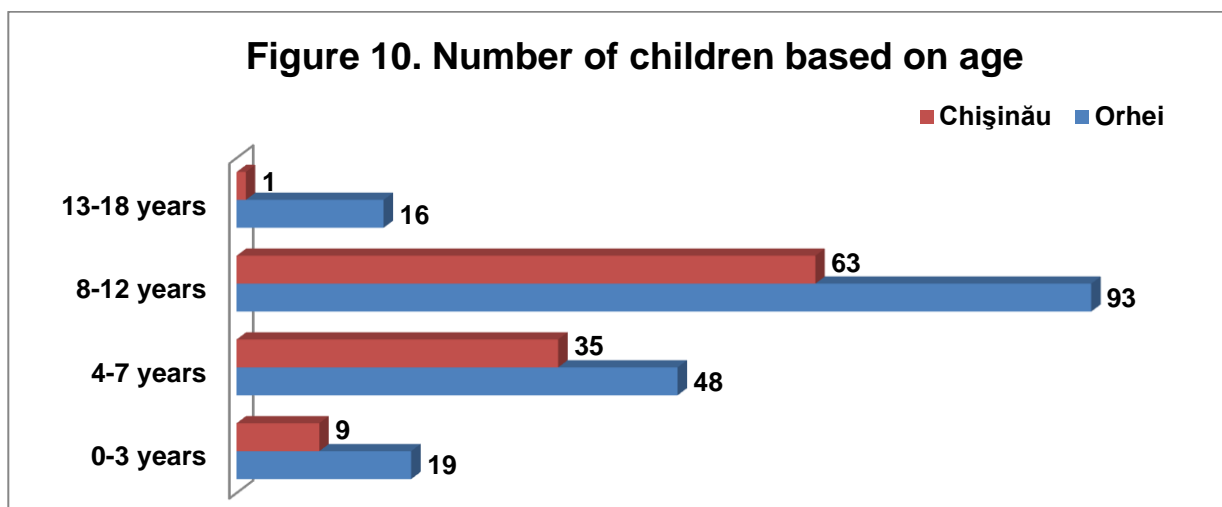
The study showed that children of preschool age require more time for care. Depending on the potential for rehabilitation with age some children acquire self-service capacities, satisfying some of their own needs without the support of the adults. But very often there is an **over tutorship** attitude towards the child, thus the child is not able to develop skills and gradually forms a lack of trust in their own forces, the child develops a high level of dependency that leads to difficulties in further integration into society. One of the factors that influence this situation is the feeling of guilt of the parents, especially when the child has received treatment and rehabilitation that have been successful, with age he/she could become more independent and the caregiver has could have more time for other activities. When the child becomes an adult, to the forefront comes the issue of independence, but their personality is already formed on **over tutorship** principles and the child does not manage to do anything by their own.

Psychological features of the child

The biggest problem of the disabled child is their isolation from the society they were supposed to grow and live in. From the early childhood the exterior of the disabled child is subject to negative appreciation from children and adults. These children are treated very rudely by the non-disabled children, and as a result, the disabled children become closed. The communication circle of the children is limited to his family.

Becoming more mature, children begin to understand that the opportunities of living are lower than that of non-disabled children. The level of self-esteem is low - leading to inferiority complex. Sooner or later children / young people with disabilities begin to understand how much they depend on "healthy" members of the society.

It is important that all family members have a positive attitude towards the child. If the child is neglected by a family member, they experience a double burden: negative attitude from society and alienation from their own family.



„My son Ion sometimes tells me that he is afraid of me, As I make him do different things, such as to crawl from one side to another; he calls me a bad mother. I tell him: “Things are not always the way you like it, this is life. What will you do when I am gone? They will take you to the orphanage!” He answers: “I will not go there; I will die there without you” (a mother, Chişinău).

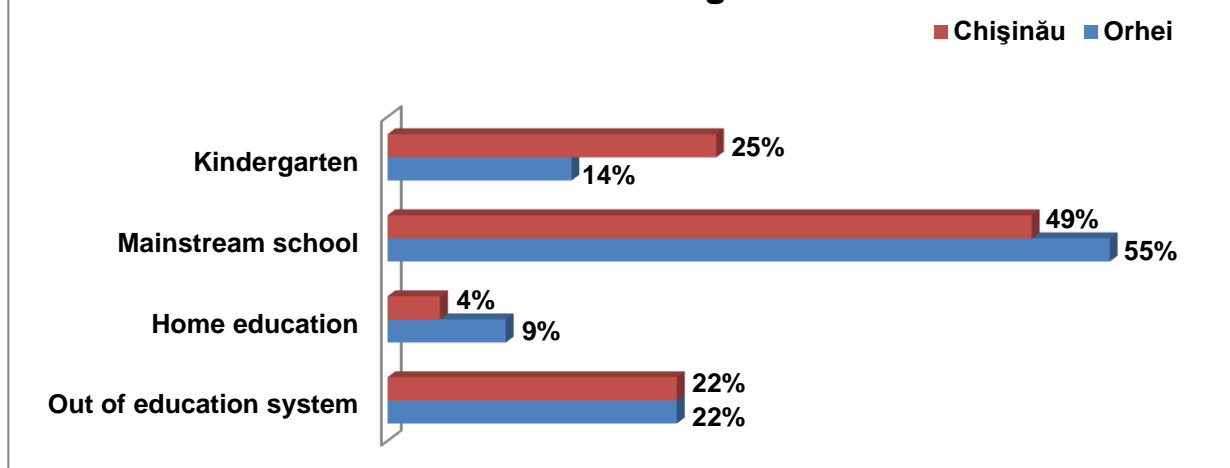
„My daughter had 78 surgeries, in so many different places, in Tula, by doctors from Saint Petersburg, Moscow. I was ready to give up everything just to see a change; I have spent thousands of lei on treatments, not on toys, as she is dependent on medicine... When she has her crises, all her muscles tighten; I do not have words to tell you the situation, as this is not something to talk about” (a mother, Orhei).

The school integration for a lot of children remains an unsolved issue. The study confirmed that the disabled children are often isolated from the society and do not benefit from complete and qualitative educational and social integration.

The majority of children attend the community schools. Parents from rural areas in Orhei noted that school attendance becomes problematic when weather conditions are not favourable, especially for the child in a wheelchair. Some of the children are educated at home, but the quality of teaching is poor.

„I have a big support from the school administration. We have a teacher coming to our home, we are just in the 7th grade. I am very satisfied and the teacher is extraordinary. I do not know how she marks him with 9s and 10s, as he barely can talk. When we do the homework, there is nothing more important for him, as he tells me to turn off the radio, the TV. We used to have another teacher, a young lady with a large cleavage and people coming to our house were always wondering what was wrong with her. She used to come to me and say: “Poor Mrs. Valentina” or would say to the boy: “Poor Ion, I brought him a chocolate”. I told her that I do not need this attitude and she had to work with him as it is required and to require knowledge from him as from a regular pupil. She used to say to me: “You see, he barely talks, and he does not sit right”. I told her that it does not change anything and she has to work with him. She told me that she would do her best. I went to school and told the director of the school and told her that the situation makes me uncomfortable and now we have another teacher. He also studies the Russian language. My son Ion is like a Russian now, can’t hide anything from him now. I think that it would be great to open a centre in each region and to take our children there every day for 2-3 hours” (a mother, Chişinău).

Figure 11. Number of children based on their educational integration



In the meantime, the study outlined that not all the preschool age children go to the kindergarten. So in Orhei, only 14% from the children have access to the preschool education, in a lot of cases in the villages of origin of the children they have no working kindergartens.

„Until the age of 3 my child had a Percutaneous Coronary Intervention(PCI), he couldn't walk, talk, just used to lay down. We made him injections, massage. If before he was 3 years old it was possible to leave him with another person, after the age of 3 everything changed. He became hyperactive, he would always get hit of something. He will be 6 soon and I can't leave him with anybody, not even with his grandmother, neighbors, not even with my sister. It is dangerous to leave him with someone. We tried half-day kindergarten, the day center, but now we stay at home” (a mother, Chişinău).

Moreover, schools and kindergartens are not adapted to the training of children with disabilities. In many cases school and kindergarten teachers do not have the necessary skills to work with these children, the fact being mentioned by both parents and professionals. 22% of the disabled children included in the study, from both Chisinau and Orhei, stay at home because of the severity of the disability or because they have not reached the age of 3 years yet, either because their parents refused their enrolment in the kindergarten, arguing that they will not feel comfortable there, because they are “different”.

Many young people are worried about their future, because the future model of these children differs from healthy children. The future mostly is viewed without colour. "I do not know what to expect in the future" - this is the view of many children and young people with disabilities. Most children and young people consider that their lives would change for the better, "if I wouldn't have health problems." Children are not confident in their possibilities.

Society should not show pity towards children with disabilities, and approach them from a position of participation, facilitation and support instead. Children with disabilities should have equal opportunities in education and development with full rights (not only legally, but practically as well) to apply their skills in different areas, including art, to have the option of achieving their potential.

Services for children with disabilities

A family with a child with disabilities benefits primarily from medical services for consultation, treatment and investigations based on the Unique Program of mandatory health insurance, but this program does not cover all the needs for rehabilitation of child and family has to pay for investigations, medicines, surgical procedures that are not set in the Unique Program of mandatory health insurance. Parents are not satisfied with the quality of medical services offered to them. They believe that their children are limited in the provision of medical services: "Our doctor has no interest in my child, if I go to him, then we might get some advice. Physicians and specialized doctors usually take care of my child. The treatment of children with disability largely depends on parents and their medical knowledge".

Among the services offered to a child with disabilities, services for social rehabilitation are usually rendered in the rehabilitation centres including physical therapy, speech therapy, massage, medical treatments, progress cognitively stimulating activities and communication services, independent living skills development services, services supporting parents of disabled children to prevent institutionalization, including consulting and advising families; service spa sanatorium, orthopaedic and prosthetic services, residential services.

Children with disabilities are offered educational services in preschools (kindergartens) and general and special schools. Children who cannot attend school are taught at home. It should be noted that in recent years more children have access to education in the community schools. This is due to the shift from a school that focuses on the integration of children with disabilities who need to adapt to the school requirements (while the school remains mostly unchanged), to a school that focuses on inclusion of children, which requires the school to change, to adapt to the child's needs.

The study revealed that some respondents know and use the services for children and young people with disabilities. A good part of parents said they were disappointed of the variety of services and their quality, while others indicated that do not even know about the existence of services or facilities to which they are entitled. Considering that in Chisinau, from the total number of children with disabilities, only 43% are registered with the Directorate for Protection of Child Rights from the Municipality sectors, it may be assumed that parents of children with disabilities often do not know about the existence of services they are eligible to, or do not trust the quality of these services. In the same time, they cannot overcome psychological or physical barriers to access them.

Services are provided to these children by local authorities and NGOs. In Chisinau the social and educational services available to children with disabilities are the following: many day centres and 1 placement centre, 4 kindergartens, 2 special schools, a Complex of curative pedagogy "Orpheus", and a Mobile Team Service.

If in Chisinau there are many services for children with disabilities in number and variety, and parents can easily access these services, in Orhei most of the existing services are concentrated in the central district and parents of children with severe disabilities cannot access them.

In Orhei due to community social workers who know almost everyone in their community, most children with disabilities are known and registered at the Directorate for Social Assistance and Family Protection. But this does not mean that all those who are registered do benefit from services.

Social services for children and youth with disabilities provided in Orhei are: two centres for children with disabilities in Orhei town and in Peresecina village, a republican boarding house for boys with severe mental disabilities; a Mobile Team service within the Directorate

for Social Assistance and Family Protection; a Community House (for 4 boys), Safe house (four young people), foster care service (three children in the service at the time of assessment) and 4 social canteens (all sponsored by the NGO Concordia).

Both in the rural areas and in Chisinau, the families with children with disabilities have big difficulties with the transportation of children to the existent social and educational services.

“Me, for example, I took my child for two months to a good centre. They used to offer us a car to take us from the entrance to Chisinau (Portile orasului). I just had to take the child from Singera to the place. At the centre it is very nice, there are lovely people and my child liked it there. My child is developed intellectually and tells me that he can't stay all day with the diaper with bad smell, as they don't like it and he does not go to the centre anymore. But if there was transportation from our house to the centre, I would find someone to pay him and convince him to change his diaper and he could stay there all day, He would have something to do, to use the computer etc. There is an extraordinary attitude towards the children at this centre. There are children that people could tell lies and they believe them, well my Sasha won't believe you. He tells me that he sees how it is unpleasant for the staff. The transportation is very important, even from Singera to the Centre, for example. It is lovely, almost for half a day, like at school, with activities and teachers that pay attention to them” (a mother, Chişinău).

A lot of parents mentioned that even if there exist qualitative services for these children, it is very difficult to access them, as the demand is bigger than the supply. *„It is very difficult to get there or you need a lot of money. If you haven't got money at all, nobody will pay attention to you” (a mother, Chişinău).*

Another aspect mentioned by the parents is that some of the staff from the centres for children with disabilities are not trained to work with their children – have an indifferent and discriminatory attitude towards these children.

The parents consider that the local authorities do not have a deep knowledge and understanding of the problems of families that have children with disabilities. From one hand, they state that all the children are the same, but on the other hand the authorities state that: “The State pays you the pension, what else do you want?” “But nobody tried to live with the pension provided. And another major problem is the fact that we cannot leave the children with anybody. If in a lot of families the children help each other, I am afraid to leave him with somebody; nobody has the guts to stay with my child” (a mother, Orhei).

„Every single time I asked for help, I was not taken into consideration; we received financial support just for the Days of the children with disabilities, but even then with scandal” (a mother, Orhei).

In their turn, during focus groups meetings the professionals said they are "very loaded and can't manage them all." They accepted that they fail to provide support to all families who need it. They also mentioned a hopeful development of new services that will enhance the coverage with services for these groups of children. "It is necessary for each community to have services for these children with disabilities" (a mother, Chisinau).

An important resource for parents is the information support. Without this information, many parents cannot access some types of help or services needed and available for them. Moreover, parents need knowledge and emotional support to be able to provide good care for children with disabilities at home. "Parents should know what awaits the child in the future, the information needs to be told in order for the parents to understand, considering the child's disability" (a mother, Chisinau).

Parents reported that their first source of information is acquaintances, friends or parents who have children with disabilities. From these people parents find out about services or

legal aspects. Mostly, parents do not know their rights and do not even know who they can find out information from.

A second source of information is the social worker, but this source is only accessible to parents who benefit from social services.

The third source of information is the medical doctor; from doctors the parents receive more health information about children and less on social services and the rights of persons with disabilities. Parents stated that: *"The doctor sometimes has no time to normally consult a child, he constantly writes something down."*

A fourth source of information is the media, but not all have access to this source, especially in rural areas.

Parents believe they should be informed more about the services they could benefit from and *"which are their rights"*. According to the parents, information can be available in places often visited by them, medical centres, schools, hospitals, post offices, kindergartens, pharmacies - these institutions must have some relevant information booklets.

We can conclude that services for children with disabilities and their families are not sufficient to cover their needs. Not all centres that provide services to children with disabilities are qualified for the rehabilitation of children; children often receive care and more seldom rehabilitation services. In this way the time which was good for the child rehabilitation is lost. Limitation of places in the day care centres blocks the possibility of parents to combine childcare with their work.

THE SHORT BREAK PLACEMENT WITHING THE FOSTER CARE SERVICE

As it was mentioned above, one of the objectives of the study was to inform, based on the accumulated opinions and perceptions the development of the short break placement for the disabled children, as part of the foster care services. In this chapter, the vision of the parents with disabled children, specialists in the area and children in the Chisinau municipality and Orhei raion regarding short break foster care are presented. The information was gathered using focus group discussion method.

The groups of children who could benefit from the short break placement

The parents' ideas regarding the children's ages that could benefit from the short break placement were divided as follows: a part of them considered that the short break placement would be perfect for children of preschool age or children with ages between 3 and 14, but the majority of parents considered that all the children between 0-18 years old could be placed. Some parents that take care of bedridden children considered that *"It would be good for children to continue to be in placement even after 18 years of age, as the parents are exhausted"*.

Regarding the children's diagnosis, the parents' opinions were also divided. The majority of the parents believed that *"it is very difficult to take care of a bedridden child, dependent on medicine."* A part of the parents were not sure about the capacities of the foster parents to take care of children with severe diagnosis: *"Us, the parents, needed time and knowledge to understand our children"*. The parents consider that children with the Down syndrome, medium and light mental disabilities are easier to be taken care of in short-break care. The other part of the parents thank that the placement should have some benefits. *"The bedridden children, to start with", "I believe that all the children would need this service, the whole family needs it"*. These parents consider that: *"We did not know ourselves how to take care of our children"*, the foster parents *"need to be trained"* and the parents are ready to share with foster carers about the care that the child, that is about to be placed, needs.

Experts, as well as parents' opinions were divided with regard to the age of children - some of them think that "Children can be placed in short-break care after the age of 3. Children up to 3 years are very attached to their parents... Firstly, bedridden children whose parents are always at home as they have to take care of them". But most experts believed that *"At every age and just consider that the priority is given to the bedridden children."*

All the professionals agreed that: *"All the children deserve a chance. Even the parent with a child with a light form of disability, but who does not have a person to leave the child with, deserves the appropriate respect, the same goes with the bedridden children. Meaning all children."*

The professionals believed that children with any type of disability, excluding the severe ones could be placed in the short break care. For severe disability it is necessary to know a lot about health care, but the existing foster carers usually have no sufficient knowledge and experience for providing proper care for children with severe disabilities.

In conclusion, according to the collected data, short-break care could be provided to all children aged between 0-18 years with any disability, except the most severe disabilities, at least at this moment in time, as it requires a more specialized medical care and endowment of the house of the foster parent with specialized equipment. It was also agreed that children under 3 of age will benefit from this service only in emergency situations.

Situations when the families with disabled children may need short break care

At this question, the parents' and professionals' opinions almost coincided. The parents with disabled children may need this support in the following situations:

„When the parents need to do some restoration works in their house”

,When parents have an intervention, a medical treatment to undertake, such as profilactical investigations, for example, once a year for the heart and lungs checks”.

“It is necessary when the parent has to stay in the hospital or needs to rest. Two years ago I was in this situation, when we wanted to go for holidays, and me with my husband and the youngest child went abroad, we left the grandparent to take care for the disabled child, and the neighbours to buy them food. We were gone just for a week, as we could not afford to be gone for longer. We are all tied to our children, in order to respect his routine.”

Even to go to a hairdresser or for recreation”, “I have two twin disabled children and I almost do not go outside at all, I degrade and I need at least an hour to go outside and communicate with someone”.

In situations when the family does not have a range of support available, when they need to solve some daily matters, *“when people collect the crop of fruit and vegetables”*, when the parent is studying or wants to attend a course.

When the family needs to have time to offer more attention to other children in the house - *“I have three children, the poor first two do not have enough of my attention, I cannot make at least a few hours for them in my time, I can't remember the last time we've been shopping together”*),

Parents believe that from this type of placement there could also benefit parents who go to work abroad, an opinion with which the professionals did not agree. They believed that short-break foster care service should aim to prevent family-child separation.

Professionals considered that short-break placement will allow *“Parents to plan family activities and they will not feel so isolated from the society.”*

As a result, it can be concluded that parents of children with disabilities could require this placement in all the situations in the statements mentioned above, except for leaving to work abroad.

The minimum and maximum length and the periodicity of the short break placement per year

This question made the most debates amongst parents and professionals.

Parents considered that the minimum duration of the placement is from one day and *“maximum a month per year. If it is divided in weeks, it means 4 times a years, if the whole month – once a year, if 2 weeks – twice a year”* or maximum 45 days. The parents stated that: *“It would be great if the days were divided according to the needs, for example I would like to use the day during the children's holidays, so I could pay some attention to them as well. 4 times a year does not sound that bad, as every season something happens to one of us, you have a tooth ache, you have to go to the hospital or visit the aunt that is sick”.*

Most professionals, alike parents, considered that the length of the placement can be from one day to 45 days, but between professionals there was also an idea that the maximum placement could last for up to 60 days per year or the family *“to receive 30 days a year, as long as it has an arranged legitimate leave.”*

The parents and professionals considered that: *“It is necessary to take into account every family individually, their needs and their need for support.” “For every child it is necessary to establish the placement’s duration individually, for example for children that go to school I think it is difficult to focus on the holidays. For children with severe disabilities, the duration has to be smaller and the placement more often.”*

The decision, according to respondents, which can be taken on the minimum and maximum placement time, is from one day to 45 days per year. The frequency of the placement is individual and depends on the family needs.

The qualities of the foster parent

According to the respondents, it is obvious that when it comes to foster parent skills, the most important would be qualities such as patience, empathy, tolerance and understanding. They believe that these qualities help in working with “special” children.

For the parents the following qualities of the foster parents are important: *“Patience to persuade the child to open his mouth, to repeat 100 times to get him to understand something, to relax his muscles, as you can break the child’s jaw, if you haven’t got enough patience”,* empathic, understanding, communicable, kind, determined, brave, resourceful, emotionally stable, deeply faithful, be careful, be able to understand the child, understand his situation and looking at him to understand what would the child need, what might help him, and even try to help him, honest, magnanimous and not the least - to love children. Parents say: *“If he/she has a good education, it will be an advantage. But for my child it is very important to be loved as he is, not to be bullied, they must have a lot of patience, especially when they feed the child. He wouldn’t always want to eat what I prepare. But I know that vitamins are important to him and do everything possible to feed them to him. Sometimes it takes two hours to feed him. The foster parent needs patience.”* For parents it is important that the person *“has the idea of working and caring for such children.”*

Professional have noted that the following qualities are required for foster parent in working with children with disabilities, *“To be empathic, to get into a parent’s skin, one who educates a child with special needs, to understand what the disability is, the special needs of the child and have a special approach and love. If the foster carer will show a human attachment, the child will feel and will create a looser attitude.”* Loving, empathetic, hearted, patient, kind, understanding, tolerant, responsible, flexible, honest, creative, calm, well trained, sociable, hardworking, active, glorifying, and insistent - these are the qualities of a foster parent”.

In fact, all the qualities listed by both the parents and by the specialists are relevant to foster carers who work with children without disabilities.

Training topics for the foster parents

Both the parents and the specialists noticed that foster carers that are going to work with disabled children need to be trained. This will help them understand the specific part of their work with disabled children.

Parents think that *“if foster carers are not aware of the age peculiarities and the type of disability they will not be capable to provide appropriate services. If analysing 2 children of the same age, but one of them being mentally disabled, it is vital to have wider pedagogical and psychological knowledge. They both have the same necessities, but their behaviours are different”.* Moreover, the foster carer should *“be aware of children’s diagnosis and know what the right thing to be done in crisis situations is”.* The *“psychological part is also important. Children have different characteristics, and depending on their behaviour, foster*

carers should be able to understand what these children want. Even if the child is not talkative, they should know how to work with him/her”.

Among the training topics mentioned by the parents are: Medical aspects; Types of disability; Psychological aspects; Communication skills; Gaining trust; Hygiene, they every-day schedule of a disabled child; Actions to do in emergency situation; Communication.

The specialists considered that: “Every person, especially the ones who have their own children, truly believe that they could manage to take care of disabled child. There should be a self-assessment, in order to decide whether the person is suitable or not for the job. It is important for the child to be seen as a usual child, but who has their own personality”. “As not everyone who wants to become a foster carer has wider medical knowledge, some workshops should be carried on, related to how to analyse and understand the diagnosis, day-to-day schedule, medicines, hygiene and others.”

The specialists mentioned the following topics: Age psychology; Disabled children psychology; Medical aspects; Types of disabilities; First Aid; Behaviour; Organising child’s free time; Games entertainment; Food; Children’s needs; children’s rights.

The majority of training topics suggested by both the parents and the specialists are quiet similar and acceptable to be included into the curriculum of the foster carers that would provide short break placement services.

The list of needs, to be fulfilled, depending on their importance to a child being placed in short break placement care services

The parents mentioned the following needs that have been classified depending on how important they are: physiological (food, leisure, hygiene), medical, security, protection, trustful relationships, living conditions, love, affection, and education. A mother says that: *“Food is essential for my child. If he is hungry he starts crying. If he is not hungry anymore, he becomes calmer. The child needs attention and although he doesn’t understand that working on their own is a part of the lesson you are trying to teach them, they become hysterical”.*

The specialists also believe that *“basic needs are essential, because the child is going to spend only little time living with the family of the foster carer and we should not make these foster carers responsible for too many things. Of course an individualised plan is going to be developed, but still there should be paid more attention on care, play and training”.* However, a part of the specialists reckon that *“although basic needs are the essential ones to fulfil, we should not forget about the emotional needs as well. For instance, if the child is hyper-active and needs to play, parents often neglect this necessity and do not pay enough attention to the child, arguing that they are too tired to play”.*

The needs mentioned by the specialists have been written down and classified according to their priority: physiology (food, leisure, hygiene), day-to –day planning (including a diet), medicines (including kinesiology), affection, individual attention, communication, relationships with relatives, psychological comfort (satisfaction of needs and wishes), occupational therapies, games, training, praise, relationship with biological family, adapting the living conditions.

We can see that when talking about short break placement, both the parents and the specialists mainly talk about child care or the satisfaction of children’s physiological necessities, children’s safety.

The kind of support that could be provided to the biological family of a disabled child as using the service of short break foster care

Specialists believed that, first of all, the family should benefit from “counselling, information about social services provided to children from the area”. If necessary, families with one disabled child should get legal advice in order to be capable to protect their rights and access health services easier, “the family should get for free some holiday vouchers, movie/theatre tickets, etc. they never have the opportunity to go out and relax a little bit. This would give them the possibility to be up-to-date”. Specialists believe that a lot of parents should be trained in order to develop their parental skills (satisfaction of children’s needs, how to cope with problematic behaviour). In this case, some training concerning the type of disability of the child and support groups could help a lot. These families should get financial support as well, because their expenses are enormous.

Parents see support as: home medical check-up to decide the degree of disability, provision of dental services (including emergency) at home, provision of a mean of transport for the transportation of the child, so he/she could benefit from other services within the day-centres, like diapers or humanitarian aid. It is obvious that parents pay more attention to the importance of the financial help and do not perceive psychological counselling as a type of help.

When creating the concept of short break placement, the needs of parents/family should be taken into account. Once the family becomes a beneficiary of the service, the provider will develop a family support plan.

Matching foster carer with the child

Both the parents and the specialists mentioned that “matching them is the most important stage and whether the placement is successful will depend on it”. This process involves the participation of: the child and their family, the foster carer and their family, the specialists from the Foster Care Services.

The role of a foster carer is to “meet the child and find out his/her necessities.” Parents believe that “the foster carer will be better at taking care of the child than the child’s biological parents when they will know about the praising/punishment methods used by the parents”. The foster carer “should know at least something about the child before meeting him/her and be aware of the child’s possible reaction, because these children sometimes do not accept their foster carers. If there is a positive relationship between them, the child would accept the foster carer. Hence, the mother of the child could accompany the child to the foster carer’s house so the child gets used to his/her presence. This ‘matching’ should take place gradually”. Parents see ‘matching’ as “a way to get to know each other: the child, their family and the foster carer. Parents believe that initially, *‘the foster carer should visit us at home, meet our child, and try to communicate in order to see if they are compatible. This can be noticed. I think that the child is able to feel whether the foster carer suits him/her during an hour. I saw that he got used to 2 of the teachers who teach him, and he has not got used to other 2 of them. He tells me: If my mathematics teacher was as nice as my history teacher, I would enjoy doing math as well’*”. Meeting the child, the foster carer should be able to assess his/her own abilities of taking care of the child, taking into account the type of disability and child’s needs.

The biological family of the child plays a vital role in the process of ‘matching’, as they have to facilitate the contact between the child and the foster carer: “*The parents have the role to present the foster carer to the child and vice-versa. They should perceive the foster carer as a friend, so the child feels safe in his/her company.*” Moreover, “*they should talk to the foster carer about the capacities of the child; what he/she eats and other habits. Otherwise,*

the foster carer would not be able to take care of the child properly". All the parents mentioned: "The child should not be forced to take part of the foster carer's family". Trustful relationships should be created between the child, his/her biological family and the family of the foster carer, "this is the only way they will manage to succeed".

The specialists should evaluate the level of compatibility. The placement can take place *"only when the disabled child will accept the foster carer, when the specialist will train the foster carer and he/she will know everything about the child and his/her family".*

All the specialists, the same as the parents, consider that *"Matching is a complex process and the compatibility between the child and the foster carer is an essential factor".* First of all, the skills of the foster carer and the needs of the child and his/her biological family should be assessed. It is important for the child to be trained by his/her parents. There should be organised meetings of the foster carer, the child and his/her family, because the foster carer needs to know details about child's interests, his/her type of disability and the specific parts of care needed. The involvement of the biological children of the foster carer at this level will be the best way of linking the disabled child and the family of the foster carer.

"The biological family has to help the child understand that they do not want to get rid of their and the foster carer is family's best friend that will help the child as long as their mother needs help" and "create a trustful relationship between the child and the foster carer. Otherwise, this is not going to be a break, but an endless worrying". Moreover, family's role is also to inform the foster carer about what type of care needs the child, in order to ensure the success of the placement. The parent becomes an assistant of the foster carer.

The placement itself should take place only when the child, the foster carer and his/her family are compatible. The process of 'matching' within the short break placement has to be identical to the 'matching' processes within the other types of placement provided by Foster Care Services.

The advantages and disadvantages of the short break placement

Parents have shown that the benefits are for both children and their parents: *"Children will feel that they have reached a higher level. They will think that this is it, they go to a family, so they want to see me, and they are not disgusted to see me at the table or something like that. As some of them chew loudly, another has his saliva flowing and someone may find the situation unpleasant. So I think they will find that they are all together."* So among the positive results provided by foster care, a very important one is the positive progress that will register the children: children will talk more, they will feel part of society, with others, and their self-esteem will rise.

For the parents, the short break placement is a *"Respite for parents "crisis rescue and hope you have a place to ask for help, you have support", "the opportunity to resolve any problems - "a little respite, I think this is the biggest advantage for me, basically I cannot leave my girl with someone not even for 10 minutes", rest, the ability to schedule family events, widening the group of friends for children and families.*

Parents have revealed more concerns than disadvantages. They are afraid that the child will get a stress for all his life, they are also concerned about child safety and confidentiality of the diagnosis, acceptance of the child by the foster parent, children attached to their parents will suffer and this will reflect negatively on their health, the child will not want to go home. *"People in the village will not understand why I gave away my child into another a family and start to gossip".*

From the specialists' point of view, the advantages *"are primarily for parents, as they day and night care for children and are bound by them and because of this service they can*

take care more for their personal lives, especially in the situation of children with severe disabilities. Furthermore, the advantages can be for a child, if they don't experience a more beneficial attitude from the biological parents, the child could have it in the foster parent's family. Similarly, there would be advantages from the point of view of socialization, which is, for example, if, being the only child in the biological family and spending all day just sitting alone watching TV or listening to radio, now they would have the opportunity to communicate with the children of the foster parents. "The family of the child will have the possibility to solve some problems, will benefit from recreation, rehabilitation, health care, after which will come back with new forces. Foster care is the support of the biological family in crisis, is a safety - the child is in good care, integration into society of families who educate children with disabilities.

The general public will also experience a positive influence, being sensitized to be aware of the children with disabilities: "*This service will reduce these secrets, recognizing that children with disabilities have rights and are full rights citizens.*"

Among the disadvantages highlighted by specialists some examples are: the risk of creating dependence of the biological family on the service, problems arise at the return of the child in the family.

It should be noted that experts are worried that the economic situation may decrease the importance of family and child services, the emphasis being put on expenses.

The attitude of the families with disabled children towards the short break placement

The parents opinions were divided when they were interviewed about their attitude towards the placement: some parents think that some families will use this service only in case of emergency or if they see positive examples and personally know the foster parent. "*It would be good if the foster parent was a relative or a family acquaintance*" but other parents think that most families will avoid short break placement, since they believe that foster parents will not have the necessary skills to meet the needs of children with disabilities.

Specialists consider unanimously that they would find such families who have children with disabilities, but their number will initially be lower: "*Any service from its starting point causes mistrust, so we started with the foster care service. At the moment there are plenty of people who apply to provide services foster care. I think that short break placement is necessary to confirm the good and reliable service*", families will face the fear of losing the child, there are parents who are very tired, some families will use this service only in case of crisis.

The vision of the children and young people with disabilities regarding the short break placement concept

Children with disabilities with the ages between 12-18 years (13 children) and disabled young people with the ages between 19-27 years (11 young people) participated in the focus groups organised within the research. In Chişinău focus-groups were organized within the *Centre for active rehabilitation and social reintegration of children and young people with physical disabilities*. In Orhei the focus group was carried out in "A.Donici" Lyceum, Peresecina village, the inclusive group.

The majority of the children and young people live together with their parents (in 3 cases with the sister, in once case - with the grandmother) and just in one case the young lady lives on her own. The majority of the young ladies have secondary education and just one of them has a higher education degree, but none of them is employed.

Young people's opinion

The big majority of people engage in their free time with the manual work (beads work, embroidery), reading, some people are passionate about Television, PC, drawings, puzzles, PC games, music. Few people are passionate about manual labour, Television and sports. Through the choices of occupations in their free time, we observe a weak socialisation process of young people with special needs, who have an isolated lifestyle and their main contacts are members of their own family environment. *„I watch TV shows..... I also listen to music, do crosswords, I draw and sleep. I draw the nature”.*

They are involved in household activities: *„I like it very much to help in the kitchen, most of all I like to cut all the ingredients for salads”.* Offering their help to the family, they feel useful: *I go to the grocery shop to buy bread and milk, I tidy up in the house (I vacuum, I whisk, clean the floor), I hand wash the socks, I make compote when my mother has to leave for work, I make tea, I heat the food, I go to the post office to buy newspapers”.* Some of them enjoy doing it; others do it when they are asked by their parents who are worried about how the children are going to handle life when they will be alone.

In their childhood, when the parents needed to go somewhere, the children were under the extended family surveillance, *„by the grandparents when they were still alive and my mother”.* They always had around them their neighbours and family friends or used to go everywhere with their parents. *I've never stayed alone, I always used to go everywhere with my parents: exhibitions, meetings (starting with 1989), weddings etc. Sometimes during the summer time I used to stay with my granny in the countryside”.*

The majority of young people stated that the main problem they face within the society is the discrimination of people around for their disabilities: *„At school my colleagues used to say nasty things to me. I wouldn't pay attention to them, as back then I didn't understand the meaning of a lot of those words”.* Young people say that with time they overcame these problems, as soon as they were integrated in peers groups. Their will to study was their motivation and facilitate their integration. Parents, teachers and friends were also mentioned, people that offered encouragement and moral support to young people in solving their problems and accepted them the way they are. The problems where nobody could help them are the personal and health ones. One of the major problems mentioned by the young people was the limits imposed in the possibility to arrange a personal life. One of them overcame these problems, ignoring them, trying to forget about them, and other would just keep them inside: *„I had problems with a girl from the neighbourhood, she was 16, and I was 18. She betrayed me and then I left her. She caused me pain and suffering. This pain lasted for 2 years; I am struggling to forget about it now, as the doctor advised me to do”.*

The most important people in the young people's lives are parents, friends, extended family, as they offer them the necessary support and have a mutual attachment: *„My grandmother is aware of all my problems and helps me”.*

„I have a neighbour for more than 10 years that I get along very well with, she is a special person; she has taught me a lot of things and given me advice. She accepts me as her equal, she does not make a difference between us. Today we still keep a positive relationship. We visit each other. She is the person one could trust”.

The young people mentioned that the potential age of the foster parent that would provide the short break placement is between 24-45 years of age, as people of this age have more necessary experience, skills and possibilities to take care of a child: *„it is good for the foster carer to have biological children with ages of 4-5 years old, children to play with. The foster parent has to be 30-40 years of age, but sometimes age does not matter, the main thing is to have something to learn from the person”.* The importance of the biological children of

the foster care, were also mentioned favouring the communication and the socialization process of the child in placement. They mentioned that the foster care has to be a patient person, able to talk to children, affectionate in the relationship with the children and with a "good physical aspect". The family of the foster parent should know the traits of the child that is about to be placed in the family, who do they talk to, the child's ethnic origin, what disciplinary methods are used in his/her biological family and if the child had been placed in a family before. The need of mutual knowledge of the families was also mentioned.

The majority of children would like to get to know the family of the foster carer before the placement, in order to see if there is some degree of compatibility between them, to be sure that they will be treated with love and with no discrimination. They would like to know the traits of the foster carer who has to "*find ways to approach the child*". The child has to know the character of the foster carer. The child also has to know what the foster carer does for their living, if they drink alcohol or not. "*I am not independent and I am afraid to be left alone. I would rather go with them or have someone to stay with me. I do not like to be locked inside the house, this is why we should have to know each other*", if the foster carer has communication skills and is able to work with children with special needs. The child also should know the occupation of the foster carer's family. Young people showed the will to take with them in the foster family things with emotional value for them, with a sense of comfort (soft toy, clothes, photographs) and thing they use on a daily basis (Personal Computer, pencils, toothbrush). In cases of some severe disabilities, young people also wished to be accompanied by a family member.

The majority of young people would like to keep in touch with the biological family during the placement in the foster parent's family, mentioning phone contacts, Internet, and direct contact with the family. The contact frequency could be once a day, or at least once a week. The majority of young people agreed to stay with the foster care for 1-2 weeks, others just for a couple of days, because "*in another family you cannot feel completely free in actions and you will be limited in actions, as you have to respect the rules in the house of the foster carer*"; there were children who said that the placement could be up to a month.

The majority of young people said that they would wish to be able to help the foster parent in the household activities. They also wanted to have fun, to rest (walks in the park, swimming pool, seaside, mountains) and to find out something new. They also mentioned that in the foster carer's family they wouldn't have liked to tidy up in the house or the garden, to wash up clothes, to take the garbage out or to get involved into another religion/confession.

Children's opinions

The majority of children spend their free time with their parents and grandparents. They are happy to go to the local Centres. Sometimes on weekends they go to visit their relatives or to have fun. Three children mentioned the recreational activities organized in the local Centre: "*I go to the Centre; they have different activities there*".

The children are involved in the care of their little siblings: "*I like to play with my brother and sister, because I love them very much, and as long as I spend time with them, my mother can do something else in the household*", other children help feeding and taking care of the animals, others help their grandmothers in the kitchen. They like the most to "*take care of the animals, as they are kind and they love them a lot*". They do not like to be forced to read or to write: "*I bring water to the birds in the household, sweep the yard, take out the garbage; we don't really like to do everything we are told to, but if we have to, we do it*".

Just 5 out of 12 children were left with other persons that are not family members (neighbours), as they usually stay with their relatives. 4 children stated that they do not

leave the house to go to stay with someone, there is someone that comes to the house and they stay with them. *“Every time she needs it, my mother leaves me with the neighbour”*.

Just two children stated that they do not like their uncles or aunts who live with them, they are always snubbed that they do not behave, that they do not arrange their things at their places. The only problem at school is that children have difficulties in transferring from one floor to another, they are not snubbed, but *“there is not a good path on their way home and it is difficult for them”*. A girl is unhappy that where she leaves the road has a lot of pits. The boy that travels from the village has opposite problems, they are not that much on the streets, someone takes him to school and back, he would wish *“an advanced wheelchair to travel alone with, so he gets to know more things”*. Sometimes people stare at the children and this makes them uncomfortable. They hardly manage to do things on their own. In the majority of cases they ask for their parents' help. For example: *“when my uncle rebukes me, I tell my mother in the evening and she solves the problem”*. *“I ask help from my colleagues, when I need to get from one floor to another or to go to the toilet”*, says a boy in a wheelchair. *“Sometimes I manage to do things on my own”*. Parents, the grandmother, the teacher in school – all of them are the people that help the children.

The majority of children think that the person has to be kind, to talk to them, to be sociable, to allow them to watch the TV; it is also important that there are other children in the family. *„I would like the person to come to my house, so I don't have to travel, as at home I do what I like, that I could not do in another house”*. *„Age does not matter, the person just has to be kind and to have children of my age, or younger children so I could be the older brother”*. *„The foster carer has to be older, so he/she has experience in the domain, as the younger ones still have to do a lot of things in life. The foster carers have to have their own children, but they have to be ready to accept a child with special needs in their family, in order for the child in placement not to be ignored”*. Young people also mentioned that: *“the foster carers need to have experience with children with special needs. There is not “a must” for them to have their own children, but to activate or had activated before in the domain with children with special needs. Or they have to be well-informed about this group of children”*.

„She has to be patient. Not to boss us around, but to communicate well with the child in placement, so that the child does not become aggressive”.

According to the children's opinions the family of the foster carer has to know what they like to eat, what animals they like, in which grade they are, if they can crochet, that they like sweets a lot. *“I do not like milk and they don't have to make me eat food prepared with milk”*. All the children want to meet the foster carer beforehand: *“If I didn't know the family, I wouldn't even go to stay with them”*, children with disabilities want to know: *“for how long I will be in the placement and why they chose me”*. They want to know about the foster carers if they have children, what they do, if they have domestic animals and birds. If they have a computer and a TV set. *“I like small children and I would like to know if they have any”*. Children would take with them different things to the foster carer's place: *“I think I would take my clothes and the thread for crocheting”*. The majority stated that they would take their books, clothes. One child said that he would take his dog. *„I would take my younger sister and brother with me”*, answered the girls who are in care of a neighbour and their very old grandmother, as parents are abroad.

The placement duration, according to children's opinions, can vary from a few hours to a few days, a week, even a month, *“if the family has a computer and I will like it there, I could stay for a month”*. There were also children who said that they would not stay with a foster carer not even for a day. 8 children stated that they would not like to stay for more than 2-3 hours, explaining that they would miss their home. *“it is OK to stay with foster carers more often, but for a few hours only”* – answered 4 children.

All the children stated that they would like to talk on the phone, to meet their parents, grandparents, even all of them to get to know each other: *“I would like to be placed in a family from my community, so I do not have to leave the village”*.

When offered to go to a foster family, we heard different answers: if the child would know the family would go for a few hours or even days, it is important to know the family. The mother could answer this question, *“she is the one that knows what it is needed or not and in what quantity”*.

At the question “what would you like to do in the foster family”, the majority of children answered that they want to do the same things they do at home, they would not want to change something: *“The things I usually do, daily.” “I would like to feel like at home”, “so they don’t ask me to do more than I can do”*.

At the question “what you would not like to do in the family of the foster carer”, the children gave usual answers – not to sleep at lunchtime, not to make them to work: *“I don’t want restrictions about when to rest or play”*.

RECOMMENDATIONS FOR THE SHORT BREAK PLACEMENT MODELING

The short break placement should last from one day to 45 days per year. The periodicity of the placement is individual and depends on the family needs.

Children with any disability with ages between 0-18 years old will benefit from the short break foster care placement, also children from 3 years old will benefit from this placement in emergency situations.

The foster carer who will provide the placement will receive the specialized training in understanding the disability.

The matching process between the child, his family and the foster carer will take place before the placement, so that before the placement, the foster carer will know all the details about the child and his needs.

In the process of the placement an important role will be played by the child's parents, who will support the bonding between the child and the foster carer.

No decision regarding the child within the placement will be taken without the parents' agreement.

The foster carer does not have to present a better family model than the one the child has in the biological family and won't make radical changes in the child's lifestyle.

During the placement the child will keep in touch with the biological family.

The child gets to understand the scope, duration, the essence of the short break placement, and what will happen after the placement.

The family of the child with disabilities will benefit from family support and psychological counselling provided by the Foster Care Service and the work will be done to strengthen the social support network of the family.