KNOWLEDGE, ATTITUDES AND CHALLENGES OF PARENTS AND CAREGIVERS OF CHILDREN WITH DISABILITIES IN THE REPUBLIC OF MOLDOVA

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This study was conducted under the UNICEF Project ‘An inclusive world starts with me, with you, with us…’, in partnership with non-governmental organization (NGO) Prietena Mea, with the financial support of the Ministry for Economic Cooperation and Development of the Federal Republic of Germany through the German Development Bank.

Authors:

Parascovia Munteanu	PhD in sociology
Tatiana Vasian	PhD in psychology

This paper was drawn up with technical support and guidance on behalf of:

Valentina Bordian	social and behaviour change programme coordinator, UNICEF Moldova
Anatolii Oprea	gender specialist
Ludmila Adamciuc	project coordinator, founder of NGO Prietena Mea
Diana Adamciuc	communications coordinator, NGO Prietena Mea

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ABBREVIATIONS

NPHA	National Public Health Agency
NGO	Non-Government Organisation
LPA	Local Public Authority
NBS	National Bureau of Statistics
CMHC	Community Mental Health Center
CRC	UN Convention on the Rights of the Child
CRPD UN	Convention on the Rights of Persons with Disabilities
NHIC	National Health Insurance Company
NCDDFC	National Council Determining the Disability and Functional Capacity
COVID	Coronavirus
RCPA	Republican Centre for Psycho-pedagogical Assistance
FGD	Focus Group Discussion
ECI	Childhood Early Intervention
MER	Minister of Education and Research
MLSP	Ministry of Labour and Social Protection
MoH	Ministry of Health
ASD	Autistic Spectrum Disorder

FIGURES

INTRODUCTION

Prietena Mea ("My friend") civil association and UNICEF Moldova have designed the first support platform for parents and caregivers of children with disabilities in the Republic of Moldova, to support them at different stages of inclusion. This platform is part of the project 'An inclusive world starts with me, with you, with us...' and is designed as a credible source of information for parents and caregivers of children with disabilities, and for professionals who work with these children.

An assessment was conducted to better understand the knowledge and attitudes of, and challenges faced by, parents and caregivers of children with disabilities in the Republic of Moldova.

THE RESULTS ARE USED TO:

1. create the first support platform for parents and caregivers of children with disabilities in the Republic of Moldova, and to better plan the assistance and support offered to children with disabilities and their families;

2. empower parents and caregivers to become support pillars and resources for their children;

3. encourage positive attitudes towards children with disabilities and their parents that contribute to improving opportunities for girls and boys with disabilities and their parents or caregivers;

4. identify and develop projects and actions that respond promptly to identified needs and help shape positive attitudes towards children with disabilities and their families.

> *„An inclusive world starts with me, with you, with us..."*


Foto: UNICEF Moldova

METHODOLOGICAL ASPECTS

The target population of this study were **parents and caregivers of children with disabilities** (0–18 years of age) in the Republic of Moldova. The following analysis methods were used.

1. DESK REVIEW

The desk review analysed statistical data on children with disabilities in the Republic of Moldova, and compared these with regional and global statistics. The analysis also covered existing policies, the main relevant studies conducted, challenges to and recommendations on inclusion of children with disabilities and support for their families, as identified by national and international experts in reports.

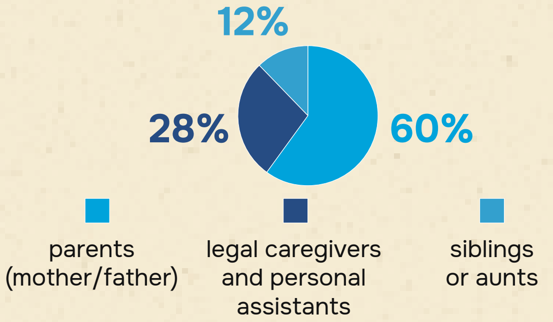
2. ONLINE SOCIOLOGICAL SURVEY (20 QUESTIONS)

In total, **846** people completed the online survey (**830** women and **16** men). About **58%** of respondents were from urban areas and **42%** from rural areas. Most respondents of both genders (**48%**) were from the centre of the country, followed by respondents from the north (**45%**), with only **8%** from the south (see Annex 1 – Profile).

Profile: online survey respondents

98% women **2% men**

How the respondents were related to the child with disabilities



According to marital status:

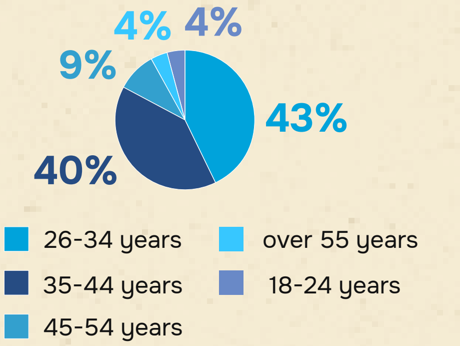
65% of respondents were married

6% divorced

5% single

4% in cohabitation with a life partner

Respondents were in the following age groups



48% of the respondents were employed

28% said they were housewives

3% said they were retired

2% said they were entrepreneurs

In terms of work, respondents most frequently cited social assistance and education.

3. GROUP DISCUSSIONS

In total, **100** parents and caregivers of children with disabilities (**90** women and **10** men) participated in the focus group discussions. These were from Edineț and Ialoveni districts, Bălți and Chișinău municipalities (see Annex 1 – Profile).

67% of participants were from urban areas

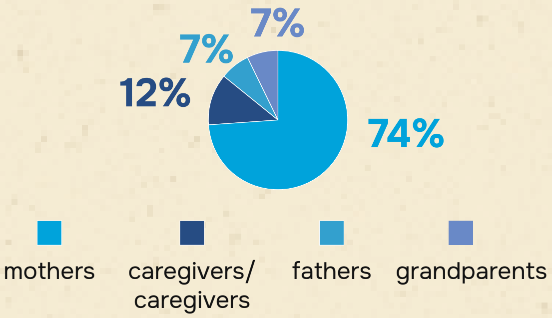
33% from rural areas

76% of participants were married

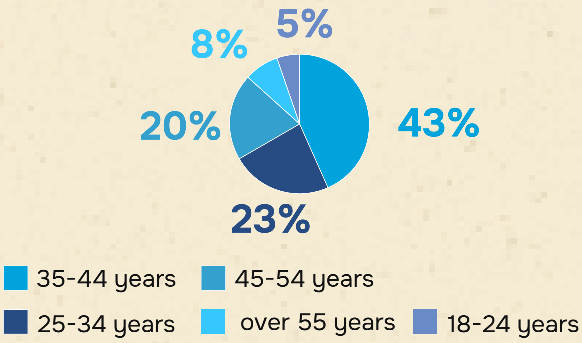
90% women

10% men

How the respondents were related to the child with disabilities



Participants were in the following age groups



According to educational status

38% of participants had higher education

37% vocational–technical education

25% secondary education

According to occupation status

53% of participants were full paid employees

10% were seasonal employees or self-employees

The main area of employment was social assistance, as some participants were employed as personal assistants.

BACKGROUND

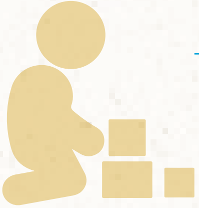
SITUATION OF CHILDREN WITH DISABILITIES IN THE REPUBLIC OF MOLDOVA

Children with disabilities comprise 2.0 PER CENT of all children in the Republic of Moldova.

There are about **162,300** people with disabilities in the country, including **10,900** children aged **0–17** years. People with disabilities represent 6.5 per cent of the country's total population of habitual residents.[1] In terms of gender, girls account for **40** per cent and boys **60** per cent.[2] According to data from the National Council for Disability Determination, **12,100** people (**85.0** per cent) were determined to have primary disability in 2022, comprising **10,500** adults (**86.8** per cent) and **1,600** children (**13.2** per cent). The main causes of children's disability in the Republic of Moldova are mental and behavioural disorders (**36.1** per cent) and birth defects (**22.4** per cent).[3]

Statistics on children with disabilities in the Republic of Moldova are not accurate and reliable.

Overall, it is complex and difficult to obtain access to data on developmental disorders. This is due to the heterogeneous and complex nature of disability, the use of different definitions for developmental disorders, and the high degree of stigma and discrimination on the grounds of disability that forces parents to keep children hidden and to refuse to determine their disability. In addition, the detection and assessment of developmental disorders is underdeveloped and many children with developmental disorders between **0** and **3 years** of age are not identified in early childhood and thus not included in statistics. In many cases, developmental disorders are identified in children over the age of three when they enter the early education system.



84 PER CENT of children in the Republic of Moldova grow according to child development standards.[4]

Thus, **16 per cent** are at risk of developmental disability, and a large proportion of these could be recognized as having a disability if they went through the disability assessment and determination process.

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[1] National Bureau of Statistics, 'Persoanele cu dizabilități în Republica Moldova în anul 2022' [People with Disabilities in the Republic of Moldova in 2022], Biroul Național De Statistică Al Republicii Moldova, Chișinău, 2023, <https://statistica.gov.md/ro/persoanele-cu-dizabilitati-in-republica-moldova-in-anul-2022-9460_60822.html>, accessed 7 June 2024.

[2] Ministry of Labour and Social Protection, Compendiu statistic [Statistical Compendium], Ministerul Muncii Si Protecteie Sociale Al Republicii Moldova, Chișinău, 2023, <https://social.gov.md/wp-content/uploads/2023/07/Compendiu-statistic-privind-monitorizarea-drepturilor-persoanelor-cu-dizabilitati-in-Republica-Moldova-pentru-anii-2019-2022-1.pdf>, accessed 7 June 2024.

[3] 'People with Disabilities in the Republic of Moldova in 2022'.

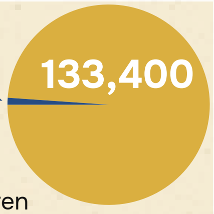
[4] United Nations Children's Fund, Country Profiles for Early Childhood Development, Countdown to 2030 Women's, Children's and Adolescents' Health, 2021, <https://nurturing-care.org/resources/country-profiles-2020#:~:text=The%20%E2%80%9CCountry%20Profiles%20for%20Early%20Childhood%20Development%E2%80%9D%20are,a%20baseline%20against%20which%20progress%20can%20be%20monitored.>, accessed 7 June 2024.

Data from the National Bureau of Statistics show the number of children enrolled in general early education institutions in 2022

197 children with disabilities

1494 children with special educational needs

1.3% of the total number of children



The current child disability assessment and determination mechanism is complex and creates barriers for parents/caregivers.

The situation analysis on early intervention for children in the Republic of Moldova by Maestral International and UNICEF Moldova[5] shows that determining disability in children is challenging due to the complex nature of child development and the absence of standard criteria and assessment tools for different age groups. Families face difficulties in submitting their children's records for a disability determination because parents/caregivers do not accept their child's disability or accept it belatedly or because of unclear and bureaucratic disability assessment and determination process.

Providing access to early education for children with developmental disabilities would help to determine children's disability early.

Children's disability is largely determined during their enrolment in kindergarten or other early development institutions. The Maestral–UNICEF study shows that, in education, children aged **0–3 years** with developmental disabilities and their families are currently not covered by territorial psycho-pedagogical assistance services, which are largely developed for children with disabilities aged **6–18 years**. The expansion of psycho-pedagogical support services in preschool institutions would contribute to the identification of children with developmental disabilities, their referral to the National Council Determining the Disability and Functional Capacity (NCDDFC), and strengthening parental capacities to care for children with disabilities or developmental difficulties.

Support services for inclusive early education depend on allocation of public financial resources.

The limited financial resources for early education in state and local budgets delay the expansion of psycho-pedagogical support services in kindergartens and creation of inclusive education support services in preschool institutions, which creates barriers to equal access to preschool and school education for children with disabilities. In many cases, the family is responsible for identifying support teachers or personal assistants to provide support for the child in kindergarten and receive no support from the state, which is, however, committed to achieving and respecting the right and equal access to education for all children.

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[5] UNICEF Moldova and Maestral, Analiza Situatiei Privind Interventia Timpurie la Copii (ITC) in Republica Moldova [Situation Analysis of Childhood Early Intervention in the Republic of Moldova], UNICEF Moldova and Maestral, 2023, <www.unicef.org/moldova/media/11426/file/Moldova%20ECI%20Sitan%20report%20RO.pdf>, accessed 7 June 2024.

INCLUSION POLICIES FOR CHILDREN WITH DISABILITIES AND FAMILY SUPPORT

The Republic of Moldova has committed to develop and promote public policies on equal opportunities for children with disabilities, and to adjust the regulatory framework to the international mechanisms

The mechanisms are based on the rights of children with disabilities, including the right to family and parents' right to exercise their parental roles. The Republic of Moldova is a signatory to the main international conventions protecting the rights of children, including those with disabilities, and has comprehensive national policies and regulatory frameworks that support the inclusion of children with disabilities. However, a desk review of national legislation on protection of children with disabilities revealed a need for revision of policies in the areas of health, social care and education to bring them in line with the Convention on the Rights of the Child[6] and the Convention on the Rights of Persons with Disabilities.[7] Support policies for families with children also integrate special protection measures for the care of children with disabilities equally with others, but the current funding mechanism for these public policies does not cover the cost of these services based on identified needs. The commitments of the state assumed through conventions are also highlighted in the Association Agreement between the European Union and the Republic of Moldova. In the 2021–2027 Agenda (2022),[8] authorities commit to provide social protection and inclusion to children with disabilities and zero residential placements.

International rights committees recommend that the Moldovan authorities develop and implement child- and family-centred policies without discrimination.

In 2017, the Committee on the Rights of the Child (2017)[9] recommended that the Government of the Republic of Moldova in 2017: (a) develop a comprehensive strategy for early childhood development (para. 30 (e)); (b) improve access to inclusive early childhood education (para. 30 (b)); (c) strengthen the coordination of health, education and social services (para. 30 (f)); and (d) implement measures to improve access to health care, which can reduce child mortality and increase immunization rates (paras. 31–32). Similarly, the Concluding Observations of the Committee on the Rights of Persons

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[6] United Nations Children's Fund, Conventia Cu Privire La Drepturile Copilului: Adunarea Generală a Naţiunilor Unite a adoptat Convenţia cu privire la Drepturile Copilului la 20 Noiembrie 1989. Republica Moldova a aderat la Convenţie în anul 1993 [Convention on the Rights of the Child ratified by Parliament Decision No 408-XII of 12 December 1990], Fondul Națiunilor Unite pentru Copii, Chișinău, undated, <https://www.unicef.org/moldova/media/1401/file/Conventia-cu-privire-la-drepturile-copilului.pdf>, accessed 7 June 2024.

[7] 'UN Convention on the Rights of Persons with Disabilities ratified by the Parliament of the Republic of Moldova by Law No. 166 of 9 July 2010', <www.legis.md/cautare/getResults?doc_id=117839&lang=ro>.

[8] Association Agreement between the European Union and the Republic of Moldova, '2021-2027 Agenda', <https://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX:52022PC0069>.

[9] Committee on the Rights of the Child, 'Concluding Observations on the Combined Fourth and Fifth Periodic Report of the Republic of Moldova', CRC/C/MDA/4-5, United Nations, New York, 29 September 2017, <www.refworld.org/docid/5a0ed42e4.html>, accessed 7 June 2024.

with Disabilities (2017)[10] recommended that the Government of the Republic of Moldova should make the main support services available to children with disabilities and implement measures to exclude stigmatizing attitudes (paras. 16–17). The provisions of both of these conventions on assistance and inclusion of children with disabilities and their families are emphasized through the 2030 Agenda for Sustainable Development.[11] Through this Agenda, the state committed to ensure access of all girls and boys to development, care and education, respecting the principle of "leave no one behind".

The Republic of Moldova has a favourable legal framework for the inclusion of children with disabilities and their families, but the implementation mechanism is challenging.

At the national level, in 2012, the Parliament adopted Law No. 60 on the social inclusion of persons with disabilities,[12] which describes early intervention contributing to the early identification of children with disabilities and developmental disorders in Article 44. The law also guarantees the right to health, education, and social protection and assistance. Thus, to implement Law No. 60/2012, the state developed and approved sectoral policy documents providing for the protection and inclusion of children with disabilities in social, education and health sectors to provide child- and family-centred assistance.

- **National Child Protection Programme (2022-2026)**[13] provides for good governance of the child protection system, prevention of child abuse and neglect, the development of support services and programmes for families with children, including children with disabilities, deinstitutionalization and prevention of institutionalization. The Programme also focuses on raising awareness about children's rights, and building the capacity of professionals and parents/caregivers on how to relate and communicate with children with different types of disabilities.

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[10] UN Committee on the Rights of Persons with Disabilities (CRPD), 'Concluding Observations on the Initial Report of the Republic of Moldova', 18 May 2017, CRPD/C/ MDA/ CO/1, <https://digitallibrary.un.org/record/1310661?ln=es&v=pdf>.

[11] Guvernul Republicii Moldova Cancelaria de Stat, 'Despre Obiectivele de Dezvoltare Durabilă' [About the Sustainable Development Goals], Cancelaria de Stat a Republicii Moldova, Chișinău, undated, <https://cancelaria.gov.md/ro/apc/despre-obiectivele-de-dezvoltare-durabila>, accessed 7 June 2024.

[12] Law No. 60 of 30 March 2012, <www.legis.md/cautare/getResults?doc_id=130550&lang=ro>.

[13] Government Decision No. 347/2022, <www.legis.md/cautare/getResults?doc_id=131899&lang=ro>.

[14] Government Decision No. 816/2016 (Annex 3), <www.legis.md/cautare/getResults?doc_id=138646&lang=ro>.

- **2024–2027 National Inclusive Education Development Programme**[14] aims to ensure high-quality inclusive education for all children and young people, including those with autism spectrum disorder (ASD), so that by 2027 all children/students, regardless of target group, are included in mainstream education institutions and graduates from this group have access to technical, vocational and higher education and other forms of lifelong learning, with a guaranteed transition to the labour market. In this context, it is planned to develop specific services: psycho-pedagogy, speech therapy, psychology, behavioural therapy to assist children with disabilities and ASD in the educational process.
- **2023–2027 National Early Childhood Intervention System Development Plan.**[15] This policy document provides for the organization and operation of early childhood intervention services, with a focus on: early identification of developmental disorders and potential risk factors for their occurrence; early intervention needs assessment for children with developmental disorders or at risk of their occurrence, and assessment of their families; provision of early intervention services for the child and family according to quality standards. Strengthening parenting capacities of parents/caregivers and training professionals in early childhood intervention are also important development areas for the next four years.

During 2023, the Moldovan Government began two major reforms:

The psycho-pedagogical services and of the social assistance system. Now is the right time to intervene and integrate support services and parenting education programmes for families caring for children with disabilities – training programmes for medical, social and educational professionals with training modules on communicating with parents/caregivers about child development difficulties, disability and the human rights-based approach to disability.

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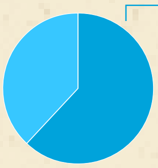
[15] Government Decision No. 950/2023, <www.legis.md/cautare/getResults?doc_id=141025&lang=ro>.

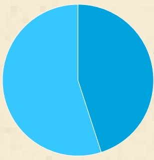
MAIN FINDINGS OF THE STUDY

1. KNOWLEDGE AND BEHAVIOURS OF PARENTS AND CAREGIVERS REGARDING DISABILITY

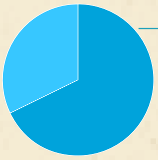
Parents and caregivers are the most important support resource for their children. Parents play a key role in raising and educating children, as they are responsible for creating and providing a safe, loving and protective environment. The way parents educate and support their children depends on their personal knowledge, beliefs and attitudes about parenting. An informed parent is able to respond promptly to the specific needs of the child, to situations of uncertainty and to challenges she or he may face at different stages of life. The knowledge and behaviours of parents and caregivers of children with disabilities influence, to a greater or lesser extent, the acceptance of a child with a disability, the quality of relationships with the child and with other family members, and the participation of the family and the child with a disability in community life. Thus, we aimed to explore parents' knowledge and attitudes concerning children with disability through focus group discussions and in-depth questionnaires. In **80 per cent** of the families, the responsibility of taking care of the child falls on the woman, and this trend is even more acute if the child has a disability.



62% of parents/caregivers have general information and knowledge about disability (but they do not know sources to obtain accurate knowledge and information about causes, risk factors, etc.).



45% are not sure how to behave with a child with a disability



68% associate disability with: **Down syndrome, physical (locomotor) difficulties, autism spectrum disorders and learning (intellectual) difficulties.**

1 in 2 parents/caregivers associate disability with **sight, hearing, speech and peer communication difficulties**.

HALF of parents/caregivers are predominantly influenced by arguments of the medical model of disability (disability = illness/disease), and in some cases, by the social model.

62% of parents/caregivers of children with disabilities have general knowledge and information about disability and disability approach models.

One in four parents/caregivers have limited information and knowledge about disability. Most parents/caregivers (**68 per cent**) associate disability with: Down syndrome, physical (locomotor) difficulties, autism spectrum disorders and learning (intellectual) difficulties. Only half of parents/caregivers (**50 per cent**) associate disability with difficulties in seeing, hearing, speaking and relating to others.

> *„I don't know how to talk to my child about building friendships, possible risks of joining a gang, binge drinking behaviour, sexuality."*

(Mother of a 15-year-old child with Down syndrome from Chișinău)

> *„I expect that my child will be like everyone else at the school, but he cannot yet. How do I teach my child?"*

(Mother of a child with ASD from Edineț)

Many parents/caregivers promote the social model of disability and one in two parents are still predominantly influenced by arguments of the medical model of disability.

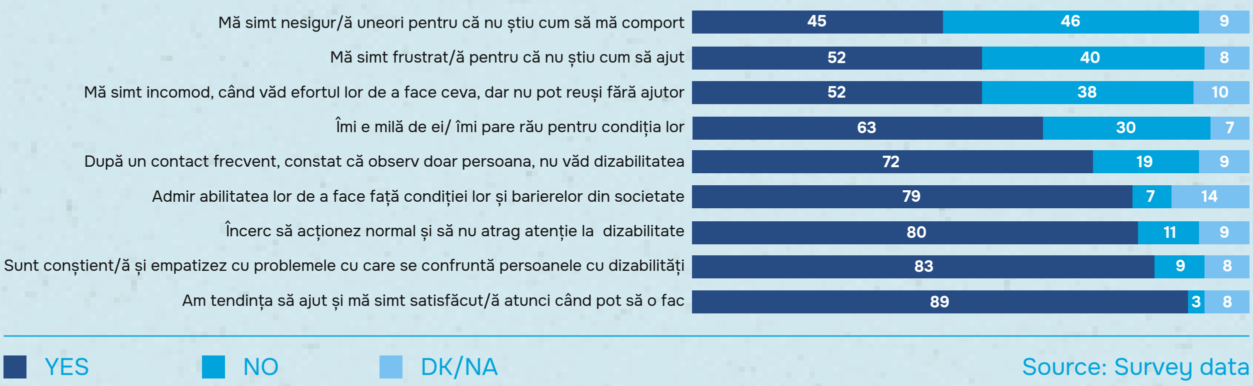
In the former (social) model, with support, children with disabilities can participate equally in community life and can learn in mainstream schools, but their rights are limited by barriers of access to transport and public buildings, and lack of support from family and service providers in addressing disability without discrimination. However, 50 per cent of parents/caregivers are still predominantly influenced by the arguments of the medical model of disability, stating that children with disabilities have a health problem that hinders their participation.

> *„I dress him, I undress him, he's sick, he can't"*
>
> **(Mother of a child with intellectual disability from Edineț)**

When it comes to another child with disabilities, the behaviour of parents/caregivers of children with disabilities is dominated by the charitable model of approaching disability (see Figure 1).

The charitable model is highlighted during interactions with people with disabilities (other than one's own child), where most respondents said they tended to help the person (**89 per cent**), and **63 per cent** of parents/caregivers felt pity for people with disabilities. The social model is obvious when parents/caregivers mentioned that they empathize with the person's problems (**83 per cent**), try to act naturally and not draw too much attention to the disability (**80 per cent**), admire the person with disability's ability to cope with barriers created by society (**79 per cent**), and after frequent contact perceive only the person, without noticing disabilities (**72 per cent**).

Figure 1. Parent/caregiver behaviours towards children with disabilities



Source: Survey data

Nearly half of parents/caregivers do not know how they should interact and behave with a person with a disability.

Half of parents/caregivers feel uncomfortable when they see the efforts of people with disabilities to achieve certain results and feel frustrated that they do not know how they can help. The share of parents/caregivers who feel insecure when interacting with a person with a disability because they do not know how to behave is **45 per cent**, similar to the share of those who feel confident (**46 per cent**) when interacting with a person with a disability.

> „We are not trained how to raise and educate such children"
>
> **(Mother of a child with ASD from Bălți)**

Lack of specific knowledge about the type of disability often influences the non-acceptance of children's disability.

Many parents/caregivers have no specific knowledge of the types of disability and still wait for a "miraculous rectification of the problem" (**"my child will heal", "it will disappear", "a relative of mine faced the same issue"**). These superstitious views are more evident among parents/caregivers of children with disabilities at an early age, when barely noticeable developmental differences may be explained by age. The explanation appears to be the parent's hope that the disability is not true, but also the lack of access to reliable information and critical analysis of the sources accessed.

Stereotypes about disability negatively impact women, mothers and caregivers.

Misconceptions of disability, and misperceptions of the origins and causes of disability, negatively impact parents/caregivers, especially mothers. They mention that children's disability would be caused by certain superstitions, such as **"God's punishment", "alcohol consumption", "mother's bad behaviour"**. These perceptions feed the guilt of parents of children with disabilities, especially women/mothers who feel guilty and responsible for their child's disability.

Limited knowledge of disability translates into behaviour that infantilizes the child and limits their participation perspectives.

Parents and caregivers feel that their child's possibilities are limited and the child often has no ability to do some things independently **("she/he can't")**, even when children did not even try. Mothers particularly feel responsible for doing everything instead of their children, and lack confidence in their children's potential future progress. This type of attitude was also observed among all caregivers (grandparents).

Parents and caregivers tend to learn from each other and form groups according to the type of disability the child has. These interest groups are informal and have sporadic activity.

Parents and caregivers believe that supportive parenting attitudes persist where there are supportive communities of parents (support groups). This gives parents the emotional comfort they need. The sense of affiliation and belonging to a community of multiple people gives them more confidence and security in the existence of a positive development path **"If they did it, we will also do it".**

„It's so good that such meetings are held. It is especially important for mothers."

(Father of a child with Down syndrome from the Bălți group)

„I felt like I was in the family."

(A father from Chișinău)

„We felt very good because we were listened to.”

(Mother from Edineț)

„The fact that I’m not alone gives me strength.”

(Mother from Edineț)

„The tasks we do are interesting, they change your vision, you find answers to the questions that bother you.”

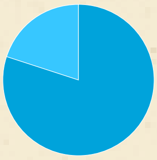
(Mother from Edineț)

„These meetings are like a breath of fresh air ”

(Mother from Ialoveni)

2. ATTITUDES AND PERCEPTIONS FACED BY CHILDREN WITH DISABILITIES AND THEIR FAMILIES

Research shows that a child's disability is a factor contributing to a change in parental attitude towards the child, which in turn influences the building of the parent–child relationship and the parent's educational practice.[16] Thus, the parent/caregiver needs support to change the representation of the child into a more positive and optimistic one, but also support in forming appropriate attitudes towards children with disability. In this respect, we tried to find out what attitudes parents and caregivers have towards children with disabilities in their family, but also towards other families in the same community.



80% per cent of parents/caregivers experienced discriminatory and stigmatizing behaviour, found it difficult to tolerate social attitudes of contempt and tried to limit their children's contact with the outside world.

Disability is one of the discrimination criteria.

The most common attitudes and behaviours

pity	**65%**
contempt/less respect	**45%**
stereotypes or prejudices	**42%**

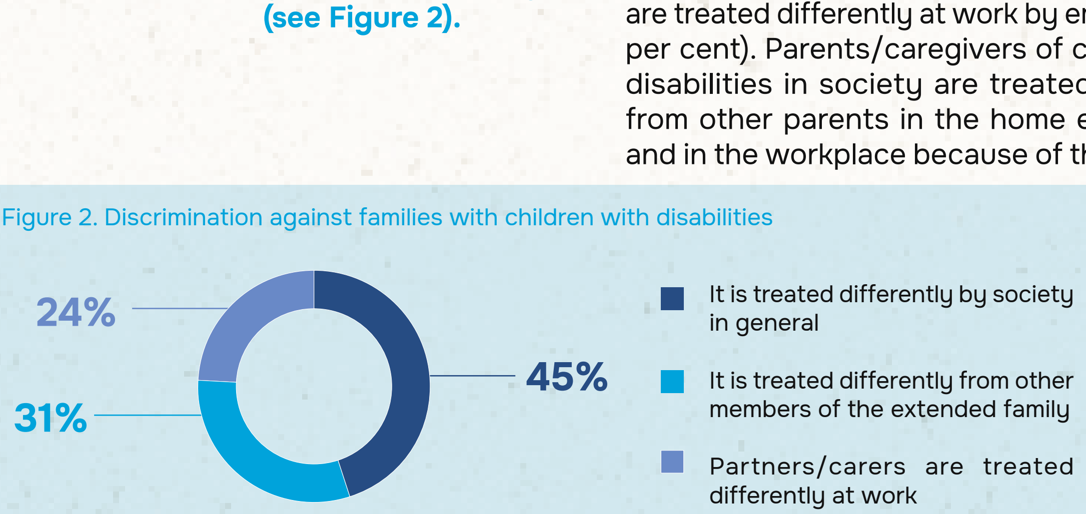
Women/mothers/caregivers of children with disabilities experience these feelings more frequently than fathers.

At the same time, fathers more often experience embarrassment when they go out in public with their children with disabilities.

Families with children with disabilities often face situations of discrimination on the ground of disability (see Figure 2).

There was a predominant opinion among survey participants that families with children with disabilities are treated differently by members of society (45 per cent), by extended family members (31 per cent), and parents/caregivers are treated differently at work by employers (24 per cent). Parents/caregivers of children with disabilities in society are treated differently from other parents in the home environment and in the workplace because of the disability.

Figure 2. Discrimination against families with children with disabilities



Source: Survey data

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[16] Bucun, Nicole, and Tatiana Vasian, 'Atitudinile Parentale Faţă De Copilul Cu Dizabilităţi: Cercetare experimentală comparativă' [Parental Attitudes Toward the Child with Disabilities: Experimental-comparative research], Institutul de Ştiințe ale Educației, Chișinău, undated, <https://ibn.idsi.md/sites/default/files/imag_file/Atitudinile%20parentale%20fata%20de%20copilul%20cu%20dizabilitati.pdf>, accessed 7 June 2024.

Parents/caregivers of children with disabilities have a high level of acceptance and tolerance towards other children or people with disabilities (see Figure 3).

They believe that girls and boys with disabilities, equally to those without disabilities, can enjoy games (**90 per cent**), can do many things independently (90 per cent), are curious (**78 per cent**) and can make new friends (**76 per cent**). At the same time, almost all parents/caregivers support friendships between their children with disabilities and other children with or without disabilities and support reciprocal visits to each other's homes (**90–95 per cent**).

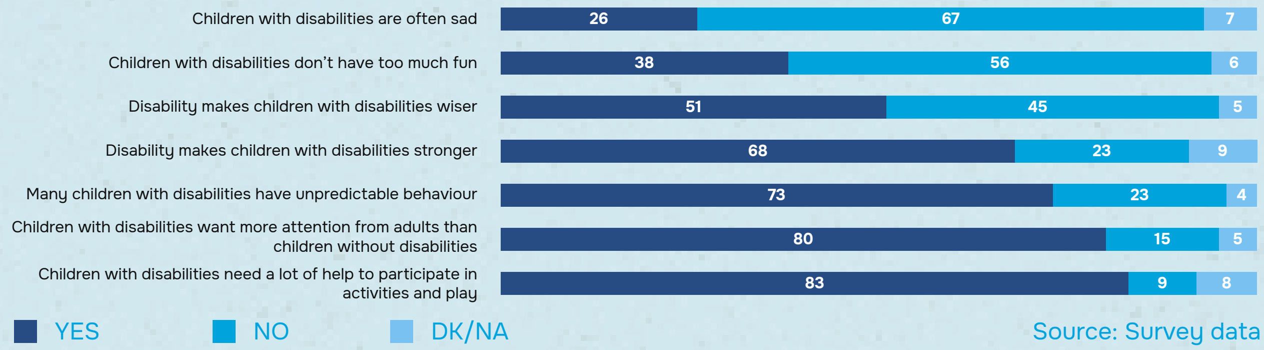
Figure 3. Attitudes of parents/caregivers

Source: Survey data

According to parents/caregivers, caring for children with disabilities requires more time and emotional involvement than caring for a child without disabilities (see Figure 4).

Compared with children without disabilities, children with disabilities need more help to participate in activities and games (**83 per cent**) and need more attention from adults (**80 per cent**) than children without disabilities. Support and attention are necessary, as many children with disabilities may behave unpredictably (**73 per cent**), which can generate certain negative attitudes and behaviours of peers and other members of the community.

Figure 4. Parents/caregivers' perceptions about children with disabilities



Source: Survey data

Disability impacts children's psycho-emotional states both positively and negatively.

Many parents/caregivers believe that disability makes children with disabilities stronger (**68 per cent**) and wiser (**51 per cent**). At the same time, disability also poses certain impediments to children with disabilities in organizing their leisure time and creating a good mood. As a result, many respondents believed that girls and boys with disabilities do not have much fun (**38 per cent**) and are often sad (**26 per cent**).

The presence of a child with a disability in the home or school environment positively influences the behaviour of other children (see Figure 5).

About **86 per cent** of parents/caregivers believe that children with siblings with disabilities are more empathetic and caring. And **74 per cent** believe that in classes where there are children with disabilities, their classmates are more tolerant towards disability.

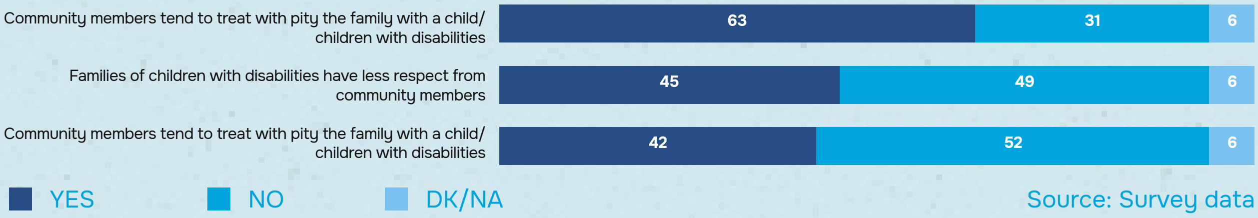
Figure 5. The impact of disability on other children's behaviour

Source: Survey data

Attitudes of community members towards children with disabilities and their families are based on pity, contempt and prejudice (Figures 6 and 7).

More than half of parents/caregivers (**63 per cent**) said that community members tended to treat families with a child with disability with pity. And **42 per cent** believed that community members avoid contact with families of children with disabilities and **45 per cent** said they have less respect for them.

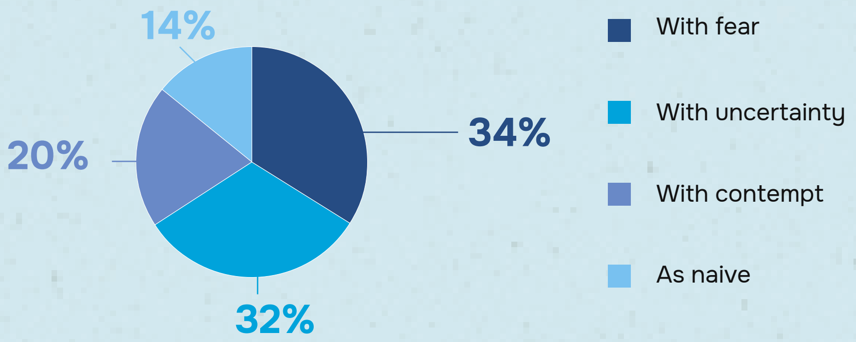
Figure 6. Attitudes towards families with children with disabilities



Source: Survey data

One in three parents/caregivers said that children with disabilities are treated by society with fear and uncertainty (**34 per cent and 32 per cent**), and one in five believed they are treated with contempt. Moreover, **14 per cent** of respondents believed that community members treat children with disabilities as naive.

Figure 7. Society attitudes towards children with disabilities



Source: Survey data

Parents and caregivers feel that society is not prepared to accept people with disabilities and is not open towards them

Discriminatory behaviour by adults also extends to children. Parents/caregivers of children with disabilities often hear the phrase **“Don’t you dare play with this child”** from both teachers and other parents who neglect or discriminate against the child with a disability.

Positive parenting attitudes are particularly noticeable in environments with better services for children with disabilities, which offer positive opportunities for their development.

From the perspective of residential environments, these are urban environments, where the diversity of recovery and support services is greater (which is precisely why some families have settled in towns).

3. SELF-ESTEEM, SHAME AND STIGMA TOWARDS PARENTS AND CAREGIVERS OF CHILDREN WITH DISABILITIES

Social exclusion is a sequential effect. Therefore, when the exclusion of people with disabilities starts in the family, it continues in other social environments. Several researchers believe that society's negative attitude towards people with disabilities negatively impacts families of people with disabilities, influencing the family's internal dynamic, including the parent's position of acceptance/non-acceptance of the child with disabilities.[17] Thus, we aimed to understand what parents and caregivers of children with disabilities feel on an individual level, but also when they go out in public with their child with a disability.

Feelings of parents and caregivers of children with disabilities

47% feel their self-esteem is affected

45% feel emotionally exhausted

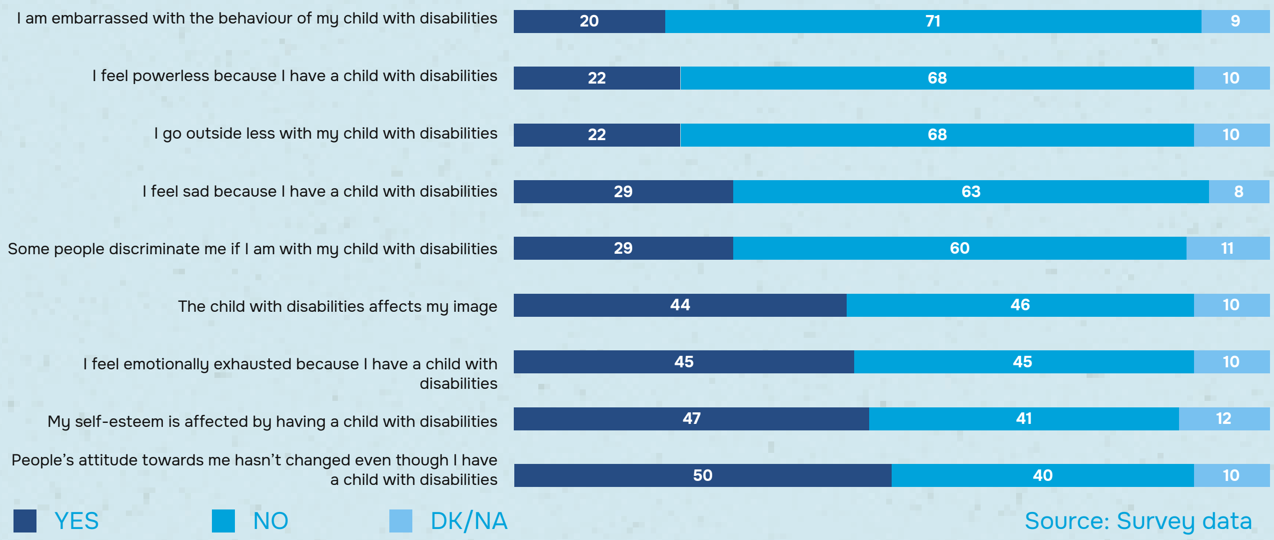
44% consider that their personal image is affected

20% feel ashamed because of their child's behaviour

1 din 3 parents/caregivers talked about feelings of guilt, embarrassment and shame experienced in public places or in hospitality contexts

Only 50% of parents/caregivers said that people's attitudes towards them remained the same after a child with a disability was born into the family. However, **1 in 3** respondents believed they experienced discrimination only when they are with their child with a disability (see Figure 8).

Figure 8. Stigma and self-stigmatization of parents/caregivers



Source: Survey data

1 in 3 participants felt an intense sense of shame due to discriminatory attitudes in society.

Participants reported stigmatizing attitudes by society when they go out with their child in public places, for a walk, shopping; they find it difficult to confront social attitudes of contempt, so many of them refuse to go out together or limit such trips.

Participants mentioned the need to inform society and to be informed about how to overcome such situations.

About 47% of parents/caregivers feel their self-esteem is affected

45 per cent feel emotionally exhausted and **29 per cent** feel sad because they have a child/children with disabilities. **One in 5** parents/caregivers said they feel powerless and helpless, so they try to go out with their child less often, because their child's behaviour leads to embarrassing situations.

1 in 3 parents/caregivers talked about feeling guilty, embarrassed and ashamed

in public places or on a visit, when someone makes observations about inappropriate behaviour of their children with disabilities. Parents are often told about "missing the seven years at home" and they feel guilty about not being able to manage the unwanted behaviour of children with disabilities. Thus, according to parents, many families become self-isolated.

Parents and caregivers of children with disabilities tend to limit contact and social relationships with friends, relatives, community members because of the sense of shame generated by having children with disabilities.

1 in 3 women/mothers admitted experiencing shame – the share is higher in rural areas. Some participants admitted they did not want to participate in activities specifically organized for parents/caregivers because they did not want other people to know or recognize they belong to this group of parents. Similarly, some parents/caregivers (particularly those from the north) avoid contact with people with disabilities, so as not to be associated with this group.

> *„Nobody understands me. I'm guilty if the girl screams; it's because I didn't educate her. The husband comes home every half a year and only gets angry because he doesn't know how to communicate with the girl”*

(Mother of child with ASD, Chișinău)

Many parents become activists, showing ‘fighter attitudes’, dedicating themselves to this cause, including doing relevant specialized studies.

A mother from Ciorescu commune, who educates a child with ASD, studied psychology and graduated with a second degree to help her child. Currently, she is employed as a support teacher in her child's school, becoming a good resource for many parents.

„I am proud to have a child with Down syndrome. This child allows me to see the world differently, which no one else can. We learned so much from her. She gives us so much joy and love!”

(Mother of a 15-year-old girl from Ialoveni)

„My daughter has great abilities, she performs ingenious calculations orally, without support, and no one understands how she does it.”

(Mother of a girl with ASD from Edineț)

„I learned to believe that my child will succeed, and I made the teachers believe. I don't give up. Currently, we look for the most suitable tasks for my child, together with teachers. They are very ingenious teachers."

(Mother of a child with phenylketonuria from Edineț)

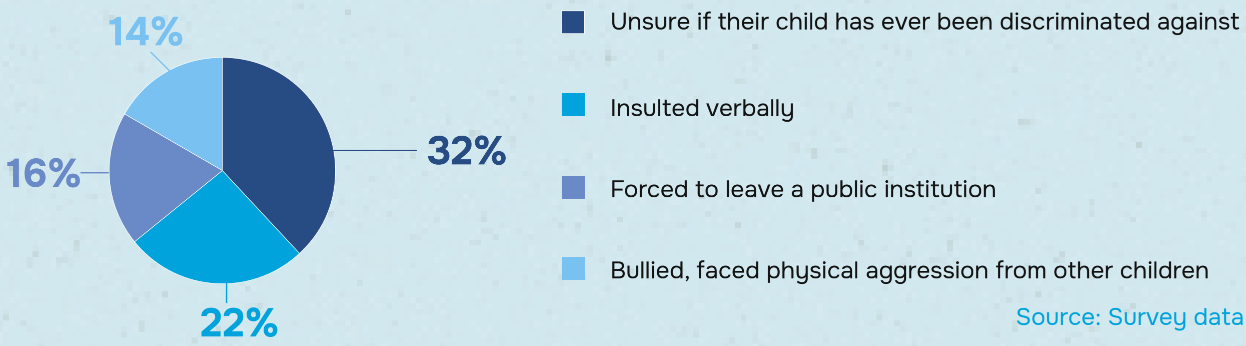
4. VIOLENCE AGAINST CHILDREN WITH DISABILITIES AND THEIR FAMILIES

Girls and boys with special needs and their families are at **up to four times greater risk** of physical and sexual violence. Children and adolescents with special needs are **three times more likely** to be bullied than other peers. In addition, women and girls with disabilities face double discrimination and thus are exposed at greater risk of gender-based violence, sexual abuse, neglect, maltreatment and exploitation. Based on the group discussions, we had to find out whether parents and caregivers can recognize situations of violence and are aware of the risks their children are exposed to.

Disability is the criterion of discrimination and a trigger for violence against children (see Figure 9).

Around 22 per cent of respondents said that children with disabilities under their care were insulted and called bad names, **16 per cent** said that there were situations when children were forced to leave a public institution because of discrimination on the basis of disability.

Figure 9. Discrimination against children with disabilities on grounds of disability



Source: Survey data

Around 14 per cent of parents/caregivers said that children with disabilities were bullied and beaten by other children and some reported situations when their child was lied to and robbed (**8 per cent**) or was suspected of certain negative actions (theft, aggression) because of their disability.

1 in 3 parents/caregivers do not know if the child with disability under their care has ever been discriminated against or suffered because of their disability.

Women/mothers and girls with disabilities face **double or multiple discrimination**, which puts them at greater risk of gender-based violence, sexual abuse, neglect, maltreatment and exploitation.

Disability is **a criterion of discrimination** and a trigger of violence against children.

5. INTERPERSONAL COMMUNICATION BETWEEN PROFESSIONALS IN DIFFERENT AREAS (EDUCATION, HEALTH, SOCIAL ASSISTANCE)

85%
of the respondents said that professionals from different areas communicate rigidly, lacking tact and empathy.

85%
believe that emotional support services are lacking – as parents discover this fact after being informed about child's disability or risk of disability.

The information provided by specialists at the first contact with parents does not focus on empowering the child, on supporting the family to accept the situation or to support children with disabilities.

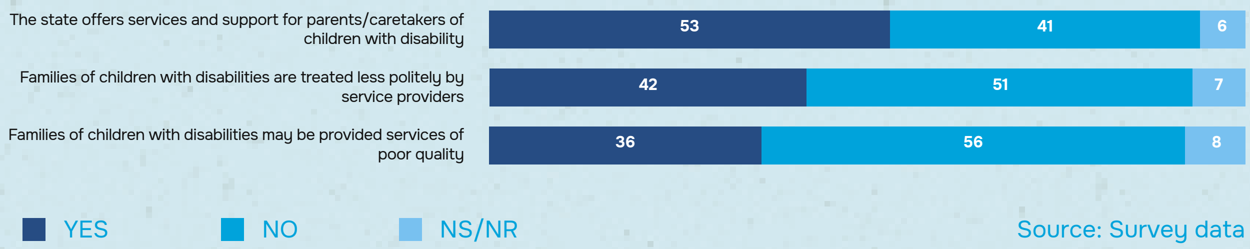
Lack of communication skills of professionals with parents/caregivers of children with disabilities about their children's developmental difficulties increases guilt and intimidates parents, especially women/mothers.

85% of parents/caregivers felt that communication from professionals in different fields with parents on sensitive disability-related topics was stiff, tactless and lacking in empathy. This was felt right from the first contact, when the professional gave them the news about the disability. Parents reported that they were often told the diagnosis without any emotional or informational support. In the absence of accurate information expected from the first source (i.e., from the professionals with whom they interact), parents and caregivers are forced to seek information about disability from other sources to understand what is happening to the child, what the disability is about, how it manifests itself in different areas of development, what can be done to empower the child, how to manage their behaviour, and so on.

Service providers tend to discriminate against families of children with disabilities (see Figure 10).

Some **53 per cent** of parents/caregivers of children with disabilities said that the authorities provide them with services and support for the care and inclusion of their children. However, parents/caregivers feel that families of children with disabilities are treated less politely by service providers (**42 per cent**), and the care and support they receive is of poorer quality (**36 per cent**).

Figure 10. Attitudes of professionals towards families with children with disabilities



Source: Survey data

The most common situations of contempt and discrimination are encountered when communicating with medical and educational professionals.

These concern both the prejudices regarding the causes of the disability, making the link with the vulnerability and antisocial nature of the family and the birth of the child with disabilities, and verbal behaviour, clearly discriminatory, in relation to the child and the family.

The discriminatory behaviours that were most reported by parents and caregivers are the experiences of being refused enrolment and provision of educational services in school/kindergarten, and support services in inclusive education (access to support teacher, individualized approach through the application of the Individualized Educational Plan), which restrict the child's access, limiting their participation and involvement.

Children with multiple disabilities, children with ASD and children with intellectual disabilities are **the most at risk** in terms of limited access to education and support services.

Prejudices about the causes of developmental disorders in children, particularly among health-care professionals, increase the vulnerability and antisocial nature of the family.

Parents recounted traumatic experiences dominated by the prejudices of professionals in different fields. Some mothers, even if they see professionals for examinations concerning their child's development, often do not receive clear information from them. One mother shared her experience saying: **"I felt that something was not right, but I felt uncomfortable talking about my concerns with my family doctor"**. These stories highlight the traumatic experiences of parents who have encountered doctors who either fail to communicate or provide irrelevant and unethical information. The collected information highlights the need to improve communication between health-care professionals and parents to ensure that parents are adequately informed about their child's developmental disorders and are given the support and guidance they need.

„He told me he was a vegetable and that I would not be able to do anything with him; he made me feel like the worst person on earth.

This child has Down syndrome. These children don't even recognize their mother.

Why would you teach the child anything (the child has ASD) if nothing works anyway? Why even bother?"

(Words of a teacher told to the mother of a child with disabilities from Edineț)

„This child is not going to be able to write, read; how dare you think this child is going to be able to do anything?"

(Words of a teacher told to the mother of a child with ASD from Edineț)

„Don't worry, your child won't live long with this diagnosis."

(Words of a doctor told to the mother of a child with phenylketonuria from Edineț)

"Why did you come? Can't you see there are more serious cases?"

(Words of a social worker told to the mother of a child with disabilities from Bălți)

Acceptance of the child’s disability depends on how the information is communicated.

Parents reported that they were often told the diagnosis without being given information about the disability, about causes, interventions and services needed to achieve outcomes, emotional support and next steps. Parents/caregivers believe that the first contact with the professional is of great importance for the acceptance and interaction of parents/caregivers with people with disabilities, especially towards the child in care.

Parents/caregivers in rural areas experience feelings of abandonment and indifference from service providers.

Parents/caregivers mentioned the lack of some kind of family guidance service caring for a children with disabilities. This type of service is mainly needed in rural areas, as family doctors in the area do not have the professional competence to guide parents/caregivers of children with disabilities, so it is obvious that families in villages face great difficulties.

6. THE IMPACT OF DISABILITY ON FAMILY LIFE FROM A GENDER EQUITY PERSPECTIVE

International research shows that fathers' active involvement in parenting improves family relationships, boosts children's self-confidence and helps them achieve more.[18] Children who receive more attention from their fathers do better in school and have better life skills. That is why the involvement of both parents in raising children is extremely important. Only 10 out of 100 respondents in the focus group discussions were men, and all of them fathers. Five of them were from urban areas and five from rural areas. In terms of education, five had higher education and five vocational-technical education. All 10 fathers are employed in the area of services (4), construction (3) and public administration (3). The data show that fathers' level of education has an impact on the degree of involvement in childcare and development.

The presence of a child with a disability in the family contributes to an increased level of empathy among family members.

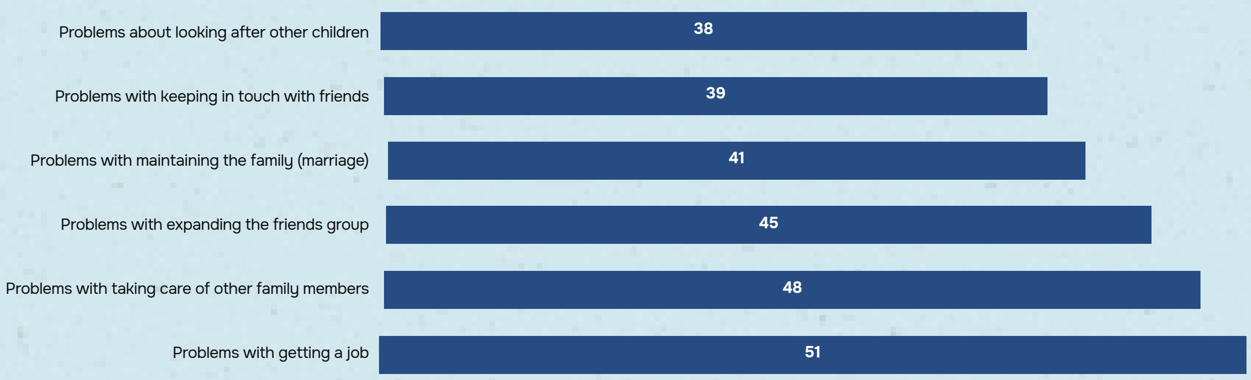
The results of the sociological survey show that 86 per cent of parents/caregivers believe that girls and boys who have siblings with disabilities are more empathetic and caring (see Figure 5), **80 per cent** believe that families with children with disabilities are more united, and **65 per cent** of respondents believe that men work harder if they have a child or children with disabilities.

Almost half (48 per cent) of respondents do not have enough time to take care of other family members.

Caring for a child with a disability takes time and commitment, and this may affect other family members, especially a partner or other children. There are also problems with expanding the group of friends (**45 per cent**), keeping in touch with friends (**39 per cent**) or even difficulties in maintaining family/marriage (**41 per cent**) and caring for other children (**38 per cent**).

The birth of a child with disabilities in the family has a negative rather than a positive impact on the family (see Figure 11).

Figure 11. Impact of disability on family life, %



Source: Survey data

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[18] Group Meeting on Family Policies and the 2030 Sustainable Development Agenda, New York, 12–13 May 2016, <www.un.org/esa/socdev/family/docs/egm16/BehsonRobbins.pdf>, accessed 7 June 2024.

The main problem reported by 51 per cent of parents/ caregivers of children with disabilities is getting a job.

In most cases, once a child with a disability is born, changes occur in the professional lives of mothers, the child becoming their main concern. The fact that they can no longer return to their previous occupation, having to take care of the child, the financial dependency that increases in such situations, makes women more vulnerable and leads to negative self-perceptions, which seriously affect their self-image and self-esteem.

Most rural women/ mothers are unemployed.

Of those in employment, many are 'employed' as personal assistants. However, their situations are not very different, as income earned is used for childcare. Experience shows that employment as a personal assistant is not the most beneficial for mothers of children with disabilities. They are not able to detach themselves from the child's care even during the working day, thus maintaining a high degree of chronic exhaustion, nor do they achieve a sufficient level of financial independence, as personal assistants receive extremely low salaries. Thus, this type of employment should only be recommended as a temporary solution. It should be noted that the share of mothers employed as personal assistants for their own child is higher in rural areas than in urban areas, as there are no other employment opportunities in villages and no non-family members available to work as personal assistants.

Women (mothers, grandmothers, caregivers) are more likely to experience self-stigma.

In particular, those in rural areas spoke about the guilt passed on by those who they interact with, including husbands, fathers-in-law (particularly if they live together). Women/mothers often act as an intermediary between the child and the husband/partner (the husband does not accept the child and blames the wife).

Women (mothers, grandmothers, caregivers) identify themselves with the child with disabilities

which affects their personal identity. In most cases, mothers 'melt' into the child they gave birth to. In other words, misconceptions about disability lead to misperceptions about oneself as a parent, and the mother (grandmother, caregiver) ends up self-stigmatizing, perceiving herself as **"a different kind of parent, who feels a lot of guilt and shame"**. This limits her ability to fully experience the joy of parenthood.

Pre-conceptions and stereotypes associated with the role of women increase financial dependency (the man is the breadwinner and the woman is the child's caregiver), and increase the women's vulnerability and self-stigma.

Women/mothers mention that they **do not manage to detach themselves from the child's care** even during the working day, thus maintaining a high degree of emotional and physical exhaustion ("my husband does not know what and how to do" – a mother from Edineț).

Women/mothers **feel guilt and remorse** even when they are trying to relax.

Women/mothers feel that they **cannot achieve a sufficient level of financial independence.**

In most cases, mothers/women **leave their pre-birth employment.**

Social norms affect the personal identity of mothers of children with disabilities, giving rise to misperceptions of themselves as parents. Women/mothers self-identify with their child with disability, which affects their personal identity.

In most cases, women/mothers associate themselves entirely with the child they have given birth to (less so with fathers and caregivers). The development of misperceptions about disability and about the child with disabilities generates the development of misperceptions about themselves as parents, so they end up self-stigmatizing, perceiving themselves as parents of another category, who feel a lot of guilt and shame. This does not allow the parent to 'grow up', to fully experience the joy of being a parent. Limited access to information, limited existing resources, financial dependence (especially as the patriarchal approach to the family is still prevalent in rural areas, where the man is the breadwinner and the woman is the one who watches over the peace and quiet of the house and takes care of the children) – together intensify the mother's vulnerability and the phenomenon of self-stigmatization.

Men (fathers, grandfathers, caregivers) are less concerned with the upbringing and education of children if a child with disabilities is born in the family.

In most families, the man is the one who is mainly responsible for the financial side, and having a child with disabilities in the family involves additional expenses for the family (treatment, expensive therapeutic services, specific food, specific equipment, care services, paid assistance, etc.) and men take on this role.

The divorce rate among families with children with disabilities is high.

A significant number of single women/mothers said that the child’s father left the family after the birth of the child with disabilities. Conversely, the fathers participating in the research said that the family becomes more empathetic after the birth of children with disabilities and the other children are more empathetic towards their sister/brother with disabilities. However, fathers strongly agree with the statement that **“it is difficult to maintain the marriage in a family where there is a child with disabilities”**. The high care needs of children with disabilities often put parents, especially fathers, in the position of giving less attention and care to other family members.

Fathers’ emotional well-being and social relationships are influenced by the presence of a child with disabilities in the family. Seven out of 10 fathers said that they need information resources and psychological support to overcome self-stigma and self-isolation.

Four out of 10 fathers agreed that “a family with children with disabilities is treated differently by other members of the extended family” and **7 out of 10** agreed with the statement that “a family with children with disabilities is treated differently by the members of society in general”. The research data show that seven out of the 10 fathers participating in the research said that they were emotionally exhausted, five experienced feelings of sadness because they have a child with disabilities, four felt powerless, and three said that they feel ashamed of their child with disabilities’ behaviour. Four fathers said that their self-esteem is affected because they have a child with disabilities and four said that some people discriminate against them by associating them with the disability. Two fathers said that they avoid going out and communicating with their child with disabilities in public places, they avoid telling people that they have a child with disabilities and, in certain situations, they isolate themselves.

7. BARRIERS FACED BY PARENTS AND CAREGIVERS OF CHILDREN WITH DISABILITIES

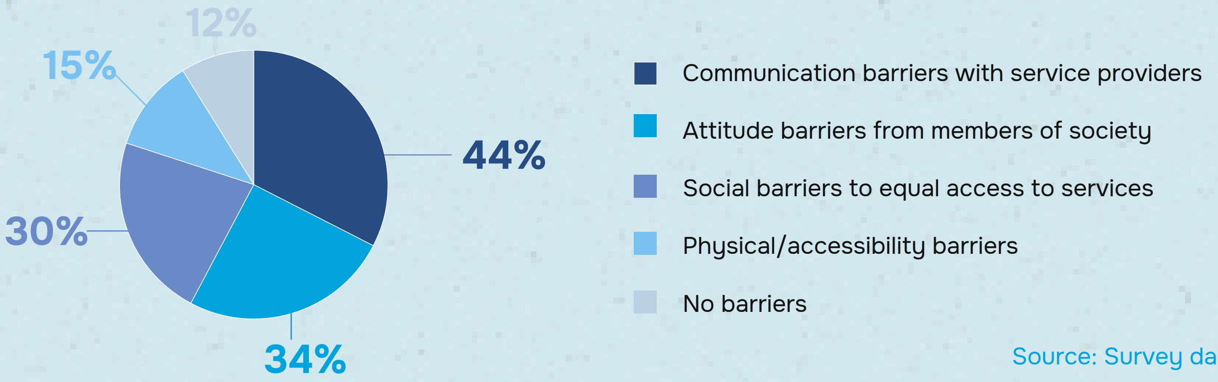
In daily life, families of children with disabilities face barriers to participating and living in the community on an equal basis with other members of the community (see Figure 12).

The main barriers that families with children with disabilities face are: communication barriers with different service providers (**44 per cent**): most professionals do not know how to approach a family with persons with disabilities. In the most frequent cases, two extremes were highlighted: the charitable approach, based on pity and compassion of the situation; and an approach based on a discriminatory attitude, where disability is associated with poverty and antisocial phenomena.

Barriers of attitude of society members were mentioned by about 34 per cent of research participants

Although there are various positive changes in public attitudes towards people with disabilities, negative and discriminatory attitudes still prevail.

Figure 12. Barriers faced by families with children with disabilities



Source: Survey data

Social barriers preventing equal access to services were mentioned by 30 per cent of parents/caregivers.

The focus group discussions also highlighted the insufficiency of psychological support services for parents, especially at the first stage of coping with stress and shock after the announcement of signs of a child's disability. Early intervention services and specialized disability-dependant assistance are virtually unavailable in the districts, especially for rural families with children. Most of the services are concentrated in Chișinău, but many of them are quite expensive (e.g., therapies for children with ASD). Publicly funded services can be accessed after a certain period of time and are not very accessible.

Limited access to the social service ‘personal assistance’

The biggest problem being the limited number of places for this type of service. Often a child with ASD or a child with intellectual disability waits for a long time for her/his turn, because the authorities are under the misperception that children with physical disabilities need more constant care than those with ASD and other intellectual disabilities. Thus, those with physical disabilities are served first. However, this service is just as essential for parents/carers of children with ASD and other intellectual disabilities, especially while a child with severe disability is attending kindergarten/school.

The parents also noted the lack of support services for inclusive education for children with disabilities, especially in kindergartens.

Concerns were also expressed about the future of children graduating from general education (in particular by parents who participated in the regional workshops in Ialoveni and Bălţi). Parents need clear perspectives on inclusion at the next level of education – vocational education, where the first attempts to individualize the learning process and develop inclusive education support services are just beginning.

Physical/accessibility barriers were reported by 15 per cent of survey respondents, while **12 per cent** of parents/caregivers said they experienced no barriers to inclusion in society.

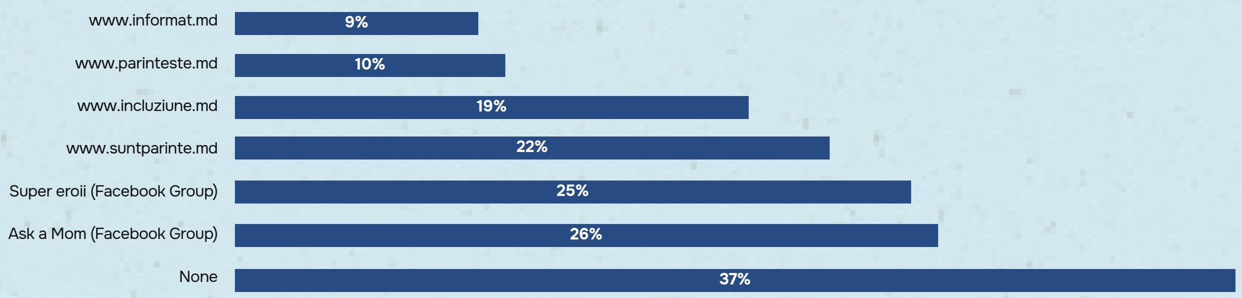
The quality of interventions and the progress made for each child with a disability depends largely on the parents’ awareness of the problem their child is facing, and their acceptance that the child or children that have a developmental disability that requires involvement and support in the planning and delivery of support services.

8. OPINIONS ON THE NEED TO DEVELOP A PLATFORM FOR PARENTS AND CAREGIVERS OF CHILDREN WITH DISABILITIES IN THE REPUBLIC OF MOLDOVA

95% of parents and caregivers believe there is a need for a support platform for parents/caregivers of children with disabilities that provides up-to-date information based on specific needs and would visit the website if it existed.

Over a third 37% of the survey participants indicated that they currently do not use any sources of information on the internet one in four accesses Facebook groups ('Ask a Mom' and 'Superheroes'), **one in five** respondents indicated that they obtain information from the websites <www.suntparinte.md> and <www.incluziune.md> (see Figure 13). **Only 10 per cent** of respondents visit <www.parinteste.md>, 9 per cent <www.informat.md> and 6 per cent the Bebbo app.

Figure 13. Online information sources used by parents



Source: Survey data

The most popular topics of interest to parents/caregivers on websites can be grouped into three main areas (see Figure 14): (1) educational and training resources (about 65–70 per cent of respondents); (2) information about specialized services and programmes (about 40–50 per cent); and (3) direct online support and assistance (requested by about 40–45 per cent).

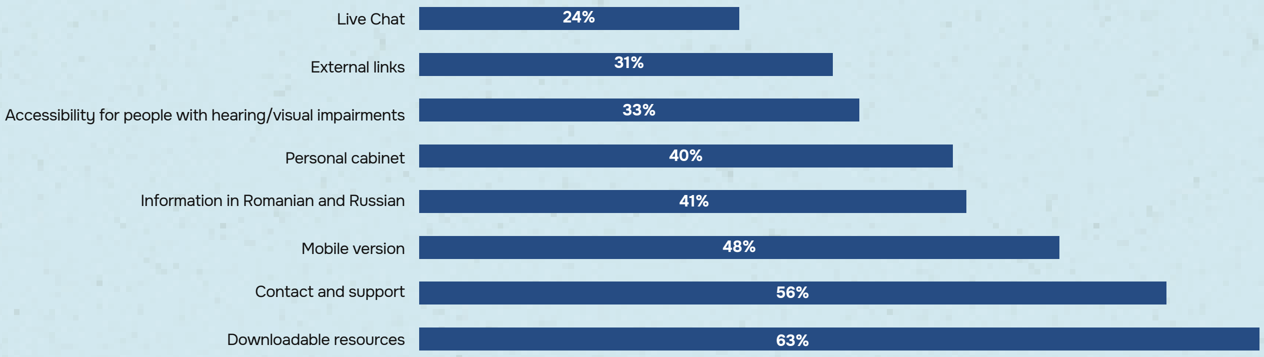
Figure 14. Types of online content that may be of interest

Information and educational resources **(65-70%)**	Information about specialized services and programmes **(40-50%)**	Direct online support and assistance **(40-45%)**
✓ Content on disability ✓ Inclusive education resources ✓ Information on specialized programmes and therapies	✓ Available social services and contacts ✓ Legal services and contacts ✓ Social benefits and financial assistance	✓ Counselling and emotional support ✓ Online discussion forums ✓ Online workshops ✓ Podcasts and stories of children with disabilities and their families

Source: Survey data

In the opinion of the research participants, the most important aspects to be considered when creating a website for parents/caregivers are: downloadable information resources; direct contact and support when needed; access to the website from a mobile phone; all content bilingual (Romanian and Russian); and user ability to create a personal cabinet on the website (see Figure 15).

Figure 15. Aspects recommended from users' perspectives



Source: Survey data

In addition, the website should be accessible to people with hearing and visual impairments, provide access other external links directly from the website, and provide the ability to access live chat.

9. NEEDS OF PARENTS AND CAREGIVERS OF CHILDREN WITH DISABILITIES

Discuțiile între părinți/îngrijitori au evidențiat următoarele nevoi cu privire la îngrijirea calitativă a copiilor cu dizabilități care ar putea fi soluționate cu ajutorul platformei de suport:

Psychological support for the mother and other family members, especially in the first stage when the child's disability is made known, to better understand and accept the situation.	Parents spoke about the need to communicate with a psychologist at the initial stage of accepting the information, of processing the shock that occurs when learning about the child's disability. This need is supported by the extremely traumatic experience of parents who, even years later, recall with pain and tears the moment when they were informed that their child had a disability. In one of the sessions at the regional workshops, parents were asked to create a parent's job description, which would describe their duties from the child's point of view, and who could help them. This task proved to be extremely difficult for the parents, as no one wanted to recall how it all started: **"I don't want to go back to everything I went through back then", "It was very hard for me, there was no one to help me, to understand me"**.
Information: access to accurate information about disability, developmental specifics, care and habitation.	There is little specific information about disability, models of approach to disability, models of care, feeding, types of recommended therapies, etc. Mothers/grandmothers are constantly striving to become the best possible carers for the children in their care that they can be. There is an acute need for accessible, accurate information presented in clear and positive language for parents.
Consultation with professionals in different fields to guide parents and refer them to other specialist services/ centres if necessary.	Very often a child's disability dictates certain specifics in care and feeding. The discussions showed that parents often find themselves alone in these difficult situations, having to search for information in different sources, not always sure of their reliability. It is therefore essential that there is an opportunity for discussion (including online) with professionals trained in a particular area to ensure that the child has a healthy, balanced and appropriate diet, that the treatment they receive is favourable to their development, and that the care and rehabilitation they receive is effective and beneficial to them.

Information on the rights of parents and children with disabilities and the legal framework that protects and supports them.

Parents' stories often described blatant violations of the rights of children with disabilities and their parents. There is also an obvious need to know some of the procedures regulated by law for enrolment in kindergarten/school, obtaining social, educational, medical services, etc.

Support in the formation/change of parental attitudes favourable to the development of the child with a disability, for the acceptance of the disability.

Communication with the parent groups revealed a big difference in their approaches to both disability and the child with disability. The sooner a parent accepts the situation and overcomes despondency, the sooner they will become a real and genuine support for their child and themselves. This is why helping to transform unfavourable parental attitudes towards a child with a disability into attitudes conducive to constructive parenting is an extremely important goal.

Support for self-discovery and growth as a parent.

A child with a disability enters the life of a family, catching them unprepared, creating many changes: at the level of understanding the situation, at the level of building relationships both with the child and with other family members. The severe stress that accompanies this moment makes one look at life in a different way. All this creates enormous changes in the functioning of the family, but above all in the personality of each parent. To be able to recognize and accept these many changes and to continue to function effectively, parents need psychological and informational support.

Ability to socialize with other parents in a similar situation, to communicate, to share emotions (the need for support groups).

Parents and caregivers of children with disabilities have a great need to communicate with other parents in the same situation, to share their experiences. It is vital for parents to know and feel that they are not alone in the face of an overwhelming challenge. While the most reliable people in this situation should be those in and around the family (e.g. life partner, parents, other relatives, friends), experience shows that peer support is most acceptable, especially from another parent who is also raising a child with a disability, because one can feel many things in common: they are in a similar situation; they experience the same emotions; they are concerned about the same thoughts and questions; they are going through the same difficulties; they have already found answers to some similar questions and can share them with others. By sharing problems with a trustworthy person, stress levels are greatly reduced. The power of communication with other parents is enormous and should be harnessed by facilitating group communication, building parenting communities and support groups. Such experiences would help the family and parents in particular to realize the importance of communication, socialization (including with the child) for the well-being of all. This would minimize the social isolation tendencies often found in families of children with disabilities, fostering a positive developmental outcome for the child.

Respite in ongoing care activities.

The role of a parent of a child with a disability requires a lot of knowledge, a lot of skills, a lot of effort. This is why the need for ‘respite’, for replenishing energy, for fulfilling one’s own needs is vital. Information about such respite can be provided by communication with other parents as an exchange of ideas, emotions, as well as periodic change of activities carried out systematically. In this regard, NGO services that organize rest or respite for parents are welcomed. This is still a challenge for many parents, especially in more specific cases, such as children with severe disabilities who also have complex needs. For parents to benefit from such services, they must be accessible and safe for any child.

CONCLUSIONS AND RECOMMENDATIONS

1

Family support policies in the Republic of Moldova are not sufficiently resilient and inclusive in terms of a human rights-based approach to disability.

The analysis of the regulatory framework showed that policies and services for psychosocial support to families do not include special measures for families with children with disabilities. Our analysis highlights the lack of counselling services for parents/caregivers and siblings on the acceptance of children with disabilities in the family and the need for protective care support, especially among rural families.

2

Parents/caregivers of children with disabilities have a low level of knowledge and information about disability.

Parents/ caregivers do not know who or from which sources they could get accurate knowledge and information about the causes and risk factors; about how children with different types of difficulties manifest themselves; the role of treatment and the importance of family support in early childhood. Professionals who interact with the family in early childhood cannot answer parents' questions and expectations about disability. In the absence of expected accurate information from the first source, parents and caregivers are forced to seek information individually, in most cases the source of information being the internet. There is no mechanism to verify the accuracy of the information on the internet; in some cases, instead of making things clearer and giving solutions to parents' challenges, the information found and analysed increases the fear of the unknown and leads to family self-isolation.

3

Support groups made up of parents or other caregivers help to improve knowledge of how to deal with children with disabilities and the interventions needed.

Parents/caregivers tend to exchange information depending on the child's type of disability, to seek out other parents/caregivers who have faced similar situations and try to get information from them: How did they act? Where did they go? What services or treatments did the follow? Such experiences have a greater impact on the family because, in addition to sharing parenting experiences that can be learned from, parents/caregivers understand that their situation is not unique and that results can be achieved by working with the child. Research participants expressed mutual interest towards the people in the group, they wanted to participate actively, to exchange experiences, to continue communication in various outreach and support activities. The internal resources of parents are extremely diverse: starting with perseverance, optimism, good will, and ending with the courage to get involved, the desire to share their experience, to change and to contribute to the change of society in general.

4

Parents/caregivers have a high level of acceptance and tolerance towards children with disabilities. Access to support services contributes to positive attitudes and behaviours towards disability.

Differences arise when children with disabilities need support in overcoming barriers to participation and interaction. If children with disabilities had access to inclusive support services, their differences would not be obvious. The share of supportive parenting attitudes is higher in environments where there are diverse and inclusive services for children with disabilities, which provide opportunities for children to participate. From the perspective of residential environments, these are urban environments, where the diversity of recovery and support services is greater (which is precisely why some families settle in towns).

5

Attitudes and behaviour of parents/caregivers towards people with disabilities are influenced by stereotypes and prejudices.

Nearly half of parents/caregivers do not know how they should interact and behave with a person with disabilities. Half of parents/caregivers feel uncomfortable when they see the efforts of people with disabilities to achieve certain results and feel frustrated that they do not know how they can help. Almost half of parents/caregivers feel insecure when interacting with a person with disabilities. These attitudes and behaviours are the result of limited knowledge about disability and poor communication skills with and about people with disabilities.

6

Among parents/caregivers who take care of a child with disabilities in the early years of the child’s life, the medical model of dealing with disability predominates. One in two parents/caregivers believes that disability is a child health issue

and tends to seek medical treatments and medical interventions to address participation and mobility issues. As a result, medical staff are of great importance in guiding and assisting the family, but research results show a high level of stigmatization of parents of children with disabilities by medical staff. Often after visits to the family doctor or to the specialist doctors, parents/caregivers return home with little information or guidance about how to deal with the child. Conversely, the behaviour of parents/caregivers who have children with disabilities older than 10–12 years is dominated by the social model and the charitable model of approaching the disability. The social model is formed over time and is influenced by the experiences of parents/caregivers. In contact with people with disabilities, they try to act normally and not draw too much attention to the disability, they admire the ability of the person with disability to cope with the barriers created by society, and after frequent contact they just perceive the person without noticing the disability. The charitable model is highlighted during interactions with people with disabilities (other than one's own child), and characterized by the tendency to help the person, as they know best how much support is needed, and in some cases they feel sorry for people with disabilities, as they understand the barriers they face and feel uncomfortable that they are unable to provide the help they need.

7

Stigma is a very common phenomenon when talking about disability, targeting both people with disabilities and their families.

Attitudes of community members towards children with disabilities and their families are based on pity, contempt and prejudice. Families with a child with disability feel the stigma from community members when they take their child out in public places, for a walk, shopping. Parents/caregivers have a difficult time facing social attitudes of contempt, so many refuse to go out with their child or limit such outings. Gender differences are also registered, with mothers of children with disabilities experiencing such experiences more frequently than fathers. Service providers tend to discriminate against families of children with disabilities on grounds of disability. Most frequently, such situations are encountered when communicating with health-care and educational professionals, expressed by the presence of prejudices with reference to the causes of the disability and verbal aggression against the child and the family. Among the most reported discriminatory behaviours are: refusing to enrol the child with disabilities in an educational institution or to provide necessary support services.

8

Disability has a big impact on family life and on relationships between partners.

In some cases, the presence of a child with disabilities in the family contributes to the strengthening of relationships between family members (families become closer, family members help each other), while in others it has a negative impact (worsening of material well-being, migration, the father works abroad, divorce). In many cases, the mother of the child with a disability feels guilty about the child's disability. Fathers have little involvement in childcare and development. The need to socialize with other parents in similar situations, to communicate, to share their emotions, the need to take a pause, are not met at community level, especially for mothers/grandmothers in rural areas. The fear of prejudices associated with disability leads to social self-exclusion.

9

In daily life, families of children with disabilities face barriers to participate and live in the community on an equal basis with other members of the community.

The main barriers that families with children with disabilities face are: communication barriers with different service providers, access barriers to support services, attitudinal barriers and physical accessibility barriers. In addition to limited access to support services, there is also a lack or shortage of qualified professionals to provide the necessary support to children and families at different stages of life. The moment when the family is informed about the existence of the disability is crucial, as it is extremely emotionally powerful and requires a lot of external support.

10

Women/mothers self-identify with their child with disability, which affects their personal identity.

In most cases, women/mothers associate themselves entirely with the child they have given birth to (fathers and caregivers are less inclined to do this). The development of misperceptions about disability and about the child with disabilities generates the development of misperceptions about themselves as parents. Such parents end up self-stigmatizing, perceiving themselves as parents of another category, who feel a lot of guilt and shame. This does not allow the parent to ‘grow up’, to fully experience the joy of being a parent. Limited access to information, limited existing resources, financial dependence (especially as the patriarchal approach to the family is still prevalent in the rural areas) – together intensify the mother’s vulnerability and the phenomenon of self-stigmatization.

RECOMMENDATIONS

- ✓ Strengthen collaboration and communication between service providers in the health, social and education sectors in providing high-quality care for children with disabilities and their families. Parent caregivers should be involved at all stages of care (planning, implementation, monitoring, progress).
- ✓ Improve the mechanism for identifying, assessing and determining disability among children with developmental disabilities.
- ✓ Increase public investment in services adapted for the needs of children with disabilities and parents of children with disabilities, including social services, family support, personal assistants, education support.
- ✓ Develop and promote parenting education programmes for parents/caregivers of children with disabilities. These programmes will be specific to the interest group of parents, with direct involvement of parents as trainers by promoting peer-to-peer knowledge and information.
- ✓ Develop gender-transformative parenting programmes to better involve men/fathers.
- ✓ Develop a consolidated online platform and develop a parent empowering programme in an accessible format with direct interaction between professionals and parents/caregivers to provide information and support as needed in short periods of time.
- ✓ Strengthen mutual support and assistance groups made up of parents of children with disabilities and empower them to provide support to other parents/caregivers who are in similar situations. The need for support groups is vital in all regions of the country.
- ✓ Organize campaigns to change attitudes towards children with disabilities, to prevent violence, neglect and risks of separation, and to inform and promote the rights of children with disabilities at national level.
- ✓ Train professionals providing family and child services according to the social and rights-based approach to disability.
- ✓ Develop interpersonal communication skills of professionals in different fields, including service providers (medical, social, educational).
- ✓ Establish a support and counselling service for families/partners who know from pregnancy about the likelihood of the birth of a child with disabilities or for families who are informed after the birth about the difficulties and the likelihood of a disability in the child. This service can be developed at regional level with the possibility to offer mobile or online services to prevent situations of partner separation or abandonment of the child with disabilities.
- ✓ Provide support to parents in advocacy activities to increase access of children with disabilities to early intervention services, social services, educational services, as well as obtaining financial support from the state for specialized therapies that are not available for free.

- ✓ Support parents in establishing a network of parents and strengthening dialogue with central and local public authorities to promote the rights of children with disabilities and the rights of women who take care of them, to have their work recognized and appreciated either as personal assistants or to ensure access for children to personal assistants outside the family so that the children's mothers can return to the labour market.

- ✓ Promote the integration of disability in all types of childcare and development services, without discrimination on grounds of disability.

BIBLIOGRAPHY

1. Changing The Way We Care, Knowledge, Attitudes, and Practices of Reintegrating Children into Families and Prevention of Child-Family Separation: Situational analysis of the care system in the Republic of Moldova, Catholic Relief Services, 2021, <www.changingthewaywecare.org/wp-content/uploads/2022/07/report-5-kap-report-184-ctwwc-md-eng.pdf>, accessed 7 June 2024.

2. Cojocaru, A., Analiza nivelului actual de dezvoltare al sistemului de intervenție timpurie în copilărie în Moldova. Report elaborat și promovat de Centrul Voinicel în acțiuni de advocacy [Analysis of the Current Level of Development of the Early Childhood Intervention System in Moldova. Report prepared and promoted by the Voinicel Center in advocacy actions], Voinicel, Republic of Moldova, October 2022.

3. Committee on the Rights of the Child, 'Concluding Observations on the Combined Fourth and Fifth Periodic Report of the Republic of Moldova', CRC/C/MDA/4-5, United Nations, New York, 29 September 2017, <www.refworld.org/docid/5a0ed42e4.html>, accessed 15 January 2024

4. Committee on the Rights of the Child, 'General Comment No. 7 (2005): Implementing child rights in early childhood', CRC/C/GC/7/Rev.1, United Nations, New York, 20 September 2006, <www2.ohchr.org/english/bodies/crc/docs/AdvanceVersions/GeneralComment7Rev1.pdf>, accessed 26 December 2023.

5. Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of the Republic of Moldova', CRPD/C/ MDA/CO/1, United Nations, New York, 18 May 2017, <https://undocs.org/Home> accessed 7 June 2024

6. COVID-19 Disability Rights Monitor, Disability Rights During the Pandemic: A global report on findings of the COVID-19 Disability Rights Monitor, COVID-19 Disability Rights Monitor, 2020, <https://covid-drm.org/assets/documents/Disability-Rights-During-the-Pandemic-report-web.pdf>, accessed 14 January 2023.

7. DataReportal, Digital 2022: Moldova, Kepios, 2022, <https://datareportal.com/reports/digital-2022-moldova>, accessed 15 January 2023.

8. Disability Unit, 'Developmental Disabilities Awareness Month: What are developmental disabilities?', UK Government, 15 March 2021, <https://disabilityunit.blog.gov.uk/2021/03/15/developmental-disabilities-awareness-month/>, accessed 25 January 2023.

9. European Commission, '"Council decision regarding the position to be adopted on behalf of the European Union within the Association Council established by the Association Agreement between the European Union and the European Atomic Energy Community and their member states, on the one hand, and the Republic of Moldova, on the other side"' [Association Agreement between the European Union and the Republic of Moldova]. 2021-2027 Agenda. <https://eur-lex.europa.eu/legal-content/RO/TXT/HTML/?uri=CELEX:52022PC0069&from=EN>, accessed 25 January 2023.

10. EUROSTAT, 'Infant Mortality Sharply Declined Over the Past Decades', European Union, Luxembourg, [2021], <https://ec.europa.eu/eurostat/web/products-eurostat-news/-/ddn-20210604-1>, accessed 15 December 2023.

11. Human Rights Council, 'Report of the Special Rapporteur on the Rights of Persons with Disabilities on Her Mission to Moldova', A/HRC/31/62/Add.2, United Nations, New York, 2 February 2016, <https://digitallibrary.un.org/record/831670?ln=en>, accessed 15 December 2023.

12. Magenta Consulting, STUDIU privind percepţiile şi atitudinile faţă de egalitate în Republica Moldova [Study on Equality Perceptions and Attitudes in the Republic of Moldova], Magenta Consulting, Chişinău, 2018, <http://egalitate.md/wp-content/uploads/2016/04/Studiu-privind-percep--iile.pdf>, accessed 15 December 2023.

13. Ministry of Health and Lumos Foundation, Situația Copiilor Cu Vârsta De Până La 5 Ani Cu Tulburări De Dezvoltare, Inclusiv Cu Dizabilitate Stabilită, În Republica Moldova [The Situation of Children Up to 5 Years of Age with Developmental Difficulties, Including Established Disability, in the Republic of Moldova], Lumos, Chişinău, 2017, <https://lumos.contentfiles.net/media/assets/file/LUMOS_Situatia_copiilor.pdf>, accessed 23 November 2023.

14. National Bureau of Statistics of the Republic of Moldova, 'Activitatea instituțiilor de educație timpurie în anul 2022' [The Report on Activity of Early Childhood Educational Institutions in Moldova for 2022], Biroul Național De Statistică Al Republicii Moldova, Chişinău, 19 April 2022, <https://statistica.gov.md/ro/activitatea-institutiilor-de-educatie-timpurie-in-anul-2022-9454_60393.html>, accessed 2 February 2024.

15. National Bureau of Statistics of the Republic of Moldova, 'Persoanele cu dizabilități în Republica Moldova în anul 2022' [People with Disabilities in the Republic of Moldova 2022], Biroul Național De Statistică Al Republicii Moldova, Chişinău, 30 November 2022, <https://statistica.gov.md/ro/persoanele-cu-dizabilitati-in-republica-moldova-in-anul-2022-9460_60822.html>, accessed on 1 February 2024.

16. National Bureau of Statistics of the Republic of Moldova, 'Situaţia copiilor în Republica Moldova în anul 2022' [Situation of Children in the Republic of Moldova in 2022], Biroul Național De Statistică Al Republicii Moldova, Chişinău, 30 May 2023, <https://statistica.gov.md/ro/situatia-copiilor-in-republica-moldova-in-anul-2022-9578_60434.html>, accessed 26 December 2023.

17. Ocertnîi, A., and Veceaslav Bătrânescu, Raport de Cercetare. Cartografierea programelor de educație parentală furnizate în Republica Moldova [Research Report. Mapping of parental education programs provided in the Republic of Moldova], Centrul Naţional de Prevenire a Abuzului faţă de Copii, Chișinău, 2021, <www.cnpac.md/ro/raport-de-cercetare-cartografierea-programelor-de-educatie-parentala-furnizate-republica-moldova/>, accessed 16 December 2023.

18. The World Bank, 'Mortality Rate, Under-5 (per 1,000 live births) – European Union', 2020, <https://data.worldbank.org/indicator/SH.DYN.MORT?locations=EU>, accessed 15 December 2023.

19. The World Bank, 'Immunization, Measles (% of children ages 12-23 months) – Moldova', 2021, <https://data.worldbank.org/indicator/SH.IMM.MEAS?locations=MD>, accessed 16 November 2023.

20. UNICEF Moldova and Maestral, Analiza situației privind intervenția timpurie la copii în Republica Moldova [Analysis of the Situation Regarding Early Intervention for Children in the Republic of Moldova], UNICEF Moldova and Maestral, 2023, <www.unicef.org/moldova/media/11426/file/Moldova%20ECI%20Sitan%20report%20RO.pdf>, accessed 7 June 2024.

21. United Nations Children's Fund, Country Profiles for Early Childhood Development, Countdown to 2030 Women's, Children's and Adolescents' Health, 2021, <https://nurturing-care.org/resources/country-profiles-2020#:~:text=The%20%E2%80%9CCountry%20Profiles%20for%20Early%20Childhood%20Development%E2%80%9D%20are,a%20baseline%20against%20which%20progress%20can%20be%20monitored.>, accessed 7 June 2024.

22. United Nations Children's Fund, Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities, UNICEF, New York, 2021, <https://data.unicef.org/resources/children-with-disabilities-report-2021/>, accessed 7 June

23. United Nations Development Programme, 'Paradigm Shift Disability Inclusive Services, Accountability and Governance in Moldova' [project], UNDP Moldova, 2021, <www.undp.org/moldova/projects/paradigm-shift-disability-inclusive-services-accountability-and-governance-moldova>, accessed 16 January 2024.