



CHILD DISABILITY IN ALBANIA

Disability prevalence, access to services
and quality of services



CIP Katalogimi në botim BK Tiranë

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Child disability in Albania: Disability prevalence, access to services and quality of services

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Foreword by World Vision



This research study marks a crucial turning point and an innovation in the field of child disability research in Albania. It establishes a distinct division between two periods: that of the medical assessment and the present biopsychosocial assessment of children with disabilities. It predominantly expands our mindset towards a new perspective and guides us in a path less taken. We are proud, that in partnership with Save the Children, after persistent and hard work, succeeded in presenting the first study with abundant data on the prevalence of disabilities and the everyday reality of children with disabilities in Albania.

I have hope that the reader of this study will be inspired by the findings, as a foundation to explore the vulnerability situation of children with disabilities. They impose on us the responsibility and the duty to face the reality and to intervene for designing policies, services, practices, and programmes, in particular at the community level, which will change children's lives. As part of its global strategy Our Promise 2030, World Vision Albania is committed to keep the promise that every child in a situation of vulnerability, particularly those with disabilities, enjoys life in all its fullness. This is why we will work persistently to ensure their inclusion, protection, education, and wellbeing in accordance with the Convention on the Rights of the Child and Convention on the Rights of Persons with Disabilities. WorldVision believes that to change the lives of children all stakeholders need to play a role: families, children, community, organisations and institutions.

I am grateful for the work and the efforts made by the professional and dedicated team that participated in the finalizing this study. I would like to express my heartfelt gratitude to 13.000 Albanian parents who gave voice to the reality of children with disabilities. Besides expressing my appreciation to the authors, the Research Advisory Board, the research company GfK, the editors and the working team of both organizations, I would also thank deeply two former leaders of WorldVision Albania, Mr. Reinder Dekker and Mr. Toni Gogu, whose commitment and support ensured the success of this research.

Many other studies will be certainly conducted in the future, but this one paves the way, laying the foundations to all future studies. May this study be the basis for dialogue and inspiration for fruitful collaboration among citizens and decision-makers, to ensure that all children with disabilities live a life with dignity, justice, peace and hope.

Eljona Boçe Elmazi

Executive Director, World Vision, Western Balkans

A handwritten signature in blue ink, appearing to read 'Eljona Boçe Elmazi'.

Foreword by Save the Children



Any child with disability is entitled to the right to access to quality services, which enables their development, education, and progress on an equal basis with their peers.

Ensuring investments and eliminating barriers faced by children with disabilities and their families regarding quality and access to inclusive services are among Save the Children's continuous efforts and support. This study, which is deemed as important and necessary in the field of disability, was carried out precisely in this framework.

This study goes beyond the provision and improvement of data by presenting and measuring through an innovatory approach the difficulties that children face in the functional areas of daily life.

The distinction of this study is attributed to the focus given to parents' perceptions on the difficulties their children encounter and on the quality of received health, educational, and support social services.

From the human rights perspective, Save the Children values and considers parents' opinions on the reality and daily difficulties on lack of access and services quality provided to their children as essential.

We strongly believe that the findings of this study will generate a wider discussion among field experts. Their opinions and conclusions will further influence both the policymaking, adapted to the needs of children with disabilities and their families and the application of best practices and models, aiming at enhancing services and guaranteeing access and quality of services provided to children with disabilities.

In order to fulfill its commitments towards children with disabilities and guarantee each of them is included and treated as equal, Albania must commit to the improvement of the services provided to children with disabilities and the fulfillment of their rights by state authorities and society.

Anila Meço

Country Director, Save the Children in Albania

A handwritten signature in blue ink, appearing to read 'Anila Meço', written over a light blue background.

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Acronyms

INSTAT	Institute of Statistics
ICF	International Classification of Functioning, Disability and Health
MSWY	Ministry of Social Welfare and Youth
WHO	World Health Organization
CEE/CIS	Central and Eastern Europe/Commonwealth of Independent States
PwD	Person with disabilities
UNCRC	United Nations Convention on the Rights of the Child
UNUNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNICEF	United Nations Fund for Children
WVA	World Vision Albania

Executive Summary

Background

In ethical terms, in any society caring about children is the primary responsibility of parents and society itself. In addition, pragmatic viewpoints suggest that care of children with disabilities increases their chances to be more prepared and active participants in the economic life of the country when reaching adulthood.

Accurate data on disability prevalence in children are missing not only in Albania, but also in other developed countries. Although studies indicate that approximately 85% of children with disabilities live in countries in development (WHO, 2011), verification of such data becomes a tremendous task, not only due to stigma, but also due to debates associated with the definition of disability itself, its identification instruments or disability assessment. This is the reason why the UNICEF (2013) world report views these worldwide data on disability as “essentially speculative”. International practice has demonstrated that including a series of questions on disability measurement in national censuses has historically been neither sufficient nor comparable. Moreover, studies involving key persons from the community to identify children with disabilities have shown that they have underestimated prevalence, hence up to date door-to-door interviews conducted by trained persons, who interview the parent of the child, remains the most effective approach.

Presently, there are contradictory data on disability prevalence in children and youth in Albania. Regardless of the urgent need, no specific study has been conducted to assess the scale of disability prevalence in Albanian children and the services available to support their needs. Furthermore, previous data collection on child disability in Albania has relied on models not in compliance with the requirements of the United Nations Convention on Rights of Persons with Disabilities (UNCRPD). Nevertheless, such data on prevalence are considered imperative also because trustworthy data account for planning and expansion of more effective interventions and support with regard to both intervention cost and time.

Countries that have ratified the UNCRPD, such as Albania, pursuant to Article 31 of the Convention are required to “undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention.” Furthermore, the same article of the UNCRPD states that the state shall “identify and address the barriers faced by persons with disabilities in exercising their rights” (UN, 2006).

The present study marks the first national study on disability prevalence in children and youth in Albania. In terms of approach and conception, methodology and selected research instruments, this study represents a new era in this field. Moreover, it has been designed in compliance with the UN-CRPD requirements regarding statistical data collection for persons with disabilities.

Apart from putting forth necessary quantitative statistical data, gathered through parents' perceptions, this study provides a clear tableau of the situation with services for these groups of children and youth and their families.

Up to date, provision of services for children with disabilities and difficulties in certain areas has been, among others, significantly hindered due to the lack of such data. For this reason, the results of this study may be a reference point for all actors to facilitate planning and improvement of services provided to children at risk of developing a disability and to children with disability, as such services, among others, shall be based on accurate and comprehensive statistical data.

Study aim and objectives

The aim of this study is to measure disability prevalence in children and youth in Albania, to estimate their possibilities of development, and to assess their access to and quality of the main services provided to them.

In particular, this study aims to meet the following objectives:

1. Measuring the national prevalence and types of disability in children aged 2-17 years old in Albania;
2. Estimating perceptions about the community-based quality services for children with disabilities;
3. Assessing potential inequalities on the grounds of demographic and socio-economic characteristics of families with children with disabilities.

Study methodology

A nationally-representative sample of 13,000 families (one child participant randomly selected per family) out of 22,333 families initially contacted, was drawn in compliance with the demographic characteristics of the general population of children aged between 2-17 years old in Albania, according to the 2011 INSTAT Population and Dwelling Census. The sampling calculation included 95% credibility interval and alpha set at 0.05, and sampling error at 0.9%.

Legal parents (mother or father) or the legal guardian of the child responsible for the child on a daily basis provided proxy responses via in-home surveys. The designed instrument included four modules:

- Module 1: Demographic and socio-economic data
- Module 2: UNICEF/Washington Group Child Functioning Module. This module incorporated 12 functional domains of development designed to assess disability in compliance with ICF requirements for children aged 2-17 years old. Included functional domains were: vision, hearing, mobility, communication, learning, behaviour, play with others, memorisation, attention, adaptation to change, social relationships, care for oneself, emotions.
- Module 3: Service access and quality. This module assessed availability and quality of health care and rehabilitation services, and of education, amongst all respondents.
- Module 4: Parental perceptions of child disability. This module was only applicable to respondents who reported that they considered their child to have a disability (irrespective of the outcome of Module 2). The interviews were conducted at 12 regions of the country through the face-to-face method.

The methodology employed in this study indicates similar limitations to those encountered in international studies. Considering that, the study measures disability from parents' perception, relevant studies have noted that parents may either overestimate or underestimate the level of difficulty that their child faces.

Disability prevalence: children were determined to have a "mild" difficulty in functioning if their proxy respondent reported "some" difficulty in one or more functional domain, but did not report "a lot" of difficulty or "cannot do" in any domain. Children were determined to have a disability if their proxy respondent reported "a lot" of difficulty or "cannot do" in one or more functional domain.

Main findings

55.8% More than half of the sample experience mild or greater difficulty (reporting “some difficulty” or higher) in functioning in at least one functional domain.

10.4% of children experience a lot of difficulty or can not do at all one activity in at least one functional domain. In other words, 1 in 10 children in Albania has a disability.

45.4% of children aged 2-17 years old included in the research are reported to have at least one mild difficulty in one functional domain (but no difficulty greater than mild).

4% of children with disability in Albania have a medical certificate.

66% of children with disabilities live in families with low income, whereas 30% of them live in middle-income families. Prevalence is higher in low-income families.

58% of mothers and 33% of fathers are unemployed or work part-time/have a seasonal job. 78.8% of these families consist of four to six members. It is reported that unemployment rate of parents of children with disabilities is considerably high.

5-14 years old is the highest prevalence age group.

38.6% Differences between the group of parents of children with disabilities and parents of children without disabilities or with mild difficulties in functioning are reported with differences regarding the overall health services. 38.6% of parents of children with disabilities are dissatisfied with the expenses they have to make to receive the service compared to 17.7% of parents of children without disabilities or with mild difficulty in functioning.

70.4% of parents of children without disabilities or with mild difficulty in functioning consider quality of health services as a reason for not receiving them.

58.3% of referrals of children with disabilities to specialists were by family doctors, and only 5.5% of referrals were by the child's teacher or educator.

75.7% of children with disabilities attend nursery, kindergarten or school. This figure is much higher for the same age groups of children without disabilities (93.1%). Such difference is further highlighted when taking into account the fact that only 61.3% of children having been assessed by the medical or multidisciplinary commission regarding their disability attend education at a pre-university educational institution.

94.3% The majority of the children with disabilities pursuing education (94.3%) attend nurseries, kindergartens or mainstream schools, 4.4% attend special educational institutions and 1.3% attend vocational schools.

36.5% of parents of children with disabilities, identified by the means of this study, are dissatisfied or not at all satisfied with the expenses they have to make to enable their children's school attendance, compared to 19.6% of parents of children without disabilities.

26.2% and 14.6% of parents of children with disabilities were dissatisfied or not at all satisfied with the infrastructural conditions of educational institutions' facilities and commute distance, as opposed to 17.3% and 3.5% of parents of children without disabilities. Furthermore, parents of children with disabilities were dissatisfied with the progress of their children at school (19.4%), with the level of teaching adaptation with respect to the needs and development of the child (13.3%) and the respect shown by the educational staff (6.3%).

7.8% of children with disabilities have received a social service in the last 12 months. Access to social services, such as specialised centres, day-care centres, mental health centres and social care residential centres is very low.

55% of parents report that the necessary expenses for receiving the service are somewhat unaffordable or totally unaffordable for them.

Parents estimate that the main reasons for not attending social services are non-affordability of financial costs related to receiving services (88.9%); lack of transport (20.0%), lack of community-based services (8.9%); rejection of services (11.1%), and inappropriate quality of the services (8.9%).

86.9% of parents estimate that financial support is insufficient or wholly insufficient to meet basic needs and to afford the service costs related to disability.

The majority of the children qualified by the medical assessment commission receive solely financial support, 13.6% receive family-based care from a specialist physician, whereas less than 4% receive other means of support, such as specialised medical and educational services, rehabilitation and or psychosocial services.

1 in 2 children with disabilities experiences discrimination in the community (52.9%), educational institutions (52.4%) and during play with peers (54.9%), whereas 1 out of 3 children with disabilities faces discrimination at other public services, such as health and social services.

Main recommendations

This study identifies the tremendous need for multidisciplinary and specialised identification of children with disabilities in Albania, support and training services at no cost (or at an affordable cost), provided to families of children with disabilities and children with severe difficulties based on the principle that service shall go to the client (and not vice versa), which shall be viewed as top priority.

Data showing that half of the children with disabilities in the study had been identified and assessed by the medical commission (only 4% out of 10.4% identified in this study) identifies the need to prioritise identification and elimination of barriers to identification, assessment and benefit of services for this huge group of children at high risk.

The study implies the need, particularly for the State both in local and central level, to increase financial support to children with disabilities and their families. According to parents' perception, financial costs for the services (to all types of services) and very low financial support are the main barriers to access.

96% of families of children with disabilities earn low or meagre incomes. The majority of these families (78.8%) consist of a large number of members (4-6) and the parents' unemployment rate is quite high. High correlation between poverty and disability implicates the need to find innovative, cost effective schemes to support to these families.

The extremely low referral rate of children to specialised services by the psychosocial and education staff imply the need for their training and for them to be better informed about supporting children with disabilities.

The study data suggest the need to continue investing access of children with disabilities to schools, as well as the quality of education in inclusive educational institutions.

It is necessary to find ways to more quality/effective coordination between crosscutting services (health, social, educational and support ones) and diversification of these services.

Children with disability encounter discrimination at considerable levels in various settings throughout their life. Consequently, interventions and activities to support their meaningful inclusion should involve all actors and factors identified in this study, at both a micro and macro level (i.e. not only at school level, but also at a community level and broader).

I. Introduction

I.1 Background on child disability

Globally, it is estimated that child disability prevalence averages 5.1% of the total child population (WHO, 2011). However, estimates vary substantially across countries and between studies. A recent UNICEF study conducted in 20 countries of the world indicated that prevalence of child disability ranges from 14% to 35% (WHO, 2011). In addition, data from various studies indicate that low or average income countries report prevalence ranging from 0.4% to 12.7% (WHO, 2011). At least some of this discrepancy is related to the use of different disability measurement tools, leading to non-comparable estimates that in some cases do not comply with the UNCRPD. However, the availability of such compliant data are considerably increasing with the incorporation of instruments complying with the UNCRPD concept of disability into research.

The latest studies conducted in developed countries show that “disability prevalence is increasing”, “the type of disability prevalence is changing”, “disability prevalence due to physical health conditions is decreasing, while disability prevalence due to neurodevelopmental and mental health problems is considerably increasing” (Kemp, 2013).

Children are both the present and the future of a country; hence investing in them to reach their full potential is a major priority for any state. Children in Albania, especially those belonging to marginalised groups, have been and remain an important and continuous focus of international and state bodies. Despite the fact that children with disabilities are a frequently marginalised and disadvantaged group, their inclusion is still being addressed based on their disability rather than on their potential.

Although there is space for optimism, the current situation of children with disabilities and their families in Albania is still harsh. They encounter many barriers and their needs are often underestimated. The majority of barriers children with disabilities and their families face are societal and environmental, rather than related directly to their functional limitations (CH Embassy, UNICEF & MSWY, 2014).

Elimination of these barriers to their empowerment and full participation in society requires the availability of trustworthy and appropriate data. The aim of this study is to secure such data, such that the study’s findings and recommendations facilitate more quality and holistic planning of appropriate programmes that best safeguard their rights.

The Ratification of the United Nations Convention (2006) on the Rights of Persons with Disabilities (UNCRPD) by Albania (2012) may be considered as a new era regarding the rights of individuals with disabilities. However, the Optional Protocol, which provides for these persons to appeal in case their rights have not been fulfilled by the party states, has not yet been signed. The UNCRPD requires

ratifying countries to report statistical data on children with disabilities for planning purposes. Such data are considered of fundamental significance for the design of accessible, inclusive and community-based services. Regardless of the great need in this respect, statistical data on children with disabilities have been absent, contradictory or untrustworthy (Kemp, 2013). Moreover, the National Census 2011 itself did not manage to provide clear data on children with disabilities (UNDP, 2015).

Previous data collection on child disability in Albania has followed models not in compliance with UNCRPD requirements. With respect to approach and methodology, it has been compiled based on similar international studies and in full compliance with the UNCRPD requirements concerning statistical data collection for children with disabilities.

The civil society and international organisations have played a vital role in the protection and promotion of rights of children with disabilities, thus this particular study was undertaken by two leading organisations in the country for children with disabilities, World Vision Albania and Save the Children. This initiative deserves to be acknowledged.

Disability is part of human condition, hence as such it shall not be viewed as a hindrance, but rather as a potential. Building inclusive societies requires viewing children with disabilities as a real wealth and disability itself as an integral part of human diversity.

1.2 Overview of legal framework for disability in Albania

The legal framework for children with disabilities in any country is examined in close relation to the obligations deriving from the ratification of two United Nations conventions: The United Nations Convention on Rights of the Child (UNCRC, 1989) and the United Nations Convention of Rights of Persons with Disability (UNCRPD, 2006). One fundamental requirement of the UNCRPD is put forth in Article 4 of this Convention, according to which “all States Parties shall adapt their legislation to the Convention”.

Among the main reasons for such a requirement is that the abovementioned Conventions are guided by the principles of dignity, individual autonomy and non-discrimination, as well as inclusion of the individual with disabilities as citizens and equal participants in all spheres of life. These principles ensure the right of all persons to enjoy all human freedoms and rights, ensure non-discrimination, equal opportunities and access, and the child’s best interest in any action undertaken for them, the capacity to raise children with disabilities as a fact to be taken into account in any decision-making concerning children, the right to be heard and the right to full participation, the right to family life, right to access to education, health care, assistance and protection from any type of violence.

Generally, the legal framework in Albania is inspired by and guarantees protection of rights of children with disabilities, although adaptation of the legal framework and other important mechanisms for its implementation in compliance with the principles and requirements of these Conventions is still incomplete (CH Embassy, UNICEF & MSWY, 2014).

Lately, a series of significant developments have been noted with regard to policies and practices towards children with disabilities in Albania. However, even though such legislation is inspired and recognises the best interest of the child, its implementation is limited and specific needs of children with disabilities in different areas and services are not recognised. Although the legislation sanctions the right to non-discrimination on grounds of disability or age, the actual application of this right is partial, and its implementation measures are inadequate (Ombudsman, 2012).

Being the foundation of the legislation in the country, the Constitution of the Republic of Albania, in compliance to main principles of the Convention on the Rights of the Child, guarantees the pro-

tection of every child from violence and any form of maltreatment or discrimination (CRIN, 2012). Although the Constitution does not explicitly refer to children with disabilities, it puts forth that all children are equal, and no one should be discriminated irrespective of their gender, race, religion, ethnicity, language, political, religious or philosophical beliefs etc. (Article 18). Additionally, its 25th Article, even though it does not specifically refer to children with disabilities, but refers to all persons with disabilities, guarantees health rehabilitation, specialised education and integration in society, as well as continuous improvement of the living conditions for all persons with disabilities (CRIN, 2012).

Unlike codes (civil, family, labour and criminal ones) and several previously approved laws (Law on Assistance and Social Services, Law on Health Care in Albania, etc.) which – based on terminology employed and other aspects of children with disabilities rights – do not comply with the CRC and UNCRPD, the laws enacted recently are in full compliance with the spirit, principles and requirements of the ratified conventions (CH Embassy, UNICEF & MSWY, 2014).

The law on Mental Health (2012) fully complies with the Convention and clearly states the rights of the children with disabilities to integrated and inclusive services. Moreover, the law in question adapts provisions for non-discrimination to the provisions of the law “On Protection from Discrimination” (2012).

Additionally, the law on Pre-University Education (2012) complying to the CRC and UNCRPD sanctions the rights of children with disability to full participation and quality education in the pre-university education cycle. In accordance with UNCRPD, the law on Inclusion and Accessibility for Persons with Disabilities (2014) promotes the biopsychosocial model (ICF) adopted by WHO regarding approach to disability. It clearly identifies the essential services of the ICF model, even though it does not specifically include and elaborate on all types of disabilities.

Irrespective of the above, the legal framework for children with disabilities in most of the countries in the Balkan region is mainly sectorial with components that hinder the complete adaptation to the requirements of the Conventions (CRC and UNCRPD). In most cases, it does not specifically refer to children with disabilities and it does not clearly promote inclusion.

Albania is changing the way it views the rights and needs of children with disabilities by incorporating them into legislation increasingly more in compliance with UNCRPD. Despite this, the complete harmonisation of legislation with Article 26 of UNCRPD, which obliges the Albanian state to guarantee developmental and rehabilitation services in the sectors of health, employment and education towards autonomy, complete mental, physical, social, vocational training, inclusion and participation in all aspects of life, will require more time. In addition, the National Action Plan for Persons with Disabilities (2016-2020), regardless of the innovations with respect to implementation of persons’ with disabilities rights, does not contain sufficient specific objectives for children with disabilities. Its main objectives are treatment and rehabilitation, notwithstanding the great gap to provision of community-based services that do not prioritise prevention and early identification of children with disabilities.

1.3 Overview of previous studies of child disability in Albania

Conducting studies that reflect the magnitude and reality of the situation of children with disabilities marks the first step towards laying the foundation and drafting policies, strategies and services to support the inclusion of children with disabilities in Albania.

Broad-scale studies in the field of children with disabilities became a common practice in Western Europe in the 1970s (Glidden, 1993). However, in Albania, national quantitative studies in this field started to appear after the 1990s. Nevertheless, national studies specially dedicated to children with disabilities were given an impetus during the 2000s.

Early qualitative studies, such as “I am like you” (Save the Children, 2003), provided the first data on the neglect and exclusion experienced by children with disabilities and their families in Albania. The study identified that most of the children with disabilities enumerated faced great economic, political and social barriers that negatively affected their development and wellbeing. Moreover, it indicated that children with disabilities of that time were not able to meet some of their basic needs, such as access to health and education services, that they were secluded in their homes and invisible to both society and the State (Save the Children, 2003). However, this national study did not provide accurate statistical data regarding children with disabilities yet provided a detailed panorama of their situation and the services provided for them in that time.

Several previous studies by international organisations have focused on the situation of children with disabilities in Albania, including their access to services, and their rights.

Most of these studies are related to education. The study “Inclusive Education in Albania” (Save the Children, 2012) qualitatively and quantitatively describes and analyses the education situation of children with disabilities in Albania. The study analyses the legal framework and collects objective evidence to portray the actual countrywide situation of children with disabilities in kindergartens and schools. Three other studies conducted in the same year by World Vision Albania considerably fill the gap with study research in the field: the study “Good Practices in the CEECIS Region and Recommendations to the Albanian Government” (WVA, 2012) provides an overview of best practices with respect to Inclusive Education for children with disabilities in the CEECIS Region and a series of recommendations for implementing inclusive education in Albania. “The Right to Inclusive Education for Children with Disabilities” (WVA, 2012) provides an analysis of the history of educational development for children with disabilities in Albania in the years 1945 – 2011. The third study concluding this cycle identifies the knowledge, stances, conduct and experience of educational staff, parents and peers of children with disabilities regarding practical implementation of inclusive education (WVA, 2012). The study in question also identified the shortcomings, barriers and possibilities to implementing the legislation, thus enabling education of any child with or without disabilities. Furthermore, the study “Inclusion practices in the Albanian preschool system” (Save the Children, 2014) explores inclusive practices implemented in the preschool education system in Albania and focuses on access, education and support of fulfilling the right of children with disabilities to quality education. Another recent study, “Facing the Challenges of Inclusive Education in Albania” (UNICEF, 2016) identifies the barriers and shortcomings that impede the educational staff from providing quality inclusive education to children with disabilities.

Additional studies on health and social services for children with disabilities, though more limited in quantity, provide supplementary data on the situation of children with disabilities in Albania. The study “Access to health services for groups in need” (SOROS, 2011) particularly focused on children with disabilities in accessing health services. Moreover, the study “A Review of the Disability Assessment System in Albania” (UNDP, 2014) reviews disability assessment and specifically references the assessment of children with disabilities.

The study “Situational Analysis of Children with Disabilities in Albania” may be considered the most thorough analysis regarding children with disabilities in Albania to date (CH Embassy, UNICEF & MSWY, 2014). The study describes in qualitative and quantitative terms the situation of children with disabilities in Albania and identifies main barriers that these children face towards inclusion and participation. Furthermore, this study sums up the regulatory framework for these children, indicates the data collection system for these children and the barriers in this field, and elaborates on the social, health and educational networks as well as the barriers to access them.

In addition, the “Study and Evaluation of legislation on Disability in Albania” (ADRF, 2014) provides an overall panorama of the Albanian legislation that regulates this field and includes all categories of persons with disability.

Other all-age disability studies are also of interest. The study “Profile of the Population with Disability in Albania” (UNDP, 2015) contributes to empirical research on the social and economic conditions of persons with disabilities in Albania. Employing data that not only broadly covers the whole country, but also involves a deep assessment of disability, this study presents a picture of the economic situation and poverty of persons with disabilities and their families in Albania as of 2011/2012. The study deploys data from the 2011 Population Census and the 2012 Living Standards Measurement Survey (LSMS), which both include disability assessment. Along similar lines, the study “The Social Exclusion Profile of Persons with Disabilities” focuses on the profile of socially excluded persons with disabilities in Albania (UNDP, 2015).

1.4 Overview of theoretical framework on disability

The medical approach to disability has prevailed to date not only in Albania, but also throughout the region. Consequently, children with disability have been viewed as “imperfect” and in need of protection from the state. Different perceptions of disability have resulted in data being inconsistent and unreliable. On one perspective, various terms are used with the same meaning in different countries, and on the other, the same term has been used to evoke different meanings. Thus, a common definition and understanding of disability is essential to understand and improve achievements of children with disabilities.

The medical model is broadly now considered as the model of the past. Instead, on all countries, disability is viewed on multiple dimensions and as a “set of features that anyone may have in different scales, forms or combinations” and is composed of biological, environmental and social components (UNICEF, 2014).

The International Classification of Functioning, Disability and Health (ICF) provides a broad framework for the classification of issues related to health and human functioning and takes into account the multidimensional and interactive essence of disability.

The ICF theoretical framework provides a holistic approach to human functioning and disability and is the basis for the description of disability described in the UNCRPD. According to the ICF, disability exists on three levels: as impairment of body functions and structures; as limitation to activities at the level of the person; and of participation restrictions at the level of society. The International Classification of Functioning, Disability and Health: children & youth version (ICF - CY) use an extension of the ICF.

Using the ICF, the UNCRPD (2006) states that any ratifying country must accept disability as an increasingly enhanced concept that it is the result of the interaction between an individual’s impairment and his or her environment (e.g. Barriers due to people’s attitudes, or the physical built environment being inaccessible) which may hinder the individual’s full and effective participation in society on an equal basis with others. The UNCRPD clearly states, “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”. Thereupon, the UNCRPD provides for a biopsychosocial model to understand disability that is quite different from the medical model formerly embraced in Albania.

The ratification of the UNCRPD, and accordingly the adoption of the biopsychosocial model of disability, has provided challenges in relation to statistical data collection. Earlier disability data collection efforts focused on identifying impairments and conditions at an individual level, with little attention given to understanding how external societal barriers may prevent children with impairments from fulfilling their basic rights to inclusion and participation. Data collection solely related to impairments generates low prevalence estimates and does not provide a complete picture of

disability. Knowing that a child is blind and that he or she has mobility or cognitive impairments does not provide important information on how these impairments impact on the child's participation within the community. Impairments are not equal to disabilities because the former focuses only on one particular aspect of disability.

Another theoretical framework that guided this study is the inclusive framework. This framework has been inspired by, and is grounded in, human rights. At the base of inclusion stands the belief that individuals with disabilities are part of the entire society and that they have a right to be included in all spheres of life. York et.al. (1991) has described inclusion as a life value, and inclusive communities as those where everyone is valued and where community members work together to support each other in order to maximise each individual's potential. In essence, inclusion as an approach requires that all children are recognised as having the right to fully participate in society and that all their rights are respected regardless of age, gender, economic status, language or disability. In accordance with the UNCRPD, inclusion also involves the removal of barriers that may impede realisation of such rights and requires the creation of appropriate, supporting and protective environments (UNICEF, 2007).

The ICF itself is a measurement tool which provides practical classifications that may be used as a baseline to drafting multifaceted disability assessments, as they grasp the complex and interactive nature of children with disabilities' experiences with their families. Owing to these practical classifications, the full picture of disability may be drawn, without which the planning of resources and services these children need would be unattainable.

Children with disabilities represent a social group that pose particular challenges in terms of assessment. Children are in constant development and transition from infancy to childhood, adolescence and eventually to adulthood. Rapidness and variation of trajectories of such changes make the identification of functioning difficulties challenging. Moreover, the distribution of disability types is different compared to adults, with a higher proportion in children related to intellectual functioning and behaviour (UNICEF, 2014).

The mandate of the Washington Group on Disability Statistics, a group of experts sponsored by the United Nations, is to design reliable instruments for disability assessment of adults and children based on the ICF model. Accordingly, the selected instrument for this study is the Washington Group Module on Child Functioning.

1.5 Study objectives

Existing data on children with disabilities in Albania are few and inconsistent, and previously collected using a number of different, non-comparable methodologies. Comparable, UNCRPD-compliant data on child disability prevalence and geographical distribution, opportunities for participation and effective access to essential services in Albania are urgently needed. Yielding the abovementioned data on prevalence and services provided to children with disabilities will affect public policy-making and inform programmatic planning for organisations that have prioritised disability in their strategic plans.

In particular, this study aims to meet the following objectives:

1. Measuring the national prevalence and types of disability in children aged 2-17 years old in Albania;
2. Estimating perceptions about the level of community-based quality services for children with disabilities;
3. Assessing potential inequalities on the grounds of demographic and socio-economic characteristics of families of children with disability.

II. Methodology

The methodology of this study was designed by an expert group from GfK, World Vision Albania and Save the Children, whereas data collection and insertion was performed by GfK staff. An Advisory Board was established, involving representatives from institutions responsible for education and service provision to children with disabilities and organisations with a focus on rights protection of persons with disabilities. The Advisory Board was frequently consulted during the design phase (methodology, instrument, sampling methods, and interviewing procedure).

2.1 Instrument

In order to meet the study objectives, the group of experts designed an instrument based on four main research modules as described below.

Demographic and socio-economic data: In order to identify different demographic characteristics of children with disabilities and potential inequalities regarding socio-economical situation of their families, the instrument included a series of self-declaring questions on age, sex, place of residence, employment and education status of the parents, the family income and its composition.

UNICEF/Washington Group Child Functioning Module: To facilitate comparison with other studies, disability prevalence assessment was based on the UNICEF/Washington Group Child Functioning Module. The Washington Group was established by the United Nations (UN) Statistics Division to encourage and coordinate international cooperation on health statistics focusing on disability measurement that would be fitting for national registration and surveys. This group, which has designed a short question list for adults included in many country censuses over the last decades, collaborated with UNICEF in 2013 to draft a module on Child Functioning. The main question set covers 12 functional areas that are appropriate for children aged 2-17, and focuses on reported difficulty functioning, regardless of the use of auxiliary equipment. Not all questions refer to all age groups due to differing developmental characteristics by sub- age group. Table 1 (below) summarises the number of questions per functional domain by main age group.

Table 1: List of areas and questions by main age groups

Area	Age group	
	2-4 yrs	5-17 yrs
Vision	2	2
Hearing	2	2
Mobility	2	2
Communication	2-3	2-7
Learning	1	1
Behaviour	1	1
Play with others	1	-
Memorisation		1
Attention		1
Adaptation to change		1
Social relationships		1
Care for oneself		1
Emotions		2

Each question has four response options on a Likert scale, representing the spectrum of functional limitation a child may have in each domain: (1) No, he/she has no difficulty, (2) Yes, a little difficulty, (3) Yes, lot of difficulty and (4) He/she cannot do it at all.

To standardise interviewees' responses each question included the preamble "Compared with children of the same age"

Service access and quality: This question set includes questions related to parents' perceptions on access to, and quality of, health, education and social services received by their children with or without disabilities.

Parental perceptions of child disability: This question set was posed to those parents who reported that their child had a disability (irrespective of the findings of the Child Functioning Module), in order to estimate their perceptions on the current process of disability assessment, services and support received, and perceived limitations to inclusion.

The full questionnaire is provided in Appendix II of this report.

When designing or adapting questions in the questionnaire, the working group was cautious to ensure that these were:

- appropriate regarding development of the child taking into account his/her age and expected abilities for that age;
- appropriate with respect to culture, posing questions on abilities children are expected to perform in their culture;
- comprehensive and simple with respect to language, being easily understood by the interviewees;
- based on the biopsychosocial model, so that the set of question was in accordance with ICF;

2.2 Sampling

13.000 interviews were conducted nationwide involving at least one child aged between 2-17 years old in both urban and rural areas in 12 regions. The participants were selected through a random recruitment process by “Number of the Electoral Zone”. Each Electoral Zone was considered a stratum (component of the sample), a widespread technique used in market research to achieve even sample distribution. In total, 1.650 strata were randomly electronically selected, and at least eight families were interviewed in each group, based on the size of population in each of the stratum. The random family selection method selected one family in every five houses in urban areas and one in every three houses in rural areas for data collection. At least three attempts were made to conduct an interview at selected households.

The implementation of this study included contacting 22.333 families, of which only 13.000 families were selected for conducting an interview. The main reasons for not qualifying 9.333 families are shown in the table below:

Table 2: Main reasons for not qualifying the contacted families, in percentage (N = 9.333)

Reason	%
Refused to conduct the interview	27
Incomplete interview	6
No person older than 18 years old	8
No children aged between 2-17 years old	53
The person is not a legal guardian	3
Refused to reveal the age of the child	4

The demographic characteristics of the sample made up of 13.000 children at the focus of this study are in compliance with the characteristics of the general population of the children aged 2-17 years old in Albania. This is based on the data of the 2011 Population and Dwelling Census, conducted by INSTAT, which is presented below, ensuring a complete representation of the data on a national scale, with 95% credibility interval and alpha set at 0.05, and sampling error of 0.9%.

Table 3: Demographic data of the population at the focus of the study according to INSTAT

Demographic variables	Level	%
Age group	2-4 yrs	15
	5-9 yrs	27
	10-14 yrs	35
	15-17 yrs	24
Sex	Male	52
	Female	48
Place of residence	Urban/Suburban	50
	Rural	50

2.3 Field work and quality control

Information was collected via home surveys, with authorised proxy interviewees – namely, the child’s parents (mother or father) or other legal guardian. Thus, contacted families would be qualified through the selected sampling method if they had at least one child aged between 2-17 years old. If the family had more than one child belonging to this age group, the family members were asked which child had the closest birthdate, and this child was selected to be interviewed.

Following identification of the child, interviewers determined the parent or legal guardian, who knew the child well and had experience in daily care of the child. At least three attempts were made to conduct an interview at every selected household to reduce the risk of bias. The parent or legal guardian selected to be interviewed was informed on the purpose and duration of the interview, ensuring confidentiality and the possibility of interrupting the interview at any time, if requested. Written consent was taken before each interview commenced.

Table 4: Main demographic characteristics of the interviewees and their relationship with the child at the focus of the interview (N = 13.000)

Demographic variables	Level	N	%
Age group	18-24 yrs	261	2.0
	25-34 yrs	3914	30.1
	35-44 yrs	6051	46.5
	45-54 yrs	2525	19.4
	55-65 yrs	229	1.8
	Over 65 years old	20	0.2
Sex	Male	3170	24.4
	Female	9830	75.6
Relationship with the child	Biological parent	12867	99.0
	Step-parent	50	0.4
	Adoptive parent or legal guardian	28	0.2
	Grandparent	47	0.4
	Other relatives	8	0.0

A complete interview lasted approximately 50 minutes. GfK conducted the onsite work during August-October 2016.

12 regional supervisors and 50 interviewers were trained by GfK to undertake the survey. Training consisted of questionnaire content, sample selection criteria, interview conduct and child protection as per the World Vision Child Protection Policy (CPP). The main aim of the CPP is to ensure a safe environment for children by taking all necessary steps and measures. All GfK field staff also submitted documentation to prove that they were not under investigation or involved in legal proceedings related to child protection.

The role of the team supervisor involved ensuring the development of the interviews in the selected stratum, visually verifying that all forms were properly filled in and other information was completed appropriately.

The quality of all onsite conducted interviews was monitored by the staff of GfK through logical control during and after the onsite work, including:

- Accuracy of selecting the interviewees according to the questionnaire's sections;
- Quality and validity of the collected data;
- Accuracy and frequency of using "special codes" in the responses "I don't know", "hard to say", etc.;
- Percentage of refusal and efforts to contact each interviewee.

60% of the questionnaires underwent logical control via telephone during and after onsite work, and no inconsistency or lack of information was identified. Specific questions were reviewed to ensure there was no missing data. The primary data collected by GfK through this study have been processed and stored according to standards applied by WV with respect to personal data collection and storage.

2.4 Data analysis

All data collected from the questionnaires were inserted by GfK into an Excel sheet. These data were first cleaned and codified and then transferred to statistical software, SPSS 25. The analysis process focused on descriptive statistics, such as frequency and crosstabulations, and then on inferential analysis, such as chi-square, which enabled cross-group comparisons. In order to estimate disability prevalence, data analysis pursued the instructions of Washington Group (Mont, 2006).

2.5 Methodology limitations

The methodology employed in this study indicates similar limitations to those encountered in international studies. Thus, despite the focus of the study on disability prevalence in children and adolescents, the interviews were conducted with their parents or legal guardians, focusing on the opinions of the latter on how they perceive the difficulties faced by their children in daily activities or received services. Other methodologies similar to other countries have shown that parents might overestimate or underestimate the difficulties faced by their children based on their individual expectations or professional assessments by specialists.

III. Findings

3.1 Characteristics of the study sample

This section consists of the demographic characteristics of the children in the research, interviews conducted with parents (mother or father) or legal guardian that had comprehensive knowledge or experience with the selected child aged between 2-17 years old, as well as their relatives' social and economic features.

Interviews were conducted with the parents or legal guardians of 13,000 children, out of which 51.7% (N = 6,725) were males and 48.3% (N = 6,275) were females. In each of the onsite interviews, a series of data were collected on the child and family's characteristics, such as the child's age, sex, place of residence, region, number of children in the family, birth order of child selected for the interview, as well as data on the level of parents' education and employment and the family's average income. Demographic data are presented in the following subsections of the findings chapter emphasising their impact on access to service and care quality for different children groups.

Table 5 below presents basic demographic data for the sample. A detailed table on the social, economic and demographic characteristics of the sample (in figures and percentage) is presented in Appendix I.

Table 5: Demographic data of the sample at the focus of the interviews (N = 13,000)

Demographic variables	Level	N	%
Age group	2-4 yrs	1,891	14.5
	5-9 yrs	3,492	26.9
	10-14 yrs	4,508	34.7
	15-17 yrs	3,109	23.9
Sex	Male	6,725	51.7
	Female	6,275	48.3
Place of residence	Urban	5,383	41.4
	Suburban	1,150	8.8
	Rural	6,467	49.7

The demographic characteristics of the sample made up of 13.000 children at the focus of this study are in compliance with the characteristics of the general population of the children aged between 2-17 years old in Albania, based on the data of the 2011 Population and Dwelling Census, conducted by INSTAT, mentioned above in the methodology chapter.

3.2 Disability prevalence

This section includes the findings of the study related to disability prevalence and distribution in the population of children aged between 2-17 years old in Albania, the difficulty level and areas they face in performing the daily activities, disaggregated by sex, age group, place of residence and geographical location. These data are important to understand and analyse the needs of children with disability and their families with regard to inclusion.

3.2.1 Level of difficulties in functioning

As described above in this report, in compliance with the employed methodology, children with disability in this study would refer to those children who are reported by their parent or legal guardian as experiencing severe difficulty or unable to do it at all activity, despite using an aid/ support item.

Based on the interviews conducted with the parent or legal guardian of the child, 10.4% (N = 1.354) of children aged between 2-17 years old are reported to have at least one type of disability. Moreover, 45.4% (N = 5.898) of the children aged between 2-17 years old involved in the study are reported to have at least one mild difficulty in the functioning areas, as shown in the Figure 1 below.

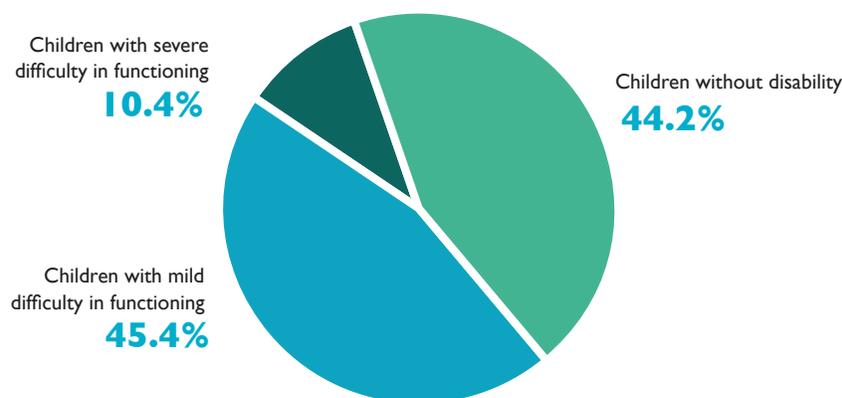


Figure 1: Difficulty severity as reported by parents or legal guardian, regarding the functioning of children aged between 2-17 years old

In this frame, through interviewing 13.000 families nationwide, it is estimated that 1 in 10 children in Albania has a disability and is facing a severe difficulty in at least one functional domain.

3.2.2 Prevalence of disability by functional domain

The study on disability prevalence was based on the biopsychosocial model, assessing the level of difficulty in functioning that children have in 12 developmental domains.

As presented in Table 6 below, the disability prevalence drastically varies among different functioning domains, ranging between 0.3% of children aged between 2-17 years old that are reported to have severe difficulties in hearing, to 6.2% of children aged between 5-17 years old that are reported to have severe difficulties in the emotional and behavioural domains.

Table 6: Disability prevalence by areas of functioning (N = 13.000)

	N	%
At least one disability ****	1,354	10.4
Vision	107	0.8
Hearing	34	0.3
Mobility	278	2.1
Care for oneself *** (Feeding or dressing up by themselves)	298	2.7
Communication (Understanding parents/others)	268	2.1
Communication (Being understood by parents/others)	351	2.7
Learning* (Names of daily objects)	26	2.1
Learning (New concepts)	357	2.7
Memorisation***	314	2.8
Attention*** (Concentration in desired activities)	330	3.0
Facing change *** (Accepting changes in routine)	399	3.6
Playing with others **	31	1.6
Social relationships ***	360	3.2
Emotions*** (Feeling worried or sad)	686	6.2
Behaviour ** (Kicking/biting/hitting others)	103	5.4
Behaviour *** (Controlling their behaviour)	603	5.4

* Posed for children aged between 2-3 years old, n = 1.241; **Posed for children aged between 2-4 years old, n = 1.891; *** Posed for children aged between 5-17 years old, n = 11.109. **** The aggregate calculation of the number and percentage of all rows is higher than the total number and percentage of children with disabilities, due to cases of children reported as having more than one disability.

Additionally, the data collected clearly show that the majority of children with disabilities face difficulties in more than one area of functioning. Thus, 1,354 children with disabilities identified by this study through sampling of 13,000 families, and interviewing of their parents or closest guardian, are reported to have difficulties in cognitive-psycho-social areas, in which at least half of the children face severe difficulties with their behaviour and/or emotions, whereas 1 out of 4 children have severe difficulties in physical development area (vision, hearing and mobility).

3.2.3 Disability prevalence by sex

The data presented in Table 7 show that parents and legal guardians report statistically important differences in the disability prevalence among girls and boys across functional domains. 11.3% of boys were reported by their parents or guardian to have severe difficulties in at least one functional domain, compared to 9.5% of girls. In addition, data show that girls are reported to have fewer difficulties than boys do in the majority of specific functional domains. Statistically significant differences are highlighted blue in the table below².

Table 7: Disability prevalence by functioning areas and sex (N = 13.000)

	Females (N = 6.275)		Males (Nr.=6,725)	
	Nr.	%	Nr.	%
At least one disability ****	595	9.5	759	11.3
Vision	59	0.9	48	0.7
Hearing	14	0.2	20	0.3
Mobility	122	1.9	156	2.3
Care for oneself *** (Feeding or dressing up by themselves)	109	2.0	189	3.3
Communication (Understanding parents/others)	102	1.6	166	2.5
Communication (Being understood by parents/others)	134	2.1	217	3.2
Learning* (Names of daily objects)	14	2.4	12	1.8
Learning (New concepts)	144	2.3	213	3.2
Memorisation***	123	2.3	191	3.3
Attention*** (Concentration in desired activities)	130	2.4	200	3.5
Facing change *** (Accepting changes in routine)	165	3.1	234	4.1
Playing with others **	14	1.6	17	1.7
Social relationships ***	149	2.8	211	3.7
Emotions*** (Feeling worried or sad)	286	5.3	400	7.0
Behaviour ** (Kicking/biting/hitting others)	43	4.8	60	6.1
Behaviour *** (Controlling their behaviour)	229	4.3	374	6.5

* Posed for children aged between 2-3 years old, n = 1.241; ** Posed for children aged between 2-4 years old, n = 1.891; *** Posed for children aged between 5-17 years old, n = 11.109; **** The aggregate calculation of the number and percentage of all rows is higher than the total number and percentage of children with disabilities, due to cases of children reported as having more than one disability.

3.2.4 Disability prevalence by age group

Reporting on disability in different age groups shows a statistically higher prevalence among children aged 5-9 and 10-14 years old, 12.3% and 10.2% respectively as compared to children aged 2-4 and 15-17 years old, where the disability prevalence is reported to be 8.5% and 9.7% respectively.

2. The sky-blue marked rows show statistically significant differences resulting from chi-square test in disability reporting between males and females, $p < 0.05$

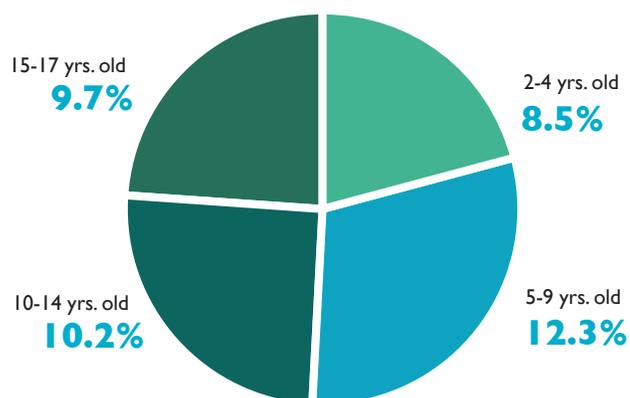


Figure 2: Disability prevalence of by age group (N = 13,000)

Differences in prevalence among different age groups become more evident in specific functional domains. Statistically significant differences by age are noted in most domains, except for “Vision”, “Hearing” and “Emotions”, as shown also in Table 8 below.

Table 8: Disability prevalence by functioning areas and age groups³ (N=13,000)

	Age Group			
	2-4 yrs	5 – 9 yrs	10-14 yrs	15-17 yrs
At least one disability ****	8.5%	12.3%	10.2%	9.7%
Vision	0.6%	0.7%	1.0%	0.9%
Hearing	0.2%	0.3%	0.3%	0.2%
Mobility	0.6%	3.1%	2.1%	2.0%
Care for oneself *** (Feeding or dressing up by themselves)	N/A	3.6%	2.4%	2.1%
Communication (Understanding parents/others)	0.9%	3.0%	2.1%	1.6%
Communication (Being understood by parents/others)	1.7%	4.0%	2.6%	2.1%
Learning* (Names of daily objects)	2.1%	N/A	N/A	N/A
Learning (New concepts)	2.0%	3.7%	2.7%	2.3%
Memorisation***	N/A	3.6%	2.5%	2.5%
Attention*** (Concentration in desired activities)	N/A	3.7%	2.8%	2.4%
Facing change *** (Accepting changes in routine)	N/A	4.2%	3.5%	3.1%
Playing with others **	1.6%	N/A	N/A	N/A

* Posed for children aged between 2-3 years old, n = 1,241; ** Posed for children aged between 2-4 years old, n = 1,891; *** Posed for children aged between 5-17 years old, n = 11,109; **** The aggregate calculation of the number and percentage of all rows is higher than the total number and percentage of children with disabilities, due to cases of children reported as having more than one disability.

3. The sky-blue marked rows show statistically significant differences resulting from chi-square test in disability reporting among different age groups, $p < 0.05$

3.2.5 Disability prevalence by place of residence

Higher disability prevalence is reported in the suburban sample (13.2%) compared to the two other subgroups; urban (10.2%) and rural (10.1%) respectively.

Moreover, the differences in disability prevalence among these groups affect nearly all functioning areas, but having a statistically significant difference in the areas of: “Communication - Being understood by others” and “Emotions”⁴.

Table 9: Disability prevalence by areas of functioning and place of residence (N = 13.000)

	Place of residence		
	Urban (N = 5.383)	Suburban (N = 1.150)	Rural (N = 6.467)
At least one disability ****	551	152	651
Total	10.2%	13.2%	10.1%
Vision	0.9%	0.9%	0.8%
Hearing	0.2%	0.2%	0.3%
Mobility	2.0%	2.2%	2.2%
Care for oneself *** (<i>Feeding or dressing up by themselves</i>)	2.9%	2.5%	2.5%
Communication (<i>Understanding parents/others</i>)	2.4%	1.8%	1.8%
Communication (<i>Being understood by parents/others</i>)	3.2%	2.8%	2.3%
Learning* (<i>Names of daily objects</i>)	2.5%	2.7%	1.7%
Learning (<i>New concepts</i>)	3.1%	2.8%	2.5%
Memorisation***	3.0%	2.9%	2.7%
Attention*** (<i>Concentration in desired activities</i>)	3.2%	2.8%	2.9%
Facing change ***(<i>Accepting changes in routine</i>)	3.7%	3.9%	3.5%
Playing with others **	1.3%	2.2%	1.8%
Social relationships ***	3.6%	3.6%	2.9%
Emotions*** (<i>Feeling worried or sad</i>)	5.4%	7.9%	6.5%
Behaviour ** (<i>Kicking/biting/hitting others</i>)	5.4%	6.5%	5.3%
Behaviour *** (<i>Controlling their behaviour</i>)	5.8%	5.7%	5.1%

* Posed for children aged between 2-3 years old, n = 1.241; ** Posed for children aged between 2-4 years old, n = 1.891; *** Posed for children aged between 5-17 years old, n = 11.109; **** The aggregate calculation of the number and percentage of all rows is higher than the total number and percentage of children with disabilities, due to cases of children reported as having more than one disability.

4. The sky-blue marked rows show statistically significant differences resulting from chi-square test in disability reporting between different places of residence, $p < .05$

3.3 Social and economic characteristics of the families of children with disabilities

As previously described, one of the main objectives in this study is the identification of the demographic and socio-economic characteristics of the families of children with disability. Recognising these characteristics helps in reaching the main objective of this study related to reframing policies that meet the real needs of children with disability with respect to inclusion.

In this frame, this section presents different characteristics of families of children with disabilities, such as level of education and employment rate of parents, monthly family income, as well as the number of members and number of children in the family of the child with disabilities.

3.3.1 Educational level of parents of children with disabilities

About 36% of mothers and 32% of fathers of children with disabilities have basic or lower compulsory education (Table 10). No statistically significant differences were noted related to the education level of parents of children with disabilities compared with parents of children without disabilities.

Table 10: Highest educational level of the mother and father of children with disabilities, in figures and percentage (N = 1.351)

Education	Mother's educational level		Father's educational level	
	N	%	N	%
No basic education	5	0.4	4	0.3
Primary education	10	0.7	7	0.5
Lower secondary education	482	35.7	431	31.9
Upper secondary education	594	44.0	657	48.6
University	222	16.4	196	14.5
Master degree	32	2.4	18	1.3
PhD	3	0.2	1	0.1
Refuse to answer	3	0.2	37	2.7

3.3.2 Employment status of parents of children with disabilities

The data on the employment status of parents of children with disabilities indicate that approximately 58% of mothers and 33% of fathers are unemployed or have part-time/seasonal jobs.

Table 11: Employment status of the mother and father of children with disabilities, in figures and percentage (N = 1.351)

Employment	Employment status of the mother		Employment status of the father	
	N	%	N	%
Full-time	427	31.6	626	46.3
Part-time	88	6.5	169	12.5
Full-time student	1	0.1	0	0.0
Unemployed (e.g. stay-at-home mother/father)	469	34.7	42	3.1
Unemployed, but seeking for a job	176	13.0	120	8.9
Self-employed	149	11.0	275	20.4
Retired	3	0.2	2	0.1
Seasonal job	34	2.5	67	5.0
Other	4	0.3	30	2.2
Refuse to answer	0	0.0	20	1.5

There are no statistically significant differences resulting from chi-square test regarding the employment level between the parents of children with disabilities or without disabilities.

3.3.3 Monthly income of families of children with disabilities

Average monthly income of the family, including wages, rents, bank interests, and others, etc., of all family members, was categorised as low, medium or high. 66% of children with disabilities live in families with low income, (less than ALL 40,000 Lek per month), 30% live in families with medium monthly income (40,001 - 80,000 Lek per month) and the remainder live in families with high monthly income.

Based on the data in Table 12 and compared to the reporting about the monthly average income with the other part of the sample, some statistically significant differences between families of children with disabilities and families without children with disabilities, who have higher monthly incomes, are given below. These data show a correlation between the monthly income and reporting of at least a disability by the interviewed families.

Table 12: Average monthly income of families of children with disabilities and of children without disabilities, in figures and percentage (N = 13,000)

		Income of families of children with disabilities (N = 1.354)		Income of families of children without disabilities (N = 11.646)	
		N	%	N	%
Low income	Less than ALL 20,000	285	21.0	1.777	15.3
	ALL 20,001– 30,000	328	24.2	2.095	18.0
	ALL 30,001– 40,000	282	20.8	2.252	19.3
Medium income	ALL 40,001– 50,000	191	14.1	1.862	16.0
	ALL 50,001–60,000	110	8.1	1.207	10.4
	ALL 60,001-70,000	62	4.6	818	7.0
	ALL 70,001– 80,000	40	3.0	645	5.5
High income	ALL 80,001– 90,000	23	1.7	430	3.7
	ALL 90,001– 100,000	18	1.3	303	2.6
	ALL 100,001-120,000	10	0.7	160	1.4
	ALL 120,001-140,000	3	0.2	60	0.5
	More than 140,000 ALL	2	0.1	37	0.3

3.3.4 Number of members and children in families of the children with disabilities

During the survey, important demographic data were gathered on the number of family members, number of children under 18 that live with the family, and the family composition. The majority of families with a child with a disability (N = 1.067, 78.8%) have four to six members. In almost half of the cases (N = 662, 48.9%), the families have 2 children under 18, whilst one in four families (N = 265, 19.6%) has three or more children under 18.

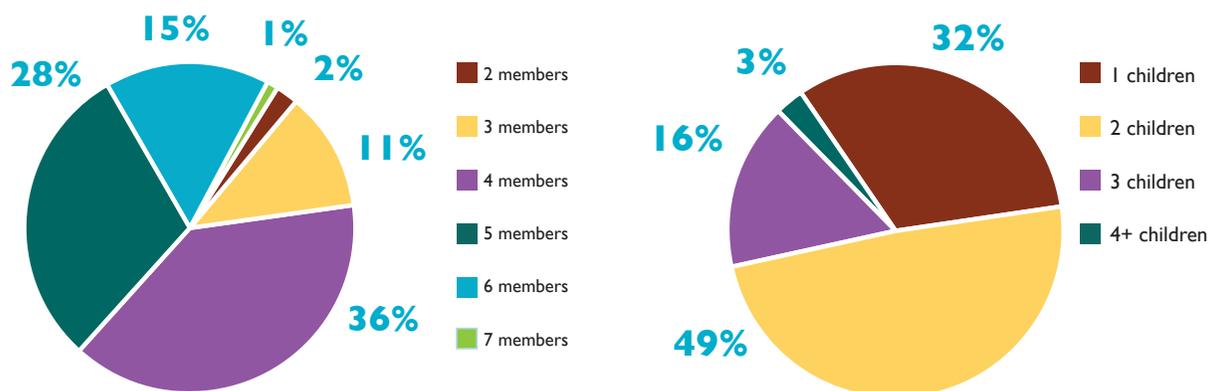


Figure 3: The number of members and children in the families of children with disabilities, in percentage (N = 1.354)

98.3% of children with disabilities live with at least one of their biological parents, and only 1.7% of the identified cases live with adoptive parents, grandparents, or with other family members.

3.4 Perceptions on health services accessibility and quality

In order to evaluate access to and quality of health services, interviewees were asked about public, general (consultations, paediatricians and/or general practitioner/nurse) and specialised health services, and about their perceptions on the quality of these services.

Despite the fact that the findings of this section and of the two previous sections focus on access and quality of the services provided to the children with disabilities, as identified by this study, parents and legal guardians have stated that in many cases, the findings are reported as a comparison between children with disabilities and children with slight or no disabilities altogether. This comparison helps us in identifying the potential inequalities with which children with disabilities face when requesting health, education, and social services in their communities.

The results in this section are presented both for children with disabilities and for children with mild difficulties in functioning.

A. General health service

3.4.1 Receiving general health service

General and specialised health services in Albania are provided for free to all children up to 18 years old. The 13,000 interviews carried out for this study show that the use of these health services for children with and without disability is below 92.4% (N = 12,006), with no statistically significant differences between the use by children with disabilities (92.9%) and by children without disabilities (92.3%). Table 13 reports the number and percent of children with and without disabilities who have previously used general health services, disaggregated by age group, sex and place of residence.

Table 13: Level of attendance of general health services, by presence of disability and demographic variables (N = 13,000)

		Children without disabilities	Children with disabilities
N.		N = 11,646	N = 1,354
Total		92.3%	92.9%
Age Group	2-4 yrs	95.3%	94.4%
	5-9 yrs	93.6%	94.2%
	10-14 yrs	91.5%	91.8%
	15-17 yrs	90.2%	92.1%
	Sex		
Male		91.8%	93.3%
Female		92.8%	92.4%
Place of Residence	Urban	89.9%	91.7%
	Suburban	90.3%	94.1%
	Rural	94.6%	93.7%

3.4.2 Frequency of using general health services

Even though reported frequency of using general health services use between children with and without disabilities is low, parents and legal guardians report that children with disabilities use this service more frequently than other children do. Therefore, 33.6% of children with disabilities regularly use such services, at least once in four months compared to 12.9% of children without disabilities. Moreover, whereas 74.2% of children without disabilities do not regularly use health service, but only in perceived health needs or in urgent cases, only 50.5% of children with disabilities require such service at a more frequent basis (Table 14).

Table 14: Frequency of using general health services, by presence of disability, in figures and percentage (N = 12.006)

	Children without disabilities		Children with disabilities	
	N	%	N	%
Weekly	27	0.3	7	0.6
Monthly	314	2.9	135	10.7
Three or four times a year	1.043	9.7	281	22.3
Once or twice a year	1.388	12.9	200	15.9
Only when ill	7.976	74.2	635	50.5
Total	10.748	100	1.258	100

3.4.3 Accessibility and quality of the general health services

Interviewees were asked to rate their satisfaction about their interaction with health services on a Likert scale from “Not at all satisfied” to “Very satisfied”, across five different metrics: the respect shown by the medical staff; the doctor’s recommendations regarding specialised or further treatment; the distance to the service provider; expenses incurred (including treatment, medication or transport expenses); and the infrastructural conditions of the facility.

Regardless of the fact that the average rating of the five given indicators of the sample included in the study is relatively low, the results show statistically significant differences in all indicators, on the assessment of the accessibility and quality of the services provided to children with disabilities and to other children.⁵ (Table 15). The three most negatively rated indicators, which also emphasise the huge difference in the assessment of the services between the parents of the two groups of children, are the ones related to the accessibility of the services.

Over one in three (38.6%) parents of children with disabilities identified in this study are not satisfied, or not at all satisfied, with the expenses they incurred to access services, compared with 17.7% of parents of children without disabilities. Similarly, 29% and 20.2% of parents of children with disabilities are dissatisfied or not at all satisfied with the infrastructure of the facility where the service is provided and with the distance from the facility, compared with 19.1% and 7.3% of parents of children without disabilities respectively.

5. Statistically significant differences resulting from chi-square test in assessing the accessibility and quality of the general health services, by presence of disability, $p < ,05$

Table 15: Assessment of the accessibility and quality of general health services, by presence of disability, in figures and percentage (N = 12.006)

		Children without disabilities (N = 10.710)		Children with disabilities (N = 1.296)	
		n	%	n	%
Respect shown by the medical staff	Not at all satisfied	99	0.9	23	1.8
	Dissatisfied	335	3.1	103	8.2
	Neutral	1.450	13.5	263	21.0
	Satisfied	6.578	61.3	646	51.6
	Very satisfied	2.271	21.2	217	17.3
Doctor's recommendations to specialised or further treatment	Not at all satisfied	86	0.8	33	2.7
	Dissatisfied	416	4.0	115	9.3
	Neutral	2.027	19.3	323	26.2
	Satisfied	6.121	58.3	583	47.4
	Very satisfied	1.853	17.6	177	14.4
Distance from the facilities	Not at all satisfied	158	1.5	75	6.0
	Dissatisfied	625	5.8	179	14.3
	Neutral	2.245	20.9	309	24.6
	Satisfied	5.432	50.6	496	39.5
	Very satisfied	2.276	21.2	196	15.6
Overall expenses (including treatment and transport expenses)	Not at all satisfied	383	3.6	133	10.6
	Dissatisfied	1.507	14.1	350	28.0
	Neutral	3.432	32.1	391	31.2
	Satisfied	4.266	39.9	317	25.3
	Very satisfied	1.111	10.4	61	4.9
Infrastructural conditions of the facility	Not at all satisfied	459	4.3	105	8.4
	Dissatisfied	1.582	14.8	257	20.6
	Neutral	3.594	33.6	425	34.0
	Satisfied	4.159	38.9	389	31.1
	Very satisfied	893	8.4	74	5.9

3.4.4 Reasons for not using general health services

As shown in Table 16, the reasons parents of children with disabilities listed for not using services are: poor quality services (47.9%); financial cost (27.1%); lack of the service in their community and lack of transport (19.8% and 11.5%); and the lack of information on provided public services (15.6%)⁶.

The main reasons for parents and legal guardians of children without disabilities are reported to be the poor quality services and lack of information on their provision (70.4% and 16.1% respectively).

6. The sky-blue marked rows represent statistically significant differences resulting from chi-square test in reporting the reasons for not using the general health service, by presence of disability, $p < .05$

Table 16: Reasons for not using the general health services by presence of disability, in figures and percentage (N = 994).

	Children without disabilities (N = 898)		Children with disabilities (N = 96)	
	N	%	N	%
Provided services quality was poor	632	70.4	46	47.9
I cannot afford to pay the service	70	7.8	26	27.1
Service is not provided in this community	59	6.6	19	19.8
I was not informed of such public service	145	16.1	15	15.6
It's too far away from our place of residence	35	3.9	11	11.5
The attitude towards us and the children was inappropriate or discriminatory	26	2.9	2	2.1
The child was denied this service	3	0.3	1	1.0

The previous table shows the indicators that present statistically significant differences between the two groups. The parents or legal guardians of children without disabilities rate the quality of the provided services more negatively than the parents or legal guardians of the children with disabilities. However, they rate more positively the other three indicators related to access to the service, such as distance, lack of transport and not being able to afford the financial costs.

B. Specialised health services

3.4.5 Using specialised health services

Unlike the situation associated with the use of the general health services, the findings regarding the use of specialised health services by children are very few, thus showing great differences between children with and without disabilities. 41.8% of children with disabilities and only 9.8% of children without disabilities have been evaluated by at least one specialised professional, such as: logopedist, child psychologist, social worker, child psychiatrist, physiotherapist, ENT doctor, ophthalmologist, neurologist, etc. This statistically significant difference regarding the use of specialised health services by the two groups of children is reflected in all of the subdivisions of the main demographic characteristics of the sample included in the study (Table 17).

Table 17: Frequency of using specialised health services, by presence of disability and demographic variables

		Children without disabilities (N = 11.646)	Children with disabilities (N = 1.354)
Total		9.8%	41.8%
Age Group	2-4 yrs	9.7%	32.3%
	5-9 yrs	11.9%	45.1%
	10-14 yrs	9.0%	43.6%
	15-17 yrs	8.7%	39.4%
Sex	Male	9.1%	43.3%
	Female	10.5%	39.8%
Place of Residence	Urban	10.7%	45.7%
	Suburban	8.7%	34.2%
	Rural	9.2%	40.2%

3.4.6 Referral/Source of information in accessing specialised health services

When asked about the main referral mechanisms or source of information in accessing specialised health services, interviewees predominantly reported making the decision themselves (42.2%), referrals from general practitioners/paediatricians (58.3%) and specialised doctors (28.1%). Only in 5.5% of cases, the recommendation for taking the child to a specialised doctor has been suggested by a teacher of the child.

Table 18: Recommendation sources to specialised health services amongst children with disabilities, in figures and percentage (N=1.137)⁷.

I, Myself	A kindergarten /school teacher	Family physician, paediatrician	Medical specialists (for e.g. ENT physician, ophthalmologist, neurologists, etc.)	A school or clinic psychologist	Social worker	Family members/ friends
239	31	330	159	27	14	56
42.2%	5.5%	58.3%	28.1%	4.8%	2.5%	9.9%

3.4.7 Assessment of the specialised health services

In order to assess specialised health services provided to children in the last year, interviewees were asked how satisfied they were with the quality of the received service. Moreover, they were asked whether the costs for directly or indirectly receiving these services were affordable, such as transport, accommodation and medication costs.

Parents were statistically more likely to negatively assess services provided to them by specialised doctors than services provided by general physicians or paediatricians. Hence, 1 in 4 parents of children with disabilities (25.4%) expressed they were not satisfied or not at all satisfied with the specialised health service provided to them, compared with 15.9% of parents with children without disabilities.

Table 19: Assessment of the quality of the specialised health service, by presence of disability, in figures and percentage (N = 1.694)

Satisfaction for received service	Children without disabilities (N = 1.132)		Children with disabilities (N = 562)	
	N	%	N	%
Not at all satisfied	46	4.1	32	5.7
Dissatisfied	134	11.8	111	19.8
Neutral	253	22.3	155	27.6
Satisfied	645	57.0	232	41.3
Very satisfied	54	4.8	32	5.7

Regarding the general expenses of the services provided, the interviewees were requested to rate on a four-level scale, from “Not at all affordable” to “Very affordable”. Table 20 shows that parents rate the general costs for receiving specialised health services as very high, thus reporting statistically significant differences between the two groups. 60.3% of parents of children with disabilities report that the expenses for receiving specialised services are unaffordable or not at all affordable, compared with 29.2% of parents of children without disabilities.

7. In this question, interviewees have selected one to three response alternatives.

Table 20: Assessment of overall costs for specialised health services, by presence of disability, in figures and percentage (N = 1.675)

Overall expenses (including treatment, medication and transport expenses)	Children without disabilities (N = 1.115)		Children with disabilities (N = 560)	
	n	%	n	%
Not at all affordable	48	4.3	96	17.1
Unaffordable	278	24.9	242	43.2
Affordable	644	57.8	182	32.5
Very affordable	145	13.0	40	7.1

3.4.8 Reasons for not using specialised health services

During the interview, interviewees were asked whether the interviewed child was referred to receive counselling over the last year in specialised health services and whether they had been provided with this service or not.

As shown in Table 21, the main reasons provided by parents of children with or without disabilities⁸ are: not being able to afford the financial costs for receiving the service (56.5%); lack of transport and lack of the service provision in the community (36.2% and 28.3%); and poor quality of services (29%).

Table 21: Reasons for not using specialised health services, in figures and percentage (N = 138)⁹.

Reasons for not using specialised health services							
Service is not provided in this community	The child was denied this service	I cannot afford to pay the service	I was not informed of such public service	Behaviour towards the child was inappropriate, or discriminatory	Provided services quality was poor	It's too far away from our place of residence	My child does not need specialised services
39	4	78	8	5	40	50	12
28.3%	2.9%	56.5%	5.8%	3.6%	29.0%	36.2%	8.7%

8. Due to the small number of responses for this question (N = 138), the results of this subsection are not given disaggregated for children with or without disabilities.

9. The interviewees have chosen one to three response alternatives for this question.

3.5 Perceptions on pre-university educational institutions' accessibility and quality

In order to assess the access and quality of services in pre-university educational institutions, interviewees were asked about educational institutions (either public or non-public) attendance and non-attendance, type of educational institution, assess the quality and access to these institutions, as well as the reasons for non-attendance.

3.5.1 Educational institutions attendance

Parents participating in this study, when asked about educational institutions attendance by their children aged 2-17 years old, reported statistically significant differences regarding nursery, kindergarten, or school attendance between children with and without disabilities. Data indicate that nursery, kindergarten, or school are attended by 93.1% of children without disabilities, compared with 75.7% of children with disabilities (Figure 4).

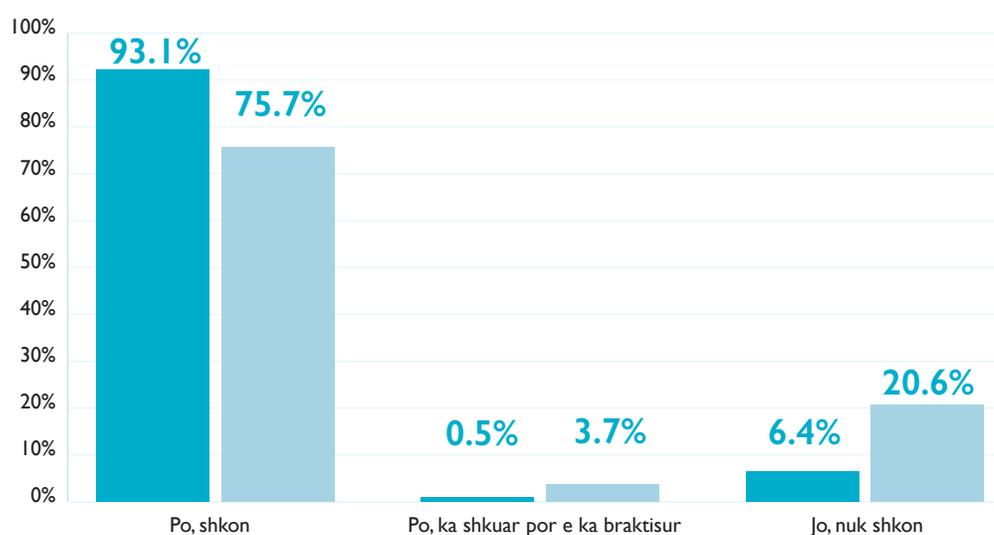


Figure 4: Educational institutions attendance level by presence of disability, in percentage

Since compulsory education in Albania begins foreseen at the age of five, it is important to analyse the school attendance level for each age group in particular. Data on Table 22 indicate that although attendance level is lower for both groups of children aged 2-4 years old, it is still reported that educational institutions attendance level of children without disabilities is still higher for each analysed age group. Children with disabilities are statistically less likely to attend school than children without disabilities in each sub age-group, by sex, and in each type of residence.¹⁰

10. Sky-blue marked rows indicate statistically significant differences resulting from chi-square test in educational institutions attendance level reporting by presence of disability, $p < .05$

Table 22: Educational institutions attendance level by presence of disability and demographic variables, in percentage (No = 13.000)

		Children without disabilities	Children with disabilities
N		11.646	1.354
Total		93.1%	75.7%
Age Group	2-4 yrs	63.3%	45.3%
	5-9 yrs	98.2%	80.5%
	10-14 yrs	99.5%	84.6%
	15-17 yrs	97.4%	71.5%
Sex	Male	93.1%	73.6%
	Female	93.2%	78.3%
Place of Residence	Urban	94.6%	76.0%
	Suburban	92.5%	82.2%
	Rural	92.0%	73.9%

When parents of children with disabilities were asked about the type of educational institution their children attended, they reported that 94.3% of children attend nursery, kindergarten, or school; 4.4% attend special educational institutions; and 1.3% attend vocational schools (Figure 5).

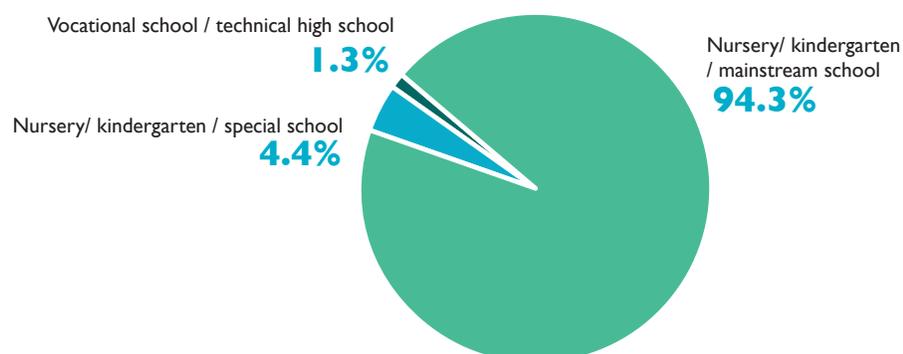


Figure 5: The type of educational institutional attended by children with disabilities in percentage (N = 1.025)

3.5.2 Educational institutions' accessibility and quality

In order to assess the perceptions of the parents and legal guardians of the children on the accessibility and quality of the general education services used by children, the interviewees were asked to rate them into a five-level scale, from "Not at all satisfied" to "Very satisfied" with respect to six indicators: Respect shown by educational staff; Level of teaching adaptation to child's needs and development; Distance to nursery/kindergarten/school; Child's overall progress in nursery/kindergarten/school; Overall expenses (including transport services) and infrastructural conditions of the facility.

Similar to results of quality and accessibility assessment of health institutions, statistically significant differences were also identified in interviewees' perceptions of accessibility and quality of access to educational institutions between children with and without disabilities (Table 23)¹¹.

11. Statistically significant differences resulting from chi-square test in accessibility and quality assessment of educational institutions by presence of disability, $p < .05$

More than one in three (36.5%) parents of children with disabilities are dissatisfied or not at all satisfied with the expenses they have to make to enable their children's school attendance, as opposed to 19.6% of parents of children without disabilities. Similarly, 26.2% and 14.6% of children with disabilities' parents are dissatisfied or not at all satisfied with the infrastructural conditions of educational institution facilities and commute distance compared with 17.3% and 3.5% of parents of children without disabilities respectively. In addition, parents of children with disabilities are dissatisfied or not at all satisfied with the child's progress in education (19.4%), level of teaching adaptation with the child's needs and development (13.3%) and respect shown by the educational staff (6.3%).

Table 23: Assessment of educational institution accessibility and quality by presence of disability, in figures and percentage.

		Children without disabilities		Children with disabilities	
		N	%	N	%
Respect shown by educational staff	Not at all satisfied	56	0.5	12	1.2
	Dissatisfied	247	2.3	52	5.1
	Neutral	1.162	10.7	164	16.1
	Satisfied	6.739	62.3	567	55.5
	Very satisfied	2.613	24.2	226	22.1
Level of teaching adaptation to child's needs and development	Not at all satisfied	58	0.5	26	2.6
	Dissatisfied	317	2.9	109	10.7
	Neutral	1.661	15.4	240	23.6
	Satisfied	6.558	60.8	497	48.8
	Very satisfied	2.196	20.4	146	14.3
Distance to nursery/ kindergarten/ school	Not at all satisfied	160	1.5	44	4.3
	Dissatisfied	590	5.5	106	10.4
	Neutral	1.823	16.8	234	22.9
	Satisfied	5.747	53.1	449	43.8
	Very satisfied	2.499	23.1	191	18.7
Child's overall progress in nursery/ kindergarten/ school	Not at all satisfied	74	0.7	44	4.4
	Dissatisfied	362	3.4	152	15.0
	Neutral	1.946	18.0	260	25.7
	Satisfied	5.819	53.9	404	40.0
	Very satisfied	2.589	24.0	150	14.9
Total expenses for school attendance	Not at all satisfied	447	4.1	89	8.7
	Dissatisfied	1.670	15.4	284	27.8
	Neutral	3.511	32.5	334	32.7
	Satisfied	4.123	38.1	263	25.7
	Very satisfied	1,068	9.9	52	5.1
Infrastructural conditions at nursery/ kindergarten/ school	Not at all satisfied	432	4.0	90	8.8
	Dissatisfied	1.441	13.3	177	17.4
	Neutral	3.227	29.8	315	30.9
	Satisfied	4.352	40.2	369	36.2
	Very satisfied	1.371	12.7	69	6.8

3.5.3 Reasons for educational institution non-attendance

Table 24 shows the main reasons for non-attendance reported by parents or legal guardians of children with or without disabilities¹². These are: not being able to afford the financial costs for receiving the service (29%); parental perception that the child with disability cannot adapt (17.8%); and also the appropriate quality of services (16.8%). Although lower in percentage, it is important to highlight the cases of children who had dropped out of school due to discriminatory behaviours (12.1%), or service denial (6.5%).

Table 24: Reasons for educational institutions non-attendance, in figures and percentage (N = 107)¹³

I cannot afford to pay for the service	The child encountered adaptation difficulties	Provided services quality has been poor	Behaviour towards the child has been inappropriate, or discriminatory	It's too far away from our place of residence	Kindergarten/school lacks appropriate conditions	I think there is no need to attend school/ kindergarten	The child was denied this service
31	19	18	13	11	10	10	7
29.0%	17.8%	16.8%	12.1%	10.3%	9.3%	9.3%	6.5%

3.6 Perceptions on social services' accessibility and quality

3.6.1 Social Services Access

Social services include, but are not limited to specialised centres, day-care centres, mental health centres and social care residential centres. Only 110 children (0.8% of the overall sample) had received a public or non-public social service during the previous 12 months, whilst a further 45 children (0.3% of the overall sample) had not received the service in the past twelve months but had previously received the service before.

Compared with the overall estimate, 7.8% (N = 106) of children with disabilities had received a specialised social service during the last 12 months. The majority of these children (80.2%) had used services from a specialised centre, 13.2% from a community centre, and 6.6% from a residential centre (Figure 6).

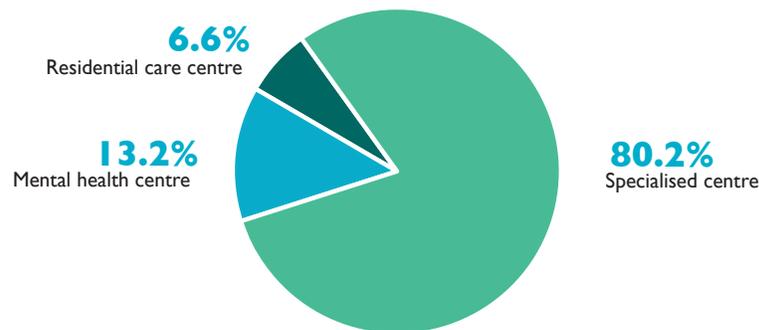


Figure 6: The type of social service received by children with disability, in figures and percentage (N = 106)

12. Due to the small number of responses for this question (N = 107), the results of this subsection are not given disaggregated for children with or without disabilities.

13. In this question, interviewees have selected one up to three response alternatives.

3.6.2 Referral/ Source of information in accessing social services

When asked about the main referral mechanisms or source of information in accessing social service, interviewees reported that they are mostly referred by family physicians/paediatrician (49.7%), decided themselves (40.0%) or referred by medical specialists (34.2%). Only a small percentage of recommendations were made by the child's school teachers or educators, psychologists, or social workers.

Table 25: Reasons for educational institutions non-attendance, in figures and percentage (N = 155)¹⁴

I, Myself	A kindergarten/ school teacher	Family physician, paediatrician	Medical specialists (for e.g. ENT physician, ophthalmologist, neurologists, etc.)	A school or clinic psychologist	Social worker	Family members/ friends
62	14	77	53	20	11	25
40.0%	9.0%	49.7%	34.2%	12.9%	7.1%	16.1%

3.6.3 Social Services Assessment

In order to assess social services received by children over the last year, parents and legal guardians were asked about their level of satisfaction with the quality of the received service, and the affordability of costs related directly or indirectly by frequenting of these services.

According to the summarised data (Table 26), parents' assessment of the received service was generally positive, as approximately half (49.4%) were satisfied with the service provided to their child with or without a disability.

Table 26: Assessment of specialised health service quality, in figures and percentage (N = 154).

Satisfaction for received service	N	%
Not at all satisfied	11	7.1
Dissatisfied	28	18.2
Neutral	39	25.3
Satisfied	66	42.9
Very satisfied	10	6.5

Table 27 indicates that parents considered the total cost of social services high, with 55.0% stating that the necessary expenses for service provision were unaffordable or not at all affordable.

Table 27: Social services overall cost assessment, in figures and percentage (N = 151).

Overall expenses (including Treatment, medications and transport expenses)	N	%
Not at all affordable	34	22.5
Unaffordable	49	32.5
Affordable	54	35.8
Very affordable	14	9.3

14. In this question, interviewees have selected one to three response alternatives.

3.6.4 Reasons for non-frequenting of social services

Table 28 reports the main reported reasons for the child's social services non access. These include: service frequency non-affordable (88.9%); lack of transport and community-based services (20.0% and 8.9%); service denial (11.1%) and poor service quality (8.9%).¹⁵

Table 28: Reasons for non-frequenting of previously used social services, in figures and percentage (N = 45)

Service is not provided in this community	The child was denied this service	I cannot afford to pay the service	Behaviour towards the child was inappropriate, or discriminatory	Provided services quality was poor	It's too far away from our place of residence
4	5	40	2	4	9
8.9%	11.1%	88.9%	4.4%	8.9%	20.0%

3.7 Disability and support services assessment system

This section summarises the findings of the study related to disability assessment, financial assistance, and other support services provided to children with disabilities, as well as parents' perception related to the services.

3.7.1 Disability assessment system

Interviewees were directly asked whether they considered their child to have a disability, following assessment by a Medical or Multidisciplinary Assessment Commission. Although 1,354 children (10.4% of the sample) experienced a disability according to the Child Functioning Module, only 563 children (4.3% of the sample) were reported to have been assessed by an official commission and of these, 514 (4.0%) had fulfilled the disability assessment medical criteria.

When asked about the medical commission's assessment process, 21.8% of parents of children with disability rated the assessment process, waiting period, the manner of their involvement in the process, the communication approach from the assessment team, and the designation of upcoming meetings, medical record etc., as "Dissatisfactory" or "Not at all satisfactory" (Table 29).

Table 29: Perceptions of parents of children with disability on the assessment process (N = 511)

Assessment Process	N	%
Not at all satisfied	35	6.8
Dissatisfied	77	15.0
Neutral	147	28.6
Satisfied	233	45.3
Very satisfied	19	3.7
Refuse to answer/don't know	3	0.6

15. In this question, interviewees have selected one to three response alternatives.

3.7.2 Assessment of financial support for children with disabilities

Financial support is not provided to all children determined by the Medical Commission in Albania to have a disability.¹⁶ When asked about the benefit of disability financial support, parents or legal guardians reported that 474 out of 514 children, who were assessed to have a disability, benefited from such support.

When asked about their perceptions on the financial support sufficiency with respect to fulfilment of basic living needs, 86.9% of parents estimated the payment as insufficient, or not at all sufficient (Table 30).

Table 30: Perceptions of parents of children with disability on disability financial support (N = 374)

Financial support	N	%
Not at all sufficient	158	42.2
Insufficient	167	44.7
Neutral	36	9.6
Sufficient	12	3.2
Very sufficient	0	0.0
Refuse to answer	1	0.3

3.7.3 Assessment of public institutions' support

When asked about type of support received from public institutions, 412 parents reported receiving some type of support, although beyond financial there are only few alternative services listed in few cases. Thus, only 13.6% of the parents of children with disability qualified by the medical commission reported to receive home care by a medical specialist, whereas other types of support such as specialised medical or educational support, and rehabilitation or psychosocial support are reported to be used by less than 4% of children with disability.

Table 31: Types of support provided to children with disability by public services (N = 649)¹⁷

	N	%
Financial support	412	63.5
Family care	56	13.6
Specialised educational service	14	3.4
Psychosocial support services	14	3.4
Specialised health service	13	3.2
Short-term accommodation in day-care centres	13	3.2
Rehabilitation service	11	2.7
Food	7	1.7
Auxiliary medical equipment	3	0.7
Home visits by an expert	2	0.5
Other; specify	1	0.2

16. Assessment by the Medical Commission and the benefit of financial support is the only officially collected and reported statistical figure by state institutions.

17. In this question, the interviewees selected one among many response alternatives.

When asked about their assessment regarding the types of support provided by public institutions, 71.4% of parents of children with disability estimated that the quality of such services was poor, 20.1% believed these to be average, and only 7.0% perceived them as good (Table 23).

Table 32: Perceptions of parents of children with disability on the public services support quality (N = 406)

	N	%
Poor	294	71.4
Average	83	20.1
Good	29	7.0
Excellent	0	0.0
I don't know / Refuse to answer	6	1.5

3.7.4 Need for support services

In order to identify the need for specialised support services, parents of children determined to have a disability by the Medical Commission were asked about the most important services they would like to be provided with in their community, municipality, or city. Financial support (37.6%); specialised rehabilitation (28.0%), health (27.6%), and educational (24.7%) services; home visits by an expert (11.6%); and specialised transport (9.7%) were reported.

Table 33: Assessment of the need for support services for children with disability (N = 649)¹⁸

	N	%
Financial support	244	37.6
Rehabilitation service	182	28.0
Specialised health service	179	27.6
Specialised educational service	160	24.7
Home visits by an expert	75	11.6
Specialised transport	63	9.7
Family and child counselling services	56	8.6
Kindergartens/schools	54	8.3
Family care	50	7.7
Short-term accommodation in day-care centres	48	7.4
Auxiliary medical equipment	45	6.9
Food	40	6.2
Information	36	5.5

18. In this question, the interviewees selected one among many response alternatives.

3.8 Discrimination of children with disability

Interviewees whose children had been determined to have a disability by the Medical Association reported on the frequency that their child had faced discrimination and social exclusion in four different settings: in the community, educational institutions, while playing with peers, and at other public services the child received.

The data indicate that 1 in 2 children in this group experience some level of discrimination in the community (52.9%), in educational institutions (52.4%) and while playing with peers (54.9%), whilst 1 in 3 experience discrimination in other public institutions, as well as health or social institutions (Table 34).

Table 34: Discrimination level on children with disability according to parents' perceptions, in figures and percentage (N = 649)

		N	%
In community	Never	295	45.5
	Rarely	208	32.0
	Often	114	17.6
	Constantly	21	3.2
	I don't know / Refuse to answer	11	1.7
In nursery/kindergarten/ school	Never	252	38.8
	Rarely	205	31.6
	Often	99	15.3
	Constantly	36	5.5
	I don't know / Refuse to answer	57	8.8
While playing with peers	Never	275	42.4
	Rarely	201	31.0
	Often	101	15.6
	Constantly	54	8.3
	I don't know / Refuse to answer	18	2.8
In other public services	Never	391	60.2
	Rarely	150	23.1
	Often	43	6.6
	Constantly	25	3.9
	I don't know / Refuse to answer	40	6.2

IV. Conclusions

The present study marks the first national study on disability prevalence in children and youth in Albania.

The study's definition, conception, methodology, instruments, and the selected approach are in full compliance with the UNCRPD. As such, its data should be considered a reference point for future studies to be carried out in this field.

Previously, the enhancement of services for children with disabilities has been significantly hindered due to a lack of thorough, reliable data on current access and quality of services. Therefore, the results of this study may be used by all actors to facilitate the planning and enhancement of services for children at risk of developing a disability and for children with disabilities.

This study aimed to assess the prevalence and type of child disability in the country; the social, economic, and demographic profile of families of children with disabilities compared to families of children without disabilities; and primary care givers' perceptions on the availability and quality of services to support children with and without disabilities and their families.

The prevalence of child disability in Albania (defined by the caregiver reporting any functional domain reported to have "a lot of difficulty" or "cannot do") amongst children aged 2-17 years old is 10.4%, or one in ten. This figure is considerably higher than previously collected data considering that 6% of the total prevalence of 10.4% is related to emotional functioning, which was not included in prior tools administered in Albania. In addition, study data suggest that over half of children (55.8%) display at least "some" level of difficulty in one of the 12 involved functional domains. However, only 10.4% of children participating in the study display a severe difficulty (face severe difficulties, or cannot perform it at all an activity), whereas 45.5% display a mild difficulty (a few difficulties in performing an activity). Data from different studies indicate that low or average income countries report prevalence from 0.4% to 12.7%, depending on assessment means used in the study (WHO, 2011). Meanwhile, the World Report on disability globally estimates that prevalence in children with moderate and severe disabilities is at 5.1%. However, a latest UNICEF study conducted in 20 different countries of the world indicated that prevalence of disability in such countries varies from 14% to 35%.

4% of children in the sample have access to a disability record granted by the medical commission. The majority of children in the study display difficulties mainly in the social emotional area. The prevalence is higher in low-income families (66%), age groups 5-9 and 10-14 years old, boys, and in suburban areas.

According to parents' perceptions, services facilitating the identification, assessment, support and treatment of children with disability in this study were generally inaccessible, unstructured, fragmented, uncoordinated, and non-holistic, thus failing to provide effective and stable support and solutions. Although services for children with disability do exist, they are neither community-based nor holistic. Access to such services remains low, mainly due to non-affordability, the need for transport and a perception that such services are of poor quality and low reliability. The range and types of health, social, and educational services are quite limited.

Although the reported number of children with disabilities attending a preuniversity education institution is relatively high (75.7%), it is still substantially lower compared to children without disabilities (93.1%). Such difference is further highlighted when considering the fact that only 61.3% (N = 315) of children having been assessed by the medical or multidisciplinary commission regarding their disability (N = 514) attend education at a pre-university educational institution.

Educational service access is hampered by unaffordable costs, transport cost and availability, low academic progress, the school's ability to adapt to the child's needs and development, and the respect shown by the educational staff. In addition, the study identified a large proportion of children in Albania with mild difficulties in functioning (not classified as disability) who may also be at risk of isolation and exclusion from education.

Only 7.8% of children with disabilities accessed support from social services. According to parents' perceptions, the majority of these services are inaccessible, due to their cost and their distant location from residential centres. In addition, financial assistance does not fulfil the demands and needs of most families of children with disabilities. A large number of families, which declare that their child has a disability, do not benefit financial assistance. Although a series of services are provided predominantly in the capital, costs for such quality multidisciplinary services are unaffordable, particularly for low and average income families.

Due to poor service quality, lack of specialists and specialised services at the local level, and inappropriate infrastructure, medical services are received mainly by those children with a medical certificate. However, to the majority of parents, the primary health service is the main service system, through which families identify the very first difficulties of their children that are then reported and referred to other services. Furthermore, specialised services and quality multidisciplinary services are not refunded by the aid scheme, by making access to such services unaffordable, particularly for low and average income families, as well as for those living in rural areas.

The study indicates that despite anti-discrimination legislation, the level of discrimination experienced by children with disabilities in their schools, by their peers and in their communities is of concern. It seems that discrimination is another factor influencing largely their isolation. Prejudice and discrimination directed towards children and youth with disability remain factors influencing significantly directly these children's and their families' social and community life exclusion and isolation.

V. Recommendations

On the necessity to collect reliable data and conduct studies in compliance with CRC

- The study marks a new era of conducting studies in measuring child disability prevalence. It is necessary that the instruments and selected data collection methodology is accurate, transparent, and in compliance with the definition of disability stated in the UNCRPD.
- Based on the experience gained by the means of this study, it is necessary to periodically conduct similar studies in compliance with disability definition and concept put forth in UNCRPD, as it is the best way to feed in objective data, which will inform state institutions and organisations working with children to design effective and impartial plans and strategies in accordance with current needs.
- The study's contemporary methodology and conception should encourage and raise the awareness of responsible bodies on initiating an agreement to prioritise the data collection for children with disability (but not limited to) in compliance with the definition of CRC, by disaggregating data according to the type of disability, as well as difficulty categories and level.

On services access and quality for children with disability.

- Data indicating the identification of less than half of children with disability (only 4% out of 10.4% identified in the study) by a medical commission point require further research. A significant number of children qualified by the medical commission do not benefit from any type of service. In order to address such an issue, it is necessary to conduct a root cause analysis, finding the means, and providing support to these children and families.
- According to parents' perceptions, financial costs of services (for all types of services) and extremely low financial support constitute the main barriers to access. Reviewing financial support schemes for children with disability and their families, as well as finding the means for affordable services may increase access to services.
- Ninety six percent of families with children with disability generate low or medium income. The majority of such families (78.8%) consist of a large number of members (4-6) and parents' unemployment rate is quite high. The high correlation between poverty and disability implies the need

to find innovative support schemes and means for these families. Along these lines and in addition to direct child services, devising of a support plan (specific for the needs of each family) may be piloted and applied as a matter of priority. Designing support plans for families of children with disability by prioritising low-income families to empower them through strategies such as employment, parents' vocational training, tax relief/removal, counselling and support, etc., should be taken into consideration during design of services for such families.

- The study states, in its essence, the prioritisation of the enormous need for cost free (or cost affordable) identification, support, and specialised multidisciplinary treatment services, for both families of children with disability and children with severe difficulties, based on the service-to-client principle (and not vice versa).
- In order to become more accessible to the community and affordable to all families, health services must become more in line with legislation and better decentralised to the local level. Given the multidimensional nature of disability, it follows that it requires continuous and long-term use of health services (both general and specialised). Therefore, long-term solutions for frequenting of these services such as cost free and appropriate transport, stay in healthcare institutions and receipt of affordable services, as well as medical services quality enhancement, are among the first steps to be considered in this regard.
- The study data suggest the need for ongoing investments regarding children with disabilities' access to schools, and their education quality enhancement in pre-university educational institutions, to prevent children with disabilities from dropping out of school. Due attention must be paid to investments in kindergarten and school infrastructure, transport, and removal of education costs. Similarly, investment is also needed in educational service quality enhancement factors, such as school board and multidisciplinary team quality functioning, drafting of quality IEP and its link to services, diversification of services both in and out of school, support teachers and the entire school staff capacity's quality training, establishment of an inclusive and non-discriminatory school environment.
- Training and development of teaching staff is crucial to the meaningful inclusion of children with disabilities in mainstream education and must be adequately resourced. Investments in early childhood inclusive educational programmes is also imperative given the role such programmes can play in early childhood identification and referral.
- Promotion of prevention, support, and treatment services in early childhood must be included as a priority in relevant plans and strategies. Early childhood identification and treatment of children at high risk may prevent the development of a disability to a considerable extent of children.
- It is necessary that all services be interconnected and have in place information, referral and coordination lines among them, in order to enable the full benefit of services by any individual throughout the developmental stages of his/her life. This connection among services is important especially when the child grows and transitions between developmental stages (e.g. from kindergarten to school). During these transition periods, it is important that services are provided to facilitate and coordinate services from one stage to the other and institutions in municipal or local level are the key stakeholders for this coordination and provision of services.
- Low level of timely disability identification serves as an indicator of the need for early childhood prevention and support services promotion.
- Children's extremely low referral level to specialised services by psychosocial and teaching staff implies the need for their training and awareness-raising in this area.
- The wide range of support services must include interventions related to children's with disabilities wellbeing, autonomy, and personal development.

- The establishing of regular procedures for the monitoring and assessment of medical, social, and educational services by using EU instruments, criteria, and standards is necessary.
- Positive practices in the region such as creating service information maps for children with disabilities, youth, and their families should be developed, monitored and implemented.
- It is necessary to conduct studies on good practice documentation, especially in support of pupils with intellectual disabilities in mainstream schools.

On health and wellbeing promotion

- Current strategies (in the social, health and educational sectors) mainly focus on objectives for children with disabilities in the lowest socio-economic strata. Study data indicating that almost half of children in Albania (45.4%) encounter at least some difficulty in at least one functional domain, must be translated into specific objectives aiming at preventing, identifying, and timely providing the appropriate quality assistance for this large group of children. The same finding suggests that the promotion of health and healthy practices, public information (including community and responsible institutions) of early identification and non neglect of early detected difficulties in children should be treated with priority. The same needs to happen with healthy behaviours in schools and community. In this frame, services must be designed to promote health and development, and prevent difficulties in childrens' development at a particular development stage, in compliance with WHO principles on health and its promotion.
- A considerable number of children demonstrate difficulties especially in the emotional aspect. This important data suggests the need for more focus on awareness regarding mental health, preventive and treatment services on mental health in community and schools; training of parents; education, social and health professionals. This focus also needs to expand at the community level in order to identify, acknowledge, and treat difficulties related to mental health; the promotion of safe spaces in schools, family and community; awareness of the value of respect and dignity for the children; positive parenting etc which are all factors which might lead to the decrease of prevalence and treatment of this number of children having difficulties in this aspect.

On raising awareness and mobilization against discrimination

- Children with disability encounter discrimination at considerable levels in various settings throughout their life. As a result, interventions and actions on its elimination must include all actors and factors identified in the study, both at the micro and macro level (for e.g. not only at the school level, but also at the community level and broader).
- Actions involving specific information and training of parents, legal guardians, communities, and professional staff working with children with disability in service centres, aiming at the holistic addressal of the issue of discrimination against them, especially against children with difficulties or intellectual/developmental disabilities are considered of importance in reducing discrimination.
- Raising awareness against discrimination must particularly focus on the need for disability to be viewed from the human rights and potential perspective (by family members, society and institutions). They must convey the message that all children benefit from inclusion and that

the latter has positive long-term effects on a country's social and democratic development, therefore it must be applied to all settings and situations, families, services, schools, and to the entire society.

- Awareness-raising must prioritise initiatives involving a change of public approach and social or cultural practices and norms, which hinders the engagement in society of children with disabilities.
- Needs for protection of children with disability and children at risk of developing a disability should be clearly included in children's protection system. The Law on the Rights and Protection of the Child (18/2017) and several of the country's strategic documents like the National Agenda for Child Rights and the National Strategy for People with Disability) prioritize the protection of children with disabilities. Besides this, considering the specifics and challenges that children with disability are faced with in understanding and reporting violence and abuse, these documents still do not clearly articulate specifically how these children can be supported in identifying and referring cases of violence and abuse. For this reason, it is necessary that the regulatory acts of the Law on the Rights and Protection of the Child (18/2017) need to clearly define the roles and responsibilities of all stakeholders seen with the lenses of a holistic approach while working towards prevention, identification, referral and support to children with disabilities facing violence and abuse. The regulatory acts need to be closely consulted with groups of interest working directly with and for children with disabilities.

On parents and families' role and inclusion

The study states clearly, based on parents' perceptions, that parents remain isolated and unsupported in facing parenting related challenges to rearing children with disabilities. Therefore, it is necessary that:

- All services for children and youth with disabilities consider parents' inclusion as main factors/actors to their provision. Parents' inclusion is considered a fundamental component to all children intervention programmes. Therefore, the inclusion of the families of children and youth with disability in the service design and provision process is important, to develop services that meet their needs. To this extent, parents and civil society organisations working in this field must not only have the necessary access to information on services to be provided, but must also participate in service planning, assessment, provision, and ongoing monitoring.
- Policies/interventions that support parents of children with disability in obtaining permission from work to fulfil their children's needs, and provide greater support and flexibility in balancing private and family life with the professional one, must be considered.
- Further empowerment of parents and organisations, as well as their encouragement for meaningful participation in all the planning and decision-making spheres regarding disability related issues are crucial. In the frame of the existing legislation on decentralisation, parents of children with disability may become active participants in public consultations, participatory budgeting processes, stakeholders at the municipal council level for demanding the necessary services that children with disabilities are entitled to, etc.

Appendix I

Sample's social, economic and demographic characteristics

Variable	Level	N	Percentage
Age group (N = 13.000)	2-4 years old	1.891	14.5%
	5 – 9 years old	3.502	26.9%
	10-14 years old	4.498	34.6%
	15-17 years old	3.109	23.9%
Sex (N = 13.000)	Male	6.725	51.7%
	Female	6.275	48.3%
Place of residence (N = 13.000)	Urban (city)	5.383	41.4%
	Urban (Suburban)	1.150	8.8%
	Rural (village)	6.467	49.7%
District (N = 13.000)	Berat	628	4.8%
	Dibra	771	5.9%
	Durrës	1.256	9.7%
	Elbasan	1.420	10.9%
	Fier	1.400	10.8%
	Gjirokastra	273	2.1%
	Korça	912	7.0%
	Kukës	526	4.0%
	Lezha	670	5.2%
	Shkodra	1.062	8.2%
	Tirana	3.338	25.7%
Number of children in the family (N = 13.000)	Vlora	744	5.7%
	01	4.600	35.4%
	02	6.203	47.7%
	03	1.876	14.4%
	04	279	2.1%
Children Order (N = 13.000)	05	42	0.3%
	This is the 1 st child	6.898	53.1%
	This is the 2 nd child	4.203	32.3%
	This is the 3 rd child	1.537	11.8%
	This is the 4 th child	280	2.2%
	This is the 5 th child	48	0.4%
Education of Mother (N = 12.960)	Other; please specify:	34	0.3%
	Not completed any education	46	0.4%
	Primary education	110	0.8%
	Basic education (compulsory 8\9-year school)	4.591	35.4%
	General high school	5.665	43.7%
	University	2.162	16.7%
	Master degree	336	2.6%
	Doctoral degree	27	0.2%
	Do not know, Refuse to answer	23	0.2%

Education of Father (N = 12.960)	Not completed any education	38	0.3%
	Primary education	100	0.8%
	Basic education (compulsory 8\9-year school)	3.823	29.5%
	Comprehensive High School	6.683	51.6%
	University	1.751	13.5%
	Master degree	209	1.6%
	Doctoral degree	18	0.1%
	Do not know, Refuse to answer	338	2.6%
Employment Mother (N = 12.960)	Full-time	4.027	31.1%
	Part-time	910	7.0%
	Full-time student	26	0.2%
	Unemployed (e.g stay-at-home)	4.481	34.6%
	Unemployed but seeking for a job	1.798	13.9%
	Self-employed	1.396	10.8%
	Retired	13	0.1%
	Seasonal job	234	1.8%
	Other	61	0.5%
	Do not know, Refuse to answer	14	0.1%
Employment Father (N = 12.960)	Full-time	6.142	47.4%
	Part-time	1.366	10.5%
	Full-time student	9	0.1%
	Unemployed (e.g stay-home)	381	2.9%
	Unemployed but searching for a job	1.255	9.7%
	Self-employed	2.762	21.3%
	Retired	38	0.3%
	Seasonal job	555	4.3%
	Other	229	1.8%
	Do not know, Refuse to answer	223	1.7%
Family Incomes (N = 13,000)	No Income	-	0.0%
	Less than 20,000 ALL	2.062	15.9%
	20,001 – 30,000 ALL	2.423	18.6%
	30,001 – 40,000 ALL	2.534	19.5%
	40,001 – 50,000 ALL	2.053	15.8%
	50,001 – 60,000 ALL	1.317	10.1%
	60,001 – 70,000 ALL	880	6.8%
	70,001 – 80,000 ALL	685	5.3%
	80,001 – 90,000 ALL	453	3.5%
	90,001 – 100,000 ALL	321	2.5%
	100,001 – 120,000 ALL	170	1.3%
	120,001 – 140,000 ALL	63	0.5%
	More than 140,000 ALL	39	0.3%
Place of Residence (N = 13,000)	Yes, the neighbourhood\town\where your family currently resides	12.499	96.1%
	No, in a district\other town	501	3.9%

Appendix II

Questionnaire: Module I

CASE # _____

My name is _____ and I am an interviewer working on behalf of GfK Albania, an independent market research company. We are currently conducting a survey with World Vision Albania and Save the Children would be pleased if you could help by sharing with us your experiences and opinions about abilities of your children to do different activities. We assure you that any information provided will be considered as strictly confidential. It will be exclusively used for statistical purposes without including your name and telephone number or any personal details. The interview will last approximately 50 minutes. Would you like to give your consent to proceed with the interview?

[INT: IF AT THE TIME OF THE INTERVIEW, YOU ARE TALKING WITH ONE OF THE CHILDREN UNDER 18 YEARS OLD, PLEASE ASK TO TALK TO SOMEONE ELSE, PARENTS OR SOMEBODY ELSE OLDER THEN HIM/HER].

Time begin of the interview: _____

Time ending of the interview: _____

Date of the interview: ____/____/16

Re-attempts:

1. 1st attempt
2. 1st return
3. 2nd return
4. 3rd return

SELECTION	
SINGLE ANSWER	ASK ALL
SE.1	INT. CODE WITHOUT ASKING
01	Berat
02	Diber
03	Durrës
04	Elbasan
05	Fier
06	Gjirokaster
07	Korçë
08	Kukës
09	Lezhë
10	Shkodër
11	Tiranë
12	Vlorë

SINGLE ANSWER	INT. CODE WITHOUT ASKING
SE.2	Area
1	Urban (city)
2	Urban (suburban area)
3	Rural (village)

SINGLE ANSWER	ASK ALL
SE.3	Are there children between age 2-17 years old, living in this family?
1	Yes
2	No [END THE INTERVIEW]

SINGLE ANSWER	ASK IF CODE 1 IN SE.2	
SE.4	What is your relationship with the children that live in this family?	
01	I am the mother	[GO TO SE.7.2]
02	I am the father	
03	I am the grandmather	[GO TO SE.5]
04	I am the grandfather	
05	I am the older sister	
06	I am the older brother	
07	I am one of the cousin/ or other family relative: Uncle/ Aunt	
08	Other : please specify	
98	Refuse to answer	[END THE INTERVIEW]

SINGLE ANSWER	ASK IF THE PERSON YOU ARE TALKING TO IS NOT ONE OF THE PARENTS [CODE 1-2 AT SE.4]	
SE.5	Is the mother and/or father of the children present at home?	
1	Yes, the mother of the children is present	[GO TO SE.7.2]
2	Yes, the father of the children is present	
3	Yes, both of the parents of the children are present	
4	No, none of them are present	[GO TO SE.6]

SINGLE ANSWER	ASK IF CODE 4 AT SE.5, IF NONE OF THE PARENTS IS AT HOME	
SE.6	Does the mother and/or the father of the children of this family live on a day-to-day basis at home with children?	
1	Only the mother of the children	[GO TO INSTRUCTION 1 AND THEN ASK SE.7.2]
2	Only the father of the children	
3	Both of them	
4	No, none of them are present	[GO TO SE.7.1]

SINGLE ANSWER	ASK IF CODE 4 AT SE.5 AND CODE 4 AT SE.6.	
SE.7.1	Who does, from the family member of this family, <u>takes care most of the time</u> for the children on a day-to-day basis?	
1	Myself	GOT TO INSTRUCTION 2 AND THEN ASK FA.1
2	The grandmather of the children	
3	The grandfather of the children	
4	The older sister of the children	
5	The older brother of the children	
6	Uncle/ Aunt	
7	Other family relatives	
8	Other (specify)_____	

SINGLE ANSWER	ASK ALL	
SE.7.1.1	Are you the legal caregiver of the children?	
1	Yes	
2	No	[END THE INTERVIEW]

INSTRUCTION 1: INT. IF NONE OF THE PARENTS IS AT HOME [CODE 4 AT SE.5] BUT AT LEAST ONE OF THEM IS LIVING ON DAY TO DAY BASIS AT HOME WITH THE CHILDREN [CODE 1-3 AT SE.6], PLEASE ASK THE PERSON YOU ARE TALKING TO, TO TELL YOU WHEN IT WOULD BE THE APPROPRIATE TIME TO COME BACK AND CONDUCT AN INTERVIEW WITH ONE OF THE PARENTS OF THE CHILD (ANY TIME WHEN THE PARENT WOULD BE AT HOME AND ASK SE.7.2. AND FILL THE QUESTIONNAIRE FROM THE BEGINNING

SINGLE ANSWER	ASK IF CODE 4 AT SE.5 AND CODE 1-3 AT SE.6.
SE.7.2	Who does, from the family member of this family, <u>take care most of the time</u> for the children on a day-to-day basis?
1	Myself
2	Me and my husband/wife
3	Only my husband/wife

INSTRUCTION 2. PLEASE CONTINUE THE INTERVIEW WITH THE PERSON WHO SPENDS MOST OF THE TIME WITH THE CHILDREN OR IS THE LEGAL CARETAKER – THE PERSON SELECTED AT SE.7.1.1 OR AT SE.7.2

FACTS ABOUT YOU THE PERSON WHO WILL CONDUCT THE INTERVIEW ABOUT THE CHILD

FA.1	☒ Whats is your name Name : _____
SINGLE ANSWER	ASK ALL
FA.2	Write without asking the gender of the respondent
1	Male
2	Female
SINGLE ANSWER	ASK ALL
FA.3	Please would you tell me your age?
1	Write the exact age: _____
98	Refuse to answer
99	I do not know
SINGLE ANSWER	CODE WITHOUT ASKING FOR THOSE WHO GAVE THE EXACT AGE. ASK IF CODE 99 AT AF.3 ASK
FA.4	Your age is very important for our statistical analyses. If you would rather not tell me your exact age, can you tell me which of these age ranges you are in...?
01	Under 18 y.o [END THE INTERVIEW]
02	18-24 y.o
03	25-34 y.o
04	35-44 y.o
05	45-54 y.o
06	55-65 y.o
07	Over 65 y.o
98	Refuse to answer [DO NOT READ]
99	I do not know [DO NOT READ]

SINGLE ANSWER	ASK ALL
FA.5	How many persons are living constantly in your household including yourself?
01	01
02	02
03	03
04	04
05	05
06	06
07	Other , Specify: _____
98	Refuse to answer [DO NOT READ]
99	I do not know [DO NOT READ]

SINGLE ANSWER	ASK ALL
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FA.6.1	How many children, under the age of 18, are living in this house? INT: PLEASE WRITE EXACT NUMBER	NR [_____]
FA.6.2	How old are the children of the family? INT: Please write down exactly the age of each child that lives in the house?	
01	[.....] Nr of children	[.....] years old
02	[.....] Nr of children	[.....] years old
03	[.....] Nr of children	[.....] years old
04	[.....] Nr of children	[.....] years old
05	[.....] Nr of children	[.....] years old
06	[.....] Nr of children	[.....] years old
98	Refuse to answer [END THE INTERVIEW]	

INT. PLEASE READ: WE ARE LOOKING FOR FAMILIES WHO HAVE CHILDREN BETWEEN AGE 2-17 YEARS OLD. WE WOULD LIKE TO CONDUCT THE INTERVIEW FOR ONE OF YOUR CHILDREN THAT HIS/HER BIRTHDAY IS NEXT TO OUR DATE OF THE INTERVIEW. CAN YOU TELL ME THE NAME OF THE CHILD WHO IS BETWEEN AGE CATEGORY 2-17 YEARS OLD AND HIS/HER EXCAT AGE?

FACTS ABOUT THE CHILD	
FA.7	<input type="checkbox"/> What is his/her Name : _____
INT: PLEASE MENTION THE NAME OF THE CHILD THROUGH THE IINTERVIEW	
FA.8	<input type="checkbox"/> What is the date of the child birth? _____ / _____ / _____
SINGLE ANSWER	ASK ALL
FA.9	What is his/her gender?
1	Male
2	Female

FA.10	<input type="checkbox"/> What is his/her age? _____
99. Refuse to answer [END THE INTERVIEWN IF THERE IS NO DATE OF BIRTH GIVEN AT FA.7]	

SINGLE ANSWER	CODE WITHOUT ASKING FOR THOSE WHO GAVE THE EXACT AGE.
FA.11	ASK THOSE THAT REFUSE TO GIVE THE EXACT AGE AT FA.10 We are asking for the age of the child to determine if he/she would be part of the target group of our study. Please tell me the age categorize of your child by the following age groups.
01	2-4 year old
02	5 – 10 years old
03	11-14 years old
04	15 – 17 years old
99	Refuse to answer [END THE INTERVIEW]

SINGLE ANSWER	ASK ALL
FA.12	Are there other children born before or after _____ [name of the child] ?
01	This is the 1 st child
02	This is the 2 nd child
03	This is the 3 rd child
04	This is the 4 th child
05	This is the 5 th child
08	Other please specify _____

SINGLE ANSWER

FA.13	What is your relationship with the child _____ [name] ?
01	The biological parent of the child
02	The step parent of the child
03	The adoptive parent parent of the child
04	The foster parent of the child
05	The grandmather of the children
06	The grandfather of the children
07	The older sister of the children
08	The older brother of the children
09	One of the cousin/ or other family relative/ Uncle/ Aunt

We would like to ask you some questions related to your child's health, comfort and well-being, and about caring for his/her needs. Please, answer to all questions by stating the option that fits best. You can make any comments/clarification and we will write down below each section.

VISION

SINGLE ANSWER	ASK ALL
VIS_1	Does your child _____ wear glasses?
1	Yes [GO TO VIS_2]
2	No
SINGLE ANSWER	ASK ALL
VIS_2A	IF THE CHILD DO WEAR GLASSES [IF VIS_1 = 1] – ASK Does your child _____ have difficulty <u>seeing</u> when wearing [his/her] glasses? Would you say..... [Read responsecategories]
VIS_2B	IF THE CHILD DO NOT WEAR GLASSES [IF VIS_1 = 2] – ASK Does your child _____ have difficulty <u>seeing</u> ? Would you say..... [Read responsecategories]
1	Nodifficulty
2	Some difficulty
3	A lot ofdifficulty
4	Cannot do at all / Unable todo
98	Refused [DO NOT READ] (GO TO HEAR_1)
99	Don't know [DO NOT READ] (GO TO HEAR_1)

HEARING

SINGLE ANSWER	ASK ALL
HEAR_1	Does your child _____ use a <u>hearing aid</u> ?
1	Yes
2	No
SINGLE ANSWER	ASK ALL
HEAR_2A	IF THE CHILD DO WEAR HEARING AID [IF HEAR_1= 1] – ASK Does your child _____ have <u>difficulty hearing</u> ,even when using a hearing aid(s)? Would you say... [Read response categories]
HEAR_2B	IF THE CHILD DO NOT WEAR HEARING AID [IF HEAR_1= 2] – ASK Does your child _____ have <u>difficulty hearing</u> ? Would you say... [Read response categories]
1	Nodifficulty
2	Some difficulty
3	A lot ofdifficulty
4	Cannot do at all / Unable todo
98	Refused [DO NOT READ] (GO TO MOB_1)
99	Don't know [DO NOT READ] (GO TO MOB_1)

WALKING

SINGLE ANSWER	ASK ALL
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MOB_1	Does your child _____ use any equipment (e.g Wheelchair or scooter) or receive help for getting around (e.g Artificial limb (leg/foot or Someone's assistance)?
1	Yes
2	No
7	Refuse to answer [DO NOT READ] (GO TO MOB_2.3)
9	Don't know [DO NOT READ] (GO TO MOB_2.3)

INT: ASK MOB_2.1- MOB_2.3 IF THE CHILD AGE IS BETWEEN 2-4 YEARS OLD

SINGLE ANSWER	IF THE CHILD USE ANY EQUIPMENT OR RECEIVE HELPFOR GETTING AROUND [IF MOB_1= 1]
MOB_2.1	Compared to children of the same age, does your child _____ have difficulty walking <u>without the use of</u> [his/her aid equipment or assistance]? Would you say... [Read response categories]
2	Some difficulty
3	A lot of difficulty
4	Cannot do at all / Unable todo
98	Refused [DO NOT READ]
99	Don't know [DO NOT READ]

SINGLE ANSWER	IF THE CHILD USES ANY EQUIPMENT OR RECEIVE HELPFOR GETTING AROUND [IF MOB_1= 1]
MOB_2.2	Compared to children of the same age, does your child _____ have difficulty walking <u>with the use of</u> [his/her aid equipment or assistance]? Would you say... [Read response categories]
1	No difficulty [GO TO [LANG_1]
2	Some difficulty [GO TO [LANG_1]
3	A lot of difficulty [GO TO [LANG_1]
4	Cannot do at all / Unable todo [GO TO [LANG_1]
98	Refused [DO NOT READ] [GO TO [LANG_1]
99	Don't know [DO NOT READ] [GO TO [LANG_1]

SINGLE ANSWER	IF THE CHILD DO NOT USES ANY EQUIPMENT OR RECEIVE HELPFOR GETTING AROUND [IF MOB_1= 2] OR IF THE RESPONDENT REFUSE OR DO NOT KNOW [IF MOB_1 = 98/99] – ASK
MOB_2.3	Compared to children of the same age, does your child _____ have difficulty walking? Would you say... [Read response categories]
1	No difficulty [GO TO [LANG_1]
2	Some difficulty [GO TO [LANG_1]
3	A lot of difficulty [GO TO [LANG_1]
4	Cannot do at all / Unable todo [GO TO [LANG_1]
98	Refused [DO NOT READ] [GO TO [LANG_1]
99	Don't know [DO NOT READ] [GO TO [LANG_1]

INT: ASK MOB_3.1 – MOB_3.6 ONLY IF THE CHILD AGE IS BETWEEN 5-17 YEARS OLD

SINGLE ANSWER	IF THE CHILD USES ANY EQUIPMENT/ RECEIVE HELPFOR GETTING AROUND [IF MOB_1= 1]
MOB_3.1	Does your child _____ have difficulty walking 100 meters on levelground, (that would be about the length of one football field or one city block) <u>without the use of</u> [his/her aid equipment or assistance]? Would you say... [Read response categories].
2	Some difficulty
3	A lot of difficulty
4	Cannot do at all / Unable todo GO TO SELF CARE [SC_1]
98	Refused [DO NOT READ]
99	Don't know [DO NOT READ]

SINGLE ANSWER	IF THE CHILD USES ANY EQUIPMENT OR RECEIVE HELPFOR GETTING AROUND [IF MOB_1=
----------------------	--

ANSWER	1] – ASK
MOB_3.2	Does your child _____ have difficulty walking 100 meters on levelground, (that would be about the length of one football field or one city block) <u>with the use of</u> [his/her aid equipment or assistance]? Would you say... [Read response categories].
1	No difficulty at all
2	Some difficulty
3	A lot of difficulty
4	Cannot do at all / Unable todo GO TO SELF CARE [SC_1]
98	Refused [DO NOT READ]
99	Don't know [DO NOT READ]

SINGLE ANSWER	IF THE CHILD USES ANY EQUIPMENT OR RECEIVE HELPFOR GETTING AROUND [IF MOB_1 = 1] – ASK
MOB_3.3	Does your child _____ have difficulty walking half a km - 500 metres on levelground (that would be the length of five football fields or five city blocks), <u>without the use of</u> [his/her aid equipment or assistance]? Would you say... [Read response categories]
2	Some difficulty
3	A lot of difficulty
4	Cannot do at all / Unable todo
98	Refused [DO NOT READ]
99	Don't know [DO NOT READ]

SINGLE ANSWER	IF THE CHILD USES ANY EQUIPMENT OR RECEIVE HELPFOR GETTING AROUND [IF MOB_1 = 1] – ASK
MOB_3.4	Does your child _____ have difficulty walking half a km - 500 metres on levelground (that would be the length of five football fields or five city blocks), <u>with the use of</u> [his/her aid equipment or assistance]? Would you say... [Read response categories]
1	No difficulty
2	Some difficulty
3	A lot of difficulty
4	Cannot do at all / Unable todo
98	Refused [DO NOT READ]
99	Don't know [DO NOT READ]
	GO TO SELF CARE [SC_1]

SINGLE ANSWER	THE CHILD DOES NOT USE ANY EQUIPMENT OR RECEIVE HELPFOR GETTING AROUND [IF MOB_1 = 2] OR IF THE RESPONDENT REFUSE OR DO NOT KNOW [IF MOB_1 = 98/99]
MOB_3.5	Compared to children of the same age, does your child _____ have difficulty walking half a km - 100 metres on levelground (that would be about the length of one football field or one city block)? Would you say... [Read response categories].
1	No difficulty at all
2	Some difficulty
3	A lot of difficulty
4	Cannot do at all / Unable todo GO TO SELF CARE [SC_1]
98	Refused [DO NOT READ]
99	Don't know [DO NOT READ]

SINGLE ANSWER	THE CHILD DOES NOT USE ANY EQUIPMENT OR RECEIVE HELPFOR GETTING AROUND [IF MOB_1 = 2] OR IF THE RESPONDENT REFUSE OR DO NOT KNOW [IF MOB_1 = 3 / 4]
MOB_3.6	Compared to children of the same age, does your child _____ have difficulty walking half a km – 500 metres on levelground (that would be the length of five football fields or five city blocks)? Would you say... [Read response categories].
1	No difficulty
2	Some difficulty
3	A lot of difficulty
4	Cannot do at all / Unable to do

98	<i>Refused</i> [DO NOT READ]
99	<i>Don't know</i> [DO NOT READ]

SELF-CARE

SINGLE ANSWER	ASK ONLY IF THE CHILD AGE IS BETWEEN 5-17 YEARS OLD
SC_1	Compared to children of the same age, does your child _____ have difficulty with self care, feeding or dressing him/hersel? Would you say... [Read response categories]
1	No difficulty
2	Some difficulty
3	A lot of difficulty
4	Cannot do at all / Unable to do
98	<i>Refused</i>
99	<i>Don't know</i>

LANGUAGE/SPEECH

SINGLE ANSWER	ASK ALL
LANG_1	At what age did your child use single meaningful words (not just mamma and Dadda? INT: PLEASE SPECIFY THE AGE
1	[_____] MONTH OLD

SINGLE ANSWER	ASK ALL
LANG_2	At what age did your child use meaningful phrases that contain at least a verb e.g. I want a biscuit; Lets go to park mummy) INT: PLEASE SPECIFY THE AGE
1	[_____] MONTH OLD

COMMUNICATION - COMPREHENSION

SINGLE ANSWER	ASK ONLY IF THE CHILD AGE IS BETWEEN 2-4 YEARS OLD
COM_1	Does your child have difficulty understanding you? Would you say..... [Read response categories]
1	No difficulty
2	Some difficulty
3	A lot of difficulty
4	Cannot do at all / Unable to do
98	<i>Refused</i>
99	<i>Don't know</i>

SINGLE ANSWER	ASK ONLY IF THE CHILD AGE IS BETWEEN 2-4 YEARS OLD
COM_2	Do you have difficulty understanding your child? Would you say... [Read response categories]
1	No difficulty
2	Some difficulty
3	A lot of difficulty
4	Cannot do at all / Unable to do
98	<i>Refused</i> [DO NOT READ]
99	<i>Don't know</i> [DO NOT READ]
GO TO LEA_1 IF THE CHILD IS 2-3 YEARS OLD .	
OR GO TO LEA_2 IF THE CHILD IS 4 YEARS OLD	

SINGLE ANSWER	ASK ONLY IF THE CHILD AGE IS BETWEEN 5-17 YEARS OLD
COM_3	Compared to children of the same age, does your child _____ have difficulty understanding other people? Would you say... [Read response categories]
1	No difficulty

2	Some difficulty
3	A lot of difficulty
4	Cannot do at all / Unable to do
98	<i>Refused</i> [DO NOT READ]
99	<i>Don't know</i> [DO NOT READ]

SINGLE ANSWER	ASK ONLY IF THE CHILD AGE IS BETWEEN 5-17 YEARS OLD	
COM_4	Compared to children of the same age, does your child _____ have difficulty being understood by other people? Would you say... [Read response categories]	
1	No difficulty	GO TO LEA_2
2	Some difficulty	
3	A lot of difficulty	
4	Cannot do at all / Unable to do	
98	<i>Refused</i> [DO NOT READ]	
99	<i>Don't know</i> [DO NOT READ]	

LEARNING

SINGLE ANSWER	ASK ONLY IF THE CHILD AGE IS BETWEEN 2-3 YEARS OLD	
LEA_1	Compared to children of the same age, does your child _____ have difficulty learning the names of common objects? Would you say..... [Read response categories]	
1	No difficulty	
2	Some difficulty	
3	A lot of difficulty	
4	Cannot do at all / Unable to do	
98	<i>Refused</i> [DO NOT READ]	
99	<i>Don't know</i> [DO NOT READ]	

SINGLE ANSWER	ASK ONLY IF THE CHILD AGE IS BETWEEN 2-17 YEARS OLD	
LEA_2	Compared to children of the same age, does your child _____ have difficulty learning new things? Would you say..... [Read response categories]	
1	No difficulty	
2	Some difficulty	
3	A lot of difficulty	
4	Cannot do at all / Unable to do	
98	<i>Refused</i> [DO NOT READ]	
99	<i>Don't know</i> [DO NOT READ]	

SINGLE ANSWER	ASK ONLY IF THE CHILD AGE IS BETWEEN 5-17 YEARS OLD	
LEA_3	Compared to children of the same age, does your child _____ have difficulty remembering things? Would you say... [Read response categories]	
1	No difficulty	
2	Some difficulty	
3	A lot of difficulty	
4	Cannot do at all / Unable to do	
98	<i>Refused</i> [DO NOT READ]	
99	<i>Don't know</i> [DO NOT READ]	

EMOTION

SINGLE ANSWER	ASK ONLY IF THE CHILD AGE IS BETWEEN 5-17 YEARS OLD	
EMO_1	How much your child _____ worry or feel sad? Would you say... [Read response categories]	
1	Not at all	GO TO BEH_2]
2	A little	

3	A lot
4	Somewhere in between a little and a lot
98	Refused [DO NOT READ]
99	Don't know [DO NOT READ]

BEHAVIOUR

SINGLE ANSWER	ASK ONLY IF THE CHILD AGE IS BETWEEN 2-4 YEARS OLD
BEH_1	Compared to children of the same age, how much does child kick, bite or hit other children or adults? Would you say... [Read responsecategories]
1	Not at all
2	The same or less
3	More
4	A lot more
98	Refused [DO NOT READ]
99	Don't know [DO NOT READ]

SINGLE ANSWER	ASK ONLY IF THE CHILD AGE IS BETWEEN 5-17 YEARS OLD
BEH_2	Compared with children of the same age, how much difficulty does child _____ have controlling his/her behaviour? Would you say... [Read responsecategories]
1	Not at all
2	The same or less
3	More
4	A lot more
98	Refused [DO NOT READ]
99	Don't know [DO NOT READ]

ATTENTION

SINGLE ANSWER	ASK ONLY IF THE CHILD AGE IS BETWEEN 5-17 YEARS OLD
ATT_1	Does your child _____ have difficulty focusing on an activity that [he/she] enjoys doing? [Read response categories]
1	Nodifficulty
2	Some difficulty
3	A lot ofdifficulty
4	Cannot do at all / Unable todo
98	Refused [DO NOT READ]
99	Don't know [DO NOT READ]

COPING WITH CHANGE

SINGLE ANSWER	ASK ONLY IF THE CHILD AGE IS BETWEEN 5-17 YEARS OLD
CHAN_1	Does your child _____ have difficulty accepting changes in [his/her] routine? [Read response categories]
1	Nodifficulty
2	Some difficulty
3	A lot ofdifficulty
4	Cannot do at all / Unable todo
98	Refused [DO NOT READ]
99	Don't know [DO NOT READ]

PLAYING

SINGLE ANSWER	ASK ONLY IF THE CHILD AGE IS BETWEEN 2-4 YEARS OLD
PLAY_1	Does your child _____ have difficulty playing? [Read response categories]
1	Nodifficulty
2	Some difficulty
3	A lot ofdifficulty
4	Cannot do at all / Unable todo

98	<i>Refused</i> [DO NOT READ] (GO TO REL_1)
99	<i>Don't know</i> [DO NOT READ] (GO TO REL_1)

RELATIONSHIP

SINGLE ANSWER		ASK ONLY IF THE CHILD AGE IS BETWEEN 5-17 YEARS OLD
REL_1	Does your child _____ have difficulty making friends? [Read response categories]	
1	No difficulty	
2	Some difficulty	
3	A lot of difficulty	
4	Cannot do at all / Unable to do	
98	<i>Refused</i> [DO NOT READ]	
99	<i>Don't know</i> [DO NOT READ]	

LOCAL SERVICES – HEALTH SERVICE

SINGLE ANSWER		ASK ALL
LSH_1	Is your child _____ under public surveillance by a pediatrician, family physician, or nurse from the state health sector?	
1	Yes	
2	No [GO TO LSH_4]	

SINGLE ANSWER		ASK IF THE CHILD IS UNDER SURVEILLANCE, [LSH_1 = 1]
LSH_2	At what frequency does your child see any public pediatrician, family physician, or nurse from the state health sector?	
1	Weekly	
2	Monthly	
3	Three to four times a year	
4	Once or twice a year	
5	Only in case of necessity	
6	Other : _ specify	

SINGLE ANSWER		ASK IF THE CHILD IS UNDER SURVEILLANCE, [LSH_1 = 1]					
LSH_3	How satisfied are you with the following components of the services delivered by the pediatrician or the family physician, nurse from the state health sector (1 means completely dissatisfied, 5 means completely satisfied)						
		Completely dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Completely Satisfied	I do not know/refuse
1	Respect shown from medical staff	1	2	3	4	5	99
2	Referral from medical doctor to specialized or continued treatment (how clear, accurate and relevant is the referral to another specialist, continuation of the treatment or nature of recommended treatment)	1	2	3	4	5	99
3	Distance / transport to go to the health center	1	2	3	4	5	99
4	Overall cost (including costs of treatment and transport)	1	2	3	4	5	99
5	Infrastructure (condition of premises: heating/cooling system, lighting, air, space, equipments, availability of ramps, adapted restrooms for people with disability)	1	2	3	4	5	99

MULTIPLE ANSWER		ASK IF THE CHILD IS NOT UNDER SURVEILLANCE, [LSH_1 = 2]
LSH_4	Why is your child not under surveillance by any <u>public pediatrician</u> or family physician, nurse from the state health sector? INT: UP TO 3 RESPONSES: PLEASE, MARK BY PRIORITY/ /DO NOT READ THE OPTIONS.	
1	The service is not available in the community	
2	The child was denied the service	
3	Cannot afford to pay for the service	
4	Not aware of such service	
5	The attitude towards us and the child was improper or discriminatory	
6	The quality of the services provided is inadequate	
7	Too far from my living area – no transportation	
97	Other , please specify	

SINGLE ANSWER		ASK ALL
LSH_5	Is your child _____ under public surveillance of any <u>public specialists</u> (speech therapist, child psychologist, child psychiatrist, physiotherapist, otorinolaringologist, oculist, neurologist, social worker) from the state health sector?	
1	Yes	[GO TO LSH_8]
2	No	[GO TO LSH_5.1]

SINGLE ANSWER		ASK ALL
LSH_5.1	Have you been recommended to see at least one of the following child specialists (speech therapist, child psychologist, child psychiatrist, physiotherapist, otorinolaringologist, oculist, neurologist, social worker) during the last year from the state health sector? INT: PLEASE DO NOT READ OUT!	
1	Yes	[GO TO LSH_6]
2	No	[GO TO LSE_1]

MULTIPLE ANSWER		ASK IF LSH_5 = 1
LSH_6	Who addressed / recommended you to that service/s....? INT: DO NOT READ OUT. UP TO 3 RESPONSES ALLOWED	
1	By myself	
2	A teacher at kindergarten / school	
3	Family doctor / pediatrician	
4	A specialist doctor (e.g. ear, throat and nose doctor or an eye doctor, neurologist, etc)	
5	A clinical or school psychologist	
6	A social worker	
7	Family member / friends /relatives	
97	Other _____	

SINGLE ANSWER		ASK IF LSH_5 = 1
LSH_7	Did you take the the recommended service to at least one of the following child specialists (speech therapist, child psychologist, child psychiatrist, physiotherapist, otorinolaringologist, oculist, neurologist, social worker) during the last year from the state health sector? INT: PLEASE DO NOT READ OUT!	
1	Yes	[GO TO LSH_8]
2	No	[GO TO LSH_9]

SINGLE ANSWER		ASK IF LSH_7 = 1
LSH_8	How satisfied are you overall with the quality of the service delivered by the recommended specialists_____from the state health sector (1 means completely dissatisfied, 5 means completely satisfied)	
1	Completely dissatisfied	

2	Dissatisfied
3	Neither satisfied nor dissatisfied
4	Satisfied
5	Completely Satisfied
98	I do not know/refuse

SINGLE ANSWER		ASK IF LSH_7 = 1
LSH_8.1	How would you evaluate the overall cost of attendance of the above services from the state health sector (1 means Not affordable at all, 5 means Completely Affordable)	
1	Not affordable at all	
2	Not affordable	
3	Neither affordable nor affordable	
4	Affordable	
5	Completely Affordable	
6	I do not know/refuse (INT: PLEASE DO NOT READ OUT)	

MULTIPLE ANSWER		ASK IF THE CHILD DID NOT VISIT ANY OF THE RECOMMENDED SERVICES LSH_7 = 2
LSH_9	Why your child did not visited the recommended service? INT: UP TO 3 RESPONSES: PLEASE, MARK BY PRIORITY/ /DO NOT READ THE OPTIONS.	
1	The service is not available in the community	
2	The child was denied the service	
3	Cannot afford to pay for the service	
4	Not aware of such service	
5	The attitude towards the child was improper or discriminatory	
6	The quality of the services provided is inadequate	
7	Too far from my living area – no transportation	
97	Other , please specify	

EDUCATION SERVICE

SINGLE ANSWER		ASK ALL
LSE.1	Does your child attend a public or private nursery / kindergarten / school?	
1	Yes	
3	The child have attended but have terminated/ drop out nursery / kindergarten / school	
4	No, Does not attend any of the above (none of the above) –[GO TO LSE_3]	

SINGLE ANSWER		ASK IF ANY CODE 1 OR 2 AT LSE.1.2
LSE_1.1	Does your child attend (or attended) a mainstream nursery / kindergarten school, special nursery / kindergarten school or professional school?	
1	Mainstream nursery / kindergarten / school	
2	Special education nursery / kindergarten / school	
3	Vocational Profesional education School	

SINGLE ANSWER		ASK IF ANY CODE 1 / 2 AT LSE.1
LSE_1.2	LSE_1 = 1 ask : At which level/ grade is your child	
	LSE_1 = 2 ask : At which level/ grade your child dropped from school?	
1	Nursery	
2	Kindergarten/ Pre-school	
3	1 st grade	
4	2 nd grade	
5	3 rd grade	
6	4 th grade	

7	5 th grade
8	6 th grade
9	7 th grade
10	8 th grade
11	9 th grade
12	10 th grade
13	11 th grade
14	12 th grade
15	Refuse/ Do not know

SINGLE ANSWER		ASKI IF [LSE_1 = 1 / 2]
LSE_1.3	Does your child attend a public or private nursery / kindergarten / school?	
1	Public nursery / kindergarten / school	
2	Private nursery / kindergarten / school	

SINGLE ANSWER		ASK ALL					
LSE_2	How satisfied are you with the following components of the services delivered by the education services your child have received (1 means completely dissatisfied, 5 means completely satisfied)						
Nr	STATEMENTS	Completely dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Completely Satisfied	I do not know/refuse
1	Respect shown from the education staff	1	2	3	4	5	99
2	Level to which teaching is individualized to your child needs and development.	1	2	3	4	5	99
3	Distance to go to nursery/kindergarten/school	1	2	3	4	5	99
4	Overall child progress in nursery/kindergarten/school	1	2	3	4	5	99
5	Overall costs (including transport, books, school supplies, or fees for meals at the nursery and kindergarten)	1	2	3	4	5	99
6	Infrastructure (condition of premises: heating/cooling system, lighting, air, space, equipments, availability of ramps, adapted restrooms for people with disability)	1	2	3	4	5	99

SINGLE ANSWER	ASK IF THE CHILD DID NOT GO TO – OR DROPT OUT FROM EDUCATION SYSTEM, LSE.1 = 2 / 3
LSE_3	Why does or did your child not attend or dropped nusery / kondergarten / school? INT: UP TO 3 RESPONSES: PLEASE, MARK BY PRIORITY/ /DO NOT READ THE OPTIONS.
1	The service (or specialist provision) is not available in the community
2	The child was denied admission to a kindergarten/ school
3	Cannot afford to pay for the education ervice
4	Not aware of the service/ specialist provision
5	The attitude of the staff/ teacher towards the child was improper or discriminatory
6	The quality of the services provided is inadequate
7	The kindergarten/ school lacks appropriate conditions (no proper temperature, no light, not cleaned, not appropriate for children with disabilities, etc)
8	Too far from my living area – no transportation
9	The parents think that the child does not need a school/ kindergarten

10	Are not aware that the child can attend a school/kidergarten
97	Other , please specify

ASK ONLY IF THE CHILD AGE IS BETWEEN 2-5 YEARS OLD

SINGLE ANSWER	ASK IF THE CHILD DO NOT ATTEND EDUCATION SYSTEM, CODE 16 AT LSE_1 =2 / 3
LSE_4	Do you plan to take your child to school/ kindergarten?
1	Yes
2	No
97	I do not know/refuse

STATE SOCIAL DEVELOPEMENT SERVICE

SINGLE ANSWER	ASK ALL		
LSDC.1	Did /does your child attend or attended in the <u>last 12 months</u> any specialized development centre (Community Mental Health Centre, Residential Care, etc)? [DO NOT READ]		
1	A specialized centre [.....	[INT: GOT O LSDC.3]	
2	Mental Health Centre [.....		
3	Residential Care [.....		
4	Other: Specify [.....		
5	Yes, - a year ago but he/she stopped		
6	No		[INT: GOT O LSDC.2]

SINGLE ANSWER	ASK ALL IF LSDC.1 = 6	
LSDC.2	Have _____ ever been recommended to attend any specialized development centre (day – care center/ Community Mental Health Centre, Residential Care, etc)?	
1	Yes .	INT: GO TO LSDC.3]
2	No	[INT: GO TO LSDC.5]

SINGLE ANSWER	ASK IF LSDC.1 = 1-5 OR LSDC.2=1	
LSDC.3	Who addressed / recommended you to that institution / service....?	
1	By myself	
2	A teacher at kindergarten / school	
3	Family doctor / pediatrician	
4	A specialist doctor (e.g. ear, throat and nose doctor or an eye doctor, neurologist, etc)	
5	A clinical or school psychologist	
6	A social worker	
7	Family member / friends/ relatives	
8	Other _____	

SINGLE ANSWER	ASK IF LSDC.2=1		
LSDC_3.1	Did you send your child to attend any of the recommended specialized development centre (Community Mental Health Centre, Residential Care, etc)? [DO NOT READ]		
1	A specialized centre [.....	[INT: GOT O LSDC.4]	
2	Mental Health Centre [.....		
3	Residential Care [.....		
4	Other: Specify [.....		
5	Yes, - a year ago but he/she stopped		
6	No		[INT: GOT O LSDC.5]

SINGLE ANSWER	IF [LSDC.1=1-5 OR LSDC.3.1 = 1-5]
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LSDC_4	How satisfied are you with the overall quality of services delivered by the specialized development centre (Community Centre Specialized Centre services your child have received) (1 means completely dissatisfied, 5 means completely satisfied)
1	Completely dissatisfied
2	Dissatisfied
3	Neither satisfied nor dissatisfied
4	Satisfied
5	Completely Satisfied
98	Refuse (INT: PLEASE DO NOT READ OUT)
99	I do not know(INT: PLEASE DO NOT READ OUT)

SINGLE ANSWER	IF [LSDC.1=1-5 OR LSDC.3.1= 1-5]
LSDC_4.1	How would you evaluate the overall cost of attendance of the specialized development centre Community Centre Specialized Centre services (1 means Not affordable at all, 4 means Completely Affordable)
1	Not affordable at all
2	Not affordable
3	Affordable
4	Completely Affordable
98	Refuse (INT: PLEASE DO NOT READ OUT)
99	I do not know(INT: PLEASE DO NOT READ OUT)

SINGLE ANSWER	[LSDC.1= 6 DHE LSDC. 2=2 OSE LSDC.3.1 = 6 and [LSDC.1= 5 OSE LSDC.3.1 =5]
LSDC_5	Why your child did not visit or interrupted the service from the specialized development centre (specialised center/Community Mental Health Centre, Residential Care, etc)? INT: UP TO 3 RESPONSES: PLEASE, MARK BY PRIORITY/ /DO NOT READ THE OPTIONS.
1	The service (or specialist provision) is not available in the community
2	The child was denied admission to a kindergarten/ school
3	Cannot afford to pay for the education ervice
4	Not aware of the service/ specialist provision
5	The attitude of the staff/ teacher towards the child was improper or discriminatory
6	The quality of the services provided is inadequate
7	Too far from my living area – no transportation
8	The kindergarten/ school lacks appropriate conditions (no proper tempriture, no light, not cleaned, not appropriate for children with disabilities, etc)
9	I do not think that it is necessary
97	Other , please specify

SINGLE ANSWER	ASK ALL
ABU_1	Has your child _____ [name of the child] been experiencing any kind of persistent violence (physical, emotional, neglect or other) by an adult during the last 12 months?
1	Yes
2	No
98	Refuse (INT: PLEASE DO NOT READ OUT)
99	I do not know(INT: PLEASE DO NOT READ OUT)

INT: PLEASE READ. WE ALMOST FINISHED, AND I WOULD LIKE TO ASK A FINAL QUESTION

SINGLE ANSWER	ASK ALL
DISA_1	Do you consider your child _____ [name of the child] has difficulties in functioning or has any disability?

1	Yes	[GO TO MODULE II]
2	No	[GO TO DEMOGRAPHY]

INT: IF THE RESPONDENT REPLIED 'YES', DECLARING THAT THE CHILD HAS A DISABILITY, PLEASE READ: I HAVE FEW QUESTIONS RELATED TO THIS AND WE WOULD BE VERY INTERESTED TO GET YOUR OPIONIN REGARDING THE SPECIALISED SERVICES THAT ARE OFERED TO YOUR CHILD.

INT: PLEASE GO TO MODULE 2 – PLEASE FILL IN THE QUESTIONNAIRE ID AND THE NAME OF THE CHILD IN THE BEGINNING OF THE MODULE. THEN FILL IN THE DEMOGRAPHY SECTION.

DEMOGRAPHY

INT: THIS PART OF DEMOGRAPHY WILL BE FILLED IN ONLY FOR PARENTS.

DEMI 1ST PERSON	Please specify for whom you are filling in this section, based on who you have been interviewing? [PLEASE REFER TO THE CODE AT SE.4 OR SE7.2]	
1	Mother	
2	Father	
SINGLE ANSWER		ASK ALL
DEM I.1	Can you please tell me the highest level of education you have completed?	
1	Not completed any education	1
2	Primary education	2
3	Basic education (compulsory 8/9grades)	3
4	General high school	4
5	University	5
6	Master degree	6
7	Doctoral degree	7

SINGLE ANSWER		ASK ALL
DEM I.2	What is your current employment status?	
1	Full-time	
2	Part-time	
3	Full-time student	
4	Unemployed (e.g household)	
5	Unemployed but searching for a job	
6	Self-employed	
7	Retired	
8	Seasonal job	
9	Other (Please specify _____)	

SINGLE ANSWER		ASK ALL				
DEM I.3	Do you have difficulty on the following aspects....would you say.....					
		Nodifficulty	Some difficulty	A lot ofdifficulty	Cannot do at all / Unable to do	I do not know/refuse
1	Do you have difficulty <u>seeing</u>	1	2	3	4	99
2	Do you have difficulty <u>hearing</u>	1	2	3	4	99
3	Do you have difficulty <u>walking</u>	1	2	3	4	99
4	Do you have difficulty <u>understanding other people</u>	1	2	3	4	99
5	Do you have difficulty <u>being understood by other people</u>	1	2	3	4	99

DEM2 2ND PERSON	Please specify for whom you are filling in this section, whether is the motehr or the father of the child. [PLEASE REFER TO THE CODE AT DEM1]	
1	Mother	
2	Father	

SINGLE ANSWER		ASK ALL
DEM 2.1 Can you please tell me the highest level of education that your partner have completed?		
1	Not completed any education	
2	Primary education	
3	Basic education (compulsory 8/9grades)	
4	General high school	
5	University	
6	Master degree	
7	Doctoral degree	

SINGLE ANSWER		ASK ALL
DEM 2.2 What is your current employment status of your partner?		
1	Full-time	
2	Part-time	
3	Full-time student	
4	Unemployed (e.g household)	
5	Unemployed but searching for a job	
6	Self-employed	
7	Retired	
8	Seasonal job	
9	Other (Please specify _____)	

SINGLE ANSWER		ASK ALL				
DEM 2.3 Does your partner have difficulty on the following aspects....would you say.....						
		Nodifficulty	Some difficulty	A lot ofdifficulty	Cannot do at all / Unable to do	I do not know/refuse
1	He/she have difficulty <u>seeing</u>	1	2	3	4	99
2	He/she have difficulty <u>hearing</u>	1	2	3	4	99
3	He/she have difficulty <u>walking</u>	1	2	3	4	99
4	He/she have difficulty <u>understanding other people</u>	1	2	3	4	99
5	He/she have difficulty <u>being understood by other people</u>	1	2	3	4	99

SINGLE ANSWER		ASK ALL
DEM 3 Can you tell me how much are your total monthly household income, including wages, rents, interest, remittances, etc. for all members of your family?		
1	No Income	
2	Less than 20.000ALL	
3	20.001 – 30.000 ALL	
4	30.001 – 40.000 ALL	
5	40.001 – 50.000 ALL	
6	50.001 –60.000 ALL	
7	60.001 –70.000 ALL	
8	70.001 – 80.000 ALL	
9	80.001 – 90.000 ALL	
10	90.001 – 100.000 ALL	
11	100.001-120.000 ALL	
12	120.001-140.000 ALL	
13	More than 140.000 ALL	

Questionnaire: Module II

PUBLIC /LOCAL SERVICES – FOR CHILDREN WITH DISABILITIES	
MULTIPLE ANSWER	ONLY IF THE PARENT DECLARES THAT THE CHILD HAS A DISABILITY [DISA_1=1]
DISA_2	What kind of disability in your opinion does your child has? [IF MULTIPLE RESPONSES SELECT ALL THE CODES REPORTED] DO NOT READ OUT
1	Mobility – not been able to walk around the house and beyond
2	Hand function – not been able to hold and touch items
3	Hearing - not been able to hear without hearing aids
4	Vision - not been able to seen without glasses
5	Personal care - not been able to wash, go to the toilet, dress, etc
6	Communication - not been able to speak
7	Communication - not been able to understand or being understood by others
8	Learning - having special educational needs (ability to comprehend the lesson and do the homework) etc
9	Behaviour - a condition resulting in socially unacceptable behaviour
10	Consciousness – loses concentration, consciousness, responsibility over the actions, has tantrums or anger outbursts)
11	Other _____
99	Hard to respond

SINGLE ANSWER	ASK IF [DISA_1 = 1]
DISA_3	Has your child had an assessment regarding his/her disability in the past 2 years?
1	Yes
2	No [GO TO DISA.5]

SINGLE ANSWER	ASK IF [DISA_3 = 1]
DISA_4	Is your child's disability <u>certified by any</u> commission - medical or multidisciplinary – center or hospital?
1	Yes Please Specify : _____
2	No [GO TO DISA.5]

SINGLE ANSWER	ASK IF [DISA_4 = 1]
DISA_4.1	Are you satisfied with the assessment/s? (the process of evaluation, waiting times, the way you were included, the way the team communicated, follow up appointments, medical report etc)
1	Completely Dissatisfied
2	Dissatisfied
3	Neither satisfied nor dissatisfied
4	Satisfied
5	Completely Satisfied
98	Refuse (INT: PLEASE DO NOT READ OUT)
99	I do not know (INT: PLEASE DO NOT READ OUT)

SINGLE ANSWER	ASK IF DISA_4=1
DISA_4.2	Does the child with disability receive a financial compensation/aid for his/her <u>disability</u> ?
1	Yes .
2	No [GO TO DISA.5]

SINGLE ANSWER	ONLY IF CODE 1 AT DISA_4.2
DISA_4.3	Is the financial aid for disability sufficient to fulfil the basic needs of your child with disability and the fees for services related to disability?
1	Completely not sufficient
2	Not sufficient
3	Neither not sufficient nor sufficient
4	Sufficient
5	Completely sufficient
98	Refuse (INT: PLEASE DO NOT READ OUT)

99	I do not know (INT: PLEASE DO NOT READ OUT)
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MULTIPLE ANSWER		ASK ALL	
DISA.5		Does the child receive any support from any public social services, municipality, NGOs, foundations, churches, mosques, faith based organisations?	
1	Yes from the state social services / municipality.	INT: Please Specify the: _____	KALO TE DISA.5.1.1
2	Yes from the NGOs, foundations, churches, mosques, faith based organisations	INT: Please Specify the: _____	KALO TE DISA.5.2.1
3	No support/assistance		KALO TE DISA.5.3.1

MULTIPLE ANSWER		ONLY IF [DISA_5 = 1] -YES FROM THE STATE SOCIAL SERVICES	
DISA_5.1.1		What kind of support/ assistance does your child receive from public, health social and education services [_____]? INT: DO NOT READ STATEMENTS	
1	Financial assistance		
2	Specialized education/training services – an individualised education services plan or assistant teacher		
3	Specialized Health services (Medications and supplies, laboratory tests, Hospital and surgical care, Audiology/ Vision/ Speech/ physical services)		
4	Rehabilitation services (Audiology/ Vision/ Speech/ physical services, Developmental therapy)		
5	Medical equipments (prothesis, crutches, deambulator, wheel chair, hearing aid, adaptable bed)		
6	Food		
7	Care at home		
8	Short-term respite in day or residential centres		
9	Home visitm from a specialist		
10	Psycho-social services (psychologist, psychotherapist, social worker)		
97	Other, please specify _____		

SINGLE ANSWER		ONLY IF [DISA_5 = 1] YES FROM THE STATE SOCIAL SERVICES	
DISA_5.1.2		How adequate is this support/ assistant your child receive sfrom public social services [_____]?	
1	Poor		GO TO DISA.5.3.1
2	Average		
3	Good		
4	Excellent		
99	Refuse/ do not know		

MULTIPLE ANSWER		ONLY IF CODE 2 AT DISA 5. YES FROM THE NGO OR FOUNDATIONS, CHURCHES, MOSQUES, FAITH BASED ORGANISATIONS	
DISA_5.2.1		What kind of support/ assistance does your child [_____] receive from the NGOs, or foundations, churches, mosques, faith based organisations? INT: DO NOT READ STATEMENTS	
1	Financial assistance		
2	Specialized education/training services – an individualised education services plan or teacher		
3	Specialized Health services (Medications and supplies, laboratory tests, Hospital and surgical care, Audiology/ Vision/ Speech/ physical services)		
4	Rehabilitation services (Psycho-social service, Audiology/ Vision/ Speech/ physical services, Developmental therapy)		
5	Medical equipments		
6	Food		
7	Care		
8	Short-term respite in day or residential centres		
9	Home visit		
97	Other, please specify _____		

SINGLE ANSWER	ONLY IF CODE 2 AT DISA 5. YES FROM THE NGO OR FOUNDATIONS, CHURCHES, MOSQUES, FAITH BASED ORGANISATIONS	
DISA_5.2.2	How adequate is this support/ assistant your child [_____]receive from NGOs, or or foundations, churches, mosques, faith based organisations?	
1	Poor	
2	Average	
3	Good	
4	Excellent	
99	Refuse/ do not know	

SINGLE ANSWER	ASK ALL					
DISA_5.3.1	Based on your experience, compare to other children of the same age, how often has your child been faced with any of the following situations of discrimination and exclusion					
NR	OPTIONS	1 = Never	2 = Rarely	3 = Often	4 = Always	99 = Do not know/Refuse
1	In the community where the child lives: the neighbors, extended family, other members of the community	1	2	3	4	5
2	In the nursery, kindergarten, school: from teachers or other pupils/students	1	2	3	4	5
3	In playground, during play or in interaction with other children	1	2	3	4	5
4	In other institutions that provide services (health centres, specialized centres, cultural centres etc.)	1	2	3	4	5

SINGLE ANSWER	ASK ALL	
DISA_6	What are 3 most important services would you like to have in your community, which would help your child (mark the most important 3 in the priority order)? INT: DO NOT READ, BUT CIRCLE THOSE THAT FALL UNDER EACH CODE. MARK THREE THE MOST IMPORTANT	
1	Special transportation	
2	kindergartens/School	
3	Employment opportunities for the child in the future	
4	Parents must be entitle to have short breaks from work during the day, weekends or the school holiday period	
5	Consultation services for the family and children	
6	Information services (legal support and information about the disability, services available etc)	
7	Financial assistance	
8	Specialized education/training services – an individualised education services plan or assistant teacher at class	
9	Specialized Health services (Medications and supplies, laboratory tests, Hospital and surgical care, Audiology/ Vision/ Speech/ physical services)	
10	Rehabilitation services (Psycho-social service, Audiology/ Vision/ Speech/ physical services, Developmental therapy)	
11	Medical equipments	
12	Food	
13	Care at home	
14	Short-term respite in day or residential centres	
15	Home visit from a specialist	
98	Other _____	
99	Do not know	

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