

We All Matter!

Situation Analysis of Children with Disabilities in Albania



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Situation Analysis of Children with Disabilities in Albania



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Foreword

Dr. Roberto De Bernardi

UNICEF Representative in Albania



As long as our environment remains conducive to our needs, we rarely consider how much our abilities depend upon it. Reading the Situation Analysis of Children with Disabilities in Albania has made me reflect greatly on this matter.

It is no surprise that, in Albania, the majority of children with disabilities and their caregivers experience survival challenges each and every day, let alone those of a meaningful personal life, quality education, health care and participation in the life of the community. Nevertheless, what struck me as remarkable is how resilient such children are despite the odds stacked against them and how optimistically they view their futures, in marked contrast to adults.

Not only does this report make a major contribution to our understanding of child disability in Albania and its impact on individual children, their families and society, but it also highlights the barriers that such children face in the health-care, education, social protection and other critical domains. The uniqueness of this study is that, for the first time, it brings children's and parents' voices together directly into the report.

UNICEF has a mandate and moral duty to address barriers to the active participation of children in every issue that affects them, and more so when they are discriminated against. In a situation in which many children with disabilities do not access quality health care, rehabilitation, education, protection and family support services, they will never get the chance to lead decent and productive lives. This report proposes interventions that are required at different levels and will serve as a valuable tool to policy makers, researchers, professionals, child rights advocates, civil society groups, parents and all others involved in addressing disability-related matters in the country.

Executive Summary

Purpose

The purpose of the present *Situation Analysis of Children with Disabilities in Albania* is to generate comprehensive knowledge about children with disabilities to inform concrete actions by the Albanian government and UNICEF Albania to address the most critical rights violations of children with disabilities.

The findings of this study provide evidence for better understanding of the bottlenecks and suggest some critical formative adjustments to fully realize the intentions of the Albanian policy and legislative framework on children with disabilities.

Context

Albania ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2012 and became a state party to the Convention in 2013. In its initial State Party submission to the Committee on the Rights of Persons with Disabilities, Albania reported that the legislation has largely been aligned with the UNCRPD.¹ The policy and legislative framework in support of children's rights and the rights of children and adults with disabilities is dynamic and evolving. However, putting policy into practice is noted to be challenging.² The most recent concluding observations of the UN Committee on the Rights of the Child in 2012³ noted the limited capacity of Albania to implement child rights-related legislation and urged the government to invest in putting policy into practice through improved coordination and resource allocation.

The present study takes place against this background and that of the reform agenda established by the current government following the

general elections of June 2017, anticipation of a date for opening of European Union (EU) accession talks and continued economic expansion.⁴ Recent reforms in public administration in late 2017 have seen a reduction in the number of ministries, from 21 to 14, contributing to a dynamic situation as departments are established, personnel reassigned and budgets allocated. Whilst this has in some instances contributed to deferrals in policy and legislative implementation it also offers opportunities for improved multi-sectoral cooperation through the amalgamation of two sectoral line ministries to create a new Ministry of Health and Social Protection (MoH&SP).

Method

The study enquiry concept considered the life-course of children with disabilities within the context of the socio-ecological framework of human development. A mixed methods approach was applied, with the collection, analysis and integration of qualitative data from focus group discussions (FGDs) and key informant interviews (KIIs), and with quantitative secondary administrative and survey data analysis.

An initial desk review found that the voices of children with disabilities and their parents were largely missing from the extensive body of recent research in Albania. Primary data collection therefore focused on gathering the perspectives and experiences of children with disabilities and their parents, the specialists who work closely with them, parents of typically developing children, and the national and local authorities responsible for implementing policy and legislation. A total of 300 people took part in the study, from four countiesⁱ of Albania, among whom 79 were children with disabilities, of age 10–17 years, 42 boys and 37 girls.

300
people took part in the study in

4
regions of Albania of whom

79

children with disabilities aged **10-17**

Synthesis of key findings

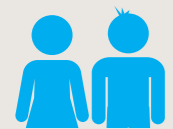
The rights of children with disabilities are increasingly at the forefront of a dynamic and evolving legislative and policy dialogue in Albania. This framework is largely in compliance with core global and EU human-rights instruments and is driving reforms in the development of inclusive services. However, implementation is lagging behind the intention and goals of this framework.

The definition of disability in the Albanian legal framework is largely aligned (with some exceptions) with the UNCRPD. In practice, however, a medical model of disability predominates, including an assessment for certification of disability to access disability allowances. This has consequent effects on access to services and inclusion. A multi-dimensional functional assessment based on the ICF has been tested in a few administrative units of Tirana however an evaluation and plans for the roll out were not available at the time of the present study.

Latest survey and administrative data indicate that 2.5- 4 percent of the child population in Albania has a disability that has been certified by the medical assessment commission.

The medical assessment of children with disabilities can be supplemented by an educational assessment to determine support requirements for inclusive education. However, there is no systemic connection between the procedures.

A focus on developmental milestones rather than definitive diagnosis has been shown to increase the chances for early intervention that will improve a child's opportunities and minimise



2.5% - 4%

of the child population in Albania has a certified disability

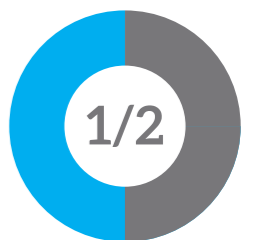
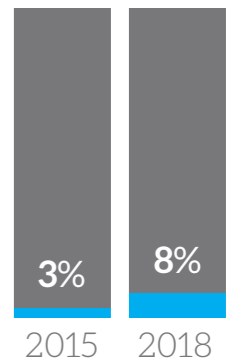
the effect of any developmental delay. However, standardised systems for early identification of developmental delay in children are currently insufficient.

Administrative data suggest that there has been an increase in the number of children with disabilities accessing services, from three percent in 2015 to eight percent in 2017. However, almost half of all social services are provided outside the public sector, and civil society organizations report a gradual withdrawal of external funds, a trend that is likely to continue. ⁵

There is no systematic provision or access to Albanian Sign Language, Braille or assistive devices and technology at affordable cost, significantly preventing the full inclusion of children with disabilities. The civil society sector has provided access on an ad hoc basis. Nevertheless, as noted above, its capacity to sustain the level of service cannot be guaranteed.

Around half of school-age children receiving disability allowance are in education, though many are not accessing education adapted to their individual learning needs. Integration into mainstream schools, has not necessarily resulted in inclusive education. Recent support for inclusive education may be contributing to more positive attitudes, but children with disabilities and their families still report stigma and discrimination in schools and in leisure and play activities, and in their communities.

Children with communication difficulties are particularly isolated.



Most children with disabilities in Albania live with their families. However, such children are also over-represented in the public system of residential care.

No matter where they are living, children with disabilities, including intellectual disabilities, have reported that they are leading busy ordinary lives and that they are enthusiastic about their futures. This is significantly different from the perceptions of their parents, who are less optimistic. Such parental anxiety can limit their ambitions for their children.

Finally, data on children with disabilities are subject to variations in sectoral reporting mechanisms and cannot be correlated. For example, education sector data on children with disabilities have different descriptors from those of State Social Services. Thus, it is not possible to compare prevalence data and access to service data. This places limits on effective strategic planning for broader inclusion of children with disabilities in current services and on planning for future services, in compliance with the existing legislation.

Implications for policy and practice

Structural (Legal and Policy)

Strengthen policies where children's rights and those of persons with disabilities intersect. Children with disabilities are not mentioned explicitly in policy and legislation on persons with disabilities and are mentioned inconsistently in policies and legislation on child protection and social services. Revising policy and, where necessary, legislation to ensure children with disabilities are more visible and that their rights are explicitly upheld could help to communicate more clearly the intentions of the Government of Albania in realizing their commitments to the United Nations Convention on the Rights of the Child (UNCRC) and UNCRPD. This revision should include specific and realistic indicators and targets, and an explicit monitoring mechanism that will support Albania's periodic reporting obligations on implementation of the UNCRC and UNCRPD.

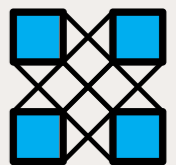


Review budget allocations to address the limited statutory, and diminishing private funding for civil society social service providers. Investment is required to consolidate gains made during the last five years, to assure continuation of service provision for children with disabilities at current levels as a minimum, and to ensure that policy commitments for inclusive services are fulfilled.



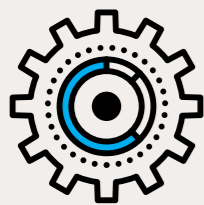
Institutional

Adopt a multi-dimensional approach to disability assessment. Immediate modifications to the current models of disability assessment applied by Medical Commission for the Assessment of Ability to Work (MCAAW) and Regional Education Directorate Multi-Disciplinary Committee for Assessment (MDC) in combination with application of learning

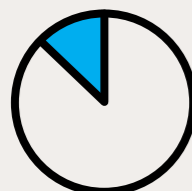


from the International Classification of Functioning, Disability and Health (ICF) assessment pilot ⁶ can support an efficient transition from a medical to a social model, as intended in the legislation. This can include social and family assessment, early identification with the application of developmental screening tools, and, for older children, an educational assessment. A unified multi-sectoral commission can authorise a multi-dimensional package of support that can be reassessed annually as children’s needs change.

- ● [Assure affordable access to Albanian Sign Language, Braille, assistive devices and technology for children with disabilities.](#)
- ● Prioritising implementation of Article 9 of the 2014 Law on Inclusion and Accessibility, which states that assistive devices should be provided, will immediately and irrevocably demonstrate robust government support for children’s right to inclusion. The World Health Organisation Priority Assistive Products List ⁷ can serve as a basis for identification of such a list for Albania, define a minimal level of availability and be expanded incrementally as resources become available.



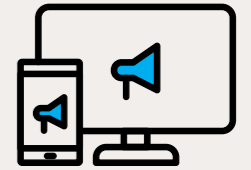
[Align information management systems related to health, education, and social protection \(social care and support, and cash allowances\).](#) Ensure correlated, accurate, disaggregated data based on age, sex and common definitions of a ‘child with disability’. As a starting point, minor adjustments to data collection mechanisms applied by the Ministry of Education, Sports and Youth (MoES&Y) and by State Social Services can create efficiencies in service planning and delivery. In the longer term a fully integrated data management system could help ensure that the situation of children with disabilities can be monitored systematically and policies and services adjusted accordingly.



[Reduce the over-representation of children with disabilities in the public residential care system.](#) There is potential for a quick win in applying the UN Guidelines on Alternative Care for Children and proceeding with deinstitutionalisation of social care services for children with disabilities in Albania.

Community

[Make sure that communities have accurate and up-to-date information about the rights of children with disabilities and government policy in support of those rights.](#) Access to accurate and up-to-date information about government reforms, and the availability of services and supports, will contribute to increased parental confidence, demand-driven access and, consequently, increased opportunities for children with disabilities. At the same time this can enhance the capacity of public sector workers to fulfil their responsibilities, and of communities to embrace diversity.



Interpersonal

[Strengthen the capacity of social care and social protection personnel to work with families and support parents of children with disabilities.](#) This requires workforce planning linked to service planning and development to ensure there are enough people with the right qualifications to ensure more equitable access to services for children with disabilities and support for their families.



Individual

[Expand the current case management approach for child protection to children with disabilities to make sure they can access systematic and holistic support.](#) Although many children with disabilities are optimistic about their futures they often do not access all of the services that they need and their changing needs over the life-course are sometimes not considered. Expanding child protection case management to embrace children with disabilities will involve regular assessment, planning, referral and review to make sure all of their needs are met over the life-course.



Prioritise the participation of children with disabilities in all aspects of societal and political discourse. This means involving them in specific discussions pertaining to their care and support needs, and also involving them alongside typically developing children in all mechanisms where the voices of children and young people can be heard.

Pay special attention to the child protection needs of children with disabilities. Whereas global data suggest that children with disabilities are likely to be disproportionately affected by exposure to violence, abuse, exploitation and neglect,⁸ for ethical reasons the present study did not include questions on the experience of violence. This is because the study of violence against children is a specialist area requiring strict protocols to ensure children are not exposed to additional trauma and risk.⁹ All future research, including national censuses and surveys, should be unequivocally inclusive of children and persons with disabilities, and can be strengthened by improved data coherence at the institutional level.





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List of Acronyms

ADRF	Albanian Disability Rights Foundation
CwD	Children with Disabilities
DCM	Decision of the Council of Ministers
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, 4 th Edition
EU	European Union
FGD	Focus Group Discussion
ICD	International Statistical Classification of Diseases and Related Health Problems,
ICF	International Classification of Functioning, Disability and Health
INSTAT	Institute of Statistics
KII	Key Informant Interview
MCAAW	Medical Commission for the Assessment of Ability to Work
MDC	Regional Education Directorate Multi-Disciplinary Committee for Assessment
MoES&Y	Ministry of Education, Sports and Youth
MoH&SP	Ministry of Health and Social Protection
NAPPD	National Action Plan for Persons with Disabilities
NGO	Non-Governmental Organisation
NSSP	National Strategy for Social Protection
PHC	National Population and Housing Census
UNCRC	UN Convention on the Rights of the Child
UNCRPD	UN Convention on the Rights of Persons with Disabilities
UNICEF	United Nations Children’s Fund
WHO	World Health Organisation

Glossary

The words we use are important because they contribute to our understanding of nuanced concepts and ideas. We need to be particularly careful when discussing disability to make sure we do not use words that can reinforce stigma and discrimination. This means that the associated terminology is continually evolving in an effort to advance the rights-based approach. The present study adopts the conventions reported below as the most widely accepted at the current time. We also reference the English language terms used in this report to describe some of the Albanian social and health services for children with disabilities.

Alternative and augmentative communication	Describes the different methods that can be used to help people with disabilities communicate with others. This can include use of symbols, signing and gesture systems, and can include technology-based devices.
Child	A person under 18 years of age.
Day Centre or Community Day Centre or Day Care Community Centre	Denotes a centre that offers therapies and treatments for children with disabilities according to a fixed timetable, mostly physiotherapy, development therapies and speech therapy. Some of the day centres may also offer day care services where children can spend a part of the day in addition to receiving therapy or treatment sessions. These centres may be: a) public, managed by municipalities or regional authorities with central state budget funding, b) non-profit private, managed by NGOs and funded by donations or payments from service users, or both, or c) profit-making private, run by professionals and offering treatment and a range of development therapies for children with disabilities and funded by fees paid by service users.
Development Centres	State-run residential care services for children and young adults with disabilities of age up to 21 years.

Family	Describes the immediate relatives of the child. This can include parents and siblings, as well as grandparents, uncles and aunts. The definition of family acknowledges that primary caregiver(s) for the child may be extended family members.
Habilitation	A process aimed at helping to gain and keep new skills, abilities and knowledge that contribute to maximum independence. The services include physical, occupational, and speech-language therapy.
Inclusion	Full and effective participation and inclusion in society (Convention on the Rights of Persons with Disabilities, Article 3). In this study inclusion means equal access and opportunity and that all children and adults should be freely and openly accommodated without restrictions or limitations of any kind.
Mental Health Community Centres	State-run and funded centres offering services for people, including children, with mental health problems. These centres provide diagnosis, treatment and therapies and referral to the disability evaluation commission.
National Centre for Care Development and Rehabilitation for Children	A national state-run and funded centre that offers: a) outpatient services for children with disabilities of age 0–6 years in Tirana; and b) 30-bed residential service for children of age 0–6 years who live outside of Tirana.

Persons or people with a disability	‘Persons with a disability 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’ (UNCRPD, Article 1). This definition is extended to include children with disabilities in Article 7, and consequent use of ‘child [children] with a disability’ in the present study. Whilst the word persons is used by the Convention, it is considered formal and for use in legal contexts, whilst people is the more usual and less formal convention. <i>Persons</i> and <i>people</i> are used interchangeably in this document.
Rehabilitation	A process of regaining skills, abilities or knowledge that may have been lost or compromised as a result of acquiring a disability or due to a change in one’s disability or circumstances.
Specialists	People skilled in a specific or restricted field, including habilitation and rehabilitation therapists, teachers and social workers, residential caregivers and day centre workers.
Typically developing child	A child who meets the usual developmental milestones within the usual timescales.
United Nations Convention on the Rights of Persons with Disabilities	A legally binding international agreement and human rights instrument that reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms.
United Nations Convention on the Rights of the Child	A legally binding international agreement and human rights instrument setting out the civil, political, economic, social and cultural rights of every child, regardless of their race, religion or abilities.

1. Introduction

The present Situation Analysis acknowledges that children with disabilities are first and foremost children,¹⁰ that all children enjoy the same rights, and that children with disabilities may need additional support in order to enjoy those rights. Equally, this study is founded on the principle that all discussion around children with disabilities should be unequivocally inclusive.¹¹

This report presents a synthesis of primary data gathered through interviews and focus group discussions (FGDs) and secondary data gathered through an extensive review of legislation, policy, regulations, research reports and official statistical information. The desk review was undertaken at the outset to identify gaps in knowledge about the situation of children with disabilities in Albania and to inform the design of the study.

The initial desk review identified that the voices of children and parents were largely missing from the extensive body of research that has been conducted in relation to children with disabilities in Albania in recent years. The primary data collection therefore focused on gathering the perspectives and experiences of children and parents. This report gives prominence to their voices and to those of others who work closely with children with disabilities and are directly involved in their lives. This does not mean that the secondary data analysis is of less importance in understanding the situation of children with disabilities, but the intention is to make more visible and tangible the lived experiences and perceptions of children with disabilities, their parents and others who are close to children with disabilities.

1.1 Immediate context

This Situation Analysis takes place against the background of the reform agenda established by the current government following the elections of June 2017, which also saw a reduction in the number of ministries, from twenty-one to fourteen. This has contributed to already dynamic situation influenced by anticipation of a date for opening of EU accession talks and expectancy of continued economic expansion.¹²

Meanwhile, civil society organizations, which have traditionally been key development partners, and which have transitioned into social service providers, are also facing a reported shrinking in fiscal space. A gradual withdrawal of external funds is squeezing capacity, a trend that is likely to continue.¹³

Albania ratified the UNCRPD in 2012 and became a state party to the Convention in 2013. In its initial State Party submission to the Committee on the Rights of Persons with Disabilities, Albania reported that the legislation has largely been aligned with the UNCRPD.¹⁴

The introduction of the 2014 Law on Inclusion of and Accessibility for Persons with Disabilities and the 2017 Law on the Rights and Protection of the Child promulgate these rights in national legislation. Similarly, the 2012 Law on Pre-university Education supports the right for free mandatory education for all children, regardless of their needs or special abilities.¹⁵

The introduction of the 2017 Law on the Rights and Protection of the Child references an integrated protection system for children (Article 3.15), while Article 32.2 makes specific provision for children's right to receive services, determined by the responsible structures for the assessment of disability.

The 2015 Albanian National Strategy for Social Protection (NSSP) refers inter alia to establishment of a benefits system based on categorised assessment of both level of disease and social circumstances¹⁶ and considers the legal and policy bottlenecks that lead to exclusion of persons with disability. With specific reference to disability this strategy aims to revise the system of disability evaluation.

The Albanian National Action Plan for Persons with Disabilities 2016–2020 (NAPPD) references significant deficits in the provision of education, social care, and health-care services, and participation and engagement in public life, for children and for the adult population with disabilities. The action plan proposes a set of eight strategic goals, one of which explicitly references children.

The policy and legislative framework in support of children's rights and the rights of children and adults with disabilities is dynamic and evolving. However, putting policy into practice is noted to be challenging.¹⁷ The most recent concluding observations of the UN Committee on the Rights of the Child in 2012¹⁸ noted the limited capacity of Albania to implement child rights-related legislation and urged the government to invest in putting policy into practice through improved coordination and resource allocation. A more detailed analysis of the policy and legislative environment is provided in Section 2.7.2.

1.2 Purpose

The purpose of the present study is to compile comprehensive knowledge about children with disabilities, to inform concrete actions by government and UNICEF Albania and address the most critical child rights violations in Albania. The objectives of the study are to assess:

- the existing and relevant national and subnational legislative, policy and regulatory framework, as well as systems and institutional setup,

- barriers to the provision of quality and inclusive services to children with disabilities,
- forms of deprivation and exclusion of children with disabilities, and the barriers and bottlenecks they encounter in securing their rights, and
- potential areas and gaps in knowledge for further research.

1.3 Approach

In line with UNICEF Guidelines for Disability Situation Analyses,¹⁹ this study applies a human rights-based approach and adopts an equity-focus to reach the most marginalised and least visible children.²⁰ The approach considers the fundamental right to participation, as articulated in Article 12 of the UNCRC, as a central provision to promote inclusive development. It acknowledges that, although a child's right to express their views and have them taken seriously in accordance with their age and maturity has proven to be one of the most challenging to implement,²¹ it is incumbent that the design of the data collection methodology is inclusive. It also acknowledges that participation rights are also connected to the UNCRC Article 13, Freedom of expression; Article 14, Freedom of thought, conscience and religion; Article 15, Freedom of association; Article 16, Right to privacy; and Article 17, Access to information. Equally, it considers the provisions of UNCRPD and particularly Article 4, General obligations, and Article 21, Freedom of expression and opinion, and access to information.

The situational analysis applies a life-course approach which recognises that the needs of infants and younger children will differ from those of adolescents, and that the experiences and development opportunities of childhood will affect an individual's prospects during adulthood.²²

Gender plays a role in exclusion, and girls with disabilities can be doubly disabled in that they confront not only the prejudice and

inequities encountered by many persons with disabilities but are also constrained by traditional gender roles and barriers.²³ With this understanding the Situation Analysis involves girls with disabilities and women who care for children with disabilities in interviews, and reviews the available monitoring data on children with disabilities through a gender lens where possible.

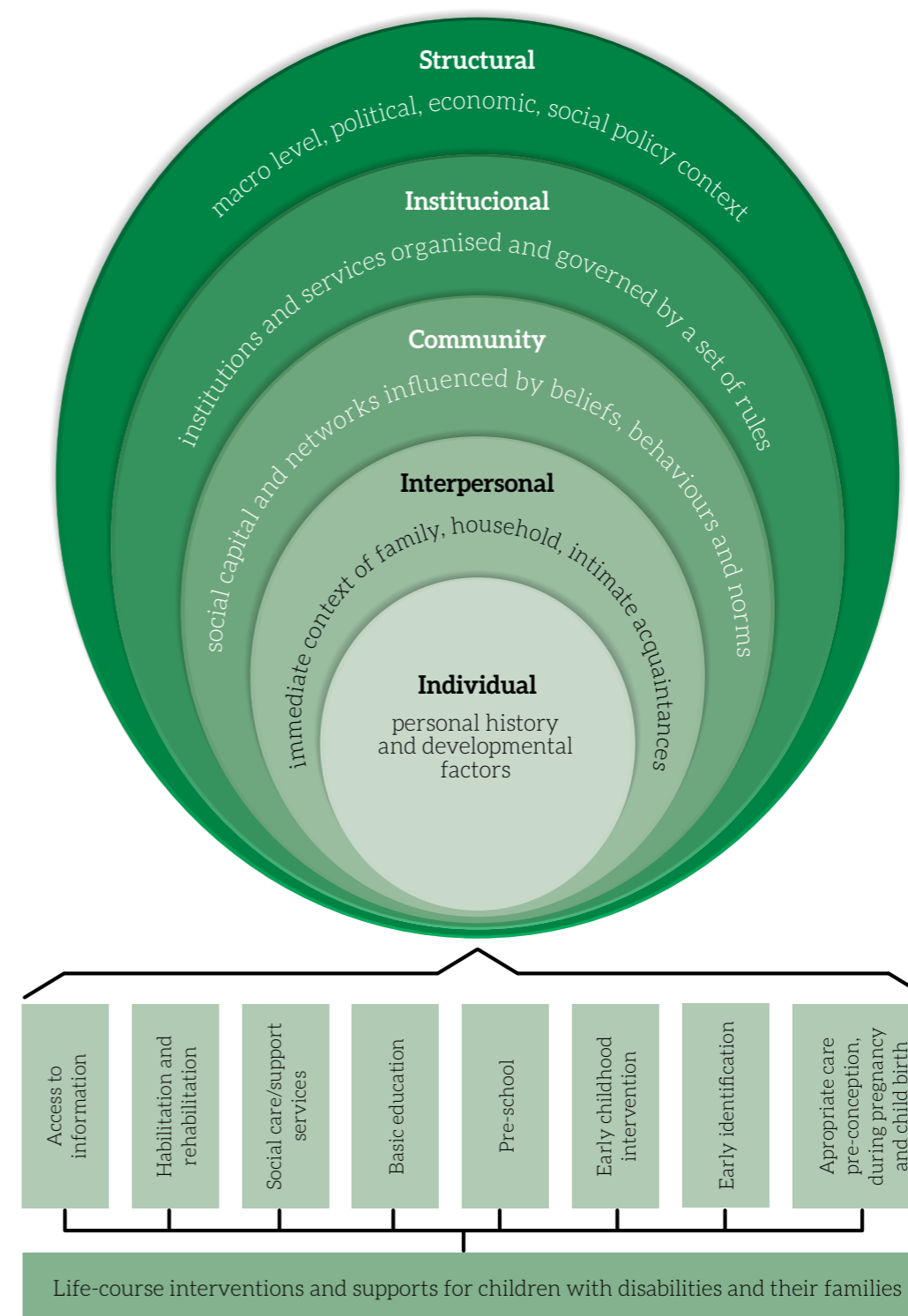
The Situation Analysis adopts a social model of disability based on a biopsychosocial understanding of disability, which is, 'a dynamic interaction between health conditions and contextual factors, both personal and environmental'.²⁴ It is intended to be inclusive, ensuring participation from all key stakeholders, especially children and young people with disabilities and their families, in assessing the environment as a determinant of disability and a barrier to inclusion and participation.

The analysis endeavours to create coherence across traditional disciplinary and sectoral boundaries, such as early childhood development, education, health, social assistance and child protection, and to inform the identification of programme priorities.

1.4 Study enquiry concept

The study considers the life-course of children with disabilities within the context of the socio-ecological framework of human development (Figure 1). It begins with the individual lived experiences of children and parents and moves in parallel through each of the socio-ecological levels²⁵ of family, community, institutions, legislation and policy framed against the basic life-course interventions and supports required to optimise independent living. The full methodology is described in Annex A.

Figure 1.
Study enquiry concept



Source: Adapted by the authors from Bronfenbrenner, U. (1979) *The Ecology of Human Development*. Harvard University Press

1.5 Data collection

This study adopted a mixed methods approach. An extensive review of secondary data informed the design of the primary data collection methodology (Annex A). The data methods were primarily qualitative and based on semi-structured interviews (Key Informant Interviews, KIIs) and focus group discussions conducted during February and March 2018. The analysis integrated quantitative secondary administrative and survey data.

Training was provided for the Albanian research and data collection team based on an extensive research guide. This was collaboratively developed by the research team, which included two international consultants, by UNICEF and by Government representatives. Ethical approval was provided by the UNICEF independent Ethical Review Board.

A total of 300 adults and children were interviewed or took part in FGDs. This included 15 FGDs with 26 regional and municipal authority representatives and 64 health, education and social care specialists and residential care staff; four FGDs with 22 parents of typically developing children.

KIIs were conducted with 79 children with disabilities of age 7–17 years (and one young person who turned 18 years of age one month before the interview), with 88 families of children with disabilities of age 2–17 years (and one 18 years of age). Nineteen carers in residential institutions were interviewed about the children in their care with disabilities of age 0–17 years (and two young people who had recently turned 18 years). Age, sex and other characteristics of the children and adults who were interviewed or who were the subjects of interviews are summarised in Table 8 (Annex A). 43 girls and boys were interviewed in rural areas (Gramsh and Berat) and 37 in urban areas (Tirana and Kukës).



Parents interviewed



53 About boys



36 About girls



Boys and girls interviewed



42 Boys



38 Girls



Children who gave partial or no response



18

Children in residential care



Carers interviewed

1.6 Study limitations

The KIIs and FGDs with children and adults were not intended to generate data that can be generalised as being representative of the experience of the whole population in Albania of children with disabilities and their parents. The data gathered are qualitative and provide some insight into their lived experiences and the experience of the teachers, social workers and other specialists who work with them. The quotations included in this report are, however, representative of the types of responses that were obtained from children, parents, caretakers, specialists and local authorities, and can provide insights into their experiences and perceptions.

The validity of responses obtained during the primary data collection may have been affected by the characteristics of the researcher and the perceived power relationships. These relate to age, gender, ethnicity, nationality, education, socio-economic status, among others, and may have had an impact on a free and open exchange of views. Some of the responses may have been affected by bias in social desirability: the tendency of some respondents to report an answer in a way they deem to be more socially acceptable than would be their 'true' answer.²⁶ This may have particularly affected the reporting of children's views that may have been inadvertently influenced by the interviewer.

Similarly, nuances in communication may have gone unnoticed during data translation.

Data collectors reported some difficulties in communication with children with some disabilities. This is referenced further in Section 3. With the exception of four FGDs with parents of typically developing children, the sample of primary data sources was limited to those with direct knowledge of disabilities. Future research may benefit from the involvement of other community members, including typically developing children, particularly with reference to social norms.

The children and parents were identified by local coordinators with a knowledge of disability and of services in the area. They were mainly identified through lists of disability allowance recipients or through local providers of services to children with disabilities. Although researchers asked respondents in FGDs, household interviews and KIIs if they know of, and could introduce the researchers to, children with disabilities whose families are not accessing services or allowances, only three of the children interviewed were not, or had never been, in receipt of disability allowances or services. This means that the perspectives of an important group of children and parents are in large not captured by this study. This illustrates the complexities of capturing accurate disability data. Future research should attempt to specifically target these children and families.

Equally, whilst global data suggest that children with disabilities are likely to be disproportionately affected by exposure to violence, abuse exploitation and neglect,²⁷ for ethical reasons this study did not include questions about the experience of violence. This is because the study of violence against children is a specialist area requiring strict protocols to ensure they are not exposed to additional trauma and risk.²⁸ Future research on children in Albania, including research on violence, should be deliberately inclusive of children with disabilities.

There are some outstanding queries on discrepancies in the administrative data provided to this study, on recipients of child disability allowances and social services and enrolment in education. These require further investigation but the data have been included in the report as they also illustrate some of the existing challenges in the data monitoring system.

2. Results and analysis

This section reports the main findings of the study, dedicating one sub-chapter to each key finding. It begins with a definition and assessment of disability in Albania and, thereafter, is structured in accordance with the study enquiry concept described in the methodology (Annex A.) Each sub-chapter draws on both primary and secondary data and highlights areas requiring further study, research and actions, where relevant.

KEY FINDING

The definition of disability in the policy and legal framework is largely aligned (with some exceptions) to the UNCRPD social model of disability. In practice, however, the medical model of disability largely prevails, and is codified by the disability assessment system.

This fundamental disconnect presents a major challenge for the ability of duty-bearers to implement the legal and policy framework. Differences in definitions and understanding of disability between social, health and education sectors impact data monitoring and planning.

2.1 Definition of disability in Albania

Defining disability has proven to be complex, dynamic, multidimensional, and contested.²⁹ The biopsychosocial model applied by the International Classification of Functioning Disability and Health (ICF) suggests that 'disability is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)'.³⁰

The biopsychosocial model of disability is currently accepted as the preferred conceptual model of disablement because it simultaneously recognises three components of disability: the biologic component (the physical and mental aspects of an individual's health condition), the psychological component (personal and psychological factors that are having an impact on the individual's functioning), and the social component (contextual and environmental factors that may also have an impact on functioning) in each particular case.³¹

UNCRPD notes that 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.³²

The definition of disability in the Law on Inclusion of and Accessibility for Persons with Disabilities of 2014 is aligned with UNCRPD, but not all legislation is similarly aligned. The 2012 Law on Pre-university Education, for example, defines a student with disability as: a person having long-term physical, mental, sensory, attitude-related deficiency, or a combination thereof, which, in concert, may prevent them from fully and equally participating in education and social life

The present study adopts the convention of the Albanian National Action Plan on Persons with Disabilities 2016–2020, derived from UNCRPD and WHO designations and considers disability in the context of:

- impairment—a problem in body function or structure,
- an activity limitation—a difficulty encountered by an individual in executing a task or action, and
- participation restriction—a problem experienced by an individual in involvement in life situations.

It recognises that a child may experience one or any combination of these three designations and that these may change throughout the life-course.

KEY FINDING

Children and their abilities continue to be defined by a medical assessment process which tends to exclude children with mild to moderate functional difficulties.

Although the legislative and policy framework on defining and assessing disability is robust and aligned closely with UNCRC and UNCRPD, there are considerable challenges in implementation.

The medical assessment for disability is the primary and most institutionally entrenched form of disability assessment. It controls entry to the system of disability allowances and services for both children and adults. In the medical assessment children with mild to moderate disability are commonly not defined as having a disability. This impacts upon the prevalence rate of children with disabilities and upon the ability of families to access support and services for a child with mild or moderate disabilities.

2.2 Disability assessment

The 2014 Law on Inclusion of and Accessibility for Persons with Disabilities makes provision in Article 10 for a multi-disciplinary commission to assess disability based on the ICF. In 2016, a Decision of the Council of Ministers (DCM) established a pilot multi-disciplinary disability assessment (based on multi-faceted ICF-based assessment) in two administrative units of Tirana. The pilot programme has been supported by the World Bank and intends to link children and persons with disabilities and their families to a more flexible package of services and support. The pilot is inclusive of children aged two years and above. At the time of reporting, the outcomes of the pilot are not yet available and no plan for scale-up has been announced.

In practice there are currently two types of disability assessment for children in Albania, one focused on health conditions, and the other on education needs.

The medical assessment is conducted by the Medical Commission for the Assessment of Ability to Work (MCAAW) and can take place at any time in a child's life.

The MCAAW evaluation committee consists of five members, specialist doctors such as a surgeon, paediatrician, neurologist, cardiologist and pneumologist. The assessment is performed in accordance with the standards adopted for this purpose. So far, the evaluation commission carries

out the assessment of people with disabilities based on the International Statistical Classification of Diseases and Related Health Problems, ICD-9.³³ The cases are referred by a specialist doctor. (FGD, medical specialists)

Children with mild to moderate disability are generally not assigned disability status as a result of this assessment.³⁴ The regulation on assessment (DCM no. 362 of 2007, as amended, 2008, 2017) lists different types of diagnosis according to ICD and DSM-IV³⁵ and is focused on assessing whether the diagnosis means that the person being assessed should be permanently eligible for disability benefits and allowances.

There is no separate directive for assessing children, though Chapter XI of the regulation is focused on Paediatric Diagnosis of Children and Adolescents, and Chapter VI on Neuropediatric Diseases.

This approach relies entirely on medical diagnosis and allows little room for consideration of the child's individual characteristics, abilities and immediate environment. Significantly, some conditions, e.g. Down syndrome, are excluded from the list. Children without a diagnosis but experiencing difficulties in functioning, especially 'invisible' difficulties such as developmental delays, intellectual disabilities or autism, are unlikely to qualify for an assessment until their condition reaches a stage of becoming obvious or visible. This mitigates against early identification and early intervention. Parents consulted in December 2017 in preparation for the field work for the present study reported difficulty in diagnosis even of genetic conditions such as Down syndrome, which can be diagnosed at birth:

“[She was born] two months premature. There was no information. The doctors said she was healthy. Then she spent two months in intensive care, and after that we were told to do a genetic chromosomal examination. We had to do this abroad, although the state should do this but doesn't, and then two months later we found she has Down syndrome.

(FGD, parents of children with disabilities)

Structurally, the MCAAW assessment can provide access to a disability allowance and pension for the child's, and a carer's allowance where the child is assessed as needing extra care, and to social services.

Some parents report considerable delays between diagnosis and applying for disability status at MCAAW. One mother explained how she could not accept her daughter's condition and this led to a long delay both in seeking medical help and disability assessment:

“In the beginning, when we realized there was something wrong, I did not want to accept my daughter's illness and it was embarrassing to be at the commission. I thought her speech was just delayed and she could go to school later. When I saw there was no development I went to Tirana and the doctors directed me to the commission here in Kukes. Actually, there is an assistant teacher for children with disabilities in the school but the results are not good. I think my daughter is more in need of a specialized individual and not just an assistant teacher.

(KII, mother of 14-year-old girl studying in grade 3 in a mainstream school diagnosed at 6 years of age with autism, and conferred disability status at 13 years of age)

Several parents who waited for many years to apply for a disability assessment for their child report that they had difficulty in accepting their children's limitations and had not wanted them to be labelled disabled:

“In the beginning, we didn't want to get the status. For us it was hard to accept the fact that our child had a disability and for a long time I didn't want to get the status. When he turned five, then we accepted his disability and decided to accept the status. The process was easy. We didn't have any problem with the process afterwards.

(KII, father of a 14-year-old boy diagnosed with epilepsy at age 3 months with disability status conferred at 4 years)

Other parents of children with disabilities report that they took a long time to apply for the disability status because they didn't know about it or about the application process:

“We didn't know at first that we could get the status. We heard about it from other parents.

(KII, mother of 3-year-old girl diagnosed with epilepsy at 1 year of age and disability status conferred at 3 years)

Of 81 parents interviewed who provided information, four had not applied for disability status for their child even though they had been diagnosed with a serious health condition, 27 had applied at the time of the diagnosis, 10 had the status conferred within one year, 18 within three years, and for 22 their child received disability



Parents interviewed who provided info

4 not applied for disability status for their child

27 applied at the same time as the diagnosis

10 had status conferred within 1 year

18 had status conferred within 3 years

22 had status conferred within 3-10 years

status within 3–10 years of diagnosis. In a few cases this was because of periods living abroad (in some cases for medical diagnosis and treatment for the child).

Otherwise the two main reasons given by parents for delaying application to the MCAAW were (i) lack of information about how to apply for disability status, and (ii) difficulty in coming to terms with the child’s condition.

For children of school age, the MCAAW assessment also forms the basis for an education assessment that provides recommendations for an individual education plan.

The education assessment is conducted by a Regional Education Directorate Multi-Disciplinary Committee for Assessment (MDC) and takes place before or during enrolment in school or at some point during a child’s school attendance. The MCAAW assessment has primacy over the education assessment:

Children with disabilities are identified by parents, then assessed in the MCAAW and then presented to the MDC. Identification of children with disabilities is also done by a school psychologist who communicates with the parent to refer to the evaluation committee. There are no legal acts defining the standardised protocols of the assessment process of children with disabilities in the MDC at Regional Education Departments. (FGD, education specialists)

It is possible, nevertheless, for children with medical disability assessment not to have an education assessment, or for schools to identify children without

a medical assessment as requiring an education assessment. Education specialists and local authorities report that some parents are reluctant to have their child assessed by the MDC, even in cases where the school or the education authorities have recommended that the child be assessed as they are not making progress in their education. The law does not currently require parents to have their child assessed. The result is that children who may require additional educational resources do not access them. Teachers also struggle because children do not have an individual education plan and because there is no adapted curriculum. Specialists report their frustration with this situation:

Although the child has a medical report that verifies his or her limited ability or is referred to as a child with special learning needs, the parents do not bring the child to the MDC. This causes the children not to be treated individually in the school, thus depriving the children from receiving the support they need during the class session. (FGD, education specialists)

Education specialists and local authorities reported during FGDs that parents did not want their children to be assessed by the Multi-Disciplinary Committee for Assessment because they fear the child would be treated differently as a result or sent to a special boarding school. However, no parents interviewed for this study confirmed this view, demonstrating a dissonance between the perceptions of professionals and parents. One parent said she hoped her child could attend a special school so that he could learn sign language. Several children of the parents interviewed were attending specialized residential boarding schools away from home, with some returning home at weekends. Some parents indicated that they have tried a number of different options to secure an education for their child. The experience of children and parents and education specialists in relation to education is explored further in Sections 2.6.1 (pre-school education) and 2.6.6 (education).



Taken as a whole,

the situation reported above means that although the legislative and policy framework on defining and assessing disability is robust and aligned closely with UNCRC and UNCRPD, there are considerable challenges in implementation. Children and their abilities continue to be defined by a medical assessment process that tends to exclude children with mild to moderate functional difficulties.

Medical assessment represents a major bottleneck to implementation of the wider legislative and policy framework that guarantees the rights of children with disabilities. It also has knock-on implications for data collection and monitoring of policy implementation and rights realization, as well as more widely for planning and monitoring service provision.

There is no systematic coherence between the medical and educational assessment procedures, reducing efficiency and possibly contributing to limited access.

Families of children with disabilities require social support from the earliest opportunity to ensure they and their children can access services.

2.3 Individual: personal history and developmental factors

KEY FINDING

Children with disabilities consider that they lead ordinary lives and want ordinary futures like other children in Albania. However, this does not align with the less optimistic views of their parents.

Consulting with children has enabled the present study to capture the highly personal and individual life experiences and vision for the future of many children with disabilities for studying, employment, living independently and having their own families.

In many cases the perspective of the children runs contrary to their parents' less ambitious vision, while parents perceive a disconnect between the ambitions of their children and the reality that the parents think their children will encounter as young adults. This points to the importance of providing information and support to parents to improve their outlook and, consequently, assist their children to achieve their ambitions. It also confirms the importance of including children with disabilities in all future studies related to their situation.

KEY FINDING

Very few children with disabilities are accessing, systematic support to realize their rights, map out their future life path and sustain their ambitions for independent lives as adults.

Supports that can be adjusted to children's changing needs over time can assist them in achieving their future ambitions and are critical to achieving inclusion. Similarly, social support is required by parents to help them encourage their children's ambitions.

Albania has initiated policies to develop inclusive education and some community-based services providing habilitation therapies. Other services delivered systematically are required to ensure full inclusion and participation, such as social work case management, whereby a professional social worker collaboratively assesses the needs of the child and the child's family and arranges, coordinates, monitors, evaluates and advocates for a package of multiple services to meet the particular child's complex needs.

KEY FINDING

Children with severe communication difficulties are particularly isolated and excluded.

Interviews with children highlight that it is communication difficulties that most profoundly limit inter-personal relationships and inclusion, and not necessarily their intellectual ability or other factors such as living in a rural area.

Further research is required to better understand children's experiences and their lives.

2.3.1 What children with disabilities and their families say about their daily lives and futures

The individual characteristics of children, their personality and personal history are factors that affect their development and their experience. A shy child, for example, might react differently during medical assessments at school or in a day centre from a child who is more outgoing and social. At this level, the nuance of individual preference and personality is important for planning developmental therapy, individual education plans and for supporting inclusion on a day-to-day basis in schools and pre-schools or in the community. For the purpose of the present Situation Analysis the focus is on responses of children that reveal their individual personality and preferences and illustrate how important these are to their daily lived experience. The things that make them happy and enthusiastic can be encouraged by their parents, teachers and social workers and can lead to greater engagement and participation in the world around them and the lowering of barriers to participation.

Leisure and play

Several children interviewed for this study describe busy lives engaged in music, sports or other activities, but these are children who have few difficulties in functioning especially in relation to communication and mobility. One boy who is blind says that he plays football (the ball has a bell inside it so the children can hear where it is) with other children who are blind at the residential school in Tirana that he attends as a boarder:

“I do lots of activities at the school. I play the ringing ball. It is my favourite game and I play it often at school. I also use the Internet and take part in music programmes at school. I want to be a football player with the ringing ball but there is no team for us to compete in or to form a competition with others. .

(KII, boy, 15 years of age)

Just as typically developing children do, a number of children with disabilities report that they spend time using the Internet. Others report that they would like to use the Internet, but don't have access. Children in residential care institutions who have moderate intellectual disabilities also describe ways that they spend their time outside of the standard activities run by the institution:

“I like to cook and sometimes I go to the kitchen where I help the cook. I like to take care of the two chickens that are here and I get eggs from them.

(KII, boy, 9 years of age, residential care institution)



Daily routines

The normal daily routines described by children with disabilities are very similar to those of typically developing children. They are affected, however, by their own personality and developmental factors, as well as their immediate family and community environment. One boy with intellectual difficulties living in an isolated rural area describes a very ordinary life, but finds it difficult to understand his friends:

“I wake up in the morning, go to the toilet and wash my face, eat breakfast and then go to school with my brother. I take the bus to reach school. After school I like to stay at home. I do all these things myself, but my mum makes breakfast. Mostly, she takes care of me. I see her every morning before school and when I come back from school she has lunch with me. I play with my brother and older sister. I don't really do chores, but I sometimes help my dad get the wood for heating. I have friends in school and I see them every day when I go to school and when we don't have lessons we play outside in the yard. I do need help understanding. I often do not understand my friends well.

(KII, boy with moderate intellectual disabilities, 14 years of age, lives with his mother and father and four siblings, both parents have incomplete secondary education and are unemployed)

A child with severe mobility difficulties living in an urban area with his unemployed divorced mother and two siblings in a rented room ought, perhaps, to have better access to services and support than his rural peers. He, in fact, describes a more socially isolated life:

“Today I woke up, had breakfast and stayed at home with my family. My mum helps me on her own. I have two younger brothers and spend a lot of time with them. I don't have friends. My parents are divorced. I don't go to school because I don't like school, I have no friends and I feel bad there. I would like to do painting and music, but don't. I would like to be able to play more outside. I need a wheelchair but don't have one.

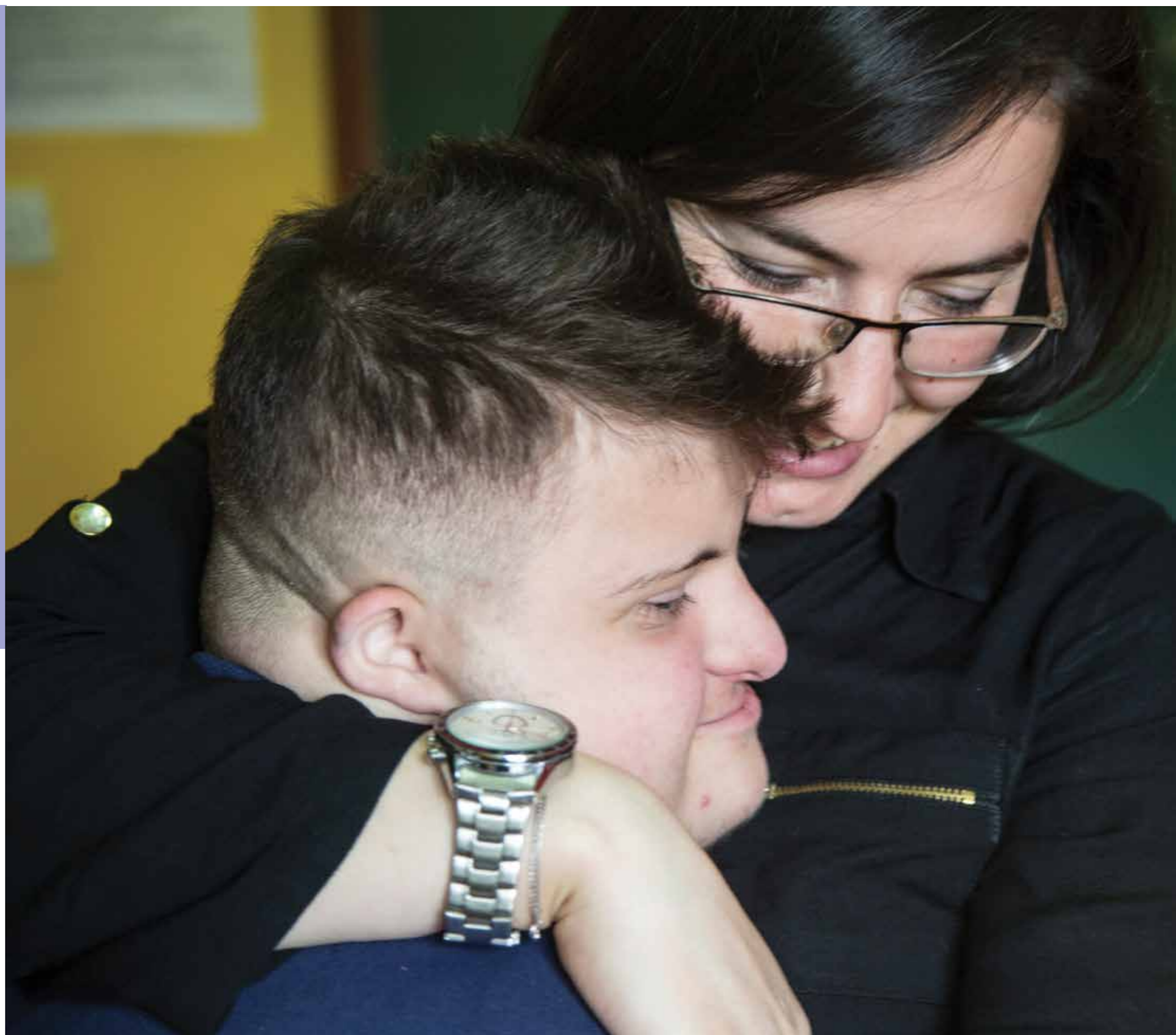
(KII, boy with severe mobility difficulties, 13 years of age)

He says that he wants 'to grow up and live with his mother abroad'. His mother, when asked if there are activities that he would like to do but doesn't said, "I don't know, he doesn't express himself much." While this boy has little contact outside his family, a girl with moderate intellectual disabilities describes what seems to be a contented life, even though isolated from both family and the world outside the residential care institution where she lives:

“Today was a normal day. I woke up, dressed myself, had breakfast and watched TV. I see my friends every day. I live with them here in the residential center. I don't need help with anything. We have two dogs and I like to play with them and I like to listen to music. I don't go to school [outside of the residential center]; we learn things here inside. I help with the laundry, in the kitchen and I help other children when they need to eat. I would like to go out of the center and go around the city. I have a brother and two sisters and I see them when I go home for the summer and winter holidays. I like to stay with my family. When I grow up I want to go to university and be a doctor and live alone in Berat or Tirana.

(KII, girl with moderate intellectual difficulties, 16 years of age)

Several interviews were conducted with children who have severe difficulties in communication, including several boys and girls with autistic spectrum disorders. Although some of these interviews yielded limited personal narratives, the interviewers were able to observe children and to note their interactions with parents or carers.



Children with severe communication difficulties appear particularly isolated, although further research is required to better understand their experience and their lives. Until then, the report is reliant on the perceptions of parents who may still be coming to terms with their child's diagnosis and the implications for their own lives:

“I want him to be like everybody else. I want him to talk and have his own life. I would like for him to live in Tirana because there are more services and opportunities. Here he doesn't have a future. All I think is what will happen to him when I am gone.
(KII, mother of a 6-year-old boy, living in a city).

Where children with severe communication difficulties did respond, their lives, like those of other children with disabilities, are noted to be both ordinary and highly individual. One girl with an autistic spectrum disorder described her love for her sister and her friends, her life with her family and her activities at school:

“I eat and dress myself and I help in the house by tidying the room when we have visitors. My mother and sister help me. I love my sister and play with her every day. I walk to school every day. It takes five minutes. I have some friends at school. I love my friends and we often play in the school yard. I like maths, music and painting. I like very much to go to the day center. All the teachers in the day center are very good and I love them very much. When I grow up I want to work in the day center.
(KII, girl aged 14 years, living in a city with her mother, father and sister).

Vision for the future

Many children who responded to a question about what they want in their future said, “I don't know,” or “I haven't thought about it.” Others, especially some of the children with few functional limitations who attend mainstream schools and participate in extra-curricular activities, have well-formulated ideas of their future plans:

“I want to be a singer and I practise singing at the cultural center. It is what I like to do. I also have said it to my mother. I want to go to the College of Arts and be a singer, but I would also like to be a policewoman if I can't be a singer. I want to live in Tirana with my sister and mother.
(KII, girl, 15 years of age)

“I would very much like to go to university to the medical faculty to become a doctor, maybe because the situation and illness I have is completely related to medicine. I would like very much to move and walk freely without anyone's help.
(KII, girl, 14 years of age)

Several children connect an interest in studying medicine with their health conditions and experience of the health system. Others reflect other aspects of their lived experience when they say they want to work in a day center or as a teacher in a school. Like many typically developing children, those with disabilities also see their futures in terms of professions that have caught

their imagination through TV and film: “ballerina”, “football player”, “policeman”, “hairdresser”, “stylist”, “truck driver”, “sometimes I think I want to be a dentist and sometimes I want to be a mechanic”, “to work in fashion”, “painting”, “basketball player”.

Several children talked about learning languages and working as translators of English, Italian or German. Many children talked about wanting to live abroad, in Italy, Greece, Germany or America.

One child who is blind is very clear that, whatever she ends up doing, she wants to use Braille:

“I want to go to university, but the books must be in Braille and I want to be a pharmacist, but on one condition, even the medicines must be written in Braille.

(KII, girl, 10 years of age)

Some children interviewed have very straight forward ambitions saying, “I just want to grow up”, “I want to walk and play with my friends.”

One child said that her mother has a clear idea of what she should do even if she doesn’t, although she does have a vision of living in her own home in a relationship:

“I don’t know what I am going to do. My mother tells me to be a seamstress. I don’t want to go to university. I want to have my own home and to live with my husband or partner.

(KII, girl, 15 years of age)

Generally speaking, the children with disabilities who were interviewed see themselves participating in society, going to university or professional college and living independent lives or semi-independent lives with their families. As a rule, however, many of their parents and carers have a more practical, less ambitious and bleaker vision of their futures:

“She sometimes says she wants to be a ballet dancer and a singer, but I want for her a more profitable and secure job. I want for her employment and to have an independent life. I want her to live in Tirana, because she can have more support there.

(KII, parent of a child with a disability)

“I want him to be able take care of himself and be independent, but I am very sceptical. I hope for a miracle. (KII, parent of a child with a disability)

“I want her to be able to live on her own. I am so afraid for her future. What kills me every day is who will look after her when I am gone. Who will take care of her?

(KII, parent of a child with a disability)

Several parents express a great deal of anxiety about how their children will cope when they are no longer able to care for them.

Others emphasize that they just want a normal life for their child, a wish that echoes the usual hopes for the future expressed by all children:

“I want her to have a normal life, to be like other Albanian girls.
(KII, parent of a child with a disability)

Others think that this normal life can only be found abroad:

“I want her to do whatever she wants. I want her to have her own family. It would be better if she lived outside of Albania, away from prejudices
(KII, parent of a child with a disability)

This echoes the vision of some of the children to move abroad. Meanwhile, many parents perceive Tirana as offering greater opportunities and more chances for inclusion and services than do other cities in Albania.

Ultimately, the vision for the future of both children and parents is as individual as each child and his or her personal situation and developmental factors. Children with disabilities are first and foremost children and, in this study, expressed similar hopes and fears as other children. Their parents, however, may be more anxious about their child's future than those of typically developing children and may communicate such anxiety in terms of limited ambitions for them.

If we had not consulted children, we would not have understood that they do not see themselves as disabled but as typical children leading ordinary lives; nor would we have understood the extent of their vision of themselves as growing up to lead ordinary lives. As they become adolescents and begin to think about their independence the dissonance between the ambitions of children and those of their families may exacerbate existing tensions arising from stigma, discrimination and lack of opportunity.

Consulting with children, and not only adults, has emphasized the importance of life-course planning for children with disabilities from birth and early childhood through to young adulthood and independent living. If parents have greater confidence in the future for their children from the outset, they will be better able to support their ambitions and hopes for one that is positive.

This approach means that children with disabilities become active agents in realising their own rights and achieving their goals in life and that their parents, family members, social workers, teachers and other people in their lives become their allies. [A system of social work case management to support life-course planning can encourage both children and parents to align their ambitions and vision and identify opportunities for development.](#)

However, making this approach to right-based life-course planning a reality is impeded by limited explicit mention of children and inconsistencies in the legislative framework.



Taken as a whole, this means that,

although children with a range of disabilities, including intellectual disabilities, told us that they are leading busy ordinary lives both in residential and family settings, this is significantly different from the perceptions of their parents. This suggests that **parents and families need improved support to become allies in supporting their children's ambitions.**

Increased capacity for alternative and augmentative communication, including Albanian Sign Language, Braille, and access to assistive devices and technology, will break

down the isolation and support the inclusion of children with communication difficulties.

An understanding of disability and disability assessment that takes into account the individual views and personal characteristics of children with disabilities and their immediate environment can help to open the door to the development of social services. A system of case management delivered by professional social workers can work with children and their parents and carers to support each individual's life-course and coordinate a package of support that is tailored to each individual as far as possible.

UNCRC general comment No. 4 on inclusive education (Article 24) and general comment No. 5 on independent living (Article 19), especially section 89 on inclusive education as preparation for independent living, provide a robust basis for further moving forward with the inclusion agenda in Albania and the realization of the rights of children with disabilities. These general comments should also be considered, especially as they intersect with UNCRC articles 2, 3, 9, 12, 18, 23, 28 and 29 on non-discrimination, best interests of the child, non-separation from parents, respect for views of the child, parental responsibilities and

state assistance, children with disabilities and rights to, and goals of, education.

Services that can accompany children through their childhood and adolescence and into adulthood and support them and their parents to have hope in the future and to map out a life path into further education, employment and independent living in the community are key to achieving inclusion in the long term. Albania has begun on this path with policies to develop inclusive education, but other services are required to ensure full inclusion and participation.

KEY FINDING

Most children with disabilities in Albania live with their families but are nevertheless over-represented in residential care.

A cautious interpretation of available administrative data suggests that most children with disabilities in Albania live in the care of their families. However, the data also indicate that children with disabilities are significantly over-represented among the residential care population, especially public residential care, and are less likely than other children to be living in family-based alternative care.

Because the numbers are small there is a realistic opportunity to achieve family-based care for all children with disabilities.

2.3.2 Where children with disabilities are living

Children with disabilities are over-represented in residential care systems around the world and in the Europe and Central Asia region³⁶ and are at risk of relinquishment or abandonment at a young age because of lack of family support, stigma and medical models of disability,³⁷ and of being placed into segregated, residential education facilities away from home.³⁸

The quality of the administrative data provided to this study on users of State Social Services allows for cautious conclusions to be made. For example, data on children with disabilities are not disaggregated for children without parental care who are in the care of residential development centers; the State Social Services only records children with disabilities in residential care for six state managed development centers (residential care institutions for children and young adults with disabilities of age 0–21 years); data for NGO, or other non-state, service providers do not distinguish between day care and residential care provision. Challenges related to monitoring data are more fully explored in Section 2.7.1 of the present report.

State Social Services nevertheless report 45 children with disabilities in public residential care at the end of 2017, around 18 percent of children in public residential care (Table 1).

The prevalence rate for children with disabilities (discussed in Section 2.7.1 of this report) is considered to be between 2.5 percent and 4 percent of the child population. Even the

conservative estimate that only counts children with disabilities in development centers points to children with disabilities being over-represented in the residential care system and significantly over-represented in the public residential care system. The proportion of children with disabilities recorded in development centers at the end of 2017 was only 0.3 percentⁱⁱ of the population of children with disabilities who were receiving disability allowances that year. Given that only 0.09 percentⁱⁱⁱ of the whole child population was in residential care in 2017, this confirms that, while only very few children with disabilities are in residential care, they are much more likely than other children to be in residential care. Caretaker services (foster/kinship care) for children with disabilities without parental care have been developing since 2012,³⁹ but children with disabilities represented only four percent of children in foster/kinship care in 2017 and this percentage has halved from eight percent in 2015 (Table 1 Line J).

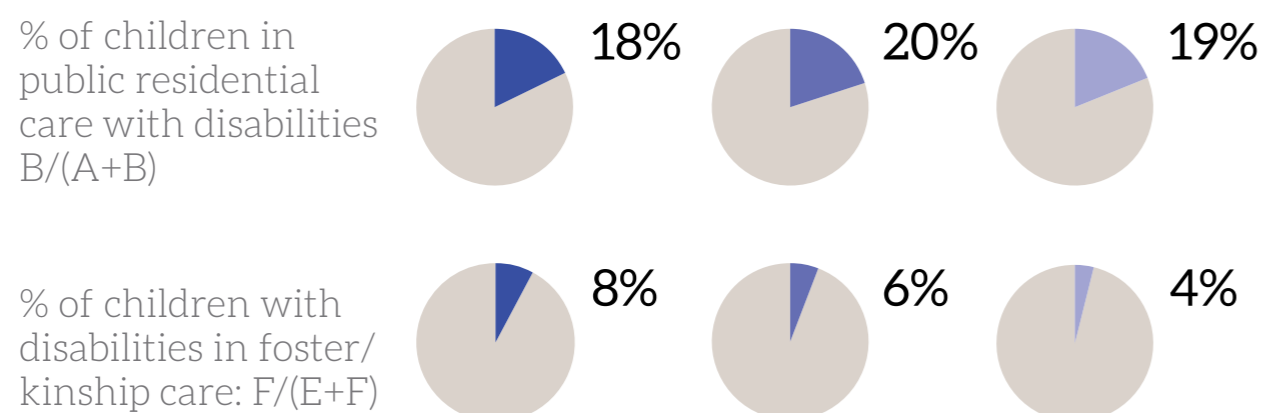


ii Based on State Social Services data 14,155 children were receiving disability allowances in 2017.
iii Based on INSTAT estimates the child population on 1 January 2018 was 631,160.

Table 1.
Number of children in public residential institutions and formal foster/kinship care in Albania, 2015–2017

		YEAR*		
		2015	2016	2017
A	Total number of children in public residential care (state children's homes)	223	179	189
B	Number of children with disabilities in development centers (public residential institutions for children and young adults with disabilities of age 0–21 years)	49	46	45
C	Total number of children in non-public residential care (NGO children's homes)	342	335	350
D	Total number of children in residential care of all kinds A+B+C	614	560	584
E	Total number of typically developing children in foster/kinship care	178	213	259
F	Total number of children with disabilities in foster/kinship care	15	13	12
G	Total number of children in alternative care of all kinds: D+E+F	807	786	855
H	Total number of children with disabilities in alternative care of all kinds: B+F	64	59	57
I	% of children with disabilities in public residential care: B/(A+B)	18	20	19
J	% of children with disabilities in foster/kinship care: F/(E+F)	8	6	4

Source: Authors calculations based on data of State Social Services; *refers to figures at the end of the respective year



The above figures suggest that although the number of children with disabilities in alternative care in Albania appears very low (57 children in total in 2017 according to the data reported in Table 1 Line H), they are more likely to be in residential care than placed in foster/kinship care and are thus over-represented among the population of children in residential care, especially public residential care.

Several children who are blind or deaf in residential boarding school have regular contact with their families, going home regularly and frequently (at least once every 2–3 months or more often). Thirteen children with disabilities in other kinds of residential care, however, are reported by residential care staff in interviews for this study as having infrequent or no contact with their parents and family. In a few cases this is because contact has been forbidden by a child protection court order, though in other cases the child has lost contact with the family, or has only infrequent contact:

“He came to the center when he was one year old and he has been here for 15 years. He doesn't know his dad. His mother sometimes comes to meet him at the center.

(K11, residential care worker)

“She goes home only for the summer and winter holidays. Her father looks after her. Her mother has a mental disability. It takes one hour on the minibus one way to her home. Otherwise her father comes once a month to see her for just 20 minutes. At each visit he says he doesn't have time.

(K11, residential care worker)

“She goes home for two weeks in the winter and two weeks in the summer holidays. Her grandmother fetches her. She lives two hours away. Her grandmother phones her sometimes and sometimes comes to see her here.
(KII, residential care workers)

Residential care workers said that they need help to communicate with many of these children who are described as having moderate intellectual disabilities or who are non-verbal. It is not clear whether reintegration work is being undertaken with these children to try and help them return to their parents or extended family.



Taken as a whole this means that

there is potential for a quick win in applying the UN Guidelines on Alternative Care for Children and proceeding with deinstitutionalisation of social care services for children with disabilities in Albania. *If the reported small number of children with disabilities living in residential care is accurate, a targeted project could support municipal social services to facilitate reintegration with extended family or placement into foster families specially recruited, trained and supported to care for many of them.* The same project

could prepare the municipal social services and gatekeeping systems to prevent or minimise any further use of residential care for children with disabilities.

50 children with disabilities being reintegrated or placed into family care over the next two to three years seems a realistic objective. If achieved, this could significantly reduce the over-representation of children with disabilities in residential care in Albania and realize their rights to only necessary separation from parents and family, inclusion and family-based alternative care that is suitable to meet their needs.

2.4 Interpersonal: immediate context of family, household and intimate acquaintance

KEY FINDING

Most children with disabilities interviewed are living with both parents and their mothers are their main carers. For the most part they have good relationships with their parents, siblings and other family members. However, some parents and specialists need support with alternative communication to better connect to and support children.

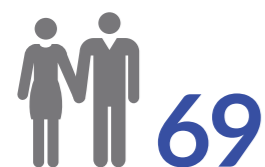
Children who are deaf are not being taught through Albanian Sign Language. They want to be able to communicate in sign language with staff at the boarding school for the deaf, and with their families.

Nearly all specialists consulted need more training to work collaboratively with the families of children with autistic spectrum disorders and children with difficult-to-manage behaviour.

There is an opportunity to fully implement Article 63 of the Law on Pre-university Education, which guarantees the right of communication for deaf and blind students through sign language and Braille, and to extend this right to communicate to all children with disabilities.



Parents interviewed



Parents living together



Parents living separately



Parents divorced



At least one parent emigrated



Single mother

Among 89 parents interviewed, 20 are living separately and 69 living together. Among those who are living separately, 13 are divorced; in five cases at least one parent had emigrated and one mother was single and had never married. In most cases, parents say that the mother is the main carer for the child and, in many cases, she has support from the father, the child's siblings and grandparents. In some cases, grandparents live together with the family. Extended family play a supportive role in caring for some children with disabilities. Nevertheless, mothers appear to be the main carers for a child with disabilities among the families interviewed.

The Albanian Institute of Statistics (INSTAT) reports 24.7 divorces per 100 marriages in 2016,⁴⁰ suggesting that the commonly held belief that having a child with a disability contributes to marriage breakdown does not necessarily hold in Albania. However, this finding should be considered cautiously since the sample for this study was not representative.

As noted, alternative and augmentative communication methods could be an important additional support for many children. Article 63 of the Law on Pre-university Education includes the right to communication for deaf and blind students using sign language and Braille. However, participants in the present study report that they are not currently accessing such assistance. Support for communication for all children with disabilities is not included. Some parents say they need help with communication for children with various types and levels of difficulty in communication. In one family, the parents reported that they cannot communicate with their child as they do not know sign language.

Another parent said that she wanted her son to attend the boarding school for deaf children so that he could learn sign language, but they did not accept him because of his hyperactive behaviour, which the school found difficult to cope with.

[Children who are deaf experience difficulties in communication at home, in the community and even at the school for the deaf](#). Two children from the residential school for the deaf said they would like the nurse and doctors who provide them with health services in the institution to speak sign language. One disabled persons organization reports that teachers working in the school for the deaf do not know or use sign language and a 2015 survey reported that 97 percent of deaf adult persons are functionally illiterate.⁴¹

Children with severe communication difficulties associated with autistic spectrum disorders are particularly isolated, both in their relationships with family members and with other people outside the family. Nearly all specialists consulted confirmed that they require additional training to support collaborative work with families of children who have autism diagnoses and children with difficult to manage behaviour.

Most children interviewed who have siblings report having positive relationships with their brothers and sisters and that they spend time together. In a few isolated cases, parents said that their child with disabilities displays aggressive behaviour and cannot establish relationships with their siblings.

Many children with disabilities, but who have few functional limitations and attend school, including children attending special boarding schools, say that they have friends. Children with moderate intellectual disabilities and deaf children mainly have friends at school. In the case of deaf children, they say they find it difficult to communicate with non-deaf peers in the community. The more complex a child's disabilities, the greater difficulty that they have with communication and cognition, and the more likely

parents are to say they do not have friends outside of the immediate family circle even if they go to school. Parents of these children see both school and day centers as an important opportunity for their child to receive education or therapy, but also to interact with other people. For example, one parent said, "At least he can be social to some extent".

Parents describe caring and rewarding relationships:

“She doesn't speak but we have created a great bond and I understand her, though not all the time. If she could learn to write it would be great and helpful for us to understand her better.

(KII, mother of 16-year-old, non-verbal girl)

“We have built a very strong communication. She is very social and has friends at school, at home and at day care. She goes out to play every day.

(KII, mother of 6-year-old girl with Down syndrome)

Some children with disabilities interviewed express positively their desire to live with their parents and family. For example, "[When I grow up] I want to live with my Mum." The degree to which each child and parent interviewed has rewarding interpersonal relationships is highly individual.



Taken as a whole, this means that

systematic support to engage with children who have communication difficulties is not being offered either to families or to teachers and other staff in specialized or mainstream services.

Ensuring that parents, siblings and other family members, as well as teachers and other staff working with children in schools and social services, can use sign language or other alternative means of communication can create a step change in the quality of interpersonal relationships and consequent inclusion in the wider community.

2.5 Community: social capital and networks influenced by beliefs, behaviours and norms

KEY FINDING

Despite some progress, social norms that stigmatise children with disabilities and their families continue to create barriers to inclusion.

There appears to have been some positive progress in attitudinal change towards children with disabilities during the last three years, in part driven by inclusion of children with disabilities in schools.

Some parents confirm that they experience stigma because of their child with disabilities, but other parents say that they do not experience these kinds of attitudes from their communities.

Parents of typically developing children think that attitudes towards children with disabilities in the classroom are changing for the better but acknowledge that stigma is still an issue in schools.

Stigma because of disability may be compounded by stigma against people living in poverty.

Prejudice against children with disabilities and their families is reported by some local authorities and specialists as a barrier to inclusion. Others emphasize instead the barriers in the built environment.

Specialists from all counties included in the study reported that children with disabilities are largely excluded from community life for a range of reasons including prevailing negative attitudes, physical barriers in the built environment and infrastructure, and social and cultural barriers:

“In terms of community involvement of children with disabilities, it can be said that they are little or not at all involved in such activities. There are no suitable facilities for either cultural or sports activities. There are no sports grounds to conduct such activities ... The cultural center provides various courses but children with disabilities are not part of these courses. They are simply included to attend some cultural performances. (FGD, specialists)

Nevertheless, some local authority representatives included in this study see activities organized by schools and kindergartens as community activities that are inclusive of children with disabilities and emphasize that the parents of typically developing children, “have to change their mentality, to encourage involvement of children with disabilities even when teachers are reluctant”. Another view expressed by local authorities is that it is the parents of children with disabilities who are creating barriers to inclusion by keeping their children at home and out of education. Although some parents interviewed for this study reported reluctance in accepting their child’s disability, they did not confirm the view that they discourage inclusion.

Making the built environment more accessible in order to promote inclusion is considered a priority by other local authority representatives:

“The municipality does not have a structured accessibility plan. Through projects such as road or school reconstructions they have tackled construction adaptability. Nevertheless, this is only partial. The construction infrastructure in the city has been adjusted. Improvement of the infrastructure has made it possible for the new roads to have ramps on the pavements. [However], there are no signs for deaf people or for those who are blind ... In many schools there is a ramp at the entrances to the buildings, but these are completely absent inside. (No lift, no adapted toilets or facilities to help the movement of blind children.) ... Accessibility to information or tools is missing. (FGD, municipal authorities, composite response)

Representatives of one city authority acknowledged that achieving inclusion into community life will require greater effort to address prejudice, and more services will be needed to address structural, as well as cultural and social, barriers to inclusion:

“Despite the improvement and strengthening of social policies and programmes for the benefit of children with disabilities, there is still exclusion, prejudice and lack of services for this group. We emphasise the existence of attitudes, infrastructure, social, educational, cultural and health barriers. (FGD, regional authorities)

Many children and parents confirmed that there are few activities available to them in the community apart from those organized by the school or the day center. Children in one residential care institution said that they take part in separate sports and museum programmes organized by the institution that children in families cannot access. These activities are organized within the institution rather than in the community with other children.

Some of the children with fewer functional difficulties, those that attend mainstream schools with greater success, also take part in activities that other children in their communities can access: for example, taking part in music activities in the local cultural center.

Around 50 percent of the parents of children with disabilities interviewed reported that mothers and fathers in the family are unemployed. Thirty fathers (around 40%) and only 19 mothers (around 20%) were reported as employed. This means there is, overall, a low family income, impacting access to general social services. *Moreover, it also limits the potential for children and families to be involved in community activities for play and leisure, and can also increase the isolation of primary carers of children with disabilities, increasing their risk of mental health problems such as depression.*

Negative attitudes towards children with disabilities and their families may be compounded by prejudice and negative attitudes towards people living in poverty. Some parents of typically developing children perceive the families of children with disabilities as being poor (lacking sufficient money to live at a standard considered comfortable or usual in a particular community):

“Parents of children with disabilities are unemployed ... They are poor ... This affects children with disabilities. They do not provide children with the proper conditions, they do not meet the needs ... and many other problems are created ...

(FGD, parents of typically developing children)

A representative survey conducted in 2017 by World Vision and Save the Children indicates that 66 percent of families with children with disabilities (according to parent perceptions) report incomes that classify them as low-income households (income from all sources that is less than 40,000^{iv} Albanian Lek per month) compared to 44 percent of families with typically developing children.⁴² This finding accords with empirical evidence from across the world that indicates that children with disabilities and their families are more likely to experience economic and social disadvantage than those without disability.⁴³ Disability can be both a cause and a consequence of poverty.⁴⁴ The right to an adequate standard of living is a fundamental component of UNCRC (Article 28) and UNCRPD (Articles 26 and 27) and adequate social protection systems are required to support children with disabilities to enjoy their rights both as children and as persons with disabilities. Families of children with disabilities are, therefore, likely to be economically disadvantaged and this can compound the stigma they experience in the community, as well as limit access to general social services.

^{iv} Approximately 370 USD.

Attitudes towards children with disabilities in the community

Parents of typically developing children, consulted during FGDs, said that they are not against inclusion of children with disabilities, “but that some other parents are”, and emphasized that more information on disability is needed to help other parents to understand the situation better:

“Often other parents do not want their children to stay in the same classroom with children with disabilities in case they are aggressive ... Not all parents of the other children are receptive; many of them object to their children being taught in the same classes with children with disabilities ... They discriminate against them. This is because they lack information on disability and react negatively.

(FGD, parents of typically developing children)

These parents also understand the need for support for teachers to be able to teach children who have special educational needs together with other children:

“We are positive about the inclusion of children with disabilities in schools and kindergartens. But they need a lot of specialized support to be really involved. Teachers have difficulty responding to the needs of children with disabilities.

(FGD, parents of typically developing children)

One parent of a typically developing child mentioned that parents themselves, not only teachers, have to support their children to understand disability and create an inclusive environment

“I work hard at home with my child teaching him to be more receptive and supportive of children with disabilities in the classroom, to help and communicate more.
(FGD, parent of typically developing child)

Some specialists note that children play an important role in overcoming barriers to inclusion:

“It should be noted that parents of other children often object to their children being in the same classes with children with disabilities as they may be aggressive and their children can model the behaviours of these children. Meanwhile, other children are very receptive to their disabled peers and play an important role sometimes, more so than the teachers.
(FGD, specialists)

Some parents of typically developing children perceive a change in recent years towards more acceptance of children with disabilities and more positive attitudes:

“The community is receptive. The situation has changed. I have a personal example to attest this. In my daughter’s classroom, there are three children with disabilities. The parental community is receptive.
(FGD, parent of typically developing child)

“Attitudes to children with disabilities in the community have, over time, become relatively positive. There are of course exceptions, but it can be said that there has been a big change in comparison to previous years.
(FGD, parent of typically developing child)

Some of these parents, however, also say that in spite of these positive changes, it is parents of children with disabilities themselves who try to keep their children hidden and are therefore at fault in isolating them from the community:

“Still parents of children with disabilities continue to keep their children unexposed to society, feeling ashamed.
(FGD, parent of typically developing child)

Specialists, especially teachers and some residential care workers, also tend to perceive some parents of children with disabilities as difficult and not acting in their child's best interests, preferring to leave their child in the residential facility or not wanting them to be assessed for special educational needs. Teachers especially see a need to 'force' some parents to have their children assessed and to act upon the decisions of the MDC.

Nevertheless, many parents of children with disabilities see themselves as the only people who can help their child, moving mountains, spending fortunes and travelling halfway across the world to support their child's best interests and meet their child's needs. Some parents say that they feel stigma and discrimination in the community and are made to feel guilty for causing the child's disability:

“The community is very judgmental and doesn't see you as equal to them. They also blame the parents for the situation. They say things like, “Who knows what they or their predecessors did to deserve this”.

(KII, parent of child with disabilities)

“There is no stigma for children. Some of our relatives blame the parents.

(KII, parent of child with disabilities)

However, many more parents of children with disabilities say that they don't feel any overt prejudice or stigma. They say that neighbours and community members are either indifferent or disinterested or they are “kind”, “loving” and “helpful”

Attitudes of teachers and local authorities towards parents of children with disabilities in relation to accessing education

Education specialists noted that it is a matter of parental choice to have a child assessed by a Regional Education Directorate Multi-Disciplinary Committee for Assessment and then taking the decision on whether to act on the outcome. Specialists note that the decision of the MDC has the character of a recommendation rather than an order with which parents have to comply:

“The decision is a recommendation and not a decree. Under the law the final decision is taken by the parents in terms of in which educational institution the child will be taught.

(FGD, specialists)

This situation may result from inconsistencies in the Law on Pre-university Education. For example, Article 64 allows parents to remove their child from school if they believe they are not benefitting from attendance, while Article 5 (1) guarantees the right to education of every child, including children with disabilities. Many of the teachers and education specialists consulted across the different counties proposed that parents be forced to send their child for assessment when a school identifies him or her as having additional educational needs and that the MDC decision should be a mandatory requirement:

“... a sub-legal act is needed to force parents to bring their child for evaluation when children are declared disabled or when referred to as such by the school authorities. ... there are times when the child is not willing, because of the level of their disability, to be included in the mainstream school, while the parent wants the child to be included. It is therefore necessary to have a sub-legal act to determine the decision of the MDC as binding in some cases for certain diagnoses
(FGD, specialists)

The specialists, however, also report that this issue could be related to the way in which the schools interact with parents and children (both typically developing and those with disabilities) to create an inclusive educational environment, citing the limited capacity and skills of personnel and, most importantly, the requirement for additional resources to accommodate children and their special needs:

“[It has been a] difficult start, especially with parents who are agitated and with high expectations and has, in the meantime, become a hindrance to the work of the teacher with the child. At the moment the parent was convinced and a joint plan drafted, the job became easier and the child made some progress.
(FGD, specialists)

This finding suggests that both the law and the way it is implemented may require amendment.

Parents and children should be fully informed of the choices they have for acquiring a quality basic education, either in a specialized education environment or with additional resources that can be allocated to support inclusion into mainstream schools. Staff in schools should have the additional resources, training and knowledge to create an inclusive environment for all children. The related institutional challenges are discussed further in Section 2.6.6.

The findings from the present study suggest that there has been some progress made in attitude change since the studies conducted in 2014 and 2015 concluded that stigma and discrimination are a continuing feature of life for children with disabilities and their families and caretakers in Albania.⁴⁵ It also appears that the move towards inclusion in schools in recent years may be driving these changes as children with disabilities become more visible in the community. However, the present study cannot conclusively state that attitudes have changed significantly. Some parents of children with disabilities interviewed here confirmed findings from previous studies on community attitudes, including those that consider disability a potentially contagious disease, or a punishment visited upon a family for some previous action. Previous studies have found that professionals sometimes express hopelessness concerning a child with a disability, suggesting there is nothing to be done to improve the child's life situation and that media reporting on disability issues tends to be mostly negative. with a disability, suggesting there is nothing to be done to improve the child's life situation⁴⁶ and that media reporting on disability issues tends to be mostly negative.⁴⁷

While the Commissioner on Children's Rights was appointed in May 2018, in the preceding period the Office of the People's Advocate (Ombudsperson) and the Office of Commissioner for Protection from Discrimination were tasked with upholding the rights of children with disabilities.⁴⁸ The NAAPD 2016–2020 also

intends to tackle discrimination. However, there is no definitive strategy to address social norms that contribute to community disengagement and consequent social isolation.



Taken as a whole, this means that

although there seems to have been some progress made in attitude change, in part driven by increased inclusion of children with disabilities in mainstream schools, more information and communication about the goals of the government reforms on disability, and especially about inclusive education, are needed to galvanise changes in attitudes. Regional and local authorities should prioritize as they have the responsibility and mandate locally to create inclusive environments and support inclusion not only in schools but also in the wider community.

Communication campaigns explaining inclusion that target the general public, including parents of typically developing children, could help to change attitudes to disability and support inclusion, not only in schools but also in other public services where children with disabilities are currently excluded or only minimally included, such as in sports and cultural activities.

Children with all kinds of disabilities have told us that they want to play sports, play music, paint and engage in other activities that all children do. Facilitating inclusion of children with disabilities not only in schools, but also in other community-based activities together with other children could offer some quick wins, in terms of not only quality of life for children with disabilities and their families, but also knock-on effects for the implementation of inclusive education.



2.6 Institutional: institutions and services organized and governed by a set of rules

KEY FINDING

Parents, local authorities and specialists report that there are considerable delays in early identification for some children and major gaps in provision of early intervention and early childhood development services. This is confirmed by administrative data.

The Albanian National Health Strategy goes some way to supporting the call for the legal framework to provide for early identification, as mentioned by both parents and specialists during FGDs. However, the absence of linked activities or indicators mitigates against the potential for this commitment to be translated into action.

There is a requirement for one post-partum home visit by a doctor. Although it is reported by UNICEF that health service providers conduct follow-up visits more often, the actual number and frequency of visits is not clear, neither is the monitoring mechanism for these visits. This is a key bottleneck to ensuring early identification and early intervention.

The precise level of under-provision of pre-school services is unknown.

Physiotherapy, speech therapy and other habilitation therapies are provided mainly in day centers. However, parents and specialists report that provision of the service is limited and does not adequately meet the needs of many children.

Some children with disabilities from economically disadvantaged families have access to fewer therapy sessions than is needed

because they cannot afford to pay for additional services to those offered by the state or by NGO service providers in their local area.

2.6.1 Early identification and early intervention

Systematic monitoring of children's early growth and development is important for identifying any delays in meeting developmental milestones and to ensure that where a delay is identified children get the help they need as soon as possible. At this early age a focus on developmental milestones rather than definitive diagnosis will increase the chances of early intervention, which will improve a child's opportunities and minimise the effect of any delay. In their 2012 discussion paper on Early Childhood Development and Disability, the World Health Organisation and UNICEF note that 'Systems for early identification are required in order to facilitate timely access to services to support the development of children at significant risk of developmental delays'.⁴⁹

Early intervention and early childhood development consist of services and supports to ensure and enhance children's personal development and resilience and are designed to support young children who are at risk of developmental delay or who have been identified as having developmental delays or disabilities.⁵⁰

A systematic review of 55 studies on early childhood development reports that while knowledge gaps remain, there are significant causal links between early intervention and sustained effects over time.⁵¹ Early intervention services can mitigate the effects of any disability and lead to advantages in later life in the areas of cognition, language, socio-emotional health, education and, eventually, the labour market.⁵²

Currently, there is no national system for monitoring of early child development allowing for individualised early interventions, though the National Health Strategy 2016–2020 (approved in 2017) makes reference to improved care for mothers and the newborn. This strategy also specifically references 'neonatal, infant and

child screening for development, hearing and sight impairment, screening for and early diagnosis of autism disorders' as part of Objective 1.2. However, the plan for its introduction is not detailed. Whilst this objective goes some way to supporting the call for the legal framework to provide for early identification, as mentioned by both parents and specialists during FGDs, the absence of linked activities or indicators mitigates against the potential for this commitment to be translated into action.

Objective 1.3 of the same strategy—Reduce the infant and maternal mortality rate and ensure a healthy start of life—while stating as an action 'Assurance of quality and holistic health care for all children, focusing particularly on the vulnerable groups, including children with disabilities', also has only limited reference to activities or indicators mainly for screening or early identification without any explicit follow-up actions or indicators.

Early identification of developmental delays is identified by UNICEF as a critical component of strengthened governance for equity and social inclusion that could be enhanced through the Albanian National Health Strategy.⁵³ UNICEF reports that monitoring of child health and development is conducted through home visits and visits to child consulting centers in urban areas or the family doctor in rural areas. Doctors at the child consulting center, or the family doctor, should conduct one home visit within 24–48 hrs of discharge from maternity, and the patronage nurse should conduct six home visits for children up to three years of age. The rest of the required number of well-child visits take place at the health center. More home visits may be planned according to the needs of the child. The basic package of public health care describes these provisions. Health personnel conduct child development assessments based on a national protocol for child development approved by the Ministry of Health. However, UNICEF notes that the capacity of health-care providers to assess child development is an important bottleneck.

Newborn screening tests can assist in early identification of serious health conditions (developmental, genetic and metabolic disorders). This can lead to early intervention and treatment, which can improve health and prevent severe disability. Specialists of the MoH&SP⁵⁴ report that new-born hearing tests have recently been introduced at hospitals in Tirana, Kukes and Pogradec within the scope of an EU-funded project, though there is currently no legislative provision for its national introduction and limited available information regarding future financing. Thus, sustainability and scale-up is not yet guaranteed.

Other screening mechanisms, for example the neonatal heel prick, or Guthrie test, where a few drops of blood taken from a baby's heel are sent for analysis, and pulse oximetry, in which a sensor is placed on its foot to identify critical congenital heart defects, are not routinely available in Albania. However, the introduction of specific screening mechanisms in a resource constrained setting should be carefully planned and include a thorough analysis of public health impact and cost effectiveness.⁵⁵

There can be many reasons for disabilities among children. Identifying the cause leading to eventual diagnosis may be a long process. A child who waits for this process to be completed before intervention loses out on early opportunities. For example, a child who is not communicating appropriately may have a hearing difficulty. However, the screening equipment for a definitive diagnosis may not be available. In this case simple techniques for improving communication can be demonstrated to parents, including being in the child's line of sight when speaking, using gestures and simple signing. If parents wait until a definitive diagnosis is made, the developmental losses and subsequent impact on cognitive learning and socialisation may not be reversible.

A recent review of the international literature on the assessment of child development published by the British Medical Journal concluded that whilst health-care practitioners should note that ‘every consultation is an opportunity to ask flexible questions about a child’s development,’ they should also ‘consider use of developmental screening questionnaires and measurement tools to supplement clinical judgment’.⁵⁶

In Albania the 2009 National Family Planning Protocol includes reference to monitoring child development, and details are provided in Ministry of Health and Social Protection Child Development Protocols. The primary health-care package includes provision for two home visits after birth, one for the child and one for the mother. The remaining 0–6-year-old checks are conducted at health centers. However, UNICEF report capacity gaps among health personnel in monitoring child development in their everyday clinical practice⁵⁷ both in home-visiting services and health centers and there is no evidence to suggest that additional developmental screening questionnaires are available or that staff have been trained in their use. Similarly, the pilot test of assessment using the ICF framework applies only to children over two years of age.⁵⁸ As a result the opportunities and potential for early identification of developmental delay and consequent intervention are significantly constrained.

The National Agenda for Child Rights 2017–2020 includes Objective 5, dedicated to improving early childhood care and education and setting out actions to improve standards in nursery and crèche care for children aged 0–3 years; improving parenting skills and knowledge of child development in early childhood (though targets are set for only 10% of local government units); and establishing early childhood development programmes and ensuring staff charged with implementing them are trained. Objective 10 on health services includes an action on ‘improving the quality of service for development problems and/or mental health’, which includes the ‘drafting of protocols for early identification and treatment of child development problems’, and a review of ‘protocols for early identification of mental health problems for children 0–18 years of age’.

The government Child Care and Development Centre in Tirana provides outpatient services for children with disabilities of age 0–6 years. It also has a 30-bed residential service for children living outside Tirana. The multidisciplinary team assesses children and provides therapeutic services including physiotherapy. The center’s specialists noted, during a FGD conducted for the present study, that the provision of physiotherapy is limited to two 45-minute sessions per week, which is inadequate, and that when a child reaches six years of age therapy stops, which can result in a reversal of gains made and impact their continued opportunities for development. Families who can afford the costs therefore access additional services in privately run centers. Some parents of young children with disabilities in Tirana and other counties where interviews were conducted also confirmed that the provision of physiotherapy and other therapies without payment (mainly in day centers) is limited to a few hours per week and in some cases does not meet children’s individual needs. [Children’s access to the habilitation services that they need and to which they have a right under UNCRC and UNCPRD is therefore constrained by inadequate provision by the state and the economic situation of each child’s family.](#)

Early childhood education

Although pre-school services are nominally inclusive of all children, key informants at MoES&Y report that interventions for children with disabilities at this level is in the early stages of development. The National Agenda for Child Rights 2017–2020 sets out activities (5.3 under Objective 5) explicitly targeting school-preparedness and school inclusion for children of aged 5–6 years, but without explicitly mentioning children with disabilities.

State Social Services provide data on children with disabilities attending services at day centers only for the age group 0–16 years without further disaggregation. The data on recipients of disability allowances are disaggregated for 0–6-year-olds and indicate that

just under 50 percent of children of this age receiving disability allowances are recorded as being in pre-school education in 2017. [It requires further investigation into how the indicator is defined and recorded in each county especially in relation to children who are under 3 years of age and not eligible for pre-school.](#) This highlights wider issues of data validity, reliability and comparability which is further discussed in Section 2.7.1 of the present report and noted as one of the limitations to the study.

Parents of children with disabilities who took part in focus group discussions and interviews for this study indicate that early intervention should be a priority:

“...from the moment a child is born, from the moment of detection we should move onto education and services. These should function at all levels for these children to have access to special care and services.
(FGD, parents of children with disabilities)

The parents in general do not have a positive experience of early identification linked to early intervention:

“There is nothing in Albania for children 0–6 years of age.
(FGD, parents of children with disabilities, Tirana)

They describe difficulty in accessing the services that should be available to young children, including physiotherapy, “The only service provided by the state,” according to one parent, and kindergarten, “What can we do to make the pre-school want to register our children?” Many describe having to pay for their child to

access services such as such as kindergarten or physiotherapy.

Tirana Municipality, however, described extensive provision of nursery and kindergarten services, with reduced fees for some children from low income families. They also referenced attempts to establish early intervention services involving both health and social services, and other initiatives aimed at supporting children in early childhood in Tirana, though this assertion could not be supported by additional evidence.

There is evidently a gap between the demand for services and the provision and this needs to be more clearly defined in each county. In Tirana, for example, State Social Services data indicate that 926 children of 0–6 years of age at the end of 2017 were receiving disability allowances. Of these, 519 children (56%) were attending pre-school. The other 44 percent may be among the 100 children with disabilities attending day-care centers reported by Tirana Municipality. Some of these children may not require any services. Accurate data, based on assessments that are sensitive to early childhood developmental delays, are required to understand the full demand in order to organise the necessary supply of early intervention and early childhood development services.

Interviews with 27 parents of children aged six years and younger conducted for this study suggest that many have experienced considerable delays between diagnosis and conferment of disability status that can help them access specialized services and support. Four children with Down syndrome had received disability status between the ages of six months and two years. Given that Down syndrome can be reasonably accurately diagnosed at birth and early intervention support is critical for early development such delays in accessing services are significant. Several parents of young children said that they did not have information on how to access assessments and support. Others said they were helped by the doctors at the hospital where their child’s disability was diagnosed. This suggests there are significant variations in service provision.



Around half of the children of these parents are not accessing pre-school, a rate similar to the national rate for pre-school attendance (based on State Social Services data). In some cases this is because the child is too young or parents prefer to keep the child at home. In the case of two parents in one village in Berat there is no pre-school for either children with disabilities or typically developing children. In the case of three children in Tirana, the pre-school would not admit them. The main reasons given by the kindergartens, as reported by parents, was the lack of a special assistant. Parents are also concerned that if their child attends kindergarten they may not receive the attention they need:

“Once I sent him for two weeks to kindergarten and stayed with him. But it was impossible to stay and nobody took care of him [if I was not there].

(KII, mother of 6-year-old non-speaking boy with epilepsy)

“There is no educator assistant for specific children; I can't just leave him there alone.

(KII, mother of 3-year-old boy who is blind)

Some of these children are accessing privately provided therapy, paid for by parents, or attending a day center that provides therapy without charge:

“He attends a day center three times a week and has two hours of therapy. He seems to like the therapist. It takes 40 minutes to walk there. I am very satisfied with the therapy but I think he needs more hours. The center said they don't have capacity for more hours.

(KII, mother of 6-year-old non-speaking boy with epilepsy)

Some parents report that their children attend both kindergarten and a day center. In these cases the pre-school provides education and the day center provides a mixture of habilitation therapies, such as physiotherapy and speech therapy, as well as play and developmental activities:

“We are happy with his education; he goes to pre-school every day. He needs help and the teachers help him. At the day care center, he has physiotherapy and development therapy. It would be better if they had more equipment there.

(KII, mother of 4-year-old boy with epilepsy)

Many parents of young children attending pre-school say they are dissatisfied with the school as the education programmes are not adapted to their child or there is no assistant teacher.

“He goes to pre-school every day where his sister helps him most of the time even though she is in a different class: she helps him during the break between classes and takes him to the toilet. His educator also helps sometimes. I'm not pleased with the education. I think that my child doesn't get the attention he needs.

(KII, mother of 6-year-old boy)

“It is not adapted for him, but at least he is in a social environment.

(KII, mother of 6-year-old boy)

They tend to be more satisfied with the quality of the services at the Day Centres:

“...physiotherapy at the day center is good for her...”
(KII, mother of 3-year-old girl)

In some cases, attendance at the day center or pre-school is limited to a few hours per week. Several parents in Tirana say their child goes to the day center four times per week for one hour each time. One parent mentions that her child needs more therapy

“He goes to a special pre-school every day and it takes 20 minutes to get there by car (a cost of around \$45 per month). He doesn't like school; he prefers home. He goes to the day center for four hours a week and it takes 40 minutes to get there. He needs more training and therapies.”
(KII, mother of 6-year-old boy with Down syndrome)

The day centers provide specialist services rather than day care, and some parents report travelling considerable distances at some cost in order to attend one-hour sessions, even if the service itself is provided at no-cost to the user.

Specialists in education and social services emphasize the absence of early intervention as constraining the ability of schools to provide quality education to many children with disabilities:

“In most cases, problems with the inclusion of children in school stem from the fact that no preliminary work was done beforehand with these children.

(FGD, day center specialists)

“The legal framework should also provide for early identification. Children, whether they come to a special school or an ordinary school, are at a stage of development that makes it difficult to work with them and achieve inclusion goals. No work was done with them before and they have not received any kind of disability service.

(FGD, education specialists)

Some specialists also perceive a need to strengthen provisions for inclusive early childhood education in kindergartens where the legislation does not currently specify provision of teaching assistants for children with disabilities:

“...a sub-legal act needs to be determined for the assistant teacher or educator for children with disabilities who are involved in kindergartens. So far, it is not determined which institution can appoint these teachers, while the kindergartens have been subordinated to the municipality.

(FGD, education specialists)



Taken as a whole, this means that

early identification is not given sufficient priority and actions are required to strengthen capacity for monitoring child development in early childhood.

The full scale of the need for early intervention services is unknown as there can be considerable delays in identification of developmental delays and, therefore, monitoring of the numbers of children needing support. Existing data on pre-school inclusion is unknown. In the absence of data, planning for services is constrained. The delivery of important early intervention services—such as physiotherapy, speech therapy and occupational therapy—are either absent entirely in some areas or families have to travel considerable distances or incur considerable costs to access them. This creates inequities in the system of early intervention and early childhood development services.

Improved data and assessment systems could help to strengthen planning by municipal and regional authorities for the provision of early intervention services. While there is

some provision of outreach and home visit services mentioned in the health sector, none are mentioned in the social services sector, which seems to be wholly reliant upon center-based service provision. Mobile early intervention teams can be effective in reaching out to children with developmental delays in their families if they live in remote areas or in areas far from the day centers.

According to parents interviewed day centers appear mainly to offer physiotherapy, speech therapy and developmental therapy, with other disciplines such as occupational therapy, social work and psychology mentioned less often. Best practice in early intervention indicates that a multi-disciplinary team coordinated by a social worker through a system of case management can best identify and assess the needs of a child and work with parents to provide a range of interventions to support maximum development in the early years and throughout the life-course.^v

Education specialists note that the absence of early intervention and the lack of inclusive pre-school services means that children are completely unprepared as they enter the school system and this means inclusion is even more difficult to achieve.

^v Resources and information on early intervention best practices can be found here for example: <http://www.eurlyaid.eu/>

2.6.2 Rehabilitation and habilitation services

KEY FINDING

Day centers are the main providers of rehabilitation and habilitation services, though some health centers also provide these services. Parents are largely satisfied with the services their children receive in day centers but, as with early intervention services, the amount of therapy provided without charge is inadequate to meet the needs of many children.

The pre-service training of physiotherapists, speech therapists and development therapists is reasonably well institutionalised, but a greater focus on children with disabilities could help to strengthen practice. The system of continuous professional development for these specialists requires strengthening and systematising.

Rehabilitation and habilitation services for children are provided through the health services at medical centers and hospitals and through municipal, NGO or privately run community-based centers also called Day Centres, Day Care Centres or Community Day Centres. According to both parents and children interviewed, Day Centres provide physiotherapy, speech therapy and other types of developmental therapy. Medical centers and hospitals provide some medicines and medical treatments, but no therapy. Although one group of specialists noted that the MoH&SP has initiated the introduction of a speech therapist or logopedist into the health structure of each regional hospital, not all counties have prioritized this and therapies offered in hospitals remain limited to physiotherapy with limited numbers of specialists available.

Some parents pay for therapy privately. Several parents report that they have travelled abroad, to other countries in Europe, for diagnosis, habilitation, treatment and rehabilitation and borne the costs of this themselves.

Many parents report that their child attends a day center where speech therapy, development therapy or physiotherapy are offered. Some parents pay for private therapy as well or instead of public day center services. Many are satisfied with the physiotherapy and speech therapy that their child receives.

“...he goes to the day center for therapy four times a week from 8 am to 9.30 am. After this he goes every day to kindergarten, from 10 am to 1 pm. He has made progress, names the days of the week, the alphabet. We will continue to go to the day center.
(KII, grandfather of 8-year-old boy with epilepsy)

“The transportation cost is very high and, sometimes, is an obstacle to follow the therapy. He goes to the day center most days for a few hours. The curriculum is good and helpful and he shows some good progress in understanding when he regularly follows the therapy, but he needs more speech therapy.
(KII, mother, 15-year-old boy)

However, not all parents or children are satisfied with day center services:

“My daughter is 16 years old and has intellectual disabilities. She does not talk. She goes to the day center every day from 8:00 to 14:00. There is no curriculum. They don't have any programme and I don't know what my daughter does there. No, I am not happy at all. There are not enough staff; there are no personal therapies. The staff are not well trained. She doesn't learn anything there, only what I teach her myself at home.
(KII, mother of 16-year-old girl)

“I went some time ago to a day center for two weeks to do physiotherapy sessions. Then the physiotherapist left the job. Also, the road from the bus station to the center is long and very tiring for me. But, the most important thing is that I wasn't satisfied with the therapy in that center.

(KII, girl with cerebral palsy, 14 years of age)

Some parents mention that their child was receiving therapy and then the therapist left and was not replaced so the therapy stopped. Others mention that staff need more training. Mostly, however, parents want their child to have access to more therapy from the day centers but are told by the day centers that they cannot provide more.

FGDs with specialists who provide therapy in day centers confirm that transport can be a problem for children and families and that proper materials and equipment are important for delivering good quality services. They note that parents may pay unregulated private service providers if they are not satisfied with the public service:

“A speech therapist needs his own material base, which he often has to find himself. The speech therapist is very important and often plays a crucial role in rehabilitation, especially in pre-school or elementary education. The day center encounters difficulties with regard to the children's transport. There is not enough budget to cover the fuel. Many parents who have children in schools want to provide the children the necessary therapies, and when there are no public providers they turn to private providers, often using the little financial means they have. Private service providers are not inspected by the state. Lack of qualifications and standardisation of instruments used for assessment and therapy for disabled children need to be addressed.

(FGD, specialists)

Training and up-to-date information for specialists is also noted as a critically important area that requires strengthening, and an area that requires investment from government service providers, usually municipal authorities:

“There is a lack of in-depth training for specialists. The municipality has supported the 3-month training offered for specialists from an NGO to provide various therapies for children with autism. Meanwhile, professionals often cover their own participation in various trainings. There is no information center for disability in Albania.

(FGD, specialists)

“I am privately attending a four-month course at a specialized center in Tirana, for individual therapy with autistic children ... I cover the course's expenses with my own income ... I really need to acquire new knowledge and learn how to apply therapy according to the needs of autistic children ... There is a lack of training of specialists in line with the job profile they have ... There are professionals that feel a strong need to be trained as quickly as possible in order to work as extensively as possible.

(FGD, specialists)

Some specialists report active and extensive support from NGOs over many years. This has included training for therapists, social workers and psychologists in some day centers, but also the professionals in allied services such as schools, health services and local authorities. Such an approach has built understanding of disability and the role the services have in increasing functioning and maximising the opportunities for children's inclusion in school

and in the life of the community, and is an approach that could be used more widely to strengthen municipal services. However, there are anecdotal reports that external support for the NGO sector has been diminishing, and thus their continued capacity to provide supplementary services is at risk.

Specialists who have had extensive training in disability demonstrate a strong understanding of the multi-disciplinary nature of working with children with disabilities and the necessity of involving their parents as full partners in the habilitation or rehabilitation programme:

“Specialists work with children on individual plans that they draft based on the assessment they make of the child. Assessment at the center is carried out by specialists: a speech therapist, psychologist, physiotherapist, social worker and educator, as well as the child’s parent or guardian. The center has a physiotherapist who has completed tertiary education, with a master degree.
(FGD, specialists)





Other specialists noted that increasing provision contributed to increasing demand and was not balanced with service availability:

“Speech therapy and other new therapies have yielded results. This has increased trust but also parents’ expectations, increasing the demand for therapy, while human resources are limited.
(FGD, specialists)

The teaching of physiotherapy, speech therapy and development therapies seems to be well integrated at the university modules. The Faculty of Technical Medical Sciences at the University of Medicine in Tirana offers both Bachelor and Master programmes in logopaedics (speech therapy) and includes compulsory modules

with a specific focus on children with disabilities (see Table 2). The extent and quality of delivering these subjects to students may be subject to further enquiry.

Table 2.
Compulsory modules with a focus on children with disabilities

MODULE NAME	LEVEL	CONTENT	
Logopaedic Rehabilitation	Bachelor 	Speech and communication disorders in children. Includes the specifics of assessment, working with children with Down syndrome, children with autistic spectrum disorders, and children with severe and multiple disabilities	48 lectures, 24 seminars
Paediatric Rehabilitation	Bachelor 	General training in therapeutic treatments and techniques in physical and rehabilitation medicine	16 lectures, 8 seminars
Development Rehabilitation	Bachelor 	Basic knowledge on developmental problems in children and the rehabilitation strategies used for improving this development	16 lectures, 8 seminars
Special Logopaedic Rehabilitation	Master 	Includes lectures specific to Down syndrome, hearing impairment and autistic spectrum disorder	27 lectures, 9 seminars

The curriculum for the Bachelors course in General Nursing and Midwifery does not reference children with disabilities. However, it includes a module on the principles of medical genetics and the most common genetic diseases. .

Key informants at the university note that some graduates work in State Services. However, most are reported to be working in the private sector, and in the Municipality of Tirana, or to have moved abroad. Retention of staff, especially trained and experienced habilitation and rehabilitation specialists, will be key to building up accessible quality services that can meet the needs of children with disabilities.



Taken as a whole, this means that

the specialist disability workforce deployed in social services is reasonably well-developed compared to some countries in the region, but is largely not deployed in state-run or state-funded services. *There is a need for workforce planning linked to service planning and development to ensure there are enough specialists with the right qualifications to meet the need for services throughout the country, including health and social care services.* Such planning will also ensure more equitable access to these services, which are so important for early identification and for maximising children's functioning and thereby facilitating inclusion and participation in school and, subsequently, empowering young adults into leading independent lives.

Knowledge and skills specific to children with disabilities are included in curricula but could be strengthened further to ensure greater specialisation. Building a rights-based understanding of disability into curricula for training disability professionals, as well as allied professionals, such as nurses, teachers, social workers and public administrators, would help to strengthen implementation of government policies and legislation relevant to disability.

Equally, as external funding for NGO service provision for children with disabilities seems to be diminishing, this is a critical time for Government planners to consider how this gap can be filled in a currently constrained statutory system.

2.6.3 Assistive devices and technology

Access to assistive devices and technologies is considered critical to enhance participation of children and adults with disabilities and to contribute to overall well-being.⁵⁹ There are no current data on access for children in Albania to assistive products. Nevertheless, 'today only 5–15 percent (approximately 1 in 10 persons) of the population in need globally have access to assistive products and the problem is more acute in low- and middle-income countries'.⁶⁰ The World Health Organisation has produced a priority assistive products list, similar to its model list of essential medicines, to enable governments to raise awareness and mobilise resources.⁶¹ The list includes hearing aids, wheelchairs, communication aids, memory aids and other essential items. This has been developed as part of its flagship programme Global Cooperation on Assistive Technology (GATE), which also promotes access to information and communication technology. Further investigation is needed to consider how investment in technology to make it available and affordable can enhance opportunities for inclusion of children with disabilities.

Article 9 of the 2014 Law on Inclusion and Accessibility states that assistive devices should be provided based on an assessment by a commission (without specifying which commission) and that the Mandatory Health Care Insurance Fund under the Ministry of Health and Social Protection is responsible for provision of assistive devices. The ICF

KEY FINDING

There is no systematic access to assistive devices and technology at affordable cost for children with disabilities.

Several children interviewed needed, but did not have, wheelchairs at the time of the interview and parents did not have the economic means to purchase one. Moreover, availability of assistive technology for augmentative communication was not evident.

Meanwhile, the legislative provision to support access to assistive devices and technology for children with disabilities is opaque.

assessment pilot (DCM no. 431) refers to wheelchairs and hearing aids but does not specify any other forms of assistive devices or technology.

Parents of children with disabilities, children and specialists all report in interviews that there is little or no access to assistive devices and technology provided by the state. Several children interviewed needed, but did not have, wheelchairs at the time of the interview and parents stated that they did not have the economic resources to purchase one. In some cases assistive devices have been purchased privately or are provided by NGOs or other non-public organizations.

Some respondents report that they have equipment provided by the health service: one boy with asthma reports that the hospital provides a breathing pump and one girl says she has, “a small hearing aid, but I need a new one”. Local authority representatives from all four counties confirm that provision of assistive devices and technology is much needed, but is not prioritized:

“The municipality does not offer any assisting tools other than wheelchairs provided by donor organisations. The Public Health Department does not have a list of needs for assisting tools, prostheses, orthotics, hearing aids, etc. However, this is a legal obligation not recognised and implemented by this institution. There is a need for wheelchairs. There is a total lack of other assisting tools or technological equipment for blind children or deaf children.

(FGD, regional authorities)

“Access to ancillary equipment is missing. No information is provided tailored to the needs of children with disabilities. The construction

adaptability of institutions and service providers, as well as physical infrastructure, both inside and outside of the buildings, is almost completely lacking. There is a lack of didactic materials, as well as information materials tailored to children with disabilities.

(FGD, regional authorities)



Taken together, this means that

lack of access to assistive devices and technology at affordable cost is not only a major rights violation under Article 4 f/g/h and Article 9 on accessibility of the UNCRPD, but also represents a major bottleneck in supporting inclusion and accessibility and fulfilment of rights to inclusive education (Article 24), independent living (Article 19), personal mobility (Article 20) and several other rights under the UNCRPD.

Assistive devices and technology can help to maximise functioning and lower barriers to participation for children with a range of different functioning difficulties in communication, mobility, hearing, seeing and cognition.

The WHO Priority Assistive Products List^{vi} of 50 items that are ‘highly needed or an absolute necessity to maintain or improve an individual’s functioning and which need to be available at a price the community or state can afford’ provides a basis for government planning and resourcing.

vi http://apps.who.int/iris/bitstream/handle/10665/207694/WHO_EMP_PHI_2016.01_eng.pdf;jsessionid=DF289A6A533D3CDC5E4DABC422E9D58C?sequence=1

2.6.4 Social care and support services

KEY FINDING

Children with disabilities and their families are significantly underserved by social care and social support services.

One source of administrative data suggests that there has been an increase in the number of children with disabilities accessing services, from three percent in 2015 to eight percent in 2017.

An independent survey conducted in 2017 reports that 28 percent of children with disability allowances are accessing social services, as reported by parents.

Accurate data on the numbers of children with disabilities needing services is required to support planning and monitoring of service development that ensures equitable access to services across all counties of the country. Further investigation is required to verify and validate this apparent trend in increased service provision.

Some day-centers have social workers who are delivering social services, but primarily provide habilitation services.

Current legislative provision suggests that, in future, access to free-of-charge social services may be based on parental income.

Social work education includes only limited knowledge and skills pertinent to children with disabilities.



The introduction of the 2017 Law on the Rights and Protection of the Child references an 'integrated protection system' for children (Article 3.15). Article 32 makes specific provision for the child with disability and their right to receive services, 'determined by the responsible structures for the assessment of disability' (Article 32.2). Although nominally free-of-charge, this same article opens up the possibility of means-tested service provision, 'free of charge, whenever possible and taking into account the financial resources of the parent or legal guardian'.

The Law also places the onus on parents and caretakers to comply with legislation, 'assisted by [undefined] child protection structures' (Article 32. 3). In contexts of limited service provision, extreme poverty and vulnerability, and combined with the stigma and discrimination related to disability, this continues to place an impossible burden on families.⁶² The Law further provides for residential institutional care provision for children with disabilities (Article 32.4) and sweepingly requires responsible authorities to:

Eliminate all infrastructural, social, environmental, institutional and legal barriers in the field of education, employment and vocational training, health care, rehabilitation, and cultural, recreational and sports activities, in order for disabled children to exercise the rights foreseen in this law.
(Article 32. 5)

Many of these provisions are envisaged in the 2014 Law on Inclusion of and Accessibility for Persons with Disabilities. However, related secondary legislation and budget allocations to support implementation are limited.

The 2016 Law on Social Care Services aims to,

establish the instruments and modalities for ensuring and delivering social care services in the community through institutional and non-institutional forms, with

the ultimate goal of ensuring social welfare and social inclusion of individuals and families in need of social care. (Article 1)

This framework provides the basis for social services to promote the inclusion of children with disabilities.

Around half of social service delivery, including residential care, is provided by NGOs with private funding and the other half by government authorities.⁶³ It is not clear whether systemic planning processes are in place to ensure that the need for services is fully assessed and met in any of the counties. Lack of stable funding for NGO-run services that are providing services for children with disabilities is a recurrent theme in the literature reviewed for this study. While the Law on Social Care Services aims to regulate this major bottleneck in the system, the present study did not find that the provisions of the law that enable contracting of social services are being systematically implemented. *The system as a whole is still over-reliant on NGO funding and lacks coordination and systemic planning to ensure adequate supply of services to meet demand for all children in all counties within a national social services framework.*

Data provided by State Social Services record the numbers and types of services (residential and daily) for people with disabilities provided by public and non-public (NGO) service providers and paid for by public funding; and the total numbers of clients accessing these services (adults and children), and of these, the number up to 16 years of age. These data are not disaggregated to permit analysis of the numbers of children with disabilities receiving residential or daily services; only the numbers of children up to 16 years of age receiving both types of service.

Due to irregular reporting practice of municipalities, the data from State Social Services are not able to provide the full picture. For example, Tirana Municipality reports that 100 children with

disabilities are receiving day services at four day-centers but these children and centers are not recorded in the State Social Services data even though they are paid for by public funding. Analysis of these data is nevertheless worth considering as it reveals some important trends, though without fully valid data it is possible to draw only cautious conclusions.

The proportion of clients of both residential and day services that are children with disabilities up to 16 years of age appears to have increased from 28 percent in 2015 to 49 percent in 2017, possibly reflecting the implementation of new policies (such as the National Action Plan on the Rights of Persons with Disability 2016–2020, and the Agenda on Child Rights, 2017–2020) and new legislation (Law on Inclusion of and Accessibility for Persons with Disabilities, 2014, and Law on Social Support and Services 2005; Law on Social Care Services, 2016). These include measures to increase access to services, especially non-residential community-based day services, for children with disabilities. However, given the data gaps noted above, this cannot be considered a conclusive finding.

If the numbers of service users up to 16 years of age reported by State Social Services are calculated as a percentage of the numbers of children of age 0–15 years receiving disability allowances each year then, across the country, there has been an increase in the proportion of children of this age receiving services, from three percent in 2015 to eight percent in 2017. Again, this may be a result of efforts by regional and local authorities to implement social services legislation, national disability policies and the child rights agenda.

The State Social Services data also show that children receiving services, as a percentage of children of the same age in the same county receiving disability allowances, has increased over the last three years, particularly in Gjirokaster, Vlore and Elbasan and is significantly lower and not increasing in Tirana, Lezhe, Berat and Kukes. However, the data for these, and possibly

other, counties with a very low percentage of service users may contain significant gaps due to irregular reports delivered by the municipalities and thus cannot be considered as entirely valid. The data indicate, for example, that there are no services for children with disabilities in Kukes, though municipal authorities operate a day center and specialists in a FGD report that they are working with children with disabilities albeit a 'limited number'.

[The State Social Services data confirm that there are significant gaps in data that constrain planning and monitoring at the national level.](#) Meanwhile, the numbers of children with disabilities officially recorded as using social services paid for by government are significantly less than those receiving disability allowances.

A quantitative survey⁶⁴ conducted by World Vision and Save the Children in 2017 found that 106 children with disabilities of age 2–17 years were receiving social services, representing 7.8 percent of the 1,354 children whose parents report 'a lot of difficulty' or 'severe difficulty' in at least one functional domain. This represents 28.3 percent of the 374 children reported by parents to be receiving disability allowances. This rate is much higher than obtained from calculations from official data, which indicate that eight percent of children with disabilities of age 0–15 years were receiving social services in 2017 when calculated as a percentage of children of that age group receiving disability allowances last year. The slight differences between the age of the population of children surveyed (2–17 years) and that recorded by State Social Services (0–15 years, i.e. <16 years) may lie behind some of these discrepancies, though it is more likely that gaps in State Social Services data are at fault and the higher percentage reported by the survey is more accurate. Without addressing the gaps in the State Social Services data, it will not be possible to verify the situation.

Nevertheless, both the quantitative survey and the official administrative data indicate children with disabilities were significantly underserved by social services in 2017. These data

confirm the findings from the desk review that extensive gaps in local service provision for children generally and children with disabilities more particularly are noted to exist across early childhood development, formal education and health sectors⁶⁵ and in social services where some large counties have no community based social services available for children with disabilities.⁶⁶ Fragmented and short-term project-based initiatives have not brought about improvements in institutional level service delivery for children. Decentralisation policies may be both facilitating and hindering the ability of local authorities to 'eliminate all infrastructural, social, environmental, institutional and legal barriers in the field of education, employment and vocational training, health care, rehabilitation, cultural, recreational and sports activities, in order for children with disabilities to exercise the rights foreseen' as set out in the Law on the Rights and Protection of the Child.

Social services for people with disabilities, including children, have historically been delivered as residential services⁶⁷ but since 2002 community-based services have been delivered by both NGOs and local authorities, including personal assistant services (allowances and some services for caregivers) and day care services.

There are pockets of promising practice emerging in community based social services and to date they have mainly taken the form of habilitation and rehabilitation services and day care services operated by NGOs or by municipal authorities in different types of community or day centers. Specialists in FGDs mentioned one center that is focused on supporting children and young people with disabilities to develop independent living skills. The center is funded by fees paid by the parents and not by municipal or central government funding.

Social workers are deployed in some of these services and play a key role in supporting inter-disciplinary work and coordinating

services around children with disabilities. According to focus groups with specialists, some of the day centers have social workers who have been trained in case management. However, the number of available social workers and their roles and responsibilities remains unclear. Overall, case management is nascent in Albania and while policies and procedures are in place compliance is limited.⁶⁸ A great need for services is noted but capacity to react and implement is weak. The absence of support plans specific to the needs and requirements of individual children with disabilities and their families limits children's access to appropriate services.⁶⁹

The social work profession is regulated by Law No. 163/2014 'On the Order of the Social Worker' and Bachelor and Master level programmes are offered through universities in Tirana, Shkodra and Elbasan. A recent analysis on provision of social work education notes that whilst the requirement for social work professionals is reflected in policy and legislation, capacity constraints remain.⁷⁰ In particular the curricula do not include specific modules on work with children with disability and, consequently, 'graduate social workers are not equipped with the appropriate knowledge and skills to practise with children with disability in community-based services'.

Parents of children with disabilities interviewed for this study do not refer to social workers at all when talking about social services, only to therapists. In fact, both children and parents interviewed largely do not identify any social services or social support apart from the disability allowance and in some cases the carer's allowance. Most respondents when asked about social services either mention day centers and the disability allowance or say that they do not know about any such services.



Taken together, this means that

the availability of community based social services for children with disabilities appears to have increased in recent years so that from 8–28 percent of children with disabilities or functional difficulties are now accessing social services. Nevertheless, children with disabilities were significantly underserved by social services in 2017. At the same time, provision of residential care services for children and adults does not appear to be decreasing significantly.

Given that approximately half of all social services provision is provided outside the statutory sector, and that external funding for NGO service provision for children with disabilities seems to be diminishing, the trend in increasing service provision may not be sustainable. Equally, given that families of children with disabilities are more likely to be living in poverty, their capacity to access fee-paying services is severely constrained. **Thus, the double bind of disability and poverty is likely to continue and contribute to increasing inequity.**

Most community based social services are in fact habilitation and rehabilitation services staffed by therapists rather than social services with qualified social workers. There are some promising practices emerging from project-based work such as multi-disciplinary teams working in some day centers and supported independent living services, but these are available only to very small numbers of children and young people with disabilities who may need them.

Accurate aggregated data based on clear definitions of each type of service are required at the central level in order to coordinate planning and service provision and to identify gaps in coverage across the country. At the same time municipal and regional authorities need to continue monitoring service delivery at the local level in order to be sensitive to local needs.

2.6.5 Rural services and supports

The secondary data reviewed for this study note that while statistical data are disaggregated to some extent for rural and urban differences, there is only limited information about how the lives of individual children in rural and urban settings differ. Research on inclusive education notes that rural settings are more challenging for achieving inclusion but there is little information on how this translates in the experience and lives of individual children.⁷¹ Some of the interviews with children with disabilities presented in Section 2.3.1 suggest that living in a rural area does not necessarily contribute to greater exclusion and that a child's individual personality or communication difficulties may represent more important factors in their exclusion from interpersonal relationships or community life than living in a rural setting. Given, however, that the present study interviewed children with disabilities who are mainly accessing disability allowances and services, further research is required to really understand how living in a rural setting impacts upon the experience and lives of children with disabilities who are not accessing services.

The gaps in monitoring data discussed in the previous chapter mean it is not possible to use such data to assess accurately the extent to which services are lacking in rural areas compared to urban areas.

Specialists and parents involved in FGDs in urban areas suggest that access to services in rural areas is extremely limited and considerably worse than the limited provision in urban areas:

KEY FINDING

There is a dominant narrative among some respondents that access to disability assessment and services for children with disabilities in rural areas is considerably worse than in urban areas, but this study has not been able to confirm the accuracy of this perception.

Transport represents a major challenge (and cost) for some children with disabilities from rural areas who were interviewed, though some parents of such children report that they have no major difficulties. Some financial support is available from local authorities to defray transport costs for reaching school and some services provide their own transport.

“The ministry allows for only the children that have been diagnosed. If you go into remote and rural areas there will be many more children who are not diagnosed. If my child lost five years in Tirana what has happened to children in rural areas? It is the health-care system that should obtain the information and relay it to the parent.

(FGD, parents of children with disabilities in urban area)

“Rural areas are completely uncovered and children in these areas cannot attend the day centre. For rural areas, there is only one administrator who handles economic aid, all the problems with children, disability problems, and so on. Villages of a unit are often far apart and one administrator finds it very difficult to serve and to follow up every case.

(FGD, specialists, urban area)

Many children and parents interviewed in rural areas, however, report that they do have access to a similar range of services and supports that urban children and parents have. There are of course exceptions:



“We don't have a day center near here and often I get bored because there is not a lot I can do around here.

(KII, girl, 7 years of age)

The lack of activities or services reported by this child, however, may be an issue for all children in rural areas and not only for children with disabilities.

Transport is more problematic, time-consuming and costly for rural residents than for those in urban areas. Municipal authorities, through MoES&Y funding, are obliged to provide transport for all students living at a distance from school. In cases where this transport is not accessible, for example for a child who uses a wheelchair, parents can make their own arrangements. Some parents in rural areas report that the municipal authorities help to cover 50 percent of the transport costs for their children to reach school. Meanwhile, some rural residents report they have good access to health services while others report that they have to travel at least half an hour, if not more, to reach hospitals or health centers. In one village more than one parent reported that there is no pre-school service.

Supplementary evidence from Disabled Persons Organisations suggests that access to transport is constrained for parents in rural areas, with implications for access to health care, education, other social services, as well as participation in social and community life.

Further investigation of statistical and monitoring data is required to understand whether children with disabilities who have disability status but who are not receiving disability allowances (discussed in Section 2.7.1 of this report) has in fact to do with lack of access to services and support particularly for rural families as some respondents have suggested in focus group discussions.



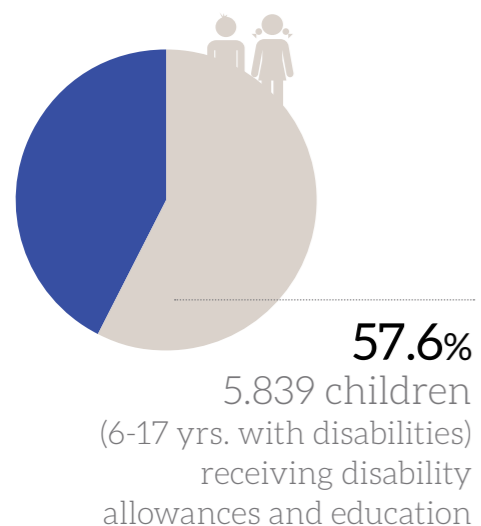
Taken together, this means that

the present study has been unable to identify conclusive evidence of the ways in which the lives of children with disabilities in rural areas differ from those in urban areas. Analysis of official data permitted any conclusions to be drawn on gaps in coverage of children with disabilities in rural or urban settings by disability allowances and services.

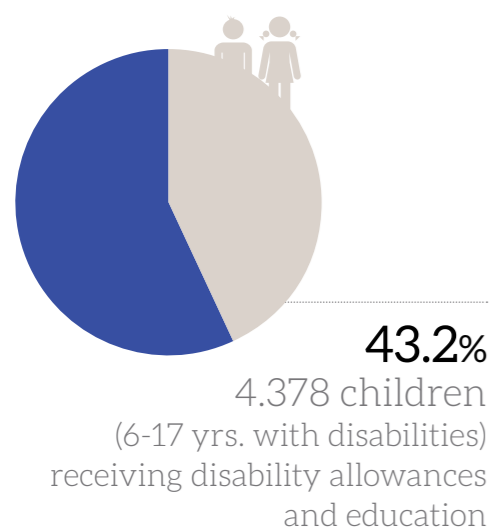
Further investigation focused on this question is needed in order to establish more conclusively whether children with disabilities in rural areas are disproportionately excluded from accessing services compared those in urban areas.

Transport, however, is clearly a challenge for children with disabilities in rural areas and, as reported in sections on early intervention, social services, health and education of this report, consideration should be given to outreach services (mobile teams) where center-based services are difficult to access for children with disabilities living in more remote areas.

State Social Services Data



Ministry of Education Data



2.6.6 Education

KEY FINDING

Around half of school-age children receiving disability allowance are in education, though many are not accessing quality education adapted to their individual learning needs. Some children may be integrated into mainstream schools, but this is not achieving inclusive education.

Some 57.6 percent of children receiving disability allowances and of school age (5,839 children with disabilities aged 6–17 years) were also recorded by the State Social Services as being in education. However, MoES&Y recorded only 4,378 children with disabilities enrolled in education in the 2017–18 school year (43.2% of children receiving disability allowances of age 6–17 years). Discrepancies in data are significant and require further investigation.

The number of children with disabilities enrolled in mainstream schools is increasing slightly, but the experiences of children interviewed for the present study suggest that many of them are not accessing teaching or acquiring a quality education.

Teachers and classroom assistants require greater levels of support and training to be able to facilitate inclusion.

UNCRPD General Comment No. 4 sets out a framework for inclusive education for children with disabilities that reinforces principles of non-discrimination, reasonable accommodation and compulsory, free basic education for all. In Albania, chapter XI of the Law on Pre-university Education supports inclusive education and has resulted in changes in pre-service and in-service training and in school-based interventions.⁷² Teachers in specific project sites have demonstrated a willingness to work with parents, caretakers and the community. However, collaborative work with non-education professionals is less evident. Provisions for inclusive education, such as teaching assistants in classes to support children with disabilities, are not currently extended to pre-school.

A separate system of seven special education schools continues to operate in parallel and government intends these facilities to become resource centers to support mainstream schools with inclusive education according to the Strategy on Pre-university Education 2014–2020. The deaf population in Albania is, however, noted to have restricted access to education, contributing to high levels of functional illiteracy among adults who are deaf and impacting their opportunities for employment and participation.

Article 6.6 of the 2012 Albanian Law on Pre-university Education notes that, ‘Students of vulnerable families, disabled students and those being in learning difficulty shall be ensured specific care’. Article 19 notes that students with a disability are entitled to special care, determined by a DCM. Chapter XI Articles 63–65 deal explicitly with the provision of education to children with disabilities, including the prioritisation of inclusive education in kindergartens and schools. The Law also

KEY FINDING

The Law on Pre-university Education includes provision for parents to remove a child with disabilities from school if they believe they are not benefitting. This is contrary to the child’s right to quality education as envisaged in UNCRC and UNCRPD.

makes provision for assistant teachers for children with disabilities and rehabilitation services. Conversely, the Law potentially supports the exclusion of children with disabilities, in Article 64 (1) which allows for parents to remove a child with disabilities from school if they consider the child is not benefitting from education. This runs contrary to the child's right to quality education as envisaged in the UNCRC.

The National Strategy on Pre-university Education 2014–2020 sets out measures to establish the conditions for quality inclusive education, including for children with disabilities, and explicitly includes, among others, the following actions:

- MES&Y in cooperation with other institutions will create the conditions to particularly help children with disabilities throughout the educational cycles.
- Teachers will undergo qualification and re-qualification for inclusive education.
- Special institutions will be transformed into resource centers to facilitate inclusion processes in mainstream schools.
- Psycho-pedagogical counselling will be provided in schools to help with inclusion.
- Support teachers will be recruited for the special education of children with disabilities.
- Multidisciplinary teams will be set up to assess and monitor children with disabilities at the Regional Education Department level, and to diagnose and systematically oversee education.

However, it sets unambitious targets for ensuring children with disabilities are enrolled in inclusive education, with, 'Number of disability pupils in general education increasing from 3,201 in 2013 to 4,000 in 2020'.

The National Strategy envisages the segregated, special education system will continue to grow with a target set to increase the numbers of children with disabilities in special institutions from 704 pupils in 2013 to 900 in 2020. This target contradicts the overall policy of moving towards fully inclusive education. Continuing to provide separate special education may help to ensure at least some provision of education for children with disabilities in the short term, but in the long term runs counter to commitments of the Government of Albania under UNCRPD.

The National Agenda on Child Rights also sets out measures for improving quality, and access to, education for children in basic education (Objective 6) and especially targets Roma and Egyptian children, though it does not explicitly mention children with disabilities. Objective 7 of the National Agenda on Inclusive Education explicitly mentions children with disabilities in the context of enabling home education 'for children with disabilities who cannot attend regular school'.

The MoES&Y reports that in 2013 there were no teaching assistants in schools to support inclusion of children with disabilities, but by the beginning of the 2017–2018 academic year there were 585 teaching assistants deployed.

However, data provided by State Social Services indicate that only around 58 percent of 6-17-year olds receiving disability allowances in 2017 were in education, with the proportion relatively stable

Increasing target of children with disabilities in special schools contradicts to overall vision of shifting towards fully inclusive education in Albania.

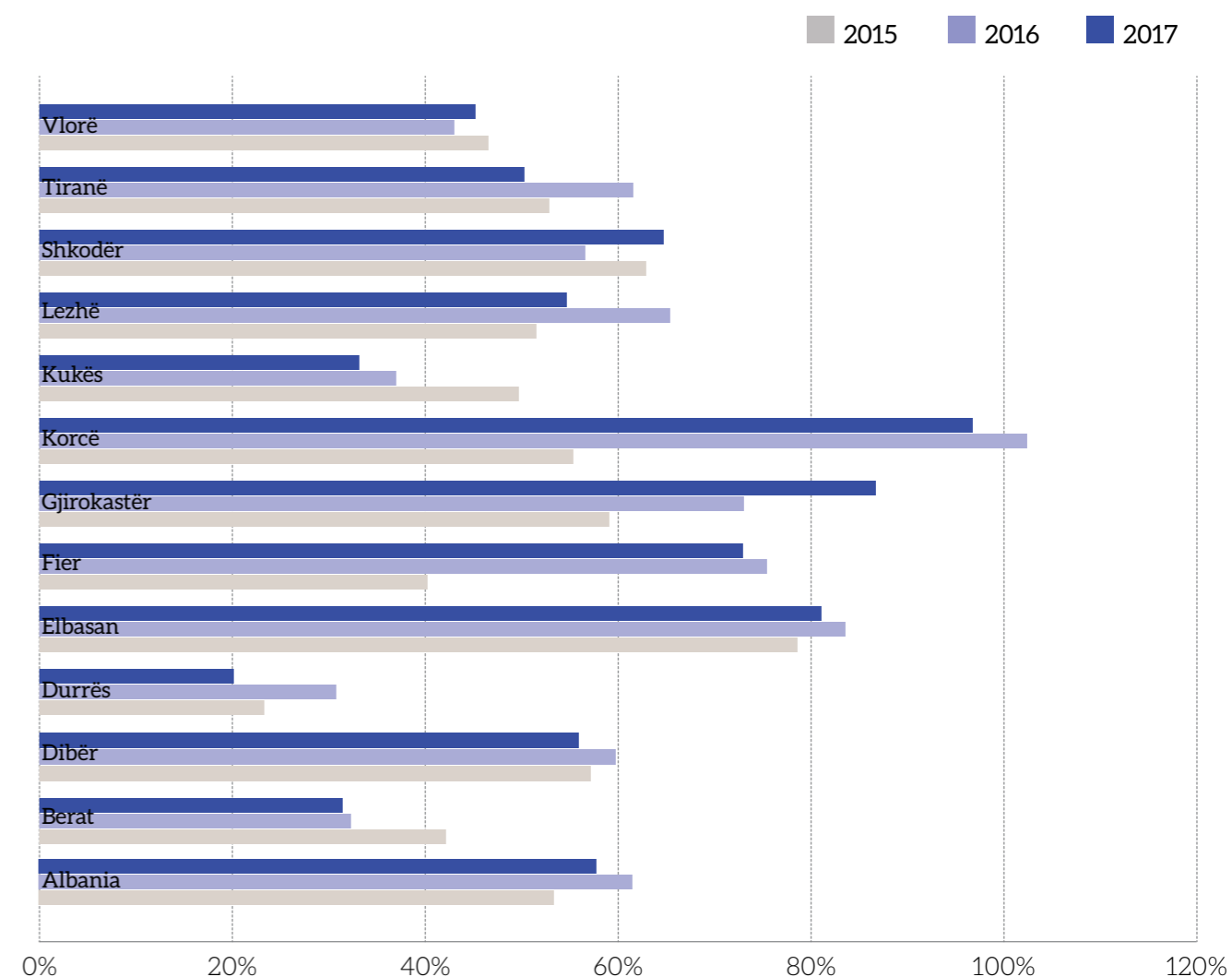
over the last three years^{vii}. Considerable variation between the counties, however, and between the years 2015-16 and 2017 in some counties can be noted, as illustrated in Figure 2.

The data presented in Figure 2 are based on same State Social Services data presented in Section 2.6.1 of the present report in relation to pre-school attendance and should be treated with the same caution, as the regional variations may be connected to the way in which this indicator is defined and data recorded in each county. If these data are based on parents self-reporting that their children is or is not enrolled in education at the point when they are applying for disability allowances for their child, then it may not be fully accurate as parents may over report or under report enrolment and attendance at school if they think there may be an advantage or disadvantage in doing so. If the data are based on school enrolment or attendance records then the regional variations may be reflecting availability of school places, barriers to inclusion or simply data administration issues.

According to the 2017 State Social Service data, 10,130 children of school age (6–18 years) were receiving disability allowances and 5,839 children of age 6–18 years were recorded as being in education (e.g. grades 1–12). Thus, the percentage of children with disability allowances of school age enrolled in school was 58 percent in 2017, a figure that significantly exceeds the unambitious targets for 2020 noted above. However, MoES&Y data report fewer children with disabilities enrolled in education and the discrepancies between these two sets of monitoring data require further investigation.

vii State Social Services Data is provided for the categories 0-6, 6-15, and 15-18 years-old.

Figure 2.
Percentage of children with disabilities of age 6–18 years receiving disability allowances who are in school in each county, 2015–2017



Source: State Social Services data, 2018; authors' calculations

It should be noted, though, that this simplistic measure of children in education (defined by State Social Services and MoES&Y when recording this data) does not provide real information on the extent to which children with disabilities are actually attending and participating in education.

MoES&Y data (see Table 3) indicate only 4,378 children with disabilities in grades 1–12 in 2017–2018 and a lower prevalence rate of disability at around one percent among children enrolled in grades 1–12 than the median three-year prevalence rate of 2.5 percent of children receiving disability allowances among the child population as a whole reported in Section 2.7.1 of the present report.

The differences between MoES&Y and State Social Services data in the number of children with disabilities may result from the different ways in which disabilities are defined and assessed by MDC and MCAAW. Firstly, the purpose of the assessments is different: to either support development of individual education plans or to support access to disability allowances and other benefits.

The data can also be influenced by the extent to which parents are informed about and agree with their child undergoing education and health assessments. The data indicate that not all children in receipt of disability allowances have had an education assessment and, consequently, been registered by MoES&Y as having a disability. Alternatively, the data could be indicating that parents overstate their child’s education status when claiming disability allowances (assuming that the State Social Services data are based on self-reports by parents). FGDs with specialists and local authorities tend to support the first interpretation.

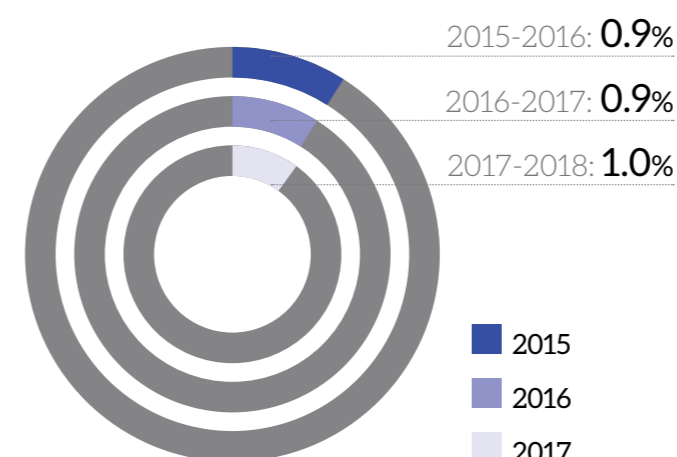
Table 3.
Summary of MoES&Y and State Social Services data on children with disabilities in education, 2015–2017

MoES&Y data				State Social Services data		
Academic year	Total students enrolled grades 1-12	No. of CwD in grades 1–12	% of CwD among enrolled students	End of calendar year	No. of children with disability allowance in grades 1–12	% CwD among enrolled students
2015-2016	479,000*	4,159	0.9%	2015	6,566	1.4%
2016-2017	459,488	3,915	0.9%	2016	6,506	1.4%
2017-2018	439,733	4,378	1.0%	2017	5,839	1.3%

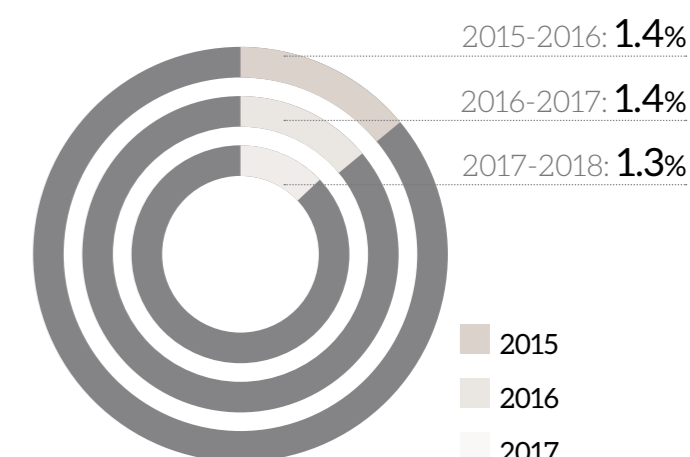
Source: MoES&Y, 2018; State Social Services, 2018; authors’ calculations. *Estimate based on the data provided by MoES&Y for 2016–17 and 2017–18

Over the last three years, there has been no significant increase in the number of children in education in receipt of disability allowances.

MoES&Y data



State Social Services Data



Experience of education – children, parents, specialists and local authorities

When asked about barriers to inclusion of children with disabilities, meaning inclusion into society and the life of the community in the broadest possible sense, most specialists and local authority representatives took the question to mean inclusion in education, testifying to the visibility that this reform has and its dominance in the minds of local implementers of government policy on children with disabilities. FGD participants identified the following priorities to remove barriers to inclusion in schools:

- Preparation of children: Early intervention and inclusive pre-school provision will increase the child's chances for success because they are prepared for school.
- Preparation and training: Equipping all teachers with the knowledge and skills to teach children with a range of disabilities alongside their non-disabled peers will increase capacity for inclusion.
- Resources: Provision of specialist teaching equipment, for example for assistive and augmentative communication, will contribute to improved quality of teaching and consequent improved learning outcomes for children.
- Information and preparation for parents of children with disabilities will help parents to fully understand the education options for their child and work together with teachers to agree on the best educational plan tailored to their child's abilities and development.
- A physically accessible environment in the school buildings and grounds.
- Auxiliary staff such as teaching assistants and psychologists to be fully trained and fully deployed so that teachers and children are being supported adequately as they work toward full inclusion.

The experiences of some children and parents confirm that in some cases children are being enrolled into mainstream schools where little has been done to prepare for their inclusion (see also Box 1) and where the programme has not been adapted or the teaching assistant can only come on an occasional basis: *I don't like it much, I have no friends* is a typical comment of children with disabilities experiencing poor inclusion efforts. One boy explained that as he cannot see, he could not understand the lessons and he no longer goes to school:

“I don't go to school because when I tried it I felt bad and tired and I can't understand the lessons. I would like to go to school but I can't think of a solution. I would like NGOs and the Union of Blind People to be active because for example until you came [the interviewer] I didn't know anything about JAWS^{viii} and Braille.

(KII, 9-year-old boy)

Another blind girl goes to school, but only benefits from music education as no other teaching is accessible to her:

“I need help almost for everything since I became totally blind (I used to be partially blind). I go to school every day and I like school but I can't really follow all the subjects only those professionals regarding music, because there is no assistant teacher. I need help for mobility to get around school, there is no adapted signage”.

(KII, 17-year-old girl)

viii Job access with speech (JAWS) enables people with vision loss to independently use a computer with a keyboard, speech, or Braille display.

Placing children in mainstream schools without preparation results in some children enrolled in schools but not really participating or accessing education.

Some children only attend for a few hours a week. Alternatively, as is the case for the girls in the case study described in Box 1, children might attend every day but do not appear to be involved in the classroom teaching. In many cases, children enrolled in a mainstream school, but who have significant unmet needs there, also attend day centers that attempt to compensate for inadequate education.



BOX 1.

Case study twin girls, 8 years old

The twins have severe difficulty in moving and a lot of difficulty in speaking, and require assistance with all self-care tasks. One of the sisters also has great difficulty with cognition, understanding and communicating. They both attend a general public school.

At the time of the interview, the family had one wheelchair for both girls and kept the wheelchair at school so that they can take turns moving around the school building. Their father drives them to school every day.

“The curriculum is not at all adapted. Their teacher puts them alone with each other and doesn’t integrate them and says bad things to them. They feel bad at school because of the teacher (although the assistant teacher is good). I want them both to continue going to school and one of them to go to university.
(KII, father of twin 8-year-old girls with disabilities)

Other children and parents, especially children who have few functional difficulties in terms of cognition, communication and mobility, have positive experiences of attending mainstream schools:

“I go to school almost every day. When I am upset I don’t go. I like school. I like mathematics and biology. When you go to school you learn to read and to write.
(KII, girl, 10 years of age)

“Yes, I like school very much. I like very much biology and experiments we do in the classroom with my teacher. There are some classes where it is very humid and where I cannot stay long because it makes breathing harder.
(KII, girl, 10 years of age)

“I don’t go to school regularly. There are many days, especially in the winter, when I have a lot of pain and cannot walk. Yes, I like very much to go to school. I like biology the most. I also like the time spent drawing very much. No, I can’t get around by my own. I need to rely on someone to move. Sometimes my friends give me help.
(KII, girl, 14 years of age)

“I like school, I like history and language. We plant trees and clean the classroom. I like basketball, which I have played but which I stopped for a while when I had an epileptic crisis and I have a damaged leg.
(KII, boy, 15 years of age)

Several children interviewed at home with their families were attending the residential school for the blind in Tirana. They go home at regular intervals and are more or less happy with their education. One boy attends the school on a daily basis. Children who are deaf also attend a residential school in Tirana and report that they are satisfied with their education, though they sense that they are isolated by not being able to communicate with friends, and in some cases family, outside of the institution as they can only communicate in sign language. Further, it is reported that the teachers at the school cannot sign, resulting in poor educational outcomes. A 2015 study noted that 97 percent of deaf adults in Albania are functionally illiterate, though 74 percent of these have completed basic education⁷³.

Children with moderate intellectual disabilities living in residential care (not boarding schools for deaf or blind children) were interviewed in connection with the present situation analysis. In one facility they attend school in the same building where they live whilst in a second facility the children travel by bus to school, though it was not clear from the interviews whether they attend a mainstream school or a specialized school for children with disabilities.

Most children who are old enough, both those living in residential care and in families, say that they are learning skills for independent living: they mainly mention cleaning and learning about money; only a few children say they are learning how to cook.

Whilst provision for inclusive education is envisaged in legislation and policy, children with disabilities in Albania can be said to be primarily in special education or integrated education systems (Table 4) rather than truly inclusive education.

The challenge is to put in place measures to ensure that inclusive education, which does not require children to be separated from their families, becomes a reality for more children with disabilities. These measures require

investment both in the capacities of teaching staff, reasonable accommodation, accessible infrastructure, transport and assistive devices and technology, aligned with UNCRPD General Comment No. 4 Article 12, core features of inclusive education, that can maximise participation. Adequate funding allocations are required to ensure that inclusive education can become a reality.

Table 4.
Education systems for children with disabilities and options available in Albania

Special education	Integrated education	Inclusive education
Two parallel education systems: one for typically developing children and a separate one for children with disabilities	Placing the disabled child in the classroom without or with limited additional support	All children are different; the system is changed to accommodate everyone and provide all the additional support that individual children require
Education options currently available for children with disabilities in Albania		
7 special schools for children with disabilities	Enrolment of children with disabilities in mainstream schools and pre-schools	All children are different; the system is changed to accommodate everyone and provide all the additional support that individual children require
Day centres that provide some education services	Day centres provide social care and support services and children with disabilities are enrolled in mainstream schools and pre-schools	All children are different; the system is changed to accommodate everyone and provide all the additional support that individual children require

The Office of the Commissioner for Protection from Discrimination reports that the majority of cases the office reviews in connection with disability are complaints lodged by parents about a child with a disability having a support person in the classroom:

“The decision on education support is made by a multi-disciplinary commission at the regional directorate level who consider how many hours support a child requires. This decision is shared with the school and it is the responsibility of the school director to allocate these hours. Support teachers have no special training: a secondary school teacher of biology who has insufficient hours to fulfil his or her full-time workload can be allocated additional hours as a support person for a child in elementary school. Consequently, the child may not receive enough quality support. This also has a disruptive effect on the other children in the class and their parents are complaining. The schools can be generally overcrowded and so the presence of a child with a disability can limit the attention the teacher pays to the rest of the class. It also contributes to further stigmatisation of the child with a disability who is seen as the cause of the disruption.

(KII, Office of the Commissioner for Protection from Discrimination)

Both the offices of the Commission for Protection from Discrimination and the People’s Advocate (Ombudsperson) concur that the legislation is adequate but that execution is poor, and that improvements can be made at both national and local planning levels in funding allocations and training to support inclusive education. An education policy review conducted in 2017 reports that significant barriers remain in Albania that continue to contribute to exclusion of children with disabilities, including poor infrastructure and attitudes.⁷⁴ The review recommends expanding teacher training and professional development to support inclusive teaching practices. The UNCRPD General Comment No. 4 on inclusive education confirms

that inclusive education requires recognition of changes across the education system. It can only be achieved through a commitment to ensuring the *availability, accessibility, acceptability and adaptability* of the education system as a whole.



Taken as whole, this suggests that

there are inconsistencies in the Law on Pre-university Education that contribute to exclusion, and that inclusion is perceived by some stakeholders as being achieved through enrolment of children with disabilities in mainstream school.

However, their right to access quality education on an equal basis with all children means that in practical terms, they are given the opportunity to attend school and, when required, provided with extra support to do so. This requires that both support teachers and class teachers are trained, that appropriate infrastructure is in place and that assistive devices and technology are made available to enhance learning opportunities.

Teachers and Government authorities recognise the need to increase resources if inclusive education is to be achieved and advocacy will be required to ensure that the necessary budgets for training, capacity building of staff and for reasonable accommodations in schools can be realized.

Awareness of the inclusive education reform is high among parents, professionals and local authorities, but ongoing communication campaigns are required to support both professionals and parents in moving forward with inclusion and addressing social norms that are creating barriers to inclusion.

Significant effort is required to maintain the gains and move towards full inclusion in a sustainable manner.

UNCRPD General Comment No. 4 on inclusive education provides a robust framework for supporting inclusion in education and highlights the need to ensure adequate investment in all aspects of inclusion, not only in assistant teachers.

KEY FINDING

Access to health services for children with disabilities is constrained by cost and availability, while transport (to reach services) remains a critical gap.

Many families seek services in Tirana, and also report travelling abroad at considerable expense to seek diagnosis and treatment for their child as they do not have confidence in the health system in Albania. About a quarter of families are satisfied with the health services they receive for their child with disabilities.

2.6.7 Health services

Diagnosis and medical assessment of disability is conducted in the health system and discussed in Section 2.6.1 of the present report. Some parents report incurring considerable costs in travelling to Tirana for diagnosis and treatment and several others report having sought diagnosis and treatment abroad for their child with disabilities at considerable expense. The main reasons driving parents to seek treatment abroad are the persistent perception of disability as a medical problem, as well as perceptions of incompetency, corruption and low capacity in the Albanian health system:

“The medical services do not work at all, they ask for bribes for the services they should do without charge. I have obtained all the services in Italy. Three operations and medicines (glasses, lenses, medicines) I obtained from there—doctors are trying to repair the eye that the Albania doctors damaged. I spent 1,000 Euro on the operation, requiring loans from the bank and I owe money to relatives. There are very high costs for treatment: medications cost 100 Euro every month.

(KII, mother, 3 year old boy)

“My child is treated by Italian doctors and they are expensive. In Albania I have also spent a lot of money and have not been given a diagnosis. In Italy my family supported me and we go every year for the usual checks for my child.

(KII, mother, 15 year old boy)

Several parents of children with disabilities report that doctors are ‘totally indifferent, nobody is interested’ or that they lack confidence in the health services. Many parents of children with disabilities report that their experience of medical services for the child has been ‘very stressful’. About a fifth of the parents of children with disabilities interviewed report that they are largely satisfied with the medical services they have received for their child:

“When we need to use medical and rehabilitation services we go, the staff is helpful and we never had any problems.

(KII, mother, of 4-year-old boy)

Given, however, that rehabilitation services are delivered outside of the health system in day centers, further investigation is required to understand the experience only of health system services.

Some parents of children with disabilities report that they have to pay for medicines or procedures, while others report that they do not have to pay and that the health authorities reimburse the cost of medicines. Further investigation is required to understand the reasons for, and the extent of, these different experiences.

These findings align with the those of the representative quantitative survey of parents conducted in 2017 that found that cost is a considerable barrier to accessing health services, especially for children with high levels of reported difficulties (28%). Parents reported cost as a major barrier to accessing health services, though, more importantly, 68 percent reported that inadequacy of service quality is the primary reason for not accessing public sector health services.⁷⁵

Whilst public services, where available, are nominally delivered free of charge, the associated costs, for example transport, are cited as a reason for not accessing them both by parents interviewed for this study and parents in the 2017 quantitative study. Private services are available, but are unaffordable for many families, and are not widely available outside Tirana.

Access to basic health care (including dentistry)

A recent study suggests that the introduction of fresh national legislation has had a positive impact on the overall health status of women and children. However, the outcomes still seem to be insufficient because of the persistence of several socio-economic negative factors.⁷⁶

While some conditions associated with disability result in poor health and extensive health-care needs, others do not. However, all children with disabilities have the same general health-care needs as everyone else, and therefore need access to mainstream health-care services. Children with disabilities can often face barriers in accessing health care because families cannot understand the complex health needs of their children, or do not have the information about available services and resources, or because there are financial barriers in seeking health care. Equally, access limitations may be related to physical infrastructure and staff knowledge and attitudes.

Many parents of children with disabilities interviewed for this study report that cost is a considerable barrier to accessing services such as dentistry. The parents who have taken their child to the dentist report high costs in the private sector. Only one or two parents report that their child has accessed free dental services. Many parents have not taken their child with disabilities to the dentist, though this could reflect common practice for parents of typically developing children and not be specific to children with disabilities.

A 2016 study noted that,

“Poor coordination between departments of health, social services and education ... have serious implications for the extent to which children with disabilities enjoy their rights to support and other services. This also makes it difficult for parents and children to determine the benefits to which they are entitled, creating wide variations in the availability and quality of support and services for children and their families⁷⁷”

Mental health services

In many cases doctors and other professionals conflate disability and mental health, often dismissing the symptoms of one by attributing them to the other. The World Health Organisation (WHO) Mental Health Action Plan 2013–2020 applies the term ‘mental disorders’ to denote a range of mental and behavioural disorders that fall within the International Statistical Classification of Diseases and Related Health Problems, tenth revision (ICD-10): ‘These include ... intellectual disabilities, and developmental and behavioural disorders with onset usually occurring in childhood and adolescence, including autism’ (WHO 2013, page 6). This action plan further separates mental health as a sub-category and places emphasis on developmental aspects for children including, ‘having a positive sense of identity, the ability to manage thoughts, emotions, as well as to build social relationships, and the aptitude to learn and to acquire an education, ultimately enabling their full active participation in society’.

IA mental health difficulty can be considered a disability if it has a long-term effect on an individual’s day-to-day functioning. Equally a person with a disability can also have a mental health difficulty. For example, children with a disability can be bullied, can have difficulty

engaging with their peers, and particularly in adolescence can find it hard to be involved in social activities, all of which can manifest in depression and anxiety or other mental health disorders.⁷⁸

WHO report that depression is the largest single cause of disability worldwide and that it can be both a cause and a consequence of disability.⁷⁹

There are ten Community Centres for Mental Health across the country, but only one of them, in Tirana, provides services for children of age up to 18. Referrals are made by schools, kindergartens and family doctors. The center conducts assessments and can refer to the MCAAW. They also conduct home visits and offer therapeutic treatments. No reference was made to these services by the families interviewed for this study, though some families do know about and use these services.⁸⁰

This study did not specifically examine questions of mental health of children with disabilities and further research is required to explore questions of bullying, isolation, depression or other mental health problems that may be associated with disability and the stigma of disability.

The interviews with parents do indicate a general lack of support for parents coping with diagnosis and coming to terms with their child's disability and struggling with decisions about treatment, habilitation or rehabilitation and education. Several parents interviewed reported that they feel excluded and need psychological support. Other parents find support less formally through contact with other parents who have children with similar conditions and have organized themselves into NGOs or informal groups. Some local authority representatives acknowledged in FGDs that in the absence of formal services, helping to create links between parents of children with disabilities can be an important alternative source of support.



Taken together, this means that

the findings of the present study are aligned with those on access to and quality of health care from the representative household survey conducted in 2017.

Further investigation is required, however, to understand the experiences and requirements of children with disabilities and their parents in relation to mental health and basic health services including dentistry. It is also necessary to consider the inclusion of adolescents in sexual and reproductive health services, and to document in more detail the costs that families of children with disabilities incur in relation to health care compared to costs for typically developing children.

2.7 Structural: macro-level political, economic and social policy context

KEY FINDING

State Social Services administrative data on child recipients of disability allowances indicate the prevalence of disability consistently at around 2.5 per cent of the child population across the country.

The 2017 representative qualitative survey of households with children found that four percent reported a child who had been assessed by the MCAAW as having a disability.

There are counties' variations in the prevalence rate for children receiving disability allowances, from as low as 1.7 percent up to 3.6 percent, on average. The reasons for these variances require further investigation.

56 percent of children with disabilities live in the four most populated counties—Tirana, Elbasan, Fier and Durrës—so there is a requirement to plan for provision of more services in these counties than in others to meet this greater demand.

Boys are over-represented among recipients of disability allowances, by as much as eleven percent in some counties, but the reasons for girls to be less likely to receive disability allowances are unknown.

It is likely that children who are eligible for disability allowances are not claiming them. Further investigation is required to understand the reasons.

Reliability and validity of data on children with disabilities across sources is uncertain, impacting the capacity of stakeholders to plan and allocate resources effectively.

2.7.1 Prevalence of disability and data issues

Children of age 0–17 years (n=631,160) represent just above one-fifth (22%) of the estimated total Albanian population of 2.87 million on 1 January 2018.⁸¹ According to INSTAT estimates, the child population has decreased by around 108,830, or 15 percent, since the census of 2011 fixed the population of age 0–17 years at 739,990.

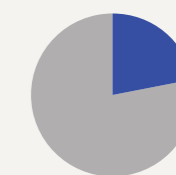
In Albania official data on disability are available only for persons above 15 years of age who, during the 2011 national Population and Housing Census (PHC), 'self-identified as having serious or extreme difficulties/impairment in at least one of the following: sight, hearing, mobility, sensory impairment, self-care, and communication. Responses concerning children under 15 years are excluded from the reporting on national census data because of concerns over erroneous responses.⁸² INSTAT elaborated in response to questions for this study that the answers of parents were subjective and there were concerns about the level of understanding of interviewers in relation to health and disability.⁸³


Prevalence among older children and adults (aged 15 years and above), as recorded in the 2011 national population census, who experience severe or extreme difficulty in at least one domain of functioning is 6.2 percent, or 178,000 persons.⁸⁴ Prevalence increases with age, from one percent among 15 to 24-year-olds to 23 percent among those 65 years and above.

2.87 Million Total Albanian population


631.160 Children 0 -17 yrs


22%



2017  ALBANIAN Children 0-17 yrs in receipt of disability allowance
14.155

 **2.38%**
Average over 3 years

 **5%**
Global prevalence estimate

 **2.5%**
median value over 3 years

In Albania, given the limited availability of survey data relating to children under 15 years of age, prevalence of disability amongst children is primarily based on those children who have been assessed by MCAAW as eligible for disability allowance and who are recorded as receiving the disability allowance by the Albanian State Social Services agency.

State Social Services data on recipients of child disability allowances from 2015–2017

Data provided by the agency in February 2018 report 14,155 children of age 0–17 years (up to 18 years) in receipt of disability allowance (Table 5) at the end of 2017. This equates to approximately 2.2 percent of the total child population of age 0–17 years (estimated by INSTAT as 631,160 children on 1 January 2018), significantly below the global prevalence estimate of five percent of age 0 - 14.⁸⁵

On average over three years, 2.38 percent of the child population of Albania has been receiving disability allowances (Table 5 and Figure 3). The median of the three-year average across the twelve counties is 2.5 percent. Given the range of the three-year average percentages of child disability allowance recipients across the counties and the presence of several outlying counties below two percent and above three percent, the median may be a more useful way of expressing the prevalence rate than the three-year average.

Table 5.
Children of age 0–17 years receiving disability allowance in 2015–2017 in Albania and its counties

County	No. of children of age 0–17 years receiving disability allowance at the end of the year			% of children of age 0–17 years in each county receiving disability allowance				% of total child population in each county (n=631,160)	% of total number of child disability allowance recipients in each county (n=14,155)
	2015	2016	2017	2015	2016	2017	Average 3 years	2017	2017
Albania	17,560	14,742	14,155	2.62	2.26	2.24	2.38		
Berat	631	804	842	1.99	2.67	2.99	2.53	4.46	5.95
Dibër	1,278	1,102	1,097	3.80	3.41	3.59	3.61	4.84	7.75
Durrës	1,814	1,845	1,520	2.83	2.89	2.40	2.71	10.03	10.74
Elbasan	2,670	2,073	2,082	3.85	3.10	3.27	3.41	10.09	14.71
Fier	1,826	1,397	1,434	2.56	2.03	2.18	2.26	10.43	10.13
Gjirokastër	350	268	249	2.32	1.87	1.90	2.04	2.07	1.76
Korcë	1,345	988	1,020	2.60	1.99	2.17	2.26	7.44	7.21
Kukës	636	655	626	3.00	3.18	3.19	3.12	3.11	4.42
Lezhë	750	697	723	2.42	2.32	2.51	2.42	4.56	5.11
Shkodër	1,507	1,293	1,035	3.04	2.72	2.28	2.69	7.20	7.31
Tiranë	3,942	2,932	2,897	2.08	1.56	1.55	1.73	29.70	20.47
Vlorë	811	688	630	1.99	1.74	1.64	1.79	6.08	4.45

Source: State Social Services, 2018; INSTAT, 2018; authors' calculations

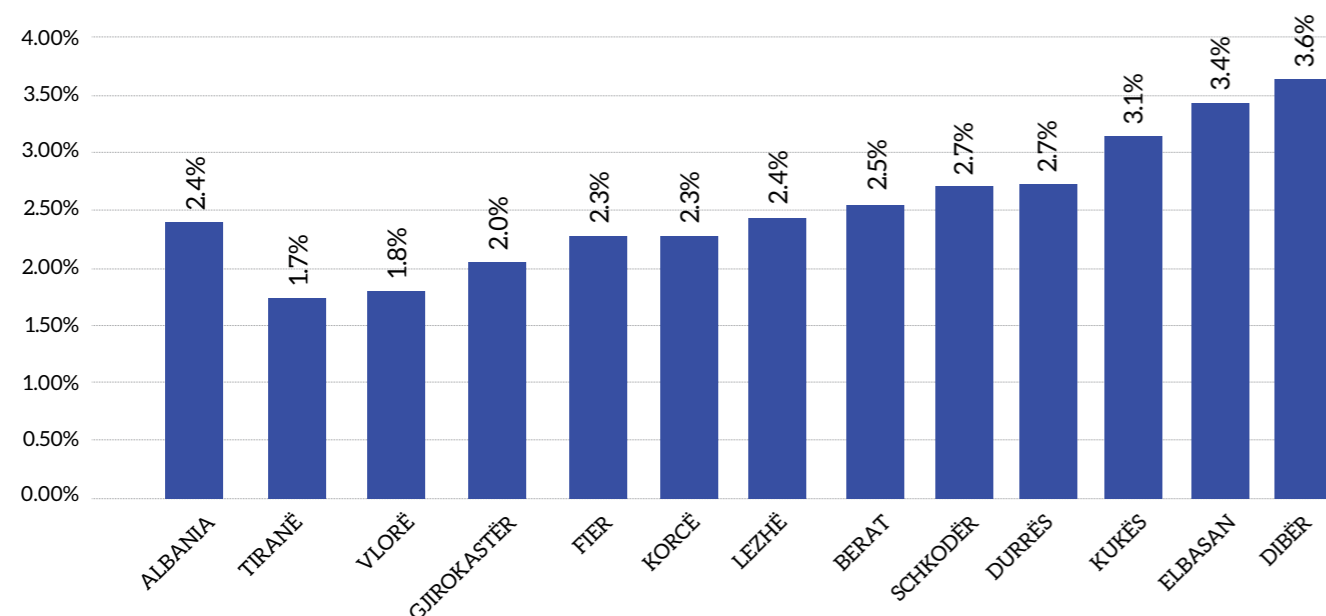
Prevalence rates among counties vary slightly, with some counties reporting up to around 3.6 percent of children receiving disability allowances on average over the last three years and others around 1.7 percent. The final two columns of Table 5 further illustrate that children receiving disability allowances in 2017 were particularly over-represented in Elbasan where ten percent of the child population lived but where almost 15 percent of the child disability allowance recipients lived, and under-represented in Tirana:

30 percent and around 20 percent, respectively (INSTAT, 1 January 2018). The reasons for these variances require further inquiry but could be linked to differences in administration of assessments and allowances in each county, in socio-economic indicators or in the ways in which parents of children with disabilities engage with the system, or a combination of all three. Further investigation is required to fully understand the underlying reasons, given that in all cases the number of children receiving disability allowances is significantly below the estimated global prevalence rate of five percent. The data reported in Table 5 also highlight that 56 percent of children with disabilities live in the four most populated counties: Tirana, Elbasan, Fier and Durres. Thus, for the purpose of planning, it should be noted that there is a greater demand in these counties and, therefore, a requirement for a greater supply of services.

Figure 3.

Average percentage of the child population of age 0–17 years receiving disability allowances in each county and the whole country for the years 2015–2017

Source: State Social Services, 2018; INSTAT, 2018; authors' calculations



A reduction in the number (and percentage) of children receiving child disability allowances can be noted after 2015 except in Berat^{ix} where an increase can be noted. More than one source links this overall reduction to the 2015 initiative by government to check the way in which disability assessments were being conducted and criteria applied to allow access to this form of cash benefit that results in stricter application and fewer recipients in most counties.⁸⁶

The number of children receiving disability allowances fluctuates within any given year and from year to year because children have to be reassessed and re-certified as eligible every year. Some recent changes to the assessment regulations, through DCM no. 813 of 27.12.2017, simplify some aspects of the reassessment process but have yet to take effect in all counties.

The average percentage across several years of the child population receiving the disability allowance at the end of each year (Figure 3) can provide a proxy prevalence rate that—while likely to be an underestimate as it does not include children considered to have less severe disabilities and children with disabilities who have not undergone a medical assessment or applied for the disability allowance—nevertheless provides some indication of variations among counties and a national average rate as a benchmark. It should be emphasized again, however, that the assessments on which this indicator is based are medical assessments of impairments and not disability assessments based on a rights-based definition of disability (described in Section 2.1 of the present report) and, therefore,

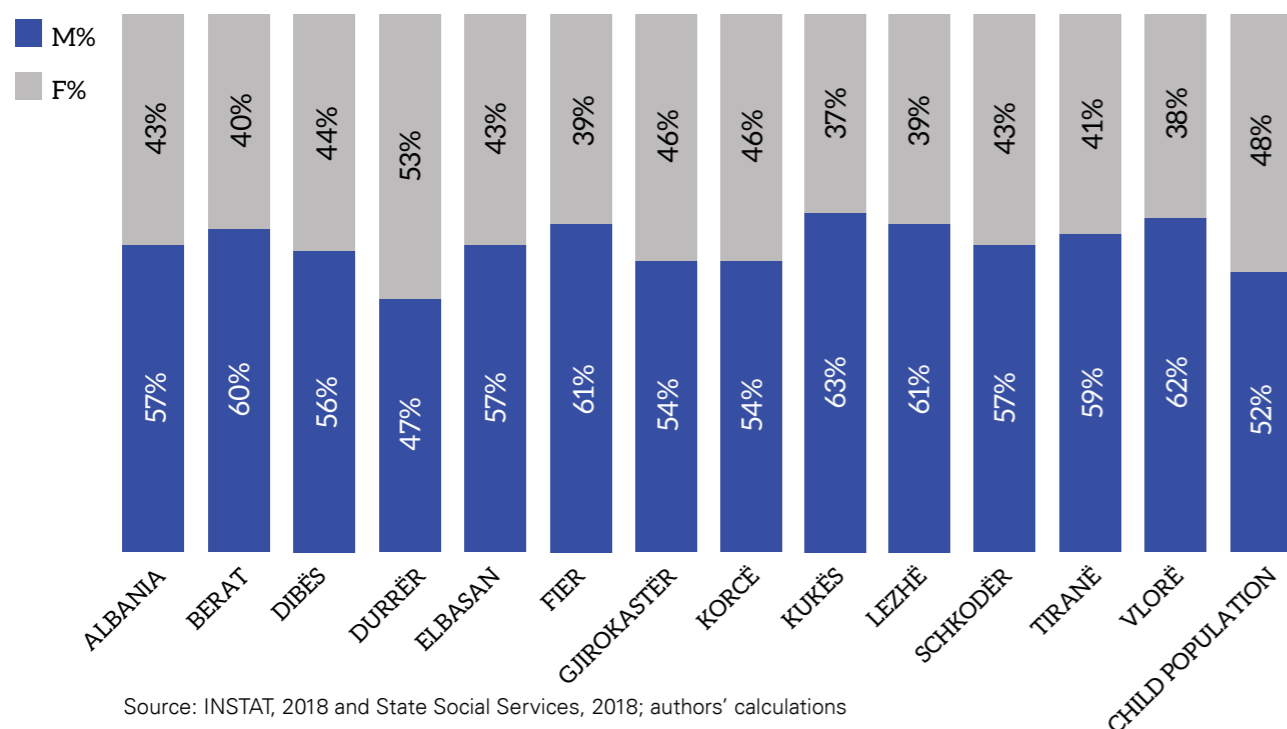
ix Increases in the percentage of children receiving disability allowances in Kukes and Lezhe from 2015 to 2017 can also be noted, but this is a result of the reducing child population rather than an increase in the numbers of children receiving disability allowances.

Official administrative data indicate that prevalence of disability among children is 2.5 percent or around half the rate that would be expected according to global estimates.

could more accurately be called impairment assessment and allowance rather than disability assessment and allowance.

The State Social Services data are disaggregated for male and female recipients of disability allowance and there are more boys than girls receiving it. Given that there are more boys than girls in the child population of age 0–17 years this might be expected. However, in 2017, boys were over-represented among children receiving disability allowances by about five percent for the whole country compared to the proportion of boys in the child population (see Figure 4). The available data indicate that around the same proportion of girls (43%) and boys (57%) were receiving disability allowances in the previous two years also.

Figure 4.
Percentage of girls and boys in the child population of Albania (final column) and of girls and boys receiving disability allowances in Albania as a whole and by county, 2017



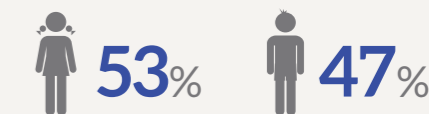
Source: INSTAT, 2018 and State Social Services, 2018; authors' calculations

Data from INSTAT indicate that the proportion of girls and boys in the child population is evenly distributed across counties, yet there is some variation in the distribution of girls and boys receiving disability allowances in each county. Durres stands out as the only county with a greater proportion of girls (53%) than boys (47%) receiving disability allowances. In Vlore, Kukës, Lezhe, Fier and Berat the proportion of boys receiving disability allowance is around 8–11 percent higher than the proportion of boys in the child population. Only 37 percent of disability allowance recipients in Kukës are girls compared to 48 percent girls in the child population in both Kukës and Albania as a whole.

The reasons for the 5 percent over-representation of boys among disability allowance recipients nationally, and for the 5–11 percent variances in the representation of boys and girls between counties, require further investigation. They could be linked to cultural norms that lead to parents being less likely to apply for disability certification for girls (except in Durres) or they could be linked to some aspect of the medical assessment that assesses more boys than girls as having a disability. The data on prevalence in Albania based on the 2011 PHC note there are no significant geographic differences in prevalence, and that there are some differences in prevalence between men and women, especially among older women (who live longer than men), but not between girls and boys between 15–18 years of age. This gender variation in the population of children receiving disability allowances therefore requires further investigation.

Distribution of girls and boys receiving disability allowances

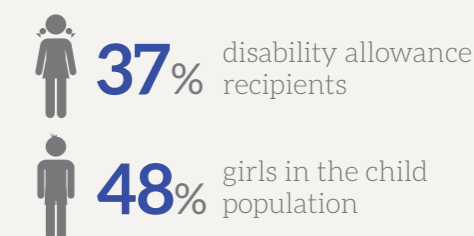
DURRES



VLORE, KUKES, LEZHE, FIER BERAT



KUKES



10.4% have a functional difficulty
1,354 children

4.3% had been assessed for disability by an official medical commission
563 children

4.0% had fulfilled the medical criteria of the disability assessment
514 children

374 children (73%) reported by parents to be receiving disability allowances

World Vision and Save the Children prevalence survey 2017

A quantitative study conducted in 2017 by World Vision in Albania and Kosovo and Save the Children in Albania used the UNICEF/Washington Group Module on Child Functioning that asks parents questions about the child’s functioning in twelve domains, including physical, cognitive and emotional domains. The sample of 13,000 households in all counties of the country was representative of the child population of age 2–17 years and the study found that 10.4 percent of parents interviewed define their child as having ‘a lot of difficulty’ or ‘severe difficulty’ with at least one functional domain. This result should be treated with caution given the challenges of interpreting parent perceptions of their child’s abilities, while the importance of challenging the way in which disability is assessed and defined should be acknowledged.

Although 1,354 children (10.4% of the sample) have a functional difficulty according to the Child Functioning Module, parents reported that only 563 children (4.3% of the total sample of 13,000 households interviewed) had been assessed for disability by an official medical commission and, of these, 514 (4%) had

fulfilled the criteria of the disability assessment. Of those 514 children, 374 (73%) were reported by parents to be receiving disability allowances (2.9% of all families surveyed).

One of the most important findings from the quantitative survey is that four percent of households report a child with an MCAAW disability assessment. When this is cross-referenced with the 2.5 percent prevalence rate of disability allowance recipients of age 0–17 years reported by State Social Services, it seems probable that four percent is a more valid indication of the prevalence of disability in Albania and a large number of children with disabilities are not accessing allowances to which they have a right under Albanian legislation.

There could be several reasons for parents to have had their child assessed and not to have subsequently applied for the disability allowance including: stigma associated with disability, more economically secure households not needing or wanting additional financial support or services, and difficulties in the application process. Some parents of children with disabilities interviewed for this study indicated that their child was assessed by MCAAW as having a disability and they did apply for and receive the disability allowance for some years, though the allowance was then cancelled for several years after a reassessment did not find the child was eligible, and then reinstated. So, some children with disability assessments in the past may not have been receiving disability allowances at the time that the quantitative survey was conducted. Further investigation is required to determine fully the number of children who have a MCAAW assessment and are not receiving allowances, and to understand the reasons for them not receiving those allowances.

Summary of data monitoring bottlenecks identified by the present study

The 2016–2020 National Action Plan on Persons with Disabilities (NAPPD) notes that cross-sectoral (cross-ministerial) collaboration on data collection and information sharing is critical to the achievement of its strategic goals. The plan further notes the challenges related to the collection and analysis of appropriate administrative data to support effective implementation, monitoring and evaluation of the action plan, and proposes the collection of empirical data. DCM no. 708 of 26.8.2015 on statistical data on disability sets out a robust framework for data gathering, but as yet these proposed measures are not being implemented. Further inquiry should be undertaken to assess the feasibility of sectoral data management systems in producing the indicators outlined in the DCM.

In the absence of reliable census and survey data on children with disabilities there are three main sources of official government data on such children, as follows:

- data on children receiving disability allowances recorded by the State Social Services;
- data on children using social services also gathered by State Social Services and Local Government (Municipalities); and
- children assessed as having special educational needs by local commissions of MoES&Y.

As this report has demonstrated in Sections 2.1 on assessment, 2.6.1 on early intervention and early childhood development, 2.6.4 on social services, 2.6.6 on education and in this section on prevalence there are discrepancies between the three sets of data that require further inquiry.

A new management information system has been developed and is being used along the implementation of the new disability assessment system in Tirana. Until that system rolls out nationally, the current MCAAW in each county has data (not reviewed by this study) that could provide important insights into the number of applicants for disability assessments, the number of approved applications each year and the number of re-applications each year that are either approved or not approved. These data could help to identify a population of children that have applied for a disability assessment and, therefore, have some level of functional difficulties noticed by parents or medical professionals, but where the applications have not been approved and the children are therefore unable to access support or services.

The 2017 quantitative study provides some insight into the population of children who have functioning difficulties according to their parents, but who do not necessarily have an MCAAW assessment. Regular monitoring is required to fully understand how the needs of this population of children who may have moderate or even severe functioning difficulties could be better assessed to ensure they receive the supports they need for inclusion in education and community activities.

Until questions oriented on a rights-based definition of disability are introduced into the census or other household survey that can accurately capture the prevalence of disability among children, the data from State Social Services on child disability allowance recipients and users of social care services may continue to be the best available indicator that is gathered systematically and frequently. Some adjustments that could help address some of the

Systematic monitoring and analysis of MCAAW data could provide more accurate estimates of prevalence than recipients of disability allowances, as well as build understanding of gender and regional variance.

bottlenecks and challenges in data analysis identified by the present study, and make these data more useful for monitoring the situation of children with disabilities in keeping with Article 31 of the UNCRPD on statistics and data collection, include the following:

- 1. Introduce a unified method for defining, recording and verifying** that a child who is receiving a disability allowance is in education; develop clear definitions of what 'in education' means for children with disabilities of all ages, including consideration of attendance (i.e. number of days per month) and other indications of quality beyond enrolment; ensure that staff and administrators who are recording data for the State Social Services have training and guidance to apply the method consistently in all counties.
- 2. Introduce a mechanism for gathering data from** all MCAAWs on children who have inquired about or applied for disability assessments or reassessments that can be cross-referenced with the State Social Services datasets on recipients of disability allowances and services; ensure that the MCAAW data are disaggregated for gender, age and functional difficulties (or diagnosis) reported by parents at the point of inquiry or application, as well as recorded by the MCAAW if the application is approved; maintain data on children who have had their disability status removed and on those who have been reinstated following reassessment.
- 3. Address the bottlenecks in the State Social Service and** local government records of social care service users to disaggregate child service care users from adults; to disaggregate for children with disabilities attending residential and daily care services for all typologies of services; to disaggregate by county and for public and non-public service providers; disaggregate for rural or urban residence, gender and age group (early

childhood, child, young adolescent, older adolescent) and for different areas of functional difficulty.

These relatively small adjustments related to disability assessments by the MCAAW, disability allowances and social care services could achieve relatively quickly results in ensuring that the kind of data collection framework envisaged in DCM no. 708 can be more fully implemented.

The data collected by MoES&Y are aligned to some extent with DCM no. 708 but are not aligned with those collected by State Social Services partly because they are based on the academic year and partly because it is not clear whether the definition 'child with disabilities' that MoES&Y is using differs from that used by State Social Services for its data. The cause of the discrepancies between MoES&Y and State Social Services data based on disability allowance recipients needs to be investigated and the two methods for counting children with disabilities in education aligned. Indicators for attendance and quality of inclusion in education should also be developed and UNCRPD General Comment No. 4 can provide a robust framework for monitoring quality of inclusion. Targets in the Strategy on Pre-university Education for inclusion of children with disabilities into mainstream and special education should be adjusted to reflect the actual numbers of children with disabilities (with MCAAW assessment) included in education and to articulate and monitor the move from integration to inclusion that should begin to take place in the medium to long term. The indicators should monitor not only actual numbers, but the proportion of children with disabilities (assessed by MCAAW) who are in education with the goal of moving from 55 percent enrolment to achieving the same proportion of children with disabilities in education as for typically developing children.

More broadly, efforts should be made to both integrate disability related data into all administrative data collection mechanisms, including national surveys and regular monitoring data, to ensure cross-sectoral correlation of data and disaggregation by age and sex.⁸⁷



Taken together, this means that

the prevalence of children with disabilities is likely to be higher than that indicated by the numbers of children receiving disability allowance and to be closer to 4 percent than 2.5 percent. Planning for early intervention services, social care services and inclusive pre-school and school education services should be based on the higher estimate and on the assumption that prevalence is likely to be equally proportionate across counties and between boys and girls until the variance identified in this study can be more fully investigated.

Efforts in capturing national-represented prevalence data for people/children with disabilities should be enhanced in the context of upcoming Census 2020 or other household surveys, led by INSTAT.

Accurate disaggregated data based on clear definitions of 'child with disabilities' for each type of service are required at the central level in order to monitor implementation of policies and legislation and to coordinate planning and service provision and to identify gaps in coverage across the country for early intervention, habilitation and rehabilitation, social services including alternative care services and supported independent living services, inclusive education and inclusive employment services that can support young people with disabilities to realize their vision for the future.

A fully integrated data management system based on a case management approach could help to ensure that the situation of children with disabilities can be monitored systematically and policies and services adjusted accordingly. This, however, may take some time to establish and in the meantime minor adjustment to indicators and data that are already being collected regularly in health, education and social sectors could greatly increase understanding of the situation of children with disabilities. Staff who collect and record data may require guidance and training in a rights-based understanding of disability and specific definitions of key indicators to ensure robust implementation.

Children who have had an MCAAW disability assessment that certifies their disability but who are not claiming disability allowances or using services are a priority for further research in order to understand the reasons for not benefiting from the available system of support. Examining the discrepancies between indicators and data gathered by education and social services and data collected by MCAAW is also a priority so that policies can be adjusted to take into account the actual numbers of children with disabilities and not only those who are receiving disability allowances. Education policies currently have very unambitious targets as they are based upon underestimates of the number of children with disabilities in need of education calculated in 2013.

KEY FINDING

Albania has introduced a robust policy and legislative framework to support children with disabilities that is largely compatible with the UNCRPD and UNCRC. However, the consistent, systematic and explicit mention of children is required to ensure full coherence, and full implementation of the provisions is required to support the rights of children with disabilities as defined in UNCRC and UNCRPD.

This requires review of legislation and policies, guidance, training, information and communication campaigns for implementing bodies and funding allocations, as well as mechanisms for coordination and on-going monitoring.

2.7.2 Policy and legislative framework in Albania relating to children with disabilities

Albania ratified UNCRPD in 2012 and became a state party to the Convention in 2013. In its initial State Party submission to the Committee on the Rights of Persons with Disabilities, Albania reports that legislation has largely been aligned with UNCRPD,⁸⁸ including in relation to definitions of disability set out in the international framework, and that ‘in case the norms of the national legislation run contrary to the Convention, the Convention prevails’. The shadow report on the UNCRPD is currently being prepared for submission in 2018.

Introduction of the 2014 Law ‘On Inclusion of and Accessibility for Persons with Disabilities’ and the 2017 Law ‘On the Rights and Protection of the Child’ promulgate these rights in national legislation. Similarly, the 2012 Law ‘On Pre-university Education’ supports the right to ‘free mandatory education for all children, regardless of their needs or special abilities’.⁸⁹

Introduction of the 2017 Law ‘On the Rights and Protection of the Child’ references an ‘integrated protection system’ for children (Article 3.15), while Article 32.2 makes specific provision for the disabled child and their right to receive services ‘determined by the responsible structures for the assessment of disability’.

The 2015 Albanian National Strategy for Social Protection (NSSP) refers inter alia to establishment of a benefits system based on categorised assessment

of both disease level and social circumstances,⁹⁰ and considers the social structures involved in creating exclusion. With specific reference to disability, this strategy aims to revise the system of disability assessment. It concurs with the life-course approach recognising that the needs of children change as they age. This strategy also references the introduction of social care service standards for children and for persons with disabilities, suggesting these have contributed to improved service delivery. The NSSP also notes that ‘non-institutional social care services are very limited and the governmental sector does not possess the expertise, neither the capacities necessary to provide them more broadly’. It further reports that the legal foundation for facilitation of NGO service providers through a National Licensing Council is in place, though the mechanisms for regulation and financing of these services is not determined.

The Albanian National Action Plan for Persons with Disabilities 2016–2020 (NAPPD) references significant deficits in the provision of education, social care and health-care services, and participation and engagement in public life for children and the adult population with disabilities. The action plan proposes a set of eight strategic goals, only one of which explicitly references children: Strategic Goal 4—Ensure quality inclusive education for all children with disabilities. Children are included in Strategic Goal 6—Ensure accessible, affordable, and equal health care for persons with disabilities—with a specific target to ‘Develop prevention, integration and rehabilitation services for children and adults with disabilities’, and Strategic Goal 7—Enable persons with disabilities to represent their interests and participate in Albania’s political and civic life—

with a specific target for the Ministry of Culture to make venues accessible for children. The same action plan also proposes investing 26 percent of the total budget in education, whilst the envisaged allocation for social care (for children and adults) is 9 percent.

The policy and legislative framework in support of children’s rights and the rights of children and adults with disabilities is dynamic and evolving. However, putting policy into practice is noted to be challenging.⁹¹ The most recent concluding observations of the UN Committee on the Rights of the Child in 2012⁹² noted the limited capacity of Albania to implement child rights-related legislation and urged government to invest in putting policy into practice through improved coordination and resource allocation.

Table 6 provides some analysis of the key features of the legislation as it relates to realization of the rights of children with disabilities with key bottlenecks highlighted in bold that may require review or reconsideration to make their relevance to children with disabilities more relevant.

Table 6.
Summary of key pieces of legislation, regulation and policy impacting on children with disabilities

Legislation or regulatory document	Analysis of key features impacting children with disabilities
Law on Inclusion of and Accessibility for Persons with Disabilities 2014	Supports implementation of UNCRPD. No explicit mention of children with disabilities except in Article 4.d, on participation. Makes provision in Article 10 for a multi-disciplinary commission to assess disability based on the ICF.
Law on Social Support and Services 2005 (amended 2006)	Outlines the measures for social support and services for individuals and groups in need, based on the economic, physical, psychological and social disabilities including children. Based on this law, persons with disabilities are supported by: 1) the payment benefits programme for disability, and 2) the social service provision programme for individuals in need. Disability assessment makes a child eligible for services and benefits and parents eligible for carers’ allowances.
DCM no. 618, date 07.09.2006, ‘On determining the criteria, documentations and benefit rate of the persons with disability’	The assessment of disability is based on procedures set out in this DCM, which also defines the main groups that benefit based on a list of diagnoses that lead to disability. The list was reviewed and updated in 2007 (DCM no. 362 of 26.02.2007) and procedures adjusted in 2008 (DCM no. 872 of 18.06.2008) and 2017 (DCM no. 813 of 27.12.2017). This decision codifies assessments based on ICD-10 and DSM-IV medical diagnosis that has to be re-confirmed annually to ensure eligibility for services and disability allowances. The latest adjustments aim to simplify reassessment but have not yet taken effect in practice and implementation requires systematic monitoring.
Law on the Rights and Protection of the Child 2017	Supports implementation of UNCRC. Article 32 makes specific provision for the disabled child and their right to receive services, ‘determined by the responsible structures for the assessment of disability’ (Article 32.2). Requires responsible authorities to ‘eliminate all infrastructural, social, environmental, institutional and legal barriers in the field of education, employment and vocational training, health care, rehabilitation, cultural, recreational and sports activities, in order for children with disabilities to exercise the rights foreseen in this law’ (Article 32. 5). Does not provide for financial or institutional mechanisms to support responsible authorities in this major transformational goal. Provides for residential care for children with disabilities (Article 32.4).

Law on Pre-university Education 2012	Supports the right for 'free mandatory education for all children, regardless of their needs or special abilities'. Students of vulnerable families, disabled students and those having learning difficulty 'shall be ensured specific care'. Article 19 notes that students with a disability are entitled to special care, determined by a DCM. Chapter XI Articles 63–65 deal explicitly with the provision of education to children with disabilities including the prioritisation of inclusive education in kindergartens and schools. The Law also makes provision for assistant teachers for children with disabilities and rehabilitation services.
Law 121/2016 on Social Care Services	Establishes the instruments and modalities for ensuring and delivering social care services in the community through institutional and non-institutional forms, with the ultimate goal of ensuring social welfare and social inclusion of individuals and families in need of social care (Article 1). Development centers for children with disabilities are described in Article 16 as 'local community services delivered with the goal of ensuring and improving the status and quality of life of children with disabilities until the age of 21 years'. It does not make clear that separation from parents and placement into residential care should be a last resort.
Law on Mental Health 2012	Disability impacts the mental health of child and family, and mental health can become a disability if it is long term (more than 6 months). This law needs to be reviewed to ensure that it aligns with other legislation in the field.
DCM no. 431 dated 8.6.2016, 'On piloting new eligibility criteria for disability benefits and services'	Piloting the use of the ICF assessment in two administrative divisions of Tirana. It provides for mild and moderate degrees of, as well as severe, disability. Provides for a package of support including personal assistant allowances.
DCM no. 708 dated 26.8.2015, 'On types, periodicity and reporting manner of statistical data on disability by the responsible state structures at central and local level'	The indicator framework proposed for data collection is divided sectorally: health, education, accessible infrastructure, justice and employment. There is no section on social allowances or benefits. For education the indicators are focused on attendance and graduation without specifying a definition of attendance (i.e. more than a certain number of days per year) or capturing any indication of attainment or quality in education acquired by the child. There are no definitions of, e.g., child with disability, type of disability or accessibility. This framework is reported by specialists as not being implemented.

Policy document	
National Action Plan on Persons with Disabilities 2016–2020	Proposes a set of eight strategic goals, only one of which explicitly references children: Strategic Goal 4—Ensure quality inclusive education for all children with disabilities. Children are included in Strategic Goal 6—Ensure accessible, affordable, and equal health care for persons with disabilities—with a specific target to, 'Develop prevention, integration and rehabilitation services for children and adults with disabilities', and Strategic Goal 7—Enable persons with disabilities to represent their interests and participate in Albania's political and civic life—with a specific target for the Ministry of Culture to make venues accessible for children. Proposes investing 26% of the total budget in education, whilst the envisaged allocation for social care (for children and adults) is 9%.
National Agenda for Child Rights 2017–2020	Sets out three main strategic pillars: i) Good Governance in promoting, respecting and protecting children's rights; ii) Eliminating all forms of violence against children; and iii) Child and adolescent friendly systems and services. There are several indirect components including 'promotion, respect and protection of the rights of children in vulnerable situations especially children with disabilities, poor children, Roma and Egyptian children, children without parental care, children on the move, etc.' (p. 6). The indicators that will be used for monitoring implementation set out an intention to support children with disabilities and their families, e.g., 50% increase in number of children with disabilities receiving social care services in targeted areas and support for increased employment of parents of children with disabilities. Children with disabilities are mentioned in relation to some aspects of education and health services or early childhood development, but they are not consistently and systematically and explicitly mentioned in relation to all aspects of rights fulfilment, inclusion and participation.

<p>Strategy on Pre-university Education 2014–2020</p>	<p>Sets out a strategy and action plan for achieving inclusive education including for children with disabilities. Actions to establish rehabilitation services and appropriate conditions for children with disabilities specifically include:</p> <ul style="list-style-type: none"> • MoES&Y in cooperation with other institutions will create the conditions to help particularly children with disabilities throughout the educational cycles. • Qualification and re-qualification of teachers for inclusive education. • Special institutions will be transformed into resource centers to facilitate inclusion process in mainstream schools. • Psycho-pedagogical counselling will be provided in schools to help with inclusion. • Support teachers will be recruited for the special education of children with disabilities. • Multidisciplinary teams will be set up to assess and monitor children with disabilities at the Regional Education Directorate level, and to diagnose and systematically oversee education. <p>Unambitious targets for ensuring children with disabilities are enrolled in education: the strategy aims for 4,000 children to be enrolled by 2020, when state social services agencies report that 5,839 children receiving disability allowances were already enrolled in grades 1–12 in 2017.</p>
<p>National Strategy for Social Protection 2015</p>	<p>Does not explicitly define disability but rather refers inter alia to establishment of a benefits system based on categorised assessment of both disease level and social circumstances (NSSP, 2015, p. 8) and considers the social structures involved in creating exclusion (Ibid., p. 9). With specific reference to disability, this strategy aims to revise, ‘the system of disability evaluation’ (Ibid., p. 7). It concurs with the life-course approach recognising that the needs of children change as they age. This strategy also obliquely references the introduction of social care standards for children and for persons with disabilities, suggesting these have contributed to improved service delivery, though the evidence base is unclear (Ibid., p. 19).</p>

<p>National Health Strategy 2016–2022</p>	<p>Includes no explicit mention of medical rehabilitation services for children with disabilities. Objective 1.2 of the Albanian National Health Strategy (2016–2020) explicitly references, ‘Early detection programmes ... neonatal, infant and child screening for development, hearing and sight impairment, screening for and early diagnosis of autism disorders’, though no linked activities or indicators are given. Objective 1.3 of the Strategy, to ‘Reduce the infant and maternal mortality rate and ensure a healthy start of life’, while stating as an action ‘Assurance of quality and holistic health care for all children, focusing particularly on the vulnerable groups, including children with disabilities’, also has only limited reference to activities or indicators mainly for screening or early identification without any explicit follow-up actions or indicators.</p>
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Monitoring policy and legislative implementation is largely the responsibility of government through its ministries, the National Council on Disabilities, and also the independent monitoring bodies, namely the People’s Advocate (Ombudsperson) and Commissioner for the Protection from Discrimination. The National Assembly (Parliament) makes decisions based on the People’s Advocate and Commissioner for the Protection from Discrimination annual reports. In May 2018, a Children’s Commissioner was appointed within the office of the Peoples Advocate with responsibility for pro-actively reaching out to children with disabilities and their families.⁹³ The office of the Commissioner for the Protection from Discrimination reviews cases of discrimination in both the public and private sector. The Commissioner has the mandate to make a decision and issue sanctions (fines). The appellant has the right of appeal through the court once the decision has been issued. Most of the cases brought by children with disabilities to the Commissioner relate to limited support for inclusive education. This is noted to be in part related to poor execution of the law because of limited resources.⁹⁴ The solution proposed by the Commissioner is improved local pro-active planning and adequate resource allocation to ensure that children receive the quality services to which they are entitled under the law.



Taken together this means that

coordination and cross-sectoral collaboration to create a coherent system for provision of support and protection for children and particularly children with disabilities, is noted to be challenging.⁹⁵ This 'siloed approach' at the structural level impedes progress in policy implementation and, as can be seen below, trickles down to the institutional community levels of service provision, ultimately contributing to continued exclusion of children with disabilities. A silo stands alone to deliver on one specific task, while children with disabilities have myriad needs that may change over time. In order to meet those needs a coherent and multi-sectoral approach is required that can deliver supports in an integrated fashion.⁹⁶

This is acknowledged by the Albanian government: in their recent report to the UN Committee on the Rights of Persons with Disabilities the state notes that, 'All ministries and local government officers shall have an officer in charge of disability rights ... [but that] this provision has not yet been implemented'.⁹⁷ Appointing an officer in charge of disability rights in each ministry and in each local authority and mandating them to coordinate closely with child protection teams could help to give greater impetus to implementation and ensure systematic monitoring.

Pursuing a collaborative approach is complex. In Albania it is not fully conceptualised for interconnected sectors to work together to better meet the needs of children with disabilities and improve the quality and effectiveness of service provision. The recent amalgamation of the Albanian Ministry of Health and the Ministry of Social Welfare, Youth and Sports to form a Ministry of Health and Social Protection provides an opportunity for the state to clarify the critical attributes that shape cross-sector service provision.

Challenges to policy and legislative implementation and monitoring at the local level

Representatives of counties and municipal authorities who participated in KIIs and FGDs consistently state that they are familiar with and understand government policy and legislation in relation to children with disabilities. They particularly reference the laws 'On Inclusion and Accessibility', 'On Social Services', 'On Pre-university Education' and 'On Urban Planning', as well as legislation 'On economic aid'.

Regional representatives of health, education, housing, social policy, child protection and employment confirm that the legislative framework for people with disabilities is closely aligned with UNCRPD and international best practice but is poorly implemented. Reasons cited during FGDs with regional authorities include:

- lack or insufficiency of financial resources to implement institutional obligations and responsibilities;
- lack or low level of information and familiarisation with the legal framework and the respective or joint obligations of the implementing structures;
- low professional level of law enforcement staff to handle and implement disability policies with competence and quality;
- lack or low level of cross-sectoral cooperation and coordination;
- non-inclusion of persons with disabilities in public discussions and hearings or technical round-tables at drafting and policy implementation levels; and
- low-level exchange of expertise between civil society structures and relevant authorities that provide public services.

Nearly all regional and municipal authorities consulted across a range of sectors including child protection, education, social services, vocational training, employment, housing and transport assert that more detailed guidance is required to support implementation of legislation:

The law on pre-university education must be supplemented by sub-legal acts: e.g. no specifications are given on assistant teachers in pre-school (kindergarten) education. The legal act in force only defines the role of the assistant teachers in mainstream schools but not in kindergartens.

(FGD, municipal authorities)

The lack of by-laws of the Law on Transport causes problems in terms of reimbursement for public transport as the municipality has no competence and financial resources for this and cannot influence the setting of conditions for operators offering public transport services in the city.

(FGD, municipal authorities)

Legislation leaves room for improvement and is not understandable by everyone. It leaves room for diverse interpretations, and this makes it difficult to implement. There is a lack of information on recent legal changes such as the Law on Inclusion and Accessibility and the DCM on its implementation. We do not receive the official journal. We need manuals and handbooks that help in implementation of laws.

(FGD, regional authorities)

A legal act is needed to regulate participation in vocational training courses for children who do not have secondary education. The current law has as a criterion that people with disabilities should have graduated from high school in order to attend these courses. There should be an exception for marginalised groups, including children with disabilities.

(FGD, municipal authorities)

As well as guidance and sub-legislative acts, clear funding allocations are required to support implementation of legal provisions related to people with disabilities including children:

Any decision should be accompanied by funding. Every legal act must be accompanied by an explanatory guide to how it will be implemented

(FGD, regional authorities)

Laws and sub-legal acts are not accompanied by financial analysis, and consequently no decent budgets are provided for their implementation.

(FGD, regional authorities)

Specialists further emphasize that lack of agreement between the regional and local level on allocation of resources means that the provisions of the law cannot be realized. This is particularly notable in trying to establish inclusive education for children with disabilities that cannot operate without considerable additional resources for reasonable accommodations in the classroom;

The normative provisions are clear regarding the number of assistant teachers in relation to the number of children but we do not apply them ... We cannot implement them due to the lack of approval by the ministry of additional quotas submitted by the Regional Education Department for these teachers.

(FGD, specialists)

Several regional and municipal specialists and managers highlight the need for reliable data and statistics to properly count children with disabilities in order to be able to plan services and programmes and to monitor implementation;

Statistics in the municipality continue to be collected with the same out-dated formats, regardless of the new data collection requirements that stem from the Law on Inclusion and Accessibility. Consequently, data indicating the needs of persons with disabilities for specialized services are missing

(FGD, municipal authorities)

The lack of consistency in mainstreaming the rights and needs of children with disabilities across all aspects of legislation and policy noted above is reflected in a lack of coordination between implementing bodies at the municipal and regional levels. Examples cited include the needs of children with disabilities in relation to child protection issues or gender-based violence may be overlooked:

Child protection units and sectors of gender equality and domestic violence, in the municipality, have no part in daily work that addresses and guides the problems of children with disabilities and of women with disabilities.

(FGD, municipal authorities)

Issues of coordination between central and local authority actors are also cited as adding to a dysfunctional implementation environment at the local level:

There is no contact person at the municipality to coordinate the cross-institutional relations on issues related to disability. Even in other institutions at the local level, there is no contact person who would be constantly participating in joint meetings. Various specialists attend various meetings so there is no follow-up to the issues being discussed. There is a lack of inter-institutional cooperation ... they report only along the vertical line, to the central level institutions to whom they are subordinate ... There are no guidelines and regulations to show how the legal framework should be applied in this regard.

(FGD, municipal authorities)

One municipality reports that some areas of policy implementation are being prioritized over inclusion for people with disabilities, again reflecting some of the gaps and inconsistencies across the national policies noted above:

In the municipality we have a social plan for inclusion of Roma and Egyptian communities. We do not have a plan for inclusion of people with disabilities. It must be done.

(FGD, municipal authorities)

All regional and municipal authorities highlight the need for more information and training in disability for local specialists as an important requirement for supporting implementation:

Staff at the local level are informed with delay, or even uninformed, about the legal and political framework in the area of disability ... The new approach and the concepts of the CRPD often remain unknown in some of the central-level sectors, and even more so at the local level.

(FGD, regional authorities)

There is no information on the Law on Inclusion and Accessibility, nor on legal acts for its implementation. The National Action Plan for Persons with Disabilities 2016–2020 is unknown.

(FGD, regional authorities)

One regional authority points out, however, that the legislation and regulations relating to cash benefits is an exception, with information being provided as soon as decisions are taken:

The exception is the legal framework related to cash benefits for which information is timely and complete.

(FGD, regional authorities)

According to specialists however, teachers, health workers and social workers may have good knowledge of the legislation relevant to their sectors, but weak knowledge of policy and legislation as it affects the child with disabilities across all sectors. For example, education specialists (teachers, school directors, school psychologists and other school staff) indicate that they are fully informed about the legislation relating to inclusive education in the Law on Pre-university Education, but that they have little or no knowledge of other legislation relating to children with disabilities:

... the Law on Pre-university Education is well known and the by-laws related to this law, while there is a lack of recognition of specific legal and political acts in the area of disability that directly or indirectly have links with the education of children with disabilities.

(FGD, specialists)

Social care services specialists (residential and day care specialists and care givers, therapists, psychologists, social workers) report that they are familiar with the Law on Economic Aid and Social Services and regulations on standards for service provision in day and residential services, but have only a superficial knowledge of other legislation and policy relating to children with disabilities. They confirmed their need for more detailed guidance and training:

Legislation in the disability area is known but only at a superficial level. The standards of social services are well known.
(FGD, specialists)

The law we recognise, and on whose basis we work, is the Law on Economic Aid and Social Services and Social Services Standards, as well as the standard of services for persons with disabilities in residential centers. We know these standards very well and apply them in our work.
(FGD, specialists)

We have limited knowledge of the legal framework in the area of disability. This is because central and local governmental level institutions do not provide us with official information about legal changes that occur and send us laws, decisions or other information material ... On the other hand, even when we are familiar with the legal framework, we need help, instructions to interpret, understand, to consult how we should apply and refer to our work. For this we need training or information sessions.
(FGD, specialists)

A final fundamental issue raised by local and regional authorities as a barrier to implementation of legislation is a lack of consultation with local level stakeholders when decisions and legislation are being drafted with, therefore, a significant and very challenging disconnect between the legislation and reality on the ground where the laws have to be implemented,

Local stakeholders are often not consulted on drafting laws, and this leads to the contextualisation of laws at regional and local level being difficult. There is no legal library.
(FGD, regional authorities)

[There is] lack of coordination between the central and local institutions in order to delegate the tasks at the local level and to take measures to ensure the completion of the legal framework.
(FGD, municipal authorities)



Taken together, this means that

policy and legislation are not being consistently implemented and practical measures are required to help make it a reality, including sub-legislative acts, funding allocations, detailed guidance and training for the responsible local authorities and for people implementing on the ground, inter-sectoral coordination, dedicated personnel, such as disability rights officers, and consultation with local implementing authorities on new legislation, policies and monitoring systems.

These issues, however, are similar to other governance issues, such as policies on inclusion of minorities, child protection or economic aid. The lack of consistency in explicitly including children with disabilities across legislation and policy means that they fall through the gaps and there is no implementation plan such as exists for minorities, or no disability rights officer designated to monitor implementation as there is for child protection or no standards for implementation of legislation on assistive technology as there is for social services and economic aid.

There are differences between counties in terms of implementation but these require further investigation as existing monitoring data do not provide reliable information as discussed elsewhere in this report.

3. Implications for policy and practice

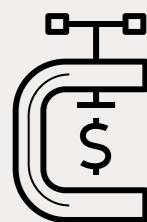
The purpose of the present Situation Analysis is, as described in the ToR, to generate comprehensive knowledge on children with disabilities that will inform concrete actions by government and UNICEF Albania to address the most critical rights violations of children with disabilities. Priority concrete actions emerging from the findings of this study include the following:

1. Strengthen policies where children's rights and those of persons with disabilities intersect

Children with disabilities are not mentioned explicitly in legislation and policy on persons with disabilities and only inconsistently in policies to support legislation on child protection and social services. Revising policy and, where necessary, legislation to make children with disabilities more visible could help communicate more clearly the intentions of the government of Albania in realising the rights of children with disabilities under commitments to both UNCRPD and UNCRC.

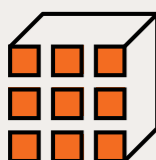
Aligning policy and legislation with UNCRPD general comment No. 4 on inclusive education (UNCRPD Article 24) and general comment No. 5 on independent living (UNCRPD Article 19), especially section 89 on inclusive education as preparation for independent living, provides a robust basis for further moving forward with the inclusion agenda in Albania and the realization of the rights of children with disabilities. These general comments should also be considered especially as they intersect with UNCRC articles 2, 3, 9, 12, 18, 23, 28 and 29 on non-discrimination, best interests of the child, non-separation from parents, respect for views of the child, parental responsibilities and state assistance, children with disabilities, and rights to and goals of education.

The revision of policy framework should include specific and realistic indicators and targets, and an explicit monitoring mechanism that will support Albania's periodic reporting obligations on implementation of the UNCRC and UNCRPD.



2. Address the budgetary limitations to effectively meet the needs of all children with disabilities

Relevant budgetary mechanisms and allocation need to be committed to implement institutional obligations and responsibilities for children/persons with disabilities and to address the limited statutory, and diminishing private funding for civil society social service providers. Investment is required to consolidate gains made during the last five years, to assure continuation of service provision for children with disabilities at current levels as a minimum, and to ensure that policy commitments for inclusive services are fulfilled.



3. Adopt a multi-dimensional approach to disability assessment

Immediate modifications to the current models of disability assessment applied by the MCAAW and MDC in combination with application of the learning from the ICF assessment pilot⁹⁸ can support an efficient transition from a medical to a social model, as intended in the legislation. This can include social and family assessment, early identification applying developmental screening tools and, for older children, an educational assessment. A unified multi-sectoral commission can authorise a multi-dimensional package of support that can be reassessed annually as children's needs change.

The approach can be further extended to include multi-sectoral systems for early identification of developmental delay, including roll-out of the standardised tools for measuring childhood development.

4. Assure affordable access to Albanian Sign Language, Braille, assistive devices and technology for children with disabilities

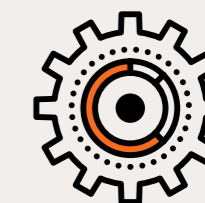


Prioritising implementation of Article 9 of the 2014 Law on Inclusion and Accessibility, which states that assistive devices should be provided, will immediately and irrevocably demonstrate robust government support for children's right to inclusion. The WHO Priority Assistive Products List⁹⁹ can serve as the basis for identification of a priority assistive products list for Albania that can define a minimum level of availability and that can be expanded incrementally as resources become available.

5. Target the de-institutionalisation of children with disabilities.

There is potential for a quick win in applying the UN Guidelines on Alternative Care for Children, considering the present number of children with disabilities in residential care. Efforts should aim the reduction in the over-representation of children with disabilities in the public residential care system, proceeding with deinstitutionalisation of children with disabilities in Albania.

6. Align information management systems related to health, education and social protection (social care and support, and cash allowances)



Ensuring correlated, accurate, disaggregated data based on age, sex and common definitions of 'child with disabilities' is essential. As a starting point, minor adjustments to data collection mechanisms applied by State Social Services, Local Government (Municipalities) and MoES&Y can create efficiencies in service planning and delivery. In the longer term, a fully integrated data management system would help ensure that the situation of

children with disabilities can be monitored systematically and policies and services adjusted accordingly.

and

Correlated information management systems can provide data indicators to support improved efficiencies in policy and service planning including budget allocations, and can support workforce planning to ensure there are enough people with the right qualifications to ensure more equitable access and inclusion. This will in turn assist government in managing the current risks associated with shrinking civil society sector funding and the potential effect on provision of social services.

Equally, good data can assist in renewing the focus on the rights of children with disabilities to access quality education on an equal basis with all children.



7. Provide accurate and up-to date information about the rights of children with disabilities and policies in support of their rights among local service providers, parents and communities in large.

Access to accurate and up-to-date information about government reforms, and the availability of services and supports will contribute to increased parental confidence, demand-driven access and consequently increased opportunities for children with disabilities. At the same time this can enhance the capacity of public sector workers to fulfil their responsibilities.

An information campaign can be supported through the assignment of Disability Rights Officers to regional and local authorities in the short term, and development of social services staffed by professional social workers in the longer term. Disability Rights Officers should be additional to the

current staff complement and trained and provided with protocols and guidance for working at the intersection of disability and child rights.

8. Adopt a case management approach for children with disabilities to make sure they can access systematic and holistic support

Social work case management would allow for a method of providing services whereby a professional social worker collaboratively assesses the needs of the child with a disability and the child's family, and arranges, coordinates, monitors, evaluates and advocates for a package of multiple services to meet the specific child's complex needs.

Capacities of professionals should be strengthened on how to work with families, support parents of children with families, and involve parents and children with disabilities, where possible, in specific discussion pertaining to their care and support needs.

9. Future research on children in Albania, including violence research, should be deliberately inclusive of children with disabilities.

Whilst global data suggest that children with disabilities are likely to be disproportionately affected by exposure to violence, abuse, exploitation and neglect,¹⁰⁰ for ethical reasons this study did not include questions about the experience of violence. This is because the study of violence against children is a specialist area requiring strict protocols to ensure children are not exposed to additional trauma and risk.¹⁰¹

Specific research is also indicated on the following:



- i. the life experience of children with severe communication difficulties
- ii. the number of children who have a MCAAW assessment and are not receiving allowances, and if so the reasons for them not receiving allowances, as well as the identification of currently invisible children with disabilities and their families who are not receiving disability allowances or services
- iii. identification of the precise level of under-provision of cross-sectoral prevention, early identification and early intervention and pre-school services
- iv. whether children with disabilities in rural areas are disproportionately excluded from accessing services compared to children in urban areas, and gaining an understanding of the broader determinants of exclusion and inclusion
- v. an understanding of the experiences and requirements of children with disabilities and their parents in relation to mental health and basic health services, including dentistry and sexual and reproductive health in adolescence, and documentation in more detail of the costs that families of children with disabilities incur in relation to basic health care compared to those borne by families of typically developing children.

4. Annex A: Study Methodology

Introduction

This study adopted a mixed methods approach - collecting, analysing and integrating qualitative data from FGD and KII with quantitative secondary administrative and survey data. An initial desk review found that the voices of children with disabilities and their parents were largely missing from the extensive body of recent research in Albania. Primary data collection therefore focused on gathering the perspectives and experiences of children and parents as well as of specialists who work closely with them and local authorities responsible for implementing policy and legislation that directly impacts them. KII were conducted with 79 children with disabilities aged 10 to 17 in four counties of Albania and with their parents or carers. FGDs were also conducted with parents of typically developing children and with local authority representatives. A total of 300 people took part in the study.

Research Team

This study was undertaken by a Research Team consisting of two international consultants with extensive experience in research and disability, working with the Albanian Disability Rights Foundation. In partnership with UNICEF the Research Team selected and supervised the data collection team: the national research coordinator, 3 national researchers, and 9 data collectors. Two members of the team were Albanian sign language interpreters and all had some experience of work with children with disabilities and their families and caregivers. ADRF also identified local site coordinators in each location, who knew the area and who could

assist in locating families and making the necessary introductions.

Study Phases

Guidance and supervision was provided by UNICEF in partnership with the MoH&SP and the MoES&Y.

The study was conducted in three phases:

- Phase one - an extensive review of secondary data to understand the current situation for children with disabilities in Albania based on the available global and national literature, and national administrative data;
- Phase two - participatory development of methodology and study enquiry concept for primary data collection, including key informant interviews with government and non-government stakeholders and children with disabilities and their families and care takers. This was followed by a validation meeting with stakeholders to confirm the methodology and enquiry framework;
- Phase three - primary data collection, data analysis, final report and final validation workshop with stakeholders.

Preliminary consultations

Preliminary consultations were conducted with 39 key stakeholders in Tirana during December 2017 (Table 7). These preliminary consultations informed the study design.

Table 7.
Preliminary consultations Phase Two

Participants			
		# Female	# Male
Focus Group Discussions (FGD)	Parents of children with disabilities	10	2
	Disabled persons organizations	8	3
Key Informant Interviews	UNICEF	5	1
	Ministry of Health and Social Protection	3	0
	Ministry of Education, Sports and Youth	1	1
	Disabled Persons Organisations	1	0
	Non-governmental organizations	3	1
Total		31	8

Stakeholders including representatives of UNICEF, MoH&SP, MoES&Y and NGO representatives reviewed initial findings and endorsed the research design in December 2017, and reviewed the findings and conclusions in May 2018 prior to finalisation of the study report.

Study Enquiry Concept

In combination, the secondary data review together with the preliminary consultations contributed to the design of the study enquiry concept, research questions and data collection methods.

This study considers the *life-course of children with*

disabilities within the context of the socio-ecological framework of human development. This allows for the availability of significant life-course interventions and supports to be assessed against government commitments and real-life experiences.

The five levels of the socio-ecological framework can be described as relating to:

1. **Structural** – legislation and policy,
2. **Institutional** – organizations and services,
3. **Community** – factors such as social capital and networks influenced by social norms and beliefs,
4. **Interpersonal** – factors such as the immediate context of family, household and intimate acquaintances, and
5. **Individual** – factors such as personal history and developmental features.

The study reflects on the interactions between these elements of the wider child protection system as well as how they are affected by the social, cultural and policy environment when placed alongside significant life-course interventions and supports.

Key life-course interventions and supports for children with disabilities include:

1. **Appropriate care pre-conception, during pregnancy and childbirth** – for example, public-health campaigns for shifting social norms related to alcohol and tobacco use; anaemia prevention in adolescent girls, pre-pregnancy folic acid supplementation, adequate antenatal healthcare, hospital birth (or skilled birth attendant), immediate post-natal counselling if required; etc.

2. **Early identification** – systematic monitoring of children’s early growth and development for identifying any delays in meeting developmental milestones and to make sure that where a delay is identified children get the help they need as soon as possible.
3. **Early childhood intervention** – consisting of services and supports to ensure and enhance children’s personal development and resilience.
4. **Pre-school** – preparing for children to enter the education system, “school-readiness”
5. **Basic education** – all children, including children with disabilities have the right to basic education (primary and lower secondary) and inclusive education has been a central tenet of the rights based approach since its emergence in the 1990’s.
6. **Social care/social support services** – individually designed support and assistance using a systematic approach to delivery of a broad range of social services.
7. **Habilitation and rehabilitation** – specialist services to keep or improve skills for daily functioning and to regain skills and abilities that may have been lost. These can include speech and language therapy, occupational therapy and physiotherapy and assistive devices and technology.
8. **Access to information** – which enable children and families to claim their rights and contributes to changing social norms.
9. **Other cross-cutting** – exposure to violence, abuse exploitation and neglect; representation in residential care systems; gender-based discrimination.

Key Research Questions

The findings from the secondary data review and preliminary consultations, reviewed against the conceptual enquiry structure, contributed to the development of the key research questions for this study.

How do policy and legislative provisions support the rights of children with disabilities?

What services and supports are available for children with disabilities and their families?

How do children with disabilities and their families participate in community life?

What help and support do children with disabilities and their families have from extended family, friends and neighbours?

What is it like to be you?

Data Collection

Taking into account:

- the considerable amount of recent research on children with disabilities in Albania (since 2015), including the 2018 quantitative survey based on UNICEF/Washington Group Module on Child Functioning question set (data collected in 2016-2017)
- the noted absence of the voices of children with disabilities and their families, the primary data collection for this study

prioritized a qualitative approach to gather information from children with disabilities themselves and their families, carers and those who work most closely with them.

Nine semi-structured conversational interview schedules were designed to ensure relevant contexts were brought into the dialogue. The KII and FGD were designed as face-to-face interactional exchanges of dialogue between participants, using a narrative-thematic approach but with a flexible structure:

1. KII parent or other carer of child with a disability in the family
2. KII residential carer of child with a disability in residential care
3. FGD parents of typically developing children (without disabilities)
4. KII children aged 7 to 9 years
5. KII younger adolescents aged 10 to 14 years
6. KII older adolescents aged 15 to 17 years
7. KII and FGD national, regional and municipal government
8. FGD specialists and service providers
9. FGD medical commission members (disability assessments)

The instruments were pre-tested in Tirana during the training of the data collectors and any required adjustments made.

Study Participants

Primary data collection was organized during the period 12th February-9th March 2018. A total of 300 adults and children were interviewed or took part in focus group discussions.

- 15 FGD with 26 regional and municipal authority representatives and 64 health, education and social care specialists and residential care staff;
- 4 FGD with 22 parents of typically developing children;
- 80 KII with 38 girls and 42 boys with disabilities age 7 to 17 years old (and one young person who turned 18 years of age one month before the interview)
- 88 KII with families of children with disabilities age 2 to 17 years old (and one 18 year old).
- 19 KII with carers in residential interviewed about the children in their care with disabilities aged 0 to 17 years (and two young people who had recently turned 18 years).

Participants were purposively selected based on their actual disability, their relationship to a child with a disability or their involvement in social policy planning and service delivery. The study aimed to include, as far as possible an equal number of girls and boys. In addition, four FGDs with parents of typically developing children were included to solicit community views in the four locations where primary data was gathered.

Table 8.
Characteristics of children and parents interviewed in February 2018

Family interviews about their child with disabilities				Child interviews			Of which:		Carer interviews
Total no. of parents interviewed (58 parent-child pairs)	about boys	about girls	Age of child interviewed or subject of interview (years)	No. of boys	No. of girls	Total no.	No. of children who gave partial or no response*	No. of children in residential care	Total no. of carers interviewed (about children in residential facilities)
2	-	2	1	-	-	-	-	-	-
2	1	1	2	-	-	-	-	-	-
5	3	2	3	-	-	-	-	-	-
4	4		4	-	-	-	-	-	-
5	4	1	5	-	-	-	-	-	-
9	7	2	6	1	1	2	-	-	1
5	2	3	7	3	4	7	2	-	-
7	4	3	8	4	2	6	3	-	-
7	5	2	9	4	2	6	-	1	1
13	8	5	10	6	8	14	3	2	2
1	-	1	11	1	1	2	1	1	1
1	-	1	12	-	1	1	1	-	-
6	3	3	13	4	3	7	2	1	1
5	3	2	14	6	6	12	4	5	4
11	7	4	15	7	4	11	1	2	2
3	1	2	16	3	3	6	1	3	-
2	1	1	17	3	2	5	3	3	4
1	-	1	18		1	1	-	-	2
89	53	36	Total	42	38	80	22	18	19

*Of whom 3 were children in residential care and 12, girls; all recorded as being with autism spectrum disorders, epilepsy, intellectual disabilities or cerebral palsy and/or with some, moderate or severe difficulties with speech, communication, comprehension

Local site coordinators were engaged in each locality including a Roma community leader, in order to facilitate the identification of households for interview and to support the logistics and administration of organising FGDs.

The Convenience-snowball approach was used to identify participants; hence, asking respondents in interviews and group consultations to provide information about families with children with disabilities.

Data Collection Locations

Four locations (Figure 5) Tirana, Kukes, Gramsh and Berat, were selected for primary data collection:

- in consultation with and on the advice of the MoH&SP, MoES&Y and UNICEF, and local civil society/disabled person's organizations;
- in consideration of emerging prevalence data; and
- in view of logistical considerations for access during winter conditions.

Tirana and Kukes targeted an urban population, Gramsh (Elbasan) and Berat selected households with more rural characteristics, for example, households should not be within 3km of a petrol station or supermarket.

Figure 5.
Map of Albania with primary data collection locations

Ethical Approach

The Research Guide for the Situational Analysis on Children with Disabilities in Albania was subject to the UNICEF independent Ethical Review Board approval process. Its development was guided by the:

- Regulation of the Government of Albania on "Ethics of The Research and Publishing Activity", and specifically article 1.1.4 which requires that institutions, "Maintain a climate of cooperation that promotes responsibility and ethics during research". The Guide has been issued by the Government of Albania to orient on ethical related issues companies/institutions/consultants undertaking research;
- UNICEF Procedure for Ethical Standards in Research, Evaluation, Data Collection and Analysis (2015);
- UNICEF Guidance Document on the Protection of Human Subjects' Safety; and
- UNICEF Guidance Document for Protection of Research Data.



The Research Guide upholds and commits to apply in practice the fundamental standards:

- that subjects are not placed at undue risk;
- that participation is voluntary, and subjects agree to informed consent prior to their participation; and
- that written protocols are in place to assure subjects confidentiality or anonymity.

Following receipt of ethical approval, the data collection team, were involved in a 5-day training programme upon completion of which they signed a written undertaking to comply with the ethical guidelines. This included guidelines to safeguard research participants and a protocol for reporting if a child or adolescent shared that they or others risk harm, or if the data collector witnessed or heard evidence of incidents likely to cause harm, in line with the Albanian Law on Child Rights and Protection Article 67. The Research Guide also included detailed instructions on the management and storage of data.

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