



ASSESSING DISABILITY OF CHILDREN IN NORTH MACEDONIA

COUNTRY CASE STUDY



Acknowledgements:

This case study has been authored by Jerome Bickenbach, ICF and disability expert, Switzerland and Aleksandra Posarac, disability expert, Serbia under the guidance of Nora Shabani and Aaron Greenberg from the UNICEF Europe and Central Asia Regional Office.

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This case study maps the systems and policy for disability assessment of children in North Macedonia and has served as background material for the preparation of the Main Report on Assessing disability of children: a five-country mapping (Armenia, Georgia, Moldova, North Macedonia and Serbia).

Disclaimers:

The desk research and collection of information for this report took place until May 2022. As such, the analysis does not contain developments that have taken place since late 2022.

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Cover photo:

Young boy with visual impairment from Tetovo, North Macedonia reads from a textbook in Braille alphabet.'

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1. Disability and needs assessment system reform

At the end of 2021, North Macedonia introduced a new model of disability assessment of children and youth up to 26 years of age.¹ The new model states that it is founded on the International Classification of Functioning, Disability and Health (ICF) and that it represents a shift from a medical to the bio-psycho-social approach to disability. It collects information needed for both a status assessment of disability and the needs assessment, and includes a referral to available education, health and child and social protection services and benefits. It is aimed at an integrated response to persons with disabilities' needs for health, educational, and social protection support. The assessment is expected to serve as a single-entry point for children and youth to access various support services in health, education and social protection that would enable them to fully participate in social life and enjoy their human rights.

North Macedonia has been deliberating on and preparing the reform of its disability assessment system for over a decade now. Initially, with UNICEF support, functional assessment was incorporated in the Law on primary education as a basis for providing educational support to children with disability. By the end of 2020, with UNICEF support, three pilot centers for ICF-based assessment of children were established – one national and two regional covering the Skopje region – and staffed with trained teams. Subsequently, these 3 expert bodies for functioning assessments were incorporated into the state healthcare system. The Public Health Center (PHC) Skopje opened a new Service for functioning assessment of

children and youth up to 26 years of age, and from January 1, 2021, these three centers started regular assessments of children and youth from the Skopje region. The child's parent(s) are now full members of the disability assessment team, together with a qualified special educator, a pediatrician, a social worker, and a psychologist. To date, more than 1,050 children and their families used the assessment services. In 2021, three more regional centers were opened, and the plan is to open 3 more in 2022, thus completing the transition process.

The change required several key laws to be amended. The amendments to the Social Protection Law, the Child Protection Law, the Health Insurance Law, and the Law on Health Protection. The amendments were submitted by the Government to the Parliament in 2021. The amendments to the Social Protection Law, the Child Protection Law, and the Health Insurance Law, were adopted. The amendments to the Law on Health Protection are pending.² With the amendments to this Law, the disability assessment will become legal responsibility of the Public Health Institution Health Center Skopje, the cost of the assessments will be covered by the Health Insurance Fund, and the beneficiaries will be enabled to make appointments for this service through the electronic system for scheduling of the public healthcare services.

The full transition to the ICF based model is planned in about three years, to allow time to develop and test disability and needs assessment tools and to give time to relevant government agencies to adjust to the new rules and train staff in their application.

2. Current legal and institutional provisions

Several laws and bylaws pertain to the assessment of disability of children and youth (until the age of

26) and their access to benefits. Below, we briefly present some of the relevant provisions.

¹ In North Macedonia, according to the Law on Child Protection, a child is a person up to 18 years of age and for persons with physical and mental disabilities, up to 26 years of age.

² The Proposal for the Law on Changes and Amendments to the Law on Health Protection was submitted to the Parliament on November 30, 2021. The Proposal, in Article 6 states: "In the Article 73, after Item 5, Item 6 is added: The Public Health Institution Health Center Skopje, in addition to the activities of the health center for the area for which it was formed, can also perform activities, exclusively for the functional assessment of children and young people with affected health state up to 26 years of age, at its headquarters and in internal organizational units, as well as on the territory of the Republic of North Macedonia in expert teams for the functional assessment of children and young people with affected health state up to 26 years in Strumica, Stip, Veles, Bitola, Gostivar, Ohrid and Kumanovo"

2.1 The Law on Social Protection³

This Law regulates issues pertaining to social protection (specifically social assistance and social welfare services) of the population.

According to this Law, persons with disabilities are “persons with long-term physical, intellectual, mental or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others”. “Social risk is a situation that potentially can make it difficult or to prevent social functioning of an individual, family or a particular group, which may result in the need of social assistance. The main social risks in the context of this Law are motherhood, disease, age, death, injury, and disability”. “Basic activities of everyday life are maintenance of personal hygiene, dressing, self-use of the toilet, functional mobility in the home, self-feeding, and other similar activities”, and “Instrumental activities of everyday life are cleaning, repairs, washing, cooking, buying products, external mobility, taking medical therapy and other similar activities”⁴

The law establishes the following principles of social protection: solidarity, equal treatment and non-discrimination, participation (including that “the child has the right, in accordance with his age and maturity, to participate and express his or her opinion in all procedures in which decisions about her or his rights are made), individual approach, strengthening capacity for independent living, privacy, respecting integrity and rights of beneficiaries, best interest, least restrictive environment, data protection, trust and individual’s access to her or his data, social justice.

The Law stipulates the following forms of monetary assistance (Article 27) to persons who satisfy eligibility requirements:

- (i) guaranteed minimum (income) social assistance;
- (ii) compensation for disability (for adults 26-65 years of age “to encourage social inclusion and equal opportunities for a person with severe

or deep intellectual disabilities, with the most severe physical disabilities, a blind person and a deaf person” – Article 44);

- (iii) compensation for assistance and care by others (eligible are adults with disabilities 26 years of age or older – Article 48);
- (iv) compensation for part-time work “due to the care of the child with disabilities and the most severe forms of chronic diseases, as determined by the Labor Relations Act, is exercised by the parent at the social work center, regardless of the age of the child – Article 55);
- (v) housing allowance;
- (vi) permanent compensation, and
- (vii) one-time assistance.

Article 70 provides for the following social services:

- (i) information and referral services;
- (ii) professional assistance and support services;
- (iii) counselling;
- (iv) services in the beneficiary’s home;
- (v) services in community and 6. out-of-family protection services.

Article 295, regulates that a Centre for Social Work, based on the finding and opinion of a professional body, decides on the type and degree of disability, and records the person with disabilities. The method for determining the type and degree of disability is regulated by the Minister of Social Protection in agreement with the Minister of Education and Science and the Minister of Health.

2.2 Changes to the Law on Social Protection

In December 2021, the amendments to the Law on Social Protection were adopted by the Parliament. Some key points:⁵

³ The Law on Social Protection, Consolidated and clean version that includes Basic text of the Law published in the Official Gazette of the Republic of North Macedonia 104/2019, https://www.mtsp.gov.mk/content/pdf/zakoni/2019/28.5_zakon_SZ.pdf. The Law has been amended afterwards several times: Law on Amendments to the Law on Social Protection, Official Gazette of the Republic of North Macedonia, 146/2019, The Law on Amendments to the Law on Social Protection, Official Gazette of the Republic of North Macedonia, 257/2019, The Law on Amendments to the Law on Social Protection, Official Gazette of the Republic of North Macedonia, 302/2020, The Law on Amendments to the Law on Social Protection, Official Gazette of the Republic of North Macedonia, 311/2020, and The Law on Amendments to the Law on Social Protection, Official Gazette of the Republic of North Macedonia, 163/2021. The latest changes were adopted in December 2021.

⁴ Ibid.

⁵ We only had access to the draft Law. We assume that the changes were adopted as proposed in the draft.

In Part I of the draft proposal – “Objectives, principles and basic solutions”, the following is stated: “The Draft Law ... aims to allow the application of a new model for assessing the needs for persons with disabilities. The model is designed in accordance with the International Classification of Functioning (ICF). The Draft Law ... establishes that a functional assessment of children and young people up to the age of 26, the determination of the need for additional educational, health and social support and the finding and opinion on the type and degree of disability are given by professional bodies carrying out a functional assessment. Social work centers decide and record persons with disabilities, based on the finding and opinion of experts for functional evaluation...”

The Draft Law introduces the term “affected health condition” – a disease (acute or chronic), disorder, injury or trauma. The affected health condition may include other circumstances, such as stress, congenital anomaly or genetic predispositions and other conditions that affect the psychophysical development of children and young people”

Article 7 of the Draft Law amends the Article 295 of the Law on Social Protection as follows: “The Centre for Social Work, based on the finding and opinion of the Service for Functional Assessment at the Public Health Institution – Health Centre Skopje, decides on the type and degree of disability and records the person with disabilities. The functional assessment ... establishes measures of additional support in education, health, social protection and protection of children and young people with affected health conditions up to the age of 26”. The Minister (of Social Protection) in coordination with the Minister of Education and Science and the Minister of Health, adopts detailed rules on functional assessment, needs assessment, determination of additional support measures, etc. for children and young people with affected health conditions up to the age of 26.

2.3 The Law on Child Protection

This Law stipulates that a child up to 26 years of age with disability in physical or mental development with specific need has the right to a special allowance (Item one, Article 32). “Finding,

assessment and opinion on the right to a special allowance is issued by a professional body for the assessment of type and level of disability in physical or mental development” (Item 2, Article 32)⁶. To receive a special allowance, the child with developmental disabilities and specific needs in the context of this law (Article 33) is a child with:

- severe, very severe and most severe disability in physical development,
- moderate, severe and deep mental disability,
- most severe forms of chronic diseases,
- the highest level of damage to vision, hearing, and speech (blind persons, almost blind persons, almost deaf and deaf persons, mute persons, persons with severely damaged speech due to child paralysis, persons with autism, and a person who has lost or has a damage to previously developed speech).
- Down syndrome
- Multiple developmental disabilities.

2.4 The Rulebook for the assessment of type and degree of disability of persons with physical and mental disabilities⁷

The Rulebook pertains to children and young people up to 26 years of age. In Article 4, this Rulebook states that “for the purpose of the Rulebook, persons with disabilities in intellectual and physical development who have special needs are persons with:

- impaired vision (low vision and blindness),
- impaired hearing,
- voice, speech and language disorders,
- body (physical) impairments,
- intellectual impairments (mild, moderate, severe and profound),
- autism spectrum and other pervasive developmental disorders,

⁶ The Law on Child Protection, consolidated text. <https://www.mtsp.gov.mk/content/pdf/2021/Закон%20за%20заштита%20на%20децата%20консолидиран%20февруари%202021-converted.pdf>.

⁷ We assume that this Rulebook is still in effect as the Rulebook to replace it is currently being drafted. Ministry of Labor and Social Policy. Rulebook for the assessment of type and degree of disability of persons with physical and mental disabilities. The Official Gazette of the RM, 172/2016. <http://www.zapovim.mk/dokumenti/propisi/Правилник%20за%20оцена%20на%20видот%20и%20степенот%20на%20попреченост%20на%20лицата%20во%20менталниот%20или%20телесниот%20развој.pdf>

- chronically ill person, and
- persons with several types of disability.”

Each of these 8 categories of impairments and disabilities is separately described and defined. And each has its own specific categorization of disability (although autism, chronically ill and multiple disabilities are not disaggregated into groups and/or degrees of disability). For example, **Article 8 defines persons with physical development impairments** as person with decreased or lost function of one or several body parts that decrease the person’s capacity to satisfy basic life needs. Depending on the degree of impairment, persons with physical development impairments are classified in the following groups: (i) a person with severe impairment in physical development is a person who can independently meet her or his basic life needs with the assistance of technical aids and accommodation in physical environment; (ii) a person with more severe impairment in physical development is a person with who can independently meet her or his life needs but only with the help from other person; and (iii) a person with the most severe impairment in physical development is a person who needs constant care and assistance from others to meet her or his basic life needs. **Article 9 defines persons with impairments in**

intellectual development as persons with delayed or incomplete psychological development as characterized by impairment of age specific capacities, which contribute to the development of the general level of intelligence such as cognitive, speech, motor, and social capacities. They are classified as persons with mild, moderate, severe, and profound (“deep”) disabilities in intellectual development. Each degree is then defined, including in terms of the IQ level. For example: a person with moderate disability in intellectual development shows delayed and limited development in the use of language and speech, self-care, and motor development. In standardized IQ tests performs at about 35-49. Article 10 defines that a person with **autism** is a person with other perverse developmental disorder characterized with qualitative damage of reciprocal social interactions, non-verbal and verbal communication, imagination and limited number of activities and interests, accompanied with various levels of disabilities in mental development, various neurological symptoms, epilepsy, and various behavioral syndromes such as aggression, auto-aggression, destructive behavior, and rage.

The Rulebook also regulates other matters relevant for the assessment.

3. Changes under preparation: Draft “Rules on the Method and Procedure for the Assessment of Functioning and the Needs for Additional Educational, Health and Social Support for Children and Youth”⁸

Currently, with UNICEF’s assistance, a new rulebook is being drafted: Draft “Rules on the Method and Procedure for the Assessment of Functioning and the Needs for Additional Educational, Health and Social Support for Children and Youth.” This Rulebook, according to the information from government officials in charge of the reform, is meant to be a “transition” Rulebook (see above).

The **Draft Rulebook** regulates procedure for implementing the assessment of functioning and needs of children and young people, lists available measures for additional educational, health and social support, describes the composition and professional profile of the

members of expert assessment bodies and the way bodies perform the assessments, reporting forms for the assessment, findings and opinion on additional support, and record keeping requirements.

The Draft Rulebook is composed of two parts. In the first part, the authors explain which changes are introduced to the assessment of needs, and the second part proposes a rulebook for assessing the needs of children and young people with developmental disabilities.

Below we present key points from the Draft. **It should be noted the text below is what the Draft says, not our interpretation of it.**

⁸ The Draft Rulebook was shared with the project team by the UNICEF North Macedonia Office staff. As it is being finalized, the changes are likely.

What are the key changes?

- The model is based on the International Classification of Functioning (ICF).
- The ICF classifies functioning and disability, does not classify people and does not classify them into categories.
- The term “categorization commission”⁹ is replaced by the term “expert assessment body”.
- Existing “categorization committees” are abolished and nine new permanent regional expert assessment bodies and one national expert assessment body are established.
- The functional assessment bodies will recommend only services that existing institutions are able to provide and to that end they will be in constant coordination with support services and with the institutions responsible for providing them.
- Members of the expert bodies are professionals.
- Standard forms are introduced for the work of all expert bodies.
- A central electronic record keeping system/data base for the work of expert bodies is introduced.

Who identifies and refers the case for an assessment? Identification can be done by anyone noticing that a child may be experiencing a developmental problem – parents, relatives, friends, neighbors, health care workers, educators, teachers. Anyone can encourage parents to start the evaluation process. However, formal referral to the assessment can only be done by the child’s family doctor who refers the child to the regional expert assessment body.

What is the role of a regional expert body? The main task is to systematically collect information about the child and her/his environment and apply procedures for measuring functioning and assessing the underlying health condition. Based on the assessment carried out, the regional expert body issues a finding and opinion on each individual case. It describes two key aspects of functioning (body functions and participation), describes potential for development and recommends services to achieve the set objectives.

How many and where will regional evaluation bodies be formed? Nine expert evaluation bodies are formed: 2 in Skopje, and one each in Bitola, Gostivar, Stip, Strumica, Ohrid, Veles and Kumanovo. This geographical distribution was made based on the regional incidence of new births in 2018.

How many members are there and who can be a member of the regional expert body? The regional expert body has permanent members and temporary members. Permanent members of each regional expert body are medical doctor-specialist pediatrician/specialist in family medicine or general medicine physician, psychologist, social worker and special educator and rehabilitator, with a minimum of 5 years of work experience. Permanent members have deputies. The number of temporary members will change depending on the child’s need. They are medical specialist doctor – according to the need of the child, otorhinolaryngologist, orthopedic surgeon, physiatrist, psychiatrist, neurologist, and ophthalmologist; speech therapist; parent and one person of confidence to be chosen by the parent himself. Each regional expert assessment body has a technical person-secretary.

How many members are there and who can be a member of the National Expert Body? The national expert body is composed of permanent and temporary members. Permanent members are a special educator and rehabilitator, psychologist, and social worker. Temporary members are a pediatrician and a psychiatrist. All members of the National Expert Body should have at least 10 years of work experience in assessing children and young people with disabilities and are trained and licensed to apply the ICF in the assessment of functioning.

Who finances the work of regional and national expert bodies? Members of the regional and national expert bodies are part of a newly formed functional assessment service at the Public Health Institution “Health Centre”- Skopje.

Are legal changes or new bylaws needed and which? The following changes need to be made to adopt this model:

- Adoption of a new Rules for the Assessment of Functioning and the Need for Additional Educational, Health and Social Support for a Child or Youth.

⁹ These commissions are replaced by the regional expert bodies.

- Existing laws to comply with new assessment model.

New standardized forms are introduced. The aim is to standardize and make uniform data collection, and reporting and the work of all expert bodies to provide comprehensive, uniform, and comparable data. The following standardized forms are introduced:

- (i) A form for findings and opinion,
- (ii) A form that all members of the expert bodies will use to collecting detailed data,
- (iii) A form for consent by a parent for the use of data,
- (iv) A form for submitting a report from the regional expert body to the national expert body,
- (v) A form for submitting a report from the national expert body to relevant institutions and organizations,
- (vi) A form for record keeping by regional and the national expert bodies.

Why has the form for issuing an opinion changed?

To provide exhaustive information in a standardized format, the opinion contains information on the current level of development and an assessment of the target level of development that can be achieved if the identified needs and recommended interventions are met.

Which institutions and organizations are or will be involved?

For the full implementation of the ICF, coordinated planning and action is needed to provide support services to children and young people in education, health and social protection. No individual, service or sector has all the knowledge, resources and expertise needed to solve all problems and overcome all barriers. Therefore, this process should involve everyone. It is necessary to ensure a common understanding of well-coordinated planning and decision-making for parents, teachers or other professionals working with the child to benefit from the findings, opinion and recommendations of the expert body. The following institutions are included:

Health Care: Ministry of Health, Institute of Public Health, Health Insurance Fund, **Visitation** (Patronage) services, Public Health Centers (Skopje, Kumanovo, Tetovo, Kocani, Stip, Strumica, Veles, Ohrid, Bitola and Prilep), Public and private

maternity wards (Skopje 2, Kumanovo, Tetovo, Stip, Strumica, Veles, Ohrid, Bitola, Prilep, Gostivar, Kavadarci, Kocani, Struga, Kicevo, Debar, Kriva Palanka, Negotino, Resen, Vinitsa, Valdandovo), Development Counselling Centers (Skopje, Bitola, Veles, Stip), Preventive teams in public health, Center for Mental Health of Children and Youth (Skopje), Center for Mental Health Service (Bitola), Hearing, Speech and Voice Rehabilitation Institute (Skopje and Bitola), Institute of Physical Medicine and Rehabilitation Skopje, Local health centers/clinics and clinical hospitals, University hospitals.

Social protection: Ministry of Labor and Social Policy, Social Policy Institute, Social work centers, Day care centers for children with disabilities, Kindergartens, Early childhood development centers.

Education: Ministry of Education and Science, Bureau for Education Development, Vocational Education Centre, Adult Education Centre, Universities, Primary schools, High schools, Primary schools with resource centers.

Other: National Co-ordinating Body for the Implementation of CRPD, Disabled people organizations, Local governments.

Key points from a draft of the Rulebook “Rules on the Method and Procedure for the Assessment of Functioning and the Needs for Additional Educational, Health and Social Support for Children and Youth”. Again, we present the key points mostly verbatim from the Draft or with some shortening.

The **Draft Rulebook** regulates procedure for implementing the assessment of functioning and needs of children and young people, measures for additional educational, health and social support, the composition and professional profile of the members of expert assessment bodies and the way bodies perform the assessments of functioning, forms for the assessment, findings and opinion on additional support, and record keeping requirements.

The assessment of functioning covers children and young people with an affected health condition up to the age of 26. An affected health condition (this term was introduced in the December 2021 amendments to the Law on Social Protection (see above) for the purpose of the rulebook is a general term for disease (acute or chronic), disorder, injury, or trauma. The health condition may also include other circumstances, such as stress, congenital anomaly or genetic predisposition and

other conditions affecting the psychophysical development of children and young people.

The assessment is carried out in accordance with the World Health Organization International Classification of Functioning, Disability and Health (ICF).

Additional support is provided in accordance with regulations in education, health care, child protection, social protection, employment and mandatory health and other types of social insurance, based on findings and recommendations by the expert bodies for the assessment of functioning.

3.1 Additional support in health, education and social protection for children and young people

The needs of children and young people to participate in preschool institutions, in the education system, as well as the exercise of children's, social and health care and family support rights, are established on the basis of the assessment of functioning based ICF. Additional support is provided by and in co-operation with the state administration bodies responsible for education, health and social and child protection and with other bodies and institutions in these areas, as well as local self-government units.

The expert assessment bodies, based on the assessment of the child's functioning, and needs, give an opinion on support measures to the child/ young person and her/his family. The measures that exist currently are:

In health care

- (i) health services in counselling centers and early intervention programs,
- (ii) health services for diagnostics, rehabilitation, and treatment,
- (iii) orthopedic and other aids depending on the need of the person,
- (iv) support to the family through nurse visitation ("patronage") services,
- (v) support for children with chronic diseases in kindergartens and schools by health workers,
- (vi) reimbursement of the transport costs from the place of residence to the health institution in accordance with the mandatory health insurance regulation.

In education

- (i) education according to an individual educational plan,
- (ii) education through an adjusted/modified program,
- (iii) educational assistance services,
- (iv) individual educational work with a professional associate,
- (v) counselling work with the person and family by a professional team in the school,
- (vi) use of adapted teaching/learning tools and aids and assistive technologies,
- (vii) training students to use Braille, improve mobility, use of technical aids, sign language or other alternative means of communication,
- (viii) overcoming language barriers, as well as supporting children where the mother tongue is different from the language of instruction,
- (ix) educational support in the case of longer absence from school due to severe or chronic disease, to ensure continuity in education, in the form of strengthened additional teaching, individual work in hospital or at home,
- (x) training educators in kindergartens and primary schools, in accordance with inclusive practices and principles, training for the use of assistive technology, alternative means of communication,
- (xi) free transport regardless of the distance to and from primary school.

In child and social protection

- (i) special allowance in cash,
- (ii) priority for admission in a preschool,
- (iii) implementation of an early learning and development program for children with disabilities,
- (iv) counselling work with parents/ guardians,
- (v) salary compensation for part time work for parents who work part-time to take care of a child with disabilities and the most severe forms of chronic disease,

- (vi) exemption from the co-pay in the case of hospital treatment and costs of one companion,
- (vii) services provided at home – care and assistance at home by others,
- (viii) personal assistant services,
- (ix) community based services such as daily care, rehabilitation and reintegration services, halfway house.

In other areas

- (i) recommendations for the accommodation interventions to improve accessibility of home, apartment buildings, institutions, etc. (building entrance, interior, ramp installation, elevators, toilets, signs in Braille, dual language signage, etc.).
- (ii) sensitization and education of peers and their parents to accept children who, due to disabilities, learning difficulties, and other reasons need additional support.

3.2 Persons with disabilities

A person with a disability is a person who has long-term physical, intellectual, mental or sensory impairments, which, in interaction with various barriers, can prevent her full and effective participation in society on an equal basis with others. Disability is a general term for impairment, activity limitations and restrictions on participation of the person. The term disability designates the negative aspects of the interaction between the individual (with an affected health condition) and the contextual factors for that individual (environmental and individual factors).

A person with a disability, for the purpose of this Rulebook, is a person with:

- impaired vision (low vision and blindness),
- impaired hearing,
- voice, speech, and language disorders,
- body (physical) impairments,
- intellectual disability (mild, moderate, severe, and profound),
- autism spectrum of disorders and persons with other pervasive developmental disorders,
- chronically ill person, and

- persons with several types of disability (persons with combined development impairments).

For each of the above groups, the rulebook provides a more detailed description in relation to degree of disability. For **impaired vision and impaired hearing**, it defines acuity measurements for low vision and blindness, as well as decibel measurements and verbal speech development for low hearing and deaf persons, in order for persons experiencing them to be regarded as persons with disabilities. After a hearing impairment has been detected, the child (as well as a child with a cochlear implant) is referred to the audiology rehabilitation in specialized institutions licensed to provide such services, before her/his referral to primary education.

A person with **voice, speech and language disorders** is a person whose speech does not correspond to age, or is not understandable, it is not grammatically developed and has poor syntax, with convulsive obstacles to the fluency of speech, which is why there is a need for speech therapy and treatment. According to the type and degree of disorder in verbal communication, persons are classified in the following groups:

- a person with a complete absence of speech – alalia,
- a person with pathological speech development,
- a person with severe nasalization – rhinolalia,
- a person with absence and severe voice impairment – aphonia and dysphonia,
- a person with severely impaired speech due to polio,
- a person with impaired or lost previously acquired speech- aphasia and dysphasia,
- a person with a combination of the above disorders.

A person with **physical impairments** is a person with reduced or lost function of one or more parts of the body, significantly reducing a person's ability to meet basic life needs. According to the degree of physical impairment: (i) a person with severe physical impairment is a person who can independently meet her/his needs with appropriate orthopedic aids or adaptation of the physical environment, (ii) a person with very severe physical impairment is a person who can independently

meet her/his needs only with assistance from another person, and (iii) a person with profound physical impairment is a person who needs constant attendance and care meet basic life needs.

A person with **intellectual impairments** is a person with slow or incomplete intellectual development adversely affecting her/his cognition, speech, motor and social abilities. Persons with intellectual disabilities are classified into following groups:

- a person with mild intellectual disabilities is a person with slight reduction in the level of intellectual, speech, language, motor and social abilities; speaks with a certain delay but can use speech in everyday life. In standardized IQ tests, the score is 50 to 69,¹⁰
- a person with moderate intellectual disabilities shows slow development and limited capacity to use speech and language, motor abilities and self-care. On standardized IQ tests, the score is 35 to 49,
- a person with severe intellectual disabilities is similar to a person with moderate intellectual disabilities in the clinical picture, but with severe limitation in the speech and language development and use, motor abilities and self-care, pronounced motor and/or other associated disabilities indicating significant damage in the development of the central nervous system. In standardized IQ tests, the results are within 20 to 34, and
- a person with profound intellectual disabilities is a person with pronounced limited ability to understand communication, has a very limited and rudimentary forms of non-verbal communication, is semi-mobile or stationary, unable to control sphincters, and take care of herself/himself, and is in need of constant assistance and supervision. In standardized IQ tests, the results are below 20.

A person with **autism and a person with another pervasive developmental disorders** is a person with difficulties in reciprocal social interactions, nonverbal and verbal communication and imagination and a limited number of activities and interests, accompanied by a variety of mental disabilities, various neurological signs, epilepsy

and various behavioral aggression syndromes, auto aggression, destructiveness, and unprovoked anger.

Chronically ill person is a person with the most severe form of a chronic disease and with seriously impaired health, who with various obstacles in the environment cannot fully and effectively participate in society on an equal basis with others, caused by carcinogenic diseases, heart disease, hemophilia, diabetes, leukemia, a more severe form of bronchial asthma, arthritis, rheumatism, dialysis,¹¹ cystic fibrosis and other diseases with a causal link between impairment and limited activities.

A person with **multiple types of disabilities** is a person with two or more types of disability.

Hence, to conclude based on the above, during the transition period of the next three years, considering that the Draft Rulebook keeps the operational definition of children with disabilities, while North Macedonia adopted the ICF and CRPD definition of disability, for operational purposes, categorization of children and young people with disabilities that is based on their health condition and impairment, although, in some cases a description of a degree of disability includes some description of activities and participation in terms of the ICF), continues to be used.

3.3 Composition and method of operation of the expert bodies for the assessment of functioning

The assessment of functioning is carried out by a separate internal organizational unit, the Functional Assessment Service of Children and Young People within the Health Centre-Skopje (The National Expert Body – NEB). The Service performs the assessment of functioning through 9 regional expert bodies. Each regional expert body covers municipalities that are part of the region.

The NEB performs:

- education of members of the regional expert bodies for the implementation of the assessment of functioning,
- guidance and expert methodological assistance,
- monitoring of the application of the ICF in the assessment,

¹⁰ Note: In international practice, IQ tests are not any longer considered useful.

¹¹ Note: Dialysis is a renal replacement therapy, not a disease.

- collecting and analyzing data from regional expert bodies,
- managing a central database for all persons who have been assessed,
- monitoring the situation concerning the needs for additional educational, health and social support for children and young people,
- proposing measures to improve services for children with disabilities,
- preparation of annual reports with recommendations and delivering it to the relevant ministries,
- handling of and deciding on grievances to the functioning assessment decisions of the regional expert bodies.

NEB comprises a doctor, psychologist, a social worker and a special educator and rehabilitator with at least 10 years of work experience in the profession and at least two years of experience in implementing a functioning assessment. Based on the needs of the child, a specialist doctor from a particular field (otorhinolaryngologist, orthopedic surgeon, psychiatrist, neurologist, ophthalmologist), speech therapist, physiotherapist participates in NEB proceedings. The head of the Office for the Assessment of Functioning of Children and Young People manages the work of NEB. The NEB's administrative and technical work is carried out by an administrator.

The regional expert body is composed of a psychologist, social worker, special educator and rehabilitator and employees of the Skopje Health Centre – Functional Assessment Service for Children and Young People, according to the work tasks and competences established by the acts of the institution.

The regional expert body's work involves a doctor, psychologist, social worker and special educator and rehabilitator with at least five years of professional experience and at least one year of experience in implementing a functional assessment. Depending on the condition and need of the child, other professionals may be involved: otorhinolaryngologist, orthopedic surgeon, psychiatrist, neurologist, ophthalmologist, speech therapist, physiotherapist. The parent and a person of trust chosen by the parent who knows the well are included as well.

Administrative and technical work in the regional expert body is carried out by an administrator. The regional expert body should submit a report on its work to NEB each month.

The regional expert body carries the assessment based on medical documentation provided and a meeting with the parent and the child/young person with disabilities and give an opinion. The opinion must be presented in the formal format (see the relevant form below). The assessment is carried out upon a formal referral by a chosen family physician. The assessment can also be initiated by educational, health or social and child protection institutions or another social service provider by written notification to the parent of the need to carry out the assessment and the reasons for it. Following the notification, the parent must report back within one month whether the assessment has taken place. If the parent disagrees with the initiative, or has not taken any action within one month, the institution that has written to the parent should submit the initiative to the relevant center for social work. The center for social work implements the procedure for establishing the best interest of the child.

The regional expert body begins the assessment procedure after receiving a referral from the person's chosen doctor, meets with the parent or guardian of the person and receives required documents. The documents are transmitted directly or electronically to the expert body by the parents or guardian, seven days before the scheduled assessment term. One of the members of the regional expert body is determined to be responsible for the case. She/he is responsible to ensure that all necessary procedures are carried out and that relevant information is collected and appropriately presented as a finding and opinion, and to take appropriate and timely steps to review the case. After the meeting with the parent or guardian, the regional expert body begins the assessment process and is due to complete it at the latest within 30 days. The coordinator of the regional expert body should explain the joint finding and opinion. Upon the request of the parent or guardian, each member of the expert body should explain the finding and opinion in a simple and clear way. The parent/guardian may object to the finding and opinion within eight days from the date of receiving it. The grievance should be resolved within 30 days.

If necessary and only if the necessary information cannot be obtained from the parent or guardian

or other professional who is familiar with the child's situation, the expert body will recommend that additional examinations are conducted. Each member of the regional expert body will determine the needs for support within her/his expertise. Each member should submit her/his opinion to the member leading the case.

The regional expert body should develop a plan of interventions and a timeframe for its implementation. When the case is reconsidered, the results achieved are considered, a control functioning assessment is conducted, and additional measures are proposed. The period for reassessment cannot be longer than two years for children and young people up to 18 years of age. The regional expert body is obliged to carry out a control assessment at least three months before the young person reaches the age of 26.

The parent/guardian should give her/his consent to the assessment and should agree to provide needed information. The data privacy protection should follow legal requirements pertaining to it.

The institutions whose services are recommended by the findings and opinion by the regional expert body should implement them by developing an individual program for working with the person and periodically informing the regional expert body of the progress. The reporting period is determined by the finding and opinion issued by the regional expert body.

The assessment records are kept by the regional and national expert bodies. NEB operates a central database for all persons who have been assessed. The central database is kept electronically. The data base contains the following standardized data entry formats: format for record keeping at the regional expert bodies, a format for findings and opinion, grievance form, form for individual findings and opinion by experts, form referral from a center for social work, parental consent to the use of data.

This Rulebook should be issued jointly by the ministers for education, health and labor, science and social policy.

3.4 Examples of standardized forms to be used in the assessment

A format for keeping records by the regional expert bodies

Regional official assessment body in (city) _____

a) First assessment of functioning

Case number								
Name/ surname/ place and date of birth/ full address								
Father and mother's first and last name/ full address								
Number and date of the findings and opinion								
Type and degree of disability and diagnosis ICD-10 code								
Recommended rights and services in health care and insurance								
Recommended rights and services in education								
Recommended rights and services in child and social protection								
Note								

b) Reassessment

Case number								
Name/ surname/ place and date of birth/ full address								
Father and mother's first and last name/ full address								
Numbers and dates of first assessment and of reassessment								

Regional expert body								
Type and degree of disability and diagnosis ICD-10 code								
Recommended rights and services in health care and insurance								
Recommended rights and services in education								
Recommended rights and services in child and social protection								
Note								

3.5 Findings and opinion on the state of functioning and the need for additional educational, health and social support to a child or youth

Name of the expert body _____

Full address _____

e-mail: _____

Tel: _____

BASIC AND PERSONAL DATA

Assessment body	
Identification number:	
Regional expert body:	
Assessment/case manager:	
Basic information about the person	
First name, father's name, last name:	
Date and place of birth:	Unique ID number:
Address and place of residence/municipality:	Phone number:
Gender:	Mother tongue:
Place of assessment:	Assessment date:

HEALTH CONDITION/ EXPECTATIONS OF PARENTS (Descriptive)

According to the parent and/or child	
Diagnosis (ICD-10 code)	
Current treatments	
Expectations of parents or child	

PERSONAL ASPECTS AND ANAMNESIS (Descriptive)

Personal traits of the child (age, gender and other characteristics)	
Anamnesis: information from parent/guardian, the child, and medical documentation	
Stage/phase of development	

ENVIRONMENT (Descriptive)

e1: Products and technologies	
e2: Natural environment and human-made changes to environment	
e3: Support and Relationships	
e4: Attitudes	
e5: Services, systems, and policies	

Note: e1-e-5 are ICF codes

BODY STRUCTURES

OBSERVATION	
s1: Structures of the nervous system	
s2: The eye, ear and related structures	
s3: Structures involved in voice and speech	
s4: Structures of the cardiovascular, immunological and respiratory systems	
s5: Structures related to the digestive, metabolic and endocrine systems	
S6: Structures related to the genitourinary and reproductive systems	
s7: Structures related to movement.	
S8: Skin related structures	

Note: s1-s8 are ICF codes.

BODY FUNCTIONS

OBSERVATION	ASSESSMENT	
	ICF CODE	ICF QUALIFIER
b1: Mental functions		
B2: Sensory functions and pain		
b3: Voice and speech functions		
b4: Functions of the cardiovascular, hematological, immunological and respiratory systems		

b5: Functions of the digestive, metabolic and endocrine systems			
b6: Genitourinary and reproductive functions			
b7: Neuromusculoskeletal and movement-related functions			
b8: Functions of the skin and related structures			

Note: b1-b8 are ICF codes. The ICF impairments qualifiers for body functions are no impairment, mild, moderate, severe and complete.

ACTIVITIES AND PARTICIPATION

	OBSERVATION	ASSESSMENT			ENVIRONMENTAL FACTORS		
		ICF CODE	QUALIFIER	INDICATOR	FACILITATOR	BARRIER	SPECIFICATION
d1: Learning and applying knowledge							
d2: General tasks and demands							
d3: Communication							
d4: Mobility							
d5: Self-care							

d6: Domestic life							
d7: Interpersonal interactions and relationships							
d8: Major life areas							
d9: Community, social and civic life							

Note: d1-d9 are ICF domain (level 1 codes). No two-level codes are provided. Qualifiers in the ICF are no difficulty (0); mild difficulty (1); moderate difficulty (2); severe difficulty (3) and complete difficulty (4).

4. Observations

When discussing a disability (and needs) assessment system in any country several issues need to be investigated. They include the definition of disability, the purpose of the assessment, the criteria, methods and tools and instruments used in the assessment, the algorithm to determine whether a person has a disability and of what degree, and administrative procedures through which the assessment is organized. Based on information that was made available to us or we could find on the internet, we briefly reflect on two such issues below.

Definition of disability in children in North Macedonia.

In North Macedonia, the Social Protection Law defines persons with disability as “persons having a long-term physical, intellectual, mental or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.” This is the ICF definition of disability and aligned with that in CRPD. It is included in various legal acts pertinent to persons with disabilities. While the formal definition of disability in children is ICF- and CRPD-aligned, the operationalization of the definition used for eligibility for services is medical. According to the official involved in the reform, it is expected that this inconsistency will be addressed in the next three years.

Criteria and method. The legal changes at the end of 2021 and the Draft Rulebook presented above state that the assessment of disability in children is “the assessment of functioning based on the ICF.” The Draft Rulebook does not make a reference to specific tools or instruments to be used to assess functioning or needs, or to any method to decide whether a child has a disability or what needs he or she has. The standardized reporting forms collect about health conditions and expectations of parents, personal traits of the child, environment, Body Structures and Functions, and Activities and Participation. For the last of these – Activities and Participation – the form asks for qualifier for the ICF domain, and whether environmental facilitators or barriers are involved. What is missing is how this information is collected – and validated – and more importantly, how the assessment is made in terms of that information. Disability assessment is a summary ‘whole person’ assessment of the degree or level of disability that a person experiences. This assessment must be based both on the individual’s health state, including impairments, on specific levels of performance of representative and relevant activities as performed in the person’s actual environment, and, finally,

a summary scoring algorithm that combines this information into a single score. To the best of our knowledge, none of that is in place in North Macedonia. Similarly, there is no needs assessment instrument, which is crucial for assessing the needs.

DOCUMENTS CONSULTED TO PREPARE THE CASE STUDY

The Law on Child Protection, consolidated text. <https://www.mtsp.gov.mk/content/pdf/2021/Закон%20за%20заштита%20на%20децата%20консолидиран%20февруари%202021-converted.pdf>

Proposal for the Law on Amendments to the Law on Social Protection submitted by the Government of North Macedonia to the Parliament of North Macedonia in November 2021.

The Law Amending and Supplementing the Law on Social Protection Act, Official Gazette of RSM, No. 294/2021

The Law on Health Protection. <https://www.refworld.org/pdfid/54edef434.pdf>

The Law on Social Protection, Consolidated and clean version that includes Basic text of the Law published in the *Official Gazette of the Republic of North Macedonia* 104/2019, https://www.mtsp.gov.mk/content/pdf/zakoni/2019/28.5_zakon_SZ.pdf

The Law on Amendments to the Law on Social Protection, *Official Gazette of the Republic of North Macedonia*, 146/2019, The Law on Amendments to the Law on Social Protection, *Official Gazette of the Republic of North Macedonia*, 257/2019, The Law on Amendments to the Law on Social Protection, *Official Gazette of the Republic of North Macedonia*, 302/2020, The Law on Amendments to the Law on Social Protection, *Official Gazette of the Republic of North Macedonia*, 311/2020, and The Law on Amendments to the Law on Social Protection, *Official Gazette of the Republic of North Macedonia*, 163/2021.

(Unofficial – working version) Draft Rulebook for the assessment of additional educational, health and social support for children and youth.

Ministry of Labor and Social Policy. Rulebook for the assessment of type and degree of disability of persons with physical and mental disabilities. The *Official Gazette of the RM*, 172/2016.

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Please contact:
UNICEF Regional Office for Europe and Central Asia
Route des Morillons 4, 9th Floor, CH 1211 Geneva
ecaro@unicef.org

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