



ASSESSING DISABILITY OF CHILDREN IN SERBIA

COUNTRY CASE STUDY



Acknowledgements:

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This case study maps the systems and policy for disability assessment of children in Serbia 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. Links to non-UNICEF sites do not imply endorsement by UNICEF of the accuracy of the information contained therein or of the views expressed. The opinions expressed are those of the author and do not necessarily reflect the policies or views of UNICEF.

Cover photo: Children playing at the Dream Playground built on the wings of children's ideas, designed by primary school children Credit: © UNICEF/UN0497057/Maccak

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1. Reform of the disability and needs assessment of children

In the early 2000s, Serbia implemented some important actions to reform its policies and systems to protect and support children with disabilities throughout their lifecycle. The ratification of the UN Convention on the Rights of Persons with Disabilities (CRPD) has provided an impetus for the reform. The main changes implemented as part of the reform included:

- Conceptually and as reflected in various legal documents, Serbia moved away from a medical approach to disability to a contemporary understanding of disability (the so called biopsychosocial or interactional understanding of disability, initially developed by WHO and unanimously adopted by the World Health Assembly in 2001¹ and later espoused by CRPD in 2006).
- The laws and public policies were changed to emphasize human rights of persons with disabilities, non-discrimination (any discrimination based on disability is expressly prohibited), inclusion, independence, individual choice, participation in decision making, universal design and accessibility, the right to live in a family and community, etc. In general, the laws recognize independence, life in the family and community and dignity of children with disabilities as the most important principles.
- The old rules (from 1986) for categorizing and classifying children with disabilities were voided in 2009.² Instead, through the introduction of the Municipal Intersectoral Commissions for the Assessment of Needs for Additional Educational, Health and Social Support to a Child, Pupil and Adult

(ISC) and changes in various regulation³ an approach where children with disabilities and developmental difficulties are identified and their needs assessed using assessment tools based on functioning was promoted. However, to access benefits in the social welfare system, the child must be assessed as having a disability through a procedure that to a large extent follows a medical approach to disability.

- New benefits and services, including in health, education, and social protection, have been introduced to support deinstitutionalization of care, inclusion of children in all aspects of life in a family and community environment and independence.⁴
- Significant efforts were made under the overall reforms to ensure mechanisms for implementing new affirmative measures for members of vulnerable social groups.
- Institutional changes to support policy reforms have been implemented as well, including the establishment of the above mentioned ISCs. Also, efforts to strengthen early identification and early intervention system, revive the developmental counselling units within the primary health care and to (re)introduce the system of home visits by nurses have been made.

However, as noted in various studies, there is a significant discrepancy between legal provisions and realities on the ground and there is an overall impression that the progress has been very slow.⁵ Many services crucial for inclusion of children with disabilities, including in education, are responsibility of municipalities. Financial and human resource capacity varies

1 See: WHO, 2001, International Classification of Functioning, Disability and Health (ICF), Geneva.

2 "Decision on the criteria for categorization of children with disturbances in development and on the manner of work of the Commission for Examination of Children with Disturbances in Development," The Official Gazette of RS, 16/1986.

3 For example, The Law on Social Protection, Official Gazette of RS, 24/2011

4 Appendix 1 to this Case Study provides detailed description of benefits and services to persons with disabilities with emphasis on children in Serbia in education, health, and social protection.

5 See, for example: National Organization of Persons with Disabilities of Serbia (NOOIS), 2017, Situation analysis: Position of children with disabilities in the Republic of Serbia. Belgrade. This analysis was prepared in collaboration with UNICEF and other donor organizations and the Government of Serbia. (<https://www.unicef.org/serbia/en/position-children-disabilities-republic-serbia>, and <https://www.unicef.org/serbia/media/156/file/Situation%20Analysis:%20Position%20of%20children%20with%20disabilities%20in%20the%20Republic%20of%20Serbia.pdf>); UNICEF and Open Society Foundation Serbia. 2018. Situation Analysis of Services for Infants and Young Children with Disabilities in Republic of Serbia. Belgrade. Serbian version available at: <https://childhub.org/en/child-protection-online-library/situational-analysis-services-babies-and-young-children-disabilities-serbia>; a Summary Report is available at: <https://www.unicef.org/serbia/en/situational-analysis-services-babies-and-young-children-disabilities-serbia>.

tremendously across municipalities and so does the service provision. Some services are provided in only a handful of municipalities. Similarly, the developmental counselling units (DCUs) within the health system, which are essential for early interventions in children with developmental problems are functional in only about 30.0 percent of central district's municipalities in Serbia, but many are understaffed and under resourced. However, there have been efforts to improve the DCUs capacities and a new evidence-based family oriented early childhood intervention services led by DCUs and bringing together professionals from pre-schools and social services through multidisciplinary teams around the family and child have been piloted since 2017. While the ISCs were established in almost all municipalities, they face operational, methodological, financing, and human resource problem.⁶ The case management in social work is yet to be fully implemented in practice. The deinstitutionalization process is yet to be finished and most children in institutions are children with disabilities. Even children younger than 3 years are among institutionalized children, although the Law prohibits it. The transformation of special school into resource centers and the advancement of inclusive education has been very slow and special schools (which are called schools for education of children with disabilities in Serbia) and special classes are still an important feature of the education of children with disabilities in Serbia.

In Serbia, definition of a child with a disability varies from sector to sector. Serbia does not have a single definition of a child with a disability, which would apply to all sectors and policies relevant to children with disabilities. Various legal acts provide their own definitions. For example, "The Rulebook on conditions and procedure to realize the right to be absent from work or to work part time to take special care of a child"⁷ defines children with developmental disabilities and disabilities as

"children who have serious or complete difficulties in one or more developmental domains, as well as children with severely impaired health conditions and damage to body structures". The Law on Primary Education and Upbringing (Article 10)⁸ defines a "student with developmental disabilities and disabilities" as "a child with intellectual disabilities, a child with sensory disabilities, a child with motor disabilities, a child with learning difficulties, a child with speech-language disabilities, a child with behavioral problems, a child with emotional difficulties, a child with developmental disabilities that manifest themselves simultaneously in several areas and due to which the child faces numerous obstacles in meeting basic needs and is in need of complex support, or a child with other disabilities in need of support". Article 41 of the Law on Social Protection⁹ defines beneficiaries of social welfare services. Among minors, particularly noted are "children and youth with developmental difficulties – physical, sensory, intellectual, mental, speech, communications, socio-emotional, multiple difficulties – whose needs are bigger than capacity of their families to meet them". The Law on the Prevention of Discrimination against Persons with Disabilities¹⁰ defines persons with disabilities as "persons with congenital or acquired physical, sensory, intellectual or emotional (psycho-social) impairment who, due to social or other barriers, are unable or have limited opportunities to engage in social activities at the same level as others, regardless of whether they are capable of carrying out such activities with the use of technical aids or support services". In most regulatory acts children with disabilities are simply referred to as "children with disabilities and developmental difficulties" without any definition. This lack of an overarching definition and an integrated process for identifying children with disabilities¹¹ creates problems for some children and families in accessing benefits and services.

6 Vlaovic-Vasiljevic, D., Miloradovic, S., Pejovic-Milovancevic, M. 2016. A Guide for the work of the Interdepartmental Commissions for the Assessment of Needs for Additional Educational, Health and Social Support to a Child and a Pupil. Center for Social Policy. Belgrade. (Available in Serbian only: <http://csp.org.rs/sr/događaji/vodič-za-interresorne-komisije-za-procenu-potreba-za-pružanjem-dodatne-obrazovne,-zdravstvene-ili-socijalne-podrške-detetu-i-učeniku.html>.) Center for Social Policy, 2015. An Analysis of Intersectoral Commissions and Additional Support in 10 Municipalities and Cities. Belgrade. (Available in Serbian only.) http://csp.org.rs/sr/assets/publications/files/Analiza_interresornih_komisija_i_dodatne_podrske_u_10_opstina_i_gradova_CSP.pdf

7 The Official Gazette of the Republic of Serbia, 56/2018

8 The Official Gazette of the Republic of Serbia, 55/2013, 101/2017, 10/2019, 27/2018, 129/2021

9 The Official Gazette of the Republic of Serbia, 24/2011

10 The Official Gazette of the Republic of Serbia, 33/2006, 13/2016.

11 An identification process may or may not include a disability status determination (certification).

2. Pathways to identification of disability and access to disability services

Serbia currently features a complex net of ways to identify children with disabilities and developmental difficulties and pathways to benefits in health, education, and social protection. The two systems that use a process that could be characterized as disability assessment are a social protection system for children with disabilities and their families to access social assistance benefits in cash and recently introduced registry of children with disabilities. Other pathways are needs assessments of children with disabilities. The pathways are regulated by a large body of laws and bylaws.

Below we describe *five* to a large extent separate mechanisms for disability and needs assessment of children. Through these processes, children will be:

- (i) identified (diagnosed) as having a developmental problem by the health system (see 2.1),
- (ii) assessed as having or not having a disability (based whether they have “serious” or “complete difficulty” on not) for the purpose of accessing cash social welfare benefits for children with disabilities and their families (see 2.2),
- (iii) assessed for needs for additional health, education, and social protection support by ISCs (2.3),
- (iv) assessed for a degree of support in the social welfare system by centers for social work and social care services providers (there are four degrees of support – see 2.4), and
- (v) assessed by the health system for the purpose of the registry of children with disability as having severe or very severe (cannot do) disability. They do not count for the purpose of the registry if they are assessed as having mild or moderate disability (see 2.5).

2.1 Identification through the health system

In Serbia, it is most likely that health problems and developmental delays especially for younger children will be identified in the health system. All children are covered by free health insurance and access to health services. Almost all births in Serbia happen in maternity wards; if a child experiences and observable problems, it will be detected.¹² Immediately after the child’s birth and subsequently in the first, second and fourth year of the child the family should be visited by a home visiting nurse who supports parents in their parenting functions. For families with children with disabilities additional visits are part of the basic benefit package. In the first three years of the child, the parents/children are entitled to at least ten visits to a chosen pediatrician for health and developmental checkup and immunization. Developmental screening and monitoring combine clinical examination and parental reports through standardized instruments (e.g., The Ages and Stages Questionnaire is

recommended in Serbia at least at the 9th, 18th and the 24th month of a child). Depending on child’s situation, the parent is provided counselling and additional visits to the pediatrician and/or referred to developmental counselling units for a comprehensive assessment and support by multidisciplinary team or referred to other levels of health care for further diagnostics. An examination of health and development is performed before children enroll in kindergarten/preschool and again before enrolling in school. Regular health checkups for school aged children should be performed every 2 years (at 8, 10, 12, 14, 16 and 18 years); however, since they were moved from schools into a primary health care centers their coverage has significantly decreased.

Initial diagnostic is therefore not an issue, although some studies¹³ report parental denial in some cases (particularly in the case of mental

¹² Several studies consulted for the preparation of this report have given examples of parents being advised in the maternity ward by a doctor or a social worker to give up their newborn with a congenital condition. While the Law on Social Protection prohibits institutionalization of children under 3 years of age, still a very young children are found in institution. As a rule, medical professionals should encourage parental care, not abandoning the child to the state care.

¹³ Ibid.

health issues) or medical professionals taking the situation lightly (the child is “spoiled”), which may cause delays in identification and treatment and support. Availability and quality of needed medical specialists and therapy is more of an issue, as they vary tremendously across Serbia. Pediatricians are in short supply, and they are overloaded. Similar situation is with some other relevant medical specialists, e.g., rehabilitation doctors and nurses, speech therapists, psychologists, etc. Another big problem is that developmental counselling units are functional in less than on third of central district’s municipalities, significantly limiting capacity of the health system to provide needed therapeutic interventions to children with disabilities and developmental problems beyond bigger cities. Similarly, there is a lack of knowledge among professionals, as well as parents about early childhood development; not all professionals are familiar with or use screening and measurement and assessment tools. Importantly, the linkages between the health system and other systems are not clear. This is especially important for education and social protection, which are very important in assessing the needs and providing services to children with disabilities.

In 2017, Serbia began developing and introducing

a new family-centered, routine based, cross-sectoral, evidence-based early childhood intervention (ECI) model for families with children with developmental risks, delays, and disabilities. This model is based on the European standards and its implementation has received significant expert support from EURLY AID (European Association for ECI). The model focuses primarily on parents, aiming to empower them to support their child’s development and mitigate early risk factors. It is based on family priorities, delivered in the child’s natural environment (home, pre-school) and integrated into the daily routines. It uses a routine-based interview with the parent and observations and prompting behaviors with the child to assess the child’s development and jointly with the parent define goals related the child’s functioning for the child and the family as part of an individualized family support plan. The ECI services build on already existing DCUs in the primary health centers. They bring together professionals (psychologists, special educators, speech therapists, etc.) from DCUs, pre-schools and social welfare services into multidisciplinary ECI teams that provide direct support to families. The ECI model is piloted in 5 locations in Serbia and is planned to be gradually expanded to all 25 districts.

2.2 Accessing the right to extended paid leave/ the right to work part time

Introduction

A person legally responsible for the child younger than five in need of special care due to developmental problems and disabilities, has the right, upon the expiration of maternity leave and absence from work for the care of the child, to an extended paid leave or to work part-time for special care of the child, in accordance with the relevant labor legislation. The conditions and procedure for accessing this benefit (and other benefits in cash for children with disabilities in the social protection system, such as an allowance for assistance and care by others) are regulated by the “The Rulebook on conditions and procedure to realize the right to be absent from work or work part time to take special care of a child”.¹⁴ This Rulebook establishes conditions, procedure, and

manner to exercising this right. It also determines the composition, competency, and manner of operation of the commission that performs the assessment.

The Rulebook defines children with *developmental difficulties and disabilities as children who have serious or complete difficulties in one or more developmental domains, as well as children with severely impaired health conditions and damage to body structures*. The child’s developmental domains to be evaluated are socioemotional development (emotional functions and activities), cognitive development, functions and activities of communication, physical development – functions of movement activity, adaptive skills – functions of activities of

everyday life, and functions of the senses (sense of vision, hearing and feeling of pain).

The assessment, at the referral of the local government, is conducted by a commission established by the local branch of the Fund for (mandatory) Pension and Disability Insurance. The commission at the end of the assessment issues an **opinion about the state of health of the child** by stating that the **child has or does not have developmental difficulty and disability**. This is essentially a disability status certification for the purpose of a child with a disability and her or his family to access benefits within the social protection system.

Below we provide relevant sections from the Rulebook regarding the criteria and administrative procedure.

A health condition of the child influencing the realization of the right

A child with *disabilities in socioemotional development* (emotional functions and activities) is considered a child with:

- serious difficulties in emotional functions (a child who has serious disturbances in emotional reactions to individual situations, which has serious problems in the intensity and adequacy of emotions, which shows a lack of emotional exchange with other persons),
- complete difficulties, i.e., a child without emotional regulation and with unpredictable emotional response,
- difficulties in relations with others longer than six months, present on a daily basis, which seriously damage relations with others in all circumstances (environments) with the absence of interest in social interactions,
- complete difficulties in interpersonal interactions and relationships,
- characteristics of repetitive play and inability to participate in common games,
- complete inability to play or perform a targeted activity, individually or with others.

A child with *cognitive developmental disabilities* is considered a child with:

- serious difficulties in attention function that interfere with activity, learning processes and child play,
- complete difficulties in the function of attention (a child with complete absence of targeted activity, with extreme difficulties in all areas that require attention),
- serious learning difficulties through interaction with objects,
- complete learning difficulties through interaction with objects,
- serious difficulties in developing language function,
- complete difficulties in developing language function.

A child with *disabilities in functions and activities of communications* is considered a child with:

- serious difficulties in the function of the voice,
- complete difficulties in the function of the voice (absence or loss of voice function),
- serious difficulties of articulation,
- complete difficulties of articulation (complete inability to produce and use sounds and achieve verbal statements),
- serious difficulties in the function of rhythm and fluent speech,
- serious difficulties with the use of language and nonverbal messages,
- complete difficulties with the use of language and nonverbal messages.

A child with *disabilities in function and activities of movement* is considered a child with:

- severe difficulties in muscle tone function,
- complete impairment of muscle tone function,
- severe difficulties of hand use activities,
- complete absence of hand activity,
- severe difficulties in the activity of taking standing position,

- complete absence of standing activities, serious difficulties in walking activities,
- complete absence of walking activities,
- serious difficulties in coordinating willing movements,
- complete absence of coordination of willing movements.

A child with *disabilities in the activities of daily life* is considered a child with:

- serious difficulties in performing daily activities,
- complete difficulties in performing daily activities,
- serious difficulties in performing physiological needs, dressing and feeding,
- complete difficulties in performing physiological needs, dressing and feeding.

A child with *sensory function disability* is considered a child with:

- serious hearing difficulties – hearing threshold 70 to 95 dB,
- complete hearing difficulties – 95+ dB threshold,
- serious vision difficulties – visual acuity is between 0.05 to 0.1 with correction in the better eye,
- complete vision difficulties – vision sharpness is less than 0.05 with correction on the better eye or field of vision is reduced to less than 10 degrees around the point of central fixation, regardless of visual sharpness,
- pain: a score on visually analogue scale/face scale 6; on a verbal scale – intense pain; on a numerical scale 6-7,
- pain: on a visually analogue scale/face scale 8-10; on a verbal scale unbearable pain; on a numerical scale 8-10.

A child with *impaired health condition* is considered a child with severe forms of chronic diseases (cancers, severe disorders in rare diseases, juvenile diabetes mellitus, severe heart defects, severe asthma, epilepsy, etc.), and who receives continuous therapy with the necessary

assistance from parents, adoptive parents, guardians or foster parents.

A child with *impairment of body structures* is considered a child with congenital or acquired bodily deficiencies, i.e., severe body deformities that make it difficult for them to function daily.

Administrative process

To acquire the right to a paid leave or compensated part-time work, a parent must submit a request for his/her child's health to be evaluated (or reevaluated). The parent may also request "other allowances," such as an allowance for assistance and care by another person. The requests are submitted on a standardized form with medical documentation to the local self-government unit, which then informs and submits the documents to the local branch of the Fund for Pension and Disability Insurance (PDI). The branch organizes a commission that would evaluate the request and schedules a meeting. The self-government unit informs the applicants. The needed medical documentation includes: (I) the findings of the child's physician concerning the child's functioning by developmental domains (based on an immediate examination, findings of child development specialists or other medical experts), or a form in which the child's developmental disabilities are reported; (II) the findings of other specialist medical doctors or health care associates, and (III) other documentation relevant to the realization of the right. The commission decides based on medical documentation and examination of the child during a face-to-face meeting. The decision could be made without a face-to-face meeting in "undisputable" cases. The commission decides positively or negatively (yes disability or invalidity and no disability or invalidity). If the decision is positive, the duration of the benefit is determined as well. The commission informs the local self-government about its decision, which in turn informs the applicant and the applicant's employer. There is an established grievance redress process as well.

The commission that evaluates the children is composed of a representative of the relevant local branch of the Fund for PDI (chair), one child development medical specialist, one medical associate and a relevant self-government representative (usually from the child protection office who is a secretary to the commission, as well).

Formal opinion/decision format

The commission decision is issued on formally prescribed forms. It approximately reads as follows:

Opinion of the First Instance Commission about the health state of the child and needed leave from work, i.e., half-time work, as well as the need for a control visit

Place, date, date of request, etc.

Opinion about the state of health of the child

The first Instance Commission is of the opinion that a child _____, unique ID number _____ **has/does not have developmental difficulty and disability** according to the Article _____ of the Rulebook on conditions and procedure to realize the right to be absent from work or work half-time to take special care of a child" (The Official Gazette of the Republic of Serbia 56/2018) with primary diagnosis and its ICD10 code _____.

There is/there is no need for the applicant to be absent from work or to work half time to take special care of the child _____ (name and family name of the applicant), Unique ID number _____, from _____, St _____ No. _____, employed with _____ (employer's name and HQ address) for the period of _____ months, from _____ to _____ (date).

Control visit is/it is not needed. If needed, the date is _____ (date.)

Some observations

Criteria. The above listed criteria to identify disability are a mix of health conditions (certain diagnoses), impairments of body structures (a child with congenital or acquired impairments of body structures), sensory impairments (vision and hearing), several functioning domains (socio-emotional, cognition, communication, mobility (which also includes motor functions)) and life activities, which also include self-care and eating, with a strong tilt towards medical status of the child. The criteria do not seem to be combined to generate a score. To the best of our knowledge, the instrument has not been psychometrically tested. No information is available on how the decisions on whether a child does or does not have a disability are made.

Qualifiers. The assessment uses ordinal scale qualifiers. While a qualifier "complete" is intuitively clear as it is equal as saying "cannot do at all"; "severe" is not a precise notion and it is open to judgement and subject to interpretation, i.e., my understanding of "severe" may be different from that of my peer in the assessment commission. One of the key requirements for credibility of disability assessment is reliability, i.e., different assessors of the same person should come to the same rating. When ordinal scale qualifiers are used detailed guidelines are very important.

Adequacy and applicability of listed criteria for children under five. Assessing disability in young children is different from assessing disability in older children. Expected developmental benchmarks are different for children old 12, 18, 24, 30 or 36 months and again different for children old 48 or 60 months. The criteria used seem more applicable for adults and adolescents.

2.3 Intersectoral commissions (ISC)

Introduction

This innovative mechanism was introduced in 2010. The role of ISCs is to assess the needs of a child, a pupil, or an adult for additional support to ensure her or his inclusion in everyday family and community life activities. For simplicity, we will refer to the needs assessment of a child, but the rules are applicable to a pupil and an adult as well. The needs assessment covers individuals living in a family or an institution.

ISC assesses the needs of a child, a pupil and an adult, however 'adult' refers to pupils above the age of 15 years who attend education in schools for adult education. Every child (pupil, adult) who because of social deprivation, disabilities, learning difficulties or any other reasons requires additional support to develop and be included in education and community with fewer difficulties is entitled to such support. Based on its assessment of the child's needs for support, the ISC issues a written opinion including the following: the child's

personal data; data on the ISC members; the place of the assessment; the assessment methodology; a description of the child and the circumstances in which the child and his/her parents live; identified barriers (social, medical, educational, community) encountered by the child; an individual support plan for the child laying out the rights and services in the healthcare system, social protection system and education system; an additional support needs assessment for the child; the type of additional support the child needs and how it may help the child overcome barriers, including coordinated inter-sector cooperation; the timeframe in which additional support measures will be implemented; and the place where additional support will be provided. Thus, an important role of ISC is to state the measures required to provide holistic support for the child to ensure his/her equal participation with other children in education. The ISCs are an important mechanism for coordinating services to facilitate social inclusion of the child at local level.

Below, we provide details about the establishment and operation of ISCs as regulated by the Rulebook on Additional Educational, Health and Social Protection Support to a Child, a Pupil and an Adult.¹⁵ They are established and financed by local self-governing bodies under the education system regulation. *It should be noted that provisions of the Rulebook are presented as originally stated, including the terminology it uses (e.g., the Rulebook refers to a profession of a “defectologist,” which is not used in the language associated with disability any longer*

The ISC Rulebook stipulates that the assessment should be based on a comprehensive and individualized approach to the child, with the aim of providing additional support to enable her/his inclusion in education and community. Additional support includes rights, services and resources that ensure that the child overcomes physical, communication and social barriers within educational institutions and communities. Additional support is provided, without discrimination on any grounds, to every child for the purpose of inclusion, participation and progress in, as a rule, an unsegregated educational

environment until the end of secondary education, as well as to ensure the child’s smooth performance of daily life activities and quality of life in the community. Additional support is provided within the education, health, and social care systems.

Principles

The assessment is carried out based on the following principles: respect for the right to education; prohibition of discrimination; respect for the right to reasonable adaptation to the individual needs of the child, to enable her/him to be educated on an equal basis with peers; respect for dignity, individual independence and freedom of choice; recognizing differences and accepting them as human diversity; respect for the right of every child to preserve her/his personal identity; ensuring full inclusion in the education and education system, community and quality progress; and collection and processing of personal data about the child should have a clear purpose, be reasonable in size and ensure full privacy protection.

Additional support measures

Additional support measures are:

1) Additional support measures which are implemented based on the ISC’s *opinion*:

- subsidies for attending preschool education and education programs for children with developmental disabilities,
- delaying enrollment in the first grade of primary school by one year, exceptionally and with additional explanation, when it is in the best interest of the child,
- adoption of an individual educational plan (IOP2),¹⁶ which involves adjustments/modifications to the objectives, content and manner of learning and teaching outcomes, i.e., changes to the curriculum and teaching whereby they are adjusted to the child,

¹⁵ The Official Gazette of the Republic of Serbia, 80/2018

¹⁶ The Serbian education system differentiates between three levels of support. The initial support for children not realizing expected educational achievements is provided by differentiated and individualized teaching and extracurricular activities. If these do not result in improvement in the child’s achievements, then an individual education plan is drawn up with the adapted program (adaptation of methods, teaching and didactic material, space and learning environment) according to which the educational/development process for that child/student will be performed – IEP1. This plan is drawn by the school expert team for inclusive education and implemented by the team that provides support to the child/student. If the support measures stipulated in the IEP1 document are unsuccessful, the team supporting the child, with the parents’ consent and the agreement of the ISC, draws up an individual educational plan with modified/reduced content, outcomes, and standards – IEP2.

- placing the child in the development group in the preschool, or in the school for education of students with developmental disabilities (special school),
- engaging educators, teachers and professional associates, who are employed in special schools to support children with disabilities enrolled in regular schools,
- the right to increased child allowance.

2) Additional support measures based on the ISC's recommendations:

- provision of play, didactic and teaching resources in accessible formats and in accessible languages including the sign language,
- provision of customized textbooks,
- provision of assistive technologies and/or other services of the Resource Center for Assistive Technologies (alternative ways and means of communication, customized keyboards, touchscreens, etc.
- training of teachers, educators and professional associates working directly with children with disabilities to acquire specific skills and strategies for working with such a child,
- training of parents or other child's caregivers to acquire knowledge, skills and strategies for supporting the child,
- adjust the environment according to the needs of the child,
- provide support from experts in a particular field, in accordance with the needs of the child,
- secure priority in access to health examinations and treatment; provide services of a physiotherapist or occupational therapist at home,
- secure funding for recreational classes, excursions, cultural, sports and other activities,
- ensure transportation for the child (and if applicable her/hic companion) not able to use public transport to attend education or use other social and health care services, regardless of the distance from the place of residence,
- funding the cost of after class stay for the child from low-income family receiving social assistance.

3) Other additional support measures from the education, health, and social care systems about which ISC informs the parent or legal representative and refers them to responsible institutions:

- language support to children whose mother tongue is different from the language of instructions,
- educational support in the case of prolonged absence from school, to compensate for the missed classes and to ensure continuity,
- providing a personal companion to the child in accordance with the legal provisions,
- realizing the to an increased amount of child allowance and an increased amount of allowance for assistance and care of another person,
- provision of aids (cochlear implant, hearing aid, wheelchair, braille machine, etc.),
- providing psychosocial support services to the family,
- other rights and services.

ISC can also recommend other forms of support that are not listed in the Rulebook.

The establishment and operations

An ISC is established as a working body by a local self-government unit in charge of social activities (health, education and social protection; in Serbian "drustvene delatnosti") in accordance with the law regulating the basics of education and the education system. The ISC comprises five members, four permanent and one temporary (case specific) member. Permanent members and their back-ups are appointed for a period of four years. They are a representative of the health care system (a pediatrician), a representative of the educational system (professional associate psychologist in preschool, primary or secondary school), representative of the social protection system (a professional from the social welfare affairs) and a *defectologist* of the appropriate specialty. Permanent members of ISC are required to have at least three years of work experience in the profession. A temporary member is someone who knows the child and is appointed for each case separately at the proposal/consent from the parent/legal representative. She/he could be from a pre-school institution/school attended by the child,

health care center where the child is registered and treated, or from the social welfare system (social care professional, case manager, representative of the social care institution in which the child is placed). The municipality appoints a Coordinator of the Commission who provides administrative, operational, and technical support to ISC.

The ISC is funded by the local self-government, which should also provide necessary conditions for its work. The ISC members work for the ISC on a part-time basis (they are employed full time elsewhere). One municipality can have more than one ISC; two municipalities can establish a joint ISC, too.

The ISC assessment can be requested by a parent/legal representative, by an educational, health or social care institution with the consent of the parents/legal representatives, in conduct of official duty (when parents do not give their consent). The request is submitted formally on prescribed form (Form 1). ISC reviews the request in a meeting within seven days of the date of receipt of the request. The meeting must be attended by a parent/legal representative.

Assessment of needs

The assessment method is based on observation of the child directly (and separately) by each member of ISC in the natural child's environment (family, preschool or school). Each member of ISC uses data obtained during the evaluation process: from parents and other persons who know the child, from a conversation with a child, insight into data on school achievements, review of relevant documents submitted with the application or additionally requested, etc. to determine the needs of the child for additional support within her/his field of work. The opinion is formally submitted to ISC on a prescribed form (Form 2).

In the process of assessing the needs for additional support, ISC must:

- ensure that procedure and results of the assessment are aimed at overcoming obstacles to inclusion and development,
- perform observation and conversation with the child in a safe, pleasant and natural environment,
- ensure that the privacy and dignity of the child is respected during assessment,

- ensure that the assessment instruments and other materials used in the assessment process are customized, impartial and provide credible data on the functional status of the child,
- ensure that procedures, assessment instruments and other material were selected and implemented in a language best understood by the child (mother tongue/ sign language) or by using other appropriate way of communicating,
- ensure that a parent or other legal representative of the child are always present during the assessment,
- postpone the assessment if a child is distressed or ill and agree to a new timetable,
- ensure that members of ISC and the Commission Coordinator keep the data on children in accordance with the law governing the protection of personal data.

ISC's opinion

Each member of the Commission submits her or his opinion to the Commission Coordinator. She/he must explain his or her opinion to the parent/legal representative in a simple and clear manner. The ISC chair should explain the decision to a parent/legal representative.

ISC, based on the individual assessment of each member of the ISC, issues its opinion. The opinion contains an individual plan of support for the child, and the deadline for reporting on the implementation of proposed support measures by relevant institutions/service providers. The opinion contains: personal information about the child, the student, the adult; data on Commission members; place of evaluation; assessment methodology – used instruments and techniques in the evaluation process; description of the functional status of the child, student and adult and the circumstances in which the child, the student, the adult and the family live; identified obstacles facing the child, student and adult (physical, communication and social barrier); assessment of the needs for additional support to the child, student, adult and type of additional support required; individual child, student and adult support plan based on rights and services within the health, social care and education system that it already uses or has the right to use, competent authority or service to provide additional support; timeframe for the implementation of additional support measures.

A parent/legal representative may object to the Opinion. ISC reviews its opinion upon the objection and adopts a final opinion, within 30 days of the date of admission of the objection. The final Opinion is delivered to the parent/legal representative, and offices responsible for the provision of particular types of services, in accordance with the law. All parties including the ISC process must keep the information about the child and her/his family confidential.

Tracking the additional support provision

Each member of ISC should monitor whether the additional support in her/his sector has been provided according to the ISC opinion. The government bodies responsible for services listed in the individual support plan are obliged to report in writing to ISC on the realization of the proposed support within six months, as well as to report on the support measures that were terminated and provide the reasons for that.

An ISC is obliged to submit regular reports on its work and on the proposed and achieved support to the municipal and city administration twice a year (on the Form 4). The summary report, after it is adopted by the municipal/city council, is submitted by the ISC to respective ministries.

Data collection and processing

The Rulebook stipulates that ISC must (i) collect and process data on the child that was assessed; (ii) collect and process data and documentation about its work; and (iii) maintain ISC's work data collection and records of that data collection. The Rulebook provides a detailed list of data that should be collected, and records maintained on each child for whom the assessment has been initiated.

The forms

Form 1: application form (it contains basic information on the applicant)

Form 2: ISC's individual opinion on the need for additional educational, health and social protection support

- Data on the member of ISC (filled in by the member herself/himself): name and family name, coming from which system (health, education or social protection), permanent or temporary member, profession, name of the employer, address of the employer, job position, telephone and email of the employer, the member's email and telephone number.
- Sources of information: list all documents of any type, the member used in the assessment.
- List all places where the assessment was made, date and duration of each, assessment methods, techniques and tools used, who was present at each meeting (name and family name and relation to the child).
- List of all support measures the child had access to in education, health and social protection: type of intervention, provider (name and address), type of provider (public, private, non-governmental), the source of financing, when and for how long the support was provided. Each member provides only support measures from his/her sector.
- Description of the child's life situation based on the assessment (The member should note facts about family and other circumstances, but from the perspective of her/his sector that positively or negatively impact the child (a pupil, an adult). For example: (a) health – whether the child and family members have health insurance card, whether the child's living conditions meet basic health standards, whether the child was taken to the clinic for regular health and growth/development checks, whether the child has been immunized as stipulated, etc. (b) education – whether the child is enrolled in education (name the institution) and at which level, whether the family has capacity to help the child with learning, whether the child has a space to do homework and study, the distance to the school, whether the family can afford textbooks and other learning material, etc. (c) social protection – material situation of the family, the state of family relations, participation in social, cultural, sports life, family relationship with neighbors and community, whether the child is safe in a family, etc.
- Data on the applicant ((filled in by the ISC Coordinator): name and family name, date of birth, unique ID number, the data when the request for assessment was submitted.
- Description of the child's functioning status: strengths and barriers in the environment (physical, social, communication) that provide obstacles to the child's inclusion in education and life in the community. When describing

the functioning status, the following should be taken into account: health status, cognition (learning and how the child learns), social skills and relations (the ways the child interacts with others, exchanges information, the knowledge of the local language, as well as obstacles in the use of verbal, visual and symbolic means of communication), independence in taking care of oneself.

- The ISC member *opinion* about additional support (from the own sector perspective): list relevant measures from the Rulebook.
- Other support measures in health, education and social protection about which the member *informs* the parent: service/benefit and responsible government body.
- Additional comments/observations.

The member signs the consent to keep the information she/he has acquired confidential.

Both the ISC member and the ISC coordinator sign and date the form.

Form 3: The joint opinion of the ISC

- Data on the applicant (filled in by the ISC Coordinator): name and family name, date of birth, unique ID number, the data when the request for assessment was submitted.

EXAMPLE:

INDIVIDUAL SUPPORT PLAN			
Overall objective			
Expected outcome	Task/activity/measure/service	Responsible person/ Government agency	Timeframe
1.	1.1		
	1.2		
	1.3		
2.	2.1		
	2.2		
	2.3		
3.	3.1		
	3.2		
	3.3		

All present persons sign a confidentiality agreement.

The Opinion is signed by the Chair, members, a coordinator and a parent/legal representative.

- Data on all members of the ISC (filled in by the ISC Coordinator): for each of the 4 permanent members and on the temporary member (name and family name and the number of contacts with the child and her/his family members each of them has had).
- List of other persons attending the meeting (parents/legal representative, adult applicant, trusted person, interpreter).
- An integrated list of all support measures the child has had access to in education, health and social protection: type of intervention/measure, provider (name and address), type of provider (public, private, non-governmental), the source of financing, when and for how long the support was provided. Each member provides only support measures from his/her sector. The ISC chair integrated individual members' reports.
- The description of the child and her/his state of functioning – an integration of the individual members descriptions done by the ISC chair: strengths and barriers.
- Agreed *opinion* of the ICD members on the need for additional support (from the list provided in the Rulebook).
- Other support measures in health, education and social protection about which the ISC *informs* the parent: service/benefit and responsible government body.

Form 4: This form contains a very detailed reporting requirement about the ISC operations. The report is submitted to the responsible municipality twice per year. The design of the reporting requirements is such that it allows not only to follow the work of the ISCs but to get disaggregated information about the assessed children (by age, gender, location,

main/dominant functioning problem, recommended and received services, outcomes, etc.). This of course depends on whether the reporting is done as envisaged. The proper reporting would also allow for a good data collection at the level of the Republic. Below, Table 3 from the data reporting requirements:

Table 3.1: Assessed children by dominant difficulty

DOMINANT DIFFICULTY	NUMBER OF CHILDREN
Developmental disturbances and invalidity (disability)	
1.1 Disturbances in intellectual functioning	
1.2 Disturbances in communication (disturbances related to autism and ADHD)	
1.3 Invalidity: bodily impairments, motor disturbances (difficulty moving or/and use of hands, total incapacity to move and/or use hands), sensory impairments (vision, hearing).	
1.4 Multiple disturbances (combination of any of the above)	
Specific difficulties learning	
2.1 Difficulties reading, writing, counting (in cases where there are no intellectual or sensory impairments – disturbances)	
2.2 Difficulties learning due to behavioral difficulties and emotional development.	
Children from socioeconomically unstimulating environments	
3.1 From poor families	
3.2 From families who do not speak the main language of instruction	
3.3 Children staying in hospital/ social care institution for a long time	
3.4 Migrant and asylum-seeking children.	
Other children (add)	

Observations

The concept underlying the establishment of ISCs is inclusion, focused on the child’s needs for support in health, education, and social protection, irrespective of their origin (talents, disability, stressful family circumstances, poverty or migration). ISCs are a rights-based needs assessment mechanism for children who need support: a child needs help – a child gets help. It is an approach where children do not need to be labeled and categorized to receive

support interventions that would help them achieve their full developmental potential and inclusion in society.¹⁷ Two other features are important as well: (i) ISCs are established by municipalities (i.e., where people live) and (ii) they are inter sectoral by nature with a great potential to serve as an integrator of all local actors crucial for the provision of benefits and services to children and their families, where the child is placed at the center, including the municipal center for social work, local educational establishments, local developmental counselling

¹⁷ In 2018, Portugal adopted a similar approach to the assessment of needs. See the Portugal Case in the Main Report.

units and other health care establishments. The ISC design has many innovative features such as full participation of parents (but also other persons who know the child well), the involvement of the child, direct observation of the child in her/his own environment, multisectoral approach to the assessment and consensual approach to decision making and others.

However, several studies have noted some of the problems ISCs encounter in their operations.¹⁸ Below we briefly present some of the observed issues, noting that Serbia with support from the EU recently started implementing a project to strengthen ISCs.

Stuffing arrangements: All members of ISCs have their regular full-time jobs. Their work for an ISC, although modestly compensated for, is essentially an extracurricular activity to them. Assessing the situation of the child and her/his needs and then monitoring the delivery of support interventions requires a serious time commitment from everyone involved in the work of ISCs.

Funding: Adequate funding of ISCs is an issue, as many municipalities struggle to fund all functions devolved to them. Since ISCs are of vital to children in need, ensuring their high-quality functioning across all municipalities in Serbia should be in the national interest and, thus, their financing could be covered by the republican

budget (in the form of targeted transfer to municipalities).

Monitoring of the plan of support implementation. The ISC members are not only expected to conduct the assessment, but to also monitor the implementation of the support plan in their respective fields. To a certain extent, they are expected to be the case managers as well. This may not be the best idea, given the time that a proper case management requires and the fact that the case management requires special skills.

Assessment methods and tools and instruments. It is not clear which tools and methods the ISC members use to perform the assessment, categorize children and issue their opinions.

Information system. An integrated, automated information system is lacking. Having a data management system to support the ISCs operations, where all business processes and the flow of documents and data is automated, including referrals to services would make the work of the ISCs more effective, data collection and reporting automated, linkages between sectors instant and monitoring easier with real time information uploading and exchange. Serbia has invested a lot of efforts into the e-Government and creating such an integrated data management system should not require much additional resources.

2.4 Determining the degree of support in social welfare services

Introduction

The Rulebook on Conditions and Standards for the Provision of Social Welfare Services ("Official Gazette of RS", No. 42/13, 89/2018 and 73/2019) defines conditions and standards for the provision of all social welfare services. Social welfare services are provided by local governments. They include placement in residential care, temporary shelters, respite care, day care, services at home, personal companion for a child with disabilities, supported independent living and personal assistance. The need for social welfare services and the degree of support are determined by a responsible social work center (SWC). SWCs are also responsible for administering social welfare benefits in cash, including to children with disabilities and their families.

The SWC determines the degree of support considering the overall individual functioning of users and the types of assistance needed, in relation to (1) the ability to take immediate care of oneself, and (2) participation in the activities of life in the community.

First Degree Support: A person is not able to take care of herself/himself and participate in activities of daily life in the community; she/he needs physical presence and continuous help from another person.

Second Degree Support: A person can take care of herself/himself and engage in activities of daily life in the community with the physical presence and assistance from another person.

¹⁸ Ibid.

Third Degree Support: A person can take care of herself/himself and engage in activities of daily life in the community, but due to insufficient knowledge and skills she/he needs the supervision and support from another person.

Fourth Degree Support: A person can perform all life activities on his own independently/ or with reminders.

A responsible SWC and or a service provider, based on identified needs, capabilities, and risks, prepare *an individual service plan* for each user. The plan must contain:

- objectives to be achieved by providing the service,
- expected outcomes,
- concrete activities/interventions to be undertaken, including activities in the process of adjustment,
- a timeframe in which the individual service plan is to be implemented,
- the deadline for reviewing and revisiting the individual service plan,
- names of the persons responsible for the realization of the individual service plan.

The service plan review is carried out in accordance with the deadlines set out in the individual service plan, the estimated intensity of support, defined goals and outcomes. The review enables all parties concerned to monitor progress and to customize activities to the needs and objectives of the user and to enable better outcomes for the user. The plan review is carried out: at least: 1) once every six months, for children and youth, and 2) once every 12 months, for adults and older users.

Assessing a degree of support

According to the above-mentioned Rulebook, the degree of support and the development of an individual service plan are based on the results of an assessment. What follows is a description of a tool that is used in this assessment. As above, we present the tool using its original language, because it illustrates institutional thinking.

This assessment uses the term *functional efficiency*, which can be reduced because of disability, age, mental illness, developmental disabilities, behavioral

problems, etc., leading to restrictions in meeting everyday life needs. In the context of the tool *functional efficiency* means the ability of the user to independently meet needs in different areas of daily life. The tool evaluates the beneficiary ability to perform daily life activities (ADL – Activities of Daily Life) and instrumental activities of daily life (IADL). It also evaluates functioning in a social environment and mobility. Within the functioning of the social environment, the user's ability to establish functional and adequate relationships with other persons (peers, family and known and unknown persons with whom he interacts), the quality of those relationships, as well as behavior in the social environment reflected in respecting social norms and how to respond in everyday situations in which the user can be found. Mobility, which refers to assessing a person's independent movement within the space in which they live, i.e., spends most of their time, as well as in the outside environment, is singled out as a special domain because it greatly affects the assessment of the user's ability to perform other activities that require movement (e.g., use of toilets, use of public transport, public services, shopping, etc.).

The level of intensity of support is determined in relation to the overall functioning of the user. In relation to the assessment, the type of support is determined, which differs by content and intensity. The accuracy of the assessment directly depends on how familiar the immediate service provider (professional worker) is with the daily functioning of the user. Better user knowledge contributes to a more accurate assessment of a user's functional ability.

Purpose of the assessment instrument: The purpose of the instrument is to assess functional ability and determine the intensity of support. It is intended for skilled workers, in all social services, regardless of the user group, i.e., the services provided. The tool description asserts that it is applicable to all ages of users, including very young children. The instrument should be administered by experts at responsible CSW, especially in situations where users are referred to other services in social care. The instrument is intended for a basic assessment of functional ability; if needed, social welfare services professionals may use other instruments (e.g., psychological, etc.), sensitive to specific characteristics of the service target group. The instrument's write up states that it enables: (I) individualized approach; (II) an assessment of the needed level of support regardless of the type of service; (III) a more focused individual planning, with defined realistic goals, actions and outcomes;

and (IV) evaluation of changes in functional ability during the reassessment and consequent adjustments in the plan of support.

What is assessed? Functional ability is determined by many factors resulting in its different degrees. It is thus important to evaluate the current state of a person's functional ability and determine the level of support the person needs to improve it. It is also important to define the support expected outcomes and to project a functional ability development trajectory (stable level, a decline, an improvement). Thus, the instrument does both: it assesses the state of functional ability and level of support, but also estimates expected outcome and development of the functional ability over time. It should be noted that the expected outcome in this context means in the period until the reassessment (6-9 months after the initial assessment).

Degrees of support: Article 15 of the Rulebook defines four levels of support (see above). The first degree requires permanent presence of another person in satisfying everyday life needs. The second degree indicates that the service user has partial ability to meet her own needs, with the support and occasional presence of another person. It implies that the user has fully (or partially) developed awareness, but due to physical limitations she is unable to satisfy her needs or participate in certain activities of life in the community. The third and fourth degrees of support mean that the user has the potential to take care of herself on her own and to participate in activities in the community. Specifically, the third level of support entails a supervision of another person. The fourth level of support does not require the physical presence of a professional worker, but only an occasional reminder.

The instrument: In addition to personal information an information about the service provider and the date when the provision of the service commences, the instrument comprises four parts: (i) Self-Care/ Daily Life Activity Abilities (ADL); (ii) Participation in community daily living activities/instrumental life activities (IADL); (iii) Functioning in social environment (SOC); and (iv) Mobility.

Self-Care/Daily Life Activity Abilities (ADL): the following is assessed – the use of toilet, maintenance of personal hygiene, dressing and undressing, putting on/taking off shoes, taking meals and taking prescribed therapy.

Participation in community daily living activities/ instrumental life activities (IADL). The following is

assessed – use of public transport, use of public services, money management, grocery shopping, keeping the hygiene of the personal/group space, work and education, preparing food and beverages, the use of a telephone and orientation in space.

Functioning in social environment: attitude towards rules (following and respecting the rules), communication, attitude towards peers, attitude towards known persons and strangers, maintaining family relationships, group activities/participation in community activities, keeping safe/avoiding danger, aggression and orientation in time.

Mobility: mobility within home/institution, mobility outside home.

For each of the activities there is a description of the activity and then the description of ability to perform it rated by degrees 1-3 (the fourth degree denotes full ability). For example:

Maintaining personal hygiene

What is assessed? The degree at which a person can maintain independently (on her own) a hygiene of hands, face, and body.

Degrees of support:

- **Degree one:** a person cannot on her own wash hands/face/teeth/body.
- **Degree two:** a person needs partial support to maintain personal hygiene due to limited movement of upper extremities (for example the person cannot hold a shower head or gauge the water temperature, hold toothbrush etc.).

Dressing and undressing

What is assessed? Whether a person on her own can put on/take off all pieces of clothing.

Degrees of support:

- **Degree one:** Cannot do at all.
- **Degree two:** a person can put on/take off only simpler pieces of clothing (pants, T-shirt, sweater), but needs help of other person to put on/take off pieces of clothing that require fine and coordinated body movement (putting on socks or pantyhose, gloves, closing buttons, closing/opening a zipper, etc.).
- **Degree three:** a person can on her own put on/ take off all pieces of clothing, but the clothing is often not weather adjusted, or it is untidy.

The instrument

Filling in the form: Below is the instrument that is used/filled in during the assessment.

The scale to assess the intensity (degree) of support

Personal information: Name, middle name and family name Date of birth Place of birth	<hr/> <hr/> <hr/>
The institution: Type of service The name of the institution Address Tel.	<hr/> <hr/> <hr/> <hr/>
The assessor Name and family name Date The number of the questionnaire	<hr/> <hr/> <hr/>

ACTIVITIES OF DAILY LEAVING (ADL)					
1	2	3	4	CS	EO
1. The use of toilet					
Not able to use the toilet on her own ¹⁹	Needs help of other person to use the toilet and maintain the hygiene of the genital area and the toilet itself.	Uses the toilet independently but needs to be reminded to clean the toilet and maintain the hygiene of genitals	Uses the toilet independently, maintains the hygiene of genitals and keeps the toilet clean.		
Comment					
2. Personal hygiene maintenance					
Maintain independently hygiene of hands/ face/ teeth/ body	Needs help to maintain personal hygiene or to develop skills to maintain it.	Capable of maintaining personal hygiene independently but does not have hygiene habits.	Capable and has hygiene habits.		
Comment					

¹⁹ It should be noted that a person may not be able to perform some activities because of physical, intellectual, mental, or other limitations. However, limited ability to perform some activities can also be age related. A small child would need full support, not because she/he has a health condition/developmental delay, but simply because she/he is not able to perform certain activities at that age.

ACTIVITIES OF DAILY LEAVING (ADL)					
1	2	3	4	CS	EO
3. Dressing/undressing					
Cannot dress/undress on her own	Capable to independently or with help from other person dress and undress simple pieces of clothing.	Capable to independently dress and undress all pieces of clothing. From time to time does not adjust clothes to weather or does not keep the clothes clean and tidy.	Dresses/undresses independently, clothes weather appropriate and tidy.		
Comment					
4. Putting on/taking off shoes					
Cannot put on/take off shoes on her own.	Puts on/takes off on her own simple footwear.	Capable to independently put on/take off shoes, but not always weather adjusted or clean.	Capable to independently put on/take off shoes; weather adjusted and clean.		
Comment					
5. Eating					
Cannot take food on her own.	Eats, but with help from other person or technical aids.	Able to eat on her own but lacks appropriate habits and manners (eating regularly, healthy eating, use of utensils, table manners)	Eats on her own with appropriate habits and manners.		
Comment					
6. Taking prescribed therapy					
Cannot take prescribed medication/therapy due to physical and intellectual limitations.	Can take medicines on her own, but the medicine ought to be prepared and supervised by another person.	Can take the medicines on her own but needs to be reminded by another person.	Takes medicine on her own.		
Comment					

PARTICIPATION IN ACTIVITIES OF DAILY LIFE IN THE COMMUNITY/INSTRUMENTAL LIFE SKILLS (IADL)					
1	2	3	4	CS	EO
1. Use of public transport					
Cannot do it at all.	Uses public transport accompanied by another person or in adjusted means of transport.	Can use public transport independently but has difficulty orienting and respecting rules.	Uses public transport with no difficulty.		
Comment					
2. Use of public services					
Not able to use public services.	Needs assistance to use public services due to physical or intellectual limitations.	Understands the purpose of public services but cannot use them adequately. Not sufficiently independent and has no initiative.	Fully capable of using public services on her own.		
Comment					
3. Money management					
Does not understand the purpose, value of use of money.	Needs help to use money.	Understands the use of money but cannot manage it rationally.	Fully capable of using money.		
Comment					
4. Grocery shopping					
Cannot do it.	Needs assistance to shop due to physical or intellectual limitations.	Can do the shopping but spends money carelessly.	Fully capable of shopping independently.		
Comment					
5. Maintaining hygiene of personal/group living space					
Cannot do it.	Needs assistance to maintain the hygiene of personal/group living space.	Can do it independently but has no habits and initiative.	Capable of doing it with fully developed habits of tidying/cleaning the space.		
Comment					

PARTICIPATION IN ACTIVITIES OF DAILY LIFE IN THE COMMUNITY/INSTRUMENTAL LIFE SKILLS (IADL)

1	2	3	4	CS	E0
6. Work/education					
Not able to do any work.	Can perform some work tasks but with help.	Can perform work tasks independently but has no work habits, has no skills and does not show responsibility.	Fully capable of performing her work tasks with required skills and responsibility.		
The child is not included in education.	Needs help from another person to be included in education in regular school.	Attends school independently but lacks studying habits, truant, learning results not commensurate with capacity.	Attends school independently, diligent, studies, learning commensurate with capacity.		
Comment					
7. Preparing food and beverages					
Cannot do it at all.	With assistance can cook simple meals and prepare beverages.	Can prepare simple meals independently but not more complex ones.	Fully capable of cooking.		
Comment					
8. Using the phone					
Cannot do it at all.	Need help to use phone.	Independently uses the phone but not in accordance with needs.	Fully uses the phone independently.		
Comment					
9. Orientation in space					
Does not have sense of orientation even in familiar space.	Can orient herself in familiar space (home, backyard, neighborhood...)	Has difficulties with orientation in unfamiliar spaces.	No issues in orienting herself.		
Comment					

FUNCTIONING IN SOCIAL ENVIRONMENT					
1	2	3	4	CS	EO
1. Following and respecting rules					
Does not understand rule or not able to follow them due to physical limitations.	Needs help from another person to understand and follow rules.	Understand the rules but is dismissive of them. No developed habit of following them.	She has positive attitude toward the rules. Follows them.		
Comment					
2. Communication					
Very limited capacity of communication.	Experiences difficulties understanding and communicating and needs help from another person or a technical aid.	Understands others and can communicate but not clearly enough – needs attentive listener to be understood.	Fully capable of communicating. Clearly expresses opinion, thoughts, wishes...		
Comment					
3. Relationship with peers					
Does not engage with peers.	At the initiative of another person communicates with peers but superfluously and without real engagement.	Communicates with peers but without forming a friendly relationship.	Initiates contacts with peers. Develops and maintains friendships.		
Comment					
4. Attitude towards known and unknown persons.					
Does not recognize persons she sees every day.	Recognizes persons with whom she is in daily contact but not those she sees sporadically.	Communicates with persons she knows, but not with persons she does not know.	Does not have any problems communicating with known or unknown persons.		
Comment					
5. Family relations					
Not aware of the meaning of family relations, cannot form them or has no wish to form them.	She is aware of family relations but does not form them in any meaningful way.	Aware of the importance of family relations and wishes to form them but needs support.	No problems at all.		
Comment					
6. Group activities/participation in activities in the community					
No participation at all.	Passive participant/observer and only at the initiative of another person.	Participates but only if interested and rarely initiates them.	Spontaneously, voluntarily and actively participates. Frequently initiates group activities.		
Comment					

FUNCTIONING IN SOCIAL ENVIRONMENT					
1	2	3	4	CS	EO
7. Avoiding danger					
Not aware of risky situations for her or others.	Needs help to understand the consequences of risky situations she involves herself or others.	Understands risky situations but deliberately endangers herself or others.	Recognizes risky situations and avoids them.		
Comment					
8. Aggression					
Frequent aggressive or self-aggressive behavior without obvious causes.	Frequently reacts aggressively physically or verbally when provoked.	Occasionally reacts aggressively physically or verbally when provoked.	Reacts appropriately when provoked, seeks to find peaceful resolution to a conflict.		
Comment					
9. Orientation in time					
Does not have a sense of time.	Aware of current events and from near past but not able to plan.	Has sense of time but has difficulties planning.	No problem at all.		
Comment					

MOBILITY					
1	2	3	4	CS	EO
1. Mobility inside the house/institution					
Cannot move.	Can move in accommodated space but needs help from other person or technical aid.	Can stand up and move but not firmly.	Moves independently.		
Comment					
2. Mobility outside house/institution					
Cannot move.	Can move but only with help from another person or a technical aid.	Can move independently but have difficulties with movements that require bigger effort.	Independently walks, jumps, runs.		
Comment					

**The scale for assessing functional efficacy:
The form for the assessment of the degree of support**

USER NUMBER:

Name: _____	Type of service: _____
Family name: _____	The year in which the service provision begins/has begun: _____
Middle name: _____	The name of the assessor: _____
Gender: M/F	Family name of the assessor: _____
Date of birth: _____	Data of assessment: _____
Place of birth: _____	The name of the institution: _____

ACTIVITIES OF DAILY LEAVING	CURRENT STATE				EXPECTED OUTCOME				R+	R-	P
	1	2	3	4	1	2	3	4			
Toilet use	1	2	3	4	1	2	3	4			1
Personal hygiene maintenance	1	2	3	4	1	2	3	4			2
Dressing/undressing	1	2	3	4	1	2	3	4			3
Putting on/taking off shoes	1	2	3	4	1	2	3	4			4
Eating	1	2	3	4	1	2	3	4			5
Taking prescribed therapy	1	2	3	4	1	2	3	4			6
INSTRUMENTAL ACTIVITIES OF DAILY LEAVING	CURRENT STATE				EXPECTED OUTCOME				R+	R-	P
	1	2	3	4	1	2	3	4			
Use of public transport	1	2	3	4	1	2	3	4			1
Use of public services	1	2	3	4	1	2	3	4			2
Money management	1	2	3	4	1	2	3	4			3
Grocery shopping	1	2	3	4	1	2	3	4			4
Maintaining hygiene of personal/group space	1	2	3	4	1	2	3	4			5
Work/education	1	2	3	4	1	2	3	4			6
Preparing food and beverages	1	2	3	4	1	2	3	4			7
Use of telephone	1	2	3	4	1	2	3	4			8
Orientation in space	1	2	3	4	1	2	3	4			9

FUNCTIONING IN SOCIAL ENVIRONMENT	CURRENT STATE				EXPECTED OUTCOME				R+	R-	P
Following and respecting rules	1	2	3	4	1	2	3	4			1
Communication	1	2	3	4	1	2	3	4			2
Relationship with peers	1	2	3	4	1	2	3	4			3
Attitude towards known and unknown persons	1	2	3	4	1	2	3	4			4
Maintaining family relations	1	2	3	4	1	2	3	4			5
Group activities/activities in a community	1	2	3	4	1	2	3	4			6
Avoiding unsafe situations/danger	1	2	3	4	1	2	3	4			7
Aggression	1	2	3	4	1	2	3	4			8
Orientation in time	1	2	3	4	1	2	3	4			9
MOBILITY	CURRENT STATE				EXPECTED OUTCOME				R+	R-	P
Mobility with house/institution	1	2	3	4	1	2	3	4			1
Mobility in the outside environment	1	2	3	4	1	2	3	4			2

SCORES

	CURRENT STATE		EXPECTED OUTCOME		R+	R-
	SCORE	LEVEL OF SUPPORT	SCORE	LEVEL OF SUPPORT	SCORE	SCORE
ADL						
IADL						
Functioning in social environment						
Mobility						
TOTAL						

Explanation:

Current station – refers to the assessment of the current state of functional ability. The answer is entered by marking the number that corresponds to the assessed level of support.

Expected outcome – refers to the expected change in functional ability. The answer is entered by marking the number that corresponds to the assessed level of support.

Positive progression risk (R+) – refers to the positive difference between the expected outcome and the current situation. The positive difference is calculated subtracting the expected degree of support from the current degree of support. For example, if the current degree of support is 3 and

the expected is 4, then $4-3=1$. The number to be written in the assessment sheet is 1. R- is 0, as no negative change for that particular activity is expected. If no change is expected, then both R+ and R- are 0.

Deterioration (R-) indicates activities where the situation is estimated to regress over time. If the current estimate of a particular activity is 4 and the expectation is that it would regress to 3 than the difference of 1 is penciled in in the R- column.

P denotes a priority for intervention. It indicates activities where the assessor estimates that the beneficiary has the highest potential for improvements. For ADLs and IADLs more than one activity can be chosen as a priority.

Determining the dominant degree of support

A degree of support for each of the four groups of activities is calculated by scoring each group and using the following table:

	ADL	IADL	SOCIAL ENVIRONMENT	MOBILITY
First degree	6-9	9-15	9-15	2-3
Second degree	10-15	16-22	16-22	4-5
Third degree	16-20	23-30	23-30	6-7
Fourth degree	21-24	31-36	31-36	8

Determining the degree of support by each group of activities enables professionals providing services to make more focused individual plans with realistic goals and expected outcomes. It is also important as a tool based on which a service provider can plan the allocation of human resources and tasks, they will be conducting in service delivery.

After calculating the level of support by groups of activities, the assessor determines **the dominant degree of support**. It is determined by choosing the lowest degree of support among the four groups of activities.

Observations

The approach and the instrument to assess the degree of support to persons with decreased functional ability used by social welfare services in Serbia is comparable to similar instruments, with similar purpose used in other countries (e.g., the assessment of the need for Personal Income Support in UK, some elements in the French disability and needs assessment instrument – GEVA, etc.). The assessment is a base to determine

the needs of a person to improve functioning and the choice from available services that would help the person. In the Serbian case, the tool is used to determine the degree of support in the social welfare system, in particular in cases of institutional placement and determination of services that need to be provided to institutionalized persons.

Two issues are observed. One is that the instrument does not differentiate between what children cannot do because they have not reached a stage of development where they can do a particular activity (talking, walking, etc.) and what they cannot do because they are experiencing health problems and developmental delays in an environment with barriers to functioning. The second is whether and to what extent the social welfare system uses information from the health system that identifies and assesses health and developmental problems in children from birth and through regular health and growth check-ups. Similarly, it is not clear to what extent the assessments performed by the social welfare system are used in the work of the ISC.

2.5 The National Registry of Children Identified as Having Disabilities

Introduction

To implement CRPD requirement that the state parties collect information about persons with disabilities (Article 31), necessary for the development, implementation and evaluation of policies and programs aimed at improving the situation of children with disabilities, Serbia decided and legally sanctioned

in 2015 to establish the Registry of Children with Disabilities (hereinafter Registry). It is fully operational since 2021. The Registry is established and maintained by the Institute for Public Health of Serbia. Access to personal information in this Registry is given only to the data base administrators and to persons who have assessed functional ability of the child (a chosen pediatrician).

Below, we present the Registry as it is described in its technical and methodological guide (T&M Guide). We try to remain true to the original language from the guide, as it reflects understanding of concepts, approaches, and technical and methodological choices made by the authors of the Registry.²⁰

The primary objective of the Registry, as stated, is to determine the prevalence and incidence (newly discovered cases) of children with disabilities in the total population of Serbia. It should allow disaggregation by children's age, gender, location, and other characteristics (see below). The Registry is expected to also allow to analyze trends in developmental problems, cohort analysis, calculation of years of healthy life lost because of disability, etc. With strict data use rules, the information currently cannot inform the work of other systems such as ISCs or SWCs.

The legal base

The legal base for establishing the Registry is the *Law on the Health Documents and Record Keeping in Health*²¹ (articles 29 and 31). The content of the Registry (and other mandatory health reporting forms and registries) is defined by the *Rulebook on forms and their content for health documents, record keeping, reports and electronic medical files*, issued by the Minister for Health.²² The "Book of records and registration of a child with developmental disabilities" has the following list of required data entry:

Data on institution: (1) The name of health care facility, (2) Facility code, (3) Organizational Unit/Service, (4) Organizational Unit/Service Code, (5) Official signature number, (6) Date of examination.

Child demographic data: (7) Last Name, and (8) First name of one of the parents/ guardians, (9) First name, (10) Unique citizen identification number, (11) Date of birth, (12) Age, (13) Gender, (14) Health insurance card number, (15) Personal number of the insured person, (16) Health record number, (17) Address – street and number, (18) City, (19) Municipality, (20) Municipality code,

(21) Child lives with/in, (22) Is child enrolled in education?, (23) The highest level of child's education, (24) The highest level of father's education, (25) The highest level of mother's education.

Assessment of functioning – Socioemotional functions and activities: (26) Date of assessment, (27) Emotion function – degree/level, (28) Interpersonal interactions and relationships (degree/level), (29) Participation in play (degree/level),

Cognition and metacognition: (30) Date of assessment, (31) Attention function (degree/level), (32) Learning through interaction with objects/ things (degree/level), (33) Language development (degree/level).

Communication function and activities: (34) Date of assessment, (35) Voice function (degree/level), (36) Articulation (degree/level), (37) Speech – rhythm and fluency (degree/level), (38) Use of language (degree/level), (39) Nonverbal communication (degree/level).

Motor function and mobility: (40) Date of assessment; (41) Muscle tonus (degree/level), (42) Control of voluntary movements (degree/level), (43) Changing the position of the body (degree/level), (44) Fine hand movements – use of hand (degree/level), (45) Walking (degree/level).

Activities of daily life: (46) Date of assessment, (47) Routine daily activities (degree/level), (48) Toilet use (degree/level), (49) Dressing (degree/level), (50) Eating (degree/level).

Sensory functions: (51) Date of assessment, (52) Vision (degree/level), (53) Hearing (degree/level), (54) Pain (degree/level).

Need for support: (55) Support the child needs, (56) Support the child is receiving.

Diagnosis of developmental disability: (57) Date of diagnosis, (58) Primary (basic) diagnosis, (59) Date of secondary diagnosis – secondary (one) condition, (60) Secondary diagnosis.

²⁰ Plavšić, S. Jović, A. Editors. 2021. The Registry of Children with Disturbed Development. Technical and Methodological Guide to the Implementation of the Registry. Institute for Public Health of the Republic of Serbia. Belgrade. The methodology was developed by a group of Serbian experts in consultations with international experts and support from UNICEF. Document is available in Serbian only. We refer to this guide as T&M Guide.

²¹ The Official Gazette of RS, 123/2014, 106/2015, 105/2017/25/2019.

²² The Official Gazette of RS, 109/2016, 20/2019.

Reason from removal of the record from the Registry: (61) Reason, (62) Date of removal.

Below, we present the key aspects of data collection and reporting as set out in the T&M Guide.²³

Conceptual basis for the Registry

The T&M Guide states that conceptually, the Registry is based on modern approach to disability where disability is understood as interaction between a person (here a child) with a health condition and her/his environment (WHO ICF, CRPD). It posits that a shift from a medical approach to disability to restrictions on participation in society on an equal basis with others also requires changes in the assessment of developmental disabilities and disabilities. Thus, the assessment for the Registry is based on an assessment of functioning, as understood by ICF and later the ICF- Children and Youth version.

Functional ability assessment methodology

Domains:

As per T&M Guide, the assessment includes 6 domains:

- **Socio-emotional functions and activities** (Establishing and maintaining relationships with others. Empathy, cooperation, waiting for her/his turn, fair-paly, trust in oneself and self-confidence, emotional control).
- **Cognitive functions and activities** (Ability to learn, think, understand, solve problems).
- **Functions and activities of communication** (Ability for verbal expression, verbal communication with others).
- **Physical development** (Development of gross and fine motoric, moving, balance, development of big muscle groups – for running, jumping, climbing; development of fine motor skills).
- **Skills to adapt – activities of daily living** (Ability to adapt to environment and adopting a routine, dressing, eating, maintaining hygiene, toilet training, etc.).

- **Sensory functions** (seeing, hearing, sense of pain).

The Working Group that developed T&M Guide, decided to adopt the recommendations of the Washington Group (WG) implemented in the Serbian 2011 Census of the Population to consider as children with disability and developmental problems only children whose degree of difficulty is assessed as 3 (a lot of difficulty) and 4 (cannot do at all) in one or several assessed domains (page 16 of T&M Guide). In other words, children with mild (1) or moderate disability (2) are not considered as having a disability for the purpose of the registry and will not be recorded in the Registry.

T&M Guide lists the following principles of the Registry:

- The primary purpose of the assessment is to identify children with developmental difficulties and disabilities.
- Identification of developmental difficulties and disabilities is conducted through the assessment of functional difficulties a child experiences and the degree of such difficulties.
- ICF-CY (WHO, 2007) is a conceptual framework for selecting relevant domains and the assessment methods.
- The choice of assessment domains respects the specifics of children's development.
- Early identification of developmental delays or developmental disabilities is key to early intervention and prevention of permanent disability, so developmental screening should be applied to children as early as possible.
- Considering the nature of the child development process and the different dynamics of the development of certain functions, the assessment should be carried out at a certain age of the children when we expect the functions to be developed, so that developmental disabilities are detected as soon as possible.
- Key periods for the evaluation are at minimum the age of 3 years, before the enrollment in primary school and at the age of 14.

²³ Ibid.

- The assessment is carried out in two steps: 1) a quick developmental assessment (development screening) is conducted for all children during regular visits to the pediatrician, 2) if a quick assessment indicates developmental deviations or delays, a detailed assessment is carried out and if functional difficulties are determined.
- Only children whose disability is assessed at levels 3 or 4 (serious and complete difficulties) in one or more assessed domains are registered in the Registry.²⁴
- Children with certain health conditions (see below the list under C) can be entered into the Registry from birth until the age 3 without the assessment.

The assessment

T&M Guide envisages two steps in the assessment of developmental difficulties and disabilities for the registration of children in the Registry:

1) Rapid assessment of child development and functionality (development screening). The rapid assessment is a quick assessment of the development and functioning of children of all ages, to be carried out during regular visits to the pediatrician and using recommended instruments in addition to the clinical examination. Guide envisages that the rapid screening for entering children in the registry is conducted for all children at the following ages: 3-4 years, 6-7 years (before

starting school) and 14 or 15 years (before starting secondary school).

For children up to 5 years of age, besides clinical examination, the Guide recommends the use of the Ages and Stages, ASQ.²⁵ ASQ age adjusted questionnaires are: 36 months (period of 34 months 16 days – 38 months 30 days); 42 months (period of 39 months 0 days – 44 months 30 days) and 48 months (45 months 0 days – 50 months 30 days).

For children aged 5-17 years, besides clinical examination, T&M Guide envisages the use of the UNICEF/Washington Group Module on Child Functioning and Disability (CFM) developed for population surveys (e.g., UNICEF MICS). This questionnaire is envisaged to be used for rapid screening during systematic health examinations for enrollment in primary and secondary school.²⁶

If rapid assessment of development and functionality indicates developmental deviations or difficulties in functioning, the second step, detailed functioning assessment is conducted.

2) Detailed assessment of children's functional abilities. Detailed assessment is conducted when children during a quick assessment (developmental screening), clinical examination, or other type of examination are observed to experience developmental problems. Detailed assessment is conducted using a range of instruments, in addition to using the tool/questionnaire developed for the purpose of data collection for the Registry and included

²⁴ There is no technical or any other reason to exclude children assessed as having a moderate disability (qualifier 2), or mild disability (qualifier 1). Information on them is as equally important as information on children having severe or complete difficulty. For individual children, it allows that their individual trajectory of disability development over time is followed. More importantly, the use of ordinal scale to assess difficulties inevitably includes errors in assigning the degree of difficulties by assessors, particularly when the judgment call is made between two levels where differences are very subtle.

²⁵ <https://agesandstages.com>

²⁶ Any instrument that is used for screening or assessment must be "fit for purpose" and must pass the psychometric test. The CFM was developed to be implemented in population surveys (such as UNICEF Multi Indicator Cluster Survey – MICS). Empirical testing of this instrument and using qualifiers 2 (moderate difficulty), and 3 and 4 found "good to excellent" accuracy in identifying seeing, hearing, and walking difficulties. See: Sprunt, Beth, Hoq, Monserul, Sharma, Umesh and Marella, Manjula. 2017. Validating the UNICEF/WG Child Functioning Module for Fijian schools to identify seeing, hearing and walking difficulties. *Disability and Rehabilitation*, 2017 <https://doi.org/10.1080/09638288.2017.1378929/>. "Fair" to "poor" accuracy of the CFM in cognitive domains was reported in another empirically based article. The article explored the validity (sensitivity and specificity) of different cut-off levels of the CFM and the inter-rater reliability between teachers and parents as proxy respondents, for disaggregating Fiji's education management information system (EMIS) by disability. The method used was a cross-sectional diagnostic accuracy study comparing CFM items to standard clinical assessments for 472 primary school aged students in Fiji. The analysis shows only "fair" to "poor" accuracy of the cognitive domains (learning, remembering, and focusing attention) and "fair" of the overall CFM. Authors conclude that for identifying children with disabilities, the CFM "should be part of a broader data collection including learning and support needs data and undertaking eligibility verification visits" See: Sprunt, Beth, McPake, B. and Marella, Manjula. 2019. The UNICEF/WG Child Functioning Module–Accuracy, Inter-Rater Reliability and Cut-Off Level for Disability Disaggregation of Fiji's Education Management Information System. *International Journal of Environmental Research and Public Health*. 2019. An earlier study compared the WG Extended Set on Functioning (ten core/ four non-core domains) and the draft UNICEF/WG Extended Set on Child Functioning and Disability (eight core/ four non-core domains) to clinical impairment screening. The study included 3,567 persons in Cameroon and 3,574 in India. The WG set correctly identified only 33% of participants in Cameroon and 45% in India as disabled, i.e., the sensitivity of the questions ranged between 30% and 45%. Authors concluded, "a large proportion of people with moderate or severe clinical impairments did not self-report functional difficulties despite reporting participation restrictions" See: Mactaggart I, Kuper H, Murthy GV, Oye J, Polack S: Measuring Disability in Population Based Surveys: The Interrelationship between Clinical Impairments and Reported Functional Limitations in Cameroon and India. *PLoS One* 2016, 11:e0164470.

in the Guide. The level of difficulty is rated 0-4, according to the ICF/ICF-CY:

- (i) No difficulty (0-4%) – 0
- (ii) Mild difficulty (5-24%) – 1
- (iii) Moderate difficulty (25-49%) – 2
- (iv) Severe difficulty (50-95%) – 3; and
- (v) Complete difficulty (96–100%) – 4.

The Registry includes all children 0-18 years of age, and the Guide pertains to all of them. The Guide instructs that the age of the child should be considered in the assessment. No specifics are provided to guide the pediatricians and other medical staff involved in the assessment.

Only children whose degree of difficulty is 3 or 4 in one or more domains of functioning are recorded in the Registry. It is required that changes in functional status or diagnosis are recorded in the Registry.

3) Registration of children with certain types of health conditions. The Guide provides the list of ICD-10 codes whose diagnosis should trigger immediate detailed assessment of functioning. For children younger than 3 with one of those diseases the entry into registry is done without detailed assessment which is conducted when they reach the age of 3 years. The ICD-10 codes are: H53 (visual disturbances); H54 (blindness and low vision), H90 (conductive and sensorineural hearing loss), F20 (schizophrenia), F70 (mild intellectual disabilities), F71 (moderate intellectual disabilities), F72 (severe intellectual disabilities), F84 (autistic disorder), F90 (attention deficit/hyperactivity disorder), G23 (other degenerative disorders of basal ganglia), G24 (Dystonia), G35 (multiple sclerosis), G60 (hereditary and idiopathic neuropathy), G70 (myasthenia gravis and other myoneural disorders), G71 (primary disorders of muscles), G80 (cerebral palsy), G81 (hemiplegia and hemiparesis), G82 (paraplegia and quadriplegia), Q02 (microcephaly), Q90-Q99 (chromosomal abnormalities not elsewhere

classified – congenital malformations, Down syndrome), E00 (congenital iodine deficiency syndrome), E70.0-3 (classical phenylketonuria), E71 (disorder of branched-chain amino-acid metabolism and fatty acid metabolism), E72 (other disorders of amino-acid metabolism), E74.2.0.4 (other disorders of carbo-hydrates metabolism), E75 (disorders of sphingolipid metabolism and other lipid storage disorders), E76 (disorders of glycosaminoglycan metabolism), E77 (disorders of glycoprotein metabolism), E79.1 (Lesch-Nyhan syndrome), E80.3 (Crigler-Najjar syndrome) and E83.0 (disorders of mineral metabolism).

Assessment instrument

As noted, the assessment of functioning is conducted in 6 domains. T&M Guide provides detailed instruction about what is estimated and how to grade (rate difficulties).²⁷ The summary is provided in the text below. As an illustration we present from T&M Guide the assessment of socio-emotional functions and activities in entirety.²⁸ Then we only present key points for other domains.

The instrument for assessment, to the best of our knowledge had not been tested for its psychometric properties (on this, see Annex 1 above), i.e., it has not been empirically established that it represents the construct of disability of children in a reliable and valid manner. The assessment uses an ordinal scale (no difficulty, etc.) and thus no statistical algorithm can be constructed to generate a numerical score (which, in turn can be valid only if the instrument is psychometrically sound). The instrument combines body functions and indicators of activities and participation, which is not recommended in psychometric instruments, as the impact of the state of body functions impacts activities, i.e., performance (and so does environment) – see Annex 1 above. Also, the Guide does not address the issue of how the child's wishes, and opinions are to be systematically considered during the assessment process.

²⁷ The same team that developed this T&M Guide, also developed in 2018 a Technical and Methodological Guide and an instrument specifically for the assessment of functioning of children up to five years of age. It is not clear whether that instrument is used for children younger than five. It would appear not, and that the decision was made to use a single instrument that is presented here. Plavšić, S. and Jović, A. Editors. 2018. An Assessment of the Status of Functioning of Children up to Five Years of Age – Technical and Methodological Guide. Institute for Public Health of the Republic of Serbia. Belgrade. For the accuracy and reliability of the assessment, it would make sense to have two instruments (one for young children and one for children 5 and over).

²⁸ Ibid.

Assessment Domain 1: Socio-emotional functions and activities

Introduction

Emotions consist of a series of related reactions to a particular event or situation and include an individual's relationship with an object or event, a recognizable mental state and emotional expression. Emotions are also intense, short-lived, accompanied by different physiological changes and lead to interruption of current behavior. Emotions regulate intrapersonal and interpersonal behaviors and affect a person's adaptation. Three main characteristics of emotions relate to physiological changes, subjective experience, and manifestation of behavior. Emotions as a consequence of social experiences in the environment motivate cognitive processes and behaviors by regulating the physiological, cognitive and behavioral aspects of individuals' behaviors in the environment.

The main hallmark of emotional development in children is the recognition of emotions through social cognition. It is only at a pre-school age that the ability of children to adapt to the emotional expressions and situations in the environment can be clearly verbalized based on their personal and emotions of others. The intensity of a child's emotional response is a function of the child's temperament, and the child's ability to regulate her emotional reactions and behavior.

Indicators of a child's good emotional state are his ability to control a wide diapason of emotional experiences and appropriate reactions in these emotional situations. Children who have mastered their emotional experiences/reactions are considered emotionally able.

During the process of socialization in which society shapes a child's beliefs, expectations and behaviors, children's emotional development and psychosocial adjustment related to it are influenced by various factors such as the nature of a child's attachment to a mother, father, guardian; ability to talk about emotions, warmth, support and supervision of parents, interactions with peers and relationship with adults outside the family.

Children's adoption of emotional expression, recognition and understanding of emotions is influenced by both the rules and norms of emotional behavior of the culture in which the child develops and is learned very early in life. Therefore, the ways in which children and adults exchange affective

signals in emotionally colored social interactions are of paramount importance to children's socialization of emotions. If the child does not sufficiently recognize and understand emotions, i.e., if the developmental level of emotional maturity is not reached due to various developmental problems, further learning of social norms, customs and rules of conduct of the group to which the child belongs or acquiring social skills will become more difficult.

Children's ability to create relationships with their environment is a strong predictor of mental health in adulthood. Children seek social support from their parents, relatives, their friends and friends of their parents, educators, teachers, doctors, etc., to better deal with life's stress, life changes and to enable the encouragement of their own cognitive and social development. With family, one of the biggest influences on a child's socio-emotional development is made by the child's peers in preschool. Children's interactions with peers in the play in nursery, kindergarten, school contribute to social competence, psychosocial behavioral skills and less aggressiveness.

Social development includes behaviors, attitudes and affections that manifest in children's interactions with adults and peers. Different theoretical directions differently define the social development of the child. The most modern of these approaches is the ecological development approach. The overall context in which children's development takes place significantly affects the course of her/his development and developmental outcomes, while not neglecting the individual traits of the child; on the contrary, this approach considers that development is the result of the interaction of the child's traits and the environment in which the child grows

Assessment of socio-emotional function and activities

For the purposes of the Registry, the following are assessed: (1) Emotion functions (ICF code b152); Basic interpersonal interactions and references (d710), and Engagement in play (d880).

Emotion functions (b152)

What is assessed? Specific mental functions related to the experience of emotions and expression of affective states. They are evaluated through the adequacy of emotions, regulation of emotions and range of emotions. In situations where difficulties are identified, an assessment of their degree is required (duration, frequency of expression and how pervasive they are). Longer duration, higher frequency and presence in many situations signal

adverse effects on the development and functioning of the child. When assessing, it is necessary to consider the age of the child.

Adequacy (b1520): implies that feelings and affections are appropriate for the situation (adequacy of feelings such as sadness, happiness, anxiety, affection, fear, anger, frustration, etc.).

Regulation (b1521): implies control of experiencing and expressing feelings (volatility and control of feelings, “flattening” of reaction).

Range (b1522): implies the intensity (quantity) of present feelings and reactions.

Assessment: Information about difficulties in this area is obtained from a variety of sources (by putting together an anamnesis) – child, parents, kindergarten, school, application of assessment instruments and clinical diagnostic procedures. Child age counts. The guide refers the assessors to several instruments such as The Scale of Strengths and Difficulties, Vineland II, Development Test Cuturić, or other standardized emotional development assessment instruments and scales. For children 0-6, early childhood development assessment instruments such as ASQ and Guide for Monitoring Child Development (GMCD) are suggested. If needed, a clinical assessment by a medical specialist should be conducted. Specialist findings should contain a defined level of intensity of difficulty according to the scale below.

Scale (qualifiers): The qualifiers are described in the following way:

- 0. There are no difficulties in emotion functions.**
The child reacts emotionally adequately (congruently) in all situations. She/he regulates the level of emotional response. The child exhibits an age-adequate range of emotions in existing situations.
- 1. Mild difficulties in emotion functions.** The child has occasional and slight disturbances in emotional reactions to specific situations. She/he shows mild problems in intensity and adequacy of emotions.
- 2. Moderate difficulties in emotion functions.** The child has a frequent and more pronounced disturbances in emotional reactions to specific situations; shows directional moderate problems in intensity and adequacy of emotions.

- 3. Severe difficulties in emotion functions.** The child has severe disturbances (greater intensity of emotional reactions than the qualifier 3, and in more than half of life situations); she/he lacks emotional exchange with other people.
- 4. Complete difficulties in emotion functions.** The child is without emotional regulation and her/his emotional reactions are unpredictable.

Interpersonal interactions and relationships (d710)

What is assessed? Interpersonal interactions and relationships describe interactions with other people. Social development depends largely on the experiences a child has in relationships with loved ones and the wider social environment. Difficulties in this area adversely affect the child’s development and jeopardize her/his participation in education and society. This function is assessed by looking at how the child makes, maintains and adjusts her interactions with others in a socially adequate manner and in accordance with the context. Included are also how the child responds to the feelings of others, shows respect in relationships, as well as proper physical contact.

Respect and warmth in relationships (d7100): socially adequate expression of concern for the other, sympathy, appreciation and respect.

Social interactions (d7104): establishing and maintaining interactions, adequate reaction (expressing and responding) to social signals in interactions with others.

Physical contact in relationships (d7105): achieving and responding to bodily contact with others, in a socially adequate manner and in accordance with context.

Assessment: Information about difficulties in this area is obtained from a variety of sources (by putting together an anamnesis) – child, parents, kindergarten, school, application of assessment instruments and clinical diagnostic procedures. The age of the child should be considered. Assessment instruments (SDQ, Vineland II, other instruments, tests, and standardized assessment scales) can also be used. At an early age (0-6 years) information about possible significant difficulties in social functioning can also be obtained by applying early childhood development assessment instruments (ASQ, GMCD, other standardized instruments, tests, and screening assessment scales). If difficulties are present, a more detailed assessment of the functioning of the child in this area needs to be carried out.

“The presence of moderate difficulties in emotional functioning (level 2) poses a significant risk and aggravating factor for the development and participation of the child in social and educational situations, at all ages. It is not enough as an independent criterion for registering a child in the Registry, but it also speaks of the need for intervention in order to help the child.” – Guide, page 24).

If the child is assessed at degrees 3 or 4, this signals significant difficulties for a child to be participating in educational and social life. The child is recorded in the Registry, and she/he should be helped (e.g., additional specialist assessments, parent counselling, social skills training, etc.).

Scale (qualifiers): The qualifiers are described in the following way:

0. **There are no difficulties in interpersonal interactions and relationships.** The child has no difficulties in interacting with others.
1. **Mild difficulties in interpersonal interactions and relationships.** Difficulties in relations with others for less than six months, which can be explained by the transient difficulties of adaptation.
2. **Moderate difficulties in interpersonal interactions and relationships.** Difficulties in relationships with others for more than six months, a few times a week, and with problems in relations with others.
3. **Severe difficulties in interpersonal interactions and relationships.** Difficulties in relations with others for more than six months, present daily, seriously damage relations in all circumstances (environments), absence of social interests.
4. **Complete difficulties in interpersonal interactions and relationships.** Complete problems in all aspects of interpersonal interactions and relationships.

Participation in play (d880)

What is assessed? Participation in play is defined as targeted, purposeful engagement in activities with objects, toys, materials or in different types of play, independently or with others. The age of child should be considered, as well as well as opportunities to play alone or with others (toys, environmental influences). For the purposes of the Registry, social aspects of play are

especially important, i.e., the possibilities to play with others. This is a complex category, because not only can it be an indicator of a child’s ability, but also an indicator of the characteristics of the environment, as well as a significant indicator of child participation. Difficulties in this area at an early age may indicate serious problems in many areas of child development (cognitive, socio-emotional, speech-language, motor development), as well as significant environmental deficiencies (insufficient or inadequate stimulation).

Plays on her/his own (d8800): able to only engage in play (various types of games with objects, toys, various materials).

Watches the play of others but does not join (d8801): observes the game of others but does not join.

Parallel play (d8802): plays in the presence of others (among others) who also play but does not join them.

Common (cooperative) play with others (d8803): joins others and shares with them the intentions and goals of the game.

Assessment: Information about difficulties in this area is obtained from a variety of sources (by putting together an anamnesis) – child, parents, kindergarten, school, application of assessment instruments and clinical diagnostic procedures. The age of the child should be considered. Significant information can also be obtained by observing a child’s play during an examination. Assessment instruments (Vineland II, other standardized assessment scales) can also be used. At an early age (0-6 years) information that indicates possible significant difficulties in this area can also be obtained by applying early childhood development assessment instruments (ASQ, GMCD, other standardized instruments). If difficulties are present, a more detailed assessment of the functioning of the child in this area needs to be carried out.

“The presence of moderate difficulties in emotional functioning (level 2) poses a significant risk and aggravating factor for the development and participation of the child in social and educational situations, at all ages. It is not enough as an independent criterion for registering a child in the Registry, but it also speaks of the need for intervention to help the child.” – T&M Guide, page 25).

If the child is assessed at degrees 3 or 4, this signals significant difficulties for a child to be participating in educational and social life. The child is recorded in the Registry, and she/he should be helped (e.g., additional specialist assessments, parent counselling, social skills training, etc.).

Scale (qualifiers): The qualifiers are described in the following way:

0. **There is no difficulty in organizing play.** The play is age appropriate.
1. **Mild difficulties in organizing play.** The play is age adequate with mild delays relative to age expectations and context (known and unknown environment). There can be occasional difficulties when playing with others.
2. **Moderate difficulties in organizing play.** The play is below expectations for age, mostly the

same, stereotypical, and repetitive. There are more frequent expressions of frustration if the child is distracted from the game. The child has difficulties following a team play.

3. **Severe difficulties in organizing play.** The game is significantly below what is expected for her/his age. The play is often repetitive, with limited choice of toys and activities, participation in common play only in the simplest activities and with the support from others.
4. **Complete absence of play.** Absence of targeted activity that would have the characteristics of play, independently or with others (see, T&M Guide for full text).

For easier presentation, we summarize the content of the assessment in other domains in a table below.

DOMAIN 2: COGNITIVE FUNCTIONS AND ACTIVITIES	
Attention Function (b140)	<p>B1400: Concentration and maintaining attention (ability to focus for a certain period).</p> <p>B1401: Shifting attention (shifting attention from one to the other stimulus).</p> <p>B1402: Dividing attention (dividing attention between two or more stimuli).</p> <p>B1403: Joint attention (focus on the same stimulus jointly with the other person, e.g., same toy).</p>
Learning through interaction with objects/things (d131)	<p>d1310: Learning through simple activities with one object.</p> <p>d1311: Learning through activities that include two or more objects at the same time.</p> <p>d1312: Learning through activities by relating two or more objects with regard to their specific feature (e.g., putting a lid on a box).</p> <p>d1313: Learning through symbolic play (feeding or dressing a doll).</p> <p>d1314: Learning through pretend play.</p>
Basic cognitive functions (b163)	<p>Mental functions involved in acquisition of knowledge about objects, events and experiences; and the organization and application of that knowledge in tasks requiring mental activity.</p>
Application of knowledge – basic academic skills (b160, b170, b172)	<p>D166: Reading, understanding written language.</p> <p>d170: Writing</p> <p>d172: Counting</p>

DOMAIN 3: COMMUNICATION FUNCTIONS AND ACTIVITIES	
Voice function (b310)	
Articulation function (b320)	
Speech function (fluency and rhythm – b330)	b3300: Fluency. b3301: Rhythm b3302: Speed b3303: Melody
Understanding speech (d310)	
Verbal expression (d330, d331)	
Non-verbal expression (d335)	d3350: Creation of body language d3351: Making signs and symbols and using them d3352: Making pictures, drawings, photos
DOMAIN 4: MOBILITY FUNCTIONS AND ACTIVITIES	
Muscle tonus (b735)	b7354: Muscle tonus of all extremities
Fine use of hands (d440)	d4400: Lifting small objects d4401: Gripping objects d4402: Hand shaking d4403: Dropping objects
Changing and maintaining body position (d410)	d4104: Standing
Walking (d450)	d4500: Walking short distances
Control of voluntary movements (b760)	b7600: Control of simple voluntary movements b7602: Coordination of voluntary movements
DOMAIN 5: ACTIVITIES OF DAILY LIVING	
Sleep function (b134)	b1341: Falling asleep b1342: Staying asleep b1343: Sleep quality b1344: Sleep cycle b1340: Quantity of sleep

Eating (d550)	d5500: Indicating hunger. d5501: eating properly (using utensils, etc.)
Dressing/undressing (d540)	d5403: Taking off shoes d5402: Putting on shoes d5401: Undressing d5400: Dressing d5404: Choosing appropriate clothing.
Use of toilet (d530)	
DOMAIN 6: SENSORY FUNCTIONS	
Hearing (b230)	
Vision (b210)	
Pain (b280)	b280.0: General pain b280.1: Pain in one body part b280.2: Pain in several body parts

Overall, there are 6 domains with 25 functions/ activities that are rated from 0 (no difficulty) to 4 (complete difficulty – cannot do it at all).

Implementing the Registry

Obligated to fill in the form reporting a child with disability/developmental disability (see the Legal base section above) have all: (i) chosen pediatricians and medical doctors employed on children’s health care at local clinics; (ii) chosen pediatricians, medical doctors of other specializations and medical doctors employed by the child development units in the local health clinics.

In cases when the full assessment cannot be conducted at the responsible local clinic and requires engagement of other medical doctors in other health care institutions, once the assessment reports are received, chosen pediatricians and medical doctors employed on children’s health care at local clinics fill in the required form and report the child for the entry into the Registry. In addition, they should include into the Form, if applicable, information on the child from the Intersectoral Commission and the Fund for Pension and Disability Insurance (see above sections for details).

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APPENDIX 1

GUIDE TO THE RIGHTS OF PERSONS WITH DISABILITIES IN THE REPUBLIC OF SERBIA²⁹

1. Introduction

Protection of persons with disabilities is one of the most sensitive and specific elements of development and social and economic policies. Our task is to promote the development of policy to protect persons with disabilities within the framework of modern, pluralistic social policy, considering that a person with a disability is an individual with her/his general and specific needs. Systemic solutions must enable each group of persons with disabilities to shape, express and realize their basic developmental needs, as well as special interests, to have equal opportunities as people without disabilities, and above all to have the right to diversity. Today, the situation of persons with disabilities must be seen primarily as a human rights issue. Disability is a complex social phenomenon that touches upon all areas of modern life and requires a multi-sectoral approach and cooperation between different authorities, local self-governments, the civil sector and the persons with disabilities and their organizations themselves. The emphasis is on guaranteeing equality for persons with disabilities, non-discrimination, and their full participation in society.

The status of persons with disabilities in our country is governed by numerous laws and bylaws, and thus provisions related to the rights of persons with disabilities can be found in all important laws adopted by the National Assembly. Almost every legal act in at least one of its paragraphs talks about some right of persons with disabilities. In addition to the national legislation, the position of persons with disabilities is governed by international conventions ratified by our country, making them part of national law and as such can be applied directly. The most significant document of international law is the Convention on the Rights of Persons with Disabilities, the first human rights instrument adopted by the United Nations in the new Millennium. Of the regional, European documents, the revised European Social Charter

is particularly important. Article 15 of the Charter guarantees to persons with disabilities the right to independence, social integration and inclusion in the community.

Through the establishment of the *Sector for Protection of Persons with Disabilities* at the then Ministry of Labor, Employment and Social Policy in 2004, (currently the Ministry of Labor, Employment, Veteran and Social Affairs) people with disabilities had finally gained an equal partner whose primary task is to protect and improve their situation through cooperation with organization for and of persons with disabilities, and directly with persons with disabilities. This Ministry is responsible for social protection policy and for development and delivery of services to the population, including to persons with disabilities, with the objective of ensuring their full participation in society.

The National Organization of Persons with Disabilities of Serbia (NOOIS) plays a particularly important role in the partnership between the Department for Protection of Persons with Disabilities and organizations of and for persons with disabilities. NOOIS is an umbrella organization that represents the interests and needs of all persons with disabilities and their legal representatives, works to increase the inclusion of persons with disabilities in society, ensure full respect for their human rights and non-discrimination based on disability, through participation in the enactment and application of laws and other documents in the field of disability, in accordance with international standards and documents.

In this Guide (fourth, revised edition) information can be found on the rights of persons with disabilities and conditions for their realization, including in social protection, health care, protection of children and family, education and upbringing, employment and working relations,

²⁹ The document was prepared by the Ministry of Labor, Employment, Veteran and Social Affairs of the Republic of Serbia, Sector for Protection of Persons with Disabilities. Original in Serbian is available at: <https://www.minrzs.gov.rs/sites/default/files/2021-02/Vodic%20kroz%20prava%20osoba%20sa%20invaliditetom.pdf>. What is presented here is an abbreviated version with focus on provisions relevant to children with disabilities. The original was abbreviated and unofficially translated by Aleksandra Posarac. Important Note: The guide seems not to have been updated since 2015.

old age and disability social insurance, traffic, tax system, prevention of discrimination, etc. The guide aims to inform in an easy-to-understand manner both people with disabilities and all those who engage professionally and or officially with them.

2. Key legal acts regulating the rights of persons with disabilities

The rights of persons with disabilities are regulated by:

- The Constitution of the Republic of Serbia, ("Official Gazette of RS" no. 98/06),
- International documents relevant to persons with disabilities (general and specific),
- Laws and other regulations governing the realization of rights in different areas within our legal system (social protection, health care, protection of children and family, education and upbringing, employment and work/labor relations, old-age and disability insurance, transport, tax system, housing ...),
- Several documents are particularly important: (i) the Law on Prevention of Discrimination of Persons with Disabilities was enacted in 2006 ("Official Gazette of RS", no. 33/06); (ii) the Strategy for Improving the Position of Persons with Disabilities in the Republic of Serbia was adopted in 2007 ("Official Gazette of RS", no. 1/07). The Strategy was accompanied by the Action Plan for its Implementation of the Strategy for Improving the position of Persons with Disabilities in the Republic of Serbia until 2015. (iii) an umbrella law, the Law on Prohibition of Discrimination was adopted in 2009 ("Official Gazette of RS", no. 22/09).

Constitution of the Republic of Serbia

The Constitution of the Republic of Serbia ("Official Gazette of RS", no. 98/06), as the highest legal act in the Republic of Serbia prohibits any discrimination, including discrimination against persons with disabilities.

Before the Constitution and the law, everyone is equal. Everyone is entitled to equal legal protection, without discrimination. The Constitution prohibits direct or indirect discrimination, discrimination on any grounds, especially based on race, gender, nationality, social origin, birth, religion, political or other beliefs, wealth, culture, language, age, mental or physical disability.

Freedoms and rights are exercised, and duties are fulfilled under the Constitution, except when the Constitution stipulates that the conditions for exercising certain freedoms and rights are determined by law.

The law can prescribe a way of exercising certain freedoms and rights when necessary for their realization.

The abuse of freedoms and rights of humans and citizen is unconstitutional and punishable, as required by law.

The Constitution ensures legal protection of freedoms and rights it guarantees.

The Constitution stipulates that:

- Everyone has the right to health care.
- Children, pregnant women, and older adults are entitled to public health care, if they are not covered by other health insurance arrangements.
- Everyone has the right to work.
- The freedom of work, and a free choice of occupation and employment, including in government jobs, are guaranteed. Everyone should have equal access to jobs.
- Citizens who are partially able to work should be provided training and support for finding an appropriate job, in accordance with the law.
- The state should support citizens who are unable to work and cannot support themselves.

3. Social Protection

In March 2011, the National Assembly of the Republic of Serbia adopted the Law on Social Protection ("Official Gazette of RS", no. 24/11). Social protection, in terms of this law, is an organized social activity of public interest whose objective is to assist and empower individuals and families for independent and productive life in the society, as well as to prevent the occurrence and to remove consequences of social exclusion.

Article 3 of this Law defines social protection goals, including creating equal opportunities for independent living and encouraging social inclusion. The goals of social protection are achieved by providing social welfare services and

other activities that prevent, reduce, or eliminate the dependence of individuals and families on social services.

Every individual and family in need of social assistance and support to overcome social and life difficulties and create conditions for meeting basic life needs are entitled to social protection, in accordance with the law.

Social welfare services are activities of supporting and assisting the individual and family (hereinafter: the user) to improve, or preserve the quality of life, eliminate, or mitigate the risk of adverse life circumstances, as well as to create opportunities to live independently in society.

Income support measures are provided to ensure minimum living standard and to support social inclusion of users.

The rights to social protection are realized through provision of social welfare/care services and income ("material") support.

The Law regulates that social protection entities can be founded by the state, the autonomous region and local self-government bodies, as well as natural and legal persons who meet legal requirements, thereby affirming the pluralism of social protection providers. However, only local self-governments can establish centers for social work; and only the Republic and the autonomous province can establish an institute for social protection.

The Law stipulates that the human rights and dignity of the users of social protection services must be respected (Article 24) and prohibits their discrimination (Article 25), including based on disability. Services must be provided in the least restrictive environment (Article 27), to enable the user to stay in her/his local community. The provision of social protection services must be organized in a way that ensures that they are near the users, while also considering cultural and other diversity. Social protection services must be provided following individualized approach and principles of case management (each case is assigned to a social worker).

The beneficiary of social protection services is entitled to:

- Information,
- Participation in decision-making,

- Free choice of social protection service,
- Data confidentiality,
- Privacy,
- Grievance.

Article 40 defines the following groups of services:

1) *Assessment and planning of services* – an assessment of the situation, living conditions, family environment, needs, strengths and risks a user is experiencing; an assessment of guardians, foster care providers and adoptive parents; drafting of an individual or family plan for providing services and measures of legal protection and other assessments and plans.

2) *Day services in the community* – day care; help in the house; shelters and other services that support the users to stay in the family and community environment.

3) *Support services for independent living* – supported housing; personal assistance; training for independent living and other types of support necessary for independent leaving and active participation of users in society.

4) *Counselling, advice, therapeutic and socio-educational services* – intensive support services to families in crisis; counselling and support to parents, foster parents and adoptive parents; support to a family that cares for a child or an adult family member with developmental disabilities; preserving family relations and reuniting the family; counseling and support in cases of violence; family therapy; mediation; SOS phones; activation and other advisory and educational services and activities;

5) *Accommodation services* – placement with relatives, foster or other family for children, adults and the elderly, placement in residential care, shelters or other types of accommodation.

The Law, for the first time in Serbia, introduced *support services for independent living*: housing with support, personal assistance, and training for independent living.

Article 41 defines *beneficiaries of social welfare services*. Among minors, particularly noted are children and youth with developmental difficulties – physical, sensory, intellectual, mental, speech, communications, socio-emotional, multiple

difficulties – whose needs are bigger than capacity of their families to meet them. Among adults, the Law specifies adults whose well-being and productive life are affected adversely by their disability, in particular if they have physical, sensor, mental, communication and other difficulties who “due to social and other barriers experience functional limitations in one or several domains of functioning and life activities”. *This legal definition is based on the biopsychosocial model of disability.*

Social welfare services are organized as (I) services for children, youth, and family, and (II) services for adults and older users. Service delivery must respect the integrity, stability of connections and environment of users and family. Services are provided temporarily, periodically, and continuously, in accordance with the users’ needs and best interest.

Daycare services in the community include activities that support the users to remain in the family and immediate environment (Article 44). These services are provided by the local government unit.

Services supporting independent living are provided to the individual to equalize her or his capacities to meet basic life needs with those of other members of society, in order to improve her/his quality of life and enable her/him to live independently in society (Paragraph 1, Article 45).

The Law regulates conditions for placement, including in small home units.

Placement service is provided by accommodating users:

- In kinship, foster and other types of families,
- In residential care facilities, including small home units,
- In shelters,
- In other types of accommodation, in accordance with the law.

Accommodation services are provided by the Republic of Serbia, the autonomous province and a local self-government unit, in accordance with this Law.

Placement in residential care facilities is provided to users for whom the family care, placement in the family and services in the community cannot be provided or this is not in her/his best interest.

Children under three years old cannot be placed in residential care, except in extreme circumstance and justifiable situation. Even in such cases, the child cannot spend more than 2 months in residential care. To extend the stay, a consent from the Ministry responsible for social protection is needed.

The placement and stay in a residential care facility should be used to prepare the user for her/his return to biological family, placement with other family or independent living, in accordance with the family resources and the users’ needs and best interest.

Residential placement can be:

- standard residential care,
- residential care with intensive or additional support services,
- emergency placement,
- temporary placement,
- other types of residential facilities.

Details on residential placement are regulated in an act issued by the minister in charge of social protection.

Residential care can be provided only by service providers licensed for this type of service.

A home for working age and older adults cannot have a capacity bigger than 100 residents; a home for children and youth cannot have a capacity over 50 residents.

Article 61. of the Law envisages that services for developing work skills and providing employment opportunities can be provided in social care institutions and *work centers* (“radni centar”) in accordance with the provisions of the Law on Professional Rehabilitation and Employment of Persons with Disabilities.

If social protection institutions established by the Republic, the autonomous province or local self-government are not capable of providing social welfare services on a needed scale, such services can be contracted out to licensed private sector service providers (Article 64) through a public procurement process. The purchaser of services must consider the cost and quality of services, while also taking into account the interests of user; the service provider must respect the quality standards of the services (Article 66).

The administrative procedure for accessing services (an assessment and eligibility determination) from this Law is carried out by a responsible center for social work (CSW) as part of its official duties, or at the request of a user. The request for services can be submitted by any natural or legal person. CSWs cover specific territory and serve its residents. CWSs refer user to services provided by the Republic of Serbia or the autonomous province, or authorized service providers whose services have been procured by local self-government units and with whom the service contract was concluded. If an authorized service provider refuses to provide services to a referred user, it is obliged to notify the SWC and the user immediately, in writing, and to provide reasons for the refusal.

A person/her or his legal representative may also independently choose the social welfare service and the provider, and conclude an agreement with it, except in the case of following services: 1) residential placement for a child; 2) residential placement for adults deprived of legal capacity; 3) residential placement for children and youth in an institution for child upbringing; 4) family placement, except in cases stipulated by law.

An appeal against the decision on the provision of the social welfare service should be submitted to the service provider: a responsible self-government, the autonomous province, or, if the provider is the Republic of Serbia, to the ministry in charge of social protection.

Material support is provided through:

- social assistance in cash,
- allowance for assistance and care by another person,
- increased allowance for assistance and care by another person,
- allowance for training,
- one-time assistance in cash,
- assistance in kind or other types of assistance.

Eligible to receive material support are individuals or families whose income from various sources falls below the threshold determined by the Law.

The family, in the context of eligibility to material assistance is defined to consisted of spouses (including in civil union – not formally married),

children (both biological and adopted), a first and a second cousins, provided they live in a common household. A work capable person, or a family member taking care of own child with developmental disabilities is entitled to material assistance, despite being capable of work. An individual who is incapable of working, a family whose all members are incapable of working and a single parent are eligible to receive an increased amount of social assistance. The Law specifies that the following individuals entitled to an increased amount of social assistance:

- a person who is completely incapable of working according to labor regulations and pension and disability insurance rules,
- a pregnant woman and a parent of a child on maternity leave, or absent from work for the care of the child, according to labor regulations,
- an unemployed person who cares for a family member who is a beneficiary of assistance and care on any grounds,
- a person with certified third degree of work ability in accordance with regulations governing the employment of persons with disabilities,
- a person undergoing a work capacity assessment process or a deprivation of business ability process – while the procedure is ongoing.

Eligible to assistance and care by another person is a person who due to bodily or sensory impairment, intellectual difficulties or changes in the health condition needs the help and care of another person to perform basic life activities (Article 92, Item 1). Specifically, the need for assistance and care by another person exists when a person who due to bodily impairment, impaired sense of vision caused by the loss of sense of light and/or needs correction of 0.05, intellectual difficulties or changes in the health condition needs help and care of another person to meet basic life needs and who cannot get out of bed, move inside the apartment without the use of aids, and is not able to eat, dress/undress, and maintain basic personal hygiene without the help of another person (Article 92, Item 5).

The right to assistance and care by another person is realized following the procedure prescribed by the regulations on pension and disability insurance.

Eligible to increased assistance and care by another person is a person who has been assessed as

having 100 per cent bodily impairment on one count, under the pension and disability insurance regulations, or to have permanent neurological or psychological disorder (Article 94). Eligible is also a person with multiply impairments, provided that two are assessed as at least 70 percent.

The Law envisages that one of parents – not employed and who has for at least 15 years taken care of a child receiving the increased allowance for assistance and care by another person, is entitled to a lifetime special monthly allowance equal to the amount of the lowest pension in employee pension insurance, once he/she has reached general retirement age and provided that she/he does not otherwise qualify for an old-age pension.

Social assistance, and allowance and increased allowance for assistance and care by another person are demand-based forms of social assistance. The procedure to acquire them can be initiated by persons themselves or by responsible government agencies. These benefits are administered by centers for social work established for the territory in which the applicant resides.

The right to assistance for training for work includes support for education and training for work.

Eligible to receive it are children and young people with developmental disabilities and adults with disabilities who, according to their psycho-physical abilities and age, can be trained for certain work, but cannot realize that right on other legal grounds. The assessment of the need for additional support in education is carried out in accordance with regulations governing the education system, and the assessment of the ability to work is determined by regulations governing professional rehabilitation and employment of persons with disabilities.

This assistance covers the cost of training, the cost of accommodation in the student dormitory, and transportation costs. The training cost is paid to a company for professional rehabilitation and employment of persons with disabilities, or another organization in which the person is trained. The payment is made based on the contract concluded by a responsible CSW with the company. The accommodation in a dormitory/boarding school is paid based on a contract concluded by a responsible CSW with the accommodation provider. Both contracts require an opinion from the ministry responsible for social protection. A person referred to the training for work who needs transportation from the place of residence to the place of training is entitled to compensation

for transportation costs in the amount of the lowest price of public transport.

The Rulebook on Conditions and Standards for the Provision of Social Welfare Services ("Official Gazette of RS", No. 42/13) defines conditions and standards for the provision of all social welfare services (hereinafter: minimum standards). The conditions and standards must be obeyed by all social welfare service providers. The Rulebook specifies the following concerning the services:

1. the purpose of the service,
2. users for which the service is intended,
3. activities to be undertaken to meet the needs of certain user groups.

Minimum standards are basic requirements that must be met for the social welfare services to be provided. They comprise:

- minimum "structural" standards, which establish requirements concerning needed infrastructure (premises), human resources and other organizational requirements to provide the service,
- minimum "functional" standards, which determine the technical value, content, and quality and quantity of professional procedures and methods.

Common minimum structural and functional standards are requirements that must be met independently of the user groups for which the service is intended. The Rulebook defines in more detail the common minimum structural requirements in terms of public disclosure, location of the building and equipment, hygiene requirements and maintenance, disposal of toxic and other materials, smooth/undisturbed service flow, etc. The common minimum functional standards cover user admission, client assessment, degree of support, etc. The degree of support is determined considering the overall individual functioning of users and the types of assistance needed, in relation to (1) the ability to take immediate care of oneself, and (2) participation in the activities of life in the community.

First Degree Support: A person is not able to take care of herself/himself and participate in activities of daily life in the community; she/he needs physical presence and continuous help from another person.

Second Degree Support: A person can take care of herself/himself and engage in activities of daily life in the community with the physical presence and assistance from another person.

Third Degree Support: A person can take care of herself/himself and engage in activities of daily life in the community, but due to insufficient knowledge and skills she/he needs the supervision and support from another person.

Fourth Degree Support: A person can perform all life activities on his own independently/ or with reminders.

Based on identified needs, capabilities and risks, *an individual service plan* is prepared for each user. The plan must contain:

- objectives to be achieved by providing the service,
- expected outcomes,
- concrete activities/interventions to be undertaken, including activities in the process of adjustment,
- a timeframe in which the individual service plan is to be implemented,
- the deadline for reviewing and revisiting the individual service plan,
- names of the persons responsible for the realization of the individual service plan.

The service plan review is carried out in accordance with the deadlines set out in the individual service plan, the estimated intensity of support, defined goals and outcomes. The review enables all parties concerned to monitor progress and to customize activities to the needs and objectives of the user and to enable better outcomes for the user. The plan review is carried out: at least: 1) once every six months, for children and youth, and 2) once every 12 months, for adults and older users.

Restrictive procedures and measures in the case of users who put themselves, other users, staff, visitors or property at risk by their behavior can be envisaged and applied only on the basis of planned, monitored, supervised and time-limited interventions, in accordance with a special regulation. For any restriction of movement, isolation or control of user behavior, a service provider must define procedures, appoint a person

responsible for restrictive procedures and measures and keep records of their application, in accordance with special regulation.

The service provider provides programmatic interventions, which must be specially tailored to the capabilities and interests of users. If the service provider is not able to provide certain activities, it should provide them in the community in collaboration with other organizations, or by engaging experts of different profiles, in accordance with the identified needs of the users and their individual service plans.

Placement in residential care is temporarily provided to children and youth until the completion of schooling and work training up to the age of 26.

Residential placement is provided to children and young people whose needs cannot be met in a biological, kin, or foster family or through services in the community. The placement is based on a decision of the guardianship body or the court upon referral from the responsible CSW. The placement can last until the child/ young person returns to a biological family, is placed in a kinship or foster care, is adopted or becomes independent. A child under three cannot be placed in residential care, except in cases specified in the law governing social protection.

Residential placement is provided to adults and the elderly:

- 65 years of age or older in cases when they have difficulty living on their own, without all-day support, care, or supervision, and
- 6 years of age or older, who due to physical, intellectual or difficulties in psychological functioning need intensive all-day supervision, and care and support for 24 hours, and whose needs cannot be met in a family environment or through services in the community.

Residential placement in small residential institutions is provided to:

- children and youth with the third and fourth degree of support, for no longer than until the end of secondary education, and
- children and youth with the first and second degree of support.

Respite service is provided for a maximum of 45 days during the calendar year (an up to continuous 20 days), for children and young people with developmental disabilities aged five to 26 years of age: 1) with intellectual difficulties and autism; 2) with multiple developmental disabilities; 3) with sensory disability; and 4) with physical disability.

The purpose of respite care is short-term and periodic residential placement of a child with developmental and other disabilities (could be day care, over the weekend or up to 20 days continuously), providing support to both the child and her/his family, in maintaining and improving the quality of their life with the aim of keeping the child in the family.

Services provided in residential care:

1. *Assistance and support activities provided in residential care institutions are aimed at meeting the basic needs of users, while ensuring safe and pleasant environment for them, in accordance with to the assessment of their individual needs. They include:*

- nutrition in accordance with the development and health needs of users,
- help with dressing/undressing and changing clothes,
- help with feeding and personal hygiene (showering and bathing),
- help with movement,
- help maintaining oral hygiene, and hygiene of feet and nails,
- help with shaving and hair trimming,
- help with maintaining bed and space cleanliness,
- following prescribed therapy,
- help and care in the case of minor injuries,
- control and monitoring of vital functions (blood pressure, body temperature, sugar level, etc.),
- purchase of age and season appropriate clothing and footwear,

- help with decorating personal space reflecting individual tastes and the wishes of the user,
- sufficient living space and equipment that enables the user to have privacy,
- cleaning of common areas, rooms, and related sanitary facilities,
- washing and ironing of bedlinen,
- washing and ironing of personal laundry,
- help with tidying the area in which the users reside and with caring for personal possessions,
- accompanying the users to visit a doctor or conduct other business outside their residential institution.

2. *Activities aimed at developing and preserving the potential of the user, as well as at the preparation for a sustained independent living are implemented in accordance with the purpose of the residential placement, users' group characteristics, individual capacity, and individual service plan. In accordance with the individual needs assessment, activities can be individual and group activities:*

- support to build and maintain positive relations with other persons in the environment,
- organization of occupational, work, and educational activities that encourage the acquisition of new knowledge and skills,
- support in maintaining contact with the biological family and other persons important to the user,
- organizing leisure time in accordance with the needs and interests of the user,
- organizing cultural and entertainment activities in accordance with the interests, desires, and abilities of users in and outside the institution,
- development of problem identification and solving skills,
- development of communication skills,
- development of skills for self-protection,

- development of skills and knowledge needed for life and work outside the institution,
 - rehabilitation and therapeutic services,
 - help to strengthen and maintain acquired knowledge and skills.
3. Activities aimed at supporting education and employment, in accordance with the user's capacities and assessment of user's needs, include:
- assistance to start and continue education,
 - assistance in seeking employment opportunities within the community,
 - motivation and other support in the early days of new employment.

The *Rulebook* defines in more detail the common minimum "structural" standards for residential institutions, small residential homes, respite care facilities and shelters for: accommodation, nutrition, food service, maintenance of hygiene, basic staff complement, common living area, celebration of birthdays and holidays, availability of service 24 hours a day every day of the year. For example, for adults and older adults placed in residential care, the staff complement is defined as:

Adults with intellectual disabilities and mental illness: one professional worker or one professional associate per 25 residents, and one caregiver per ten users with established First or Second Degree of Support, and one instructor per workshop.

Adults with physical disabilities: one professional worker or one professional associate per 40 users, one caregiver per ten users with determined First or Second Degree of Support, and one instructor per workshop.

The *Rulebook* separately specifies minimum "structural" standards for institutions accommodation children and youth. The minimum standard for staff complement is defined in the following way:

Children and youth with intellectual difficulties: one professional worker or one professional associate per 15 residents and one caregiver (nurse) per ten residents with established First or Second Degree of Support.

The *Rulebook* also defines *minimum standards for small residential care institutions* (i.e., family like institutions) for children and youth with the Third and Fourth Degree of Support: up to 10 children can be housed in the housing unit with up to three residents per room. The size of the housing unit should be at least 12 square meters per resident. The housing unit must have living area, kitchen, and separate bedrooms for boys and girls. One bathroom should be provided per 5 residents. The bedrooms, a living room, the kitchen, and toilets should be cleaned daily with the participation of residents. The minimum number of skilled workers and professional associates directly engaged in working with users is determined as follows: (i) day shift – five skilled workers or professional associates per two small homes; (ii) night shift – a professional worker or professional associate per two small homes.

For the users with the established First and Second Degree of support, the *Rulebook* defines the following minimum standards for small homes: maximum of 12 users per home and 3 per bedroom, 6 users per one toilet. Users are assigned to rooms taking care of their individual characteristics and needs. The rooms should be equipped with at least beds and wardrobes for each resident. For users with mobility difficulties, appropriate accommodation equipment should be provided. The screens must be provided to protect privacy during assistance with personal hygiene and needs. Users are provided with support in maintaining personal hygiene in accordance with the estimated level of support. A separate room must be provided for educational and occupational activities, with needed didactic and other material, in accordance with the needs and interests of residents. The minimum staff complement per home is defined as follows: four professional workers or professional associates and six nurses. The nightshift must have at least two staff members.

The *Rulebook* also defines minimum structural and functional standards for respite care services.

Day care services are (also) available to: (1) children and youth with physical and intellectual difficulties in need of daily care and supervision, and support in maintaining and developing their potential, in a way that does not impede their education; and (2) adults with physical and disabilities who need daily care and supervision, and support in maintaining and developing their potential.

The day care service purpose is to improve the quality of life of users in their own social environment through maintaining and developing social, psychological, and physical functions and skills, to make them as capable of independent living as possible. Activities carried out during the day care service are aimed at developing and preserving the potential of users and preparing them for sustained independent living. Day care service activities are tailored according to the defined purpose of the service, user group characteristics, user capacity, and individual plan, in accordance with the assessment of the needs of the user. Activities may include:

- support in building and maintaining positive relationships with adults and children,
- support in learning, and maintaining and developing contacts with relevant local self-government units,
- organizing occupational and educational activities, which encourage the development of new knowledge and skills,
- encouraging users' participation in community activities,
- organizing leisure time in accordance with the needs and interests of users,
- organizing appropriate cultural and entertainment activities and enabling users to attend activities in the community,
- development of skills for recognizing and solving problems,
- development of communication skills,
- development of skills for self-protection,
- development of skills and knowledge needed for life in the community,
- rehabilitation and therapy,
- program activities of the child's personal companion, in accordance with the provisions of the Rulebook.

The minimum standards pertaining to the minimal number of skilled workers and associates directly engaged in working with the users attending the day care services is as follows: (i) for children and youth with physical and intellectual difficulties –

two professional workers and one associate for capacity of up to ten users; one professional worker for every additional five beneficiaries and one associate for every additional ten users; (ii) for adults with physical and intellectual difficulties – one professional worker and two associates for capacity of up to ten users; one associate for every additional five users and one professional worker for every additional ten users.

Services at home are provided to children, adults and older adults who are experiencing limitations in physical and mental capacity due to which they are incapable of living independently in their homes without regular assistance to carry out activities of daily living and care and supervision by others, in situations when family support is insufficient or unavailable. Services at home include help with:

- nutrition, including grocery shopping, ordering prepared food, preparing light meals, preparing refreshing beverages, help with eating,
- personal hygiene and house cleaning, including help with dressing and undressing, physiological needs, washing, bathing, washing hair, combing, shaving, cutting nails, washing bedlinen, taking care of clothes and footwear, cleaning the house, washing dishes, cleaning house appliances,
- house heating, including lighting fires, cleaning the furnace, helping to get firewood,
- assistance to satisfy social, cultural, entertainment, and other needs, including assistance in moving inside and outside the house, purchase of newspapers and books, initiating social contacts and engaging users in appropriate cultural activities in the local community, help with payment of electricity bills, telephone, utilities, etc.,
- help with ordering services such as plumbing, repair of electrical and other installations, TV repair, repair of house appliances, house painting and other services,
- purchase and monitoring of drug taking and following medical advice, taking the user to medical appointments, etc.
- minor injuries care,
- control of vital functions (blood pressure, body temperature, blood sugar levels, etc.),

- program activities for the child's personal companion, in accordance with the provisions of the Rulebook.

Services at home are carried out by a housekeeper with completed training under the accredited home assistance program. The housekeeper carries out activities in accordance with the individual plan of the service.

Personal companion to a child with a disability is available to a child with a disability attending school who needs support to meet basic needs in everyday life – to move, maintain personal hygiene, eat, dress and communicate with others, etc. The services of a personal companion are available until the end of regular schooling, including the completion of high school. The purpose of this service is to provide the child with appropriate individual support to engage in regular education and community activities, and to achieve as high a level of autonomy as possible. The services provided by a personal companion are planned and implemented in accordance with the individual needs of the child in the area of movement, maintenance of personal hygiene, feeding, dressing and communication with others. They may include:

- *help at home:* with dressing, maintaining personal hygiene (washing, combing hair, brushing teeth), feeding (preparing and serving lighter meals, feeding, or helping to use utensils, etc.), preparation of books and equipment for kindergarten or school,
- *help in the community,* including: (i) assistance in the use of public transportation, (ii) help with movement (space orientation if the child has visual impairment, pushing a wheelchair or using other aids, etc.), (iii) taking/accompanying a child to playgrounds or places to spend free time (support in the game, support, and mediation in communication, etc.), including cultural or sports activities and other support services.

The service provider is required to have at least one professional employee. The service is provided by an associate – a personal companion of the child. The professional worker and a personal companion must complete training under the accredited program for providing personal companion service.

The supported housing service (or supported independent living) is a long-term service available to persons with physical, intellectual, or mental

disabilities once they have reached the age of 15. The purpose is to assist and support people with physical, intellectual, or mental disabilities in gaining as much independence as possible and enable them to live a better quality of independent life in the community. The activities included in this service are realized according to the purpose of the service, user group characteristics, user capabilities, and individual service plan, all in accordance with the assessment of the needs of the user. They may include:

- support to establish and maintain positive relations with persons in the environment,
- organizing occupational and educational activities that encourage the acquisition of new knowledge and skills,
- mastering practical skills, which are used in everyday life, especially those skills related to food preparation, maintenance of personal hygiene and house cleaning, household management, knowledge and use of community resources, etc.
- support in the development of autonomy in decision-making and taking responsibility,
- assistance in house maintenance and taking care of personal belongings,
- organizing leisure time in accordance with the needs and interests of users,
- organizing entertainment activities in accordance with the interests, desires and abilities of users,
- development of skills for recognizing and solving problems,
- development of social and communication skills,
- development of skills for self-protection.

The size and structure of the housing unit must ensure smooth performance of basic life functions: sleeping, dining, living space, and maintenance of personal hygiene. The housing unit can house a maximum of six users (and a maximum of two per bedroom). The service provider must have at least one professional employee, responsible for organizing and coordinating service provision for at least three housing units. Each user must have a professional

counselor for independent living. The Rulebook stipulates the following minimum standard for the staff complement: one professional worker – consultant for eight to ten beneficiaries and one caregiver per four users.

Personal assistant services are available to adults with disabilities with determined First or Second Degree of Support, who are eligible to receive an increased amount of allowance for care and assistance by others, can make decisions on their own, are working or are actively involved in different citizens' associations, sports societies, political parties, or other forms of social engagement, or are enrolled in regular or individual educational programs. The purpose of this service is to provide individual support that the user needs to meet personal needs and engage in educational, work and community activities, in the way of establishing as high a level of independence as possible. The services of a personal assistant may include:

- help to maintain personal hygiene and satisfy basic personal needs (dressing/ undressing, performing physiological needs, bathing, washing hair, grooming, etc.),
- help with house cleaning and to perform basic activities of daily living (grocery shopping, meal preparation, feeding, house cleaning, etc.),
- help with mobility (moving inside and outside the user's house, workplace, and place where social and educational activities take place, assistance in the use of transportation),
- assistance in the use of therapeutic and health services and use and maintenance of aids,
- assistance in communication, social contacts and satisfying social, cultural and entertainment, and other needs,
- help with various work, educational and social activities.

Based on identified needs and available resources, the service provider and the user determine the scope and type of personal assistant services. The service provider compiles a list of potential personal assistants based on defined criteria and procedures for recruitment, selection, and basic training of personal assistants. The service provider concludes the service agreement with the user and the

personal assistant. The contract regulates rights, obligations and responsibilities of parties concerned and, if necessary, the role of a family member or other person important to the user.

The service provider must employ at least one professional. The service is provided by an associate – personal assistant. The personal assistant must complete basic training under the accredited training program for personal assistant services. The user is also required to complete training on using the personal assistant service. As a rule, one personal assistant provides service to one user. She/he cannot be a member of the user's family/household, her/his sibling, or a first-degree cousin. The personal assistant services cannot be less than 20 or more than 40 hours per week, according to the estimated needs and capabilities of the user, in accordance with the law governing working relations. The service provider, service user, and personal assistant may agree to redistribute the working hours of the personal assistant, according to the individual needs of the user, in accordance with the law governing working relations.

The service user and her/his personal assistant prepare an individual weekly and monthly work schedule. Depending on the estimated capabilities of the user and her/his family, the individual service plan defines activities to be conducted. A parent or other important person for the user may participate in the development of a weekly and monthly work plan.

The Rulebook on Licensing of Social Welfare Organizations ("Official Gazette of RS"; No. 42/13) regulates conditions for issuing a license, license form, and manner of issuance, renewal, suspension, and revocation of license. It also regulates the management and content of the *Registry of Licensed Social Welfare Providers*.

The Law on Social Housing ("Official Gazette of RS"; No. 72/09) regulates conditions for sustainable development of social housing and how to provide and use funds for the development of social housing, as well as other issues of importance for social housing. Funds for social housing are used *inter alia* to encourage different forms of social and supported housing for persons with disabilities. Eligibility requirements include lack of appropriate housing and no income to acquire it. Disability is listed as one of priority criteria for access to social housing.

4. Legal and financial protection of the family

Family protection is regulated by *the Family Law* ("Official Gazette of RS"; No. 18/05, 72/11 and 6/15) and by *the Law on Financial Support for Families with Children* ("Official Gazette of RS"; No. 113/2017, 50/2018, 46/2021).

The rights stipulated by these two laws are realized through a CSW and other related offices of the local government on the territory of the municipality where the beneficiary resides.

The Law on Financial Support for Families with Children provides for the following types of financial support to families with children:

- salary compensation during maternity leave, absence from work to care for a child and absence from work for special care of a child,
- parental allowance,
- child allowance,
- Compensation for the cost of a preschool for children with developmental difficulties.

Salary compensation: Eligible to a *salary compensation* are employed/self-employed parents, adoptive parents, guardians, and foster parents on maternity leave or leave from work under the labor regulation. The amount of compensation is equal to 100% of the monthly salary prior to the leave (but with the ceiling of 5 times the average salary in Serbia), on condition that the person had contiguously been employed for 6 months prior to the leave. For those employed for 3-6 months prior to the leave, the compensation is 60% and for those who had been employed for up to 3 months, it is 30% of the salary prior to the leave.

Parental allowance: Eligible to receive the parental allowance is a mother for her second, third and fourth child, on condition that she is a citizen of the Republic of Serbia, has residence in Serbia and is covered by the public health insurance scheme. The mother is also required to take care of the child for whom she has applied to receive the supplement, that her other children are not placed in residential care, for adoption or with foster parents, and that she had not been deprived of parental rights in the case of her other children.

Child allowance: Eligible to receive the child allowance is one of the parents for up to four

children (own, foster children or children under their guardianship), on condition that she/he takes care of the child/children, is a citizen of the Republic of Serbia, has residence in Serbia and is covered by public health insurance scheme. The child's allowance can be received by a child up to the age of 19 if she/he is attending school. The duration can be extended to up to the age of 26 if a child with a disability is in regular education or work training, as well as for a child with a disability for whom the parents got their parental rights extended until the child is 26 years old. The allowance is increased by 50 percent for a child with a disability if she/he lives with parents and is receiving the allowance for care and assistance by others (Article 33).

Compensation of the cost of the preschool education is another measure to support children with developmental disabilities.

Two areas regulated by the Family Law, particularly relevant for persons with a disability are: Parental rights and Rights to support.

Parental rights

Parents have the duty and right to look after their child, to look after him, raise him, educate, support, represent and manage and dispose of his property.

Parental rights can be extended even after the age of a child if it is due to illness or interference in psycho-physical development, unable to take care of itself and the protection of their rights and interests, or if by its actions it endangers its own rights and interests.

The decision to extend parental rights is made by the competent court in an out-of-contest proceeding at the suggestion of the parent or custody body. In the same decision, the court will determine whether the person over whom parental rights are extended is equated with a minor younger than 14 years of age.

The proposal for extending parental rights is submitted before the child's age, but the court may extend parental rights even when the proposal was not submitted in a timely manner, if there were reasons for extending parental rights at the time of adulthood.

Decisions on deprivation, return, extension and termination of extended parental rights will be entered into the birth registry, if the person has real estate in both land and other public records of real estate.

When the reasons for extending the parental right of an adult are terminated, the court will, at the suggestion of that person, parent or custody body, decide on the termination of extended parental rights.

Right to support

The right to support is one of the rights under the Family Law and implies the implementation of certain measures in the interest of the person to whom a certain form of protection is provided according to the provisions of this Law.

A spouse who does not have sufficient funds to support, is unable to work or cannot get a job, is entitled to support from his spouse in proportion to his abilities.

Parents are obliged to support their underage children.

If the child has not completed his education by the time he reaches adulthood, parents are obliged to support him according to their abilities until the end of the time of school in the appropriate school or university, and if the education for reasonable reasons is extended no later than the age of 26.

If an adult child is unable to work and does not have sufficient means of support, parents are obliged to support him while the condition persists.

If the parents of a child unable to work who does not have sufficient means of support have died, or do not have enough property to support him, the obligation to support them moves to the blood relatives of the child in a straight line, according to their possibilities.

Children are obliged to support their parents who are unable to work and do not have sufficient funds to support themselves.

5. Health care

There are several laws and bylaws regulating health care that are relevant to persons with disabilities. All children up to 18 and school children up to 26 are covered by mandatory health insurance, irrespective whether they are insured through their parents or by the law. Persons with disabilities have the right to all forms of health care, adequate diagnosis, treatment and medical rehabilitation, including the provision of assistive devices and technical aids.

Health insurance rights:

- The right to health care
- The right to compensation of earnings during temporary disability (sick leave)
- The right to compensation of travel expenses related to the use of health care.

The right to health care

Health care and the health care system are governed by the Law on Health Care, which stipulates that citizens' rights to health care are realized in health care institutions, and that primary health care covers inter alia:

- children until the age of 15 (26 if in regular education),
- women related to family planning, pregnancy, childbirth, and motherhood up to 12 months after giving birth,
- persons older than 65 years of age,
- persons with physical and mental disabilities.

Health care includes:

- Prevention and early detection of diseases,
- Examinations and treatment of women related to family planning, during pregnancy, birth and motherhood 12 months after giving birth,
- Examinations and treatment in case of illness and injury,
- Examinations and treatment of mouth and teeth diseases,
- Medical rehabilitation in case of illness and injury,
- Medicines and medical supplies,
- Dentures, orthosis and other aids for movement, standing and sitting, eye support, hearing, speech, as well as other aids (medical and technical aids).

The following is not considered health care:

- medical examinations to determine the health condition, impairment and disability, except upon referral by a medical doctor to the relevant medical assessment commission,

- health examinations for enrollment in secondary and higher schools, faculties and courses, obtaining certificates for driver's licenses, for court and other disputes, and in other cases when the examination is not performed for the purpose of health care,
- examinations of employees sent to work abroad by organizations, as well as preventive health care measures for private travel abroad and health checks for these trips.

The health care is provided: (I) at the local clinic; (II) secondary health care (specialists, hospital treatment), upon referral from the primary care physician, and (III) tertiary health care, upon referral from a treating physician; (iv) medical rehabilitation, upon referral.

Insured persons are provided with 100% coverage for health care and no co-pay for services related to the examination and treatment of multiple sclerosis, progressive neuro-muscle diseases, cerebral palsy, paraplegia and tetraplegia, as well as for the procurement of medical and technical aids, implants and medical devices related to the treatment of mentioned diseases and injuries (Article 44 of the Law on Health).

War invalids, civilian disabled people from war, blind persons, permanently disabled persons and recipients of assistance by other people are covered by health insurance free of contributions and co-pay (Article 50 of the Law on Health Insurance).

Sick leave benefits

Covered are employees covered by mandatory health insurance, self-employed, and other economically active persons covered by mandatory health insurance.

Technical aids

Insured persons are provided with medical and technical aids that serve to functionally and aesthetically replace lost body parts, i.e., to enable reliance, prevent body deformities, correct existing deformities and facilitate the exercise of basic life functions.

Insured persons are provided with medical and technical assistance needed for treatment and rehabilitation that enables improvement of basic life functions, enables independent living, enables overcoming obstacles in the environment.

The Health Insurance Institute (Fund) of RS regulates types of medical and technical assistance, indications for their use, standards of materials from which they are made, expiration dates, procurement, maintenance, and other matters related to the provision of medical and technical aids. The regulation also includes a reduced/tax free regime for some of the technical aids.

The Rulebook on Medical and Technical Aids issued by the mandatory health insurance fund specifies the following types of aid (with or without co-pay): prosthetics, orthotics, special types of aids and sanitary devices, vision aids, hearing aids, aids enabling voice and speech, and dentures. Indications for prescribing aids are medical diagnosis established in accordance with the International Classification of Diseases – Tenth Review (hereinafter: ICD10), age or anthropometric measures (body weight; body height) of the insured person; number of aids prescribed for certain types of aids; housing conditions relevant for the use and proper application of certain aids (housing, electricity, water, hygiene level, level of mental capacity, smoking habits, etc.). The Rulebook also regulates quality standards for technical aids. To access the device/technical aid, the insured person must have a prescription issued by relevant medical doctor. The process is regulated in detail by the Rulebook, including relevant prescription forms and their validity. For some types of aid, an opinion of the territorial branch of the health insurance fund is needed. The Rulebook regulates separately procedure for acquiring technical aids for persons whose health condition is diagnosed as permanent (congenital deficiency of the extremities, congenital deformities, post-amputation of the extremities, quadriplegia, paraplegia, cerebral palsy, etc.). The Rulebook also regulates in detail conditions and procedure for maintenance, repair, and replacement of technical aids on the account of the health insurance fund.

The Decision on participation of insured persons in health care costs (co-pay rules) regulates the participation of users/co-pay for the use of health care services. Exemptions from the co-pay include:

- children and school children up to the age of 18,
- women during pregnancy and childbirth and 6 months after childbirth,
- war invalids and civilian disabilities of war,
- blind persons and permanently immobile persons (quadriplegia, paraplegia, etc.), as well

as persons who receive allowance for other people's care and assistance,

- insured persons with cerebral palsy, multiple sclerosis, progressive muscle diseases, epilepsy and psychosis are exempt from the co-pay under certain conditions.

The Patient Rights Act ("Official Gazette of RS"; no. 45/13) regulates patients' rights when using health care, manner of realization and manner of protection of such rights, as well as other issues related to the rights and duties of patients.

The Law on Protection of Persons with Mental Disabilities ("Official Gazette of RS"; no. 45/13) regulates basic principles, organization and implementation of mental health protection, manner and procedure, organization, and conditions for treatment and accommodation without the consent of persons with mental disabilities in residential and other health care facilities. The law stipulates that a person with mental disabilities is an insufficiently mentally developed person, a person with mental health disorders, or a person with addiction.

Mental health protection includes prevention of mental health disorders and disabilities, diagnosing of mental health issues, improvement of mental health, analysis and diagnosis of a person's mental state, treatment and rehabilitation of mental health disorders. Protection of persons with mental disabilities must be performed without discrimination on the basis of race, gender, birth, language, citizenship, nationality, religion, political or other beliefs, education, legal or social status, age, disability or any other personal characteristic. Discrimination on the basis of mental disabilities is prohibited. Any person with mental disabilities is entitled to humane treatment, with full respect for his dignity. Any abuse, neglect, exploitation, or degrading treatment of a person with mental disabilities is prohibited.

A person with mental disabilities is entitled to protection and improvement of mental health through prevention, care, treatment and psychosocial rehabilitation in appropriate health and other institutions, recovery and inclusion in the family, work and social environment, while respecting his choice. A person with mental disabilities is entitled to equal treatment conditions suitable for their health needs, under the same conditions as other health care users. A person with mental disabilities is entitled to treatment in the least restrictive environment, with the application of the least restrictive and forced medical procedures.

A person with mental disabilities is entitled to privacy, in accordance with his best interests. A person with mental disabilities is entitled to exercise civil, political, economic, social and cultural rights, in accordance with the Constitution and the law. The rights of persons with mental disabilities may be limited by this law and other laws, only when necessary to protect the health or safety of persons with mental disabilities or other persons. Health care professionals are obliged to organize the implementation of medical measures and the treatment of persons with mental disabilities who to the least extent limit their rights and freedoms, only when there is an absence of opportunities for another solution. No one can be forced to the evaluation of the health condition to determine the existence of mental disabilities, except in cases and under procedures stipulated by law.

The law details the procedure and methods of medical treatment of people with mental disabilities, including treatment without the consent of those persons. If a person with mental disabilities is unable to give her/his consent to the proposed treatment, and there is no legal representative or no requirement to obtain the consent of the legal representative, she/he may be subjected to a medical treatment without consent, exceptionally if: a treatment necessary to prevent a significant deterioration in health, medical treatment is aimed at restoring the ability to make a decision on consent to the proposed medical treatment, and to prevent endangering the life and safety of that person or the life and safety of others.

If a person with mental disabilities does not have a legal representative, the health care institution is obliged to notify the relevant guardianship authority and to propose to initiate proceedings for the establishment of a legal representative, in accordance with the provisions of the law governing family relations.

The law also regulates in detail voluntary placement of persons with mental disabilities in a psychiatric institution, as well as the retention and placement of such persons in a psychiatric institution without the consent of that person. A person with mental disabilities for whom a medical doctor or psychiatrist assesses that, due to mental disabilities, seriously and directly endangers his own life or health or safety, i.e., the life or health or safety of another person, can be placed in a psychiatric facility without his consent, only if less restrictive ways of providing health care are not available. The placement without a consent is decided by the court.

Data on health condition, i.e., data from medical documentation of persons with mental disabilities, are personal data classified as “particularly sensitive personal data”

Physical restraint and isolation of persons with mental disabilities who are placed in a psychiatric institution will be applied, exceptionally, when it is the only means to prevent this person from seriously endangering his own life and safety or the life and safety of other persons. The law regulates in detail the procedure and prescribes conditions under which physical restraint and isolation of persons with mental disabilities is allowed. The law also prescribes conditions for and procedures for electroconvulsive treatment of persons with mental disabilities and absolutely prohibits psychosurgery and sterilization of these persons.

6. Right to education

The Law on the Foundations of the Education System (“Official Gazette of RS”, 88/2017, 27/2018, 10/2019, 6/2020, 129/2021) is an umbrella law governing preschool, primary and secondary education in Serbia. All children have equal rights and access to education without discrimination, including based on disability.

In Article 8, the Law states that the key objectives of education and upbringing are to: 1. ensure well-being and support for comprehensive development of the child, pupil and adult, 2. ensure stimulating and safe environment for a comprehensive development of the child, pupil and adult, development of non-violent behavior and zero tolerance for violence, 3. ensure full intellectual, emotional, social, ethical and physical development of each child, pupil and adult in accordance to her/his age, developmental needs and interests.

Special attention is paid to ensure that children, students and adults with developmental difficulties and disabilities, regardless of their own social and material conditions, have access to all levels of education. ... Every person has the right to education and upbringing.

Citizens of the Republic of Serbia are equal in exercising the right to education and upbringing, regardless of gender, race, national, religious and

linguistic affiliation, income, social and cultural background, age, physical and psychological state, developmental disabilities and disability, political orientation or other personal characteristics.

Persons with developmental disabilities and disabilities are entitled to education and upbringing that respect their educational and upbringing needs in the regular system of education and upbringing, in the regular system with individual or group additional support or in a separate preschool (developmental) group or school, in accordance with this and other laws. The child aged 3 years until she or he starts primary education (6.5-7.5 years of age) is enrolled in the separate preschool (developmental) group or school based on the opinion of ISC and with the consent of the child parent or guardian.

Education and upbringing for persons who use the sign language can be performed in the sign language and by other means of that language.

Discrimination based on disability and developmental disability (or any other grounds) is prohibited in educational institutions. Two rulebooks were adopted,³⁰ regulating in detail what constitutes discrimination and discriminatory behavior, how to recognize it and what the procedures in such cases are. These are the first antidiscrimination legal documents that describe segregation and define it as an aggravated form of discrimination.

Primary education institutions (schools) realize education program and when relevant they pursue an individual educational plan for students and adults with developmental difficulties and disabilities.

Secondary schools realize programs of general, professional and arts education and, when pertinent, individual educational plan for students and adults with developmental difficulties and disabilities.

For a child and a student in need of additional support in education and upbringing due to social deprivation, disability and other reasons, educational institutions (schools) strive and take actions to remove physical and communication barriers to learning and participation in education

³⁰ The Rulebook on criteria to recognize discrimination of the child, pupil or third party by an employee of an educational institution and the Rulebook on what an educational institution must do in the case of suspected or confirmed discriminatory behavior and offense against the reputation, honor and dignity of the person.

and where relevant develop an individual educational plan.

The **Individual Education Plan** (hereinafter: IEP) is a special document that plans additional support in education and upbringing for a particular child and student, in accordance with its strengths and abilities. The aim of the IEP is optimal development of a child/ pupil, inclusion in the peer collective and achieving general and special outcomes of education and upbringing, i.e., satisfying the educational needs of the child. The IEP is developed based on previously realized and recorded measures of individualization and the elaborate pedagogical profile of the child/ student. IEP is made according to the educational needs of the child and can may include:

- adapting methods of teaching, as well as the teaching environment (IEP1),
- adaptation and modification of the curriculum, outcomes and standards of achievement (IEP2),
- enrichment and expansion of curriculum for children and students with exceptional abilities (IEP3).

IEP2 is preceded by the adoption, implementation and evaluation of IEP1, as well as the acquisition of the opinion of the responsible ISC.

Exceptionally, for a student following the IEP2, in addition to the curriculum, the learning plan can be adapted as well, based on the opinion of the responsible IC.

The IEP is adopted by the educational institution pedagogical board, based on the proposal from the schools' technical team for inclusive education, or the team for providing additional support to the child or student (the latter is formed for a specific child).

The team in a preschool consists of an educator, professional associate, associate, parent, or guardian, and, if needed, a pedagogical assistant and/or the child's personal assistant (companion), at the suggestion of the parent or guardian.

The team at the school consists of a class teacher or relevant subject teacher, a professional associate, a parent, or a guardian, and if needed, a pedagogical assistant and/or the child's personal assistant (companion), at the suggestion of the parent or guardian.

The parent or guardian must consent to the implementation of the IEP. During the first year of implementation, IEP is evaluated quarterly, and in each subsequent school year semi-annually. Implementation IEPs is monitored by the Ministry of Education and Upbringing. Detailed instructions on IEPs development, implementation and evaluation are provided by the Minister for education.

Students with developmental difficulties and disabilities take the final exam, in accordance with their motor and sensory abilities, i.e., conditions required by a certain type of disability. Students with developmental disabilities and disabilities pass the general graduation in accordance with their motor and sensory abilities, i.e., conditions required by a certain type of disability, and may be exempt from taking part in certain graduation exam subjects for which their standards of achievement had been adjusted during education.

A pedagogical assistant provides assistance and additional support to a group of Roma children and children with disabilities or students, in accordance with their needs. She/he also assists teachers, educators, and professional associates to improve their work with children or students who need additional educational support. She/he should cooperate with parents and guardians, and together with the school director cooperate with relevant institutions, organizations, associations and local self-government unit.

Article 54 of the Law stipulates that an educational institution can obtain the status of a resource center for professional support to children, pupils and adults with developmental disabilities and invalidity, to their families and other educational institutions. The resources center also extends its support related to the choice, purchase, and use of technical aids in educations and follows new developments in the area of support to children, pupils and adults with disabilities. Detailed conditions for obtaining the status of a resource center, organization of its work and abolishing the status are regulated by the minister for education with consent of the ministers for local self-government, health, and social protection.

Article 89 stipulates that a school for education of children and adults with disabilities, as well as other education institution where such children are enrolled are obliged to in accordance with their capacities provide additional support for the education of children and adults with disabilities in

developmental groups, other schools and families, as per criteria established by the minister for education.

Preschool education and upbringing

The system of preschool education and upbringing is regulated by the Law on Preschool Education and upbringing ("Official Gazette of RS", no. 18/10) as part of a single system of education and upbringing. The objective of the pre-school education and upbringing is to support comprehensive development and well-being of a pre-school child by providing conditions and incentives for the child to develop her/his capacities, expand experiences and develop cognition about oneself, others and the world. The key principles include equal and universal access to preschool education and upbringing, authenticity and a holistic approach to the child. Discrimination based on any form of difficulties and disabilities is prohibited. When enrolling children in a preschool founded by the Republic of Serbia, an autonomous province or local self-government unit, the priority for enrollment is given to children from vulnerable groups.

The preschool program should follow an individualized approach to learning and provide additional support to children, especially children with developmental disabilities, children in hospitals, children from disadvantaged socio-economic background, while respecting the developmental, educational, health and socio-cultural needs of children.

A parent is obliged to enroll child in preschool to attend a school preparation program, in accordance with the Law. The number of children with developmental disabilities enrolled in the developmental group is 4 to 6 children.

Children with developmental disabilities are eligible for preschool education and upbringing in the educational group, in the educational group with additional support and individual educational plan and in the development group, based on the individual educational plan, in accordance with the Law.

A preschool that has enrolled a child with developmental disabilities and identifies the need for additional educational, health or social support, sends a request for an assessment of needs to the child's physician at the local health care center, and to the local IC. There can be no more than two children in one educational group with developmental disabilities. The number of children

in the educational group, which enrolls one child with developmental disabilities, is reduced by three children compared to the number of children per group determined by this law.

Children with developmental disabilities can join the education group when enrolling. During the attendance of the preschool program the development of the child is monitored and based on the proposals of the pedagogical board and the technical (expert) team for inclusive education, a child with developmental disabilities can be transferred from developmental to educational group, in accordance with the Law.

Assessing the needs for the provision of additional educational, health or social support to the child, the composition and manner of work of IC, and other matters related to their work are regulated by a document issued jointly by ministers of health, education, and social policy.

The Law regulates educational requirements for educators who can work with children with developmental disabilities.

Pre-school children with developmental disturbances and disability have the right to a compensation of the cost of the pre-school in cases where the pre-school institution requires a co-pay from parents as regulated by the municipality and approved by the Ministry of Education.

Primary education

The Law on Primary Education and Upbringing ("Official Gazette of RS", number 55/13) regulates primary education and upbringing, as part of a single system of education and upbringing.

A student with developmental disabilities or disabilities, in terms of this law, is a child with intellectual, sensory and motor developmental disabilities. A student with developmental disabilities and disabilities acquires primary education and upbringing as a rule in the school together with other pupils, and when it is in the best interest of students in the school for students with developmental disabilities (special schools), in accordance with the Law. A student with developmental disabilities and disabilities is entitled to an individual educational plan, in accordance with the Law.

Children are educated at the school for the education of students with developmental disabilities (special school), regardless of the type

of impairment. To promote inclusive education and upbringing, the school for education of students with developmental disabilities provides support to the school in the system of regular education and upbringing.

The school in the system of regular education and upbringing that has enrolled students with developmental disabilities/disabilities can hire an educator, teacher, or professional associate to work with students with developmental disabilities. The school enacts a development plan. This plan also includes measures to improve availability of appropriate forms of support and reasonable adjustments and quality of education and upbringing for children and students in need of additional support. IEPs of all students who have them are included in the school curriculum.

In mainstream schools, the class size in primary education is limited to up to 30 students. There can be up to two students in one class with developmental disabilities and disabilities. The number of pupils in the class is reduced by two per each pupil with an IEP, and by three students per pupil who is following an IEP with adapted standards. The class size in special schools is limited to up to ten pupils.

In special schools, the class size is limited to 10 children. In cases when the class enrolls children with very severe disabilities in multiple domains with complex needs, the class size is limited to 6 children.

Parents/guardians have the right to organize their child's basic school education and upbringing at home. Details are regulated by the Law.

Primary school starts when the child is at least six and a half years of age (and maximum of seven and a half years). Exceptionally, the enrollment in the first grade can be delayed by one year.

Children are enrolled in special schools based of the opinion of the relevant IC, with the consent of the parent or guardian.

A student with developmental disabilities and disabilities is entitled to free transportation regardless of the distance of his residence from the school.

Primary education lasts for 8 years (grades 1 to 8) and is completed through a final exam. Adjustment in the final exam for students with developmental

disabilities and disabilities, depending on the type of additional support required, is performed according to the individual educational plan. A student with developmental disabilities and disabilities takes the final exam in accordance with his motor and sensory abilities, i.e., conditions required by a certain type of disability.

Additional support in education and upbringing. For children in need of additional support because of their social deprivation, developmental and other disabilities, learning problems, and at risk of dropping out of school, the school should take actions to remove physical and communication barriers, adjust teaching methods, and prepare and implement an individual learning plan. The objectives of additional support are optimal inclusion of the child in education, achieving independence within the peer group and her or his development. To realize additional support, the school principal, teachers and other relevant school staff, parents or guardians can see and get professional support pertaining to inclusive education and upbringing. In this, the school should collaborate with local government, as well as with special schools, schools that have classes of children with disabilities and other pertinent organizations. The school is obliged to collaborate with the school where the child continues her or his education.

Secondary education and upbringing
The Law on Secondary Education and Upbringing ("Official Gazette of RS", No. 55/13) regulates secondary education and upbringing as part of a single education and upbringing system.

In special schools (i.e., "schools for students with developmental disabilities"), students are enrolled upon ISC opinion and parental consent. They are educated for occupations deemed as appropriate for a particular student as advised by the ISC opinion.

The school's development plan also includes measures to improve the availability of appropriate forms of support and reasonable adjustments and quality of education and upbringing for students who need additional support. Individual educational plans of all students who are educated according to the individual educational plan contribute to the school curriculum.

For a student and an adult who needs additional support in education and upbringing due to developmental disabilities and disabilities, specific learning difficulties, social deprivation and other reasons, the school should remove physical and

communication barriers and, depending on needs, develop an IEP, in accordance with the Law.

Other provision concerning support to children with disabilities are very similar to those in primary education.

Education Management Information System Serbia is in the process of establishing a comprehensive single or unified Education Management Information System (EMIS). The Law on the Foundations of the Education System defines the EMIS as a set of databases and computer programs, needed to collect and process data in records and registries, while ensuring personal data protection. The Law regulates in detail the establishment, maintenance and operation of EMIS. The Ministry of Education is responsible for EMIS. Below, we present EMIS aspects that relate to children with disabilities.

The Ministry, within EMIS, keeps the following registries:

- registry of individual enrolled in education (children, pupils, adults, students)³¹,
- registry of educational institutions (preschools, primary and secondary schools, and affiliated institutions),
- registry of accredited higher education institutions,
- registry of employees in preschool, primary and secondary institutions and institutions affiliated with them,
- registry of employees in higher education institutions,
- registry of teaching and learning plans and programs,
- registry of accredited higher education programs.

Upon enrollment in education, an individual student is assigned a Unique Educational Number (UEN) which would follow the person until she or he exits education system. The number that contains 16 digits is automatically generated by EMIS in an automated procedure upon an educational

establishment when a person enrolls in the education system for the first time.

For children, pupils and adults the following data is entered into the registry of persons enrolled in education:

- data for determining the identity of a child, pupil, and adult: UEN, gender, date, place and country of birth, country and place of residence,
- data for determining the educational status of the child, pupil and adult: previously completed education and educational programs, level of education, qualification codes, language in which previous levels of education had been completed, institutions, groups, class and department in which the person is enrolled, type and duration of the education program, language in which educational and educational work is performed, mother tongue, nationality (not obligatory), grades, exams, commendations and awards won , etc.
- data for determining the social status of a child, a student and an adult: whether a child comes from a socially disadvantaged group, housing conditions, family status, social status of parents or guardians (education, occupation and form of employment),
- data for determining the physical and motor status of students within the educational system, obtained through the system of monitoring the body and motor status of students in the physical education classes,
- data for determining the functioning status of a child, a student and an adult: data obtained through the assessment of the needs for additional educational, health and social support conducted by ISCs, and entered into the registry as data on the existence of functioning difficulties in vision, hearing, gross and fine motor skills, communication and intellectual difficulties.

For students, the data entered comprises the following:

- personal demographic data: UEN, age, place and country of birth, place and country of permanent residence, nationality, marital status,

³¹ In Serbia, children enrolled in primary and secondary education are referred to as pupils, while persons enrolled in higher education are referred to as students.

- data for determining the educational status of the student: previously completed education, the language in which primary and secondary education was completed, the enrolled study program, the type of study, the year of study and the year of first enrolment in the study program, the year of completion of the study program, the average assessment in the course of the study program, the language in which the study program conducted, data on credits, and the public documents issued,
- data for determining the social status of the student: the means of the study financing, the means to support oneself during studies, work status during study, the highest level of education of parents or guardians,
- data for determining the health status of students, i.e., the need to provide additional support when performing daily activities at a higher education institution.

7. Tax and customs benefits

Persons with disabilities are largely exempt/pay reduced amounts from various tax (VAT, income, property tax, etc.), customs duties, administrative fees for government services, etc. To benefit from the exemption and reduction in taxes, fees, customs and import duties, etc. a disability certificate is required.

8. Transportation

The following persons with disabilities have the right to free/discounted tickets for local transport:

- blind persons,
- diagnosed with dystrophy and related muscular and neuromuscular diseases,
- persons diagnosed with quadriplegia, paraplegia,
- cerebral and child paralysis and multiple sclerosis patients,
- as well as companions of the persons listed above.

To access transportation benefits persons listed above should acquire a card issued by the following association:

- Union of blind and visually impaired persons, for blind persons,
- Association of Dystrophy of Serbia for persons diagnosed with dystrophy and related muscular and neuromuscular diseases,
- Association of paraplegics and quadriplegics of Serbia for persons with paraplegia and quadriplegia,
- Alliance for cerebral and childhood paralysis for person suffering from it,
- Society of multiple sclerosis of Serbia for the person suffering from multiple sclerosis.

The issuance of parking permits is regulated by local authorities.

To acquire a road toll vignette, a person with a disability should apply to the "Roads of Serbia" office. The person should submit several documents, including a disability certificate issued by the Fund for PDI and a copy of a decision of a relevant center for social work stating the % of bodily impairment for minors.

9. Accessibility

The Law on Planning and Construction ("Official Gazette of RS", No. 72/09, 81/09; 64/10 and related subsequent amendments) and the respective rulebook (The Rulebook on technical standards for planning, design and construction of building to ensure unimpeded movement and access to persons with disabilities, children and older people) provide detailed standards of accessibility. This is the first legal document introducing the Universal Design. The documents stipulate that the public buildings must be designed and built to enable persons with disabilities, children, and the elderly to access, move, stay and work seamlessly. Residential and residential-commercial buildings with ten or more apartments must be designed and built to enable persons with disabilities, children, and the elderly to access, move, stay and work seamlessly.

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