



ASSESSING DISABILITY OF CHILDREN:

A mapping in Armenia, Georgia, Moldova,
North Macedonia, and Serbia

MAIN REPORT

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Cover photo:

Six-year-old Mateo plays with his peers in the kindergarten in the town of Čakovec, Medjmurje county, Croatia. Thanks to the cross-sectoral cooperation and support by Early Childhood Intervention experts, Mateo was first diagnosed with a hearing disability and then was provided with services, such as social skills trainings, hearing and speech exercises, and sign language classes, from which him and his family are benefiting from to this day. UNICEF is supporting the development of integrated Early Childhood Intervention services and access to early education for children with disabilities in Croatia. Credits: Danijel Soldo/UNICEF Croatia

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1. The Framework

1.1 The Task

1.1.1 Terms of the Consultancy

This consultancy examined the extent to which disability assessment systems for children (ages 0-18) in five Eastern and Southern European countries (Armenia, Georgia, Moldova, North Macedonia and Serbia)

- i) are currently aligned with the human rights-based approach to disability,
- ii) contribute to more effective support for children with disabilities transitioning from institutions to families and communities, and
- iii) more broadly, contribute to improved policy and service planning and provision for children with disabilities throughout their life cycle.

The focus of this consultancy was both on underlying conceptual frameworks, found for example in legislation, and on the structures of systems. The analysis examined the role of the World Health Organization's International Classification of Functioning, Disability and Health (ICF) – or other frameworks – in providing a common language about disability among the different professionals who focus on the phenomena of functioning and participation and facilitating cross-sectoral collaboration for improved policy, service planning and provision.

The analysis aimed to bring together the **person's perspective** (including the child's talents, interests and needs, and situation) and the **system perspective** (including the community, the different professionals and institutions involved in the process, alignment between the different assessments, the capacity of professionals, funding, accessibility, management, monitoring and evaluation). The system perspective also considers the extent to which administrative and institutional processes have, in these five countries, enabled the involvement of children with disabilities, their parents and families, disability groups in the design and implementation of disability assessment.

This report is the primary deliverable of this consultancy. It describes the disability assessment systems in the five countries, identifies potentially transferable best practices, general and specific observations about practices, and, finally, provides

recommendations for technical guidance and further disability assessment system reform in the region and beyond. Specifically, this report:

1. examines the extent to which disability assessment system reform in five countries has led to understanding of disability in line with human rights-based approach to disability, improved assessment of individual child needs and the extent it has contributed to effective policy and service planning and provision for children with disabilities and families,
2. examines the extent to which the use of ICF in disability assessment, certification and eligibility determination has facilitated a transition from medical towards a human-rights based approach to disability inclusion,
3. examines the extent to which disability assessment reform has contributed to a common understanding of disability and strengthened cross-sectoral collaboration, particularly in the context of de-institutionalization and transition to family and community-based care, early identification, and response to risks of family separation, family support (and reintegration) services, gate-keeping system (decision-making in the best interest of the child), promoting case management,
4. examines the extent to which it has led to systemic transformation (human and financial resources, capacity building, legislation), and
5. provides a synthesis of the key findings and recommendations for future reforms.

1.1.2 Preliminary caution

The terms of this consultancy have directed us to review reforms in terms of certain concepts. A project such as this raises the very real concern of misunderstanding caused using terms and concepts that, in practice, are understood in different ways and in different contexts, especially across languages and cultures. Terms such as 'disability assessment', 'disability determination', 'needs assessment', 'special educational needs assessment', 'human rights', 'functioning', and indeed, 'disability' itself are not univocal and are differently understood across sectors and countries. The same can be said for conceptual frameworks, theories, and methodologies.

As authors of this study, the only solution we see is to be clear how we use these terms and to then describe the disability assessment systems in each country. Transparency in usage is especially important as national legislation seeking to reform this area of policy will use very general and abstract notions (often derived directly from international legal documents), while in practice the resulting implementation of the legislation provisions may not be consistent with what appeared to be the clear intention of the legislation. Often this mismatch between legislative intent and concrete practice is caused by alternative understanding of key terminology and concepts. Our obligation as consultants is to be clear (and consistent) in how we use these terms. We have endeavored to do so.

In this spirit, and before the mapping of the systems of disability assessment in the five countries included in this study, we describe our understanding of terminology and the components of the conceptual framework for this consultancy as described above – specifically, the nature of disability assessment (as compared to other, but related administrative actions), the content and implications of the ‘human rights approach’ to disability assessment for children, and the ICF and its application to disability assessment. This discussion is based both on a literature review, our own published work, and our experience as consultants on disability assessment regimes in other countries. Our intention is to be as clear as possible about how we understand these components so that our analyses of the five national systems are comparable and our recommendations meaningful. In the following sections we clarify how we are using the key terms and concepts of this consultancy.

1.2 Disability assessment, disability determination, needs assessment

1.2.1 Disability assessment

In a 2015, World Bank and World Health Organization publication¹, we provided an open-ended description of disability assessment as

Disability assessment is an authoritative determination about the kind and extent of

disability a person has, as part of a larger administrative process usually called disability evaluation or disability determination. Disability assessment is part of a process that determines the eligibility of a claimant for some social benefit, service or protection that comprises a country's disability policy.

Although the terminology varies, disability assessment in most countries is the initial administrative act that often serves as a ‘gateway’ to the disability benefits, services and supports the country provides. It is an ‘assessment’ rather than a ‘determination’, in the sense that it provides the basis for a decision about a person’s level (or severity or degree) of disability, and sometimes also the kind of disability. Historically, because of the importance of employment, disability assessment has been a matter of assessing ‘work capacity’ or ‘work ability’, but now the term is more widely used. In some countries the preferred terms are ‘disability evaluation’² or ‘impairment evaluation’, reflecting the primarily biomedical methodology of the assessment.

As we understand disability assessment, it is an authoritative, typically legally-sanctioned, administrative process – possibly involving several steps and official actors and occurring once or several times – that provides the entry for eligibility for some form of support, service, or assistance to individuals. The assessment procedure identifies the kind, degree, or level of disability that a person experiences. The results of an assessment may be expressed as a percentage, grade, or level, that forms the basis for an administrative decision (often called ‘disability determination’) that can take the form of a certification or statement of eligibility. The disability determination step, based on the results of the disability assessment, may be joined with other administrative procedures that further identify preconditions of eligibility – income level, geographical location, legal status, employment status, age, and so on. Disability assessment is a technical issue whereas disability determination is a political issue, one in which the country decides who it will support.

As this characterization of disability assessment is very general and abstract, we also propose a more

¹ Bickenbach J, Posarac A, Cieza A, Kostanjsek N. Assessing Disability in Working Age Population - A Paradigm Shift: from Impairment and Functional Limitation to the Disability Approach. Washington DC: The World Bank; 2015. Available at: <https://openknowledge.worldbank.org/handle/10986/22353//>.

² E.g., Rondinelli R, Ranavaya M (eds.) Medical Impairment and Disability Evaluation, & Associated Medicolegal Issues, An Issue of Physical Medicine and Rehabilitation Clinics of North America. 2019, Elsevier. <https://www.elsevier.com/books/medical-impairment-and-disability-evaluation-&-associated-medicolegal-issues-an-issue-of-physical-medicine-and-rehabilitation-clinics-of-north-america/978-0-323-68212-1//>.

operational characterization. To do so, however, we must be clear about what we mean by 'disability'. The term has evolved over time and disability assessment has reflected this evolution. Very roughly, the notion of disability has evolved from essentially a medical phenomenon (fully explainable in biomedical language), to the capacity of a person in light of their health condition to carry out basic activities, to in the last three decades, the current consensus represented both by the United Nations' *Convention on the Rights of Persons with Disabilities* (CRPD)³ and the World Health Organization's *International Classification of Functioning, Disability and Health* (ICF)⁴. In the above-mentioned report, we described the history of disability assessment as moving from a purely impairment approach (relying on medical information and so-called Baramic tables), to the functional limitation approach (in which additional information about limits on activities of daily living was added) to what we termed the disability approach in which assessment is shaped by the current consensus on disability.

This current consensus is our starting point in this report⁵. The CRPD indirectly characterizes disability as follows:

"Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."

This reflects what has been variously called in the literature the 'social model', 'interactive model' or, borrowing from the ICF, the 'biopsychosocial' model. Since we are concerned to operationalize assessment of disability, we focus on the direct consequences of this model for assessment:

First, disability is conceptually grounded in health states, represented as health conditions – diseases, injuries, and other biomedical sources of impairments – and as impairments of body functions and structures.

We believe it is important not to apply the term 'disability' outside of the domain of health problems and impairments. Many of the

disadvantages that affect the lives of children and call upon state support are not themselves health states: poverty, migrant status, lack of knowledge of language used in schools, stressful family situation, etc. The notion of disability simply does not apply to these determinants of disadvantage.

Second, and using the ICF terminology, disability is neither a health condition nor an impairment. This means that assessing a person's intrinsic health capacity to perform actions – simple or complex – is not disability assessment. Rather, disability assessment requires the assessment of the outcome of the interaction between intrinsic capacity and contextual factors – and specifically for assessment, the impact of environmental factors. This outcome of the interaction of health states and environmental factor is called *performance*: the actual, observable, execution of actions – simple or complex – in the person's actual world. The CRPD focuses on the most important dimensions of performance – participation in family life, education, employment, community – but disability is also a matter of limitations in many other domains – learning and applying knowledge, communicating, mobility, self-care, interpersonal relations, etc.

To avoid confusion, 'disability' – the overall phenomenon that is experienced by people as a matter of degrees of severity – should be distinguished from individual 'disabilities', namely limitations of activities and restrictions of participation (e.g., communication disability, mobility disability, education, and work disability).

Disability assessment is a matter of assessing the overall, or summary level or extent of disability that a person experiences. This experience can be disaggregated in discrete disabilities, but the overall experience of disability is more than the sum of the experience of these distinct disabilities: the impact of disabilities on people's lives cannot be simply added together to arrive at a summary score. Distinct disabilities interact between themselves, often leading to greater performance problems than each individual disability causes on its own.

We believe, therefore, that it is important to view disability as an overall experience that is holistic, emergent, and not merely the sum of separate

³ <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html/>.

⁴ <https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health/>.

⁵ Bickenbach J E et al. *Ethics, Law, and Policy*. Volume 4 of *The SAGE Reference Series on Disability: Key Issues and Future Directions*. Sage Publications (2012).

disabilities. To emphasize this holistic approach, we chose to call the administrative procedure **disability 'status' assessment**, to highlight that the administrative significance of disability assessment is that it provides the basis for a determination of the status of being a person with disability.

Our working definition of disability assessment for this study is therefore: ***Disability assessment is a summary statement and measure of the overall status of disability as a determined summary level of a person's performance of ordinary, everyday behaviors and actions, simple to complex, in his or her actual or usual environment, in light of the person's state of health.***

1.2.2 Disability assessment and disability determination

Disability assessment is different from disability determination: one is a technical assessment, the second a political and administrative decision. Nonetheless, in practice in our experience it is rarely put into practice. In nearly all the countries that we have examined for the purpose of this study, and others from previous consultancies, the individual assessor, multi-disciplinary assessment team, or assessment agency that carries out the disability status assessment also makes the determination of status. Certainly, that is true for the five countries we investigated in our study. For this reason, we ignore the distinction in what follows

1.2.3 Disability assessment and disability needs assessment

In many countries, a certified status of disability (often including a degree of disability) is one of several eligibility criteria for benefits and services. Others may include citizenship, residency, or income level. But by including disability among this list of eligibility criteria, some level of need is presumed, and may be administratively predetermined. For example, if a person has a severe disability and meets income and family criteria, he or she may automatically qualify for income support, while a person having disability status and not capable of working, may immediately qualify for disability pension. In short, in some countries, disability status assessment and determination directly entail eligibility for benefits and services.

However, in a growing number of countries, the process of disability status assessment and

determination is followed by a more complex and detailed set of procedures, involving several sectors, that seek to identify the individual's disability-related needs or requirements. The assessment of needs may entitle the individual to a rehabilitation plan including an automatic referral to existing benefits and services, creating an integrated system that provides a range and continuum of benefits and services focused on the individual and her or his needs.

People experiencing disability may have needs and requirements because of disability. These needs may be medical in nature – surgery, therapeutic treatment, mental health interventions, medication, medical rehabilitation – and if so, can only be assessed by medical professionals in the normal fashion. A person experiencing disability may also have rehabilitation needs to optimize her or his capacity to perform actions by means of therapy, orthotics and prosthetics, and assistive technology. A considerable broader set of needs are associated with fundamental areas of life that are constitutive of the experience of disability – family and relationships, housing, transportation, education and training, work and employment, community and social participation, and others. In a well-functioning system, these needs and requirements are matched to available supports, services, or benefits, provided by legally mandated authorities, agencies, public and private organizations, and others.

Unfortunately, it is a common feature of nearly every country that the services and supports that an individual can benefit from are fragmented across several sectors, which invariably requires individuals to undergo a multiplicity of needs assessments for different kinds of needs. This phenomenon of lack of cross-sectorial services coordination, let alone integration, appears to be endemic to the modern welfare state, and considerably beyond the scope of this consultancy.

The process by which these needs are assessed is often called an **'individual' (or 'comprehensive') needs assessment**. This is an administrative process that identifies the needs and requirements of persons based on evidence of the person's discrete problems in functioning, that is, specific disabilities. Needs assessments may be generic or specialized (e.g., special educational needs assessment); but all are individualized in the sense that to be effective and relevant they must focus on the actions a person has difficulties performing because of her or his underlying health conditions

or the environmental barriers she or he confronts in daily life (for example, sensitivities to air pollution or obstacles to mobility).

There are many examples of needs assessments instruments: forms, clinical tests, performance tests and questionnaires. The better tools collect a full range of information that contextualizes the individual, his or her short and long-term goals and aspirations, family and social circumstances, a survey of impairments and their severity, a review of experienced disabilities, environmental barriers faced or facilitators that might improve performance, and so on. These instruments can

be long or short, conducted at the same time as the disability assessment or later, and can be focused on specific areas or more general. The only feature they have in common is that **individual needs assessments are not the same as disability assessments.**

The differences between the two cover a range of content, administrative and practical issues. The table below summarizes the key differences in aim, purpose, uses, information requirements and scope between disability assessment and needs assessment for persons with disabilities.

Table 1: Disability status assessment and disability needs assessment

	DISABILITY STATUS ASSESSMENT	DISABILITY NEEDS ASSESSMENT
Aim	Whole person, summary assessment of the overall experience of disability by an individual	Discrete needs and requirement created by specific disabilities experienced in daily life
Purpose	Basis for determining eligibility for social benefits, services and supports	Basis for determining needs that might be met by available social benefits, services and supports
Varieties	Generic (although specific disabilities may be used for summary)	Generic or specialized by participation domain (e.g., education, work)
Uses	Used as an entryway into disability system	Used for individualized plans or case management and for monitoring progress
Information required	Information about limitations in performance in actual environment	Wide variety of information relevant to the identification of needs and the context of provision of supports
Scope	Restricted to disability domain	May not be restricted to the disability domain but include needs more generally

Disability assessment serves the limited function of dividing all applicants into essentially two categories, those who will qualify by virtue of disability for social benefits and supports and those who do not. Needs assessment, by contrast, is a highly detailed, individualized, and contextualized process of identifying and quantifying needs

and requirements of persons with disabilities and matching these with services. Disability status assessment is the basis for a clear-cut administrative decision to allow the applicant to enter the disability system; needs assessment is the basis for an on-going negotiation between the individual and providers of supports and services⁶.

⁶ Sometimes the merging of disability and needs assessment is unintentional: "In line with the principles and vision of the CRDP, disability assessment mechanisms must concentrate on participation restriction and on support needs of the disabled person more than on her/his impairment or functional limitations. This implies also that these mechanisms take the environment into account, most often overlooked in assessments." But disability status assessment does not identify support needs, that is only accomplished by means of a needs assessment. See: Carlyne A, Barral C, Eddy B, Castelein P, Chiriacescu D, Cote A. Disability Assessment Mechanisms: Challenges and Issues at Stakes for the Development of Social Policies in Light of the United Nations Convention for the Rights of Persons with Disabilities. Summary Report of Fondation Internationale de la Recherche Appliquée sur le Handicap (FIRA), 2012.

We believe that this is an important distinction and are concerned that systems for child assessment in the five countries of this study may confuse or conflate disability status assessment and needs assessment. This can lead to problems: **Because it provides a summary assessment of whole-person disability, disability status assessment requires a summarizing algorithm that has scientific validity and is psychometrically sound. By contrast, needs assessment does not require a summarizing methodology as it is purely descriptive of salient features of the individual's life relevant to her or his needs and the context for the provision of needs.**

1.2.4 Needs assessment and SEN assessment

Special Educational Needs (SEN) assessment is a specialized form of needs assessment for children. For historical and administrative reasons, there may be a tendency to characterize any problem that a child has in learning or any obstacle the child has to fully and beneficially participate in education as the result of a 'disability'. We believe that this is a mistake.

There are many reasons why a child may not fully participate in education or may need assistance to fully benefit from the school experience. Not all of these reasons are associated with a medical health problem or impairment: a child may be poor, undernourished, experiencing trauma at home, or simply not be fully competent in a second language in which instruction is provided. In some instances, using the label 'disability' facilitates access to resources that the child needs, even when there is no underlying health problem or impairment. But, while this may be a practical approach, it does not serve children well as it may obscure the cause of learning difficulties. On the other hand, not all children with disabilities have special educational needs.

We note that the literature identified this concern as one potential cause of over-medicalization of 'learning problems' or other causes of inability to fully participate in education. This may reflect either the state of the science or a temptation to provide services and supports to children who can benefit from them, whether experiencing disability or some social or situational disadvantage.

1.2.5 A note about discretion

Disability status assessment and disability needs assessment are paradigm examples of what in administrative sciences are called *professional discretionary actions*⁷. These are judgments that are required to administer social programs defined by authoritative eligibility conditions. Accountability for discretionary actions involves the legitimacy of the underlying authority to decide and public justification of the decision. In disability assessment, the authority is generally assigned to a professional who is qualified and competent to apply the criteria of assessment, and the ground for the decision is the assessment methodology that is employed.

Since these assessments are applied to individual applicants in specific circumstances, some level of discretion is inevitable to individualize the assessment. In that sense, the assessment is 'subjective', i.e., it must be made by a human assessor. Concerns about fraud, corruption and 'gaming the system' arise almost automatically in cases where benefits are determined by professional discretion. Since discretion is unavoidable, the only safeguard against corruption (or arbitrariness) is the second criteria of accountability: the reasons and evidence used for the discretionary judgment must be available for public scrutiny. Disability assessment is contentious and can be criticized on the facts; but if the reasons for the decision are publicly available and subject to scrutiny, the precondition of public accountability is met.

1.3 CRPD and the 'human rights approach' to disability status assessment

We have been asked whether reforms in the five countries have been aligned with 'the human rights-based approach to disability'. We believe that the CRPD gives us concrete guidance on what this phrase entails.

First, we understand the human rights approach to be grounded in the provisions of the *Convention on the Rights of the Child* (CRC)⁸ and the CRPD. Secondly, we understand the human rights approach to speak primarily from the system perspective, although the beneficiary of human

⁷ We are relying in this section on Molander, A., Grimen, H. and Eriksen, O. Professional Discretion and Accountability in the Welfare State. *Journal of Applied Philosophy*, Vol. 29, No. 3, 2012.

⁸ <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child/>

rights are individual persons: the child, the family and other significant individuals in the child's immediate environment. Finally, human rights concern both procedural and substantive issues – both matter to how people are treated and the positive benefits and opportunities to which they are entitled.

We therefore understand the human rights approach to disability status assessment for children as one that is grounded in the rights set out in both CRC and CRPD, that shape both the procedural and substantive features of disability assessment, reflecting both the system's and person's perspective. (Although CRPD does not focus on children (other than Art. 7), there are more general rights that apply to both adults and children that are involved in disability assessment.) It is important to underscore that these rights include but go considerably beyond the biopsychosocial model of disability:

1) Substantive human rights of the child and significant others in the context of disability assessment:

- A child who can form his or her own views has the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child. (CRC Art 12; CRPD Art 7)
- State Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. (CRC Art 9)
- Rights and duties of parents, members of extended family or community or legal guardians shall be respected in a manner consistent with the evolving capacities of the child. (CRC 5; CRPD Art 5)
- A mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance, and facilitate the child's active participation in the community. (CRC Art 23)

The disabled child, recognizing special needs, must have effective access to and receive education, training, health care services,

rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development. (CRC Art 23; CRPD Arts 23-27)

2) Substantive children human rights for systems related to disability assessment

- In all actions concerning children, the best interests of the child shall be a primary consideration. (CRC Art 3; CRPD Art 7)
- States Parties shall recognize for every child the right to benefit from social security, including social insurance, and shall take the necessary measures to achieve the full realization of this right in accordance with their national law. (CRC Art 26; CRPD Art 28)
- Every child has a right to a standard of living adequate for the child's physical, mental, spiritual, moral, and social development. (CRC Art 27)
- Every child has the right to be protected from all forms of sexual exploitation and sexual abuse, torture or other cruel, inhuman, or degrading treatment or punishment. (CRC Arts 34-37; CRPD Arts 15-16)

3) Substantive human rights provisions regarding disability assessment

- Disability assessments should consider not only the impairments but also environment facilitators and barriers that improve or hinder their full and effective participation in society, and the right to be included in the community, of persons with disabilities on an equal basis with others. (CRPD Arts 1, 19)
- The design and conduct of disability assessments should comport with basic human rights principles: equality of opportunity and non-discrimination, dignity; individual autonomy; full and active participation and inclusion; respect for difference; and accessibility. (CRPD Art 3)

4) Procedural human rights provisions regarding disability assessment

- Disability Assessment should be conducted in a way that is accessible (physical access and

information). (CRPD Art. 9)

- Disability assessment should include complaint, review and appeal procedures. (CRPD Art 13)
- Appropriate training should be provided for “professionals and staff” involved in disability assessments, including human rights training. (CRPD Arts 4,13)
- There should be involvement of disabled people, their organizations, and human rights bodies, in the design and regular review of assessment systems. (Art 4(3) and 33(3))

Other, closely related procedural fairness principles are found in the discussions of children disability assessment in the literature:

- Disability should be identified as early as possible in the child’s life, optimally as soon as developmental delay, physical or intellectual issues are observed. Without prejudice for any of the right of the child.⁹
- It is important to keep in mind the purpose of assessment, needs, service planning, monitoring, revisions, follow up assessments at different ages and phases of development.¹⁰
- For instance, for educational purposes, assessment of functioning is not sufficient and needs to be complemented with assessment of educational needs for participation in learning.¹¹
- It is important to assess for stage of transition into adulthood.¹²
- The administrative burden on applicants should be reduced by eliminating duplicative or multiple assessments.

These principles will be our guide in the application of ‘the human rights approach’ in this report.

1.4 The role of ICF in disability status assessment

The final preliminary issue for clarification is the role of WHO’s *International Classification of Functioning Disability and Health* (ICF) in disability assessment. Over the past decade, the ICF and its ‘biopsychosocial’ model of functioning and disability has been one driver for reforming disability assessment. In part this has come from the CRPD Committee’s consistent message in its Concluding Observations, which evaluate, and make recommendations about countries’ progress in implementing the CRPD. Often the Committee states that a country must move away from the ‘medical model’ to an approach that focuses on functioning and the role of the environment as a barrier to participation. Sometimes the Committee explicitly recommends the ICF. The result is that many countries, in legislation and public statements, give the impression that using (or sometimes just mentioning) the ICF will suffice to reform disability assessment in a manner aligned with the human rights approach. It is important to address this misunderstanding.

1.4.1 Understanding the ICF

The ICF is an international standard classification that WHO created to augment its *International Classification of Diseases* (ICD), now in its 11th edition. WHO did so to ensure that it had access to standardized and internationally comparable health data from its member states. While ICD is a diagnostic classification of diseases and other health problems – ensuring internationally comparable morbidity and mortality data – the ICF is a classification of the lived experience of

⁹ World Health Organization. 2012. Early childhood development and disability: discussion paper. World Health Organization. <https://apps.who.int/iris/bitstream/handle/10665/75355/?sequence=1>

¹⁰ There is a vast literature on these points. Just a few examples: <https://agesandstages.com/free-resources/articles/success-screening/>; Washington State Office of Superintendent of Public Instruction: A Guide to Assessment in Early Childhood; Infancy to Age Eight. Washington State Office of Superintendent of Public Instruction, 2008.

<https://wvde.state.wv.us/oel/docs/Washington%20Assessment%20Guide.pdf/>; Watch Me! Celebrating Milestones and Sharing Concerns, <https://www.cdc.gov/ncbddd/watchmetraining/docs/watch-me-training-print.pdf/>.

¹¹ OFSTED. 2010. The special educational needs and disability review. London. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/413814/Special_education_needs_and_disability_review.pdf.

¹² See, for example, Department for Education and Department of Health. 2015. Special educational needs and disability code of practice: 0 to 25 years. Statutory guidance for organizations which work with and support children and young people who have special educational needs or disabilities. London: <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25/>; Mary McClanahan, MD, Shannon Strader, DO. 2021. Transition to Adulthood for Persons with Childhood Onset Disabilities. Originally published: November 10, 2011, Last updated: September 23, 2021. <https://now.aapmr.org/transition-to-adulthood-for-persons-with-childhood-onset-disabilities/>.

health conditions, for internationally comparable functioning data. ICF in effect is a data dictionary, an epidemiological standard, that uses a simple hierarchical ('genus-species') classification ontology to ensure its digital application in electronic formats.

But this is not the feature of the ICF that figures prominently in the CRPD Committee's recommendations; it is ICF's underlying model of functioning and disability. In the ICF, disability is a problem in functioning. There are four dimensions of functioning: Body Functions (BF), Body Structures (BS), and Activities and Participation (A&P), captured by three classifications. The classifications break down these dimensions into specific domains (e.g., vestibular functions, structure of eyeball, seeing, walking, maintaining informal relationships, education, work, community participation, etc.)

Functioning is both a matter of internal, intrinsic biomedically-described capacity in terms of the BF and BS components. **Capacity** is the underlying health state of a person, possibly affected by diseases, injuries or other health-affecting events like aging. Functioning at this bodily level may be nominal or in one way or other sub-nominal (as determined by the health sciences), in which case we speak of 'impairments'. In the ICF classification, impairments are less than nominal or optimal levels of functioning in some domain of BF or BS.

By contrast, **performance** is understood as the actual carrying out ('doing', 'executing') of activities, tasks and social roles – that is, domains in the A&P classifications – in the individual's actual environment. Problems in performance are what ICF understands by 'disability', and disability is the outcome of the interaction of the person's health state – diseases, injuries, ageing, and resulting impairments – with the person's physical, human-built, interpersonal, attitudinal, social, political, economic environment. A person's environment (broadly construed) may constitute for the individual a barrier to performing activities; or it might be a facilitator. The fourth and final classification in the ICF is therefore the Environmental Factors (EF) classification.

In order to accurately describe (or assess) disability as an actual lived experience, we need to describe both the impact of the health problem (the disease states and impairments the person experiences) and the impact of the physical environment (e.g. air pollution or uneven ground for walking), the human-built environment (e.g. narrow walkways, no elevator), the attitudinal environment (e.g.

stigma, people's positive or negative attitudes) and the complex social environment (e.g., how work is organized, whether and how social services are provided).

1.4.2 Misapplications of ICF

In the context of disability assessment, in our experience, the ICF has been misinterpreted and misapplied. Firstly, the ICF is sometimes applied by merely cosmetically changing the vocabulary used in the instruments and procedures of disability assessment, without any significant substantive changes to it. This is done by using the ICF basic vocabulary ('body functions', 'body structures', 'activities', 'participation', 'environmental factors') and collecting information in terms of the domains of the four ICF classifications (e.g., using terms like 'vestibular functions', or even the ICF coding system, b325 – Vestibular functions). This is, as far as it goes, a proper use of ICF; but merely using ICF vocabulary will not alter the underlying model of disability or underlying methodology for assessing disability.

Some countries make the mistake of thinking that ICF is itself an assessment instrument, or that ICF can be directly used to assess disability. To be sure, the ICF document suggests this reading by providing 'qualifiers' that have five-point severity options of No problem, Mild, Moderate, Severe, and Complete problem (unfortunately, few have paid attention to the commentary in the ICF that these options are given as examples and any true scale must be empirically derived). Nonetheless, believing that 'applying ICF' means directly using ICF as an assessment instrument, some commentators have expressed bewilderment about how, precisely, the 1,400-plus categories in the ICF can be used as a feasible assessment tool. The answer is that that is not the role of ICF.

Another, more potentially damaging misapplication of the ICF involves the use of the ICF vocabulary beyond the health context. This is particularly concerning in the case of children. It should be apparent from its title that the ICF only applies to circumstances in which health is a determinant of limitations in functioning. Unfortunately, one of the key ICF terms, namely 'participation', is problematic, not because it is difficult to understand, but because it is easily confused with the same word in ordinary speech. A child participates or fails to participate in school. That may be a disability in the ICF sense, if 'participation' is meant as a technical ICF term. But not every failure to participate (in the ordinary sense) in school is a disability. There are many reasons

why a child does not participate in school that have nothing to do with disability, since these reasons do not link to a medical problem or impairment.

Finally, the ICF does not determine at what level of functioning in a particular domain – or overall, as a summary of the functioning of the person as a whole – constitutes a disability. As functioning is

conceptualized on a continuum (from perfect or total functioning to no functioning), there are an infinite number of potential disability thresholds. Since ICF is not an assessment tool, the threshold must be determined by the user, in line with population data, statistical norms (if available), the purposes of the application and, not infrequently, political negotiation.

2. Mapping Disability Status Assessment

During the preparation for this study, we conducted desk research from material provided by UNICEF and other material we found and conducted interviews with UNICEF staff in five countries (Armenia, Georgia, Moldova, North Macedonia, and Serbia), and government officials in two (Moldova and North Macedonia). As comparator countries, we reviewed the disability assessment and needs assessment regimes in Portugal and Switzerland. We reviewed legislation and regulations, instrumentation and formulae used in various disability and disability needs assessments of children, previous consultancy reports, and miscellaneous other reports, including those from UNICEF itself. In our previous work on disability assessment, besides this basic research, we also conducted multiple face-to-face interviews with government officials and staff, health and social service professionals, individuals who conducted assessments, as well as their managers. None of this was feasible for this consultancy as time and other factors (including the COVID pandemic) made this impossible. Although in the end we believe we have a clear enough understanding of the situation in each country, we wish to make it very clear that we are fully aware of the limitations of our desk research data collection¹³.

2.1 Reports of the CRC and CRPD committees

It might be helpful to begin with summary comments concerning human rights and children, especially regarding inclusive education, of the two United Nations human rights committees relevant to disability – the Committee on the Convention on the Rights of the Child and the Committee on the Convention on the Rights of Persons with Disabilities. This information is important as it indicates the kinds of human rights concerns that an external, international agency has had about

disability assessment. For comparison, we also include the comments from these committees on Portugal and Switzerland – in part to highlight that even in high-resource countries, well-advanced in making reforms to policies concerning children, human rights issues remain. (A fuller summary of the committees' comments on all seven countries can be found in Annex 2 to the Main Report):

Armenia

Both the CRC and CRPD committees praised the adoption of the legislative reforms on inclusive education in 2005, 2012 and 2017 (the last committee report was 2017). They expressed concern about the high levels of institutionalization of children, the lack of early intervention programs, and more generally the slow pace of the transition from segregated to inclusive education and insufficient support and training for administrative and teaching staff. Neither committee commented on disability assessment directly.

Georgia

Only the CRC Committee has recently (2017) reviewed Georgia and has praised its efforts to integrate children with disabilities in social, recreational, and cultural activities. The committee was concerned, however, about slow progress in deinstitutionalization, limited availability of early identification and intervention programs, incomplete data on children with disabilities and the need to improve the standard of living of children. As for disability assessment, the CRC Committee recommended the adoption of the human rights-based approach and in particular to "Introduce individual functional assessments of disability status, based on the ICF and a biopsychosocial approach for their support, train service providers

¹³ Initially, we prepared a survey instrument (in both long and short versions) to collect legal, institutional and policy information relevant to childhood disability assessment in countries under study. The intent was for UNICEF country office staff to fill in the questionnaire. Unfortunately, this turned out to be unrealistic and we did not receive any completed surveys.

on the assessments, guarantee effective cooperation between services and timely medical interventions and referral to adequate health and educational services”

Moldova

Only the CRPD Committee has recently (2017) reviewed Moldova and has praised the government’s approval of an action plan on deinstitutionalization and programs to develop inclusive education and to provide equal opportunities for all children to access quality education. The Committee was concerned about the prevalence of stigmatizing attitudes, reinforced by a lack of community services, by life-long institutionalization still in practice, and the fact that children with disabilities do not systematically participate in making decisions that affect their lives. The Committee was also concerned about the continued existence of ‘special schools’ and ‘home education’ and recommended amending the 2014 Education Code to ensure that no child is refused admission to mainstream schools on the basis of disability. No comment was made about disability assessment.

North Macedonia

Only the CRPD Committee has recently (2018) reviewed North Macedonia and has praised the renewed ban on the institutionalization of children and its commitment to end the placement of very young children in institutions. The Committee expressed concern about the lack of specific legislation on the rights of children with disabilities, continued violence against children with disabilities, and the prevalent stigma and discrimination that these children experience. The Committee worried about the lack of early assistance and services for independent living, the absence of mechanisms to guarantee children with disabilities are involved in decision-making processes affecting their lives, and the fact that there was no comprehensive strategy aimed at an inclusive education system. No comment was made about disability assessment.

Serbia

Both committees reported on Serbia, the CRPD in 2016 and the CRC in 2017, and both praised Serbia for its efforts to ensure equality for children with disabilities. At the same time, both committees expressed concern about the high levels of institutionalization of children, the limited supports

for parents and families of children with disabilities, the lack of usable data on children, and the lack of a comprehensive strategy to ensure broad social inclusion, especially for those with intellectual and psychosocial disabilities. The CRPD Committee in particular was concerned that children living in residential care institutions did not participate in education and that there were no procedures for providing individual education plans or to provide relevant technologies and forms of communication to ensure accessibility for students with disabilities at all levels of education. Neither committee commented on disability assessment.

Portugal

Both committees reported on Portugal, the CRPD in 2016 and CRC in 2019, praising in particular the legislative measures to implement a shift towards inclusive education. Yet, although the great majority of students with disabilities attend regular schools, the CRPD Committee noted that there is a lack of support and, because of austerity measures, human and material resources have been cut putting the right to and opportunity for an inclusive education of high quality at risk. There was also concern that the system of diagnosing disability as a precondition to placement in programs was under-developed, full inclusion in all areas of life was limited by lack of resources and the inability to monitor inclusion, and there was a lack of coordination between social security, educational and health authorities to ensure the effective implementation of the social inclusion benefit. No direct comment was made about disability assessment other than that no clear method for identifying education-related disabilities was evident.

Switzerland

The CRC Committee reviewed Switzerland in 2021 and the CRPD Committee in 2022. While both committees praised Switzerland for ensuring access of children with disabilities to inclusive education in mainstream schools, they noted that some children with autism continue to attend special schools or classes outside mainstream schools or are sometimes placed in institutions. They noted that a high number of children remain in segregated educational settings and that inter-cantonal agreements tended to stream children with disabilities into special education. There is a lack of resources in mainstream schools to support inclusive education and barriers in gaining access to vocational training and higher education faced

by students with disabilities, particularly those with intellectual or psychosocial disabilities. Both committees encouraged the country to strengthen the right to inclusive education in mainstream schools for all children with disabilities, including children with autism and children with learning difficulties, strengthen teaching training in integrated classes, and provide clear guidance to cantons that still apply a segregated approach. There was concern that Switzerland should legally prohibit the practice of “packing” autistic children (whereby the child is wrapped in cold, wet sheets) in the public and private sectors and promote specialization in autism among health professionals. The CRPD Committee was concerned about the lack of support and consultations with organizations of persons with disabilities at federal, cantonal and municipal levels, and that steps needed to be taken to address the fact that children with disabilities face multiple and intersecting forms of discrimination, and their views were not heard in decisions that affect them, including in criminal and asylum proceedings. Neither committee commented on disability assessment.

2.2 Country summary mapping

2.2.1 Armenia¹⁴

Reforming disability assessment of children in Armenia

As part of a general initiative to develop a framework to protect the rights and fundamental freedoms of persons with disabilities and children – consistent with CRPD (which Armenia ratified in 2010) and CRC (ratified in 1993) – since 2013 the Armenian Government has been engaged in reforming disability assessment and determination, eligibility definitions and provisions of services for persons with disabilities (children and adults). This includes a commitment to revise the disability model from medical to ‘biopsychosocial’, implement the ICF framework for the assessment and definition of disability, and mainstream inclusive education in pre-schools and schools within the frame of the UNICEF funded projects.

Under the UN Partnership on the Rights of Persons with Disabilities (UNPRPD)¹⁵ project on “Improving

Access to Services and Participation of Persons with Disabilities on the Conceptual Framework of UNCRPD and ICF” – Armenia begun in 2014 to pilot a new model of disability assessment and certification based on the ICF framework and aligned with CRPD principles. The project, the first phase of which concluded in 2017, also engaged in capacity building, revising the individual rehabilitation plans, reformulating the individual service delivery plans, incorporating health, education, employment, social services, as well as strategic initiatives to enhance employment opportunities. Phase 2, 2017-2019 rolled out on a trial basis the ICF-based model of disability assessment and determination, established information exchange mechanisms between sectors to ensure service provision across education, health, and employment sectors; and strengthened the gender responsiveness of services.

An assessment package was created that consisted of sets of ICF Body Function and Structure codes, Activity and Participation codes, and Environmental factors that were rated – using the ICF 5-point scale – by experts of the Medical-Social Expert commissions from the Ministry of Labor and Social Affairs (MOLSA) trained by the consultants. The assessment package was used for all applicants and consisted of a Self-assessment Form, an Administrative Form, and an Administrative Act to be filled in by a Medical-Social Expert Commission, and a Social Worker Form on Activity and Participation, and Environmental Factors to be filled in based on observation of routine activities. The package also includes a technical methodological guide for information collection. Summary scores were analyzed in terms of distribution, reliability was based on internal consistency, and criterial validity was indirectly established. Based on analysis of the pilot results, the assessment package was revised. The new package for disability assessment consisted of 21 disability and age-specific protocols and previously developed methodological guides and was based on four ‘disabilities’ types: Hearing, Visual, Mobility, and Mental, and four chronic disease-types: (cardiopulmonary, hematological, immunological, metabolic and endocrine). Sets of ICF categories were assigned to each focused

¹⁴ The full version of the Armenia Case Study is available as a separate publication.

¹⁵ The UNPRPD provides the framework for a cooperative arrangement between the following UN agencies: United National Development Program (UNDP), UNICEF, United Nations Population Fund (UNFPA), World Health Organization (WHO), and United Nations Industrial Development Organization (UNIDO).

protocol, while the rest of codes, including Environmental Factors, included in focused protocols, were used for development of individual service delivery plan for provision of need-based support and services.

Other reforms that resulted were:

- The MOLSA and the Ministry of Education, Science, Culture and Sports (MOESCS) agreed to exchange data on children during SEN assessment and provision of services, particularly the Republican Pedagogical Psychological Center (RPPC- under the MOESCS) and Medical-Social Expert Committees (under MOLSA).
- ICF-based checklists were created for common conditions for early identification and intervention for children (such as cerebral palsy, autism and mental/intellectual developmental delays) to be used in the rehabilitations centers within health sector. The Ministry of Health (MOH) approved updated Licensing Requirements, Regulation and Norms on Provision of Rehabilitation Services for Children with Developmental Delays and/or Disabilities.
- A rapid assessment of rehabilitation services for children with disabilities and developmental delays was initiated in 2018 to identify the gaps and develop recommendations for strengthening pediatric rehabilitation services.
- A draft of the Law on the Rights of Persons with Disabilities was submitted to the Parliament in 2018, which was annulled in favor of two laws, *The Rights of Persons with Disabilities* and *The Law on Functional Assessment*, which were eventually approved in 2021. The Law on Functional Assessment will come into force in the beginning of 2023, while 2022 will be used to develop and approve related by-laws and regulations.
- With respect to administrative data, the RPPC supervises the maintenance of regional center databases on children with special education needs (both with disabilities and not) receiving educational services across the country. The introduction of the database on SEN assessment into the Education Management Information System (EMIS) is in process.
- In the case of pre-school children, the commitment for inclusive education was

confirmed by the revision to the Law on Pre-school Education, adopted in May 2021, which regulated assessment of SEN and provision of pedagogical-psychological support services. A transition plan was approved to develop SEN and child development assessment tools and procedures, for professional support training of staff at the regional centers by the RPPC.

Disability Assessment, Needs Assessment and Special Educational Needs Assessment

Since the enactment of the “Assessment of Functionality of the Person” on May 5, 2021, Armenia has established an organizational system of ‘assessment of functionality’ as the legal basis for determining eligibility of persons with disability, adults, and children for services. A ‘person with disabilities’ is defined according to the Law on the Rights of Persons with Disability as “a person who, as a result of the interaction between person’s physical, mental/intellectual, psychological and (or) emotional long-term problems and environmental barriers, may have a restriction for their full and effective participation in society on an equal basis with others”: “Independent life- a set of environmental and individual factors and services, which enables a person with a disability to make decisions related to his daily life, to choose living place, to live in the community, to use the community services intended for the population opportunity on an equal basis with persons without disabilities.” Finally, the ‘assessment of functionality of persons’ is defined as “...an ongoing process that involves a person’s health problems, activities and participation, and environmental barriers to recognize (or to reject) a person with a disability, to determine the degree of limitation of a person’s functionality, and to determine social services adequate to individual needs...”

These definitions reflect a salient feature of the Armenia situation: the use of the same assessment methodology for both disability assessment and needs assessment. Identifying as components of assessment of functionality the person’s health problems, activities and participation and environmental barriers reflects the motivation to use the ICF model of functioning, and therefore, of disability as well. But international practice distinguishes disability assessment from needs assessment in this manner: Disability assessment is used to establish the whole person ‘status’ of disability. Once this status is formally established and a person is issued a certificate of disability, needs assessment is the next, distinct step, in which the needs of the individual that result from a

health condition and impairments are identified for the purpose of providing supports and services to optimize functioning. Finally, a disability certificate and the needs assessment are necessary (but not always sufficient) input into a process typically called eligibility checking and determination-- this individual is formally eligible to various social insurance and other social protection, etc., benefits if she or he meets other benefit and service specific eligibility criteria.

However, in practice the situation in Armenia appears to be that 'functionality assessment' is viewed as a two-step process using the same protocols in conjunction with the Methodological Guide, to collect information: firstly information from ICF items associated with the four types of 'disabilities' of Hearing, Visual, Mobility, and Mental (for adults also four chronic disease-types: cardiopulmonary, hematological, immunological, metabolic and endocrine); secondly, focusing on information from ICF 'd' and 'e' domains, namely activity and participation, and environmental factors a needs assessment is conducted to determine an individual service delivery plan. (In a parallel reform, since 2017 the MOLSA gradually introduced the provision of assistive technologies (AT) by means of a voucher system: in case of children regardless of the disability status, in case of adults the disability status is not mandatory, but the applicant should be included in a pre-defined socially vulnerable group.)

The concern here is that disability assessment should be an assessment of the overall, summary disability a person experiences while a needs assessment should be a highly individualized assessment to determine needs. It is reported that the protocols currently in use have been validated. These focused protocols are not yet in use, but it is reported that they were tested in 2019, where it was determined that these protocols are more comprehensive and complete, and so more suitable for needs assessment. No testing reports were shared with us, and we have no information about psychometric validity and reliability of the protocols. A scoring method, based on the 5-point ICF response options, was devised. It was decided that a total score between 0-30% meant that the person is independent, has no disability although may require preventive services to prevent development of further complications of the

functioning; 30-50% meant that a person can live independently but with some supportive services, such as AT; 50-75% meant that in order to manage everyday life a person needs regular support and AT; and finally that 75-100% meant that a person has profound disability and requires very intensive care and provisions.

Early identification and rehabilitation intervention

To improve early identification of children with developmental problems in Armenia, a plan for early Intervention was developed in collaboration with UNICEF and approved by Ministry of Health in 2005. The plan described a three-level system of early identification, assessment, and rehabilitation of children with developmental disorders. As a next step, a special chapter on early intervention and rehabilitation was included in the National Strategy for the Child and Adolescent Health and Development and Plan of Actions for 2015-2020.

Pediatricians, family doctors and nurses conduct screening and assess children using Child Developmental Inventory-Harold Ireton¹⁶. Both Ages & Stages Questionnaire (ASQ) and Parents' Evaluation of Developmental Status (PEDS) have been piloted and used within specific projects, but not introduced nationwide. The screening is being performed during the 0-5 age group growth monitoring and health child visits (partially combined with other screenings and vaccinations) and consists of clinical examination and questionnaire to be filled by health workers and parents. Proper implementation of the screenings leads to identifying the children of risk group for future reassessment and referral to other levels of care.

Since 2005, Armenia in collaboration with partners and sponsors (e.g., Zurich Kinderspital, Japan Government, Jinishyan Memorial Foundation, Armenian Eye Care Project Charitable Foundation) implemented neonatal screenings for congenital hypothyroidism, phenylketonuria, hearing, congenital hip dislocation and some vision disorders. Community and primary care services for early childhood interventions, besides general out-patient care, include access to rehabilitation services for all children as well. Overall, there is no structured system of community-based rehabilitation services in Armenia, but there

¹⁶ Assessing children's development using parents' reports. The Child Development Inventory. Clin Pediatr (Phila). 1995 May; 34(5):248-55. Ireton H1, Glascoe FP

are several NGOs acting at community level in some regions and providing basic rehabilitation services. Specialized, secondary, and tertiary level, rehabilitation is provided by multidisciplinary teams, including occupational therapists, physiotherapist, speech therapists, psychologists and physical medicine and rehabilitation physicians.

Armenia reform of the Special Educational Needs Assessment

Armenia has spent considerable effort to reform SEN. Since 2007, the Yerevan Medical Psycho-Pedagogical Assessment Centre has had the mandate to “identify and assess children’s physical and/or psychological development characteristics to inform the way in which provision is made for their education as per their established abilities and capabilities”. The Centre was responsible for SEN assessment and providing educational institutions with program recommendations suited to meet educational needs. Prior to 2013, only medical information was used to assess special educational needs. Since then, the Armenian Government has made efforts to reform its disability determination generally, and for SEN by making various attempts to integrate ICF into the system. The 2014 Law on General Education established 2025 as the year in which Armenia’s education system would be fully inclusive. The three-tier system for special educational needs assessment was established. Yerevan Medical Psycho-Pedagogical Assessment Centre was renamed into Republican Pedagogical-Psychological Center with revised charter that specifies roles of the Center in the full cycle of the special educational needs assessment, service provision, monitoring and evaluation process.

Up until 2017 the MOESCS supported the Special Education Needs Assessment Criteria which included 20 items from five groups (voice and speech, auditory, visual, intellectual, motor skills). Some of the items are identified by code number as ICF body function and activities, others appear to be merged ICF categories (e.g., “functions of walking, moving around and keeping the body position”), some are only roughly linked to ICF categories (e.g., “emotion expressiveness and management of emotions”), while a few are not ICF categories at all (e.g., “behavior control”).

Based on the consultants’ observations since 2019, a fundamental revision of the SEN assessment toolkit for school age and development of the

special education and development need (SEDN) assessment toolkit for preschool age children was initiated in 2021. SEN assessment is conducted within the education sector (in all education settings to support continuity during entry into education, and during the transitions from one educational level to the next). There are plans for data sharing with other sectors to ensure comprehensive services and avoid redundancy. Currently the Toolkit has assessment protocols by age groups for seven domains: speech and language, motor, hearing, vision, mental, communication and behavioral-emotional. Each protocol lists activity and participation domains and environmental factor items relevant to each domain. The Toolkit also lists international standard assessment tools that assess educational needs, by age group. Some of these international tools are compatible with the ICF, others are not. Finally, the toolkit presents a revised Individual Education Plan template including general and specific education goals, environmental adaptation goals and required assistive technology aids. (A separate group within SEN disaggregation for children with exceptional abilities is under discussion.)

It is reported that children can undergo SEN without having a prior disability assessment- SEN is a needs assessment designed to identify educational needs that may, or may not, be linked to an underlying health problem resulting in a limitation of functioning. It has been reported to us that the SEN assessment takes place in two stages: all children identified as having difficulties in school are assessed in the school to determine if the learning difficulties are the result of underlying health problems or to the fact that the child speaks a different language, is an immigrant and so on. A methodological guide is provided to the school for this assessment. If the health-related functioning problem is identified, then at a second stage, the SEN assessment, as described above, is conducted by the Regional pedagogical-psychological support centers (RPPSC).

The Armenian ICF Assessment Protocols

The functional assessment protocols used for both disability assessment and needs assessment for both adults and children (by age group) are built around the four functioning domains (called ‘disabilities’ in the legislation and forms): Motor, Hearing, Visual and Mental. In case of adults also chronic conditions are considered. Each domain is represented by several ICF terms, using the ICF five-point qualifier scale. The SEN

protocols are divided by age group (3-6 years, 6-10, 10-14, 15-18). The recently revised Special Education and Development Needs Assessment Toolkit (2021) lists currently used and proposed international instruments by age groups. These instruments are linked to SEN categories and domains of development. These categories and domains are (more or less) the same ones used in the ICF protocols (by age group), namely Motor, Hearing, Visual, Mental, Speech and Language, Communication, Behavioral-Emotional.

To support and guide the completion of functional assessment protocols detailed methodological guides linked to ICF scoring are being developed to ensure that two assessments of the same individual will have similar results. In a parallel activity, international standard tools and open-source available tests (such as the Gross Motor Function Measure (GMFM) for ICF Activity and Participation Mobility domain, Canadian Occupational Performance Measure (COPM) for the Self Care domain and Matching Assistive Technology (MATCH) for the Environmental Factor Products and Technology domain) are to be adapted and validated for later introduction.

We note that, generally, developing assessment tools that have sound psychometric properties of validity, reliability and sensitivity to change over time, is a substantial research effort and requires time and resources to accomplish successfully. Although Armenia's endeavors are welcome, this should be kept in mind going forward.

2.2.2 Georgia¹⁷

Reforming disability assessment of children in Georgia

Since 2001 the governing legislation on disability and needs assessment for children in Georgia was the Law on Medical and Social Examination. Article 10 refers to the medical model of disability by stating that "Disability comprises substantial physical, psychical, intellectual or sensory impairments, which cause temporary or permanent limitation of capabilities"; a definition which ignores the impact of the person's environment. Limitations of capacities are identified by severity as mild, moderate, severe, and major, with disability status established only as moderate, severe and major. With respect to

children, the Law specifies that disability status of children is established when the person has been determined to be disabled before reaching the age of 18. There is no provision for recognizing levels of severity of disability in children.

For children, the process was based on certification governed by the N62/5 Order of the Ministry of Labor, Health and Social Protection that establishes the "Status of a Children with Limited Abilities". After a medical examination a decision was made, in a healthcare facility, of the severity of disability, and once status was granted, the Social Service Agency (an agency of the Ministry of Internally Displaced Persons from the Occupied Territories, Labor, Health and Social Affairs – MOIDOTPLHSA) provides disability benefits – cash and in-kind. For its services and assistive technologies, a separate application is required.

In March 2018, UNICEF and the MOIDOTPLHSA reviewed the process in the Adjara Region of Georgia and found the assessment and disability determination process problematic in that it was based entirely on medical information, was stigmatizing, and for children, not only were developmental problems (such as Down Syndrome and Autism) not recognized, but the procedure did not differentiate levels of disability resulting in identical benefits for children with different disability levels. Moreover, there was little cross-sectorial and inter-ministerial collaboration making it difficult to implement reforms in the education sector for more inclusive education for children with disabilities.

In April 2019, UNICEF Georgia, supported by MOIDOTPLHSA and the Georgian Association of Social Workers (GASW), began a nine-month pilot study of disability assessment and determination of disability status (for adults and children) in the Adjara Region. (A later pilot in Tbilisi addressed unanswered questions in the Adjara pilot.) The pilot aimed to introduce a functioning assessment, a needs assessment called 'social assessment' and a case management system within the existing system that is based on medical examination.

The objective of the pilot was to develop ICF-aligned assessment instruments for children and adults with disabilities based on the biopsychosocial approach and to incorporate this

¹⁷ Sincere gratitude to Ketevan Melikadze from the UNICEF Georgia Office for time and help with information gathering and the report preparation. The full version of the Georgia Case Study is available as a separate publication.

approach into the status determination process, by means of two additional kinds of assessors: the **Case Manager** and **Functional Assessment Specialist**. The physician-coordinator continued as before to assess functioning from the medical perspective and provide a medical diagnosis of the overall health condition and functioning from the medical perspective and a medical diagnosis to the participant. Originally for children, no degree was determined, but after the Tbilisi pilot addressed this issue, a scoring system for the child functioning instrument was developed to determine a degree of disability.

The piloted **Social Profile Questionnaire** (currently being updated) is essentially a needs assessment instrument used for both adults and children and includes a medical assessment (focusing on vision, hearing, motor, mental and intellectual domains) and collects basic information about education, employment, and residence. It enumerates supports and services, from personal assistant, assistive devices, social services, and cash benefits. The Functional Assessment for adults was WHO's WHODAS 36 question version. For children it is the **Child Functioning Assessment Tool**, a 57-question instrument based on the WHO's Model Disability Survey (MDS). This tool was developed, piloted, and validated by the consultant Educational Policy and Research Organization, using a Rasch modelling approach. The questionnaire is administered by a Functional Assessment Specialist. Only parents or the child's legal representative respond to questions. To ensure 'meaningful participation' of the child in the assessment process, a concept and guidelines were developed with support from UNICEF and submitted to the MOIDOTPLHSA.

The decision-making process for disability status determination in the pilot and subsequently, is to use the functioning assessment scores to define severity of disability and the medical assessment to verify that this functioning profile corresponds to the health condition of the person. (This raised the issue of what to do when there is a conflict between the functioning score and the medical diagnosis, and the multidisciplinary meeting does not reach an agreement. It is reported that an algorithm is being developed to resolve these conflicts.)

Current situation for childhood disability assessment, status determination and needs assessment

The *Law on the Rights of Persons with Disabilities* was approved by the parliament of Georgia in July 2020. Besides reiterating provisions of CRPD, it requires a transition from the current medically oriented disability assessment system to the social model, based on the lessons learned from the pilot. Specifically, Article 26(1) states that "The establishment of the status of disability for a person shall be based on a biopsychosocial model.... The status of disability within the biopsychosocial model shall be determined on the basis of the assessment of the functional abilities and health status of a status seeker..." The biopsychosocial model is characterized in subsection (2)(k) as a model for "determining and measuring a person's health status and disability and forming a policy which is focused on psychological, biological and social factors, and that considers the relationship between the human body/organic system, behavioral style, cognitive processes, and environmental factors in combination." Finally, Article 37(2)(a) explicitly requires that the Ministry "ensures the approval of the plan of activities to be implemented with respect to the introduction of a biopsychosocial model mechanism for establishing disability status" before 1 January 2023.

The current aim, based on UNICEF consultant's recommendations, is to fashion a single stage process for children in which information relevant to both the decision about disability status certification and the results of a complex and individualized needs assessment (leading perhaps to a personal plan under a case management arrangement) are done at the same time. However, in certain municipalities, the process has remained as two stages: a combination of medical and functioning assessment determining disability status, followed by a needs assessment using an interdisciplinary and functioning-based approach.

Current outstanding issues

Assessment Instrumentation

- Although the Children Functioning Assessment Tool One is structured similarly to and uses the same domains and question patterns as the WHO's Model Disability Survey, and although numerical qualifiers are provided, currently there is no standardized way for recording or reporting the results of the tool, or a way of summing up the individual results for a single disability assessment score.

- The Report on the Standardization of the Functional Assessment Instrument for Children with Disability conducted by the Educational Policy and Research Association in 2020 was inconclusive regarding the validity or reliability of the Tool as a whole, although there was some success in modelling some combination of items of the total 57 items in questionnaire.
- Some of the functional assessment specialists found it difficult to assign the severity levels of mild, moderate, severe, extreme to the functioning domains. It was thought that if the tool was more standardized and more thoroughly validated that it would better capture the child's functional status.
- As the questions in the Tool are not asked to children directly but their parents, there is a concern that the responses may not accurately reflect the experience of the child, and indeed may have downplayed the actual difficulties that the child experienced. As noted above, this issue is expected to be addressed by a recently developed tool.
- The medical assessment includes ICF body function and structure domains, to describe the medical state, as well as the activities and participation domains from the performance perspective. The former is used to validate the latter. International practice suggests that the order should be reversed since functioning assessment instruments, such as WHODAS, offer a more valid construct of ICF disability than medical assessment instruments, so it would be better to validate the medical assessment in terms of true functioning assessment tools.

Decision-making

- Without a summary score or established psychometric properties of the medical assessment and the Functioning Assessment Tool, it is not possible to determine whether, or to what extent, the decision of the three-member team is governed by the Tool or is simply discretionary, in the sense that there is no scientifically reliable correlation between the evidence for the decision and the decision itself.
- In the case of needs assessment, the concern about discretionary decisions is less important, as needs assessment should be an individualized assessment allowing for

particular variations.

- During the pilot, it was observed that in the multidisciplinary meetings, the medical specialists sometimes tended to dominate, with the result that the medical diagnosis also dominated the final decision about the disability status.
- When there is a conflict between the determination of functioning status by the Functioning Tool and by the medical assessment, some statistically sound protocol, or even algorithm, should resolve the conflict.

Staffing issues

- In terms of capacity building, the doctors, case managers and functioning specialists should all undergo pre- and in-service training that includes learning about the biopsychosocial approach (that is, the interactional model of functioning and disability in the ICF), introduction to the assessment instruments, and training on how to administer the tools. UNICEF is collaborating with the Ministry of Education and MOIDOTPLHSA to institutionalize training of functioning assessment specialists in the educational institutions. Curricula and training material are also being developed.

Other issues

- As the experience in other countries indicates, reforms are difficult to sustain, and the key is to secure coordination and cooperation between sectors. It is also important to develop professional support and supervision systems, and mechanism to monitor for quality control and prevention of fraud. UNICEF is working with the State Regulation Agency under MOIDOTPLHSA to develop capacity for professional supervision and a new system of monitoring.
- A special effort will need to be made to engage the Ministry of Education in the implementation of a new system of disability assessment and status determination. Procedures for determining special needs for education that are currently in place need to be coordinated with the new system.
- A mechanism for identifying developmental issues in children below the age of 2 is currently being developed.

2.2.3 Moldova¹⁸

Reforming disability and needs assessment of children in Moldova

Moldova reformed its disability assessment system in 2012 by adopting the *Law on Social Inclusion of People with Disabilities*¹⁹ and related operationalization and implementation government decrees²⁰. The Law adopted definitions and language from CRPD and moved to determine disability in terms of medical and functioning information.

This law regulates the rights of disabled people for their social inclusion, ensuring the possibility of their participation in all areas of life without discrimination, at the same level with other members of society, enjoying all basic rights and fundamental freedoms. It defines a disabled person as a person with physical, mental, intellectual, or sensory disabilities which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

According to the Law, disability of children under the age of 18 years is determined based on “the severity of deficiencies in individual functioning caused by diseases, impairments and traumas that lead to activity limitations and participation restrictions expressed in relation to psychosocial functioning corresponding to the child’s age and is of three degrees: very severe, severe and moderate”.

²¹ Employed older children (15-18) are assessed for work capacity under the rules for adults.

Very severe disability is granted to children who, in relation to their age, have not yet developed, or have lost capacity for self-care, and have a high degree of physical or mental dependence. The autonomy of the person is very low due to very severe limitation in activity. The child requires constant care and supervision from another person.

Severe (“accentuated”) disability is granted to children unable to carry out activities according to expected development and age due to important functional limitations of motor, sensory,

neuropsychic or metabolic body functions resulting from severe, advanced health conditions, with complications.

Moderate disability is granted to children who have reduced physical (motor, metabolic) or intellectual capacity, corresponding to a low functional ability, which leads to limitations in activities and participation relative to the expectations corresponding to the age.

The Law also regulates benefits for persons with disabilities in health, education, social protection, housing and transport and communication.

The Law established the National Council for Determination of Disability and Work Capacity (CNDDCM), whose responsibility is to determine disability and needs of children and adults²². The CNDDCM is under the Ministry of Health, Labor and Social Protection. Disability assessment and determination is a single process (for adults, children, general diseases, and work accidents and professional diseases). The administrative process is designed to minimize rent seeking opportunities by, for example, randomly assigning cases to the assessment teams in the morning and requiring them to complete the assessment that day. The assessment is based on a comprehensive set of documents that include medical status, information about functioning (WHODAS for adults, and a 93 item Activities and Participation Questionnaire for children), information from the employment office and social protection office, information from a responsible psycho-pedagogical assistance service or early intervention service (for children). The information serves a dual purpose: to determine the degree of disability (moderate, severe or very severe) and to determine the needs of a person. The latter serves as a basis to formulate an Individual Program of Rehabilitation and Social Inclusion. The Program covers needs for medical care and rehabilitation, assistive aid, accommodation, educational needs, social protection needs, and employment support. The certificate of the degree of disability and Individual Program are both issued by the same

¹⁸ Sincere gratitude to the UNICEF Moldova and Geneva Office staff and Ms. Stela Pinzaru from the National Council for Determination of Disability and Work Capacity for time and help with information gathering. The full version of the Moldova Case Study is available as a separate publication.

¹⁹ The Law on Social Inclusion of People with Disabilities. Law Number 60 from March 30, 2012. <https://cnddcm.msmps.gov.md/legislatie/>: <https://www.lawyer-moldova.com/2012/08/law-on-social-inclusion-of-people-with.html/>.

²⁰ Government Decision No. 357 from April 18, 2018, On the Determination of Disability. The Official Gazette No. 126-132 art. 399 from April 20, 2018. https://www.legis.md/cautare/getResults?doc_id=119169&lang=ro/.

²¹ Ibid. These qualifiers replaced the previous disability categories I, II and III, respectively.

²² The website of CNDDCM is <https://cnddcm.msmps.gov.md/>.

NCDDMC assessment team. The system is simple and straightforward and appears integrated, with NCDDMC serving as a gateway to existing benefits and services with an institutionalized monitoring and feedback loop.

Disability and needs assessment system

The Government Decision No. 357 from April 2018²³ lists 21 tasks for which CNDDCM is responsible, including determination of the degree and duration of disability according to the approved criteria; establishing circumstances and a cause of disability; formulating general recommendations on the needs for rehabilitation and social inclusion of person with disabilities and ensuring monitoring of their execution by responsible institutions; storing and keeping all records of disability assessment and reassessment in the Automated Information System (AIS), including audio recording of the meetings and the video monitoring of the work process, issuing a Certificate of Disability and an Individual Program of Rehabilitation and Social Inclusion (Individual Program); and ensuring scientific and methodological improvements concerning criteria for determining a degree of disability.

The Decision establishes the CNDDCM's organizational structure, which includes: a Scientific and methodological development, analysis and evaluation unit, a Control of the disability degree determination unit, the Service for determining disability degree, and Territorial structures. The service for determining disability degree is organized in 15 teams of which 12 for adults and 3 for children. Each team determining disability of children is composed of 3 disability determination experts with higher education in medicine (pediatric), psycho-pedagogy and rehabilitation. This service determines degree and duration of disability, and associated needs for support. Territorial structures of the CNDDCM inform the citizens about procedure for determining the degree of disability and receive and process documents required for disability assessment.

Application process: The process of disability assessment starts with a reference sheet (Form F-088/e, printed format) issued by a medical institution. The referral must indicate the state of health of the applicant, including a degree of

problems in body structures and body functions, as well as the results of treatment and rehabilitation measures. It can be issued only after all available treatment and rehabilitation measures have been exhausted. An application and a reference sheet should be submitted to a CNDDCM territorial structure where the applicant's address is.

The application can be submitted personally, by an appointed representative or online. The application must be registered in the Register of Applications, and the applicant is issued personally or electronically a receipt where the date, the registration number and the responsible person who received the documents are indicated. For children, a dossier for determining a degree of disability and needs, in addition to the application documents, also contains the following documents, which the territorial structure obtains ex officio: a standardized form issued by a psycho-pedagogical assistance service or an early intervention service, with information about the child's development, services she or he has received, situation regarding education, training, rehabilitation, etc.; and standardized form issued by a territorial office of social assistance, with information on the family and household composition, socio-economic situation, benefits and social services received, etc.²⁴ The territorial CNDDCM's structure compiles the electronic file and transmits it to the registration and archiving office.

Criteria for assessing a degree of disability:

NCDDNM determines whether a person has a disability and at what degree based on the person's file, and in the presence of the person at his/her request, respecting the approved criteria. "In the process of determining the degree of disability, the responsible persons analyze the documentation from the person's file, which also contains data on the health status of the person and the severity of the individual functional deficiencies caused by diseases, traumas, which lead to activity limitations and participation restrictions expressed in relation to the psychosocial functioning corresponding to the age, in the case of children under the age of 18, and socio-professional demand, in the case of adults of working age."²⁵

In assessing disability, medical, social, psycho-pedagogical, professional, personal and other should

²³ Ibid.

²⁴ Examples of relevant standardized forms are provided in the full version of the Case Study published separately.

²⁵ The Government Decision 357. Ibid.

be taken into account. Basic factors are ability to study and train, intellectual skills and behavior, self-care ability, communication skills (seeing, hearing, speech) and ability to adapt, motor skills and dexterity, capacity to work, capacity to participate in social and professional life as determined by long-term physical, mental, intellectual or sensory impairments. The Government Decision lists the following causes of disability: general medical condition, congenital disease, childhood affliction, occupational disease, accident at work, a condition related to participation in the liquidation of the damage caused by the Chernobyl Nuclear Plant disaster or in other nuclear accidents, medical condition related to military or special service.

Duration of disability: Depending on the situation, the degree of disability is established for a period of 6 months or one year. For cases where a longer period of medical treatment and rehabilitation or social assistance and/or psycho-pedagogical assistance (in the case of children) is required, it could be for a period of 2 years. In cases where the conditions are considered irreversible, the duration of disability could be without a time limit.

Issuing a Certificate and an Individual Program of Rehabilitation: Upon the decision on the degree and duration of disability, a person is issued a certificate. A certificate is also issued to a person assessed as not having a disability. For those with a determined degree of disability, an Individual Program is issued as well. It contains recommendations on benefits and services in health, social protection, education and employment the person needs in the process of social inclusion. Local authorities responsible for these sectors implement recommended benefits and services. The certificate of disability and work capacity, as well as the individual program of rehabilitation and social inclusion are subject to strict data privacy protection rules. In the conduct of official duty, they are shared with the relevant social insurance and social assistance bodies, as they are responsible for implementing actions from the Individual Program. The certificate and the individual program are issued to the applicant, who can contest the decision within a certain period and following prescribed grievance procedures.

Specific criteria to determine disability of children

On January 28, 2013, then Minister of Labor, Social Protection and Family, Minister of Health

and Minister of Education issued a Joint Order No. 13/71/41 approving Criteria for Determining Disability of Children under the Age of 18²⁶. The order contains (i) a list of diseases and pathological conditions for determining disability in children; and (ii) a questionnaire to assess children's capacity and performance in activities and participation. The order specifies that both should be used to determine disability of a child and to prepare an individual rehabilitation and social inclusion program.

In January 2019, CNDDCM issued an Order to pilot new criteria for determining disability of children based on the World Health Organization International Classification on Functioning, Disability and Health – Children and Youth version (WHO ICF-CY). The pilot testing included testing of the Social and Educational Criteria for Children with Disabilities (Evaluation questionnaires of children's abilities and performance in activities and participation as well as environmental factors). However, because of the COVID-19 pandemic, the pilot testing could not be concluded. CNDDCM is planning to conduct the pilot anew, which is an excellent opportunity to review the questionnaires, to keep them abreast with the scientific developments in this field. Meanwhile, the Order No. 13/71/41 remains in effect.

A list of diseases provided in the Order, contains 200 diseases from the 17 ICD-10 Chapters (but without individual ICD codes). To each listed health condition, a level of the degree of disability is assigned as very severe, or severe, or moderate. This link between a health condition and severity of disability is not backed by science: health conditions are determinant of disability, not disabilities. According to the ICF, a disability is the experience of a health condition in the person's everyday life (as expressed by activity limitations and participation restrictions). It would be better simply to list health conditions and then during the assessment process establish whether the associated impairments are mild, moderate, severe, or complete – these are the ICF qualifiers). In this way, a very important input into the determination of disability will be provided, opening room for an automated algorithm for combining medical and functioning information.

The second part of the assessment pertains to the assessment of performance, i.e., activity limitations and participation restriction. Information on activities and participation is

²⁶ http://www.ms.gov.md/sites/default/files/legislatie/ordinul_nr_13_71_41_din_28.01.2013.pdf/.

collected using a questionnaire, which comprises three sections: 1. Personal information, 2. Demographic information (gender, age, level of education the child is enrolled in), and 3. Activities and Participation. The activities and participation section contains 9 domains with 93 categories of the ICF Activities and Participation classification. The categories are age-specific (0-3, 4-6, 6-11 and 12-18 years of age) and only children in the age 12-18 are expected to be able to perform all of them. The interview is conducted with the child and her or his parent or a guardian, or, depending on the child's situation a representative of the social service, or educational or medical institution. It lasts about 10-15 minutes and is administered at the territorial CNDDCM office. The collected information is confidential and will be used only by specialists involved in the assessment process.

Each item is assigned 1 or 0: 1 – when the child can perform activities and participation, according to the age group; or 0 – when the child cannot perform activities and participation, according to the age group. For each domain, according to the age group of the child, a sum of points is derived, which are then all summed up into a single score. Below is the example for children 0-3.

The score accumulated in all fields relevant for the child old 0 – 3 years (*interval 0- 24 points*)

- Up to 5 points – the child's abilities and performance in activities and participation present a **very severe (complete)** problem,
- From 6 points up to 11 points – a **severe** problem,
- From 12 points up to 17 points – a **moderate** problem,
- From 18 points up to 23 points – a **mild or slight** problem,
- 24 points accumulated – the child's abilities and performance in activities and participation **do not** present a problem.

The model of disability and needs assessment in Moldova has many positive features such as the inclusion of functioning in disability status and needs assessment, well-organized and

straightforward administrative process, referral to services through the Individual Rehabilitation Program and so on. There are also some concerns. To the best of our knowledge, the A&PQ was not tested psychometrically before being deployed in 2013, so it is impossible to determine whether it validly captures the ICF construct of disability. Secondly, there are only two response options: NO (0) or YES (1). While 'no' is clear, the 'yes option does not tell anything about whether difficulty is mild, moderate, severe or complete. It is preferable to use the ICF options of no (0), mild (1), moderate (2), severe (3) and complete (4) difficulty. Thirdly, the overall score is calculated by simple addition by groups. Without statistical analysis, the validity of the score is questionable. Fourthly, there is no information on how the medical, functioning, and other information are combined by members of the determination teams to come to the decision of 'no disability', 'moderate', 'severe' or 'very severe' disability. The forthcoming piloting of the new instrument for determining disability of children provides an opportunity to develop psychometrically valid and reliable instrument and an empirically based scoring algorithm. Another concern is that disability status and needs assessment are determined based on the same information. As pointed out already, these are two different process and need to a large extent different information.

2.2.4 North Macedonia²⁷

Reforming disability assessment of children in North Macedonia

At the end of 2021, North Macedonia introduced a new model of disability and needs assessment of children and youth up to 26 years of age²⁸. It collects information needed for both a status assessment of disability and the needs assessment, and includes a referral to available education, health and child and social protection services and benefits. It is aimed at an integrated response to persons with disabilities' needs for health, educational, and social protection support. The assessment is thus expected to serve as a single-entry point for children and youth to access various support services in health, education and social protection that would enable them to fully

²⁷ Sincere gratitude to the UNICEF North Macedonia staff and Goran Petrushev from the Center for Functional Assessment and Support of Children and Youth, Health Center Skopje and Lidija Dojchinovska, Advisor, Office of the President. The full version of the North Macedonia Case Study is available as a separate publication.

²⁸ In North Macedonia, according to the Law on Child Protection, a child is a person up to 18 years of age and for persons with physical and mental disabilities, up to 26 years of age.

participate in social life and enjoy their human rights.

The reform, with close engagement of UNICEF, had been prepared for several years. It includes both institutional changes, as well as changes in the assessment criteria, orienting them towards an assessment of functioning. The change required several laws to be amended. The amendments to the Law on Social Protection, the Child Protection Law, and the Health Insurance Law were adopted at the end of 2021. The amendments to the Law on Health Protection are pending²⁹. With the amendments to this Law, the disability assessment will become legal responsibility of the Public Health Institution Health Center Skopje, the cost of the assessments will be covered by the Health Insurance Fund, and the beneficiaries will be enabled to make appointments for this service through the electronic system for scheduling of the public healthcare services.

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

Current disability and needs assessment of children

Several laws and bylaws pertain to the assessment of disability of children and youth (until the age of 26) and their access to benefits.

*The Law on Social Protection*³⁰ regulates issues pertaining to social protection (specifically social assistance and social welfare services) of the population. According to this Law, persons with disabilities are “persons with long-term physical, intellectual, mental or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.” Social risk is a situation that potentially can make it difficult or to prevent

social functioning of an individual, family or a particular group, which may result in the need of social assistance. The main social risks in the context of this Law are motherhood, disease, age, death, injury, and disability.³¹ The Law provides a list of types of monetary assistance and social services provided to persons who satisfy eligibility requirements. Article 295 regulates that centers for social work based on the findings and opinion of a professional body decide on the type and degree of disability and record the person with disability for the purpose of awarding cash benefits. The method for determining the type and degree of disability is regulated by the Minister of Social Protection in agreement with the Minister of Education and Science and the Minister of Health.

*Changes to the Law on Social Protection*³²: “The Draft Law ... aims to allow the application of a new model for assessing the needs of persons with disabilities. The model is designed in accordance with the International Classification of Functioning (ICF). The Draft Law ... establishes that a functional assessment of children and young people up to the age of 26, the determination of the need for additional educational, health and social support and the finding and opinion on the type and degree of disability are given by professional bodies carrying out a functional assessment.”³³

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

The Draft Law amends the Article 295 of the Law on Social Protection as follows: “The Centre for Social Work based on the finding and opinion of the Service for Functional Assessment at the Public Health Institution – Health Centre Skopje, decides on the type and degree of disability and records

²⁹ The Proposal for the Law on Changes and Amendments to the Law on Health Protection was submitted to the Parliament on November 30, 2021. The Proposal, in Article 6 states: “... The Public Health Institution Health Center Skopje, in addition to the activities of the health center for the area for which it was formed, can also perform activities, exclusively for the functional assessment of children and young people with affected health state up to 26 years of age, at its headquarters and in internal organizational units, as well as on the territory of the Republic of Northern Macedonia in expert teams for the functional assessment of children and young people with affected health state up to 26 years in Strumica, Stip, Veles, Bitola, Gostivar, Ohrid and Kumanovo”

³⁰ The Law on Social Protection, Consolidated and clean version that includes Basic text of the Law published in the Official Gazette of the Republic of North Macedonia 104/2019,

https://www.mtsp.gov.mk/content/pdf/zakoni/2019/28.5_zakon_SZ.pdf//. The Law has been amended afterwards several times; the latest changes were adopted in December 2021.

³¹ Ibid.

³² We only had access to the draft Law. We assume that the changes were adopted as proposed in the draft.

³³ The source for this citation is the explanation accompanying the draft Law.

the person with disabilities.” This rule pertains to eligibility for benefits in cash provided to persons with disability.

The Law on Child Protection: This Law stipulates that a child up to 26 years of age with disability in physical or mental development with specific need has the right to a special allowance (Item one, Article 32). “Finding, assessment and opinion on the right to a special allowance is issued by a professional body for the assessment of type and level of disability in physical or mental development” (Item 2, Article 32)³⁴. To receive a special allowance, the child with developmental disabilities and specific needs in the context of this law (Article 33) is a child with:

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

*The Rulebook for the assessment of type and degree of disability of persons with physical and mental disabilities:*³⁵ The Rulebook pertains to children and young people up to 26 years of age. In Article 4, this Rulebook states that “for the purpose of the Rulebook, persons with disabilities in intellectual and physical development who have special needs are persons with: impaired vision (low vision and blindness), impaired hearing, voice, speech and language disorders, body (physical) impairments, intellectual impairments (mild, moderate, severe and profound), autism spectrum and other pervasive developmental disorders chronically ill person, and persons with several

types of disability.” Each of these 8 categories of impairments and disabilities is separately described and defined and each has its own specific categorization of disability (except for autism, chronically ill and multiple disabilities).

For example, Article 8 defines persons with physical development impairments as person with decreased or lost function of one or several body parts that decrease the person’s capacity to satisfy basic life needs. Depending on the degree of impairment, persons with physical development impairments are classified in the following groups: (i) a person with severe impairment in physical development is a person who can independently meet her or his basic life needs with the assistance of technical aids and accommodation in physical environment; (ii) a person with more severe impairment in physical development is a person with who can independently meet her or his life needs but only with the help from other person; and (iii) a person with the most severe impairment in physical development is a person who needs constant care and assistance from others to meet her or his basic life needs. Article 9 defines persons with impairments in intellectual development as persons with delayed or incomplete psychological development as characterized by impairment of age specific capacities, which contribute to the development of the general level of intelligence such as cognitive, speech, motor and social capacities. They are classified as persons with mild, moderate, severe and profound (‘deep’) disabilities in intellectual development. Each degree is then defined, including in terms of the IQ level. For example: a person with moderate disability in intellectual development shows delayed and limited development in the use of language and speech, self-care and motor development. In standardized IQ tests performs at about 35-49. The Rulebook also regulates other matters relevant for the assessment.

Changes under preparation

Currently, with UNICEF’s assistance, a new rulebook is being drafted: Draft “Rules on the Method and Procedure for the Assessment of Functioning and the Needs for Additional Educational, Health

³⁴ The Law on Child Protection, consolidated text.

³⁵ Ministry of Labor and Social Policy. Rulebook for the assessment of type and degree of disability of persons with physical and mental disabilities. The Official Gazette of the RM, 172/2016.

<http://www.zapovim.mk/dokumenti/propisi/Правилник%20за%20оценка%20на%20видот%20и%20степенот%20на%20попреченост%20на%20лицата%20во%20менталниот%20или%20телесниот%20развој.pdf/>.

and Social Support for Children and Youth”³⁶
This Rulebook, according to the information from government officials in charge of the reform, is meant to be a “transition” Rulebook (see above).

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

Persons with disabilities

Draft Rulebook defines a person with a disability as a person who has long-term physical, intellectual, mental, or sensory impairments, which, in interaction with various barriers, can prevent her full and effective participation in society on an equal basis with others. It then provides that “A person with a disability, for the purpose of this Rulebook, is a person with: impaired vision (low vision and blindness), impaired hearing, voice, speech and language disorders, body (physical) impairments, intellectual disability (mild, moderate, severe and profound), autism spectrum of disorders and persons with other pervasive developmental disorders, chronically ill person, and persons with several types of disability (persons with combined development impairments). For each of the above groups, the Draft Rulebook repeats provisions from the current Rulebook (see above).

Hence, during the transition period of three years, according to the Draft Rulebook, while North Macedonia adopted the ICF and CRPD definition of disability, for operational purposes, categorization of children and young people with disabilities will continue to be based on their health condition and impairment, although, in some cases a description of a degree of disability includes some description of activities and participation in terms of the ICF.

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

The assessment of functioning is carried out by a separate internal organizational unit, the Functional Assessment Service of Children and

Young People within the Health Centre-Skopje (The National Expert Body- NEB) and regional expert bodies covering entire country (for a total of 9 expert bodies). The NEB provides technical and methodological guidance to regional expert bodies, monitors the application of ICF, train staff to be engaged in the regional expert bodies, handles grievances, and trains wider audience (teachers, social workers) in ICF. NEB comprises a doctor, psychologist, a social worker and a special educator or rehabilitator. Based on the needs of the child, a specialist doctor from a particular medical field, speech therapist, and physiotherapist participates in the NEB proceedings. Similarly, a regional expert body is composed of a psychologist, social worker, and special educator or rehabilitator. Depending on the need of the child, other professionals may be involved. The parent and a person of trust chosen by the parent who knows the child well are also included.

The assessment is carried out upon a formal referral by a chosen family physician. The assessment can also be initiated by educational, health or social and child protection institutions or another social service provider.

The regional expert body begins the assessment procedure after receiving a referral from the person’s chosen doctor, meets with the child’s parents or guardian and receives required documents. The documents are transmitted directly or electronically to the expert body by the parent or guardian, seven days before the scheduled assessment meeting. One of the members of the regional expert body is to be responsible for the case as a case coordinator. She/he is responsible to ensure that all necessary procedures are carried out and that relevant information is collected and appropriately presented as a finding and opinion, and to take appropriate and timely steps to review the case. After the meeting with the parent or guardian, the regional expert body begins the assessment process and is due to complete it at the latest within 30 days. Its findings and opinion must be presented in the formal format (the relevant form is provided in the full version of the case study).

The regional expert body should develop a plan of interventions (in, health, education, and social protection) and a timeframe for its implementation. When the case is reassessed, the results achieved

³⁶ The Draft Rulebook was shared with the project team by the UNICEF North Macedonia Office staff. As it is being finalized, the changes are likely.

are considered, a control functioning assessment is conducted, and additional measures, if needed, are proposed. The period for reassessment cannot be longer than two years for children and young people up to 18 years of age. The regional expert body is obliged to carry out a reassessment at least three months before the young person reaches the age of 26.

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

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

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

In summary, institutionally, establishing a single gateway – a dedicated structure for the assessment of disability and needs of children and young people, with referral to responsible health, education and social protection authorities is a good institutional solution creating an institutional environment for an integrated system of support to children and young people with disabilities.

Criteria and method

The legal changes at the end of 2021 and the Draft Rulebook presented above state that the assessment of disability in children is “the assessment of functioning based on the ICF”. The Draft Rulebook does not make a reference to specific tools or instruments to be used to assess functioning or needs, or to any method to decide whether a child has a disability or what needs he or she has. The standardized reporting forms provided in the Draft Rulebook are: 1. A form for keeping records by the regional expert body with a

column for “type and degree of disability and ICD code”; and columns for recommended rights and services in health, education and social protection; 2. Findings and opinion on the state of functioning and the need for additional educational, health and social support to a child and youth comprising: information on the expert body that conducted the assessment; the child or young person’s personal information; description of the health condition (ICD code and current treatment) and expectations of parent and child; description of personal aspects and anamnesis; description of the environment (listed are all ICF “e” codes); body structures (all ICF “s” codes- body structure one level codes are listed – there are 8 of them), body functions: all body functions “b” codes (eight in total) are listed, with the assessment expected to identify the ICF specific code and its qualifier (no, mild, moderate, severe or complete impairment); activities and participation – all 9 domains are listed and for each of them the assessors are expected to provide, observations, ICF code, ICF qualifier (no, mild, moderate, severe and complete difficulty), and associated environmental factors – facilitators, barriers and description).

What remains unclear is how this information is collected – and validated – and more importantly, how the assessment is made in terms of that information, i.e., how all the information that is collected is combined into a holistic picture to determine on the one hand the child’s degree of disability and on the other her or his needs.

The ICF is a classification, not an assessment instrument. Normally, the countries choose only some of the items in a select number of domains, test the instrument for psychometric properties and, if valid and reliable, deploy it for disability status assessment. In other words, to decide about the ‘whole person’ level of disability – which is the aim of disability status assessment – it is necessary to use a standardized and validated assessment tool. Merely collecting information in terms of ICF categories and qualifiers is not an assessment, it is a collection of information. The resulting decision on the disability status, as it is presented, signals discretionary approach based on the assessors’ opinions about what the information means.

Similarly, there is no specific needs assessment instrument, which is crucial for assessing the needs (the status and the needs assessment need different instruments, although they could be administered as part of the same process).

Developing an instrument that is fit for purpose is a challenge, particularly given that needs for support in very different areas such as education, health and social protection are assessed. Hopefully, in the next three years, the authorities will develop, pilot test and deploy functioning and needs assessment instruments needed for valid and reliable assessment of disability and the needs, including special educational needs of persons with disabilities.

2.2.5 Serbia³⁷

Reforming disability assessment of children in Serbia

In the 2000s, Serbia reformed systems and policies aimed at protecting and supporting children with disabilities. The ratification of CRPD in 2009 further motivated the reform:

- Legally, Serbia moved away from a medical approach to disability to one based on the CRPD and ICF.
- Following the ratification of CRPD, laws and policies were changed to reflect human rights principles of non-discrimination, independence, individual choice, respecting dignity, participation in decision making, universal design and accessibility, and the right to live in a family and community.
- The 1986 rules for categorizing and classifying children with disabilities, in terms of their “capability” to enroll in education and decision on whether the child will attend mainstream or special education, based on medical criteria and inter alia including IQ measurement, were rescinded in 2009³⁸. In their place, the Municipal Intersectoral Commissions for the Assessment of Needs for Additional Educational, Health

and Social Support to a Child, Pupil and Adult (ISC) were created³⁹. They identify children with disabilities and developmental difficulties and assess their needs using tools based on the ICF notion of functioning. However, to access social benefits children are still assessed using medical criteria.

- New health, education and social protection benefits, and services were introduced to support deinstitutionalization of care, inclusion of children in all aspects of life in a family and community environment and independence.⁴⁰
- Institutional changes to support these policy reforms have been implemented, including the establishment of the above mentioned municipal intersectoral commissions for the assessment of additional support needs in health, education, and social protection. Also, efforts have been made to revive the developmental counselling units within the primary health care and to introduce the system of evidence-based, family oriented early interventions that are implemented by multidisciplinary team of professionals from three sectors (health, education, and social welfare) in child’s natural settings through home visits and visits to pre-schools.

As noted in various studies, however, there is a significant discrepancy between legal provisions and implementation on the ground, with an overall impression that progress has been slow⁴¹.

- Disability assessment for social welfare benefits is at its core medical.
- Many services crucial for inclusion of children with disabilities, including in education, are

³⁷ The full version of the Serbia Case Study is available as a separate publication.

³⁸ “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 the Republic of Serbia (RS), 16/1986. The legal ground was provided by the Law on Primary Education (The Official Gazette of RS, No. 50/92, 53/93, 67/93, 48/94, 66/94, 22/2002, 62/2003, 101/2005)

³⁹ For example, The Law on Social Protection, The Official Gazette of RS, 24/2011

⁴⁰ A more detailed description of benefits and services for persons with disabilities is provided in the full version of the Case Study published separately.

⁴¹ 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/>

responsibility of municipalities, which vary in financial and human resource, and some services are provided in only a handful of municipalities.

- Developmental counselling units, essential for early interventions in children with developmental problems, are functional in only a third of regions (not covering smaller municipalities at all) and many are understaffed and under resourced.
- While the ISCs were established in nearly all municipalities, they face operational, methodological, financing, and human resource problems.⁴²
- The case management in social work is yet to be fully implemented in practice.
- The deinstitutionalization process is yet to be completed and most children in institutions are children with disabilities; children younger than 3 years are institutionalized, 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 and special classes remain.
- Education, health, and social protection services are not coordinated.

Modalities of disability and needs assessment of children

Definition of children with disabilities: Serbia does not have an overarching definition of a child with a disability, which would apply to all sectors and policies relevant to children with disabilities. 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 the child*⁴³ (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”, while *The Law on Primary Education and Upbringing* (Article 10)⁴⁴ defines a “student with developmental difficulties 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”. *The Law on the Prevention of Discrimination against Persons with Disabilities*⁴⁵ 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.

Pathways to identify disability and access disability related benefits and services: Serbia ended a formalized system to categorize and certify children with disabilities in 2009. Instead, it currently features several ways to identify children with disabilities and developmental difficulties and several pathways to benefits in health, education, and social protection. Below we describe five separate mechanisms for identifying and assessing disability and needs of children with disabilities and developmental problems.

⁴² 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/dogadaji/vodic-za-interresorne-komisije-za-procenu-potreba-za-pruzanjem-dodatne-obrazovne,-zdravstvene-ili-socijalne-podrske-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/assets/publications/files/Analiza_interresornih_komisija_i_dodatne_podrske_u_10_opstina_i_gradova_CSP.pdf//.

⁴³ The Official Gazette of the Republic of Serbia, 56/2018.

⁴⁴ The Official Gazette of the Republic of Serbia, 55/2013, 101/2017, 10/2019, 27/2018, 129/2021.

⁴⁵ The Official Gazette of the Republic of Serbia, 33/2006, 13/2016.

1. Identification through the health system

Health conditions, developmental delays, and problems with functioning, particularly for younger children, are first detected 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 observable problems, it will be detected immediately.⁴⁶ 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 health services package. Throughout the early years, with the increased intensity in the first three years of the child, the parents /children are entitled to at least ten visits to the chosen pediatrician for health and developmental checkup and immunization. Developmental screening and monitoring used to rely on clinical examination by a pediatrician; recently, instruments based on parental report have become part of regular clinical practice (e.g., Ages and Stages Questionnaire recommended for use at least at the 9th, 18th and 24th month of a child). Depending on the seriousness of developmental delay, the parents are provided with counselling and additional visits to pediatricians and/or referred to a developmental counselling unit for a comprehensive assessment and support by multidisciplinary teams or referred to other levels of health care for further diagnostics. Health and developmental examinations are also conducted before children enroll in kindergarten or preschool and again before enrolling in school. Regular health checkups for school aged children are to be performed every 2 years (at 8, 10, 12, 14, 16 and 18 years of age), but as they were moved out from the school settings into primary health care centers their coverage has significantly decreased. Such checkups are particularly important for identification of health issues in pre-adolescents.

Anyone can raise concerns pertaining to the child's development, learning, and behavior, which in most cases would trigger a visit to the child's pediatricians. It has been observed that identification of developmental problems and seeking professional help is sometimes delayed. This may be because of parent denial, lack of medical specialists or medical

professionals not taking the issue seriously.⁴⁷ Not all developmental counselling units are operational, and some health professionals are unaware of early childhood development or screening tools. Finally, there is little coordination between the health and other systems.

Since 2017, new, evidence-based model of family oriented early interventions (ECI) started being implemented, introducing new paradigm in service provision- from assessment to family support. The new ECI 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 daily routines. It uses a routine-based interview with the parent(s) and observations and prompting behaviors with the child to assess child development and jointly with the parent(s) define functioning goals for the child and the family as part of the individualized family support plan. ECI services build upon already existing Developmental Counseling Units (DCU) in the primary health centers, bringing together professionals (psychologists, special educators, speech therapist, etc.) from DCUs, pre-schools and social welfare services into multidisciplinary ECI teams that provide direct support to families. New ECI model was piloted in 5 locations in Serbia, and it has gradually been rolled out to all 25 regions.

2. The right to extended paid leave from work or the right to work part time

A person legally responsible for a child under five in need of special care because of 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. Eligibility conditions and procedure 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".⁴⁸ The same rules apply for children with disabilities to access other social assistance benefits

⁴⁶ Several studies report parents being advised in the maternity ward by doctor or social worker institutionalize newborns with congenital conditions, although the Law on Social Protection prohibits institutionalization of children under 3 years of age.

⁴⁷ Ibid

⁴⁸ The Official Gazette of the Republic of Serbia, 56/2018

in cash, such as an allowance for assistance and care by others.

The Rulebook 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 assessment criteria define and assess: (i) a child with **disabilities in socioemotional development** (emotional functions and activities), (ii) a child with **cognitive developmental disabilities**; (iii) a child with **disabilities in functions and activities of communications**; (iv) a child with **disabilities in function and activities of movement**; (v) a child with **disabilities in the activities of daily life**; (vi) child with **sensory function disability**; (vii) a child with **impaired health condition** (a child with severe forms of chronic diseases); (viii) a child with **impairment of body structures** (a child with congenital or acquired bodily deficiencies, i.e., severe body deformities that make it difficult for them to function daily).

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 (this Fund covers economically active persons contributing to the Fund). The commission at the end of the assessment procedure issues an opinion about the state of health of the child by stating that the child has or does not have developmental disability and invalidity.

To acquire this benefit, a parent must submit a request for the child to be evaluated (or reevaluated). The parent may also request "other allowances" from the social protection system, such as an allowance for assistance and care by another person. The commission decides based on medical documentation and examination of the child during a face-to-face meeting. 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 is composed of a representative of the Fund as chair, a child development medical specialist, medical associate, and a relevant self-government representative (usually from the child protection office who is a secretary to the commission).

The criteria to assess disability used by the Pension Fund commissions are a mixture of health conditions (certain diagnoses), impairments, and several "functioning groups and life activities", many of which do not match the ICF. There is 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, and it is likely, given the criteria, that no valid individual score could be generated. No information is available on how the decisions on whether a child does or does not have a disability are made. The assessment uses ordinal scale qualifiers. While a qualifier 'complete' is intuitively clear as equivalent to 'cannot do at all', 'severe' is not a precise notion and it is open to judgement and subject to interpretation, i.e., 'severe' may be different from that of another member of the assessment commission.

This assessment is conducted only for children under 5 years of age, but the criteria appear more applicable to older children or even adults. For example, rating the pain intensity would be too much to expect from a young child (say 2 or 3 years old), even with the help of vignettes. Similarly, self-care expectations are different from children at 2, 3 or 5. What activities of daily living do children aged 30 months are expected to perform?

3. Intersectoral Commissions for the Assessment of Needs for Additional Educational, Health and Social Protection Support (ISC)

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. The needs assessment covers all individuals irrespective of their age or living arrangements: every child (pupil, adult) who due to social deprivation, disabilities, learning difficulties or any other reason requires additional support to develop and be included in education and community with fewer difficulties is entitled to such assessment. 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*.⁴⁹

The Rulebook stipulates the assessment be carried out respecting the right to education, prohibition of discrimination, the right to reasonable adaptation to

⁴⁹ The Official Gazette of the Republic of Serbia, 80/2018. For detailed description, see full version of the case study published separately.

the individual needs of the child to enable her/him to be educated on an equal basis with peers, respecting dignity, individual independence and freedom of choice, recognizing differences and accepting them as human diversity, respecting the right of every child to preserve her/his personal identity, ensuring full inclusion in education and the education system and community.

Additional support measures are: (i) additional support measures which are implemented based on the ISC's *opinion*. Eight measures are listed, and they mostly pertain to support in education; (ii) additional support measures based on the ISC's *recommendations*. Eleven measures are listed combining support in education, health, and social protection; (iii) 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. ISC can also recommend other forms of support that are not listed in the Rulebook.

An ISC is established and funded as a working body by a local self-government unit in charge of social sector (health, education, and social protection) in accordance with the law regulating the basics of education and the education system. The ISC comprises five members, four permanent and one temporary (a 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 the so-called *defectologist*⁵⁰ of the appropriate specialty. A temporary member is someone who knows the child and is appointed for each case separately at the proposal or consent from the parent or legal representative. The municipality employs a Coordinator of ISC who provides administrative, operational, and technical support to it. The ISC members work for the ISC on a part-time basis (they are employed full time elsewhere).

The ISC assessment can be requested by a person legally responsible for the child, by an educational, health or social care institution with the consent of the parents or legal representatives, in conduct of official duty (when parents do not give their consent).

The request is submitted formally on a prescribed form. ISC reviews the request in a meeting, which must be attended by a parent or legal representative.

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

ISC is obliged, within up to 40 days from the date of submission of the application for the evaluation, to report on a specified Form a common opinion, based on the individual assessment of each member of the ISC. 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 and service providers. 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 (used instruments and techniques in the evaluation process); 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; assessment of the needs for additional support and type of additional support required and how it may help the child overcome barriers, including coordinated inter-sector cooperation; individual 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; the timeframe for the implementation of additional support measures 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

⁵⁰ A profession of a "defectologist" is still recognized in Serbia, although it is not used in the language associated with disability any longer and is considered outdated and not compatible with modern understanding of disability and human rights approach to disability.

participation with other children in education. The ISCs are an important mechanism for coordinating services to facilitate inclusive education and social inclusion of the child at local level.

A parent or legal representative may object to the ISC's Opinion. The final Opinion is delivered to the parent or legal representative, and offices responsible for the provision of specific services, in accordance with the law. All parties including the ISC process must keep the information about the child and her/his family confidential.

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.

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.

Municipal Intersectoral Commissions are an innovative needs assessment mechanism for children in need of additional support in health, education, and social protection. The needs may be due to disability, social deprivation or simply not knowing the country language (for migrant children). The objective is to maximize the child's developmental potential. The ISC operation includes 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. The ISC could easily be transformed into a single pathway into benefits and services for children with disabilities, as well as become an integrator of local actors crucial for the provision of disability benefits and services, across the life

cycle of the child, including the municipal center for social work, local educational establishments, local developmental counselling units and other health care establishments and so on.

On the other hand, several studies⁵¹ have noted some of the problems ISCs encounter in their operations, including staffing arrangements (all members of ISCs have their regular full-time jobs), inadequate funding, issues related to the monitoring of the support plan implementation, unclarity regarding needs assessment criteria and instruments used in conducting the assessment, insufficient technical and methodological guidance and training of the ISCs members, and so on. These are envisaged to be addressed through an EU project whose implementation has commenced recently.

4. Determining the degree of support in social welfare services

The need for social welfare services and the degree of support are determined by a responsible (municipal) 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. There are four levels of support:

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

Second Degree Support: The 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: The person can take care of herself/himself and engage in activities of daily life in the community, but due to insufficient knowledge and skills 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.

⁵¹ Ibid.

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

The degree of support and the development of an individual service plan are based on an assessment in terms of **functioning efficiency** reduced because of disability, age, mental illness, developmental disabilities, or behavioral problems. The assessment instrument collects personal information as well as the following domains:

- **Self-Care and Daily Life Activity Abilities:** 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 and instrumental life activities:** use of public transport, use of public services, money management, grocery shopping, keeping the hygiene of the personal or 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, communication, attitude towards peers, attitude towards known persons and strangers, maintaining family relationships, group activities and participation in community activities, keeping safe and avoiding danger, aggression, and orientation in time.
- **Mobility:** mobility within home or institution, mobility outside home.

The final assessment sheet contains degrees of support by each activity by current state and expected outcome after the support. The scores are also generated as a sum of degrees of support for each of the four assessed groups of activities. Finally, based on the final scoring values, the assessor determines the dominant degree of support. It is determined by choosing the lowest degree of support (denoting a higher need) among the four groups of activities.

5. The National Registry of Children Identified as Having Disabilities and Developmental Disturbances⁵²

A Registry of Children with Disabilities and Problems in Development (Registry) was legally defined in 2015⁵³ and is to become fully operational in 2022. It is established and will be maintained by the Institute for Public Health of Serbia (IPH). Access to information in this Registry is given only to the data base administrators and to persons who have assessed functional ability of the child (chosen pediatricians). The primary formally stated **objective** of the Registry is to determine the prevalence and incidence of children with disability, disaggregated by age, gender, location and other characteristics. The **purpose** is to collect data that would inform the analysis of trends in developmental problems, calculation of years of healthy life loss due to disability, and so on. In the future, the information is expected to inform other systems – e.g., the work of ISCs or SWCs.

According to the Technical and Methodological Guide (T&M Guide)⁵⁴ the “assessment for the Registry is based on an assessment of functioning, as understood by ICF and later the ICF- Children and Youth version”⁵⁵ The content of the Registry 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*.⁵⁶ The T&M Guide outlines assessment across 6 domains:

1. Socio-emotional functions and activities (establishing and maintaining relationships with others, empathy, cooperation, waiting for her/his turn, fair-play, trust in oneself and self-confidence, emotional control).
2. Cognitive functions and activities (ability to learn, think, understand, solve problems).
3. Functions and activities of communication (ability for verbal expression, verbal communication with others).

⁵² The Registry is extensively described and discussed in the full version of the Serbia Case Study.

⁵³ Law on the Health Documents and Record Keeping in Health, The Official Gazette of RS, 123/2014, 106/2015, 105/2017/25/2019.

⁵⁴ Plavšić, S. (IPH) Jović, A. (UNICEF). 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. Document is available in Serbian only. We refer to this guide as T&M Guide.

⁵⁵ World Health Organization has merged ICF and ICF-C&Y.

⁵⁶ The Official Gazette of RS, 109/2016, 20/2019.

4. Physical development (development of gross and fine motoric, moving, balance, development of big muscle groups – for running, jumping, climbing; development of fine motor skills).
5. Skills to adapt – activities of daily living (ability to adapt to environment and adopting a routine, dressing, eating, maintaining hygiene, toilet training).
6. Sensory functions (seeing, hearing, sense of pain).

Response options are no difficulty (0), mild (1), moderate (2), a lot of difficulty (3), and cannot do at all (4). Only children with 3 or 4 qualifiers are entered into the Registry (i.e., children with mild and moderate disabilities are not recognized as children with disabilities for the purpose of the registry).

Pediatricians and medical doctors at local clinics are used for assessment and entry into the Registry. The T&M Guide sets out steps in the assessment for the registration of children in the Registry:

A. Rapid assessment of child development and functionality (development screening). Rapid screening 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 the Guide recommends, besides clinical examination, the use of the standardized questionnaires for parents: Ages and Stages, ASQ.⁵⁷ For children aged 5-17 years, the UNICEF/Washington Group Module on Child Functioning and Disability (UNICEF MICS) is recommended for use during systematic health examinations for enrollment in primary and secondary school.⁵⁸

B. Detailed assessment of children’s functional abilities. For children who, during developmental screening, clinical examination, or other type of examination are observed to experience developmental problems, a detailed assessment is conducted feeding into questionnaire developed for the purpose of data collection for the Registry and included in the Guide. The assessment in each domain could be performed by chosen pediatricians or health associates at primary level and/or medical specialists at secondary tertiary level to whom the child has been referred to as part of the assessment and diagnostic procedures using various sets of recommended instruments.

C. 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 includes only diagnoses while information on developmental domains is required to be inserted once the child reaches the age of 3 years and when developmental delays and disability become more stabilized. Assessment of functioning prior the age of 3 is performed and used as part of early interventions but not documented in the registry as it is expected to significantly change over time.

T&M Guide provides detailed instruction about what is estimated and how to rate difficulties (see full Case Study published as a separate report).

For comparative purposes in the discussion that follows we describe how Portugal and Switzerland approach identifying children with disabilities and their needs.

⁵⁷ <https://agesandstages.com/>

⁵⁸ As mentioned throughout this report, any instrument that is used must be fit for purpose. In this case, the instrument must capture children experiencing difficulties, with as few as possible errors of exclusion. 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/Washington Group 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. For 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/Washington Group 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. Similarly, an earlier study compared the Washington Group Extended Set on Functioning (ten core/ four non-core domains) and the draft UNICEF/Washington Group 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.

2.2.6 Portugal⁶⁰

Reform of disability and needs assessment: focusing on inclusion

Since 2018 Portugal has reoriented its approach to children with disabilities: children are not categorized or labeled as having a disability; it is their needs for access, participation and achievement that are determined based on their functioning profile and environment in which they live. The services and assistance are provided across health, education and social protection in a synchronized manner to ensure that all children develop and grow to reach their full potential. This paradigm shift started and was spearheaded by efforts to change the system of segregated special education for children with disabilities about four decades ago. Statistical evidence shows that almost 100% of children with disabilities are included in mainstream schools.⁶¹ Box 1 presents a short history of conceptual evolution and related legislative changes.

The needs assessment as part of inclusion approach

The key tenet of the childhood disability system and policy in Portugal has been the support for inclusion for children with disabilities across the life cycle. Administratively, the health and education systems have been designated as platforms for comprehensive support to children with disabilities from 0-18 years and transition to adulthood (respectively 0-6 where the health system is a key gateway and 6-18 and transition to adulthood, where the education system is the anchor). Two key pieces of legislation have defined the system and policies for inclusion of children with disabilities. The Law-decree on inclusive education from 2008 and its revisions and changes in 2018.⁶²

Figure 1 below visualizes the support system for children with disabilities across the life cycle. The system features two linked sub-systems along the child's life cycle and adhering to the principles of the child-centered approach, the best interest of the child, and range and continuum of services to ensure the child's inclusion.

BOX 1: THE EVOLUTION OF EDUCATIONAL INCLUSION CONCEPT IN PORTUGAL AND RELATED LEGISLATIVE CHANGES

According to the Education Act (Law No. 46/86, 14th October), special education is a specific type of education that facilitates the socio-educational recuperation and integration of individuals with special needs due to physical or intellectual impairments.

Including pupils in need of additional support in the mainstream schooling system as an educational strategy was enshrined in Law No. 9/89, 2nd May on Prevention and the Rehabilitation and Integration of Persons with Disabilities.

Decree-Law No. 35/90, 25th January obliges learners who have special needs resulting from physical or intellectual disabilities to attend compulsory schooling.

Law No. 85/2009, 27th August, establishes compulsory schooling for children and young people of school age and guarantees the universal right to pre-primary education for children aged five years and upwards.

Decree-Law No. 54/2018, of 6th July states that every student has the right to an inclusive education that responds to their potential, expectations and needs within the framework of a common and plural education that must promote equity, participation, and sense of belonging for all learners.

National Early Intervention System – children 0-6 years of age: the ministries of education, health and social affairs are jointly responsible.

The gateway into the system is the healthcare that performs screening, detection, and referral of eligible children to the multidisciplinary Early Intervention Local Team (*Equipas Locais de Intervenção - ELI*). ELI assesses the child's and the family situation and needs and develops an Individual Intervention Plan

The ELI:

- Assesses the situation of the child and her or his family and identifies their needs for support and resources to meet them available in the geographical area where the child resides.

⁶⁰ This text was prepared extensively drawing from: OECD and the Ministry of Education of Portugal. 2022. OECD Review of Inclusive Education: Country Background Report for Portugal. ISBN: 978-972-742-498-6, Alves, Ines, Campos Pinto, Paola and Janela Pinto, Teresa. 2020. Developing inclusive education in Portugal: Evidence and challenges. Prospects (2020) 49: 281-296. Published online: 19 October 2019. <https://doi.org/10.1007/s11125-020-09504-y//>. Pereira Filomena. 2022. A power-point presentation on the experience of Portugal at the UNICEF-World Bank Webinar on Children with Disabilities. 2022. European Agency for Special Needs and inclusive Education website: <https://www.european-agency.org/country-information/portugal//>.

⁶¹ Alves, I. et al: Ibid.

⁶² Ministério da Educação (2018). Decreto-Lei 54/2018. Lisboa: Ministério da Educação.

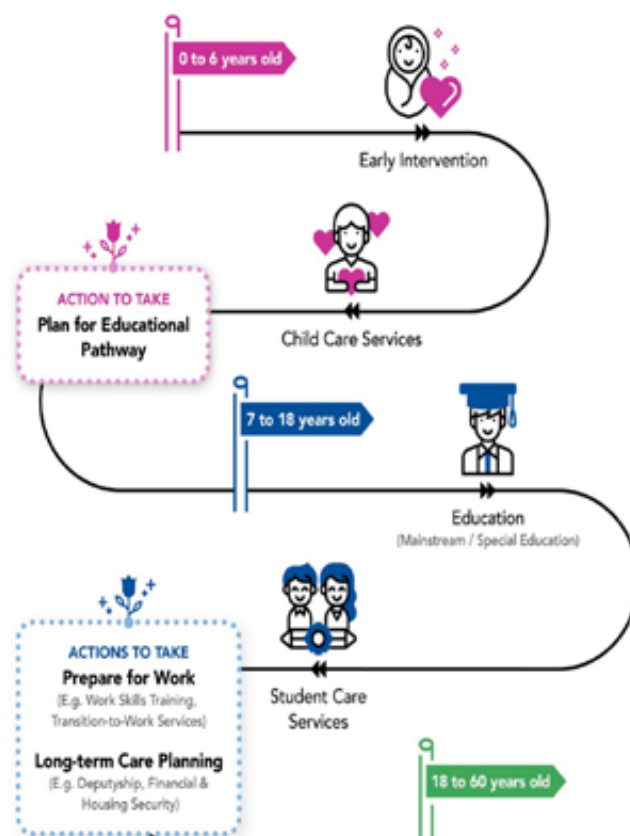
- Develops and implements an individualized family support plan- (Plano Individual de Intervenção Precoce- PIIP). PIIP includes support measures in education, health, and social protection and participation. PIIP also includes an Individualized Education Programme (Programa Educativo Individual - PEI), in case a child attends pre-school. The Plan defines the strategic goals to be achieved, the responsibilities and the roles assigned to the staff and to family members and to other persons who are involved in the child's everyday activities. The child's family must be involved in the plan's preparation and implementation.
- Case manages the child's case.
- Collaborates with other community entities involved in the support to children and families.
- Provides assistive technologies and aids.
- Provides speech therapy, physiotherapy, occupational therapy, psychological therapy and counseling, etc.
- Provides income support.
- Provides nutritional support.
- Provides mental health care.
- Prepares the child's transition process to primary education.

The multidisciplinary team conducts a holistic assessment using a combination of impairment, functioning and environmental approaches, including "alterations in the child's bodily functions or structures" that prevent their participation in daily activities and in social context; "serious risk for developmental delay" due to biological, psycho-affective or environmental conditions; and "parental and contextual factors" that may limit the child's development, well-being and participation in social activities. The assessment combines personal interaction supported by documentation. Supporting evidence includes a self-assessment (statement or structured questionnaire completed by the individual); evidence from someone who knows the applicant's situation (e.g., a relative, friend, neighbour, or colleague); evidence from a non-medical professional who knows the applicant; a medical note or letter from a doctor who treats the applicant; medical records automatically retrieved from health care system (e-health).

Compulsory Schooling – 6-18 years of age:
Responsible government agency: Ministry of Education

- School based multidisciplinary team: Cycle- Assess, Plan, implement (Do), Review
- Individual Education Plan (IEP) and Individual Transition Plan (ITP. The focus in planning is to ensure on access, participation, and progress/ achievement. The students are provided with:
 - Assistive technologies/aids,
 - Braille, digital, audio format material,
 - Case management,
 - Specialized support (special education teachers),
 - Personal assistance,
 - Speech therapists, physiotherapists; occupational therapists; psychologist counselling/support,

FIGURE 1: PORTUGAL: SUPPORT FOR CHILDREN WITH DISABILITIES ACROSS THE LIFECYCLE OF THE CHILD



Source: Filomena Pereira. A power-point presentation on the experience of Portugal at the UNICEF-World Bank Webinar on Children with Disabilities. 2022.

- Social support: transportation, schoolbooks, meals; extra-curricular activities,
- Nutritional support,
- Mental health care,
- Health care defined in an Individual Health Plan (IHP).

The school is, hence, at the center of a range of services or a point of integration – services and benefits are provided by the education system, but also social protection, health and other government agencies as applicable or needed.

Since the legal changes in 2018 Portugal has made a further push to develop inclusive schools “where each and every student, regardless of their personal and social situation, finds responses to their potential, expectations, and needs, and develops a level of education that creates full participation, a sense of belonging, and equity, contributing to social inclusion and cohesion”. The 2018 Act advances a pedagogical model based on the notion that all students have learning potential, as long as they receive adequate support. The methodological options underlying this Act are based on universal design for learning and a multilevel approach to access the curriculum. The tiered multilevel approach encompasses the implementation of three types of measures, identified in the legislation as: **universal measures**, targeted to all students in order “to promote participation and improved learning” (Art. 8); **selective measures**, aimed to fill the need for learning supports not addressed by universal measures; and **additional measures**, set in place “to respond to intense and persistent communication, interaction, cognitive or learning difficulties that require specialized resources of support to learning and inclusion” (Art. 10). Identification of students in need of support measures and the decision regarding the type of measures to be implemented is made at the school level by the multidisciplinary school-based team. Thus, no certification of disability is needed, and the needs are determined once a time.

Very importantly, the Act moves away from the notion that it is necessary to *categorize to intervene*, rather supporting the idea that all students can achieve a **profile of competencies and skills at the end of their compulsory schooling**, even if they follow different learning paths. Therefore, this new law abandons categorization systems for learners, including the ‘category’ of special education needs.

As such, it removes segregation and discrimination based on diagnosis or clinical labels, and special legislation frameworks. Exceptions are made for deaf and low vision/blind students since they need the support of specific human and material resources. The new approach views flexible curricular models, systematic monitoring of the effectiveness of the implemented interventions, and an ongoing dialogue between teachers and parents or other caregivers. It focuses on type of measure(s) provided to students within mainstream education rather than the personal characteristics of students.

The Act also advances a more holistic perspective on the educational process, emphasizing that inclusive education is not just the responsibility of special education teachers and other specialized support staff, but rather it must mobilize an interdisciplinary team and the school community. The issues related to students with special education needs due to disability are now tackled within the different domains, principles, values and competences to be developed within the scope of different curriculum documents. Nevertheless, to make schools accountable for all students, the Act stipulates the use of Individual Education Programs (IEPs) – see Box 2 on IEP.

A whole school approach applies:

- Multidisciplinary and cross-sectoral approach in identifying and assessing the needs and planning interventions.
- A stronger cooperation with a wide range of stakeholders- social services, youth services, outreach care workers, psychologists, nurses, speech, physical and occupational and psychosocial therapists, guidance specialists, local authorities, NGOs, business, unions, volunteers and the community at large.
- Each stakeholder has a part in supporting the students’ educational journey contributing for their learning experience.
- Systemic and collaborative action, so that schools can respond to the challenges associated with the growing diversity, inequalities, and social exclusion in society, and with the recent increase in migration flows.
- Individuals must achieve both the capacity and capability through innovative approaches to work in cross-disciplinary settings.

BOX 2: INDIVIDUAL EDUCATION PROGRAM

For the students who need significant curricular adaptations, an Individual Educational Program (Programa Educativo Individual, PEI) can be designed. A PEI includes the identification and implementation plan of the significant curricular adaptations and integrates the competences and learning to be developed by the student, and the identification of the teaching strategies and the adjustments to be made in his/her evaluation process. A PEI also includes other measures to support inclusion, to be defined by the multidisciplinary team for inclusive education (EMAEI) and it should contain the following elements: The total number of school time, according to the respective level of education. The assistive products/devices, when appropriate and necessary for access and participation in the curriculum. The strategies for transition between cycles and levels of education, when applicable.

It is the responsibility of the EMAEI to prepare the PEI as well as the technical-pedagogical report and the individual transition plan and to follow-up, to monitor and to assess the implementation of the learning support measures. The EMAEI includes permanent members and variable members. Schools have specialized support staff, such as:

Portuguese sign language interpreters, Speech Therapist, Psychologist, Physiotherapist, Emotional-Kinesthetic Psychotherapist, Occupational Therapist. School psychologists also do career counselling, social workers usually work with the families as well as mediators.

School psychologists do several guidance tasks throughout the school year. Three years before students with the additional measure of significant curricular adaptation reach the age limit for exiting compulsory education, the school should complement their PEI with an Individual Transition Plan (Plano Individual de Transição, PIT). The EMAEI must prepare the PIT in collaboration with all stakeholders in the student's educational process, and with families. The PIT must be prepared based on the evidence collected, within the scope of the support, throughout the student's educational process. The plan is conceived, three years before the age limit for compulsory education, for each young student who attends school with significant adaptations, designed according to the interests, competences and expectations of the student and his / her family, with a view to facilitating the transition to post-school life and complements the individual educational program.

Among the changes introduced to support the education of students with disabilities, the new decree-law creates Learning Support Centers that replace the former Specialized Units. LSC are defined as "dynamic, plural spaces, which assemble both human and material resources"

(Decree-Law 54/2018, Introduction). They should work with students with disabilities and teachers to support inclusion and promote learning. Reference schools—schools which concentrate specialized resources for teaching low-vision/blind or hard-of-hearing/deaf students—continue to operate.

The school-community hub is a model of school-community partnership that involves collaboration between schools and other sectors – social protection, health, NGO – in order to support the learning and wellbeing of disadvantaged children and their families through the provision of multiple services available in a single location or network of places in an integrated way. The Portuguese system features a network of reference schools:

Reference schools for early childhood interventions

- Schools as hubs to support Early Childhood Intervention. There are 137 reference schools acting as hubs with local ECI teams. The teams include teachers, health and social welfare staff that intervene at local level, to improve the child's learning opportunities; strengthen the skills of caregivers and promote family and community resources.

Reference schools for assistive technologies.

Schools as ICT/AT Centers – there are 25 ICT and Assistive Technologies Centers, based in schools, supporting all other schools within a defined geographic area to:

- Assessment the students' needs for AT to minimize or overcome their limitations to access curriculum and participate in school activities,
- Prescribe AT, financed by MOE and recommend other free resources, software, etc.,
- Train teachers, other professionals, parents and students in the use of AT,
- Establish partnerships with different stakeholders to develop expertise in the field of AT,
- Act as hubs for all other support services: early intervention, health and social protection services, rehabilitation, employment.

Reference schools for bilingual curriculum.

Schools as hubs to support children with hearing impairments – at present, there are 17 such reference schools.

Reference schools for blindness/low vision. Schools as hubs to support blind/low vision children. There are 32 of them.

School based resource centers for inclusion

- Inclusion Resource Centers (IRC): These are non-governmental institutions- former special schools, that were reoriented to provide support services to schools and students. They serve as hubs for non-education specific support services (early intervention, health and social protection services, occupational centers, rehabilitation and employment). At present, there are 93 former special schools, which MOE has certified as RCIs.

As Portugal progresses with the implementation of the 2018 Decree-Law, the notable challenges include:

- Improving the management of resources for inclusive education and continuing efforts to build a coherent funding system to support equity and inclusion,
- Defining clear guidance on the use of support resources within schools and communities,
- Identifying and building good practices to promote collaboration and capacity-building to address all dimensions of diversity,
- Expanding continuing professional learning opportunities for teachers to support diversity and inclusion,
- Strengthening strategies for monitoring and evaluating inclusive education practices at the local and school levels.

Sufficient financial and human resources remain key because tight budgets and inevitable prioritization, may undermine the realization of the goals of the Decree-Law 54/2018.

Assessment

The 2018 Act moves away from the concept of “support measures for learners with special educational needs.” It takes a broader view, implying a whole school approach, which considers multiple dimensions and the interactions between them. Every learner has the right to receive measures to support their learning and inclusion and for specific resources to be mobilized to meet their educational needs in all education and training offerings. The Act establishes the principles and norms that guarantee inclusion as a process that aims to respond to the diverse needs and potential of each and every

pupil by increasing participation in the processes of learning and the school community.

In each school there is a multidisciplinary team to support inclusive education, with both permanent and temporary members. Parents are part of the multidisciplinary team. Multidisciplinary teams are responsible for:

- raising awareness of inclusive education in the educational community,
- proposing the learning support measures to be mobilized,
- following up and monitoring the implementation of the learning support measures,
- advising teachers about the implementation of inclusive pedagogical practices,
- preparing technical-pedagogical reports, individual educational plans and individual transition plans,
- following up on the functioning of the learning support centers.

The schools are autonomous in terms of methods and tools the use.⁶³ Once the need for measures to support learning and inclusion have been identified, the school director requests that the multidisciplinary team prepares a technical-pedagogical report for the learner and the IEP (see Box 2 above). This report and program substantiate the mobilization of selective or additional measures for learning and inclusion. The multidisciplinary team adopts a holistic view. It considers academic, behavioral, social and emotional aspects of the learner, as well as environmental factors (namely, the school and the classroom). It collects evidence and significant data to re-balance the teaching and learning process.

Therefore, the new model promotes and enlightens the person-environment interaction. The focus of school activity is the curriculum and the student learning, based on the universal design for learning and on a multilevel approach in accessing the curriculum.

Thus, it is adopted a comprehensive and systemic-based view, recognizing the complexity, multiplicity, and interconnectivity of educational phenomena

⁶³ To support the schools’ multidisciplinary teams, the Ministry of Education has compiled a set of tools. (Available upon request from the Ministry.)

such as learning and behavior. In this way, it simultaneously contemplates, in an integrated and articulated way, individual and contextual dimensions, that is, of the student and of the educational contexts.

Monitoring and assessment are essential processes to respond to the diversity of all students. The results of monitoring and assessment integrate the decision-making processes. Decisions must be based on data about students, school, and community.

Starting from the basic principles to the multilevel approach, it is important to identify its main distinctive features:

- the multilevel organization of measures to support learning,
- determining a continuum of measures to support learning,
- focus on curriculum and learning,
- the option for practices that are theoretically and empirically supported,
- the organization of systematic monitoring processes.

One of the characteristics of this model is the organization by levels of intervention. These levels vary in terms of the type, intensity and frequency of interventions and are determined according to the students' response to them. Mobilization of different support levels depends on their effectiveness in responding to needs, interests, and potential of students throughout the school path. Teachers have to adapt their teaching processes to the characteristics and individual conditions of the students to ensure that all students have access to quality education. These measures, oriented towards learning, are determined according to the curriculum.

The focus of multilevel approaches is not on assessment of learning but on assessment for learning. Indeed, formative assessment is

central to this approach, as it constitutes an assessment centered on learning. The data from the formative assessment are relevant evidence about pedagogical actions and strategies, students' progress, and the school's educational processes. It is according to the comprehensive and integrated analysis of these data that interventions or support measures are determined.

Decisions taken at different levels regarding the intensity, frequency, duration and type of measures combine scientific knowledge about the target area of intervention with the results of the assessments carried out. Monitoring progress is essential to assess the evolution and performance of students in the identified target competencies, allowing to assess the interventions, the students' responses to the interventions and to guide the subsequent interventions to implement. Progress must be monitored frequently, using short and simple measures, or supported in the data of the formative assessment.

Multidisciplinary teams to support inclusive education also have the task to follow up, to monitor and to assess the implementation of the learning support measures of each student. A major challenge is also the definition, by these multidisciplinary teams, of indicators to assess the effectiveness of those measures.

2.2.7 Switzerland⁶⁴

Below, we present the assessment system for support to children with disabilities who have special educational needs (SEN) in Switzerland. Switzerland was among the first countries to use the ICF approach to disability to assess SEN. The methodology and the instrument used present a good example of the use of ICF to assess SEN. The disability assessment of children to access welfare benefits that in Switzerland are provided through the disability insurance system is conducted by disability insurance administration. This assessment mostly relies on health situation of the child, although the child's ability to perform everyday tasks is considered as well.⁶⁵ The full version of the case study is available as a separate publication.

⁶⁴ This case description is based on the following sources: Swiss Conference of Cantonal Ministers of Education (EDK): <https://www.szh.ch/page-d-accueil/>; Hollenweger, J. Development of an ICF-based eligibility procedure for education in Switzerland. BMC Public Health 11, S7 (2011). <https://doi.org/10.1186/1471-2458-11-S4-S7//>; Hollenweger, J, Lienhard, P und Obrist, M (2018) Standardisiertes Abklärungsverfahren. Ein Rückblick auf die Einführung und Entwicklung bis heute Schweizerische Zeitschrift für Heilpädagogik (Standardized assessment procedure, a review of the introduction and developments to date), Jg.24,10/2018 <https://www.szh.ch/themes/pes/documentation-afferente//>; "Standardized Evaluation Procedure, Guidelines, Instrument of the Concordat on Special Pedagogy for Determining Individual Needs and for the Allocation of Additional Measures"; Bern 2014: <https://www.szh.ch/themes/pes/documents//>; European Agency for Special Needs and Inclusive Education: <https://www.european-agency.org/country-information/switzerland/assessment-within-inclusive-education-systems//>

⁶⁵ For details see: <https://www.ahv-iv.ch/en/Social-insurances/Disability-insurance-DII/>.

Legal framework and context

Under the Swiss Federal Constitution, The Federal Act on Equal Rights for People with Disabilities⁶⁶, and the Inter-cantonal Agreement on Cooperation in Special Needs Education (Special Needs Education Agreement⁶⁷) all children and young people (0-20 years of age) with special educational needs living in Switzerland are entitled to special education measures. Under the Special Needs Education Agreement special educational needs are:

- for children before starting school for whom it has been established that their development is limited or jeopardized or that without specific support, they would likely not be able to follow classes in mainstream schools,
- for children and young people for whom it has been established that without additional support they can no longer follow or can only follow the mainstream school curriculum in part, and
- in other situations, in which the competent school authority has established that children and young people have great difficulties with social skills and learning or performance problems. Their personal context is considered in the assessment to determine the special educational needs.

Under the Federal Act on Equal Rights for People with Disabilities the cantons promote, as far as possible and where this serves the wellbeing of the child or young person with disabilities, the integration of children and young people with disabilities in mainstream schools through corresponding forms of schooling (Article 20(2)). The Special Needs Education Agreement specifies that integrative solutions should be preferred over segregation, taking into account the welfare and development opportunities of the child or young person and taking into consideration the school environment and the school organization (Article 2(b)).

The range of measures is specified by the cantons and contains the following services and forms of special schooling:

- remedial education in early childhood for children with disabilities or developmental delays, limitations or risks. Support measures may be provided in a family context for children from birth to up to two years after starting school,

- integrative schooling: full-time or part-time integration of children and young people with special educational needs in a mainstream class through the use of special education measures,
- special classes (only offered in some cantons),
- special school: special schools are specialized in particular forms of disability or learning and behavioral difficulties. Special schooling can be combined with in-patient accommodation or with care in day-care centers,
- educational and therapeutic services such as speech therapy and psychomotor therapy,
- the cantons also provide free transport for children and young people who, due to their disability, cannot move independently between their home, school and/or the place in which they receive therapy.

Support measures are also offered to children and young people from socially disadvantaged families and/or with migrant background. Particular attention is paid to the transition from compulsory to post-compulsory education.

As noted, a child or young person with special educational needs may be integrated into a mainstream class on a part-time or a full-time basis (integrative schooling). This integration is supported by **special education measures from the school program**. If measures carried out before starting school or in the mainstream schools are inadequate, then a decision is made if **enhanced measures** are required. Enhanced measures go beyond measures available locally. They are of long duration and high intensity, provided by highly specialized specialist staff and are meant to have significant impact on everyday life, environment or later life of the child or young person. They are approved by cantons.

The assessment of individual needs for enhanced measures is carried out through the standardized evaluation procedure to assess individual needs (SAV – abbreviation in German). In most cases, the assessment is conducted by a school psychological service. The SAV records information systematically and gives users a comprehensive, multidimensional needs assessment. Its focus is on the child's development and educational objectives.

⁶⁶ Adopted in 2002. See: <https://www.fedlex.admin.ch/eli/cc/2003/667/en/>

⁶⁷ <https://splash-db.eu/policydocument/intercantonal-agreement-on-special-needs-education-of-25-october-2007//>

Standardized evaluation procedure (SAV)

The SAV was adopted by the Swiss Conference of Cantonal Ministers of Education (EDK) in 2010 after a three-year development and testing period and made available to the cantons as a prototype from 2011. In addition to providing the common terminology and quality requirements, the SAV is one of the common instruments of the Swiss Special Education Concordat. Since its introduction, 16 out of 26 cantons have acceded to the Concordat⁶⁸, committing themselves to using SAV to recommend strengthened individual measures in the case of special educational needs. In 2013, the Swiss Institute for Special Needs Education (SZH) carried out a generally positive evaluation of the SAV on behalf of the EDK. Further consultations were carried out and a revised SAV (EDK, 2014) was published as a manual and prototype of an electronic tool following its new adoption by the EDK Plenary Assembly.

In the spirit of the Switzerland's constitutional arrangements, SAV is not mandatory, but a "standardized framework" for the assessment of a possible needs for-enhanced support measures. Practical implementation arrangements are a matter for each canton resulting in a diverse practice. For example, some cantons implement it centrally (e.g., the Canton of Basel City), in others, it takes place depending on the organization of the school psychological services, i.e., at the school and at the level of the canton, (e.g., the Canton of Zurich). Some cantons follow SAV EDK guidelines closely (e.g., the Canton of Zurich), others have made substantial changes (e.g., the Canton of Vaud) or use it only in the sense of an "internal checklist" (e.g., the Canton of St. Gallen).⁶⁹ In most cases SAV is administered by a school psychologist.

Purpose and objective: SAV purpose is to determine individual educational and developmental needs of children and young people for early specialized education, mainstream schooling, reduced-size classes or special schooling. It aims to create optimal (but not maximal) conditions for child training and development, considering international and national directives and local circumstances. It is designed to gather relevant information systematically and concurrently with multidimensionality of disability, adopts a multi-dimensional approach: a single criterion (e.g., one deficiency) is not a sufficient basis for taking measures. The aim is rather to determine

what measures will be effective on the basis of transparent developmental and training objectives.

Conceptual base: SAV is based on the ICF, in particular the now-discontinued version for children and youth (ICF-CY).

Procedure: Any child for whom developmental or learning problems are observed can be referred to the SAV assessment. For very young children, a referral is usually done by health or early childhood development service. For other children, it is educational establishment that do the referral. Recognizing that disability is a multi-dimensional phenomenon, SAV gathers information from different sources to understand the problems of a child with disabilities and assess her or his needs for support. This consists of two stages: a basic assessment and an assessment of special needs. Each comprises several elements.

Basic assessment: This assessment considers the child's present condition and includes the following elements:

- General information
 1. information about institution conducting the assessment and about the person responsible for the case,
 2. Information about the child who is being evaluated, and
 3. Information about her or his problem.
- Basic assessment
 4. Education and training context,
 5. Family context,
 6. Statement of functioning (activities, participation and body functions),
 7. Medical diagnoses (ICD codes) and health problem description.

Determination of needs: Interventions, measures commensurate with the child's present situation are recommended. The process comprises:

1. An assessment of the child's development and training objectives in the main areas of life as per the ICF (6 domains of Activities and Participation),
2. Needs assessment,
3. Recommendations (measures and institution in charge).

⁶⁶ Judith Hollenweger, Peter Lienhard und Matthias Obrist. Ibid.

⁶⁷ Judith Hollenweger, Peter Lienhard und Matthias Obrist. Ibid.

The decision on which measures the child will receive are made by the cantons. The decision-making practice varies from canton to canton.

SAV does not have age specific versions. However, it considers the child's age by assigning a different level of importance to certain elements. For instance, at a preschool age, particular relevance must be assigned to the influence of the family environment, while diagnoses have less central role because a clear diagnosis is often hard to be established at an early age. SAV also considers different ages when evaluating body functions and activities and participation. Some items are mainly assigned to children in their early childhood, others to children/young persons of school age. For very young children it is often impossible to clearly define the extent of the problem and in such cases, the problem is labeled "unspecifiable". If a significant gap between chronological age and developmental stage is noticed, information should be collected based mainly on the developmental stage. This is particularly important when working with severe disabilities or multiple disabilities.

SAV instrument:⁷⁰ The instrument has 10 forms for information gathering (for a complete version of forms, see a full version of the Swiss Case Study provided in the Annex to this report. The assessors also must attach all reports prepared by specialists from the service conducting the evaluation or outside it, including details about the specialist(s) who conducted them.

The content of SAV was developed to identify the child's/young person's needs for support, promotion, counseling, or other necessary measures to ensure that the child/young person can benefit from optimal development and learning opportunities. Thus, the choice of items reflects preschool, school and young adults' development and learning tasks. They are meant to be used in educational and developmental contexts. The items were selected based on empirical analyses: (i) Exploratory analysis using a regression model to identify the items that are particularly relevant to predicting needs: selection of the items with the highest explicative value; (ii) Exploratory factor analysis within the ICF chapters to identify relevant components/ factors, with a distinction between preschool and school domains: selection of items with the highest focus on the specific component/

factor in question; (iii) Cluster analysis to identify the "categories of needs" or different groups of ICF items that are often listed together with respect to a specific need: selection of the items deemed to be important for highest possible numbers of need categories; (iv) Frequency calculations: if based on the results from (i)-(iii), several similar items could potentially be inserted in the list, the one with the highest occurrence was selected. The SAV Guide also provides detailed description of each item to make the instrument application easier. For example:

Activities and Participation Code d100- Seeing

Using the sense of seeing intentionally to experience visual stimuli, such as watching a sporting event or children playing. This code refers to one's ability to be present in a situation through vision and visual perceptions and to focus its sight for a certain period of time to collect information through the perception of visual stimuli. "Seeing" refers to a continuous perception of visual stimuli and not to the ability to give a quick look to an object (this last action should be classified under the code d160 "Focusing attention"). This code is different from the one corresponding to the body function labeled as b1561 "Visual perception" (a sub-code of b156 "Perceptual functions") as it refers to a specific and intentional action, while perceptual functions refer to the integrity of neurological elaboration functions.

Practical examples: An eight-year-old child with a corrected visual impairment can see what the teacher writes during class only by sitting in the front row. Following a cerebral lesion, a fifteen-year-old boy is restless and lacks attention while in the classroom. He cannot focus his sight on the blackboard. Before the accident, he used to be a soccer fan, but now he cannot watch a game for more than half minute. A ten-year-old child has multiple severe disabilities and can follow with his sight only showy objects that are waved in front of him. A four-year-old girl perceives the movements of children playing only as shadows and only if there is a lot of light.

Experience with SAV implementation

The above-mentioned article published in 2018 by Hollenweger, Lienhard und Obrist presents

⁷⁰ See SAV Guide. Ibid.

experience with the SAV implementation. They point out that the introduction of SAV has given rise to discussions concerning educational policy and technical issues: “personalization vs. standardization”; “special support vs. discrimination”; “medical criteria vs. systemic view”, or “resource management vs. right to education”. These discussions have also shaped the introduction and application of the SAV in the cantons. They also observe that “The project to define binding guidelines and quality standards in

the field of special education was initially hardly perceived as an opportunity.”⁷¹ The application of SAV was in most cantons assigned to school psychologists who knew little about the ICF and were not very welcoming. Training and experience have been important factors in gaining acceptance. They also point out that a better collaboration with social welfare benefits that are provided through the social security system is needed, as in many cases, they are as important as education sector interventions for child’s development and learning.

3. Discussion of Common Issues

In this section we bring together the issues raised by the reforms during the last ten years that we mapped in the previous section in the five countries of Eastern and Southern Europe. Our primary focus, as per the terms of reference of this consultancy, is on disability assessment – as we have characterized this process in our framework above. Inevitably, the issues that we raise cross over into needs assessment and special educational needs assessment as well, but only by way of contrasting these, very different assessments from disability status assessment. After summarizing the reforms (3.1), we bring together our general comments about these reforms across all five countries (3.2). The mapping exercise in 2.2 (with more detailed case studies published as separate reports) directly links comments, as they apply, to the specific countries. We felt it is important, and indeed

our consultancy was designed in this fashion, to provide our observations as they apply across these countries (with relevant links to our two comparator countries – Portugal and Switzerland). Finally in 3.3 we directly address the four specific issues that define this consultancy.

3.1 Reforms in the five “mapped” countries

We begin with a general review of the reforms in the disability status assessment process (followed by the reforms in the linked administrative actions of needs assessment and SEN assessment) involving children with disabilities in Armenia, Georgia, Moldova, North Macedonia, and Serbia. Tables 2 and 3 bring together basic information about these reforms.

Table 2: Reforms in Disability Status Assessment

	CHRONOLOGY AND LEAD AGENCY	LEGISLATION	INSTRUMENTATION; PERSONNEL	DISABILITY STATUS ASSESSMENT
ARMENIA	2013 Ministry of Labor and Social Affairs UNICEF/UNDP	Law on the Rights of Persons with Disabilities (2021) Law on Functional Assessment (2021)	Medical information; ICF checklists/protocols of Hearing, Visual, Mobility and Mental	Multi-disciplinary team assess ‘functionality’ as legal basis for determining status disability
GEORGIA	2018 UNICEF MIDPOTLHSA	Law on the Rights of Persons with Disabilities (2020) Law on Medical and Social Examination (2001)	Social Profile Questionnaire Child Functioning Assessment Tool Case Manager	Multi-disciplinary team led by a case manager

⁷¹ Ibid.

NORTH MACEDONIA	2016, 2021 UNICEF Ministry of Labor and Social Protection Ministry of Health	Amendments to Social Protection Law, Child Protection Law, Health Insurance Law (2020) Rulebooks	No targeted instruments. Reporting Forms with ICD codes and ICF BF/BS domain categories; A&P and Environmental domain categories. Level and type of disability determined.	9 regional expert bodies, multi-disciplinary team
MOLDOVA	2012/2013/2018 Ministries of Health, Social Protection and Education National Council for Determination of Disability and Work Capacity (under the Ministry of Health, Education and Social Protection)	Law on Social Inclusion of People with Disabilities (2012) Government Decision No. 357 On the determination of disability (2018) Joint ministerial Order No. 13/71/41 Criteria for Determining Disability of Children under the Age of 18 (2013)	(i) Medical – a list of 200 diseases and impairments with no ICD codes; to each a degree of disability (very severe, severe, or moderate) is assigned (ii) A&PQ with 93 categories of A&P – organized by age groups – only the age group 12-18 is expected to perform all 93. Responses options are NO (0) and YES (1). The numbers are summed and for each age group score ranges representing no problem, mild, moderate, severe, and very severe problem are defined. No mechanism for combining medical and functioning information.	National Council for Determination of Disability and Work Capacity Multi-disciplinary team for children: 3 members: higher education in medicine (pediatric), psycho-pedagogy and rehabilitation.
SERBIA	2009/2015 Ministry of Health Ministry of Labor and Social Protection	Law on the Prevention of Discrimination against Persons with Disabilities (2016), Law on the Foundations of the Education System, Law on Social Protection, Law on Health Documentation	Disability status is determined for (i) paid absence from work and other cash social assistance benefits: criteria: certain medical diagnoses, impairments, and several “functioning groups and life activities; no scoring (qualitative deliberation and discretionary decisions); and (ii) National Registry of Children with Disabilities: the Registry uses its own 6 domain assessment; only children with at least one qualifier 3 (severe) and 4 (cannot do) are considered as disabled and included into registry.	Disability Insurance for absence from work and other cash social assistance Institute for Public Health of Serbia for the Registry

Table 3: Reforms in Needs Assessment and SEN Assessment

	NEEDS ASSESSMENT	SEN	BENEFITS REFORM
ARMENIA	Same process with modified version of the assessment instrument used in disability assessment	Since 2007 Separately administered by Ministry of Education and Science Law on General Education Law on Pre-school education (2021) SEN Toolkit	Yes
GEORGIA	Based on disability assessment	Separately administered by Ministry of Education.	No
NORTH MACEDONIA	Same process and assessment instrument as in disability assessment	No specific instrument. Same instruments that collect information for DSA.	No

MOLDOVA	Same process and assessment instrument as in disability assessment	No specific targeted instrument. Same instruments that collect information for DSA.	No
SERBIA	Municipal Inter-sectoral Commissions assess needs for additional support in social protection, health and education. Centers for Social Work determine the level of care need.	Tools at the discretion of the commission members, direct observation of the child. SWCs use a needs assessment tool based on A&P with simple scoring and dominant need for support.	Yes

3.2 General observations

Our aim at this point is to make general comments about the motivation for the reforms and the resulting changes concerning process and instrumentation for disability status assessment and needs and SEN assessment. These comments are based on information from desk research and limited interviewing of UNICEF country officers. We want to emphasize that in our experience, to understand the details and specifics of a country's disability assessment process and practice – beyond the aspirational descriptions of it in legislation and official documents – weeks of on-the-ground interviewing of people who actually participate in these processes is required. We did not in this consultancy have this opportunity.

With this caveat in mind, for the countries under consideration.

Generally

1. All reforms were said to be motivated by the political and social need to align disability assessment, and disability policy generally, with 'the human rights approach' as set out in the CRPD (and implicitly the CRC as well), the need to base assessment and determination decisions on functioning information (or alternatively, to implement the 'biopsychosocial model of the ICF').

2. In none of the countries under consideration could we discern a formal administrative distinction between disability assessment and disability determination being made: these activities are done simultaneously and by the same official, multidisciplinary team or agency.

3. In all countries under consideration, there was an intention to move away from decisions about disability status based entirely (or effectively) on medical information towards an approach in which functioning information is used as well. No country abandoned the use of medical information about underlying health conditions or impairments.

4. In some countries, we detected attempts to downplay the need for a full-blown disability status assessment for children as a precondition for needs assessment.

5. We were unable to find formal procedures designed to consider the opinion and wishes of the child, capable of forming his or her own views, or to input this into the disability assessment process; for younger children, especially, the parents spoke. For reasons explained, we were not able to investigate actual practice, where the direct participation of the child might in fact be recognized, and perhaps facilitated.

6. Without more detailed information about the administration of disability status assessment in practice, it is difficult to determine whether the relevant procedural human rights enumerated above (e.g., the process is respectful of the child, conducted in physically accessible environments) were in fact upheld.

7. In some countries disagreements between officials in multidisciplinary teams who collect information about health and those who collect information about functioning and the environment at time cannot be systematically resolved, and the medical determination is the default.

8. We were unable to investigate thoroughly issues of data collection, storage, and inter-sectoral access, although we were informed that in some countries that there were problems with data interoperability and access and that further work was being planned.

9. We were given the impression, across the five countries, that all the reforms are still in the process of being implemented, often incrementally, or scaled up and we understood this to mean that continuous, good faith, attempts to fulfil the aspirations found in legislation and governmental intentions are continuing.

Instrumentation

10. Although implementation details vary considerably across the five countries, for the most part disability status assessment for children is based on instruments or formulary that have been created by experts or consultants within relevant ministries, or else were modified adaptations of international standard instruments.
11. Although, again, there was considerable variation across countries, as a general matter:
- The instruments or forms use ICF vocabulary (Body Functions, Activities and Participation, Environmental Factors) and many also employ specific ICF classification domain names (e.g., b3100 Production of voice functions). In some cases, only ICF chapter headings (ICF level 1 categories) from Body Functions, Structures, Activities and Participation and Environmental Factors were used.
 - We did not have sufficient information to determine how the specific ICF domain items were selected, whether the selection was systematic, based on scientific literature, the result of experts' consensus exercise, or some other non-random technique.
 - No information was provided about the validation of these tools, and as far as we are aware they have unknown or unverifiable psychometric properties (validity, reliability).
 - Although all instruments collect information in terms of ICF vocabulary and classifications, we did not have access to details about how the data collected was to be systematically used as the basis for disability assessment.
 - A variety of rating scales are used. Although the ICF 5-point scale (no problem, mild, moderate, severe, complete problem) is most commonly employed, in some cases a 3-point scale (0-2) and in some cases a dichotomous rating is used (yes/no). No information was available about whether these scales were cognitively tested or statistically analyzed.
 - Some instruments use nominal scales in which each level of severity is described by examples of what a person with that rating can or cannot do. (Although easier to use, nominal scales cannot be used to produce a summary score without extensive statistical testing on large sample sizes to ensure uniformity of interpretation.)

- When a summary algorithm or procedure is provided it tended to add up the numerical scores for whatever rating scale is used. There are other ways of more accurately developing summary scores – see Annex 2 for a description of Rasch modelling.

12. Decisions about disability status or certification are said to be based on the information collected in the instruments or forms – and in some instances simple additive, summary formula is provided to reach a final score. We had difficulty finding evidence whether, or how, the final decision is made, and whether it is based on the score or not.

13. In all disability assessment systems, as currently conducted, despite the accumulated information using ICF terminology or classification categories, from what we have been able to discern, there remains a heavy reliance on medical information, in the form of ICD codes, lists of impairments, and sometimes ICF Body Function and Structure information.

14. For disability status assessment, when environmental factor information is collected, it is not clear how that information is used to assess the existence or severity of disability.

15. Multidisciplinary teams are most commonly used for assessment, with – as far as we can determine – a significant and sometimes dominant role played by the medical doctors on the team.

16. When a combination of medical diagnostic information and ICF-coded functioning information is used, both of which are used to produce summary scores or ordinal disability scales, there is no systematic way to combine the scores, leading to non-transparent discretionary decision-making.

Needs assessment and SEN assessment

17. For reforms in needs assessment there is more variations, e.g.

- In Serbia, the needs of children for “additional support in health, education and social protection”; are determined by municipal inter-sectoral commissions. Centers for social work (and service providers), through a separate process, assess the level of support a person needs in terms of social care services.
- In Moldova, the information on needs is collected as part of disability determination process and the same authority issues a decision on the

degree of disability and the Individual Program for Rehabilitation and Social Inclusion.

- In North Macedonia, there is a similar approach implemented through the expert bodies for disability and the assessment of needs for additional support in health, education, and social protection.
- In Georgia and Armenia, information on needs is collected as part of the overall disability status assessment process. SEN is conducted separately.

18. Since needs assessment does not require any form of summary algorithm, if sufficient information about the individual's functioning in a good range of everyday activities and about the individual's actual living context is collected, then the assessment is likely useful and relevant to needs assessment.

19. As a general matter and as far as we were able to determine after our review, needs assessment tools appear to collect lots of information. But we cannot confidently say that they are fully suitable for a comprehensive needs assessment. To answer this question, it would be necessary to conduct empirical research and track assessment results with provision of relevant support and service, and improvement in the person's functioning in various domains. We were not able to determine whether this research had been done – to the best of our knowledge it has not.

20. Only Serbia uses a distinct needs assessment instrument to determine the level of need for social welfare services.

21. The practice of SEN assessment also varies across countries, although there is a stronger tendency to base special needs assessment on international tools.

22. What remains unclear is how these internationally developed tools are used, what kind of input they provide for educational needs assessment and how their variety contributes to a comprehensive, holistic assessment of needs. It is beyond the scope of this consultancy to comment further.

23. Administratively, SEN assessment tends to be organized by ministries of education, independently

of the disability status assessment although, e.g., Serbia uses municipal multisectoral commissions (regulated by education related legislation) to assess additional needs for support in health, social protection and education and North Macedonia uses regional expert bodies to determine additional needs for support in health, social protection, and education. In Georgia and Armenia SEN is organized separately from the disability status and disability needs assessment.

3.3 Observations by key specific aspects of the disability assessment systems reforms

As mentioned above, this consultancy has been requested to examine four specific aspects of the reforms in these five countries in disability status assessment. To recall, we were asked to investigate the extent to which the reforms in these five countries:

- ...have led to understanding of disability in line with human rights-based approach to disability, improved assessment of individual child needs and the extent it has contributed to effective policy and service planning and provision for children with disabilities and families,
- ...use of ICF in disability assessment, certification and eligibility determination has facilitated transition from medical towards to human-rights based approach to disability inclusion,
- ...has contributed to common understanding of disability and strengthened cross-sectoral collaboration, particularly in the context of de-institutionalization and transition to family community-based care, early identification and response to risks of family separation, family support (and reintegration) services, gate-keeping system (decision-making in the best interest of the child), promoting case management,
- ...has led to systemic transformation (human and financial resources, capacity building, legislation).

On the basis of our mapping exercise – using Portugal and Switzerland merely as comparator countries and not necessarily as examples of good practice⁷² – and keeping in mind our concern that we were not able to fully investigate the practice 'on the ground' but were required for the most part to rely on desk research and limited interviews of UNICEF

⁷² We are using the word "good practice" and sometimes "promising practice." The term "best practice" would need a comprehensive comparative empirical evaluation of a particular practice to be deemed "best" practice.

personnel, we now consider each of these issues in turn.

Issue I

...has led to understanding of disability in line with human rights-based approach to disability, improved assessment of individual child needs and the extent it has contributed to effective policy and service planning and provision for children with disabilities and families.

On the information we have, all five countries have made good faith attempts to implement in their reforms of assessment processes and instrumentation the human rights approach to disability (as we conceptualized this approach in section 1.2 above).

Given the demands in achieving the substantive and procedural human rights of the child and significant others, as well as the substantial and procedural human rights restrictions on the process of disability assessment, fully achieving this in practice is likely a high standard to meet successfully over a relatively short period since the reforms started.

From our mapping of Portugal and Switzerland, it is clear that while Portugal has achieved very substantial reforms that may be a model for other countries, despite many improvements, Switzerland has not and appears to have a system that is somewhat behind other European, high-resource countries in terms of the human rights approach. Indeed, as we reviewed above in the CRC/CRPD Concluding Observations, Switzerland and even Portugal, although highly praised, nonetheless were seen by the Committees as falling short in achieving human rights objectives.

Generally, we have observed efforts to support the rights of child in each country, but we did not have access to actual, concrete practice on the ground, so it is difficult to make a final judgement.

Definitions of Disability

All five countries define disability in a manner that reflects the characterization in the CRPD, usually as a matter of formal legislation, regulation, or ministerial decree. At this level, however, this is a general, even aspirational, signal of the fundamental paradigm shift represented by the CRPD. As one goes deeper into the details of the process – for instance parsing the regulations or assessment tools used to identify children with disabilities – one gets the sense of a

continuing reliance on a list of health conditions or impairments recast as disabilities, e.g., sensory ‘disability’, developmental ‘disabilities’, physical ‘disabilities’, chronic diseases, children with autism, mental ‘disabilities’ and so on.

Unfortunately, if the initial identification of a ‘children with disabilities’ is in terms of a disease diagnosis or impairment label, then it will be difficult to remove that label as the parents apply for educational and other supports. It is nevertheless clear how much harm is done by this labelling – which continues in all five countries; when the medical approach is entrenched into the system, then reforms of the sort that these countries have entered with the very best intentions will fail to hit the target of ensuring that disability assessment is aligned with the human rights approach.

Impact on the overall system of policy and service planning and provision

It must also be said that, in our view, it would be highly speculative and scientifically risky to make any claims about how assessments of disability or needs “contribute to effective policy and service planning and provision...” There is no scientifically plausible route, based on the information we have, to make assertions about the contributions reforms have made or potentially will make to effective policy. We think it is unhelpful to resort to slogans or platitudes about the reforming capacity of ‘the human rights approach’, so we refrain from doing so.

At the same time, from our mapping exercise, and experience in other countries, disability status assessment must be understood to have a limited usefulness for policies to provide realistic and relevant supports and services to children. At most, disability status assessment categorizes a child as a child with disabilities – and perhaps also, identifies a level of severity of disability – that is all it does, by design. A well-functioning needs assessment, by contrast, especially if carried out by professionals trained to fully explore the lived experience of children (rather than their health status) – social workers, occupational therapists, even community nurses – provides much more relevant information.

The important role of needs assessment for children – and the limited role of disability status assessment – is why we have suggested that the Portugal situation may well be a good model. Here needs assessment and special educational needs assessment – carried out by multidisciplinary teams and within the context of the school setting – in effect

serve the gate keeping function of disability status assessment. Moreover, it serves the further function of integration of services, and, ultimately, budget planning. Eliminating the prior, gatekeeping, role of disability status assessment for children may not be politically feasible for a variety of reasons, but Portugal at least is an example of how it is possible.

Another comment we wish to make, although not necessarily related to disability assessment, is that it was apparent to us in the mapping exercise that every country is struggling to overcome the lack of cross-sectorial cooperation and integration. Here Portugal again is a good comparator case since cooperation between sectors has been at the forefront of their reforms. Moldova seems on a good track as well. Analytically, since disability is complex lived experience that cannot be chopped up into sectors or ministries but is rather a holistic experience, to adequately determine and address the needs of children with disability a coordinated action across sectors and agencies (particularly those responsible for health, education, and social protection) is an essential precondition to effective support.

What should be aimed for is an integrated, child-centered, system that provides a range and continuum of services for the child as he or she ages throughout life – from birth to childhood to pre-adult to adulthood. Disability assessment and needs assessment are gateways into the system, but needs should be coordinated by case management and access to benefits and services should be straightforward. The system must be easily navigable for the family and the child.

This optimal case, however, has not been fully realized in the countries whose systems we mapped (except, again, for Portugal and emerging potential in Moldova). In the four other countries and perhaps more surprisingly in Switzerland as well, there appears to be no system integration and government agencies tend to work in parallel, or at odds. Certainly, efforts have been made to integrate service provision: Serbia, for example, has multisectoral commissions at the municipal level that serve a coordinating function; Armenia has tried to link disability assessment with needs for education; Georgia is working on coordinating health and social protection; North Macedonia has recently redesigned its administrative process for disability and needs assessment, a move that

has a good potential; Moldova has an Individual Rehabilitation Program based on needs assessment that serves as an integration and coordination point. This is important progress and should be continued.

Disability status assessment

On our understanding, the central human rights concern that “disability assessments should take into account not only the impairments but also environment facilitators and barriers that improve or hinder their full and effective participation in society, and the right to be included in the community, of persons with disabilities on an equal basis with others” has been at least as an aspiration, i.e., in terms of regulation, achieved in all five countries. All countries have also made efforts to make the shift away from assessment grounded entirely in medical information and impairments and to collect information about functioning, and in particular participation, that, at least in the model of the ICF, incorporates information about environmental factors. Whether disability status assessment is an essential and unavoidable component of a CRPD-aligned policy for children with disabilities, we have our doubts.

Technical limitations

Pursuing this framing of the issue, however, unavoidably leads to more technical concerns that limited the effectiveness of the reforms. At bottom, the problem is that the CRPD does not explain what it means to ‘take into account’ environmental facilitators and barriers. Left without guidance about what this phrase means, countries make the most reasonable assumption that, at a minimum, aligning disability assessment with the human rights approach must mean collecting data from three distinct sources: health and impairments, activities and participation, and environmental factors. In line with the additionally felt necessity of using the ICF vocabulary and classifications, the result are essentially data collection tools couched in the ICF language.

Although there is a wide variety of instruments and forms used in the five countries⁷³ – both self-assessment and interview-based, using dichotomous, nominal, ordinal and quasi-quantitative scaling, and response options – they all suffer from similar limitations which, although we have made reference to them above, bears repeating:

⁷³ See full case studies published separately for full versions of some of these instruments

- They typically request health condition or impairment information; but this information can only be plausibly validated by medical professionals based on objective evidence.
- Many of the tools request environmental information. As has been explained, in the context of a needs assessment, which optimally is an individualized assessment of the actual situation of the person, based on home visits or similar inputs, this information is essential to identify the needs of a person. However, for disability assessment this information plays no role at all, since, as was mentioned, there is no evidence-based science (beyond anecdotal reports) that systematically underwrites conclusions about the kind and degree of impact on disability of any environmental barrier (let alone the summary impact of the environment on a summary statement of disability experienced).
- As the CRPD itself makes clear, a person with impairments may experience limitations in participation when confronting environmental barriers. The question for assessment is whether they do. Absent reliable evidence-based generalizations about the impact of an environmental barrier on a particular impairment, the best we can do is ask about the end result of the interaction – actual performance.
- We have argued that disability assessment should be understood as a status assessment, rather than needs assessment, and as such requires a mechanism for summarizing the overall experience of disability of a person. To achieve this summary statement and measure, the following two features of the assessment instrument are essential: a) quantitative (or statistically linear) response options that represent real phenomenon; and b) a summarizing algorithm that takes into account the statistical fact that disabilities is multi-dimensional.
- Finally, for an assessment to have scientific legitimacy it must be shown, statistically, to have respectable psychometric properties of validity and reliability: the assessment must truly assess the phenomenon it claims to assess (i.e., disability) and it must do so in a reliable manner so that the same individual, assessed by two assessors, will be assessed the same. Although Armenia and Georgia have engaged in preliminary work towards this end, we have no information about the validity or reliability of the instruments they use.

Our overall judgment, therefore, is that – to varying degrees and recognizing good preliminary work that the countries has engaged in – the instruments and forms we have reviewed are not scientifically sound disability assessment instruments. They collect valuable information, but they lack the scientific and measurement power to yield sound assessment results.

Disability assessment and determination: the decision

We noted above that, unavoidably, disability status assessment and needs assessment called for professional discretionary decision-making. Professionals are given the authority – by law – to make these decisions and using complex and multi-sourced evidence to form a judgment about an individual case can only be accomplished by a human assessor using discretion. Yet, these decisions – politically and ethically – are accountable and accountability is a function of transparency and evidence. The more it is possible to create evidence that is scientifically robust – specially in this context, in terms of a psychometrically valid and reliable questionnaire or form – the more likely the judgment is not only evidence-based, but open to public scrutiny. The primary problem that we have identified over and over is that the decision in disability assessment is not publicly and transparently linked to the (often substantial) information collected as ‘evidence’. That suggests a problem of accountability and the transformation of the decision from legitimately discretionary, to illegitimately arbitrary.

But does this mean that for disability status assessment to be aligned with ‘the human rights approach’, is it essential that the mechanism of assessment be scientifically sound? Our answer is blunt: we take it as given that an arbitrary, subjective, non-transparent and illegitimately discretionary assessment of disability, without scientific support, is a fundamental violation of human rights. Such an assessment decision cannot be fair, consistent, equitable, or indeed respectful of the individual. That said, obviously there has been no intention to institute arbitrariness into the disability assessment system in these countries – quite the contrary, the intentions behind the reforms in each country were motivated by the need to escape the arbitrariness of solely medically-based assessments. Nonetheless, if scientific legitimacy is a necessary pre-condition of an assessment process that is respectful of human rights, then more work needs to be done.

The five countries we are reviewing are in more or less the same situation as the majority of countries in Europe and the rest of the world. There are scientifically sound instruments in rehabilitation science that can robustly assess separate disabilities and can be used to statistically generate models of whole person disability.

In our view, it would be useful for countries to consider using the World Health Organization tool - Disability Assessment Schedule (WHODAS), which is a generic tool with very strong and well-demonstrated psychometric properties, applicable to persons 12 years or older that is used (with modifications) in several countries for disability status assessment. However, it is not clear that WHODAS in its current form can be successfully used for children younger than 12 (we have been informed that a WHODAS for children is under development).

More generally, for the five countries we have mapped, one gets the impression that data is collected, an instrument or form is filled out, perhaps with summary calculations, and then a decision is made – but there is no connection between the former and the latter events. The final assessment takes place in a ‘black box’. This is pretty much an example of an application of professional discretion that is arbitrary and unaccountable. It should be said that this is not an uncommon situation in many other countries, for example the same could be said for the situation in Switzerland: relevant and valuable information is collected about the child, and then decisions are made and implemented, without any clear connection to the tool (in Switzerland still many children are placed in special schools).

Is disability status assessment of children necessary?

Because of these considerations, we raised once again the question of whether, at the end of the day, there is any need for disability status assessment for children. From a human rights perspective, the real focus of policy should be on meeting the needs of children with disabilities, and that is achieved, not by disability status assessment, but by needs assessment, including SEN assessment. In most countries disability status assessment is used for adults to serve as a portal and screening device for applications for financial and other disability benefits. Countries are concerned about fraud and managing the size of disability budgets and the labor market issues.

The situation is very different for children in terms of the pathways into the system, the complexities of developmental transitions, and the importance of educational inclusion. We have included Portugal as a comparator because it has succeeded in avoiding disability status assessment, certification and categorization of children, in favor of child-centered approach to supports.

We believe that countries should consider whether for children a formalized status assessment producing a certification of disability is necessary. If a country's needs assessment process is well-designed and structured for a multidisciplinary assessment of needs for health, education, social protection, and other supports, then the system can proceed without a categorization of the child and focus on matching needs to services. Without labelling, stigma is avoided and there is a better chance of cooperation between sectors. One possible pathway would be the identification of a health or developmental problem in the health sector that triggers a needs assessment to identify both health needs and other social services and supports. At the appropriate age, the child may then be referred to the education sector where a special educational needs assessment by a multidisciplinary team, conducted within the school system itself, would identify the needs for full inclusion into mainstream schools. This is a highly simplified version of the system in place in Portugal.

Issue II

...use of ICF in disability assessment, certification and eligibility determination has facilitated transition from medical towards to human-rights based approach to disability inclusion.

All five countries have implemented in some ways the ICF into their disability assessment – most have done so for needs and SEN assessment as well. We noted above that there is a tendency for countries, in legislation or public statements, to give the impression that using the vocabulary of the ICF suffices to be adopting the biopsychosocial model. We do not have that impression for these countries; there seems to be a genuine intention to reform the approach to assessment by using the ICF both as a source of terminology and as an operationalization of the human rights approach to assessment. We acknowledge (with regret) that there is very little guidance from WHO or other organizations on how to implement ICF in this area.

We conclude that, on the evidence from these five countries, there is no doubt that the use of the ICF – both as an international information reference system and as an operationalization of the CRPD conception of disability – has facilitated the transition from a purely medical assessment to one that takes into account the phenomenon of disability, namely limitations and restrictions in functioning across domains of life. We reiterate the fact that there simply is no alternative: there is no other internationally recognized reference classification for functioning information.

At the same time, we want to underscore that the ICF on its own does not make the transition from medical to human rights approach; more fundamental changes are required. More specifically, merely collecting information, using ICF terminology, across the four dimensions is not an assessment process. It is an information collection process. What is required, on the basis of that information, is a scientifically sound – but practically feasible – instrumentation that can validly and reliably assess the level of performance across A&P domains that the individual actual experiences in his or her life.

For reasons we have already discussed, in our opinion the current assessment tools for disability status are not scientifically sound. The efforts of which we have been informed to strengthen these tools through empirical testing, revision and validation, e.g., in Moldova, is encouraging.

Issue III

...has contributed to common understanding of disability and strengthened cross-sectoral collaboration, particularly in the context of de-institutionalization and transition to family community-based care, early identification, and response to risks of family separation, family support (and reintegration) services, gate-keeping system (decision-making in the best interest of the child), promoting case management.

In each of the countries we have reviewed, the biopsychosocial model has contributed toward (or at least raise awareness about) a common understanding of disability across sectors. Yet, each country has identified in print or in conversation the lack of cross-sectoral collaboration as the primary obstacle to reforms of children support services, including in education. Whereas for adults this challenge means finding ways for ministries of health and social protection to cooperate, in

the case of children this is a matter of at least a three-way cooperation between health, social protection and education. Special educational needs assessment (SEN) is in most cases handled in ministries of education, but information relevant to this assessment is also collected for general needs assessment, and a cooperative arrangement between the two would be extremely beneficial in order to create and sustain policies for the important, child-related issues mentioned in the term of reference: deinstitutionalization and transition to family community-based care, early identification to risks of family separation, family support and other services.

Again, without more rigorous information about the situation on the ground, it is very difficult for us to make or substantiate claims about whether and the extent to which the reforms in any of these countries, resulting in a common understanding of disability, have contributed to positive policy changes in these important areas that affect the lives of children. The fact is that institutionalization of children with disabilities and special schools for their education persist, indicating that discontinuing institutionalization and achieving inclusion in mainstream education require much more than changes in the disability and needs assessments.

Issue IV

...has led to systemic transformation (human and financial resources, capacity building, legislation).

The information that we have had at our disposal about the disability, needs and SEN assessment rules, the instrumentation used, and procedures followed, has enabled us to understand the contours and even some of the details of how disability assessment works in each of the five countries. Nonetheless, far more data is needed to support any conclusion with respect to systemic transformations that may have resulted from reforms. Not only would we need more detailed and longitudinal data about, as noted, human and financial resources, capacity building, and legislation, but we would also require statistical data about all relevant inputs, outputs and outcomes- for which, relevant indicators and reliable information is difficult to collect and verify.

The precondition for any systemic transformation of policy for children is valid data about the population. But a common theme across the five countries (and, admittedly a common problem in other countries) is the lack of usable data about children with disabilities and their characteristic needs and service

gaps. Even basic prevalence data is unreliable. In Georgia for example, the official number of children with the official status of disability is 1.2% of the population of children in the country, a figure far below the UNICEF's and WHO's global prevalence estimates (5.1% and 4.4% respectively). In Serbia, the Census based estimate in 2011 using 6 Washington Group questions was 0.7%. The prevalence information is vital for policy, but so is information about many other aspects of childhood disability, including the needs and gaps in service provision. It is noteworthy that reforms in disability assessment themselves have extra administrative, training and data collection and storage costs.

Any judgment about the potential of reforms for systemic transformation presupposes important questions about system transition and sustainability. All five of the countries we have reviewed enacted legislative frameworks that affected disability assessment for children, and some of them are anticipating additional legislation in the next couple of years. But passing and enacting legislation is no guarantee either that the transition from one system of disability assessment to another will be effective, or if effective that it will be sustainable. Active measures must be put into place to continuously monitor implementation of the reforms, and in particular to review the barriers being experienced by applicants in obtaining disability benefits. A suggestion from one informant was that UNICEF can play a role in this regard by creating a sustainable inter-ministerial coordination at the systems level and strengthen partnerships with various stakeholders from the local to national level government agencies.

Sustainable inter-ministerial coordination is very difficult to achieve due to difference in agenda and working systems between ministries, even if the target population is the same. Coordination is most difficult to establish between health and education sectors at all levels because of the rigidities of their structures. Given the importance of inclusive

education as a policy goal, a special effort will need to be made to engage ministries of education to collaborate in the implementation of new systems of disability and needs assessment. Procedures for determining special needs for education currently in place need to be coordinated with the new system. Teachers could be brought into the assessment for school age children, as they work with children every day and know their learning progress and issues they are facing. For the needs assessment to be useful, teachers are crucial – they should be the first one to whom the case manager should collaborate with for education additional support measures. For needs assessment more generally, what is required is a multi-sectorial, coordinated needs assessment, with the potential for referrals to services and supports provided across ministries, and coordinated by means of case management. Whatever is put into place, however, the only institution that can institute and sustain collaboration is the government, not UNICEF or any other international organization.

To further ensure sustainable reforms toward systemic transformation, other inter-sectorial and coordinated activities will be necessary: It will be important to develop an enduring capacity for training and supervising professionals who will act as case managers or carry out functioning assessment nation-wide. On-going monitoring, quality control, public education and where needed prevention of fraud mechanisms may be required. Lastly, an information management system will be required to support case management as well as planning at the national and sub-national level. An integrated information system is an essential component of disability and needs assessment going forward. Many countries are actively engaged in building e-government and linking various sources of information on children with developmental and other health problems, and this can be extended to encompass disability. It is unlikely that a fully functional information system would need to be built from scratch; what is required is to link existing data sources into an integrated system.

4. Recommendations

These recommendations are merely summary and high-level suggestions that should be read in light of all of what has been said above.

1. Continue the reforms that have already been initiated

We especially want to emphasize the considerable progress that has been already made- the motivation is clear, and the intended outcomes are in line the high-level aspiration of alignment with the provisions of the CRPD and CRC. However, operationalization of reforms and persistent implementation to achieve intended outcomes,

require that the reforms continue.

2. Develop a proper functioning, psychometrically robust, assessment instrument

UNICEF might team up with WHO and other agencies to develop a disability status assessment instrument for children. This instrument, to be constructed using the ICF, would need to be properly clinically and psychometrically tested and should be accompanied by a manual. Please see details above.

3. Develop a short technical and methodological guide for local development of the functioning assessment instruments

Development of a UNICEF/WHO childhood disability assessment instrument will take time and countries will not be able to wait for it. For the benefit of the countries and UNICEF staff who tend to be closely involved in the reform, a guide would provide information and help concerning minimal technical standards that need to be met for any instrument to be valid and reliable. For issues to be considered in such a guide, please see details above.

4. Develop a technical guide on the early childhood development measurement, disability status assessment and needs assessment

This guide would clarify the relationship between these three technically, functionally and operationally separate processes and guide the country and UNICEF staff in their thinking and acting concerning the reform of childhood disability and needs assessment.

5. Develop a training course on childhood disability and needs assessment

For anyone engaged in the childhood disability and needs assessment, going through a proper training is a must. The course should target country stakeholders and UNICEF staff.

6. Conduct research on the operation of disability status assessment systems at the country level

This will involve substantial investment in data collection and storage initially so that the system's operations can be researched longitudinally. Academic support will be required.

7. On-going reforms should clearly distinguish disability status assessment from needs assessment

See above for the multiple reasons why eliding these processes can lead to a breakdown in the effectiveness of assessment and determination of needs for children with disabilities.

8. Investigate the possibility of eliminating the need for disability status assessment for children

This may be initially controversial for a variety of political and administrative reasons, but the example of Portugal can be used for guidance. To start with, the certification process can be abolished for young children (say of pre-school age), focusing instead on early identification of developmental issues, needs assessment and early interventions to optimize the child's development.

9. Fully implement ICD coding for all medical diagnostic applications in disability assessment

The use of the ICD-10, as well as the rolling out of the ICD-11 is an excellent opportunity to make use of a standardized electronic data system that would inform disability status and needs assessments in a fast and easy manner, reducing greatly transaction cost to parents of providing medical documentation.

10. Investigate mechanisms for capturing the voice of children with disabilities

Develop a formal guide with good practice examples.

11. Establish a UNICEF mechanism to monitor childhood disability and needs assessment systems across the world

This mechanism could include a database of legal and administrative material, instruments, and other documents, a resource team who have been qualified and evaluated in terms of their performance, and a list of properly vetted experts with proven technical and practical track record.

Annex 1: Consulted Literature

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Swiss Conference of Cantonal Ministers of Education (EDK): <https://www.szh.ch/page-d-accueil;>

Annex 2: An Introduction to Rasch⁷⁴

Rasch analysis is one of a family of probabilistic measurement methods from modern test theory that was introduced in the 1960’s by the Danish mathematician George Rasch (Rasch 1960). Practice in the field-- from Taiwan in the early 2000’s, to several eastern European countries more recently – suggests that it is a highly relevant and feasible quantitative technique for analyzing data from disability assessment instruments (primarily the

World Health Organization’s Disability Assessment Schedule – WHODAS 2.0) to produce a true measure of extent of disability. For this purpose, a polytomous version of the Rasch model, called the Partial Credit Model (PCM), has been applied (Masters 1982).

Rasch analysis allows us to test whether items from a questionnaire fulfil fundamental assumptions

⁷⁴ This Introduction was written by Carolina Fellinghauer for the World Bank projects on including functioning into disability assessment systems in Greece, Latvia and Lithuania. In all three countries WHODAS 36 was piloted, and data analyzed to propose options for evidence-based inclusion into disability status assessment. See: Carolina Fellinghauer, Aleksandra Posarac, Jerome Bickenbach. And Marijana Jasarevic. Disability Assessment in Latvia, Options for Including Functioning into Disability Assessment. © World Bank. 2022; Aleksandra Posarac, Carolina Fellinghauer, Jerome Bickenbach. Disability Assessment in Lithuania, Options for Including Functioning into Disability Assessment. © World Bank. 2021; Aleksandra Posarac, Carolina Fellinghauer, Jerome Bickenbach. Greece: Options for Including Functioning into Disability Assessment. © World Bank. 2019

of measurement so that the scores derived from ordinal scale ratings ('mild', 'moderate', 'severe', 'complete') can be transformed into an interval scale (0-100). As ordinal scaled values cannot be used to calculate means or variances, or in any true sense represents an 'assessment' of the extent of disability that an individual experiences, an ordinal to interval transformation is essential to make the information collected through disability questionnaires usable for parametric and inferential statistical testing. In other words, unless information from disability assessment tools have interval scale properties, it is impossible to compare the results of two applications of a questionnaire, as the mere summing up of the response options (as in WHODAS, for example) does not represent a true quantity, but merely a nominal sum that only applies to that one individual (comparisons over time of that one individual are possible without interval scales). Again, true assessment of disability cannot be done ordinally (or nominally).

A Rasch analysis tests the core measurement assumptions (Bond and Fox 2007, Tennant and Conaghan 2007). These assumptions, one established, mean that the data from the questionnaire can be represented quantitatively in terms of a true measure – an interval scale. These assumptions are all highly technical:

- (1) the targeting of the scale;
 - (2) the model reliability (Cronbach alpha and Person Separation Index (PSI));
 - (3) the ordering of the items' response options;
 - (4) the absence of correlation between items (local item independence (LID));
 - (5) the fit of the items to the Rasch model;
 - (6) the absence of effects of person factors such as gender and age on item responses (differential item functioning (DIF); and
 - (7) the unidimensionality of the questionnaire.
- If these measurement assumptions can be met, a questionnaire is psychometrically sound, and derived total scores can be considered interval-scaled and operative for measurement.

The metric analyses are performed with the software R (Team 2016), more specifically the package eRm for the Rasch analysis (Mair 2007). Observation with missing values (< 30%) are imputed with Amelia (Honaker, King, and Blackwell

2011) expectation maximization likelihood-based method, which has proven to be robust in the context of Rasch analyses (Fellinghauer, Proding, and Tennant 2018).

To qualify as a scientifically robust questionnaire it is expected that the difficulty of the items is matched to the level of ability of the measured population, i.e., the questionnaire should not be too easy or too difficult. If these measurement assumptions can be met, a questionnaire is psychometrically sound with interval-scaled total scores that are operative for measurement. This is the gold standard for instruments of this sort.

For a well-functioning questionnaire, the items' difficulty must match the population's level of ability. Statistically, good targeting implies that the mean item difficulty and mean person ability approximate 0 and that the items' difficulties match the ability of the population. This would mean that the items included in the questionnaire capture the disability range of a population.

A Person Separation Index (PSI) above 0.8 indicates good reliability of the scale, values above 0.9 very good reliability. The PSI indicates how well the scale can discriminate levels of functioning in the population. The Cronbach α , which is typically also reported, is a measure of the data's internal consistency, i.e., how well the items work to describe one construct (Nunnally and Bernstein 1994).

In the presence of disordered response options, an analysis of response probability curves allows to determine which response options cause a problem and to decide on strategies for collapsing i.e., aggregating, adjacent response options. For example, if an item's response options 2 and 1 appear reversed and indicate that an expected increase of difficulty is not observed in the data, the item responses can be recoded so that these options represent only one level of response.

Local item dependency often occurs when items are redundant and measure approximately the same aspect of a construct. The most widely reported statistic for item dependencies is the Q3 matrix, which is just another name for the Rasch residual's correlation matrix (Yen 1984). Marais (2013) recommends considering LID relative to the residual correlations' average because the residual correlation's magnitude depends on the number of items. Christensen, Makransky, and Horton (2017) formalized this, illustrating that if the largest Q3 value is more than 0.2 above the average, it would

indicate an anomaly. A way to address local item dependency without deleting items is to aggregate (i.e., sum up) the correlated items into so-called testlets (Yen 1993). In item testlets, the ordering of the thresholds is not expected anymore.

With good item fit, the Infit and Outfit values are below 1.2 (R. M. Smith, Schumacker, and Bush 1998). The Outfit statistic is a more outlier sensitive alternative to the Infit statistic, meaning that the Outfit statistic can sometimes indicate misfit, while the Infit does not.

Ideally, items of a questionnaire should not favor sample subgroups. The analysis of DIF with ANOVA flags exogenous variables, or DIF variables, which cause a lack of invariance of the item difficulty estimates (Holland and Wainger 1993). It is worth noting that a DIF analysis does not always indicate a metric bias but can also represent subgroups with an unequal ability (Boone 2016). A two-way ANOVA is used to test for uniform (DIF variable) and non-uniform (DIF variable x score level) DIF. The questionnaire was tested for DIF by gender and age groups.

Finally, a questionnaire should measure only one construct. If the questionnaire presents several separate dimensions, the validity of the summary total score is undermined. A principal component analysis of the residuals determined the questionnaire's degree of unidimensionality (E. V. Smith 2002). Typically, a first eigenvalue < 1.8 is deemed indicative of unidimensionality. Based on simulation analyses, R. M. Smith and Miao (1994) suggest considering the second component's size, with values below 1.4 as indicative of unidimensionality.

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Annex 3: Summary of CRPD and CRC deliberations pertaining to children with disabilities

Armenia

CRC 2013

Positive: adoption of the Law "On education of persons with special needs" in 2005 and amendments to the Law "On general education" in 2012, both of which provide for the inclusive education for children with special needs.

- concerned that not all children in all regions have full access to care and services to ensure adequate standard of living.

CRPD 8 May 2017

Positive: adoption, in 2014, of the "Law on making supplements and amendments to the Law on general education," which provides for a transition from general education to inclusive education for children with disabilities by 2025.

The adoption of the comprehensive plan for 2017-2021 on social inclusion of persons with disabilities, in 2017.

- concerned by institutionalization of a high number of children with disabilities in orphanages and residential special schools, and continued investment in such institutions,
- lack of State support, including early intervention, for children with disabilities and their families,
- neglect, violence and abuse stigmatizing attitudes towards children with disabilities,

in particular children with intellectual and/or psychosocial disabilities.

- despite the increasing trend towards inclusive education, many children with disabilities remain in segregated educational settings, lack of accessibility and reasonable accommodation for children with disabilities in mainstream schools,
- the lack of sufficient support and training for administrative and teaching staff with regard to inclusive education.

Recommendations:

- review the draft law on the protection of the rights of persons with disabilities and their social inclusion to ensure that it is in line with the Convention,
- adopt a human rights-based concept of disability and ensure that disability determination focuses on the barriers to the social participation of persons with disabilities and refers to individual requirements, will and preferences,
- provide children with disabilities and their families with adequate assistance, including early intervention, and implement specific measures to reduce poverty among them.

Georgia

CRC 2017

Positive: integration of children with disabilities in social, recreational, and cultural activities.

Concerns:

- limited availability of early identification and intervention programs,
- the system exclusively based on health needs determining disability status, which ignores some developmental disabilities of infants and young children, and the absence of an effective referral system based on cooperation between medical personnel, social workers, and service providers,
- slow progress in the deinstitutionalization of children with disabilities in rural areas,
- Incomplete data on children with disabilities.

Recommendations:

- adopt a human rights-based approach to disability, set up a comprehensive strategy for the inclusion of children with disabilities and:
(a) Introduce individual functional assessments of disability status, based on the ICF and a biopsychosocial approach for their support, train service providers on the assessments, guarantee effective cooperation between services and timely medical interventions and referral to adequate health and educational services, and establish early identification and referral mechanisms for vulnerable children,
- take steps to improve the standard of living of children as a matter of priority, paying particular attention to housing, water and sanitation.

Moldova

CRPD 18 May 2017

Positive: Government decision No. 44 (3 March 2016), approving the action plan for the implementation of reforms relating to deinstitutionalization; Government decision No. 523 (11 July 2011), approving the program for the development of inclusive education 2011-2020, providing equal opportunities for all children to access quality education.

Concerns:

- stigmatizing attitudes towards children with disabilities which are reinforced by a lack of community services,
- children with disabilities do not systematically

participate in making decisions that affect their lives and lack opportunities to express their opinion on matters pertaining to them directly.

- life-long institutionalization, from early childhood, of children with disabilities, especially those with psychosocial and/or intellectual disabilities, in inhumane conditions, where they are exposed to neglect and segregated from the community,
- progress towards inclusive education in the State party has stalled; provisions in the "Education Code" of 2014 still allow for segregated schooling; children with disabilities, mainly those with psychosocial and/or intellectual disabilities, remain in segregated educational settings, including "special schools", "special classes", and "home education", and do not receive the support they need to access inclusive education.

Recommendations:

- Amend the 2014 "Education Code" and ensure that no child is refused admission to mainstream schools on the basis of disability, ensure accessibility and allocate the resources necessary to guarantee reasonable accommodation to facilitate the access of students with disabilities to quality, inclusive education, including pre-school and tertiary education.

North Macedonia

CRPD 29 October 2018

Positive: Its renewed ban on the institutionalization of children and its commitment to end the placement of children under 3 years of age in institutions.

Concerns:

- the absence of specific legislation on the rights of children with disabilities in the State party,
- the lack of criminalization of violence against children with disabilities, including corporal punishment and sexual violence, in all settings,
- the expiration of the National Strategy for Equality and Non-discrimination 2005–2015 and the non-inclusion of the rights of children with disabilities, including the principle of the best interest of the child, in national policies, plans and programs for children,

- the prevalent stigma, discrimination, and harmful stereotypes against children with disabilities, and the enduring segregation and institutionalization,
- the lack of early assistance and provision of services for independent living,
- the absence of mechanisms to ensure the participation of children with disabilities in decision-making processes affecting their lives, particularly the lack of mechanisms to ensure the right of children with disabilities to have their views considered on matters pertaining to them and their families, including participation in all protection mechanisms,
- concerned that the “Law on Protection of Children” and the “Law on Primary Education” still allow for the segregation of students with disabilities, and that segregated education environments persist, especially for students with intellectual disabilities.
- the Committee is further concerned that there is no updated comprehensive strategy aimed at an inclusive education system, with fixed deadlines and outputs and allocation of adequate financial, human and technical resources, especially for students with intellectual disabilities,
- “Law on Social Protection” does not include disability as a basis for discrimination,
- disability benefits are age restrictive, as persons with disabilities aged between 18 and 26 are not eligible to benefits,
- administrative and bureaucratic requirements for persons with disabilities to access social benefits; persons with disabilities face challenges in meeting the additional costs of disability.
- shortage of reliable data hinders the delivery and evaluation of services for children with disabilities,
- disproportionate number of children with disabilities continue to live in institutions, owing to the stigmatization of children with disabilities and a fragmented system of social assistance that does not sufficiently encourage, and provide support for families to keep their children at home,
- parents and families of children with disabilities who are in need of constant care and assistance have limited access to services and benefits to meet their needs,
- parents may decide that a child with disabilities will not attend a school that provides inclusive education, without guaranteeing the principle of the best interests of the child, resulting in a large proportion of children with disabilities attending special schools,
- regional disparities and equity gaps, combined with financial constraints and inadequate health insurance coverage affecting a considerable portion of the rural population and vulnerable groups.

Recommendations:

- implementing nationally appropriate social protection systems and measures for all,
- adopt a human rights-based approach to disability and establish a comprehensive strategy to ensure the inclusion of children with disabilities,
- give priority to measures to facilitate the full inclusion of children with disabilities, including those with intellectual and psychosocial disabilities, in all areas of public life, such as leisure activities, community-based care and the provision of social housing with reasonable accommodation.
- simplify the administrative procedures and provisions of support for cash benefits to facilitate access by families living in the most vulnerable situations.

CRPD 23 May 2016

- concerned about the number of children with disabilities living in institutions, especially those with intellectual disabilities,

Serbia

CRC 2017

Positive: efforts being made to ensure equality for children with disabilities; the adoption of several policies to improve access to adequate health care, including the ordinance on a national health-care program for women, children and young people, in 2010, and the national program for the enhancement of early childhood development

Concerns:

- concerned that more than half of the children living in residential care institutions are not in education and that few measures have been adopted to provide standardized and regulated transparent protocols relating to individual education plans, as well as relevant technologies and forms of communication ensuring accessibility for pupils and students with disabilities at all levels of education,
- concerned about the lack of comparable data on funding earmarked for children with disabilities in mainstream and special education, as well as on affirmative measures for the enrolment of and accommodation provided for students with disabilities,
- concerned at the lack of early identification of and intervention for children with disabilities.

Portugal

CRC 2019

Positive: legislative measures taken to improve the situation of persons with disabilities in the State party, including the adoption of Decree-Law No. 54/2018 that introduces a shift towards inclusive education

Concerns:

- data on children with disabilities
- system for diagnosing disability, which is necessary for putting in place appropriate policies and programs for children with disabilities.

Recommendations:

- ensure inclusion of children with disabilities in all areas of life and allocate adequate human, financial and technical resources for its monitoring and implementation,
- reinforce coordination between social security, educational and health authorities to ensure the effective implementation of the social inclusion benefit.

CRPD 20 May 2016

- negative effects of the austerity measures taken by the State party on the availability of support services for the families of children with disabilities, as well as on the support provided

for inclusive, high-quality education for such children,

- strategies on disability and on children do not take the needs of children with disabilities into consideration,
- although the great majority of students with disabilities attend regular schools in the State party, there is a lack of support and that, because of austerity measures, human and material resources have been cut, thereby putting the right to and opportunity for an inclusive education of high quality at risk,
- concerned that even though the State party has a special quota for the admission of students with disabilities to public universities, it has not regulated the support universities should provide to such students.

Switzerland

CRC Oct 2021

Positive: ensuring the access of children with disabilities to inclusive education in mainstream schools.

Concerns:

- many children with disabilities, including children with autism, have to attend special schools or classes outside mainstream schools,
- teaching provided in integrated classes and special schools can limit the access of children with disabilities to mainstream higher education and vocational training,
- children with autism, are still sometimes placed in institutions, and sometimes together with adults,
- children with disabilities continue to face discrimination and social exclusion.

Recommendations:

- strengthen the right to inclusive education in mainstream schools for all children with disabilities, including children with autism and children with learning difficulties, and provide clear guidance to cantons that still apply a segregated approach,
- strengthen the training of teachers and professionals in integrated classes providing

individual support and due attention to children with disabilities, including children with severe autism and children with learning disabilities, and increase the amount of support available to such children,

- legally prohibit the practice of “packing” children in the public and private sectors and promote specialization in autism among health professionals,
- Expand the provision of adequate support services for children with disabilities, with a view to preventing the placement of such children in specialized centers.

CRPD 13 April 2022

Concerns:

- participation at all stages of legislative, policy and decision-making processes,
- the scope and application of the concept in the State party’s legislation of “the good of the child” does not adhere to the principle and standard of the best interests of the child contained in the Convention, leading to inadequate decisions in matters concerning children with disabilities,
- children with disabilities face multiple and intersecting forms of discrimination,
- insufficient measures to ensure that the views of children with disabilities are heard in all decisions affecting them, including in criminal and asylum proceedings,
- lack of uniform cantonal protection against the practice of “packing” that is applied to autistic children, whereby the child is wrapped in cold, wet sheets,
- institutionalization of adults and children with disabilities, including persons with intellectual or psychosocial disabilities and autistic persons, and reports of violence and abuse in these institutions,
- lack of a comprehensive system to provide individualized support and personal assistance for living independently in the community, and the shortage of affordable and accessible housing in the community for persons with disabilities,

- insufficient support available for children with disabilities and their families to ensure the enjoyment by children with disabilities, on an equal basis with others, of their rights with respect to family life, and to prevent institutionalization,
- lack of measures to support parents with disabilities to carry out parental responsibilities, to prevent the separation of children from their parents on the basis of the disability of the parents or the child,
- high number of children in segregated educational settings, and the application of the inter-cantonal agreement on special education to stream children with disabilities into special education,
- lack of resources in mainstream schools to support inclusive education, including lack of sign language interpretation, reasonable accommodation and teachers with specialist qualifications in inclusive education in mainstream schools,
- barriers in gaining access to vocational training and higher education faced by students with disabilities, particularly those with intellectual or psychosocial disabilities.

Recommendations:

- strengthen mechanisms at the federal, cantonal and municipal levels to ensure effective support and consultations with diverse organizations of persons with disabilities,
- provide organizations of persons with disabilities with accessible information, including information in Easy Read and sign languages.

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Armenia:

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Portugal:

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