



APPLYING SOCIAL AND BEHAVIOUR CHANGE APPROACHES TO SUPPORT THE INCLUSION OF CHILDREN WITH DISABILITIES

Case studies from UNICEF Europe and Central Asia

This document is prepared by Social and Behaviour Change, UNICEF Europe and Central Asia Region.

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Cover photograph: © UNICEF/UNI233787/Pancic
Anja Bozovic, aged 7, safely uses a smartphone in Serbia.

Contents page photograph: © UNICEF/UN040267/Gurgenidze
Veriko Meishvili, aged 16, at the First Step Day Care for Children with Disabilities, reading a book together with her caregiver. Tbilisi, Georgia.

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FOREWORD

The UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities acknowledge the importance of removing barriers to ensure the social inclusion of children and persons with disabilities. Nevertheless, despite progress registered by many countries in Europe and Central Asia region, most children and adolescents with disabilities still suffer from stigma and ableism, with their inevitable consequences of self-perceived inferiority among children and persons with disabilities and their families and lack of confidence that results in isolation and exclusion.

Stigma and discrimination are some of the strongest determinants of children's and adolescents' development (WHO/UNICEF, 2012). In the case of children that acquire a disability early in life, stigma is often something that they have to bear with throughout childhood, embedded in paternalistic attitudes of caregivers, overprotecting parenting, lower expectations, ableism in schools, and general neglect of their voice, needs, and capacities. Prejudice and ableism lie at the root of discriminatory and harmful practices against children with disabilities such as school segregation, institutionalization, and forced sterilization, among others. Due to ableist assumptions, children with disabilities are frequently considered to need 'fixing' and be helped, less able to contribute and participate, less worthy of attention and have less inherent value than others.

Addressing stigma and discrimination against children, adolescents and persons with disabilities require systematic multi-level approaches that address negative attitudes towards them, harmful beliefs and norms, misconceptions and ableism in the society and empower children and persons with disabilities, their families and organizations of persons with disabilities to demand their rights and participate in processes aiming to make policies, services and communities more inclusive.

UNICEF in Europe and Central Asia has engaged over the last decades with governments, civil society organizations, children and persons with disabilities, youth, media to raise awareness on the rights of chil-

dren with disabilities and develop inclusive policies and services. This document presents a few examples of how social and behaviour change interventions have been implemented in various countries in the region with UNICEF's support to remove barriers to inclusion and create an environment where all children, including those with disabilities, can thrive and actively contribute to the development of their communities. Each case has been documented with a focus on social and behaviour change, highlighting their contribution towards tangible changes achieved at individual, interpersonal, service delivery, community, and policy levels.

While different in their background, leadership, and scope, some common features can be identified among these initiatives. **They have facilitated the active involvement of persons with disabilities in addressing barriers to inclusion**, as engaging with and strengthening the disability communities is key to addressing and deconstructing pre-existing stigma and self-perceived inferiority as well as a significant factor in creating new bonds between persons with and without disabilities at the community level. Exchanging perspectives contributed to a better understanding of issues at stake and created opportunities for amplifying existing know-how and assets in the disability organizations which contributed to the development of more inclusive policies and practices. **They have all embraced a continuous horizontal learning process**, that included a critical appraisal of shortcomings and impasses. This is strategic to adjust to each social and cultural context, re-generating ideas, commitment, and partnerships and avoiding the expectation of attaining a possible recipe or a definite formula for social change. **They intervened on social expectations and opportunities**, creating an environment where diversity is valued and welcomed.

We hope that these case studies can serve as examples of how social and behaviour change interventions can be used as an integral part of activities aiming to develop inclusive services and communities, ensuring they address societal attitudes, expectations and norms in a comprehensive and sustainable manner.



GEORGIA

See every Colour: Addressing stigma against children with disabilities and supporting their social inclusion through social and behaviour change interventions



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Lile, 6, with her mother Mika Dzidziguri. Mika and Lile were part of the core group of parents and children spearheading UNICEF supported communication for social change campaign, See Every Colour. Tbilisi, Georgia.

KEY SOCIAL AND BEHAVIOUR CHANGE RESULTS

1. Wide-scale reduction of stigma and discrimination towards persons with disabilities.
2. Increased public understanding and practice towards the importance of inclusion of persons with disabilities.
3. Increased confidence, and visibility of children with disabilities and parents.
4. Creation of enabling environment at municipal level for services for persons with disabilities.
5. Increased capacity of professionals (teachers and health workers) to address the needs of children with disabilities.
6. Creation of sustainable institutional mechanism to advocate for disability issues.

INTRODUCTION

Disability in Georgia

According to the administrative data, currently there are 128,144 persons with disabilities registered in Georgia, out of whom 12,725 are children. This implies that overall prevalence of persons with disabilities is 3.4%, while prevalence in children is 1.45%, which are much below the global estimates, suggesting gaps in registration and reporting of children and persons with disabilities¹. The Multiple Indicator Cluster survey (MICS), conducted in 2018, provides information about persons with disabilities measured through functional limitations. MICS data suggest that there are 6.8% men and 9.9% women, and 8% children with functional limitations in the country. Thus, inaccurate data renders children and persons with disabilities invisible within Georgia's national legislation, policies, and services.

¹ Source: Social Service Agency, October 2021

Issue

The Welfare Monitoring Survey, a quantitative survey carried out in 2015 acted as a baseline study for the See Every Colour initiative. It measured stigma against disability and showed that more than 40 per cent of the public stigmatized children with disabilities.

Discrimination arose as a consequence of lack of knowledge, fear of difference, negative cultural biases and stereotypes related to disability. As the 2016 study on Stigmatization of children with disabilities revealed², stigma and discrimination towards children and people with disabilities in Georgia has led to institutional, cultural and social isolation of children with disabilities and has been the leading barrier to creating an enabling environment in society. Addressing stigma and discrimination has been essential to promoting the abandonment of discriminatory attitudes and practices and promoting the creation of positive social norms to increase demand for quality and inclusive services for children.

Impact

These discriminatory practices and social barriers not only exclude but also segregate and isolate children and persons with disabilities from independently participating in their communities. The predominance of these attitudes and lack of awareness not only create isolation from the social environment, but also limit their opportunities for education, recreation, employment and adequate services and infrastructure to address the needs of children with disabilities and ensure their inclusion as equal members of society.

Removing these social barriers and increasing awareness of the needs of children and persons with disabilities would significantly increase educational attainment for children with disabilities and representation of persons with disabilities within the labour market and society at large.

Action

Both studies informed the development of a comprehensive Social and Behaviour Change intervention – See Every Colour – to change harmful attitudes and beliefs and to foster social inclusion of children with disabilities. The Social and Behaviour Change intervention aimed to tackle the following challenges that people with disabilities faced in Georgia: a clear, quantifiable stigmatization of people

with disabilities, a lack of knowledge and inadequate beliefs, fear of difference, limited services, and a legacy of segregation policies. The overall goal of the programme in Georgia was to act as a catalyst, to create a sustainable value system in which children's needs are met by addressing wide-spread myths, misconceptions and stigma against people with disabilities in Georgia.

SOCIAL AND BEHAVIOUR CHANGE INTERVENTIONS AND RESULTS

Interventions

The nation-wide Communication for Social and Behaviour Change initiative “See Every Colour” was conducted by UNICEF with the support of USAID and the EU in 2017-2020 and involved a mix of interventions, including:

- educating the population about disabilities and deconstructing the prevailing myths and prejudices;
- illustrating models of attitudes and creating empathy towards children with disabilities;
- promoting interaction between young people with and without disabilities;
- empowering children with disabilities and their parents by giving them a platform for advocacy;
- initiating policy and community discussions and strengthening local government mechanisms and community networks.

The social and behaviour change interventions were implemented at individual, family/peers, community, institutional (teachers, doctors, media) and policy/systems (municipalities) levels. The main platforms used were community engagement, media and service delivery platforms, while the major approaches used were: social and behaviour change communication and social mobilization, community engagement and advocacy through mass-media and digital platforms, community-local government mechanisms, networks and CSOs, schools, universities and health facilities.

The target audiences included children with disabilities and their peers without disabilities; parents of children with and without disabilities; professional groups (teachers and doctors); public at large and media. The approaches and activities engaged children, young people and their family members as agents of change as they were involved in planning and implementation of the initiative.

² Study on Stigmatization of Children with Disabilities, 2016 <https://www.unicef.org/georgia/media/1181/file/stigmatization.pdf>

The Social and Behaviour change interventions included four interrelated cycles as outlined below:

See every colour: Four cycles of intervention	
Awareness phase	Educated audiences on needs of persons with disabilities and their abilities through self-advocacy of children with disabilities and parents utilizing digital and print materials about misconceptions and realities, highlighting approaches on how to communicate with persons with disabilities.
Acknowledgement phase	Involved influencers, celebrities and opinion leaders acting as role models in their communities to scale up public dialogue, deliberation and discussion, regional presentations and offline events country-wide involving a large number of people.
Acceptance phase	Focused on multiplying information and emphasizing collective identity and trust in the strength of children with disabilities and engagement on social networks.
Activation phase	Involved sustaining dialogue in the media and public discourse.



© UNICEF/2018/khetaguri

Orchestra of children and young adults with disabilities performed several musical selections and gave mini-music lessons to guests and other visitors at the launch of the Social and Behaviour change intervention See Every Colour. Tbilisi, 2017.

As part of the intervention, extensive outreach activities throughout Georgia have been undertaken including interpersonal meetings, media campaigns, large-scale national and regional events, as well as cooperation with professionals – such as doctors and teachers – to improve their communication with parents of children with disabilities. The initiative also strengthened the capacities of professionals (teachers and health workers) through discussions and deliberations led by experts and parents of children with disabilities to understand and address the needs of children with disabilities, and building alliances with media, celebrities and opinion leaders at national and local levels.

At international and regional levels, the See Every Colour campaign relied on the direction of UNICEF with the support of USAID and the European Union. On the local level, See Every Colour involved various stakeholders in Georgia: children with disabilities and their families; institutions such as schools, health centers, and universities; celebrities and opinion leaders; local businesses; municipalities; and relied on the support of the politicians and civil servants of Georgia. The intervention created a platform for people with disabilities and their parents to advocate for their issues. This helped render the campaign participatory and build a stronger collective identity and trust among the stakeholders and with their communities.

Main actions of the Social and Behaviour Change intervention

Outreach activities to reach large numbers of people. City celebrations, rugby games, EU Days or sport events were used for reaching large numbers of people across the country to raise awareness and influence the existing stereotypes. These events were used to educate people about disabilities and to demonstrate the abilities of people with disabilities. Quizzes, discussions, competitions took place to provide practical tips regarding equal communication with people with disabilities. Online quizzes in partnership with digital media platforms checked peoples' knowledge about disabilities and cinemas held offline events, screening videos demonstrating the abilities of people with disabilities before playing the movies.

Addressing stereotypes among young people.

Students in schools and universities learned about the needs of people with disabilities through debates and discussions. Young people with and without disabilities were paired and went through everyday situations to learn from each other and to reflect on their own experiences. Such interaction helped young people to become more sensitive towards the needs of their peers with disabilities, to better understand the personal, social and professional development needs of people with disabilities and to influence stereotypes and negative attitudes. These experiences were reflected in a series of videos called 'peer journeys' which featured how attitudes and beliefs could be changed through communication and friendship.

"After my time with Giorgi, I learned so much. He helped me see things I was not aware of before. I also learned to recognise my own prejudices towards people with disabilities. People fear the things they are unfamiliar with, and this is a great way to get rid of that fear."

Sandro, 21 year-old university student, reflecting on his peer journey with Giorgi.

Behaviour change materials. A brochure 'Myth and Realities' deconstructing current myths and prejudices on disability, and comics to illustrate positive attitudes

towards children with disabilities were produced and widely distributed. These materials were also used to support interactive discussions and quizzes.

Engagement of celebrity influencers. The intervention included an online 'Celebrity hashtag campaign', with a series of posters featuring celebrities and influencers sharing their personal stories about the relationships with people with disabilities and confirming commitments for inclusion of children with disabilities. Famous singers, musicians, conductors, actors used their platforms to reach their audiences and to talk about the abilities of people with disabilities. They also invited young people with disabilities to their performance events, concerts and enabled them to demonstrate their abilities (for example, a famous pianist invited an orchestra consisting of children with disabilities to his concert and performed together with them). Such events influenced large audiences to reconsider the stereotypes regarding the abilities of these people and change their attitudes. Celebrities also shared the information through their platforms reaching up to 100,000 people.

"People have definitely started to talk more about children with disabilities and the media has shown great deal of interest in covering the topic."

Lia, mother of 7 year-old girl with Down Syndrome and Founder of Babale, a local NGO for children with disabilities.

Engagement of parents as advocates. The parents of children with disabilities led the whole Social and Behaviour Change intervention. The initiative created a platform for parents to advocate for their issues. The parents had opportunities to talk to media about the challenges they faced, to reach large audiences and to tell the stories of their children. The online initiative 'Parents for Change' invited parents of children with disabilities to tell the stories of children and their abilities, which were widely shared through social media. The contest among parents supported specific advocacy efforts led by parents themselves to effect specific changes in their communities. The contest empowered parents with advocacy skills and enabled to change attitudes in schools and communities.

Strengthening capacities of professionals working with children. The capacities of professionals were also strengthened as teachers and health workers were better able to understand and address the needs of children with disabilities, through alliances with media, celebrities and opinion leaders at national and local levels. Around 5000 teachers, health workers, community members and young people's capacities were strengthened to promote and support inclusion of children with disabilities.

Discussions, experience design workshops created a common vision in understanding in different experiences, needs and challenges and promoted creative resolution of problems related to stigma around disability. Meetings with doctors and teachers led by parents of people with disabilities helped to improve communication and to better understand the needs and address misconceptions. Community meetings led to increased community discussions and debates about reasons for exclusion of people with disabilities and identified actions required to create proper conditions for their social inclusion. The actions led to a strengthening of communication platforms and networks required for sustained community engagement and citizen participation.

"We do communicate with the government, there is a platform for this, but in terms of real results there is still a long way to go... We need to enhance our communication with them, prevent child abandonment because of disabilities and improve overall services. The most important thing, though is that the government's attitude is changing. But this is just the beginning."

Sopiko, mother of Lele, 6-year-old with Down Syndrome.

Engaging with municipalities. A competition among municipalities identified 10 municipalities which shared their best practices in creating an inclusive and supportive environment for people with disabilities. These municipalities served as role models for other towns and villages in the country. UNICEF continued working with these municipalities in building their skills in social programming including provision of services for children with disabilities and their families.

Media engagement. Media served as a key ally, as journalists supported the initiative by sharing positive stories highlighting the talents of people with disabilities. There were a series of meetings with national and local journalists about the disability issues where parents of children with disabilities shared their experiences and journalists learned about the challenges children with disabilities and their families faced in Georgia. Talk-shows, programmes and features stories about the issue were broadcast through national as well as regional media channels that contributed to an increased awareness on the issue and helped to influence the deep-rooted stereotypes around people with disabilities. The initiative established a network of journalists which were used by parents after the campaign to advocate more effectively for their children.

Results

The social and behaviour change interventions that See Every Colour implemented supported an increase in knowledge, positive attitudes, and inclusive practice towards children and persons with disabilities at both systemic, society and individual levels. These changes are summarized via the following key results:

1. Wide-scale reduction of stigma and discrimination towards persons with disabilities

See Every Colour initiative in Georgia was successful in addressing the most wide-spread misconceptions and false beliefs around people with disabilities, reaching more than one million people and contributing to a reduction of stigma against disability from 41.5% in 2015 to 28.3% in 2017⁴.

2. Increased public understanding and practice towards importance of inclusion of persons with disabilities

The project has had large scale impact on multiple levels. The initiative's messaging reached an estimated 1,400,00 individuals. This was possible due to the leveraging of interpersonal communication, outdoor events and activities, and social media. Over, 100,000 individuals were engaged through the celebrity hashtag social media campaign alone. A core group of change makers have been established who will further serve as agents of change in further scaling this work on building a more inclusive society. For example, discussions with

⁴ UNICEF's Welfare Monitoring Study 2017

teachers, doctors and parents of children with disabilities were organized in Tbilisi and in the regions to initiate actions to create a common vision in understanding patients', teachers' and doctors' experiences, identify barriers to inclusion and share practical and creative solutions employed to overcome barriers for children with disabilities.



© UNICEF/2017/Biagonravova
Children 'fishing' for true and false facts within the well of Myths and Realities - a game aimed test knowledge about disability issues. Tbilisi, Georgia.

3. Increased confidence, and visibility of children with disabilities and parents

The activation of parental networks, empowered parents to advocate for the issues faced by their children and demand better services to address the needs of children with disabilities. The participation and engagement of children with disabilities through activities such as peer journeys also led to increased confidence and visibility of children with disabilities throughout Georgia. The collective impact of the activities resulted in creating a new value system in which children's needs are being increasingly met by addressing wide-spread myths, misconceptions and stigma against people with disabilities in Georgia.

"It is possible to get more information to the wider society because the platform is broader - a platform not only to advocate for my child but for other children."

Mari, mother of a child with Autism.

4. Creation of enabling environment at municipal level for services for persons with disabilities

Community discussions served to create a common understanding of the needs of people with disabilities in Georgia and discuss the role of communities in supporting their inclusion in society. Community events also involved national and local authorities and service providers to identify, acknowledge and remove barriers for inclusion.

5. Increased capacity of professionals (teachers and health workers) to address the needs of children with disabilities

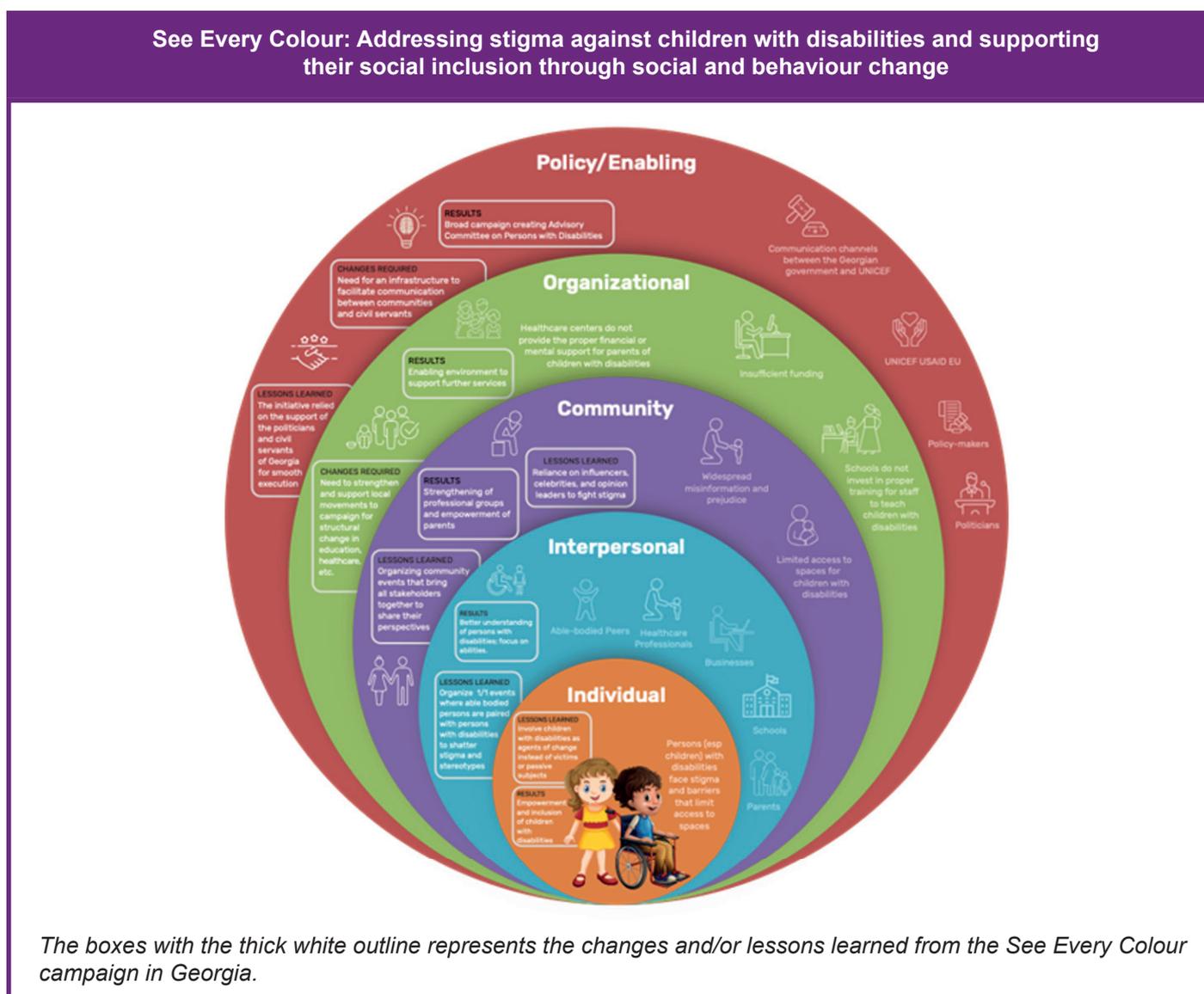
Over 5000 teachers, health workers, community members and young people gained a better understanding of the needs of people with disabilities and further amplified the knowledge to support inclusion of children with disabilities in their communities.

6. Creation of sustainable institutional mechanism to advocate for disability issues

UNICEF supported the establishment of a Disability Advisory Council that unites leaders of organizations of persons with disabilities and young people with disabilities. The Council, which consists of parents, children, a coalition of disability organizations, and relevant NGOs, representing a large cross-section of stakeholders advocating for disability issues, will monitor the implementation of the country's newly adopted social model of disability assessment. The parents who were active participants of this social and behaviour change intervention are also part of the Disability Advisory Council⁵. They actively participate in commenting and reviewing laws and policies related to disability issues and continue to advocate and be involved in this process. The Council also supports the Government in its work to transform disability-related support, including transformation of the disability

assessment system, social protection measures for children with disabilities, and related laws and policies. Its approach to child participation was formulated in close partnership with the Council, together with parental organizations for persons with disabilities.

The diagram below utilizes the Social and Ecological Model, to understand the multifaceted levels within Georgian society required to address stigma and discrimination and how individuals and the environment interact within a social system to affect this behaviour change. Specifically, it illustrates how the See Every Colour initiative created an effective ecosystem of change by addressing the Interpersonal, Organizational, Community, and Public Policy levels to achieve a reduction of stigma and discrimination towards children with disabilities. It highlights results, success factors, lessons learned, and changes required to ensure sustainability of the intervention across various levels.



⁵ Advisory Committee on Disability Issues: <https://csogeorgia.org/en/newsPost/28695f1-change-campaign-See-Every-Colour-Tbilisi-Georgia>.

LESSONS LEARNED

- **Engaging children, adolescents and their family members as ‘creators’ of campaigns** and communication materials, rather than passive beneficiaries, has proven to be instrumental in having their opinions heard and ensuring the development of relevant and targeted materials and activities. This process also supported children and their families to gain voice, asking for greater accountability from decision makers and service providers.
- **Wide range of social change strategies were employed** for advancing positive change in knowledge, attitudes and behaviour on the individual, household and community level, as well as in institutions such as schools and health centres. This multi-stakeholder approach has permitted activities to be conducted at all levels as outlined in the graphic above.
- **Meaningful participation by children with disabilities and their parents.** The #SeeEveryColour campaign addressing stigma against children with disabilities focused on the abilities of children rather than just seeing their disability, by actively engaging children with disabilities at local and national levels. Led by young people with disabilities and their parents, the campaign engaged with students, civil society, artists and actors, professional organizations, municipal governments and many more. It gave everyone an opportunity to tell their story and express their individuality, all in the name of equal rights, non-discrimination and positive messaging. Participating groups told stories, conducted social media and outdoor activities, art installations, public speeches, debates, and municipal-level contests.
- **Inclusive, nation-wide awareness raising campaign.** #SeeEveryColour started in Tbilisi in February 2017 and spread nationwide. The campaign highlighted the importance of inclusiveness, while addressing common misconceptions around people with disabilities. Overall, it reached more than 1.4 million people, changing public perception and brought real change in policy aimed at helping children with disabilities.
- **Changing negative attitudes require time and investment.** Many service providers share the same attitudes and beliefs as local communities and additional efforts are required to enable them to become aware of their biases and negative attitudes.

- **Insufficient government understanding and capacity on social change communication.** Engaging with government institutions at national and local level is critical to ensure ownership, accountability and sustainability of activities and results. There is a need to advocate for the inclusion of communication for individual and collective behaviour change into the government’s policies, strategies and budgets.
- **Sustainable change is driven at community level.** It is important to acknowledge that changing deeply entrenched social norms and negative beliefs take time, and this can be negatively affected by the lack of support services at community level. Change is more sustainable if it is driven by communities and investing in communities should be the focus of any further initiative focusing on inclusion of children with disabilities.

NEXT STEPS FOR SEE EVERY COLOUR

Changing deeply entrenched social norms and negative beliefs takes time, and this can be negatively affected by the lack of support services at community level. UNICEF is continuing the social and behaviour change efforts with a focus on reducing stigma against children with special educational needs and ensuring that all children have unhindered and equal access to both formal and informal education regardless of their needs. The goal is to raise awareness on the importance of inclusive education and increase involvement of children with special needs across the education system. Within the campaign, educational meetings will be organized with schoolteachers and parents in six different regions of Georgia.

“For me, it is not about my child anymore, or Down syndrome - it is about everyone’s children and all disabilities. I can see lots of other colour in people now.”

Mika, Mother of child with Down Syndrome.

Social and behaviour change is more sustainable if it is driven by communities and investing in communities should be the focus of these next steps of this initiative. It is crucial to further involve stakeholders such as children, adolescents and their family members and to engage them as 'creators' of activities, campaigns and communication materials, rather than passive beneficiaries. Having their opinions heard to inform the development of relevant and appropriate materials and activities is essential. This also enables children with disabilities to have greater voice and asking for greater accountability from decision makers and service providers.

In addition, there is a need to build national capacities to ensure sustainability for such initiatives. The See Every Colour initiative was led by UNICEF with parents' organizations and communities, however there is a need to institutionalize capacities in academia and government to build a pool of professionals who could support and lead the similar interventions going forward. The initiative used a diverse range of social change strategies for advancing positive change in knowledge, attitudes and behaviour on the individual, household and community level, as well as in institutions such as schools and health centres. Continued work must be done to advocate for individual and collective behaviour change into government policies and strategies in order to develop a sustainable model which enables the government to effectively guide stakeholders forward in this work.

ADDITIONAL RESOURCES AND USEFUL LINKS

[Study on Stigmatization of Children with Disabilities, 2016](#)

Social Media page for Campaign

This [series of videos](#) on peer journeys illustrates the personal stories of pairing young people with and without disabilities reflecting on their own experiences. The stories show how attitudes and beliefs could be changed through communication and friendship.

These series of [videos from the 'See Every Colour' campaign](#) illustrate the interventions, delivered over a two-year period focused on: educating the population about disabilities, deconstructing prevailing myths and prejudices; illustrating models of attitudes and promoting interaction between young people with and without disabilities; empowering children with disabilities and their parents by giving them a platform for advocacy; initiating policy and community discussions and strengthening local government mechanisms and community networks.

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KAZAKHSTAN

Accessible Kazakhstan: Addressing the impact of attitudinal and environmental barriers for a full and equal participation of persons with disabilities



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Alexandra Sharonova, Project manager, and Yerlan Kurmangazin, Regional Co-ordinator are having a discussion about the Accessible Kazakhstan app.

KEY SOCIAL AND BEHAVIOUR CHANGE RESULTS

1. Accessible Kazakhstan - a collaborative platform, where persons with and without disabilities can equally contribute to make communities more inclusive.
2. Increased local authorities and public understanding of accessibility needs and benefits.
3. Enhanced partnership between OPDs¹ and local authorities and businesses.
4. Increased empowerment of persons with disabilities and OPDs to demand and support changes at national and local level to increase inclusion of persons with disabilities.
5. Increased confidence, independence and visibility of children and persons with disabilities.

¹ OPD(s) = Organizations of Persons with Disabilities

BACKGROUND

In Kazakhstan, as in most places of the world, persons with disabilities face environmental and attitudinal barriers, including prejudice, low expectations, and social rejection. While these attitudes are not always uniform within a region or even within a country, they tend to establish elements of labeling, stereotyping, and prejudice that lead children with disabilities and their families to structural exclusion and relegation.

Attitudinal barriers and discrimination have strong consequences for children with disabilities in Kazakhstan, impacting all aspects of their lives, including their chances to access education, health care and other services, to avoid institutionalization and to move freely within their community. Due to ableist assumptions, they are frequently considered - by service providers and the community alike - as needing 'fixing' through special, segregated treatment². Furthermore, they are often seen as less able to

² B. Rohweder, Disability stigma in developing countries, Institute of Development Studies, available at https://assets.publishing.service.gov.uk/media/5b18fe3240f0b634aec30791/Disability_stigma_in_developing_countries.pdf

contribute and participate, less worthy of attention, and as having less inherent value than others.

Environmental barriers rooted in limited awareness of the needs of persons with disabilities and in disability, insensitive policies and regulations, which prevent children and persons with disabilities to access services and engage with other community members are common. All this elicits harmful feelings that have serious consequences for their psychological constitution, often resulting in anxiety, isolation, stress, and self-pity³.

Children with disabilities in Kazakhstan face great difficulties in overcoming the obstacles stigma place on their participation in the community, and even more challenges to achieve self-acceptance and a sense of pride in their lives. This case study presents the experience of taking an important step forward towards the kind of comprehensive approaches that are required to address these challenges.

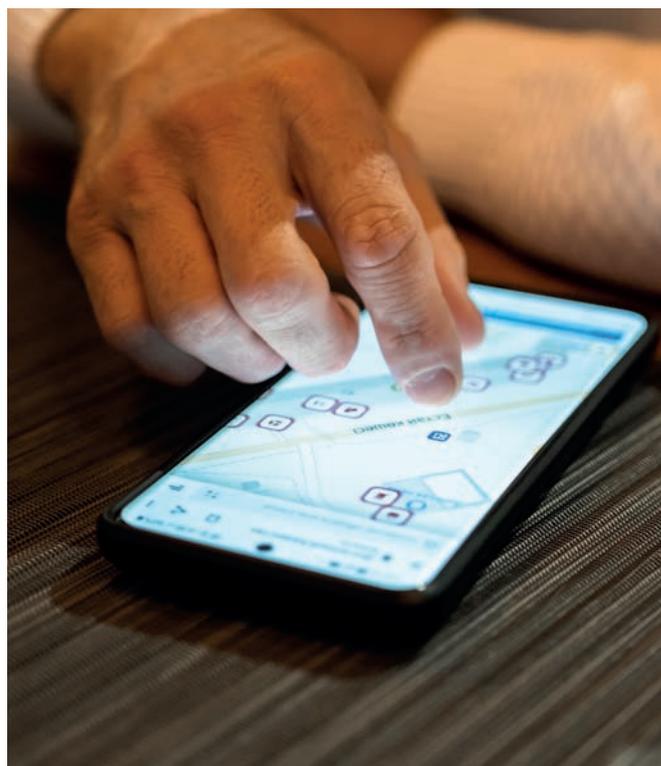
The digital platform [Accessible Kazakhstan](#)⁴, created in 2019, is an initiative that addresses the limited awareness and understanding of the needs of children and persons with disabilities by local communities and service providers, the low confidence of persons with disability to demand for more inclusive environments, and highlights the importance of accessible infrastructure among decision-makers at national and local levels. UNICEF Kazakhstan, the Central Asia start-up hub “Astana Hub” and the Public Fund “Tandau” developed an initiative where stakeholders share the process of transforming their understanding of disability inclusion, engage in a process of horizontal learning and collaboration, identify the needs of different groups by engaging civil society organizations, and facilitate a process of social and behaviour change aimed to support a gradual creation of more inclusive environments.

Disability in Kazakhstan

Accurate data on the number of children and persons with disabilities in Kazakhstan is limited and often unreliable. In 2021, Kazakhstan’s official statistics reported a total of 696,464 people with disabilities, 95,026 being children 18 years old and under⁵. This national data suggests a children disability prevalence

of 0.5% which, when comparing with the World Health Organization’s global disability prevalence rates of 5% for children⁶ seems to be underestimated.

In 2015 the Committee on the Rights of the Child⁷ acknowledged the Kazakhstan’s efforts to create a “barrier-free” environment for children with disabilities. However, they have also expressed concerns on remaining challenges with regards to stigma and discrimination affecting, for instance, the currently limited chances of children and adolescents with disabilities to be enrolled in mainstream schools or kindergartens.



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Accessible Kazakhstan app is being used at Pavlodar.

“I don’t leave my house by myself. Only with my mom. I cannot do it alone. But using the map, I can plan where my mother and I will go. And, I can also dream a little and travel in my dreams.”

Katysha Semenova, aged 17, girl with a disability, Pavlodar city.

3 UNICEF (2020) Social and Behavioral Change Interventions to Strengthen Disability-Inclusive Programming - A summary of the evidence.

4 Accessible Kazakhstan is fully in compliance with Web Content Accessibility Guidelines (WCAG) 2.0 and has also been recognized by [Global Alliance for Public Goods](#) as a ‘Digital Public Good’.

5 CABAR (2021). How Accessible is Kazakhstan for People with Disabilities? (their source: Information Portal Social Protection of Persons with Disabilities). Central Asia Bureau for Analytical Reporting. Online: <https://cabar.asia/en/how-accessible-is-kazakhstan-for-people-with-disabilities> [accessed 07 Dec 2021].

6 WHO (2011). World Report on Disability. World Health Organisation, online: http://www.who.int/disabilities/world_report/2011/en/ [accessed 07 Dec 2021].

7 CRC/C/KAZ/CO/4

THE CHALLENGES

The limited awareness and understanding of the needs of children with disabilities is persistently common throughout Kazakhstan⁸. This combines with structural barriers, including inaccessible environments and lack of accessible transportation means, with frequently negative and hostile attitudes and practices in community spaces, facilities, and services.

Social stigma attached to disability remains a major obstacle preventing persons with disabilities from developing their full potential and exacerbates inequalities in outcomes with regards to education, employment, and social participation. The combination of inaccessible infrastructure with lack of qualified, supportive and confident service providers creates a negative cycle of barriers that reinforce difficulties for children with disabilities, resulting in segregation and isolation for both children and their families. All these explains the need for strategies that go beyond sectoral interventions and address social behavior aspects as the root causes of stigmatization, and exclusion.

THE APPROACH

A platform for learning and interaction

[Accessible Kazakhstan](#) was created as a collaborative platform that seeks to address the lack of information and the limited awareness on the needs of children and persons with disabilities in relation to mobility, accessibility, and appropriate services. It provides information on accessible/inaccessible facilities on the ground, and useful data on service providers and businesses which can serve persons with disabilities and with reduced mobility.

“Accessible Kazakhstan has also become a Digital Public Good (DPG), which is open-source and follows guidelines for universal design. Being part of the DPG Registry, gives Accessible Kazakhstan regional visibility and opportunities to be contacted by funders and entities who want to support and replicate.”

Cheryl Ng, UNICEF Global Innovations Office, HQ.

8 A recent report of the Special Rapporteur on the rights of persons with disabilities, encourages the Government to do more awareness-raising campaigns and mass education on a human rights-based approach to disability. A/HRC/37/56/Add.2 2018

The platform also disseminates inclusive communication and recommendations, therefore, seeking to address socio-behavioral aspects that hinder equal opportunities and more open attitudes towards persons with disabilities in the Kazakhstan society.

“My son was still using the wheelchair at that time. The map helped me a lot. Knowing in advance where you are going is very convenient. Myself, I have included some accessible sites on the map. Now, the map has grown, just like my son. And this is very good. We travel frequently, and it is very important to have information about available sites in other cities.”

Karina Zhansultanova, mother of a 6 years-old child with disabilities, individual entrepreneur, Pavlodar city (aged 36).

Accessible Kazakhstan consists in a virtual map of the country, which displays information on the availability of accessible and inclusive public facilities and services. Not only is the map useful for children and persons with disabilities, but it is also beneficial to other users such as pregnant women, parents with small children in strollers, older people and wheelchair users, people with mobility issues, children under 7 years old. With Accessible Kazakhstan users can plan their activities to include the most accessible and safe route and facilities.

To address the challenges mentioned above, UNICEF supported a series of activities aiming to advance positive social and behaviour change.



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Yerlan Kurmangazin, use of Accessible Kazakhstan app.

Capacity Building Training

Implementing a series of capacity-building trainings has been an important aspect for Accessible Kazakhstan to make stakeholders more confident and open to providing accessible services to people with disabilities and address environmental barriers. The training was designed to target civil society organizations (CSOs), local business owners and local authorities. It provides information on disability rights, accessibility tips, and explains the different needs children and persons with disabilities may have. The training helped these stakeholders learn about creating safe and child friendly infrastructure at public sites and businesses such as hotels, cafes, banks, social service centers and educational facilities etc. The workshops showed a positive impact among business owners and public sector representatives in relation to their awareness of the benefits of accessibility for their business and the community.

“The platform offers training courses and recordings of webinars. The purpose is to protect the right of people to safely access and use the public space.”

Alexandra Sharonova, Manager of the project “Accessible Kazakhstan”, Pavlodar City

“It was a useful and timely experience for me as a Programme Officer managing the innovation portfolio in our office. I learned about international digital public goods standards. Now, every time we develop new digital solutions, we make sure it follows these standards.”

Raushan Ibrasheva, Programme Officer (Innovations), UNICEF Kazakhstan.

More than 20 Organizations of Persons with Disabilities from across 24 cities (within the 17 regions of Kazakhstan) were trained on disability inclusion⁹. Also, 17 Civil Society Organization’s staff completed the “Accessibility Expert” module which certified them to conduct accessibility assessments of facilities and advise on measures to make the services/facilities more inclusive.

The trainings increased participants’ confidence and led to many of them engaging in updating the Accessible Kazakhstan virtual map. The benefits of accessibility was an important highlight of the trainings, which led to an increased participants’ motivation to implement accessibility assessments and propose improvement on facilities in their cities and villages while adding the ratings to the virtual map.

Training topics

- “Accessibility and safety adaptations: understanding the returns of investing in inclusion”, for private and public stakeholders.
- “Accessibility Experts”, for civil society organizations and organizations of persons with disabilities.
- “Taking care of children with disabilities and their families as clients”, for business owners (in Kazakh, English and Russian).
- “Understanding home and outdoor child safety and accessibility” for parents (in Kazakh, English and Russian).
- “Monitoring public facilities and contributing to the interactive map [Accessible Kazakhstan]”, for business owners, persons with and without disabilities.

⁹ The CSOs in this context were a mixture of parents of children with disabilities networks, organisations of persons with disabilities and disability services providers and disability advocates. See list in annex 1: List of CSO/OPD partners

Accessibility and safety adaptations

Promoting a safe, accessible and child friendly infrastructure in public sites and businesses was another component of the platform. The accessibility assessments were followed with recommendations and tips for public and private entities on how to remove accessibility barriers, which in many cases helped them become 'champions and role models' at local level.

"Our college occupies three buildings. This year, we carried out a reform in one building and invited an expert from Accessible Kazakhstan for advice. This led us to being able to include five students with disabilities this year. Other adaptations are now underway in two other buildings with electric lifts being installed. This will allow us to enroll even more students with disabilities in the next academic year."

Rustam Baimuratov, Deputy Head Teacher, College Pavlodar.

One successful example was demonstrated through the collaboration with the Central Asia Astana Hub. The international IT and startup hub engaged in capacity building within its own networks and encouraged participants to learn how investing in accessibility can improve their customer base, reaching out to more than 180 business owners, architects and local government representatives. Later, they reported being more receptive and understanding of the needs for disability access and eager to provide reasonable adaptations in their businesses and facilities.

"The Accessible Kazakhstan definitely changed the views of all team members towards people with disabilities. We realised how important is to improve accessibility of facilities and services for people with limited mobility, so they have the same opportunity to study, work, play sports and move around the city without obstacles and barriers."

Dauren Salipov, Head of the ICT development team working on the re-design and building new functionality of the virtual map, Nur-Sultan.

Engaging with and empowering parents and the community to improve child safety and accessibility

Educational trainings and webinars on child safety at home and in outdoor spaces strengthened parental knowledge and understanding of practical measures they can take at home. It gave more than 150 families of children with and without disabilities the opportunity to learn and understand what an accessible environment is and why it is important for all children.

At the same time, the trainings enabled parents to gain confidence and to becoming advocates in asking local business owners to provide safer and more accessible facilities for children with and without disabilities. They also ignited a conversation amongst families and community members about disability inclusion and equal rights and opportunities for all children. As parents and project partners increased their understanding of inclusion in public spaces, children with disabilities emerged as promoters and advocates of this message as well.

"I am proud that our café was marked on the Accessible Kazakhstan map as inclusive and family-friendly. I would recommend this resource for other cafés and restaurants as an opportunity to contribute to the development of an accessible and safe environment for all children."

Nariman Shakabayev, Owner of the "Hani" Coffee chain, Nur-Sultan.

Public monitoring of accessibility

Monitoring the accessibility of facilities and services became an important aspect of collective learning and community engagement in this initiative. It led to a steady commitment of decision makers, persons with disability and business owners to aim for inclusion and accessibility as well as a participatory approach to address the needs and interests of the population.

People and disability experts were invited to contribute to the interactive map by sharing what they learned through conducting the accessibility assessments: they mapped previously 'unseen' barriers in local

infrastructure and shared comments about the ongoing progress in dynamics and interactions with persons with disabilities. Such a collaborative learning process helped to reinforce positive attitudes while monitoring the improvement of accessibility in public sites, and data started to flow into the interactive map. The accessibility self-assessments for business owners and heads of educational institutions guided them how to create safer and more accessible settings for students and children with disabilities.

A total of 21,500 facilities were assessed across all 17 regions of Kazakhstan¹⁰. The assessments were conducted by trained volunteers recruited from the public, and a group of certified accessibility experts recruited from organizations of persons with disabilities. The evaluations used standardized accessibility check lists and guides, which were also made available on the Accessible Kazakhstan app for others to conduct self-assessments. The results provided a rating mechanism from fully accessible (green); partially accessible (amber); or inaccessible (red) and provided advice for adaptations destined to improve accessibility in each facility. Each assessed facility was given an accessibility rating and the information was uploaded to the Accessible Kazakhstan virtual map. Between 2019 and 2021, more than 270 local service providers received accessibility recommendations based on the findings of assessments.

The entire process of submitting the appeals (demands for actions to remove barriers), receiving recommendations and improving accessibility, facilitated exchanges amongst authorities, representatives of organizations of persons with disabilities and business owners. This was in itself an exercise of awareness building and social change, involving various stakeholders to make their communities more accessible.

"Our experts not only collect information about public facilities, but also advise owners on how to properly adapt facilities and make them accessible to people with disabilities. And we really see how our cities are becoming more comfortable and safer for our all citizens."

Yerlan Kurmangazin, Regional Co-ordinator of the Accessible Kazakhstan project in Pavlodar region.

¹⁰ 17 regions of Kazakhstan consist of 14 oblast level cities and 3 republican level cities (Nur-Sultan, Almaty, Shymkent).

Engaging with Organizations of Persons with Disabilities

From the beginning of the project, an informal coalition of organizations of persons with disabilities became engaged as active partner of Accessible Kazakhstan as advisors, trainers, and advocates. Their engagement was key in terms of knowledge transfer, since persons with disabilities are often best positioned to explain their needs and alternatives for the provision of reasonable accommodation and appropriate support. They also played a significant role in using the evidence on accessibility from Accessible Kazakhstan to advocate for and support legislative changes and empowering the disability community to take a more active and confident role in decision making processes at national and local levels. Among key changes in legislation, achieved with the active engagement of the Organizations of Persons with Disabilities are:

1. The local executive bodies for urban planning, public and general construction are now required to consult with representatives of registered organizations of people with disabilities. This engagement must involve universal design and validation of facilities before and after the construction/renovation (Article 25: Provision of access of persons with disabilities to facilities of social infrastructure)¹¹.
2. Individuals carrying out businesses, entrepreneurs and governmental authorities are now required to ensure the provision of accessible transportation and facilities in public and private buildings such as airports, railway stations, bus stations, shopping centers, etc. (12.10.21, Paragraph amendment in accordance with the Law of the Republic of Kazakhstan, No. 67-VII)¹².
3. Failure to provide accessible transportation and facilities for people with disabilities is now a fineable offence in accordance with the Code of the Republic of Kazakhstan: Administrative Offenses (02.0721, Article 83) and a violation of the legislation of the Republic of Kazakhstan on Social Protection of People with Disabilities, No. 300-VI)¹³.

¹¹ The Law of the Republic of Kazakhstan dated 13 April, 2005 No.39. On Social Protection of Disabled Persons in the Republic of Kazakhstan <https://adilet.zan.kz/eng/docs/Z050000039> / (Закон Республики Казахстан от 13 апреля 2005 года № 39-III «О социальной защите инвалидов в Республике Казахстан» (с изменениями и дополнениями по состоянию на 12.10.2021 г.) https://online.zakon.kz/Document/?doc_id=30008935&pos=3-106#pos=3-106

¹² Law of the Republic of Kazakhstan dated October 12, 2021 No. 67-VII "On Amendments and Additions to Certain Legislative Acts of the Republic of Kazakhstan on Social Protection of Certain Categories of Citizens". Published: "Kazhstanskaya Pravda" dated October 13, 2021 No. 194 (29571); IS "Reference Control Bank of the RLA RK in electronic form" October 15, 2021.

¹³ Code Of The Republic Of Kazakhstan About Administrative Offenses (with changes and additions as of 02.07.2021) https://online.zakon.kz/Document/?doc_id=31577399&pos=5-106#pos=5-106

Empowerment of persons with disabilities

The mapping of accessible services and facilities played an important role in supporting social inclusion of children and persons with disabilities and their families. Learning about which neighborhoods and services are disability friendly and accessible, allowed them to become more independent and less reliant on other people's support. By making public and private settings accessible and prepared for disability inclusion, the project allowed a growing number of children and persons with disabilities to also become more visible. Increasing confidence to visit community services also gives children a greater opportunity to interact with their peers without disabilities and sends the message that diversity is good. Such a message is important to continue deconstructing pre-existing prejudices and misconceptions that children with and without disabilities cannot share a space to play or learn together. Increasing confidence to visit community services also gives children a greater opportunity to interact with their peers without disabilities and sends the message that diversity is good. Such a message is important to continue deconstructing pre-existing prejudices and misconceptions that children with and without disabilities cannot share a space to play or learn together.

The possibility to also map and assess services on the platform and formulate recommendations for infrastructure improvement strengthened their confidence and participation in making their communities more inclusive. The legislative changes also helped them feel more recognized and valued, providing them with a greater level of authority and respect to play a constructive role in community life.



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Ramp at the railway station in Pavlodar, Kazakhstan.

Environmental and attitudinal changes

By addressing infrastructural barriers and providing opportunities for inclusive interaction amongst stakeholders, Accessible Kazakhstan constituted an entry point for stakeholders to understand the need for change in the way they see and engage with persons with disabilities. The platform increased businesses, local authorities and service providers' understanding of inclusion, and resulted in concrete measures to remove accessibility barriers and make these services more inclusive.

Changes within UNICEF

UNICEF Office in Kazakhstan proactively reacted to the learnings from this initiative by enhancing accessibility of its premises and advancing disability inclusion awareness. This process of changes in knowledge and infrastructure also expresses a gradual transformation of attitudes and understanding of the benefits of becoming a more inclusive and diverse environment. Examples of these improvements include:

- Adequate access for wheelchairs through the main entrance. Accessible meeting room, workstation, pathway, and bathroom to complete Level 1 of accessibility.
- Introductory disability and inclusion training for all staff members facilitated by an organization of persons with disabilities and creating vacancies for persons with disabilities in the office.
- Ensuring persons with disabilities have equal changes and are prioritized during the recruitment process.

In the coming 2 to 3 years, Accessible Kazakhstan has planned to scale up its reach and coverage to include all regions and facilities within the country, and to share Kazakhstan's experience with the neighboring countries.

ANNEX 1: LIST OF CSO/OPD PARTNERS

- Corporate Fund “Eurasia Foundation of Central Asia”, Almaty
- Public Fund “Volunteers of Kyzylorda”, Kyzylorda
- Public Association “Development of Human Capital”, Taldykogran
- Public Association of people with disabilities “Qamqor plus”, Karaganda
- Public Association “Community of people with disabilities “Keg Payil”, Almaty
- Public association “Center for social and psychological rehabilitation and adaptation of children and adolescents Urker-Umit”, Shymkent
- Public Foundation “I walk by myself”, Kokshetau
- Association of legal entities “Association of people with disabilities ARDOS-Zhurek”, Petropavlovsk
- Public Association of Disabled People “Kamkor Zhurek”, Kapshagay
- Public Association “Society for the Support of Citizens of people with disabilities of the Musculoskeletal System “Arba”, Uralsk
- Public Fund “LUARA”, Aktau
- Public Association “Union of people with disabilities of Aktobe Region”, Aktobe
- Public Association “Zhambyl Zhastary”, Taraz
- Anna Olegovna Mazaeva, Ust-Kamenogorsk
- Kurmangazin Erlan Kazbekovich, Pavlodar
- Kulakhmetova Meruert Amandykovna, Almaty
- Vladimir Vadimovich Aleksanin, Kostanay
- Kosmurzieva Gulnaz Maksutovna, Ayrau
- Tazhibaeva Gulbakhira Kalmukhanovna, Turkestan
- Saduakasov Zhadrasyn, Nur-Sultan
- Anara Turebayeva, Nur-Sultan

ADDITIONAL RESOURCES AND USEFUL LINKS

- Accessible Kazakhstan: <https://doskaz.kz/en>
- Web Content Accessibility Guidelines (WCAG) 2.0: <https://www.w3.org/TR/WCAG20/>
- Global Alliance for Public Goods: <https://digitalpublicgoods.net/>
- OECD (2017), Building Inclusive Labour Markets in Kazakhstan - A Focus on Youth, Older Workers and People with Disabilities: <http://dx.doi.org/10.1787/9789264273023-en>

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MONTENEGRO

CBoard Montenegro - a tool to support social and behavior change to address stigma and discrimination, promote social inclusion for children with disabilities.



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Bojana, aged 6, uses the CBoard application at home with her sister.

INTRODUCTION

Over the last two decades, Montenegro has made significant steps towards aligning with international standards and obligations to support inclusion of children with disabilities. Some of the most significant steps forward have been the ratification of the United Nations (UN) Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) and the Convention of the Rights of the Child (CRC) in 2006, and subsequently the Convention of the Rights of Persons with Disabilities (CRPD) in 2009.

However, even with these strong human rights aspirations Montenegro still struggles to fully meet the needs of children and persons with disabilities within their policies, legislation, services, and the society as a whole. This is in part due to the predominance in Montenegro of a perception of disability from the medical rather than the social or rights-based perspectives. In addition, Montenegro has limited reliable national data on the number of children or adults with disabilities. Overall, it remains a significant

challenge for Montenegro to fully understand their needs and provide them with quality and inclusive services.

The invisibility of children and persons with disabilities in data, policy, and legislation, outdated/conflicting definitions of disability, and Montenegro's medical understanding of disability further compounds deep rooted and negative stereotypes and harmful ableist¹ social norms around disability. As a consequence, children with disabilities do not enjoy full and equal access to their rights to education, healthcare, social- and child protection services. In addition, discrimination based on the perception that children with disabilities are lesser than those without disabilities, isolation due to lack of access to services, as well as exclusion from social participation further marginalizes this group and exposes them to a greater risk of violence, neglect, and abuse².

1 Ableism(ist) = discrimination, prejudice and oppression against people with disabilities based on the belief that they are inferior to people without disabilities.

2 UNICEF (2019). Analysis of The Cross-Sectoral System Support For Children With Disabilities In Montenegro. United Nations Children's Fund, online: <https://www.unicef.org/montenegro/en/reports/montenegro-inclusive-education-strategy>. [accessed: 13 December 2021].

CHALLENGES AND APPROACH

In recent years, Montenegro has made significant efforts to introduce inclusive education for every child. This is reflected by Montenegro's adoption of an Inclusive Education Strategy (2019-2025). Its guiding principle is to promote, safeguard and ensure full and equal participation of all children with special educational needs³ within an inclusive education system, without discrimination or exclusion⁴. However, there is still a lot of room for improvement. For instance, the availability of inclusive schools needs to be increased nationwide; teachers, social workers and health practitioners need support in shifting their mind-set and building their capacities to meet the needs of children with disabilities; and children with disabilities need additional support to help them acquire skills that will support their full development, learning and social interactions with their peers without disabilities in schools and community.

Even with the above challenges and limited access to accurate data on the prevalence of disability within the child population, schools record that the number of children with disabilities attending inclusive schools in Montenegro has increased from year to year. However,

in 2020, when the COVID-19 pandemic struck, regular school attendance suddenly became an impossibility for children all over the world. For children with disabilities in Montenegro, especially those with speech and language delays, a dramatic loss of acquired skills was observed, disproportionately affecting their capacity to participate in alternative digital and face-to-face education on an equal basis with their peers without disabilities.

The [CBoard](#) initiative ensures that children with disabilities in Montenegro have access to a linguistic and culturally contextual assistive app to support their participation in education. CBoard began in 2019 as a multi-country pilot in Montenegro, Serbia and Croatia called 'A Voice for Every Child'⁵.

In Montenegro, UNICEF collaborated with the Bureau for Education; Ministry of Education, Science, Culture and Sports; 4 pre-schools, three primary schools and three resource centers for children with disabilities to implement the initiative in two phases: a pilot (2019-2021) and upscaling (2021-2022).

The CBoard assistive tool

CBoard is a free and open-source assistive tool that supports communication development. It is an Augmentative and Alternative Communication (AAC) app designed for children and adults with speech and language delays or impairments, allowing user to communicate (understand and be understood) via a series of digital symbols and text-to-speech functions. The app can easily be adapted to the specificities of each user, allowing to personalize Cboard by editing, adding, or deleting content according to the needs.

In school, the app supports communication and interaction between the child, teacher, and early intervention professionals. CBoard reinforces the teaching/learning of the child by allowing them to physically explore new linguistic concepts whilst reinforcing acquired vocabulary.

At home, the app encourages learning to continue from school into the home and everyday family life. The CBoard supports independent interaction between the child, their parents, and siblings. The app is compatible on all smartphones and tablet devices.

³ According to the legislation Education of Children with Special Educational Needs ("Official Gazette of the Republic of Montenegro" No. 80/2004, "Official Gazette of Montenegro" No. 45/2010 and 47/2017), the term 'children with special educational needs' includes children with disabilities, children with developmental, physical, intellectual, sensory disabilities, children with combined disabilities and autism-spectrum disorders, developmental difficulties, speech/language difficulties, behavioural disorders, children with severe chronic diseases, children with long-term illnesses and other children with learning difficulties and other difficulties caused by emotional, social, linguistic and cultural barriers.

⁴ MoESCS (2019), Montenegro Inclusive Education Strategy (2019-2025), Ministry of Education, Science, Culture and Sports, online: <https://www.unicef.org/montenegro/en/reports/montenegro-inclusive-education-strategy> [accessed: 13 December 2021].

⁵ CBoard webpage: <https://www.cboard.io/>

SOCIAL AND BEHAVIOUR CHANGE INTERVENTIONS AND RESULTS

The core social and behaviour change interventions adopted, and results achieved within the framework of the CBoard initiative in Montenegro are presented below.

The role of parents: capacity building for empowerment

Montenegro's Bureau of Education regularly reported that parents of children with disabilities feel stigmatised and lack confidence in supporting their child with disabilities with learning at home. This is particularly relevant in the context of the COVID-19 pandemic where home schooling and support became essential. Lack of confidence of parents can be related to factors such as:

- Isolation and consequently lack of peer support from other families.
- Assumptions that interaction with digital devices are always unhealthy for children.
- Parents may not have the necessary skills to operate digital devices or assistive technology and are apprehensive to provide support to their children.
- Assumptions that their child with speech, language and learning delays would not have the capacity to use the assistive tools or digital devices.
- Lack of access and connectivity to the internet.



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6-year-old Seid is learning to use the CBoard.

"The application helped us a lot because it facilitates a much better communication. At the same time, the bonds between the members of the whole family become stronger."

Parent of a child with disabilities.

As such, empowerment, and capacity-building on using the CBoard app for parents was vital within the CBoard initiative. The purpose of the capacity building activities was to support parents to gain:

- Understanding and confidence in using CBoard to support communication and learning interaction between family members.
- Understanding of how to support their child's development and learning at home.
- Confidence to engage other children to use CBoard and to increase positive interaction between siblings and friends.
- Problem-solving skills relating to customizing the CBoard to their child's preference.
- Confidence to seek support from other parents of children with disabilities.

Results were particularly relevant at the social behavior change level, as better communication and bonding within the family is key for confidence, self-esteem, and future progress of children with disabilities.

To ensure that the app was meaningfully used at home, parents of children with learning and communication difficulties received advice on how to stimulate development and communication skills among their children as well as how to maximize the role of assistive technology without generating dependency. Parents report that they now understand better the needs of their children and have appropriate tools to react.

The purpose of this approach was to help parents to feel confident in sending their children to mainstream schools. This is a key component for inclusive education to be consolidated as the first choice for the education of children with disabilities in Montenegro.

While the number of children with disabilities attending mainstream education is growing every year, it continues to be important to support parents and ensure their involvement in the educational process.

“Our impression is that emotional bonding and cooperation within the family has been strengthened, new channel for communication has been found, and a new space for common interests has been created where children can build their self-confidence, demonstrate their skills and enjoy the attention.”

Representative of Ministry of Education, Science, Culture and Sports.

It is also important to advance the confidence of parents to interact and collaborate with teachers by transferring their knowledge and experience on how their children learn and communicate. This is extremely important as assistive technology can bridge home and schools through mutual learning and empower parents to positively influence the education process.

Findings from the pilot phase of the project showed that in cases where family motivation was low, access to Cboard application contributed to strengthening parental self-efficacy, confronting prejudices, and improving parents' attitudes. Better and open communication helped motivation and empathy amongst family members. Many prejudices and negative attitudes of parents towards the use of technology as an assistive tool for inclusion were overcome and parents report that using the application helped to boost their self-confidence, improved family relationships, and helped them to socialize more.



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Bojana, aged 6 uses the CBoard application at home.

Strengthening the capacities of teachers and other professionals

The introduction of technologies for inclusion requires close support to pre-school and primary education teachers as well as other professionals involved in the resource centers and early intervention programmes. In response to this, UNICEF Montenegro and the Bureau of Education provided capacity-building training to teachers and professionals in participating districts. The training was aimed to contribute to gaining confidence and skills for:

- Using CBoard and supporting children and parents to use it.
- Problem-solving skills while customizing the CBoard to the child's preferences and needs.
- Understanding of how to use the app to promote child autonomy and learning in both school and at home.

Providing training to early intervention professionals, pre-school personnel, and primary school teachers sought to influence a continuum of positive behaviors and development, promoting skills so each professional understands the role of intervention at the different levels. A total of eighty-five teachers and resource center professionals received capacity-building training during the pilot phase of the CBoard initiative.

Such training was also delivered for more than seven hundred professionals from Serbia, Montenegro and Croatia. While results were positive about increasing knowledge and skills around Augmentative and Alternative Communication (AAC), participants also reported feeling more confident to interact with children with communication difficulties and support them in using assistive technology. Also, they improved their knowledge of family-centered, early childhood intervention (ECI) approaches and the acceptance of the social model of disability.

“We learned how to use assistive technology to educate children and help them communicate and participate in the class. This is what the C-board application was designed to do, and the results are good.”

Representative of Bureau for Education.

CBoard allowed most of participating teachers and preschool professionals to work with children with communication difficulties for the first time. This was a very important opportunity for them to overcome prejudices and internal bias and increase their competence and self-confidence in dealing with alternative communication means in the classroom. Still, teachers reported needing to further improve their capacities, continuing the practice, and interacting with children with complex communication and speech needs. They also highlighted the need to continue providing training and expanding capacities of schools and professionals to use technologies for inclusive education in the classroom, particularly with the youngest children.

Improving the preparation and skills of teachers and addressing their prejudices positively contributed to developing a more inclusive culture in participating kindergartens and schools. As teachers engaged in more inclusive dynamics and communicated positive messages about children with disabilities, the rest of the students started to feel more comfortable and developed skills for learning and playing together.

While a more detailed assessment would be needed to examine how the CBoard application and the programme contributed to the acceptance of children with disabilities among their peers in the classroom, testimonies of teachers confirm the increasing development of communication skills among children and a positive effect on the classroom climate. Children feel more confident and happier to use technology and interact with their peers. In the long run, this will certainly contribute to gradually expanding a culture of inclusion and acceptance of diversity in schools and communities.

Participatory customization of CBoard's pictography and communication symbols

The approach to identify and select the best symbols to be used for the CBoard app implied a process of consultation and implementation of an online voting system involving parents and the community. The goal was to select symbols that were easily recognizable for children and families and reflected the Montenegrin context and language. Through a series of workshops and discussions, the program was able to identify, select and customize a number of archetypical local buildings, foods, and gestures to be used for the application and to be disseminated among professionals working with children in the public and private sector.

These consultations were organized before the training as part of the programme's feasibility-building process, involving a total of 20 parents and education professionals. Consultations were organized in kindergartens and resource centers for children with disabilities and learning difficulties.

Using a participatory approach allowed disability and family organizations to engage in a process of collective learning and understanding some of the principles for inclusive education and development. This is an important aspect of social behavior change as it helps the entire community to speak more openly about the challenges of creating an inclusive environment and the social costs of exclusion and discrimination.

The workshops to select the application symbols were also helpful for preparing the programme implementation, as parents and professionals contributed with recommendations about engaging children and mobilizing positive attitudes of families towards the initiative.

PROMISING RESULTS AND FUTURE CHALLENGES

In 2019, during the implementation of the pilot phase of the initiative, the Psychosocial Impact of Assistive Devices Scale (PIADS) was adapted into a self-reporting questionnaire to evaluate results and explore outcomes in relation to attitudes and behavior change. The purpose was to enable real-time monitoring of the impact CBoard app had on children with disabilities, their peers and their families.

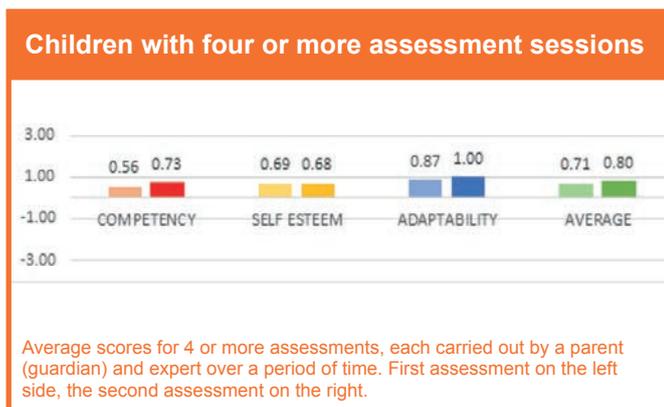
"The C-board app takes a little for children to get used to. We created activities in kindergarten to help children understand the symbols and operate the application. This helped us to communicate with children and them to engage with other children."

Parent of a child with disabilities.

Using an internationally validated scale allowed to evaluate the users' level of competence, adaptability, and self-esteem through a five-point scale that was prepared for children to respond through a series of questions and symbols.

The 26-item questionnaire was translated into Montenegrin and made available online through the digital devices provided by UNICEF for the initiative. Data was collected after three and six months of use by a parent and an early intervention professional working with the child. The questionnaire included basic demographic data, educational background of participating children and type of professional support been provided to participants.

Nine children were assessed using PIADS showing remarkable individual improvements in “competency” with one child scoring 0.53 on an initial assessment and 1.83 on their second assessment. For all the children, self-esteem appeared to be the area with less positive results, an understandable outcome giving the need for long-standing processes to modify this aspect⁶⁻⁷. In the meanwhile, the competency increased by 30% and adaptability by 15%.

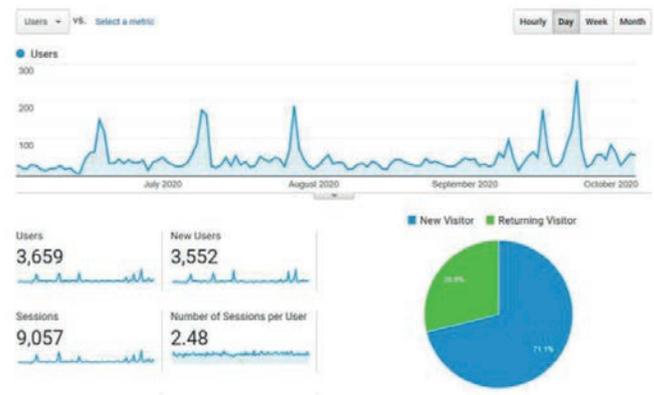


The results also showed that AAC can be beneficial to different types of disabilities if complemented with other forms of support. Data appear to suggest that change is slower in children with cognitive and/or multiple impairments and children with sensorial impairments are more challenging to engage with, but both children and families are more receptive to adopting this communication system. The overall impact is very good but slower in the case of children with more complex needs⁸.

The COVID-19 pandemic was an important challenge throughout the implementation of this project, causing school closures and learning loss for children with and without disabilities. However, CBoard has seized a unique opportunity for Montenegro to pilot a shift towards home-based activities and family engagement.

6 UNICEF (2020) Social and Behavioral Change Interventions to Strengthen Disability-Inclusive Programming - A summary of the evidence.
 7 It has been also noted that possible misunderstanding around the concept of self-esteem might have impacted on the scores.
 8 Draffan EA, Banes D, Analysis of AAC Interventions in Serbia, Croatia and Montenegro, November 2020.

Data on the use of CBoard app and the android digital devices was collected via a Google Analytics dashboard (CIREHA) showing reasonable results.



This is also an opportunity for children, families, and professionals to explore alternative modalities of communication and interaction that will create new forms of support and inclusion for children with disabilities and their families. Combined with UNICEF’s provision of devices with the CBoard app the strategy opens new roads for early intervention professionals to create online services delivery and engage families in stimulation and rehabilitation methods. It is expected that as COVID-19 restrictions began to reduce and home visitations resume professionals will perceive the benefit for the child and parents to actively engage in early development activities.

To date, the CBoard initiative has reached 75 children with disabilities and their parents in Montenegro. UNICEF Montenegro is currently entering a scale-up process with the goal to continue growing and reaching a nationwide reach. The challenge to scale up and support positive social and behaviour change require long term and consistent efforts to:

- continue empowering and building the capacity of parents and children with disabilities to advocate for inclusive education and services;
- continue training for families to learn and understand about the benefits of CBoards at home and in school;
- build the capacity of teachers to contribute to early childhood intervention and engage collaboratively with parents and early intervention professionals;
- develop a sustainable model for digital devices to be available to all children with communication difficulties in school/home.

ADDITIONAL RESOURCES AND USEFUL LINKS

- CBoard application makes communication easier for children with disabilities (2020): <https://www.unicef.org/montenegro/en/stories/c-board-application-makes-communication-easier-children-disabilities>
- C-Board aplikacija olakšava komunikaciju djece sa smetnjama u razvoju (2020): <https://www.unicef.org/montenegro/price/c-board-aplikacija-olak%C5%A1ava-komunikaciju-djeci-sa-smetnjama-u-razvoju>
- C-board helps Seid to communicate (2021): <https://www.unicef.org/montenegro/en/stories/c-board-helps-seid-communicate>
- C-board Seidu pomaže da bolje komunicira (2021): <https://www.unicef.org/montenegro/price/c-board-seidu-poma%C5%BEe-da-bolje-komunicira>
- Analysis of the cross-sector system support for children with disabilities in Montenegro (2019): https://www.unicef.org/montenegro/media/15866/file/MNE-media-1963_publication.pdf

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NORTH MACEDONIA

From exclusion to citizenship: a multi-sector approach to changing the social determinants of discrimination in North Macedonia



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Children with disabilities participating in a consultation meeting on cross-sectoral cooperation for inclusion of children with disabilities.

BACKGROUND

More than ten years ago, the concluding observations of the UN Committee on the Rights of Children (2010) for North Macedonia¹, expressed concerns at the “persisting inadequacy of educational, social, and health services for children with disabilities in their own living environment” and recommended a number of immediate measures inter alia, developing a comprehensive social protection policy and improve the availability of inclusive social, educational, and other services.

A year later, North Macedonia ratified the UN Convention on the Rights of Persons with Disabilities and started to walk the multi-challenging road from exclusion and started to invest in ensuring social inclusion of children and persons with disabilities in the country.

From the beginning, concerns were expressed about the burden that stigma places on persons with disabilities in the country and its role as an ultimate “glass ceiling” in the development of children and adolescents with disabilities².

The concluding observations of the UN Committee were also clear in recommending North Macedonia to adopt a national policy and strategy on disability awareness for “*preventing and combating discrimination*”. The report explicitly advises the country to “promote the participation of persons with disabilities in activities and campaigns aimed at combating stigma and stereotypes” and to “*conduct continuous campaigns about the Convention in the public and private sectors and among persons with disabilities and their representative organizations*”.

2 This was mentioned for instance, in the report of the UN Committee on the Rights of Persons with Disabilities that reviewed North Macedonia in 2018. The report was unambiguous about the need to tackle environmental social factors that obstruct disability inclusion and specifically recommended adopting measures to take active steps to address stigma and discriminatory behavior in services. https://vlada.mk/sites/default/files/dokumenti/concluding_observation_2018_committee_on_the_rights_of_persons_with_disabilities.pdf

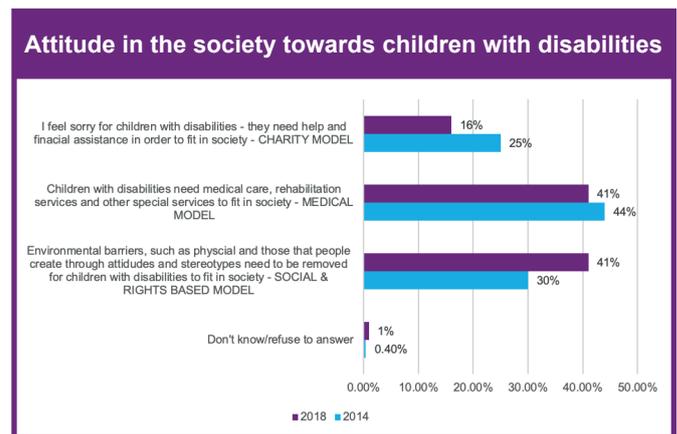
1 CRC/C/MKD/CO/2 Concluding observations: The Former Yugoslav Republic Of Macedonia Paras. 7, 52, 53, 65, 66, 84 and 85.

What these different reports have in common is the acknowledgment of the need to consider the prevailing negative environmental and attitudinal climate in North Macedonia when designing and implementing new programmes and services for children with disabilities. A predominant perception of disabilities as a health deficit in society strongly determines the experience of growing up with a disability for children throughout the country. Therefore, comprehensive approaches are necessary to advance more inclusive and welcoming environments around early childhood centers, schools, and the community as a whole.

In 2014 UNICEF commissioned a survey to test knowledge, attitudes, and practices towards children with disabilities in North Macedonia. The survey results served as baseline data and contributed to highlighting the need to address stigma as an important factor and prepare strategies and campaigns to tackle attitudinal barriers, disseminate messages about respect for diversity, foster fairness and non-discrimination in childcare services and schools, and stimulate positive attitudes towards the development, learning, and inclusion of each child³. In the same year, UNICEF undertook the mapping of disability-related organizations and informal groups to better understand their perspectives and learn about their capacities to contribute to social change and inclusive policies⁴.

Disability rights campaigns [2015-2017], the #FightUnfair social media campaign [2015-2016], and a fully integrated campaign developed in 2017 under the slogan “Be Fair - For a Childhood without Barriers”, sought to mobilize public awareness and support for the rights and inclusion of children with disabilities. These campaigns used social networks such as Facebook⁵ and YouTube⁶ and the mainstream media to engage the public with a new understanding of disability based on the commitments made by North Macedonia to the UN through its signing of the Convention on the Rights of Persons with Disabilities. The campaigns particularly sought to project positive messages about children and adolescents with disabilities and address the need for social behavior change by communicating that “*the best way to overcome stigma is to make inclusion a reality*”.

A follow-up survey of attitudes towards disability conducted in 2017, was able to evaluate positive progress in very important areas such as awareness (understanding of disability beyond the medical aspects), attitudes (eagerness to share a classroom or a playground with children with disabilities), and actual frequency of contacts and engagement between policymakers and representatives of persons with disabilities as well as between children with and without disabilities (UNICEF 2017).



CHALLENGES AND APPROACHES

The ratification of the Convention on the Rights of Persons with Disabilities in 2011 marked the rise of a strong political will in North Macedonia to advance human rights, improve the quality of life and expand opportunities for social inclusion for children and adults with disabilities and their families. UNICEF has partnered throughout this process with government officials, organizations of persons with disabilities, and other international agencies, to ensure that the needs of children with disabilities are considered throughout these changes.

Efforts made to develop a multi-centered initiative were acknowledged in the 2018 review issued by the UN Committee on the Rights of Persons with Disabilities, which specifically recognized the establishment of a National Coordination Body for Implementation of the Convention and the ongoing progress towards more policies integrated for social protection and de-institutionalization of children with disabilities in the country. Some examples of the emerging multi-sector process involving key sectors and stakeholders include:

- A national multi-year multi-media campaign focused on addressing cross-cutting barriers to inclusion-developed and implemented by a coalition of partners.

3 UNICEF, 1 07 2020 Concept for Inclusive Education, internal document North Macedonia
 4 Mapping of Disability Persons Organisations – Report, UNICEF 2014, available at <https://www.unicef.org/northmacedonia/reports/mapping-disability-persons-organisations-report>
 5 <https://www.facebook.com/unicef.mk/photos/a.255908064454535/1082368158475184>
 6 <https://youtu.be/cb1T7k0mxC4>

- Frequent community dialogues and events with a focus on identifying and addressing cross-cutting barriers, giving voice to children and young people with disabilities, and expanding opportunities for contact with children and youth without disabilities.
- Multiple partnerships to advance mainstreaming inclusion in sports, culture, and social activism.
- Public advocacy complementing ongoing capacity development for improved data and evidence generation, inclusive services delivery, strengthening capacities of teachers, health professionals and childcare providers.
- Advocacy for inclusive community-based services.



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Aldin, 10 reading Braille book in Tetovo. He joined UNICEF to promote inclusion of children with disabilities and participated in a campaign “See the child, not the disability”.

Such a multi-level approach was also replicated within key sectors and policies, using advocacy as the most frequent component to support the process of comprehensive policy changes. For instance:

- In education, the National Education Strategy for North Macedonia⁷ (2018) proposed inclusive education of children with disabilities in all its pillars. More importantly, a new Law on Primary Education adopted in 2019, introduced a normative framework for non-discrimination and equality of children in the education process, where disability is established as a discrimination ground for the first time⁸.

Still, most stakeholders would agree today on the need to continue expanding investments and strengthening the implementation capacity of inclusive education in the country. A recent report of the Network for Protection from Discrimination has asked the Ministry of Education and Science “to organize the terrain for implementation and prepare primary education for full inclusion of students with disabilities”⁹.

An example of such forthcoming challenges can be found in a number of stalemates of the implementation e.g. insufficient investments in preparing schools and teachers, but also in a still predominant (mainly medicalized and paternalistic) perception of disabilities amongst government officials and services providers. Some of these negative attitudes have been expressed in tensions and controversies with education stakeholders and interest groups that are still very much attached to the previous paradigm of specialized education and treatment of children with disabilities. While disagreement and discussions seem to focus on what are indeed realistic issues and challenges that the system needs to address (e.g. the need to provide more training and additional support for teachers and downsize inclusive classrooms) they actually cover the resistance to a change of paradigm, resulting in barriers, delays or interruption of policy implementation.

The challenge of modifying these remaining negative behavioural factors and misconceptions requires long-term strategies involving academics from the special education area that fear to become obsolete if special schools are reconverted in resources centers as well as representatives of Organizations of Persons with Disabilities who are not confident or supportive enough to the prospects of inclusive education for children with disabilities.

In **social protection**, with UNICEF support, a comprehensive reform of the social protection system is taking place in North Macedonia since 2017. This structural reform has aimed at addressing the extensive overlapping, non-integrated approaches and category-based services that contributed to chronic dependency and segregation particularly for children with disabilities and were identified in a number of previous evaluations (Gerovska-Mitev, 2018).

⁷ Available at <http://mrk.mk/wp-content/uploads/2018/10/Strategija-za-obrazovanie-ENG-WEB-1.pdf>

⁸ The Law prescribes full inclusion of children with disabilities and indicates that special schools shall continue to work as primary schools with resource centers starting from 2020/2021, with students being enrolled from the 2022/2023 school year.

⁹ The right to education of children with disabilities, Network for protection against discrimination, 2020

A new Social Protection Law (2019) and a major revision of the Child Protection Law overhauled and consolidated the cash benefit system, to ensure, among other things, increased coverage of persons with disability and better adequacy of the benefits. The disability allowance for children was increased by 15% and the part-time salary for a parent caring for a child with a disability increased to 50% of the average net salary. A permanent allowance was introduced for parents who took care of a child with a disability up to the age of 26, including also personal assistants and home care support.

In addition to these reforms, UNICEF engaged with partners from the Government and the Association of Special Educators to pilot a new model of disability assessment, based on the International Classification of Functioning, Disability, and Health (ICF). The reform of mechanisms through which disability was certified in the country implied another effort to question the traditional perceptions and avoid labeling of children with disabilities. The new multi-disciplinary and multi-sectorial assessment process is based on the ICF and focused on identifying the specific support and rehabilitation needs of children, so they relate to the appropriate resources and services. This change also sought to better connect pensions and cash transfer mechanisms with services provision for early inclusion¹⁰.

It is crucial not to classify people and children based on their abilities or disabilities, but to rather focus on their functionality – their potentials, possibilities, and abilities – so that they can fully enjoy their rights to education, health services, and social support and care.

UNICEF, 2020.

The new assessment procedures were also incorporated in the Law on primary education as a prerequisite for accessing educational support for children with disability. The strategy involves reformulating the roles of various institutions and authorities and are another opportunity to re-imagine and strengthen social protection mechanisms that promote autonomy and personal development.

Involving parents in the assessment process has also been an important component of this strategy, which resulted in positive changes in relation to changing attitudes and improving parenting skills. It also provides the assessment team firsthand information on the functional characteristics of the child. This approach represents a breakthrough from the medical diagnoses which tend to alienate the parents.

It also provides an opportunity for both parents and professionals to learn together and think creatively on the type of rehabilitation strategies that would be most beneficial for child development and functioning in each case. Such interaction and mutual learning process allow parents and the assessment team to change their understanding of what their child can do and recognize that with adequate support the child can increase autonomy and participation.

Parents are asked to sign the assessment, agree on the individual support plan and commit to monitoring development and inclusion progress. This approach has helped parents and parental associations to look at the disability assessment bodies as a place where they can seek advice and support. The provided support by the bodies also includes connecting the parents with adequate service providers and ensuring that they receive the needed services. To date, more than 1,050 children and their families used the assessment services which provided significant opportunities to learn from the process and adjust accordingly.

Besides these important sectorial improvements, the rationale for a major, multi-level and multi-institutional policy effort, involves a process of contact and horizontal learning amongst key stakeholders which is key to overcoming previous understanding of disabilities and changing negative attitudes and behaviors that are deeply rooted in social and institutional cultures.

UNICEF's perspective has been to integrate support for policy developments with awareness campaigns on the rights and needs of children with disabilities. This approach seeks to facilitate a combination of policy changes with social and behavior change through continuing communication, information, and participatory action that stimulates opportunities for service providers, families, and the community to interact, learn together and question their own responses to dealing with stigma and cultural barriers on a daily basis.

10 In 2017, North Macedonia reformed its Law on Social Protection, aiming at improving the social protection of people with disabilities. In 2019, the country adopted a new Law maintaining non-conditionality, creating further cash benefits, and integrating these with the existing and new social services. European Social Policy Network, Flash Report 2019/40

Such an interaction between policy development and change of attitudes and social behavior evolves through a process that comprises mutually influencing elements:

- A shift in the understanding of the social model emerging from the CRPD contributed to more policymakers increasing understanding of the importance to reform the disability assessment model based in line with WHO International Classification of Functioning.
- The expansion and appropriate use of the new benefits and opportunities is strongly influenced by the perception and stigma attached to disability in the local communities.
- For service providers, the opportunity to count on new practical and interpersonal tools such as CBoard and others, helped them to feel more confident with the new approaches and communicate the right messages to families.

Many initiatives were organized to familiarize authorities, parents, and service providers with a social, rights-based culture to approaching the needs of children with disabilities, for instance:

- Working with civil society organizations to expand the availability of resources on the ground to support the deinstitutionalization process and schools engaged in inclusive education.
- Improve screening of children with disabilities, strengthen parenting education, and promote access to the first-level network for early inclusion.
- Discussions on the de-institutionalization reform and awareness on the fact that the majority of children abandoned in institutions are children with disabilities.
- Working with artists, multi-media film festivals, and sports events to provoke a reflection on discrimination and challenging the taboos and most current perceptions and attitudes towards children with disabilities.
- Community events with dances, theater, and sports were proposed as a meeting point for children with and without disabilities, with the idea of spotlighting the potential of encounter and children coming together.
- Children with disabilities giving master classes in schools and communities.

RESULTS

As mentioned before, significant changes in legislation and policy took place over the last eight years in North Macedonia, reflecting a better understanding of disability as part of human diversity amongst policymakers and authorities. This is a consequence of a multidisciplinary strategy that created a new atmosphere of mutual learning and collaboration around disability challenges. UNICEF has guided this process in active collaboration with authorities at the local, regional, and national levels. All activities involved staff from health, education, and social protection programmes as well as representatives of organizations of persons with disabilities, and the media.

The opportunities provided for all these stakeholders to learn and work together have gradually translated into positive signs of increased willingness towards inclusive approaches in many areas of public policy and not just in disability-related decisions. Examples of such policy changes that reflect new, more positive attitudes can be observed in the following:

Strengthened national capacities for advancing inclusion. Since the adoption of the Law for primary education (2019) and the decision to transform special schools into resource centers, UNICEF supported the Ministry of Education and Science on a policy level (introducing inclusive education and corresponding by-laws) and at an institutional level (by supporting capacity development). Resource centers staff was supported to strengthen their capacities for implementing new responsibilities. With UNICEF support, over 500 educational assistants were trained, and more than 300 school directors and teachers attended webinars on inclusive education. In collaboration with the Bureau for Development of Education, over 2,000 teachers in mainstream schools were trained on inclusive education and additional 140 educators received training on alternative and augmentative assistive technology. At the same time, a communication app with symbols and text-to-speech technology (CBoard) was introduced in North Macedonia, as a communication aid for children with speech and language impairments.

These and other initiatives greatly contributed towards strengthening stakeholders' capacities and overcoming pre-existing negative attitudes towards teaching children with disabilities. At the same time, it has built

the confidence of parents of children with disabilities that mainstream schools provide a better social and learning environment for their children. As a result, the number of children with disabilities in special schools was decreased by half in less than three years.

Introduction of a new, rights-oriented model for assessing, certifying, and supporting children's disabilities, which proposes a recalculation of the entire social protection scheme for children and adolescents, with a vision of a more autonomy-oriented mechanism that links pension and other economic tools to rehabilitation and early inclusion. Three pilot centres have been established - one national and two for the Skopje region - and staffed with trained teams to provide disability assessments based on the ICF for Skopje region and a National expert body created with UNICEF support and taken over by the public healthcare system. New services allowed the development of a new, rights-based network of collaboration and advocacy for disability inclusion. With technical assistance and support from UNICEF to the Ministry of Labour and Social Policy, it has been a demonstration of innovative approaches and reform implementation.

The creation of a multi-institutional response to support children with disabilities and their families during the COVID-19 pandemic. With the pandemic and closure of schools, kindergartens, and daycare centers, many parents of children with disabilities lost their daily support. This undoubtedly put pressure on all parents often having to improvise the roles of teachers, caregivers, and therapists. Previous partnership building, more positive attitudes, and better preparation for collaborative action allowed governmental and non-governmental organizations, with support from UNICEF, to respond to the pandemic by rapidly implementing a number of initiatives, such as:

- Individualized support to children with disabilities and their caregivers by special educators and speech therapists, for early stimulation using online speech therapy, and counseling as well as psychosocial support for caregivers.
- Early intervention center promoted an online platform with a wealth of resources for caregivers and the possibility to connect with multi-disciplinary teams and receive online support for parents of children with developmental delays and disabilities – in collaboration with the

Association of Special Educators and Rehabilitators. These online services, accessible in Macedonian and Albanian, provided service to families outside the capital, where specialist support is often not available.

- Legal empowerment for caregivers of children with disabilities through capacity-building of staff at the free legal aid departments of the Ministry of Justice, parents, and staff at the daycare centers.

A moratoria on placing children in large-scale institutions for children with disabilities. Reforms to end the placement of children without parental care in large-scale institutions and ensure that every child has a family were reinvigorated in 2016 and resulted in zero children placed in large-scale institutions in North Macedonia by the end of 2019. Such a remarkable breakthrough would have not been possible without the climate of multi-sectoral engagement and change of attitudes in the country.

The National campaign “Every child needs a family” produced by the Ministry of Labour and Social Protection and UNICEF between 2018-2019 increased public awareness and helped to mobilize new foster families for children with disabilities. This campaign, coupled with public discussions, conferences, and events, helped increase the understanding on de-institutionalization and social inclusion among the general public and professionals, accelerating the implementation of reforms and ensuring every child receives the support they need to avoid exclusion, isolation, and institutionalization.

At the same time, it led to increased understanding of the need for communities to become more diverse and improve their ability to deal with diversity, which eased the process of establishment of community-based services.



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A child attending ballet class for beginners at the Down syndrome center in Skopje, North Macedonia.

FUTURE STEPS

The adopted approaches – to empower and support families of children with disabilities and organizations of persons with disabilities, raise public awareness on the needs of children and persons with disabilities and the benefits of inclusion, address service providers' bias and empower them to support and promote inclusion, support policy and regulatory changes around inclusion etc. – demonstrated effectiveness in shifting public attitudes towards children with disabilities, empower the

families of children with disabilities to demand their rights, advocate for and participate in changes in policies and services to make them more inclusive, strengthen service providers' self-efficacy to provide inclusive services. However, there is a clear understanding of the need to continue these processes for continuous and sustainable results at scale.

ADDITIONAL RESOURCES AND USEFUL LINKS

- Follow-up Survey on Knowledge, Attitudes, Practices towards Inclusion of Children with Disabilities, UNICEF and European Union, 2017 <https://www.unicef.org/northmacedonia/reports/follow-survey-knowledge-attitudes-practices-towards-inclusion-children-disabilities>
- Concluding observations on the initial report of the former Yugoslav Republic of Macedonia, United Nations (2018) CRPD/C/MKD/CO/1
- Gerovska Mitev, M. (2018), "Report on the rights to financial assistance from social protection, with proposals for introducing a Guaranteed minimum income", prepared for the Ministry of Labour and Social Policy of the Republic of North Macedonia (unpublished).

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SERBIA

The road to early inclusion: empowering families to enrich childhood and community life in Serbia



© UNICEF/2018/SZABO

A father reading with his two preschool-age children practicing responsive and bonding activities for early stimulation of child development and family wellbeing proposed by ECI practitioner

INTRODUCTION

Children with delays and disabilities can thrive in family contexts, particularly if parents and caregivers receive ongoing strength-based support and proper training. Conversely, a lack of knowledge about their child's condition and needs, overwhelming feelings, and lack of support for parents adversely affect parent-child interactions, child behaviour, and development. If provided with nurturing and supportive family care, children with delays and disabilities have a better chance of leading healthy and full lives, particularly when such care is provided from early in life¹.

Today, 60 000 children in Serbia up to five years, live with developmental delays or disabilities, are at risk of social segregation and are likely to stay behind their peers without a disability with regards to growth and early development.

The explanation for them to be behind is often not their disability but the fact that their learning, communication, and play needs remain unrecognized, undervalued, and unmet by adults and peers. Too often, others perceive them as “different”, less valuable, and incapable. Their capacities are neglected, and they are still sometimes treated in harmful ways. These are the main reasons why these children risk missing essential opportunities which has an indelible impact on their entire life cycle.

Their parents often feel scared and lonely. Many have lost hope, while parental joy and faith have been replaced by a daily struggle and a sense of guilt and shame. Their families, relatives and friends often do not know what to do and how to help. Over time, those around them withdraw, which further intensifies isolation and helplessness. They often ask themselves questions that are unimaginable for other parents: Will my child ever go to school? Will anyone ever want to be his

1 Collins PY, Pringle B, Alexander C, et al. Global services and support for children with developmental delays and disabilities: bridging research and policy gaps

friend? How to protect my child when they make fun of him and avoid him? What will happen when they grow older?

Also, and very much as part of the stigma and prejudices still prevailing in the Serbian society², they too often get silent as an answer to these questions, with the system lacking the capacity to identify all children and families in need and provide appropriate, timely, and quality support.

These findings, revealed by the Situation Analysis (2017, OSF and UNICEF)³, guided development of family-oriented early childhood interventions designed to address these needs from the very start of a child's life by introducing an approach that is strength-based and relying on a supporting network around the family, joining all available resources so to create enabling environment to support institutional and professional change that nurtures inclusive communities and improves life opportunities for children throughout the life cycle.

Early childhood intervention has been modelled in Serbia as an inclusive intersectoral service to address primarily:

- health, preschool and social welfare Early Childhood Development (ECD) professionals' attitudes towards children with disabilities and their parents and families, along with their self-efficacy as professionals and their capacity to engage and be supportive, and
- systemic barriers at the institutional level and supporting early social inclusion and access to quality services.

Improved Early Childhood Intervention (ECI) services were piloted in Serbia in 5 municipalities and showed the change is possible and achievable when they address not only the knowledge of practitioners, moreover the root causes within attitudes, cultural beliefs, interpersonal patterns, heritage, organization of services and social norms that underline social exclusion and segregation. Changes do need systemic and continuous support, intersectoral and transdisciplinary collaboration, adequate regulations, and network empowerment.

However, changes reflected in increased self-confidence of service providers to engage, be supportive and partner with parents bring a significant recovery in the quality of family relationships and breakthrough opportunities for child development and inclusion.

"This support programme is especially important for us parents, because this is the first time someone asks us how we feel, how we as parents cope with the whole situation of raising a child with disabilities.

It is such a valuable program because only now we see how many important moments we missed for the work and inclusion of our children in everyday life activities child can benefit from, which we parents can do ourselves, on the other hand we have invested so much in taking children to different therapists."

Feedback from the Interview session with parents during the Caregiver Skills Training.

THE PROBLEM

Children with disabilities are among the world's most stigmatized and excluded children. Limited knowledge about disability and related negative attitudes can result in the marginalization of children with disabilities within their families, schools, and communities⁴. In cultures where guilt, shame, and fear are associated with the birth of a child with a disability they are frequently hidden from view, ill-treated, and excluded from activities that are crucial for their development (UNICEF and WHO, 2012).

The Republic of Serbia has ratified relevant conventions and has integrated them into well-developed legislative frameworks across sectors that support social and education inclusion and universal health coverage of all children, including children with developmental delays and disabilities. However, there are also many gaps in the system that prohibit full realization of the rights of children with disabilities.

Very recently in 2017, the Committee on the Rights of Persons with Disabilities recommended Serbia to implement a comprehensive reform of the in-development and protection system for children with

² UN Committee on the Rights of Persons with Disabilities (CRPD). Concluding observations on the combined second and third periodic reports of Serbia, CRC/C/SRB/CO/2-3, 2017

³ <https://www.unicef.org/serbia/media/156/file/Situation%20Analysis:%20Position%20of%20children%20with%20disabilities%20in%20the%20Republic%20of%20Serbia.pdf>

⁴ Children with disabilities: ending discrimination and promoting participation, development, and inclusion. New York, United Nations Children's Fund, 2007

disabilities and their families in order to improve coordination and avoid unnecessary institutionalization. It also urged the CRPD member state to carry out public campaigns to combat stigmatization and prejudice about children with disabilities.

At the same time, there is a widely spread perception amongst professionals and disability stakeholders that children with disabilities face multiple forms of rights violations (i.e. segregation from services and social inclusion opportunities) on the basis of the negative views of disabilities still dominant in the Serbian culture and society. How much do such social stigma and low expectations of the social environment contribute to children's vulnerability and make their parents and extended families feel hopeless? While data remains scarce, the truth is that these factors emerge in most regular attitudes and services' practices from the tendency to try to 'fix' children with disabilities – rather than adjusting the environment and providing support on the basis of their functional needs – to lack of early detection and exclusion from Early Childhood Education and Care (ECEC) services and missing opportunities for social participation.

In Serbia, while recent research data showed an existent wide network of services promoting early care and development it also revealed that services do not follow the recent scientific developments⁵ and are badly prepared to meet the needs of children with more complex challenges⁶. Developmental delays are most often recognized too late (UNICEF 2021), thus not providing support to the families and children in the critical period for child's development. Parents are left to find their way through services that are fragmented between the sectors, uncoordinated, only available in major cities or too expensive.

“One parent suspected that his child was not hearing well when he was 22 months old and asked a pediatrician to have a hearing test. The pediatrician refused to refer the child for examination on the ground that parents are often overreacting. The child was later diagnosed with an autism spectrum disorder.”

*Quote from Situation Analysis:
Position of children with disabilities in the Republic.*

Also, most existing services and professionals serving children with disabilities have kept a medical (professional-centred) approach, resulting in a limited understanding of disabilities. This implies that parental capacities and parenting skills that could be key for supporting children develop and thrive if properly supported, are overlooked, or underestimated, therefore reinforcing negative feelings and low self-confidence of the parents themselves.

Parents often feel left alone and rejected at services. When they manage to get support, they often receive it in a way that is wrapped in negative attitudes: so that a “defect” of their child must be “corrected”, while psychosocial support for wellbeing or quality of family relationships is lacking. Parents are rarely invited or coached by practitioners to work with children⁷ and end up demanding specialized responses to correct ‘defects’ rather than engaging in family-centred support and responsive parenting to stimulate their children to maximize potential.

It is true that parents' attitudes may also lead to additional resistance and an atmosphere of non-cooperation⁸ and to some extent hesitance to inclusive ECI and ECEC. But the causes are often that they are not well informed, they feel experts are better equipped to support their child than themselves, they fear their children will be stigmatized, or ashamed because they are different from others.

The self-confidence of professionals and the quality of family-service providers' interaction are often compromised when a child has a disability. Limited knowledge on disability rights, prejudices, and insecurity resulting from self-perceived lack of preparation and adequate resources for inclusive and family oriented ECI, affects professional self-confidence and readiness to provide quality care to families. Lack of confidence of professionals and conservatively driven practices focused on children disability rather than strength, needs, ability and opportunity not only compromises their self-efficacy but also impacts negatively on the confidence of families to demand inclusive services. It creates a vicious cycle of negative attitudes and mutual avoidances which is contrary to basic principles of collaboration and trust. Addressing these unhelpful dynamics is key for providing encouraging and reassuring counselling to families,

⁵ <https://www.unicef.org/serbia/media/156/file/Situation%20Analysis:%20Position%20of%20children%20with%20disabilities%20in%20the%20Republic%20of%20Serbia.pdf>
⁶ <https://www.unicef.org/serbia/publikacije/situaciona-analiza-usluga-za-bebe-i-malu-decu-sa-smetnjama-u-razvoju-u-republici-srbiji>

⁷ <https://www.unicef.org/serbia/media/156/file/Situation%20Analysis:%20Position%20of%20children%20with%20disabilities%20in%20the%20Republic%20of%20Serbia.pdf>
⁸ Regional Ombudsman of the Autonomous Region of Vojvodina. Inclusion – between wishes and possibilities, 2011. [in Serbian]

which is most needed for them to develop confidence in their own feelings and capacities and to assertively pursue the highest development expectations for their children.

THE APPROACH

Guided by the evidence, in the past decade, mainstreaming disability-inclusion within early childhood development and learning has been prioritised in the UNICEF-Government partnership agenda in Serbia. This is fully acknowledging that timely support to the development and wellbeing of young children with delays and disabilities and their family helps them reach their optimal potential, increases their social participation and inclusion in schools and the community. Overall, it improves the quality of their lives.

Furthermore, when the risk of being institutionalized for the mere reason of having a disability still is a possibility for some of the most unprivileged children, addressing the needs of early inclusion becomes essential.

Most recent international experiences in providing family-centred services, perceived the role of caregivers as a critical in ensuring optimal child developmental outcomes, while positive parenting is related to fewer behavioural problems during childhood and adolescence, as well as improved emotional and social competence (Irwin et al., 2007). The empowerment of caregivers is increasingly being recognized as a critical component of care interventions, as caring for a child with developmental disorders can be challenging for caregivers who frequently report experiencing feelings of inadequacy and poor self-confidence. Therefore, family centered ECI becomes particularly useful in this context.

Considering the background and available evidence, UNICEF in collaboration with international and local partners⁹ started in 2017 a program for strengthening the ECI system in Serbia through cross-sectoral collaboration at national and local levels with a focus on increasing access and quality of services to children with developmental delays or disabilities and their families. The new ECI model is based on the international/European standards and its implementation has received significant expert support from EURLY AID (European Association for ECI) and

distinguished ECI professionals from USA and Portugal. The ECI program is established as part of UNICEF Serbia's support to the Government to scale up a new family-centered, routine-based¹⁰, cross-sectoral (involving health, education, and social welfare) early childhood intervention model aimed to address barriers that hinder the outreach and inclusion of children with disabilities. It started in five pilot locations and is planned to scale up in 2022-2023 and be expanded across all 25 districts and 10 capital city municipalities.

The child, family, and community are at the center of the ECI approach. The model introduces a new paradigm in service provision – focusing 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, neighborhood) and integrated into the simple daily routines with caregivers being active participants and the final decision-makers, without taking the main burden of the process. A gender-sensitive approach seeks to engage everyone in the family and the community to be empowered and to feel more confident and less isolated. For an ECI program to be effective, families must be supported and involved in a meaningful way from intake through transition and program exit.

A CHILD'S STRENGTHS MIRROR THEIR PARENTS' STRENGTHS!



PARENTS IN THE SPOTLIGHT.

© UNICEF/2020, Illustration from the Parenting Month 2020 advocacy national campaign

⁹ Including the EURLY AID (European Association for ECI), the Open Society Foundation, Ministries of Health, Education and Social Welfare, University Ramon Lull (Barcelona), Institute for Mental Health, Belgrade Psychological center, Pediatric Association of Serbia, the Serbian Associations for Helping People with Autism, Autism Speaks USA, Parental organization "Ringeraja", Faculty for Special Education and Rehabilitation Belgrade, Medical faculty/Department for Special Education and Rehabilitation Novi Sad and Institute of Psychology amongst others

¹⁰ Research proves the family centered intervention/service provision are more efficient compared with institution/expert centered service provision (Raab i Dunst, 2004; Jung, 2007). Skills which child develops in natural surroundings make more sense to the child and to the family (Kashinath, Woods and Goldstien, 2006), and opportunities for practicing them based on the daily routines (Woods, Kashinath and Goldstien, 2004) could be more easily integrated into the every-day participation in family life.

To support additional opportunities for parents the ECI model in Serbia has been enriched with the Caregiver skills training (WHO and Autism Speaks program). The approach is working with groups of parents to break the cycle of negative attitudes and ableism by facilitating mutual support, peer exchange, and horizontal learnings. This is particularly relevant for early inclusion as development is strongly influenced by the beliefs, attitudes, and behaviour of those individuals who spend the most time with children with disabilities.

A multi-level approach to ECI services based on the integrated practice has been key to facilitating coordination amongst already existing capacities for early intervention at the district level. The program seeks to build upon already existing Developmental Counseling Unites (DCUs) in the primary health centers as a coordination body, bringing together professionals (psychologists, special educators, speech therapists, social workers etc.) from DCUs, pre-schools, and social welfare services into transdisciplinary teams that provide integrated support to the families and children with developmental delays and disabilities.

The strategy operated at different levels, with a comprehensive vision of the complementation of actions within the policy, knowledge and social behavior change processes.



© UNICEF Serbia/2021/Pančić

Single mother Gordana and her three-year-old son Vuk in their favorite daily Walk and Play outdoor routine

At the policy and enabling environment level

In the past decade, following UNICEF advocacy efforts and technical support, early childhood development and learning, including of children with disabilities, has been put higher on the Government Agenda. In 2016, the Ministry of Health adopted a National program for early childhood development. In 2018, the Ministries of Health, Education and Social Affairs and the President of the National Child Rights Council signed a Call for Action for Early Childhood Development, where high-quality and accessible early childhood interventions for children with developmental risks, delays and disabilities are recognized as a priority. To foster system change, following strategies were applied:

- Full participation of the representatives of relevant Ministries and relevant national institutions in developing ECI model through establishing a strong and diverse advisory board (including representatives of ministries, academia, researchers, experts, practitioners, caregivers, and community stakeholders) with regular meetings and briefs and fully engaged with the process of improving professional training, strengthening institutional capacities, and disseminating inclusive practices, inter-sectorial ECI Advisory Board and their engagement in reporting on the achievements in the Council for Child Rights and on the annual National ECD Conferences.
- Engaging local self-governments in local advisory boards to promote shared values and principals of early childhood intervention and inclusive communities.
- Advocacy on national level for legislation change and investmets to ensure sufficient human and financial resources as well as quality standards of services in order to increase availability and quality of family centered early childhood intervention services.
- Promoting an enabling environment through changing the communication on children and disabilities by “involving hearts and minds”, eg. sharing with the media and decision-makers stories of parents and children and communities that provided examples of positive change¹¹.

¹¹ Media was also engaged during COVID. A new strategy is currently in preparation including fundraising and new communication campaigns.

- Organizing an annual Conference on ECD and parenting with a strong focus on ECI, which allowed the presence in Serbia of European and American experts, the sharing of results and success stories, caregivers testimonials, and helped to advocate for early inclusion amongst policymakers, professionals, and parents.
- Strengthen quality demand, by involving parents' associations in a way that nurtures capacities, strengthens mutual support, and generates empowerment. Engage these parents' associations as trainers of trainers in new locations which resulted in opportunities for expanding recognition of inclusive ECI and developing additional capacities and confidence.

On the level of quality of services – strengthening supportive relationship between services providers and families.

- Parents and providers engage collaboratively to analyse and determine which strategies might work best for the child and the family. This dynamic and personalized process seeks to expand the understanding of the child's rights and support needs while improving awareness of family strengths and existing resources.
- The relationship between professionals and the family is based on trust, respect, and open exchange of expertise, positive expectations, and insight. Families are supported to be aware of their rights and prepared on how to support their child's development and inclusion as well as given opportunities to engage at the community level to advocate for their child and family's inclusion.
- Such a participatory dynamic aims to translate into the empowerment of parents and increase opportunities for real-time behaviour change of services providers and the community. Seeking behaviour change towards self-confidence, vivacious and open attitudes, and positive beliefs of parents (and other close persons involved in parenting) is expected to result in more playful parenting and nurturing care through all daily routines¹², resulting in higher satisfaction on family relations and consequently increased community engagement and inclusion. This is key in the long run for maximizing a child's development, avoiding

secondary disabilities, and mitigating early segregation and related risk factors¹³.

The strategy sought collaboration with organizations of families and persons with developmental challenges and disabilities, so they have an active role both assisting the process as advocates and facilitators. Working with community organizations also aims to expand best practices through horizontal learning and peer-to-peer support.

ECI challenges us is to think of practitioners and service providers as a very active ingredient to making something happen/ change in the community. For the child to feel supported they need a supportive and attentive caregiver. For the caregiver to feel supported they need good counseling and a good relationship with counselors. They want somebody that comes in and listens, who notices how they feel, and is responsive. They can't necessarily fix all of the family problems, but the experience of having them there and emotionally available is crucial. Listening makes a huge difference. But practitioners can't be there for the parents if someone else is not there for practitioners too. So if at the end of the week or at the end of the month they don't have someone to speak with about how they are feeling, the difficult situations that they might be going through it may end with regressing to old practices and unwillingness to truly engage in teamwork with parents.

Practitioners need that kind of supportive supervision because they are at burnt-out risk. The more burned out they are the less empathetic they become and the more eager to just provide information and treatment without talking with parents, without listening. So the same space for listening that is required in the counseling space has to happen in a supervision space too.

Professor Tamsen RoCHAT, Human Sciences Research Council, University of Witwatersrand, South Africa in the occasion of the Fifth National ECD Conference in Serbia of Serbia, UNICEF 2017

¹² Bronfenbrenner, U. 1989. Ecological systems theory. *Annals of Child Development*. Vol. 6, 187- 249

¹³ <https://blogs.unicef.org/evidence-for-action/tag/early-childhood-development/>

Improving practices and supporting practitioners

- The principles of the ECI model aim at fostering change in both professional and personal mindsets and seek to actively address child developmental factors, including stigma and expanding expectations. Based on guidance from experts the program created a novel, open-access strategy which could be implemented in low-resource settings.
- Capacity building of professionals, in-service and pre-service training, supportive supervision, horizontal learning, opportunities to engage in innovative practice, and addressing pre-existing beliefs, prejudice and attitudes are all components of an integrated strategy for professional change. Professional training and development (certified by the Portuguese National Association for Early Intervention, ANIP) contributed to the process of increasing self-confidence and facilitating a change of attitudes and practices of service providers. Professionals were empowered by providing them with access to evidence-based international practices and opportunities for supportive supervision provided by international and national experts.

“This training helps us to communicate, to create beautiful moments together, to make us happier in the role of a parent, to make us calmer. Sharing experiences with other parents creates the feeling that we are not alone. That the difficulties we are going through are challenges that we will overcome. The training is extremely important for parents and especially for their children, because it makes us more capable, happier and better parents.”

Feedback from parent engaged in programme.

Part of the strategy also offered a combination of group sessions and individual home visits (on a weekly or biweekly basis) and skills building for engaging children in communication, play, and home routines and promoting adaptive behaviors, daily living skills, addressing challenging behavior, and caregiver coping strategies.

With the introduction of the WHO-developed Caregivers Support Training program in Serbia, local partners strengthen their capacities and acquired a type of knowledge and skills that will be applicable in working with all families.



© UNICEF/2018/SZABO

A girl with Down syndrome independently exploring the homemade bookshelves created together with her father and younger brother with the support of ECI practitioner

A few additional strategies can be mentioned as having been important to amplify professional resources for implementation but also to expanding and disseminating a culture of disability inclusion in professional and academic environments:

- Partnerships with key professional institutions in Serbia and Europe, involving regular collaboration, capacity building and advice from experts and regional collaborating centers.
- Engaging academic institutions to start bringing ECI practices and lessons learned into pre-service curricula and postgraduate training opportunities.
- Promoting a step-by-step approach to inclusive ECI, with a monitoring framework that seeks to not burden the professional teams and gives access to training and supportive supervision.

Programme Theory of change (ToC)

Programme aims to support practitioners by providing an enabling environment including intersectoral and integrated policies, quality training and guidance, supportive supervision, and promotion of positive social attitudes towards children with disabilities. This is expected to result in confidence and quality counseling for parents.

When parents/caregivers are supported to practice self-care, stress coping, conflict resolution strategies, child participation and learning through daily activities, engaging families, social network and community resources, they are empowered to provide comfort, connection, emotional security, stimulation early learning through responsive child-parent interaction and satisfaction with family life.

Finally, supported and empowered parents are the best advocates and supporters for child development and inclusion. Key tools that practitioners use when working with families are:

- Stimulate their self-confidence and self-efficiency. Build on their strengths.
- Make them aware and capable to contribute to child development in daily situations.
- Partnering them in strengthening the connection and linkages with the community.
- Providing them with relevant information while giving the autonomy to make decisions.

RESULTS

Overall, the programme implementation was largely affected by the outbreak of the COVID-19 pandemic in Serbia since February 2020. However, an initial evaluation of its process and results provides positive signs:

- Most parents feel that the program had a positive impact on their children's development and improved their own knowledge and parenting skills. Most interestingly, parents feel happier and more empowered for supporting their child's development. They also highlighted important improvements in interaction with ECI professionals, acknowledged empathic listening from ECI teams. Receiving more supportive and reassuring advice from them was associated with been given the opportunity to play a constructive role in program activities and feeling "part of the team" with primary service providers.
- Practitioners feel now more competent and confident in ECI service delivery to children with developmental challenges and disabilities. For that, receiving training and supportive supervision was mentioned as being of great importance. Practitioners mentioned that they feel now more

competent in conveying useful messages to families about everyday learning opportunities, and in encouraging parents to support the child's development. Inclusive approaches are currently becoming a core part of the rationale for creating a National Early Childhood Development and Inclusion Centre in the forthcoming years. However, surveyed professionals still feel less confident in their ability to identify children's possibilities, strengths and needs and their capacity to provide the required support and resources. They also mentioned the need for continue to improve ECI inter-sectorial perspective and cooperation with families which is currently challenged by insufficient human resources and institutional support.

- Motivation and knowledge of practitioners are prerequisites of successful ECI implementation. That requires a social and cultural context that is supportive of disability inclusive options as well as continue ECI training and supervision and incentives to collaboration with other sectors and with the community. While recognition and support to the Early Childhood Intervention model

significantly increased amongst stakeholders (which is a key message about the new way that Serbian society should approach diversity and care children with developmental challenges and disabilities) there is still a lot of space for cultural changes.

The key change for me is, in fact, the change of the position that parents, i.e families, and the expert have. Somehow, earlier, families were put in a passive position, in fact in the position of passive recipient of services. And the families were mainly guided and largely dependent on the experts, on their availability of at certain time. Today, the greatest success for me is when we feel the autonomy of the family and when the family are able to make informed decisions, to advance proposals, to identify solutions, and when the family actually feels satisfied and happy.

*Ivana Jokić, psychologist,
Preschool "Nada Naumović"
Kragujevac, Early Childhood
Intervention Team Kragujevac*

- National recognition and support of the Early Childhood Intervention (ECI) Model developed and piloted in Serbia significantly increased. It became a core professional practice to be supported through the National Early Childhood Development and Inclusion Centre, to be established by the Government in the following two years. The Centre is intended as a hub that will support the network of already available and new early childhood intervention services and professionals across Serbia and even countries in the Western Balkan region.
- Additionally, by-laws regulating the organization, staffing and services within the health system in relation to ECI are under revision, and under the leadership of MoH, new districts are engaged in capacity building for family-centred intersectoral ECI.

FUTURE CHALLENGES

In Serbia and across Europe the COVID-19 pandemic has disrupted health services and jeopardized families' access to ECI (UNICEF 2021). Restrictions to control the spread of the coronavirus have led to the closure of preschools and childcare centers, thus upsetting

opportunities for early learning. For ECI and similar inclusive programs, the increase in enrolment over recent years may have reversed, as community-based childcare have been forced to close due to the public health measures and financial constraints.

Future challenges might require re-converting existing resources and services eg. expanding the way of working with families and providing "distance" and community-based support, which for some can be a significant source of support even in non-pandemic conditions. Additionally, this creates potential opportunities for practitioners and families horizontal exchange through online platforms such as WhatsApp groups and Facebook groups. There are also opportunities of new importance for training professionals to work remotely if needed.

Mobilizing community assets (know-how, self-organization capacities and mutual support) will be important in years to come therefore making the principles of working with parents and families, integrating ability supporting and rehabilitation networks on the ground, and multi-disciplinary ECI even more important than before.

Strengthening implementation of by-laws and regulating organization, staffing and services that must focus on the provision of inclusive ECI is currently under revision under the leadership of MoH. Six new districts (in 9 municipalities) are presently engaged in capacity building for family centered inter-sectorial ECI, reaching total of 44% of district coverage (11 out of 25).

Legislative changes and expansion in less central geographic areas remain a challenge. Although the number of parents and children with developmental difficulties receiving standardized ECI support did not expand as expected due to COVID-19, it reached a total of 250 children (192 boys) with intensive and additional 968 with less intensive support.

Changing beliefs, attitudes, and practices of professionals at DCUs, pre-schools and social welfare services has proven key to move into transdisciplinary support for the families and consequently improve access and quality of services. Teamwork is also essential to advance social behavior change and facilitate better relationship with families and children.

ADDITIONAL RESOURCES AND USEFUL LINKS

UNICEF Serbia, 'Situational Analysis of Services for Babies and Young Children with Disabilities in Serbia: Development of services for early childhood interventions – Opportunities and challenges', United Nations Children's Fund, 19 February 2020. www.unicef.org/serbia/en/situational-analysis-services-babies-and-young-children-disabilities-serbia

National Organization of Persons with Disabilities of Serbia, Situation Analysis: Position of children with disabilities in the Republic of Serbia, NOOIS, Belgrade, February 2018. <https://www.unicef.org/serbia/media/156/file/Situation%20Analysis>

Together on the right track (2020) <https://www.unicef.org/serbia/en/stories/together-right-track>

Roditelji mogu pomoci jedni drugima (2020) <https://www.youtube.com/watch?v=ThAZRtag0wk>

Rana intervencija (2020) <https://www.youtube.com/watch?v=9wjjOc4Z75E>

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