Breakout session 2 – The role of education sector to ensure realization of the rights of children with disability

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As an introduction to the discussion, Ms. Katya Dunajeva will give an overview of what inclusive education systems need to take into account: what mechanisms need to be in place, what to consider in the reform of existing systems, the role of various stakeholders, and the importance of national, regional and local level planning and collaboration to meet all needs.

**[Introduction of myself as needed]**

First, I would like to express my gratitude that I can be present at such an important meeting like this one. I appreciate this possibility to learn from my colleagues and share my own thoughts during this forum.

I was given the opportunity to talk about what education systems need to take into account, how to reform existing systems, what mechanisms to put in place, and how to collaborate in the most efficient way with stakeholders in order to ensure that not only all children have access to education, but that every child receives the best quality of education as well.

Let me begin with some real stories:

1) We are in Budapest, capital of Hungary, in an educational institution for young adults with disabilities. The teacher holds classes and activities for the group. The teacher directs a question at everyone. One of the young women is deaf in the classroom. Her peers, all with various types of physical and mental disabilities, laugh and wonder what sense it would make to ask any questions or even talk to a deaf person. The teacher responds: “she does speak, but differently. Look at her indeed responding to questions, she adequately nods, gesticulates and uses body language.” The class is silent; they are thinking about what was just said. In the meantime, the deaf woman nods and expresses her appreciation.

2) Now we are in a smaller town in Hungary, away from the capital. The population has been decreasing here, and the town soon will turn into a partially deserted village. The Roma population, however, is growing. The local school sends a Romani boy, Geza, to the nearby town, where he will be examined by “experts” in order to place him to a special school for children with disabilities. The car comes to pick him up and Geza is excited to ride along in the car. He is happy to see something outside of his usual slum, which is on the outskirts of the town. He lives with his many siblings in a small run-down house with both parents unemployed. I wait for him. He comes back after a couple of hours with the same
excitement. I ask him how it was. Geza was amazed: “there are colors, there are pencils, I drew, I wrote, it was clean and so interesting.” The accompanying teachers nod: “yes, his IQ is low; he is being placed to the special school for disabled.”

3) We leave Hungary and go to Romania now. In a beautiful Transylvanian town there is a middle class family with a 12-year old son, who was born with disability. He studies in 2nd grade, his peers are all 7 or 8 years old. The family is very concerned for their son. He does not like going to school because he is an outlier. It is better, however, to be in a school than on the street, where people stare at him. They either feel pity or simply disturbed by him. “Being in school is better than on the street among people, but best would be at home, away from everyone,” says the boy.

These stories underline the multi-faceted problem we are dealing with. What is “inclusion,” who are we including and where, what is “education,” what is “disability” or “special needs,” and who are the players in a process of re-designing the system to make it more inclusive? We do, however, know the end goal – that is the highest quality training for every child, in order to assure full membership in a society, while preserving their human dignity.

I suggest that it is necessary to look at “inclusiveness” as a comprehensive and holistic concept, and good quality education as a vital pillar to improvement of our local, national and global societies.

Geza’s story, the little Romani boy, is not unique, but rather common in Eastern Europe. The example of Roma represent a particular case of segregation in educational institutions, which underlines the importance of defining inclusivity in the most comprehensive way and the significance of promoting diversity in classrooms on all levels. Consider for example European Roma Rights Center’s report, which shows that in Macedonia over 46% of children in special schools and special classes are Roma, while they comprise only approximately 3% (census) – 10% (other estimates) of the population. Disproportionately large number of Romani children are being placed to special schools for students with disabilities in most other countries of that region also, while a UK-based NGO called “Equality” found that Romany children who were placed in Czech special schools have no problems following the mainstream curriculum when they attend regular schools in the UK. Roma children, thus, suffer from a stigma based on their race, while children with disabilities are stigmatized due to their special needs, and yet both end up in the same segregated school environment with lower quality education. Inclusive education, therefore, in this case would entail a comprehensive approach promoting diversity in classrooms, fighting discrimination based on any aspect of one’s appearance or physical/mental capability, and creating inclusive societies.
I would warn policy makers to take existing societal values and culture of acceptance—which is often lacking or rudimentary especially in the post-Socialist region—seriously and lay a strong foundation before implementing laws promoting integrated education. All too often in the name of integrating Romani children into mainstream schools, we see the same result: non-Roma parents withdraw their own children en masse, schools turn into majority Roma school and then must close down because it is now a segregated institution. The very children we are trying to protect are the victims in this process.

So what is an inclusive education system and what should we take into account when building those in Central Asia and in other regions? What can we learn from the good and bad outcomes and policies from various countries in the world?

I would like to discuss 7 points that I will argue are crucial to take into account when designing inclusive education systems.

1) **HOLISTIC** approach
As mentioned in my introduction, when reforming the education system we must make sure that we are encompassing all groups; even when policies are designed with one particular group as the focus, we need to embed those policies in the broader, holistic vision of inclusivity. Inclusion in terms of one’s race, limited physical or mental ability, or other aspects – we are striving to achieve **total inclusive systems** as we know that the categories are fluid and it is easy to put one into another category. As the Roma example showed, if racial segregation is not possible, the group can be labeled as mentally disabled.

2) **VISION** of the future
Inclusion in the sphere of education should also happen with a clear future outlook: having completed their schooling, how will a previously excluded group be able to realize their potential in the society? Will their voices be heard in the decision-making process? Will they be able to participate in the labor market? Will they be accepted by the larger society in which they live? Is there appropriate access to public spaces? And importantly, will they have the opportunity to utilize their education, become productive and valuable members of the society and join the labor market? We need to make sure that these policies are harmonized and **complementary**. Today, the situation of persons with disabilities is extremely weak on the labor market. In Hungary for example persons with intellectual disabilities are not represented at all.

3) **IMMEDIATE** changes with **LONG-TERM** vision
This is a central challenge: we have to keep in mind that in environments where institutionalization and segregation is still strongly favored, where the legacy of “defectology” still informs policies and decision-making, fast change might have serious unintended consequences. We thus should have a very clear picture of the immediate needs, which step-by-step will lead us to the desired goal. Omitting the steps can
backfire, as it often does. As one of the first steps, we ought to reconceptualize “disability” by stressing the value of every individual, the contribution and potential of people with limited abilities. One way to achieve this is making these groups more visible. Ignorance is frequently an even bigger enemy of inclusive education than prejudice. Many people simply have never had a meaningful conversation with anyone with special needs. Research on race, for example the one funded by OSF about Romani students in Croatia, written by Jake Bowers, powerfully proves that “the best antidote to racism is simply meaningful contact between individuals of different backgrounds.” This statement clearly applies to all differences. In Hungary, for example, persons living in residential care\(^1\), which is the majority of those living with disabilities, are in general placed in large institutions on the edge of towns, isolated from the local community. Although de-institutionalization strategy was adopted by the Government as of 21\(^{st}\) of July 2010, the time-frame of implementation is 30 years.

There are inspiring examples also. Consider, Hozleiter Fanny who was born with Muscular Dystrophy and was told she will not survive into her adulthood. She is 24 now. Fanny has an internet blog, Mosolyka, which in Hungarian means “little smile” in which she describes her every day experience for example asking random strangers to put in her pin code to ATMs as she can not reach the machine, her struggle with public transportation, her relationships with men and her job. “I am woman first and foremost, then I am disabled,” she says. For many regular Hungarians this Internet blog means a window into people like Fanny’s life.

People like Fanny and her peers world-wide put a human-face to the disability issue for the larger society. People with various special needs should not live isolated, but should make their stories heard, and we have a responsibility in assisting and enabling this process. Fanny did it in a very touching way.

Consider another example: The African Youth With Disabilities today successfully represents the rights of disabled persons in that region. Previously, they applied and received media training from OSF’s Youth Initiative to learn how to write press releases, how to represent themselves in the media, and how to create a sustainable and viable group structure that would be able to accumulate the voices of disabled people and channel them to local and regional political figures. Their collective voices assured participation and more visibility. Furthermore, it enabled better-focused policies as those could fulfill the communicated needs from the target group, in the educational sphere or any other, for that matter, in order to create more inclusive spaces and environments.

Only by meeting the immediate needs, in other words, by the very group of affected people can we later design long-lasting change. Inclusive education in a region that has limited or no culture of accepting diversity in its schooling system might be a goal that

\(^1\) According to the figures of the Central Statistics Office, in 2010 a total of 23,347 persons with disabilities lived in residential institutions and only 1819 in small group homes.
should be reached through careful small steps, to lay the foundation and assure that inclusive education is inclusive in practice, not only in name; that it is implemented and does not only remain on paper, and also that it is seen as the right to everyone, not an imposed top-down policy designed by parties that are not aware of the realities on the ground.

4) COOPERATION and COLLABORATION on all levels
Often in order to have effective top-down changes, the bottom-up initiatives must be strengthened and finally bridged with national and international players. NGOs and various international organizations can play a crucial role in laying the ground for meaningful and inclusive dialogue between national-level policy-makers and local ones.

A comprehensive understanding of inclusive policies assumes broad cooperation between various institutions, pedagogical, rehabilitational, psychological, pedagogical ones and so on.

For example, experts in the Open Society Foundation are often invited to advise national governments, while for example the Youth Initiative’s small grant to the Tunisian Organization for the Defense of the Rights of Disabled allowed the group to get seats at the table when the country was re-drafting its constitution. This, in turn, resulted in more sensitivity towards people living with special needs.

Involving immediate families of these children into the dialogue is also crucial, as they are frequently leading the conversation about inclusion; institutional structures, consequently, through which they can channel their concerns and needs are also necessary.

Including many voices should reveal the various viewpoints concerning inclusive education: the needs of the children, their parents, school, and local community. Only by recognizing and then removing the obstacles we will be on the road towards tolerance and acceptance in the society, which then will be mirrored in the classroom.

5) Laying the FOUNDATION for an inclusive education system
My story of a boy in Transylvania clearly shows that integration does not happen overnight. Mechanisms need to be put in place to assure the most painless and effective inclusion of diverse children in educational settings.

Educating future teachers is the first step. Often special education teachers/conductors are either educated in separate courses/departments or even universities, or such trainings are electives as future professional development to teachers. Conductive pedagogy, which is based on tolerance, acceptance, participation over segregation, and group-based work, should be part of any curriculum for future educators. Current teachers in Hungary, for
example, as a study by Szilvia Dimitrous shows, were not well informed about terminology that concerns the education of children with disability, and only 38% of the schools had appropriate equipment and possibility for rehabilitation and correction exercises. Furthermore, the same study found that most teachers surveyed were not willing to participate in further, supplementary education programs due to a) lack of time, b) no perceived need (no disabled children in the class) or c) closeness to pension. A general teacher today, thus, is professionally not prepared for inclusive education or inclusion of children with special needs. It is also important that courses about inclusive education are not limited to theoretical approaches, but contain practical knowledge as well.

The second step is to pay more attention to rural environments, where disabled children are often treated as an anomaly and even less likely to attend school than their urban counterparts. Small towns and villages have no or very limited infrastructure to assist people with special needs and even in terms of information they are much behind. Elimination of such misbalance should also be a priority.

On the level of discourse, we not only have to claim that it is the right to have equal access to education for all children, but we have to believe in it, and so work towards promoting a shared belief, where most if not all members of our societies agree with this vision. We should work towards tolerant and accepting environments in schools, where international and national laws all prescribe the importance of inclusive education and where these laws are enforced by prepared teachers in equipped classrooms in accessible schools.

As an academician, I believe that research also has a place in promoting inclusivity; empirical studies should not be limited to universities, but we ought to strive to make our findings applicable to public policy and make recommendations. Existing empirical research suggests that students without disabilities in regular classrooms show no academic disadvantage from inclusive practices and may in fact have an emotional/social advantage. Despite overwhelming research persuasively proving the benefits of inclusive education—which are evident in schools by improving academic, social and behavioral outcomes, and outside of schools by providing future benefits, such as access to better jobs, and consequently better income, reduced poverty, etc.—there is

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2 The study is called “Education of Children with Disabilities in integrative/inclusive settings in Hungary” and the author examined PE teachers.
5 See for example:
nevertheless a still wide-spread exclusionary discourse among the population which posits the right of disabled children against or in opposition to the right of non-labeled children. Would a child with special needs hold back the entire class? – this is a fear still much alive among parents.

Research should not only strive to bridge academia and policy, but also compare these findings, mainly compiled in Western more developed countries with less developed parts of the world. In short, we need more research in this field and we need to provide access to findings in order to promote knowledge and information of the society regarding this issue.

6) ENFORCING laws
According to the report prepared by the Hungarian Disability Caucus, it is not only important to include grassroots and local voices with institutional orientation, and then channel them to the public policy makers, but also ensure that the participation of the civil society is not bypassed but truly included. This can be done for example by defining Disability Councils as consultative organs to the governments.

Moreover, laws should define concrete enforceable measures in connection with the accessibility of information, monitoring or evaluation of the implementation of measures and compliance with the Convention.

Furthermore, not only enforcing, but harmonizing laws is important. Hungary continues to be my example; the Caucus reports: “The situation of the approximately 3000 children with profound and multiple disabilities living in Hungary, is [very] alarming. According to the laws on public education, these children must attend special schools, however special schools are not obliged to provide education for them. That is the reason why most of them do not attend schools at all, and it is frequent that the family is forced to admit them to institutions, in order to ensure their education.”

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7) DIVERSITY and INNOVATION

Mechanisms of including children should be innovative and in a world of fast information spreading globally, we should learn from success stories and try to adopt them to our own national contexts.

Let me share an example with you from The András Pető Institute of Conductive Education and Conductor Training College in Budapest. The institution introduced an innovative approach: “reverse integration” – they integrate non-labeled children among children with special needs. This method developed almost by default: children of the employees of the institution were conveniently placed in the classes during their mothers’ working hours. The positive results were soon obvious, and the practice continued. The curriculum in this integrated class is shared, children study and play together, develop and grow together. As a first step it was possible by selecting children with mild forms of disabilities. Teachers are not only highly trained, but also sensitive to the issue of diversity and disability. They—the teachers and the students—don’t see this condition as disability any more, but rather different forms of ability.

To summarize, I discussed seven pillars that I find as crucial in redesigning the educational system to make it more inclusive. These pillars were a holistic approach, vision of the future, immediate changes with long-term vision, cooperation and collaboration on all levels, laying the foundation for an inclusive education system, enforcing laws, and finally diversity and innovation.

We are embarking on a difficult journey, which involves reforming and redesigning exclusive educational systems into inclusive ones, where the two have distinct logics, assumptions, as well as underpinning political and social values. This will be a long journey indeed, but worth in the end.

My list, naturally, is not an all-encompassing one, but hopefully laid the foundation for the exciting talks that you are about to hear.

Now let me welcome the next two speakers who will share with us exciting examples from two countries: first an example of catalyst for change at pre-school level in Tajikistan and then we will hear the results and recommendations of a study conducted in Kyrgyzstan. Please welcome the speakers with me.

[short intro about presenters as needed]

Thank you!