Legal Capacity and Inclusive Education

As a part of our 5E's plan (Empower, Elect, Educate, Employ and End segregation), Inclusion Europe focuses on the link between this year’s topic, Education and the right to make decisions.

Before we start...

<table>
<thead>
<tr>
<th>The language we use when we talk about education</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mainstream schools</strong></td>
</tr>
<tr>
<td><strong>“Special” schools¹ or segregated schools</strong></td>
</tr>
<tr>
<td><strong>Inclusive education</strong></td>
</tr>
<tr>
<td><strong>Integration</strong></td>
</tr>
</tbody>
</table>

¹ https://www.youtube.com/watch?v=kNMJaXuFuWQ
Legal Capacity and access to Inclusive Education

The right to inclusive education is closely related to the acknowledgement of legal capacity, or the right to make your own decisions. Inclusive education and legal capacity are mutually dependent, and are key factors that can determine the overall future quality of life of persons with intellectual disabilities. Education can be seen as a tool, including for people with disabilities, in finding one’s place and participating to the community. Alongside their peers, children with intellectual disabilities grow into adults, learning how to make their own decisions and choices.

“...the act or process of imparting or acquiring general knowledge, developing the powers of reasoning and judgment, and generally of preparing oneself or others intellectually for mature life.”

Education is seen as the mean to prepare an individual for their mature life. People often think that intellectual gain can be measured by how well we manage to learn and understand new theories and concepts. While this is partly true, there are other valuable aspects of education. Long term benefits of a good

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quality education include improved health, higher productivity, increased family income, and a chance to live in dignity and make educated decisions about one’s life.³

Nowadays, we are aware that lessons learned in schools are not only limited to facts and specific skills, but also socio-emotional learning. Learning about our emotions and social norms – like how to cope with stress, make decisions, and stand up for yourself, by experiencing and solving problems together – are equally important, such as effects on their ability to communicate and make friends, advocate for themselves, develop self-confidence, as well as cope with everyday challenges. All of the above-mentioned skills belong to the set of life-skills that ensure social inclusion of persons with intellectual disabilities. As presented in the table, socio-emotional learning should be seen as equally important as all other aspects of learning. It is the role of the teacher to make sure that all students learn from one another, forming them into responsible and independent young adults.

<table>
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<tr>
<th>Social-emotional learning teaches...</th>
<th>Maintaining supportive relationships, making responsible decisions, dealing with emotions, solving problems more efficiently, assertive communication, developing empathy.</th>
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</thead>
<tbody>
<tr>
<td>How is socio-emotional learning taught...</td>
<td>Concepts (e.g. say no to drugs!) that are introduced by the teacher are actively practiced among students via discussions, partner work or individual writing. Concepts are reinforced in the classroom, and students</td>
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</tbody>
</table>

For this kind of learning to be successful, it is important that all students actively participate according to their abilities. The teachers are facilitators, and students are the ones who discover new skills and knowledge. The more diverse the group of students, with different backgrounds, skills and talents, the more mutual gain it offers. Thus, when children with intellectual disabilities are segregated or excluded from general education, they lack access to these significant parts of learning but children in the mainstream education also miss a lot from what children with intellectual disabilities can teach them.

If the goal of education is seen as forming young responsible adults, able to make important life decisions, exclusion from quality education clearly prevents persons with intellectual disability from getting closer to achieving this goal. Moreover, when compared with their peers in segregated schools, students with intellectual disabilities in inclusive settings are better able to learn and improve their academic skills and develop adaptive behaviours.4

Inclusive education should not only be seen as the legal right of persons with intellectual disabilities that needs to be honoured, but also as an opportunity for

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everyone to advance in all segments of life and acknowledge the role of persons with disabilities in the community. Being fully accepted in schools gives people with intellectual disabilities the best chance to grow into more independent, self-confident adults. Segregated schools are often chosen as a last resort solution. However, they cannot provide pupils with intellectual disabilities with the same opportunities to engage in social and academic life than their peers.

The process of including a child with intellectual disabilities in an inclusive classroom depends a lot on the teacher. For teachers, inclusion also means learning how to recognise and respect the different needs of children with intellectual disabilities. As for the other children, this is an opportunity to develop empathy and learn about diversity, understanding and respecting those who learn or function differently. The opportunity for children with intellectual disabilities to learn alongside their peers makes a significant positive difference in their development. It is this crucial component of education that is lacking in segregated schools.

Respecting every child’s right to education can be understood as a mean to empower every individual and recognise them as holders of rights and duties. Recognising the worth of a quality inclusive education for children with intellectual disabilities should be understood as the basic human right.

The importance of actively participating in the community and making personal decisions was highlighted by the president of the “Sumero” association, an organisation promoting deinstitutionalisation and inclusion in Bosnia:

“The discrimination present today is a legacy of earlier systems, where they (persons with intellectual disabilities) were excluded from the schools and communities. Citizens do not know how to
communicate with them, they fear the unknown. And this creates prejudices. What we are doing here is more like putting out the fire. The real problem starts with the exclusion of children with intellectual disabilities from the mainstream system, at the age when they are forming as a person. If there would be a successful inclusive education, it would prevent in the long term the exclusion and discrimination in the future. This is why the education system is important, to give them access, to include them. And for other children to learn how to communicate, so one day when all of them grow up, they will know each other. They will know how to communicate and love each other.

They do not need humanitarian help. They need support, engagement, understanding and access to local communities.”

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5 Haris, H. (2019, December 26). Život u lokalnoj zajednici - Podrška osobama sa intelektualnim teškoćama. (Video file) Available at: https://www.youtube.com/watch?v=uEMfRdxML2Q
Background information...

What is legal capacity?

When talking about legal capacity, it is important to highlight Article 12 of the Convention on the Rights of Persons with Disabilities, which defines and explains all important aspects of legal capacity.

Legal capacity is defined as “the capacity to hold a right and the capacity to act and exercise the right, including the legal capacity to sue, based on such rights”.6 The Convention makes it clear that everyone’s right to make decisions must be respected, regardless of their abilities (or disabilities).

The right to make decisions includes access to many other rights that are important in determining the level of one’s quality of life. Those rights include:

- The right to work
- The right to marry and to have parental rights
- The right of free movement
- The right to seek legal protection before courts
- The right to make decisions about spending money
- The right to choose what to do our free time7
- Protection from humiliating treatment, punishment, violence or abuse
- The right to participate in political and public life8

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From the perspective of most of the population without disabilities, these rights seem implied and understood as basic human rights. However, for many persons with intellectual disabilities, this is not the case.

“I am under comprehensive guardianship. [...] Because of this I cannot vote and we cannot get married either. I am not the only one with these problems, there are many of us. I cannot sign an employment contract; I cannot work so I have many such disadvantages.” ⁹

Legal capacity of people with intellectual disabilities is often limited or denied, and they can be put under several forms of guardianships or substituted decision-making schemes.¹⁰

“Unfortunately [the doctor] doesn’t discuss [my treatment] with me, but with my mother.” ¹¹

What both concepts have in common is that a person with an intellectual disability is not the one making decisions about his or her life, even though they differ in name and level of restriction in different countries. The initial intention and purpose of guardianship and substituted decision-making was to “protect” people with disabilities, making sure that a person with intellectual disabilities does not make a wrong choice, hurting themselves or others. However, what both concepts mean in practice is that a person with intellectual disabilities sometimes has little or no control over their lives. Often, they cannot choose

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⁹ Man with intellectual disabilities from Hungary, FRA report on legal capacity, 2013, p.45
¹⁰ See n (5), 9
¹¹ Man with intellectual disabilities, Romania, FRA report on legal capacity 2013, p.49
where and with whom they want to live, make decisions regarding their healthcare, or have any control over their money or property.

“My mother didn’t tell me about the treatment’s side effects. [...] Unfortunately, I felt them by myself. [T]he medicine I was taking, it made me feel intoxicated, dizzy.” 12

These arrangements are never the right choice despite the level of additional needs a person might have.

Inclusion Europe strongly advocates for supported decision-making, which we believe should be the norm.

Supported decision-making

Instead of making decisions for people with disabilities, supported decision-making focuses on supporting people with disabilities in making choices of their own. It offers support dependent on the specific needs of the individual, so every person can seek guidance when needed. There are several types of supported decision-making solutions:

| Supported decision-making agreements | These agreements mean that a person can choose a person they want, to support them in finding all the information they need to make informed decisions and communicate them to others. For this kind of agreement, there is no need for a judge to give permission. |

12 Man with intellectual disabilities, Romania, FRA report on legal capacity 2013, p.51
Co-decision making

If a person needs support with making decisions, he or she can choose a person that will be permitted by a judge to provide this support. Choosing who will support them and for how long is completely up to the person with intellectual disabilities, who have a final say on all matters.

Peer support

Exchanging knowledge, experience and emotional and social, or any kind of practical help, is in the centre of peer support. For this to be effective, it is important to treat everyone’s experiences as just as important.¹³

Independent advocates

They support a person in making legal decisions and their communication with local authorities or other organisations.

Advanced directives

This is a legal document where a person can write its choices for the future. When need be, this helps others in making good decisions for the person.¹⁴

All of the versions of supported decision-making mentioned above, are designed with one common goal: the person concerned has last say regarding its future.

When a person’s legal capacity is being denied...

Although, if according to the Convention on the Rights of Persons with Disabilities, every person with a disability should have the right to make her/his own decisions, it is often not allowed in reality.

¹³ Look at Inclusion Europe project TOPSIDE on peer support.
In many countries, if a person with an intellectual disability does not have an assigned person to make decisions for them, they are limited in exercising their rights. This means they need someone else to make all the relevant legal decisions for them.\(^{15}\)

These practices only further continue the discrimination and exclusion of persons with disabilities. Often, they lead to abuse, exploitation and institutionalisation of the persons with intellectual disabilities.

Because of this, the Convention also states that measures must be taken in form of safeguards rather than substituted decision-making. Safeguard measures are there to prevent potential abuse and exploitation, offering protection to a person with intellectual disability.\(^{16}\)

Substituted decision making and safeguards, rather than guardianship measures, allow people with intellectual disabilities to exercise their rights, improves their quality of life, without fear of exclusion. Freedom to make the smallest decisions, from the clothes we want to wear and the food we want to eat, to bigger life decisions, such as with whom and where we want to live, whether we want to get married and have a family, can have an impact how happy we are in life.

Everybody makes mistakes or needs help to make big decisions, the only thing that differs for persons with disabilities is the level of support they need. If everyone has a chance to learn in life, through attempts, successes and mistakes, why would this be any different for persons with intellectual disabilities?

The objective is inclusion of persons with intellectual disabilities in our communities as equals.


Background information...
What is Inclusive Education?

According to the Article 24 of Convention on the Rights of Persons with Disabilities, “persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live”.\textsuperscript{17}

This means that all the countries who ratified this Convention are trying to achieve a fully inclusive educational system.\textsuperscript{18}

Today, inclusion, as a model of education where children with disabilities are included in regular programs, aims at avoiding further segregation later on in life, with people living in residential institutions and working in sheltered workshops. If this sounds ideal, inclusive education far from being a reality.

Inclusive education is not envisioned only for some students, but for all students – children with complex support needs, with all types of disabilities, from migration background, from the Roma community etc. Inclusive education guarantees that every child is granted an all-inclusive membership in the classroom, including the access to the needed support and services that will help the child in its personal and educational growth.\textsuperscript{19}

Over the past years, there has been a lot of effort, at various levels and from many actors, to support the right of children with intellectual disabilities to an

\begin{footnotesize}
\begin{enumerate}
\item Inclusion Europe, Exploratory study on the inclusion of pupils with complex support needs in mainstream schools, \url{https://www.inclusion-europe.eu/wp-content/uploads/2018/08/IE_CSN_Education_Report_Final.pdf}
\end{enumerate}
\end{footnotesize}
inclusive education – from the United Nations, the Council of Europe, the European Union to national and regional governments as well as non-profit organisations, advocacy groups, and citizens themselves.20

However, across Europe, there are still not many practical examples of an education system that underwent a complete structural change to become truly inclusive and is functioning. One positive example is Italy, where, in 1977, mainstream schools opened their doors to all students. Classrooms are not overcrowded, including up to 1 or 2 students with disabilities, and a maximum of 20 students. Inclusion is supported with the addition of a support teacher dedicated to complex support needs for every class with students with disabilities.21 While this is a very positive example of inclusive education, generally, inclusion is still poorly implemented and not supported enough financially. Although many organisations, including Inclusion Europe, are actively promoting inclusion (and making progress!), persistently working on transforming policies into reality, there is still a long path to achieve a truly opened to all students education.22

Are teachers ready for inclusion?

The legal framework is the first step towards changing a segregated educational system. However, reforming schools is not a simple task, and to do so, it needs support from the school's staff, mainly the teachers.

20 See n (14), 15
One of the most used arguments against inclusion is that teachers and schools are not ready, and will have to sacrifice time with other students to accommodate a student with intellectual disability.

Reforms are never an easy process. However, this should not be seen as an obstacle, but rather as an opportunity for progress and growth. For inclusion to be effective it is not enough to simply place a child into the classroom, since doing so is merely an integration. For inclusion to exist, teachers need to actively include a student with intellectual disabilities, while providing support and accommodation based on student’s needs.

When a teacher has a negative attitude does not know how to handle diversity, the outcome of education will not be positive. The teacher’s role is irreplaceable, and it affects what students learn, including socio-emotional learning, with consequences on their development.

Teachers working in inclusive classes, often say they do not have enough knowledge to work with children with complex support needs.  

“We have worked extensively to achieve better inclusion, but it is not easy, and there are no extra resources reserved.”

Another concern is the attitude of teachers. Sometimes they do not have a positive attitude towards inclusion, or are even strongly against it. Sometimes,

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regular teachers who were not prepared for inclusion claim they are ‘scared’, ‘nervous’, ‘apprehensive’, ‘angry’, and ‘worried’.26

Teaching to students with intellectual disabilities requires skills, knowledge and attitudes to support them. Teachers who specialised in teaching to children with disabilities are often more confident about their skills and knowledge, since their training was very focused on the appropriate procedures in planning and performing classes for children with intellectual disabilities.

Yet, while admitting the fact that regular teachers often do not possess enough knowledge or skills to provide quality inclusive education, it does not mean that this knowledge or skills are not available. Today there are a lot of organised opportunities for learning, as well as the teachers interested to make the most of it. Those teachers that invest additional effort and time into reforming their way of teaching towards more supportive and inclusive practices are an indicator that this is very much possible.

The goal of inclusive education is...

Many countries are struggling to achieve structural change in the education system. Often it happens that these attempts lead to integration or schools where children with intellectual disabilities are not accepted.

For every person, a school is a place that offers not only education but an opportunity to grow among peers, within the local community.

To replace segregation and exclusion with understanding and acceptance, we need to start from the beginning: education. Lessons learned at school go beyond facts and specific skills. We learn how to make decisions, stand up for ourselves and how to deal with everyday challenges. These are the life skills needed to ensure social inclusion of persons with intellectual disabilities. Education is essentially a preparation for life, no one should be excluded of this preparation.

“We’re not just teaching Benjamin, we’re learning from him: learning about how kids with disabilities are really like all kids, learning about ourselves and our fears, learning about life, and learning that all kids can learn and that all kids belong together.”

Examples of Positive Practices

Uni 2 Beyond

Created by the Centre for Disability Studies in Sydney, Australia, "Uni 2 Beyond" is a great example. Young adults with intellectual disabilities went to the university for two years. In those two years, they attended classes and had the support of their peers as mentors and friends. They participated in the university clubs and social activities, creating new relationships.

During the two years, they did a paid internship, gaining a lot of practical experiences. After finishing the internship, support is still offered by the optional and individual career advice at the university. This program allows young adults with disabilities to further connect with their peers and become part of the community, improving their quality of life and raising their chances of finding employment.

This program started in 2012, with five participants, and in 2019 they were 43, confirming that inclusive education should continue at universities.

BLuE University Programme

Another positive example comes from Pädagogische Hochschule in Salzburg, Austria. As a part of the "Blue University Programme", students that are learning to become teachers in primary schools are also mentors of young
adults with intellectual disabilities. The mentor supports a person with intellectual disability for three or four courses in the semester. There is a mutual benefit for all participants. Students with intellectual disabilities receive a certificate when they finish the program, and this certificate is accepted by the employment agency. Students who are mentors receive extra credits. Students with intellectual disabilities also improve their social skills and make relationships. Their mentors get to know closely people with intellectual disabilities and learn how to communicate and learn with them.

“One School for All” – a model for creating inclusive school environments

“One School for All” was created in Sofia, Bulgaria, by the Association of Shared Learning. This organization wanted to help teachers to feel more prepared to work with children with disabilities. It offers support to school teams, so they can change the culture and practice of their schools. It evaluates some of the important success factors in schools, such as the way teachers work in the class or how good is the relationship between schools and parents.

This helps in deciding which practices they could change and improve. Conclusions and plans are written down in the action plan. After the plan is put in action, they evaluate the results and search for ways to implement it better in the future. The program also provides training for the teachers on the topic of inclusive education.
This model first started in 2014 with five schools included. In 2018 this number was twelve. From 2019, nine schools in Greece, Portugal, and Romania, are now also included and supported by Erasmus+.

**Cleves primary school**

*Cleves School* is an inclusive primary school in London, United Kingdom. It accepts children with learning difficulties as well as with complex support needs. Cleves school offers full access to all students, designing curriculums around their needs so it helps students to achieve their full potential. The attitude of the Cleves school is that every teacher is also a teacher for children with special needs. For every child with a disability, an individual educational plan is designed and reviewed every term.

Apart from adapting the curriculum to student's needs, the school offers after-school activities for children. A place where children can play games, join art, and craft activities that promote learning, and receive additional help with their homework. Coffee mornings are organised once per week, aiming at including parents in school life. Every week a different topic is chosen, and parents can discuss these topics with the school staff in a friendly and relaxed atmosphere. Family Centres are organised to offer any additional help that might be needed.

Pupil parliaments are created to promote students' leadership abilities, communication and development of organisation and debating skills. All children can vote and choose their leaders.
Testimonies

“Inclusion is truly a win-win. When my son started the school year, he was unsure of his abilities. Recently, he read his sight words in front of his class, loud and clear. This accomplishment is the result of increased self-confidence, pride in his work and that he feels included in his class. The more confident individuals with Down syndrome are, the more likely they will be to engage with their community and share their full potential.”

Jessica Crain, parent of a child with disabilities

“We love her to death and sometimes we hope other people can overlook her differences, her different abilities. And the kids (in the classroom) seem to. And that’s every parent’s dream, that their kid has friends, and thankfully she does”.

Stacey Vogel, parent of a child with disabilities

“Tana has taught me that everybody is different and that is a good thing. Others look at her and say: ‘Oh she has disabilities we shouldn’t be friends with her’, and then I look at them and say: ‘We all have disabilities and we all have abilities’.”

A student from an primary school inclusive classroom

“It was Jamie’s birthday and I told him that he could invite four people from his kindergarten class, and he came home with four names, one of them was Amy. He didn’t differentiate her to me, didn’t have any story about her and she couldn’t walk at that stage. He didn’t include that piece of information at all. I thought that was quite an amazing example of him demonstrating a level of tolerance and understanding of differences that he wouldn’t have gotten If he didn’t have that opportunity.”

Anita White, parent of a child in inclusive kindergarten group
“Working with children who have additional support needs is not something to be concerned about or worried about, they will bring opportunities for children to learn about respect, to learn about tolerance. Not in an abstract way but in a concrete way. They will see the difference their behaviour can make.”

Nicole Koy, director of C&K Peregian Springs Community Kindergarten

“I just love being able to be like a regular student coming to the uni (university), socializing with people, getting to know people. Learning things that I wouldn’t ordinary get to learn. Jessie is a great mentor. She is always there; she could always help me. Throughout the semester they (mentors) just become friends and they are like your friends for life. Which is really good, because it is hard for people with disability to find friends. They have really been understanding of me and just encouraging me to be part of the class and getting me involved in group discussion, not leaving me on the side-lines and that’s been like fantastic. Internship changed the way I felt about myself because it is actually possible for me to get a job.”

Tahli Hind, a student with intellectual disabilities at Uni2Beyond

“I always was excited for uni, even though I had no idea what to expect. Starting uni took some getting used to, but it has become the most fun learning experience so far. My favourite part of being a uni student is just being on campus and having the freedom to do what I want at uni. Getting lunch and hanging out with my friends in my classes.”

Abdul-Karim Bouchafaa, a student with intellectual disabilities at the Uni2Beyond

“Initiatives like uni2beyond are really important. Everyone can kind of benefit from each other’s help and benefit from just teaching each other soft skills and life lessons as well.”

Jessie Wang, mentor at uni2beyond
Previous publications

Fundamental Rights Agency (FRA) report on legal capacity.

Mental Health Europe (MHE) report on exclusion.

Inclusion Europe position paper on safeguards for legal capacity.

Inclusion Europe exploratory study on the inclusion of pupils with complex support needs in mainstream schools.

Inclusion Europe report on children’s rights for all.

Inclusion Europe briefing on the lack of education for children with intellectual disabilities made worse in the Coronavirus emergency.

Inclusion Europe paper on rights of children with disabilities in the international human rights framework and European union policy.

Inclusion Europe report on better education for all.