The European Association of Societies of Persons with Intellectual Disabilities and their Families



Exploratory study on the inclusion of pupils with complex support needs in mainstream schools

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1. Executive Summary

All European countries are challenged by the implementation of the United Nations Convention on the Rights of Persons with Disabilities. In a period dominated by austerity measures, migration, growing nationalism and demographic changes States find it often difficult to invest in so-called "minority issues", like people with disabilities. This also applies to the sector of education where the CRPD takes up the vision of pedagogues, teachers and parents to create schools where all children can learn and participate independent from their social status, racial or ethnic origin, or disability.

Inclusion Europe and its members take the promise of "inclusive education for all" seriously and state clearly that also children with complex support needs should have the possibility to go to mainstream schools in their neighbourhood. The inclusion of people with complex support needs is indeed a challenge and needs a very individualised approach to accommodate the needs of each single learner to ensure that real inclusion and not mere integration or participation are taking place.

In the present study, Inclusion Europe looked with the help of its members and some national experts at some of the core issues that would make mainstream schools accessible for pupils with complex support needs. While case studies showcase individualised solutions and support, we tried to get a more general picture about the policies and practices of school inclusion of children with complex support needs.

While those children in the past often have been declared as "ineducable" and thus were denied any kind of education or training, our study shows that family members, teachers and policy-makers agree in principle that all children have the right and should have the opportunity to receive education; even children with complex support needs, pupils in hospitals or teenagers in prison. This attitude is reflected in various international legislation and declarations. Unfortunately, this general attitude does not translate at all into an inclusive practice. Learners with complex support needs still often do not receive education at all and only extremely few of them can go to inclusive mainstream schools.

Although parents and their disabled family members need reliable support, teachers and school leaders in mainstream schools often lack resources that would make inclusive education attainable. This includes the availability of sufficient and qualified staff and teachers, financial resources that can be used in a flexible way, availability of support material and availability of extra physical space. Teachers need the competence and flexibility to accommodate individual solutions and adaptations of the curriculum.

The CRPD conveys to each child the right to inclusive education. Since education policies are a complicated mixture of federal, provincial and municipal responsibilities and competencies the access to this right is extremely inhomogeneous in Europe. One reason is that the right to choose between mainstream and special education seems to be deeply embedded in most school systems. Our study shows that as long as special schools exist, students with complex support needs are most likely to be admitted there. In addition, this group is most likely to be exempted from the right to education where this possibility exist. Transition between pre-school, primary, secondary and tertiary education is as well very limited and often poorly planned.

Even if the present situation of pupils with complex support needs may be disappointing, there are some promising trends for the future that may lead to the realisation of the vision of Article 24 CRPD in European countries. Based on a strong user participation in decisions about policies and resources and the innovative power of ambitious teachers and school leaders, we propose some conclusions and recommendations in chapter 12. While all actors should focus in discussions and

descriptions more on solutions rather than on problems, the main proposals for the different actors can be summarised as follows:

States

- All States should fully implement Article 24 of the CRPD, including its General Comment and the relevant Concluding Observations.
- States should cooperate with Civil Society to explain and promote the idea of inclusive education
 to teachers and school leaders and ensure adequate training and support. Also research must
 supported and promoted that proves that all children benefit from inclusive schools and that
 there is no downgrading for any child.
- States must invest more in inclusive education, both at the level of infrastructure as well as at the
 level of teacher training and additional staff resources at school level. They should close down
 special education for all groups of learners and invest these resources and expertise fully into
 the establishment of inclusive mainstream education for all. Phasing out special education
 should be done in a way which guarantees that no children are out of school.
- States should ensure that knowledge and methods of teaching with individualised curricula are available inside the mainstream school system and that regular teachers and supporters are trained and encouraged to use them.
- States and Civil Society should publicise inclusive schools and their work. States should develop and support possibilities for networking, Study Visits, training and multiple support among ambitious individuals including teachers, family members and school leaders.
- States, civil society and the CRPD Committee must closely monitor the situation of all children which are not enrolled in school to make sure that their right to education is not denied.
- States should financially support families of people with complex support needs to enable their children to attend mainstream schools without losing disability benefits or compensations.
- States should provide the necessary financing for specific support needed by pupils with complex support needs.

Education authorities

- School authorities should aim to enlarge the inclusive capacity of mainstream schools in general to ensure inclusive education also for children with complex support needs.
- School authorities should invest in staff time and an administrative flexibility in the use of staff
 resources in the course of one child's learning process. They also must ensure that technical
 aids are available and affordable when required.
- Education authorities should ensure that curricula become flexible enough for real individualisation and inclusion. This also means providing teachers with the support they need to concretely implement individual and flexible curricula in their classroom.
- School authorities and school leaders should recruit only teachers who have been trained in inclusive education and demand such training from the teacher training facilities.
- School authorities should implement clear rules to sanction the refusal by schools of pupils based on their level of disability deemed as not compliant with their schools.

Teachers

- Individualised and flexible curricula provide advantages for all learners. Teachers should implement diversity management in the classroom and understand that every child has an individual approach to learning.
- Teachers and supporters of children with complex support needs need to be experienced and highly qualified to have the ability and confidence to develop individualised curricula and teaching methods. It is also important that they are given the time and develop the attitude to consider different curricula and teaching methods for different children.

Family members and Civil Society

- Family members of children with complex support needs face a lot of difficulties. They need appropriate support to be able to advocate for more inclusive education.
- Family members and Civil Society should continue to promote the right and ability of really every child to learning and education.
- Families with children with complex support needs should be encouraged to advocate for the
 vision of an inclusive society as an ambition also for their child and inclusive education as a way
 to realise this vision.
- Families with and without children with disabilities should embrace inclusive education as their personal objective and highlight successful examples.
- National or regional disability organisations should develop change management plans with a clear identification of the different stakeholders in order to support inclusive education at school level.

2. Introduction

All European countries are challenged by the implementation of the United Nations Convention on the Rights of Persons with Disabilities. In a period dominated by austerity measures, migration, growing isolationism and demographic changes States find it often difficult to invest in so-called "minority issues", like people with disabilities. However, the CRPD shows the way to a really inclusive society where all citizens, regardless of gender, racial or ethnic origin, religion or belief, disability, age or sexual orientation, have equal chances to participate in and contribute to society.

This also applies to the sector of education where the CRPD takes up the vision of pedagogues, teachers and parents to create schools where all children can learn and participate independent from their social status, racial or ethnic origin, or disability. This challenges, of course, the orientation of learning success towards higher grades in academic subjects and sciences, as promoted by the PISA studies. Inclusive schools accommodate diversity in their classrooms and create individual curricula for all their learners.

Inclusion Europe and its members advocate towards "inclusive education for all" seriously and state clearly that also children with complex support needs should have the possibility to go to mainstream schools in their neighbourhood. The degree to which this policy determination is implemented in reality is also a good indicator for the inclusiveness of the whole educational system.

People with complex support needs

- have one or several impairments of functioning that require high levels of reliable support with most aspects of daily life;
- have support needs that challenge support and service systems, for example the need for constant 24 hour one-to-one support, or the need to support impairments in two different areas (e.g. deaf-blindness, intellectual disability combined with health problems, physical disability combined with intellectual disability);
- may have big difficulty in communicating with other people or may have no verbal communication at all;
- may show challenging behaviour, e.g. aggression or self-aggression;
- may have significant memory, planning, orientation or structural problems.

The inclusion of people with complex support needs is indeed a challenge and needs a very individualised approach to accommodate the needs of each single learner to ensure that real inclusion and not mere integration or participation are taking place. In Europe, we are not aware of

any single country or state that has managed to resolve this challenge for all its pupils. In most countries, inclusive education in general is badly implemented and under-financed, which makes it even more difficult to include learners with higher disabilities. In many cases, children with complex support needs are thus seen as too complicated to include, resulting in school exclusion, home schooling or special schools for them.

3. Methodology

In the present study, Inclusion Europe looked with the help of its members and some national experts at some of the core issues that would make mainstream schools accessible for pupils with complex support needs. While case studies showcase individualised solutions and support, we tried to get a more general picture about the policies and practices of school inclusion of children with complex support needs.

We conducted the first step of this study through answers to a structured questionnaire with key national experts, since we were not expecting to be able to find enough statistically relevant information. Since education policies and practices are often in the competency of administrative subdivisions of a country, some experts provided information only for parts of their country.

For this report, we have analysed detailed contributions from the following countries:

- Austria
- Belgium (Flanders)
- Finland
- France
- Germany
- Italy
- Lithuania
- Luxembourg
- Russian Federation (Moscow)
- Russian Federation (Republic of Buryatia)
- Portugal
- Spain
- The Netherlands



4. Attitudes towards education for people with complex support needs

The Study firstly tried to get some indications if the attitudes of the key stakeholders (family members, teachers, policy makers) are favourable towards education for children with complex support needs. The background to this question is that those children have often been declared as "ineducable" in the past and thus were denied any kind of education or training.

This thinking seems to have changed: the key stakeholders, family members, teachers and policy-makers agree in principle that all children have the right and should have the opportunity to receive education; even children with complex support needs, pupils in hospitals or teenagers in prison. This attitude corresponds with various international legislation and declarations. Unfortunately, this general attitude does not translate at all into an inclusive practice. As we will see in the further sections of this report, learners with complex support needs still often do not receive education at all and only extremely few of them can go to inclusive mainstream schools.

Parents and other family members need reliable support

The attitude of parents towards inclusive education seems to depend on the level of the disability. The higher and more complex the support need is, the more parents have concerns regarding inclusive education. Parents of children with complex support needs in most countries seem to have very little trust that mainstream schools can handle the specific challenge of educating their children, taking care and enable good relationships to their classmates and all other people in and around the school. Some parents have had terrible experiences with regular schools, for example because their children were not accepted or were bullied. They see special schools as a safe environment where their children can finally be themselves and that guarantees continuity. They may thus see inclusive education as a threat rather than an opportunity for their children.

In addition, parents know that special schools have generally much more resources available and they think that it will be easier for their children to get what they need. Mainstream teachers often have to deal with classrooms with more than 30 pupils. Parents clearly recognise that the extra assistance for pupils with complex support needs is often not sufficient.

This often leads to extra costs for the families who may have to pay extra for therapies and transports. In Spain, for example, transport to special schools is free as well as lunch and all the therapies. In inclusive mainstream schools parents are treated like all others and have to pay for transport, lunch and for therapies since they have to look for them outside school hours. Planners need to pay attention to the family resources and ensure that families do not have to bear any extra cost for putting their children in mainstream schools.

Italian families and their associations fought hard to abolish special schools and classes, to guarantee the right to an inclusive education for their children with disabilities. They recognise special schools as the primary source of marginalization, exclusion and social stigma. Today, parents continue to believe that inclusive education is essential for the lives of their children with disabilities and both for their acceptance by society and for the strengthening of their skills and competences.

Outside of Italy, there are only few best practice examples and parents have no role model or image that they can use for orientation. Some even fight with all means for the maintenance of special schools, as they feel being welcome there and appropriately treated and educated. They want to maintain special schools for their children, at least as backup, even when they have a general sympathy for the inclusive idea.

However, there are some positive changes in this area as well. Some parents begin to recognize the potential advantages of inclusive schools also for their children with complex support needs, like short travel to the school in their neighbourhood, continuation of already existing social relationships to neighbour children or siblings without disability, or a normal family environment. They increasingly are ready to take also mainstream schools for their children into account and fight for this right of their children, at schools, or even in court. Especially when the children are young, parents quite often do not want to have their children in special education and "fight" against the system. This is not an easy process but some NGOs support and advise them.

It is important to recognise that parents of children with complex support needs connect their fight for inclusive education also with a clear list of demands, e.g. small learning groups in classrooms, temporary time-out-rooms, well-educated teachers, assistance personal, accessible infrastructure and learning material, etc. that have to be guaranteed. This is a responsible attitude towards their children who really need this support to be provided in a reliable manner. As long as this is not guaranteed by the governments, they will not be ready at all to let special schools be closed.

Teachers and school leaders lack resources

Respondents report that especially teachers are skeptical due to the fact that they see all the challenges that come with inclusive education. They often feel left alone with their tasks, criticise the lack or poor quality of the training they received regarding pupils with disabilities, or the schools material conditions. It seems that the more challenging a child is for the education and support systems, the more unlikely it is that the education is provided in mainstream schools, often because the necessary resources are lacking. In some countries, the education law still allows segregation for these children so that segregated education environments persist especially for pupils with complex support needs.

However, there seem to be nowadays fewer entirely segregated special schools and more special learning groups for these children in regular schools. There has been a trend towards inclusion, but during the economic downturn it seems that inclusion has often been used as a way to save money and therefore some children with complex support needs have been directed to regular schools and learning groups without adequate supports. This has led to some parents of non-disabled children, teachers and also the media being less favourable towards inclusion.

In some countries, "it remains the most common opinion that children with complex support needs get 'the best opportunities for learning' in segregated special education (in Flanders: 'het buitengewoon onderwijs)". Also family members of children with complex support needs are often trying very hard to find a school where their children are accepted and facilitated in their talents and learning capacities. Because regular schools are all too often not welcoming to these children, parents are relieved to find that special schools do accept their children, and provide a safe environment for them.

Pupils with behaviour difficulties, or with 24 hours care requirements, seem to be more often forced to stay at home with their parents or in institutions. In Finland, some disabled children may still end up institutions (which the Finnish government has decided should not be a long-term home for any disabled persons after the year 2020) because their needs are seen by the education system to be so complex and their education so difficult to arrange that only the schools operating in connection with these institutions are able to manage teaching them. Spain also reports that "if the school is not close by the parents' home it gets tricky since parents quite often refuse to have their children in residential care during the working week". Home schooling seems to be a rather frequent solution found in these cases, but there are few reports about quality of this form of education.

Italy has probably the longest inclusive tradition in Europe, since already in 1977 it abolished special schools and special classes and established new important elements such as support teachers, socio-pedagogical services, etc. Despite the persistence of some difficulties - for example, inadequate training of the teaching staff, including support teachers, especially for high and complex support needs - overcrowding of classes, etc. - the right to inclusive education for people with disabilities in Italy is constitutionally protected.

5. Right and access to inclusive education

There seems to be a general consensus that every child is capable to learn and to develop its individual skills, independently from its grade of impairment. There seems to be also general legislation in Europe that no child can be excluded from education in school only because of a severe impairment. There are differences in how this is encoded in law: while for example in the Netherlands the duty to education is, but the right to education is not part of the legislation, in the Russian Federation all children have the right to education to the best of their abilities.

This is a positive development, as the case of the Netherlands exemplifies: "Up until 2003 (special) schools could lawfully refuse admission of a child with a 'developmental age' below 2 years. This meant that children who were assessed as having a low IQ, compared to the level of a child of 2 years, would not profit from education and were not admitted. Since 2003 legislation changed: every child with a disability should go to school and parents have the legal duty to send every child to a school. We received also several reports that the label of "ineducable" is not used any more.

In Germany, the Second World War and the inhuman acts of the Nazi-regime in the so called "euthanasia-program" left their traces. Students with intellectual disabilities have been seen as ineducable for a long time. Compulsory education for students with intellectual disabilities was first introduced in Germany in 1962. But for students with complex support needs, this right was not granted until 1978. In the same year, the first specific curriculum for this group of people was published.

Exemptions from the right to education

However, in almost all responding countries there seem to be possibilities for exemptions from these legal principles, if demanded so by the parents. In the case of children with complex support needs, we found that especially the possibilities to apply for an exemption because of chronically illnesses, need for permanent care, or aggressive behaviour are used. While these exemptions have to be formally applied for, parents usually get permission, also if they cannot find a (special) school that will accept their child or when they turn directly to a day-care center.

We have the following information about the extent of these exemptions:

- Austria reports in the absence of reliable statistics that there is "not a small number".
- The Netherlands reported about one recent example of an alderman in Rotterdam (ca. 600.000 population) who wondered in 2016 why around 400 500 children with complex support needs were not going to school. He set up a policy to have children transferred from day care centers to (special) schools, should parents want that. His attempt resulted in 8 -10 children going from day care centers to special schools.
- In Flanders (Belgium, ca. 6,4 Million population) about 500 children with complex support needs are "discharged" of the duty to education. In addition, there is the possibility of home education which applies to another 500 children. "We conclude that more than 1.000 children in Flanders are not attending schools because of complex support needs".
- In Lithuania, pupils with special needs made up 10 % of all pupils and 90,6% of them attended mainstream school. 0,8% attended special classes and 8,6% studied in special schools. It seems to be reasonable to assume that the last group comprises a high percentage of pupils with complex support needs.
- Only in Portugal there are no exceptions and all children have the right to schooling. Families do
 not decide about the school education, they only authorize it. There is no possibility of sending
 anyone outside the education system before the age of 18, without the joint authorization from

the family and the Ministry of Education, and only when the referral is alternative or complementary to the school course.

In addition, so-called "home schooling" for pupils with complex support needs seems to spread in several European countries without much supervision. Transport problems are often cited as reasons for this. A recent trend seems to be that children who are provided care in residential care centers are considered receiving 'home education' as well.

We also have reports (but no data) of children who are excluded from special schools or from care centers and stay at home without a clear status.

The legal implementation of inclusive education

The ratification of the UN Convention on the Rights of People with Disabilities had much impact on the right to inclusive education in many countries. For example, in Germany all federal states had to revise their law concerning the right of all students to be taught inclusively. The first federal states had already conceded this right earlier, e.g. Bremen had already changed the school law in 2009. In Baden-Württemberg the students and parents had to wait till 2015. Today, in all federal states parents and students have the right to choose whether they prefer special schools or inclusion.

"The Law on Education of the Russian Federation defines the concept of inclusive education. There were proceedings initiated by parents and won by them. Supervisory authorities fine heads of educational organizations, if they do not create special educational conditions for children." In the Netherlands, in contrast, the right to inclusive education is not part of the law. The project In1School advocates for the right to inclusive education and promotes strategic litigation to ensure that all children/parents can choose inclusive education. In a recent strategic litigation case, parents who wanted their son with Down Syndrome in a regular school, lost that case. An appeal is pending.

Other countries seem to be somewhere in between those two positions. Important in this discussion are two issues: the right to choose between special and mainstream education, and the concept of reasonable accommodation.

The right to choose between mainstream and special education seems to be deeply embedded in many countries, however, this choice may not be as free as it may seem. In Austria, for example, special schools had up to 2017 the additional task to give advice to parents for their choice mainstream vs. special school, and all the control over the special needs resources. Only from now there will be "pedagogical consulting centers" established independently from special schools. Also Flanders reports a shortage of the means for support in the mainstream school. More resources are made available for a pupil attending special education, compared to the resources made available if that same pupil was to attend mainstream school.

The Constitution of Finland stipulates that no one shall, without an acceptable reason, be treated differently from other persons on the grounds of health, disability or any other reason that concerns them. Parents do not normally get to choose whether their disabled child goes to a regular school or special school. The Basic Education Act gives the municipality the right to decide this. Even if the authorities normally hear the parents' views on this issue, their decision may differ from the view of the parents.

Some countries have established for every child the right to enroll in a general education school and to receive reasonable accommodations. However, in some countries the school then has to make an assessment of the reasonable accommodations and if the school considers that the accommodations are disproportional, they can refuse the student. As in other areas of life, the concept of "reasonable accommodation" will have to be defined though strategic litigation.

In Italy, some secondary schools have not accepted the enrollment of students with complex support needs, justifying that with the absence of adequate human resources: the Courts immediately opposed these decisions. There were also some rulings that consider exclusion from school trips as direct discrimination, while the lack of assistance for personal autonomy and communication or hours of didactic support for an adequate number of hours of lessons it is considered an indirect discrimination. Thus, despite a specific and extensive legislation in Italy, every year there are thousands of families who have to go to the Courts to see the rights of their children with disabilities guaranteed.

The effects are clear: pupils with complex support needs may be treated by law completely equally to other children, but in practice such children are rejected by mainstream schools. Their rejection increases with the level of their support needs, their age and the level of schooling. They have officially a "right" to choose but in practice no possibility to do so.

The effects are clear: pupils with complex support needs may be treated by law completely equally to other children, but in practice they are rejected by mainstream schools. The more they are rejected, the more severely they are impaired, the older they are, and the higher the kind of school is. They have officially a "right" to choose but in practice no possibility to do so.

6. Education policies are a complicated mixture

In most responding countries, education policies are a complicated mixture of federal, provincial and municipal responsibilities and competencies. This leads to the fact that we were able to identify some excellent practices of inclusive education in some localities, while general education policies do not seem to keep up with the CRPD obligations on inclusive education. In almost all countries, special schools do still exist and the governments take different policy roads towards the future of their school system.

The situation in different countries

Spain's political commitment to inclusive education was traditionally very high. A new Education Law came into force, but since there was much opposition to it, it was decided not to implement it further. At the end of 2016, a debate and network started to work out a new law, but due to other issues no further action was taken and no action plan is in place. We can observe lately that inclusive education has not been put as a priority on the political agenda.

In **Austria**, since the adoption of the UNCRPD in 2008, the commitment to inclusive education among education politicians has grown slowly. The government started to tolerate claims for inclusive education and now they have started "model regions for inclusive education" in three provinces. It has agreed to a "National action plan for the implementation of the UNCRPD" 2012 – 2020 for all areas including education, but with a lot of weaknesses and with a significant lack of precise definitions, milestones and clear and binding success indicators and deadlines. The teachers unions are in general very strict and aggressive opponents of any change in the education system. Pupils with complex support needs are represented by very active and "loud" parents to remain in special schools. There seems to be some support for a "two-track approach" with inclusive and special system in parallel, but without any additional costs.

The Government of **Flanders** took a very clear position on inclusive education, stating on 11 January 2017 that a system of segregated special needs schools should be held in place in long term. Surprisingly, they argued that this is in accord with the UN Convention on the Rights of People with Disabilities. The Government did make a political commitment for "more" inclusion in education. The baseline of this policy is: "inclusive education if possible, special education if needed". And in this policy, children with complex support needs are considered as being referred to special education "in their best interest".

Inclusion was one of the key principles on which the reform of the **Finnish** Basic Education Act in 2010 was based. However, in practice the municipalities responsible for basic education in Finland have not fully embraced this, still directing many disabled pupils with complex support needs to segregated special schools or classes. Also in some cases where these pupils have been placed in regular schools and classes, in the name of inclusion, the pupils have been left without necessary supports, which are a prerequisite for proper inclusion.

The Law on Education of the **Russian Federation** defines the concept of inclusive education and regions support inclusive education that is implemented in accordance with the existing regulatory and legal acts. Measures are take to replenish the deficit of support specialists through programs for professional retraining, methodological recommendations on psychological and pedagogical support for mainstream students with health limitations, teacher training in teaching and upbringing of disabled students in inclusive education. However, the general conditions for education, such as mainstream school funding, hamper the implementation of these efforts.

In **France**, inclusive education is enshrined in the Education Code (article L.111-1). However in the implementation, this objective is not achieved. An example of this lack of effectiveness is the profession of "Auxilliaire de Vie Scolaire (AVS)" (School Life Support Person). This profession is currently the main tool used for the implementation of inclusive education, however this profession does not have the required qualification to meet the needs of pupils with complex support needs.

In **Italy**, the right to education is enshrined in the Constitution and brought forward by numerous state norms and judgments of the Constitutional Court. Thus, Italy should be considered at first place in the international arena for its legislation on the topic, but the problems still remain with practices that do not respect the rules; inadequate training of both the curricular and support teachers as well as the other scholastic operators; or the bureaucratic and inefficient organization of services for the protection and support of students with disabilities. Even the recent school reform called "Buona Scuola" ("Good School") and its implementing decrees raise perplexity because they not resolve any of these critical points and because the few innovations must be implemented "on the basis of available financial resources" - while numerous judgments of the Constitutional Court guarantee the inviolability of the right to inclusive education of students with disabilities without any budget constraint.

Planning inclusive school provision

Planning for physical accessibility, especially in new school buildings, seems to be rather standard in the responding countries. Improving physical accessibility in existing buildings seems to be either driven by the concrete needs and requests, dependent on affordability, or be part of rather long-term plans: e.g. some schools in Vienna have deadlines until the year 2042.

Other supports and accommodations are dependent on the individual needs of actual pupils. Our colleagues from the Netherlands described a complex system with its limitations, but potentially also much freedom to find individualised support options:

The organization of support for children with complex needs in the Netherlands is often very difficult. There are multiple laws that all cater for specific parts of this support. What support a child would get, would depend on the type of school a child with a disability would go to.

Schools in the Netherlands are funded through a fixed budget per pupil per year. All primary schools receive around $4.500 \in$ per pupil per year. Special schools receive an additional budget per pupil per year of nearly $10.000 \in$ for a child with an intellectual disability and $21.000 \in$ for a child with complex support needs. This support can be used to meet the very individual support needs of a child.

A mainstream school that is willing to consider acceptance of a pupil with a disability will, however, not automatically get the additional funding a special school gets, but must apply for additional funding with the regional organization of schools. These regional organizations have large discretionary freedom to decide on granting this funding to a school and what the budget for support would be. Some give out (part of) what special schools get, some give nothing, but would refer the child to a special school.

If a child needs help in going to places, help with meals and dressing or assistance due to motor impairments etc., then additional support is to be provided by the municipality. Municipalities have large discretionary freedom to decide on the support a child will get. The municipality may refer a child to a special school where more support would be available and where the municipality would have to add less. If the care is medical (for instance to be provided by a health nurse), care insurance companies are to provide the support.

If a child is assessed as having complex support needs and to be in need of one to one support, then the child can get support based on the Long Term Care Act. This act may grant up to 55.000 € a year for support. This may take the form of a direct payment system which may be freely used to finance support in school. There are examples in the Netherlands of children with complex needs who are included in mainstream schools with finance from long term care budgets (especially the 'Together to school classes' in which groups children with complex support needs are in one class within mainstream schools.¹)

If a child needs adapted tools, chairs, computers, special transport etc., such support is to be provided by an autonomous administrative authority called the UWV, but only when the child visits a mainstream school.

The system to organize and finance support is complicated. Parents have to spend a lot of time to find out which organization (the school, the regional network of school, the municipality, care insurance company, etc.) is responsible for which part of the support. Different organizations point to each other, which sometimes even leads to the situation that parents themselves support their children in the classroom.

In all countries, the planning and implementation of individualised support is dependent on the personal commitment of an individual family member, teacher, professional or headmaster. Portugal and Italy have mainstreamed processes, where individual planning processes in terms of quantity, quality and intensity are implemented in practically all schools of the country.

Unfortunately, Luxembourg seems to be rather behind in its planning processes as reflected by the recommendations of the CRPD Committee:

- The Committee is concerned that education laws still allow for the segregation of students with disabilities and that segregated education environments persist, especially for students with intellectual disabilities.
- It is also concerned about the absence of legally defined procedure for the provision of reasonable accommodation and for assistant support staff in classrooms in public and private schools

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https://www.nsgk.nl/wat-doet-nsgk/projecten/samen-naar-school

- The misunderstanding of reasonable accommodation undermines the process of identifying the response to individual requirements in dialogue with the person concerned.
- Negative attitudes towards disability in education and low expectations of students with disabilities combined with the insufficient training of teachers and non-teaching personal on inclusive education limit the accessibility of education for students with disabilities.

Quality evaluation is often absent

We have not heard about any obligatory evaluation of the effectiveness and quality of support for children with disabilities and/or complex support needs, not on the level of schools or on the level of regional organizations of schools. Some schools use voluntarily tools like the "Index for Inclusion" of Tony Booth and others to evaluate their inclusiveness and support, but they are mainly used by schools who are anyhow already on the path to inclusion.

In Italy, the associations for the protection and promotion of persons with disabilities have specifically requested structural indicators and outcome to verify the effectiveness of the interventions on each specific pupil and on the class context, based on the preventive path of knowledge of the child and planning of interventions, and proposing a checklist in the National Observatory on the condition of persons with disabilities. Unfortunately, to date, the State has only planned to adopt structural indicators aimed to detect if schools have and implement systemic actions:

- a) level of inclusiveness of the three-year plan for school inclusion;
- b) realization of paths for personalisation, individualisation and differentiation of the processes of education, education and training, defined and activated by the school, based on the specific characteristics students
- c) level of involvement of the various actors subjects in the elaboration and implementation of the plan for inclusion;
- d) implementation of initiatives aimed to enhance the professional skills of school staff including specific training activities;
- e) use of shared tools and criteria for the evaluation of learning outcomes of pupils and students, students and students, also through the recognition of different modes of communication;
- f) degree of accessibility and usability of resources, equipment, facilities and spaces and, in particular, of adopted textbooks and management programs used by the school.

Special schools for special syndromes

The separation of children into specific "homogeneous" groups identified by the same kind of disability seems to be very usual in countries like Austria, Germany, Lithuania or the Netherlands which traditionally already had such very segregated school systems. In other countries, like Italy or Portugal, this is virtually unknown because they have an inclusive school system for all, whereas in some countries parents are just happy to find any school which would take their child.

In most of the states parents have the right to decide whether their child has to attend a special school or an inclusive one. Often school authorities then decide exactly to which school a pupil is assigned. Some studies, e.g. In Germany, have shown that personal characteristics of pupils (adaptability, autonomy, communication skills) are highly influential in attendance to a special school or an inclusive school.

The separation of children with complex support needs is accompanied by special curricula for these groups. Teachers defend this system because they want to maintain a competence center for specific pedagogic expertise, parents defend it because of the good infrastructure on-site. the

(assumed) advantages of peer contacts and less risk that their children get offended and exposed, and politicians and authorities defend it because of economic synergies.

In the Netherlands, research by Dr.s G de Graaf² published in 2010 shows that among parents of children with Down Syndrome the majority prefer mainstream schools for their children and thus 56% of all these children are admitted to a mainstream school. The parents who voluntarily chose special schools had several reasons to do so: Some parents said the classes in mainstream school were too big and that were afraid the teachers would not have enough time for their children. Some said their children were cognitively not able to go to a mainstream school, or they feared medical problems and lack of support, or they feared their child would be isolated and in danger of not being able to have friendships on an equal footing with children without disabilities.

In recent times, the approach to include pupils with complex needs within a mainstream school as a complete special class besides the other classes under the same roof seems to become more and more popular: In Austria a programme has started to establish new "campus schools", where different school types and different classes that co-exist on one campus. There are also inclusive classes, but on the other hand special classes to cater for specific impairments. It must be mentioned that these "special classes in mainstream schools" are by no means inclusive and continue the process of segregated education.

In some countries, like France, there still are special schools for children with complex support needs. As a result, there is a separation between children with complex support needs and other children. As special schools are not available in every neighbourhood, it also entails sometimes long daily transportation time or attending a boarding school. It also reinforces mainstream schools' view that beyond a certain level of disability, the child is no longer in their remit.

User participation in decisions about policies and resources

In some countries, pupils and parents have a relatively strong influence in the decisions at class, school, school board and ministry level. Together with the teacher representatives they often have elected representatives with participation rights in education laws. In inclusive schools, pupils with disabilities are only a minority and are very unlikely to be elected as representatives for their peer group. So they have to convince the majority to advocate also for them as a minority.

At individual level, parents can be invited to talk with the school about admission and about the individual education plan, including the decisions on the individual support that a child requires. However, parents have seldom the right to veto, the school decides.

Such structured dialogue seems to have positive results and can prevent parents to go to the press or create more social pressure in other ways, what often seems to happen if a country lacks a structural framework for participation in policy making processes by persons with a disability. The participation of family members, pupils and their organizations is also a requirement of the CRPD and the Committee regularly "regrets the absence of advisory councils" in its Concluding Observations for different countries.

Transition between pre-school, primary, secondary and tertiary education

Transitions between different parts of the school system are often difficult for all children and even more so for children with complex support needs. While a specific school level can make individual adaptations for all children within its remit, these accommodations may be lost when a child moves to

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² G. de Graaf: Gewoon of Speciaal 2010, ISBN 978-90-8161271-1-5.

a higher level of schooling. Consequently, we received reports that the transition process is the deciding moment when ensuring a future inclusive education for children with complex needs and a lot of attention needs to be paid during these moments.

All countries also reported that the inclusion of learners with complex support needs was easier and broader at the lower education levels, whereas only extremely few were able to participate in tertiary education.

7. Flexibility to accommodate individual solutions

The inclusion of people with complex support needs will need very individualised solutions for each learner. How flexible the mainstream school system can react to individualised needs is thus of utmost importance for the learning success of people with complex support needs. There are different areas where a flexible approach can be used. School should have a large discretionary freedom to decide on accommodations and adaptations of the curriculum, support material and financial and staff resources. However, the flexibility is often limited by the level of funding that is provided.

Adaptation of the curriculum

The adaptation of the curriculum to the abilities of the student seems to be easier, the more complex the support needs of a pupil become. Our Spanish respondent tried to explain this as follows: "Since it is not 'expected' that they 'reach the academic level of others' it opens up the possibility to speak about real personal learning outcomes". Also Austria reported that for pupils with complex support needs, real individualised curricula are allowed with a lot of flexibility (verbal instead of number marks, individual learning staff, methods and targets, etc.), also in inclusive schools.

In Portugal, curricular adaptations are carried out in three levels³:

- Adaptations at the level of the pedagogical project (school curriculum) that should focus mainly on school organization and support services, providing structural conditions that may occur at the classroom level and at the individual level.
- Adaptations related to the class curriculum, which mainly refer to the programming of activities developed for the classroom.
- Individualized adaptations of the curriculum, which focus on the teacher's performance in evaluating and attending to each student.

In Italy, it is possible to provide a different school program for the pupil with disabilities (Individualized Didactic Program). This decision must be made on the basis of a complete analysis of the personal plans, of the skills and of prognostic evaluations. Italian schools can offer a differentiated school program and an individual adaptation of the ordinary didactic program. This second option requires teachers and professionals being able to work at two levels (individual and class) and thus there are a lot of difficulties to convince teachers to implement it.

Curriculum adaptations are foreseen and possible to a certain degree in all education laws and regulations, both through differentiation in the general curriculum or by working with an individual curriculum. But this legal framework does not guarantee the direct application. We notice that some

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³ MEC / SEESP / SEP 919980

of the schools and teachers, especially in the secondary schools, are reported to be uncooperative in applying adaptations of the curriculum.

Availability of support material

Support material for pupils with complex support needs is often the product of creative and ambitious single teachers, which may be shared in the same school. Sometimes teachers even buy it individually. Beyond the school, handmade material itself is not shared. However, the description about it and how to make use of it is shared over printed and electronic media of school and education authorities. The same applies to documents like concepts, guidelines, work sheets, etc. that can be stored and distributed electronically. However, a systematic exchange does not happen, so the availability of appropriate support material relies on the engagement of individual teachers, especially in inclusive mainstream schools.

Children with disabilities in most countries have the right to get the interpretation and assistance services they need to participate in education free of charge. However, we see in many countries that other aids the pupil may need, for e.g. moving around the school building, are provided by the health care system. In practice there seem to be differences between municipalities in relation to how easy or difficult it is to get various aids.

Support devices are most often available only on demand in mainstream schools, with the possible exception of Italy where "schools must be equipped with equipment and aids, including technological ones, for the inclusive education of students with disabilities". However, in all countries there is a lot of room for improvement. In reality support devices are often available only either with private initiative and financing, or with a lot of improvisation and "good will" of single persons and authorities.

Medical support in schools often is financed by the health care system on an individual basis. Depending on the health system and insurances of the person, this can result in rather large differences between individuals in the availability of such support or devices. Dietary requirements are usually met quiet well but no other resources are available. Very few schools have a nurse.

The access to costlier support materials, such as wheelchairs or IT, depends on the financing possibilities of the different providers in different countries. Sometimes access to this type of material is very complicated and sometimes it remains in the possession of the school or service and not of the pupil. This means that if a child moves, it may lose the support material it needs and is accustomed to. Support materials should always be owned by the child and move with the child.

In Lithuania, according to one research only about 50% of the need for various devices was satisfied. There was no a single school that would be well provided with all kinds of material for teaching. Also in Germany special support devices are not standard in every school. According to the needs of an individual pupil schools have to apply for different aids and support from different sources (e.g. health insurance, integration support, municipal support).

Financial resources that can be used in a flexible way

Many highly individualised solutions for pupils with complex support needs can easier be realised if a certain flexibility in the use of financial resources would be possible at school level. In systems where mainstream schools do not have a financial autonomy, like in France, schools do not have financial resources that they can used in a flexible way. Often more centralised bodies, like the regional or national education administrations have resources that, to a certain extent, can be used in a flexible way to respond to pupils needs.

Respondents highlighted here three different aspects:

- 1) In some countries the financial resources are still controlled by the special school system. They often do not want to give up that control, restrict available resources and hinder flexibility.
- 2) Secondly, respondents reiterated the principle that "the money should go with the child" and not be focused to single schools or services. That would provide children with complex support needs with the financial means to use different education options without endangering their support.
- 3) Finally, financial resources are in most cases only obtainable for very specific demands, focused on one specific child. This financing is not very flexible and encourages measures from which only the child with complex support needs benefits and not so much measures that support inclusive community activities or inclusive classroom settings.

Staff resources that can be used in a flexible way

The necessary qualifications of teaching staff are set forth in professional teacher standards and often require refresher courses or the need for additional qualifications. Specialists and existing teacher qualifications are, however, often not sufficient. In addition, teachers are often afraid to lose their job and stability and do not want to move from one school to another as flexible supports. That limits the possibilities for change.

The availability of flexible staff resources depends also clearly on the type of school organisation that has been chosen. In Belgium, special education schools have become a kind of resource centers which employ the additional staff needed by the mainstream schools. For children with complex support needs this was mostly insufficient. For some children, in addition to the staff resources from the special education school, a personal assistant provides more support. But this is on the basis of a personal budget from the department of welfare and there is a long waiting list to obtain this. From September 2017, new measures aim to provide every child with the support it needs. The former system will be replaced by "support-teams" providing support in a flexible way. There are strong doubts that this will provide all the necessary support for children with complex support needs.

In Germany, the teacher of a mainstream school gets support by a special education teacher who cares in particular for the student with complex support needs. In their lesson planning they need to come to an arrangement so that both the students with and without disabilities can receive the best possible support. There are specific regulations on how many "man-hours" per student with complex disability are provided. These specifications can hardly be adapted if there is the need of further staff support.

In Austria, since very recently, school principals have the right to hire teachers on their own, for their specific school needs. Special teachers remain under control of the school boards, as well as personal assistants. But within the granted number of weekly working hours the school can use the staff according to the individual demand.

Availability of extra physical space (e.g. for therapies or quiet rooms)

In some countries, pupils with complex support needs are rejected from mainstream schools because it is argued that the physical extra space is not available, especially in old schools which may be even 50 to 100 years old. In other countries, this argument would not be acceptable at all. Some ambitious mainstream schools find creative solutions without extra money. New buildings should take into account that pupils with (and without) disability need extra rooms for dynamic learning groups, for community activities or as place for therapies or quiet rooms.

8. Sufficient and qualified staff and teachers

Teachers and school leaders in mainstream schools in most countries complain about the large number of pupils in their classrooms. They also complain about the lack of sufficient support for children with special needs in the classrooms. There is often some support available, but it is not sufficient, which does not help to stimulate the enthusiasm of teachers and school leaders for the idea of inclusion of children with complex support needs in the regular school system.

In Lithuania there is a general problem with the shortage of teachers: while there were 1.151 mainstream schools in Lithuania in 2016-2017, catering for 331.000 pupils (among them 3.960 with special needs), there were 1.398 teacher's vacancies. This means that mainstream schools have difficulties not only to recruit assistants of teachers, but also teachers themselves.

Additional support teachers

Although in many countries there is a legal provision for support teachers in a classroom, their provision is often not judged to be adequate. Although e.g. Italian law provides for the right to a support teacher, 8.5% of the families of pupils with disabilities in primary school and 6.8% in secondary school have appealed to the judicial authority to obtain the legal support hours. The request to increase the hours of support is often induced because the mainstream teachers are unprepared to face the needs of pupils with complex support needs.

While more support may be available within special schools also that would not be sufficient to provide a child with one to one support for the whole day. However, while special schools often have direct access to the support teachers, mainstream schools often need to get external staff that can be deployed flexibly. The problem is that many of the specialist teachers seem to refuse to work in this way. They often prefer to stay based in a special school and do not want to be available "for one hour". Benefits for them are obviously not sufficient to change that attitude.

In the Russian Federation, as in many other countries, salaries for tutors, assistants, psychologists, physical therapists, etc., seem to be rather problematic. The salary of a teacher who individually works with students with complex support needs currently is most often lower than that of other teachers, which is inadequate.

Teacher training

There seem to be huge differences in this area between different European countries. Austria and the Russian Federation systematically provide a wide range of further training, refresher courses, retraining, graduate courses, conferences, seminars, and round tables in all regions. At these events, participants exchange experience, discuss topical issues, emphasize problems, etc. Besides, teachers can visit events organised by disability organisations. Participation, however, depends on personal interest and permission from the superiors. Germany remarked that due to the small number of pupils with complex support needs in regular schools these trainings are not demanded as much as other specific workshops, e.g. on challenging behavior.

In other countries there is no specific training and advice on inclusive education for children with complex support needs apart from that offered by regional school organisations or school resource centers. But that too often concentrates mainly on support for individual pupils and not on the further qualification of teachers, school staff and principals.

France provides local "resource departments" which can respond to the demands of teachers and schools. They include specialized teachers, psychologists, educational advisers, networks for the support of pupils with special needs, etc. Unfortunately, these resources are not enough developed to support pupils with complex support needs.

In Italy, disability organisations fought to have all teachers following training courses dedicated to inclusive techniques, as well as providing more stringent university training paths and specific roles for support teachers. The requirements of the trainers and the quality standards of the training dedicated to the teaching class are neither defined nor monitored.

9. Post-school options and transition processes

Participation in working life has a high priority in our society as it fulfills various functions:

- quaranteeing material livelihood
- assigning social status by belonging to a specific profession
- enhancing self-esteem and identity development
- forming and maintaining social relationships
- structuring everyday life by dividing it into leisure and work time

Therefore, it is important that adults with disabilities get the opportunity to receive a work-oriented daily structure as well and benefit from the aforementioned advantages. Aspect (4) and (5) should particularly be considered in working contexts with people with complex support needs.

However, there seem to be no real national policies for the transition from school to a life after school for pupils with complex support needs. Children with disabilities who are enrolled in special schools have mostly only two prospects, either sheltered work or day-care activities. Their educational aim will be to prepare them for either one of these prospects. The transition is then usually very smooth since children and parents are well prepared. If children are in an inclusive school setting, it may get more difficult and they may have little support in their transition process. Some schools provide specifically vocational training for pupils with complex support needs, focused on basic skills like endurance, communication or reliability.

A tailored role and fulfilling tasks in a sheltered workshop can be valuable and have dignity when an appropriate workplace in the free labour market cannot be found. But often sheltered workshops just fail in creating and sustaining that tailored role and fulfilling tasks for people with complex support needs and thus the dangers of neglect, boredom and discrimination are rather high.

In Finland, there are not enough study options for disabled children with complex support needs to choose from. They are often the least favored applicants even to vocational special schools. They also regularly have difficulties in getting the support they need in order to be able to study in such school (e.g. assistance services). Finnish disability organisations fear that the reform of vocational studies that is being implemented and that involves cutting rather heavily the costs of those studies will make it even more difficult for applicants with complex support needs to get accepted into vocational schools and institutes.

France points out that most of the time, pupils with complex support needs do not finish their education in mainstream education. At each stage of education, they are less and less included in the mainstream schools. They either move to special schools, or stay at home without education if there is no availability of special schools. Special education may include vocational training, to later work in a sheltered workshop or in the open labour market. Services supporting transition from

education to work and employments for young persons with disabilities have been mostly initiated by NGOs, there is not much support from state policies.

10. Data on learners with complex support needs

While school systems and achievements are one of the best researched public services, people with complex support needs seem to be still "invisible citizens". They do not appear in any general statistics and studies of the responding countries. Estimates can only be derived indirectly from related statistics, e.g. about recipients of high levels of care allowance or from spending patterns of individual budgets. Present statistics show only the number of children in different types of schools and the number of children that do not attend any school on the grounds of a disability or chronic illness. These studies, however, do not offer detailed information about the specific needs of the children with complex support needs.

A recent publication from Germany⁴ combines the results of several studies based on different methodologies. They report about prevalences of complex support needs among pupils in the "support area intellectual development" (Förderschwerpunkt geistige Entwicklung) ranging between 15 and 30%⁵. The authors, however, point out that lack of reliable data and different methodologies impair the validity of results. This figure would suggest that an estimated less than 3 in every 1.000 of pupils in mainstream schools would have complex support needs, if they were equally mainstreamed.

Another competent source for reliable information are disability organisations or self-advocacy groups. However, in absence of statistical data, they have to focus on qualitative aspects and information, like gathered in this report.

11. Future developments

Even if the present situation of pupils with complex support needs may be disappointing, there are some promising trends for the future that may lead to the realisation of the vision of Article 24 CRPD in European countries.

In <u>Austria</u>, there is a tendency that special schools are opened for all pupils. Pupils with complex support needs remain in separate special classes, but they participate in common activities like lunch breaks or sport and music activities, and they share some selected common lessons together with pupils without disability. The same concept can be seen with the new built "campus schools" in Vienna, where pupils with complex support needs are transferred from special schools to special classes in this "inclusive" campus schools. Of course, this development perpetuates seggregated learning and can only be promising if it is understood as a short intermediate step and will be continued on the individual level within the same class room, more frequently and in all subjects.

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⁴ Bernasconi, T. (2017): Anteil und schulische Situation von Schülerinnen und Schülern mit schwerer und mehrfacher Behinderung an Förderschulen in NRW - Ergebnisse einer empirischen Untersuchung in den Förderschwerpunkten körperliche und motorische Entwicklung und geistige Entwicklung. In: VHN 86 (4), S. 309-324

I.e. among all children who receive support in the area intellectual development, 15% - 30% are classified as having complex support needs.

In <u>Finland</u>, there are a few promising examples towards inclusion of pupils with complex support needs. The government sees that also in view of the international treaties Finland has ratified the goal in the future must be common school for every pupil where possible. The matter of inclusion is also currently being discussed guite a lot in the society.

In <u>Flanders</u>, we notice a certain change, as well in the attitude as in the policy, indicating a growing awareness of the need for an education system based on equity and inclusion. The signing of the CRPD in 2009 was a turning point and made new legislation inevitable. The CRPD offers a framework for advocating for inclusive education. Unfortunately many stakeholders and also the government stick to a minimalistic interpretation of article 24.

However, there are possibilities for a litigious reaction to the discrimination experienced by children with complex support needs. We notice the first cases brought to court and are curious about the outcome. This is supported by the Inter-Federal Centre for Equal Opportunities (UNIA) that takes a clear role as an independent monitoring body.

Another encouraging fact is that in Flanders cases of good practice prove the merits of inclusive education for children with complex support needs. They have a positive impact in a wider school community and in society in general.

<u>France</u> is communicating its willingness to transform schools to make them inclusive, but so far concrete implementation has not yet started. In particular, there is no sufficient funding to meet the numerous challenges. The Action Plan on support for persons with multiple disabilities ("polyhandicap") published in December 2016 includes actions on access to education, including inclusive education. On the ground, some interesting experiences are conducted, and there are examples of cooperation agreements between the National Education system and special education (where special education acts as a resource for inclusion in mainstream schools).

<u>Italy</u> already has rules to ensure full compliance with the provisions of art. 24 of the UN Convention. Unfortunately, these rules in many cases are not or badly applied. The primary needs of students with disabilities are not in the focus and the center of the inclusive school system. The school system is focused on the interests, albeit legitimate, of teachers.

The recent re-establishment of the National Observatory on School Inclusion at the Ministry of Education of the University and Research and the publication of the Second Two-Year Action Program for the Promotion of the Rights and Integration of People with Disabilities" give hope that in the future we can fill the gaps in the system that do not allow Italy today to be able to affirm that it acts in the concrete respect of Art. 24 of the UN Convention.

In <u>Lithuania</u>, our respondents see "a light at the end of the tunnel" in the form of the implementation of Article 24 of the UN CRPD. It is under discussion that schools must create appropriate conditions for disabled children for schooling and that the state has to ensure proper financing to provide schools with all necessary material, technical equipment, teaching staff and support.

<u>Luxembourg</u> concludes that the present situation of pupils with complex support needs is disappointing. But at least there are actually a lot of discussions, there is an initiative for a public hearing on inclusion so that they trust in a better future.

In <u>the Netherlands</u>, the Ministry of Education sent the results of a research on the right to education to the Parliament. Currently, it is being discussed how this right could/should be implemented in Dutch legislation. There are also some schools in the Netherlands that experiment with inclusive education.

In the <u>Russian Federation</u>, respondents focus especially on the issue of pre-school education for children with complex needs. This direction is supported by the Concept of Early Aid Development in the Russian Federation. There are positive experiences with the Swedish Lekotek concept as a highly effective tool used in early childhood development. In the Republic of Buryatia it is planned to publish practical methodological recommendations for the establishment of lekoteks in pre-schools.

In 2016, to develop techniques of early intervention, the Republic of Buryatia approved the programme "Development and modernisation of early care service for families with children with health limitations and disabled children". The result of the programme should be professional competencies of specialists, strong work with the disabled child's family, further development of early care services and organization of transition from pre-school to school. So far, about 1,600 teachers passed vocational training courses, 20% of them are pre-school teachers. Pre-school teachers also receive refresher courses on inclusive education. Methodical recommendations on teaching and upbringing of children with severe multiple developmental disorders have been developed.

In <u>Spain</u>, a first big step forward has been done by recognizing people with complex support needs, presenting them to the public, and raising awareness that "all means all". The next step will be to raise awareness with parents and try to get some good examples, to show that inclusive education is also possible for pupils with complex support needs.

For all responding countries, we can probably agree on the evaluation of the researcher Serge Ebersold of the situation in France: he characterised the education of pupils with complex support needs as a "heroic patch-up job" by teachers, family members and all citizens who work for the full inclusion of people with complex support needs in mainstream schools.

12. Conclusions and recommendations

Pupils with complex support needs provide challenges and chances to any mainstream school system. While their numbers are small (perhaps 3 of 1.000 learners), they need flexible resources and support that are adapted individually to the needs of each person. From the results of our present study, we can conclude that while positive local examples exist, no school system in the responding countries has met the need for a systematic reform that would indeed allow all children to attend mainstream neighbourhood schools. In this chapter we will try to deduct the reasons for this and analyse the need for changes in policies and practices.

It is encouraging that in the past years, especially due to the discussions promoted by the implementation of the CRPD, the attitudes towards education of children with complex support needs have changed: Only very few people would today still maintain the traditional approach that those children are "ineducable" and thus should not receive any education at all. Legislation, family members and education professionals generally agree that also children with complex support needs should receive education. The discourse has shifted from the question "if" to the questions "what", "how" and "where" and the

Training of education professionals at all levels must always be based on the foundation that every human being can learn and that everyone has the human right to education.

CRPD with its General Comment on Article 24 provide some possible answers to these questions.

 $\frac{\text{https://www.la-croix.com/Famille/Education/Handicap-travail-enseignants-tient-bricolage-heroique-2016-01-29}{-1200736172}$

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⁶ Handicap, le travail des enseignants tient du « bricolage héroïque »:

However, we found a tendency in some countries in Europe to practically <u>circumvent the right to education</u> and thus deny children with complex support needs their right to a quality education. One example for this is the so-called "home schooling" which often is little controlled and places an additional burden on the families. <u>States, civil society and the CRPD Committee thus must closely monitor the situation of all children which are not enrolled in school</u> to make sure that their right to education is not denied.

The key to success: individualised curricula

Children with complex support needs challenge traditional views about the content of education and the composition of curricula. There seems to be a growing consensus in Europe, that more individualised and flexible curricula provide advantages for all learners. In many countries, the management of diversity in the classroom has started to enter teacher training courses and education laws allow for a growing flexibility of the curricula. Pedagogues understand that every child has an individual approach to learning and they are more and more able to implement this in their teachings.

Pedagogues understand that individualised and flexible curricula support the management of diversity in the classroom and the learning success of all children.

Unfortunately, in most schools and countries this flexibility and individualisation happens in practice only for the main core of school children. Children who are too different, e.g. because of their ethnic origin, socio-economic status, very high or very low learning ability, or a disability still do not find optimal learning conditions in Europe and are often sidelined and excluded. The promise of "mainstream education for all" is thus often meaningless for these children.

Children who are too different are still discriminated against because of their ethnic origin, socio-economic status, very high or very low learning ability, or a disability.

However, there are many examples how individualised curricula for children with complex support needs can look like. "Special" educationalists have in the past developed <u>unique</u> and <u>highly individualised approaches</u> that prove that indeed children with any kind of disability and support need can be

Individual curricula exist since a long time, but they are taught in special schools.

taught and can learn. In all responding countries most children with complex support needs thus receive at least some kind of education, however the quality and appropriateness varies vastly. We can conclude from the materials we received that in no European country the learning potential of these children is in any way fulfilled.

States should thus ensure that knowledge and methods of teaching with individualised curricula are available inside the mainstream school system and that regular teachers and supporters are trained and encouraged to use them.

How to teach children with complex support needs

The way of teaching children with complex support needs is characterised by high flexibility and high support. This brings about a number of requirements that need to be fulfilled in the classroom:

 Teachers and supporters of these children need to be experienced and highly qualified to have the ability and Inclusive education of children with complex support needs requires qualification, flexibility, extra staff resources and technical aids.

- confidence to develop individualised curricula and teaching methods. It is also important that they are given the time and develop the attitude to consider different curricula and teaching methods for different children.
- Children with complex support needs may require one-to-one teaching and support. It is
 essential for their learning success that this high level of support is available and reliable. This
 requires in many situations <u>additional investments by States and school authorities in staff time
 and an administrative flexibility</u> in the use of staff resources in the course of one child's learning
 process.
- Finally, they may need in addition to basic physical accessibility specific technical aids, devices or IT solutions and staff who knows how to use them in specific situations. It is important, however, that these aids do not create contact barriers with other children in themselves. It would be ideal if resource centers could offer schools to test various possibilities directly with the children concerned. States and school authorities must ensure that technical aids are available and affordable when required.

Special versus inclusive education

From the reports of the responding countries - with the possible exceptions of Italy and Portugal - we understand that these necessary conditions for learning are still more prevalent in special schools than they are in mainstream schools. The availability of high support in mainstream schools has mainly been realised only in some locations. In countries which have

Children with complex support needs in Europe are still to a large extent educated in special schools.

completely abandoned special schools, the availability of support in mainstream schools seems to be much better, but still far from ideal.

Parents who are concerned about reliable education and support for their children fully understand that special schools today have often more equipment and staff resources that they fear to lose in mainstream schools. Since they want the best support for their child, they often have no choice, but to send it to the special school system.

Parents understand that special schools as they are today usually offer more equipment and staff resources than mainstream schools.

It seems to be important that <u>families with children with complex support needs understand the vision of an inclusive society as an ambition also for their child and inclusive education as a way to realise this vision. It is thus important that they are part of a progressive parents movement that unites them in their struggle.</u>

From the responses to our questionnaire, we can conclude that inclusive education in Europe is poorly implemented in general. Especially in those countries which maintain two parallel systems (special and mainstream) there is much too little investment in inclusive education, both at the level of

Inclusive education is poorly implemented in Europe in general.

infrastructure as well as at the level of teacher training and additional staff resources at school level. This causes dissatisfaction and disruption:

- Teachers and school leaders feel that inclusive education has been dropped on them with much too little support, even though they in principle would support the idea of inclusion.
- Curricula and school administrations are still too rigid and not flexible enough for real individualisation and inclusion.
- Children with disabilities in mainstream schools suffer from lack of support.
- Families criticize the lack of resources and support in mainstream schools and try to secure a good and reliable education for their child. They may even become advocates against inclusive education.

• Families of non-disabled children fear a downgrading of the education for their children which may also make them oppose inclusive education.

It is thus clear that the poor implementation of inclusive education in general is one of the biggest factors determining the educational inclusion of children with complex support needs. <u>States and school authorities thus must enlarge the inclusive capacity of mainstream schools in general</u> to ensure inclusive education also for children with complex support needs.

That this is possible with a dedicated political leadership and that this does not depend on available financial resources show the examples of Portugal and Italy which have closed the special school systems completely in favour of inclusive education for all. States are thus called upon to close down special education for all groups of learners and to invest these resources and expertise fully into the establishment of inclusive mainstream education for all. In addition, the following measures would support this process:

- Civil Society and States should explain and promote the idea of inclusive education to teachers and school leaders and ensure adequate training and support.
- States and education authorities should ensure that curricula become flexible enough for real individualisation and inclusion.
- Family members of children with complex support needs face a lot of difficulties. They need appropriate support to be able to advocate actively for more inclusive education.
- Families with and without children with disabilities should embrace inclusive education as their personal objective and highlight successful examples.
- Research must be made available that proves that all children benefit from inclusive schools and that there is no downgrading for any child.
- Phasing out special education should be done in a way which guarantees that no children are out of school.

The basis for future work

A hopeful factor in this generally dark picture is, however, the fact that there are local inclusive schools in all responding countries which have successfully managed to introduce inclusive education also for children with complex support needs despite the generally unfavourable circumstances. While national or regional policy changes are often not sufficient,

Ambitious individuals have created inclusive schools for everybody, despite of the currently adverse conditions.

ambitious individuals including teachers, family members and school leaders have proven to be essential for the implementation of inclusion at local level. These developments have even led parents of children with complex support needs to relocate their house into the catchment areas of such inclusive schools.

Based on these good examples in all European countries, States and school practitioners should now address the implementation of inclusive education for all not only top-down, i.e. from the top policy levels to the school level, but also from the bottom up:

 States and Civil Society should publicise inclusive schools and their work, create and support networks between them and build possibilities for Study Visits. Ambitious teachers, family members and school leaders should be supported in their work through networks and exchange possibilities.

- School authorities and school leaders should recruit only teachers who have been trained in inclusive education and demand such training from the teacher training facilities.
- All actors should focus in discussions and descriptions more on solutions rather than on problems.
- States should develop and support possibilities for networking, training and multiple support among ambitious individuals including teachers, family members and school leaders.

National or regional disal identification of the different	bility organisations and stakeholders in c	should develop order to support	change managemer inclusive education	nt plans with a clear at school level.

13. Country-specific resources and reports

Several countries

- http://inclusion-international.org/better-education-for-all/
- http://www.includ-ed.eu/sites/default/files/documents/inclusive_education_disability.good_practices_from_around_europe.pdf
- Information on the website of the European Agency for special needs and inclusive education: https://www.european-agency.org/country-information
- The Academic Network of European Disability Experts (ANED). Theme: Education http://www.disability-europe.net/theme/education-training
- Synthesis report on inclusive education for young disabled people in Europe: trends, issues and challenges. A synthesis of evidence from ANED country reports and additional sources by Serge Ebersold with Marie José Schmitt and Mark Priestley - April 2011:
 - http://www.disability-europe.net/downloads/72-aned-2010-task-5-education-final-report-final-2-0

Austria

- Information on the website of the European Agency for special needs and inclusive education: https://www.european-agency.org/country-information/austria/national-overview/legal-system
- Key facts and figures about schools and adult education in Austria: https://www.bmb.gv.at/schulen/bw/ueberblick/statisticalguide_2016.pdf?61edtv
- National Education Report 2012: Https://www.bifie.at/system/files/dl/NBB_en_Band_3_web.pdf
- BIFIE-Report "Individuelle Förderung im System Schule Strategien für die Weiterentwicklung von Qualität in der Sonderpädagogik" (2007): http://www.cisonline.at/fileadmin/kategorien/Bifie-Report 2007 5.10.07.pdf
- Model Regions for Inclusive Education ("Modellregionen für Inklusive Bildung"): Obligatory
 Guideline of Ministry of Education for the Development of Model Regions for Inclusive Education
 ("Verbindliche Richtlinie des Bildungsministeriums zur Entwicklung von Inklusiven
 Modellregionen", 2015):
 - https://www.bmb.gv.at/schulen/bw/abs/rl_inklusive_modell_2015.pdf?61edru
- First Report on Model Regions for Inclusive Education (2017): https://www.bifie.at/system/files/dl/Inklusive Modellregionen final.pdf
- Case Studies on Model Regions for Inclusive Education (2017):
 https://www.bifie.at/system/files/dl/Fallstudien_Inklusive_Modellregionen_web.pdf
- Schüler mit schwerer und mehrfacher Behinderung im inklusiven Unterricht: Praxistipps für Lehrkräfte (Inklusiver Unterricht kompakt) by <u>Claudia Omonsky</u> (Autor) Ernst Reinhardt Verlag 2017

Belgium (Flanders)

- Departement Onderwijs & Vorming (2017). Meta-evaluatie M-decreet. Synthese van evaluatieve publicaties verschenen sinds de inwerkingtreding van het M-decreet in 2015. Brussel: Vlaamse Overheid.
- Verbruggen, M (2016). 'Zijn kinderen met een beperking beter af met het M-decreet?' Tijdschrift voor Jeugd en Kinderrechten (TJK), 17(2016)2: pp. 155-161
- Rapport Commissie Criteria vrijstelling leerplicht (2015).
 http://www.multiplus.be/informatiedocs/RapportCommissieCriteriaVrijstellingLeerplicht.pdf

Finland

- Several publications on inclusion and related subjects by Professor Timo Saloviita: https://www.iyu.fi/edupsy/fi/laitokset/okl/henkilosto/saloviita-timo/julkaisut-saloviita-timo
- Vaativa erityinen tuki esi- ja perusopetuksessa. Kehittämisryhmän loppuraportti (2017): http://julkaisut.valtioneuvosto.fi/handle/10024/80629
- Oppimisen ja hyvinvoinnin tuki: Selvitys kolmiportaisen tuen toimeenpanosta (2014): http://julkaisut.valtioneuvosto.fi/handle/10024/75235
- General infomation in English on support in basic education (by the Finnish National Agency for Education):
 http://www.oph.fi/english/education_system/support_for_pupils_and_students/support_in_basic_education
- General information in English on education in Finland (by the Finnish Ministry of Education and Culture): http://minedu.fi/en/general-education and http://minedu.fi/en/general-education and http://minedu.fi/en/brochures and http://minedu.fi/en/bro

France

There are statistics and studies on inclusive education of children with disabilities, but they do not identify pupils with complex support needs as a special category. These pupils can be found in several categories used (e.g. children with intellectual or cognitive disorders, children with multiple disabilities, etc.), preventing the use of consolidated data concerning children with complex support needs.

- Statistics on inclusive education from the statistical department of the National Education (DEPP) can be consulted in its general statistical report: DEPP, Repères et références statistiques, enseignement-formation-recherche (2017) (in particular section 1.6)
 http://cache.media.education.gouv.fr/file/2017/83/0/depp-rers-2017-maj-dec-2017 861830.pdf
- In 2013 the results of an applied research on persons with complex support needs have been published, containing some data on inclusion of children with complex support needs, mainly in preschools: CEDIAS, Recherche-action nationale. Les situations de handicap complexe, besoins, attentes et modes d'accompagnement (2013) http://www.firah.org/centre-ressources/upload/notices2/decembre2013/situationdehandicapcom-plexe.pdf
- In 2011 a report was submitted on education of children with disabilities by Senator Paul Blanc, which gives a general picture of education of children with disabilities in France (however some of the data is outdated). Paul Blanc, La scolarisation des enfants handicapés (2011) http://www.ladocumentationfrancaise.fr/var/storage/rapports-publics/114000307.pdf

Germany

- Theo Klauß: Die Schule aus der Perspektive der Eltern von Kindern und Jugendlichen mit schwerer und mehrfacher Behinderung. In: Klauß & Lamers (2003) (Hrsg.): Allen Kindern alles lehren... Grundlagen der Pädagogik für Menschen mit schwerer und mehrfacher Behinderung. S. 239 ff
- Monika Seifert: Schule und Elternhaus zwei verschiedene Wirklichkeiten. Erfahrungen von Eltern Schwerbehinderter Kinder. In: Klauß & Lamers (2003) (Hrsg.): Allen Kindern alles lehren... Grundlagen der Pädagogik für Menschen mit schwerer und mehrfacher Behinderung. S. 223 ff
- Bernasconi, T.; Böing, U. (2015): Pädagogik bei schwerer und mehrfacher Behinderung, Stuttgart: Kohlhammer.
- Elternumfrage Bertesmann Stiftung: IB_Studie_Elternbefragung_Inklusion_in_Deutschland <u>https://www.bertelsmann-stiftung.de/fileadmin/files/BSt/Publikationen/GrauePublikationen/IB_St</u> udie Elternbefragung Inklusion in Deutschland.pdf

- Vera Heyl & Stefanie Seifried "Inklusion? Da ist ja sowieso jeder dafür!?" Einstellungsforschung zu Inklusion. Studie_Inklusionseinstellung Eltern und Lehrer: https://www.beltz.de/fileadmin/beltz/leseproben/978-3-7799-2918-5.pdf
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Italy

- http://www.gruppocrc.net/
- Adoption of the second two-year action program for the promotion of the rights and integration of people with disabilities http://www.gazzettaufficiale.it/eli/id/2017/12/17A08310/SG

Lithuania

- The Council for the Affairs of the Disabled under the Government of the Republic of Lithuania http://www.ndt.lt/en/about-us/
- Shiauliu University SPECIALIOJO IR INKLIUZINIO UGDYMO INOVACIJOS (special and inclusive education innovations)
 http://www.su.lt/index.php?option=com_content&view=article&id=16784&Itemid=17915&lang=It
- LR MInistry on Education and science https://www.smm.lt/
- LR Ministry on Social security and labour http://socmin.lrv.lt
- Naujasis pedagogų reingimo modelis http://www.smm.lt/web/lt/pedagogu-rengimo-pertvarka
- Specialusis ugdymas(is), mokymosi ir švietimo pagalba http://www.smm.lt/web/lt/smm-svietimas/specialusis-ugdymasis-mokymosi-ir-svietimo-pagalba

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Portugal

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Spain

- http://inico.usal.es/publicaciones/pdf/Educacion-Inclusiva.pdf
- http://www.plenainclusionmadrid.org/wp-content/uploads/2015/08/ImpulsoEducacionInclusiva.p df
- http://www.sciencedirect.com/science/article/pii/S217197480870031X