



Persons with disabilities in France

**Alternative Periodic Report
to the
United Nations Committee on the Rights of persons with
disabilities**

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of France**

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ASSOCIAZIONE COMUNITÀ PAPA GIOVANNI XXIII (APG23)

The Associazione Comunità Papa Giovanni XXIII (APG23) is an International Catholic Association of the Faithful of Pontifical Right. Since 2006, APG23 is accredited with Special Consultative Status to the Economic and Social Council (ECOSOC). Founded in Italy in the early '60s by the Italian Catholic priest Fr. Oreste Benzi, the Association is located in 40 countries on five continents. The Association runs 500 hosting structures all over the world, the majority of which are family homes where orphaned children, mentally and physically disabled, and others marginalized persons find a substitutive family. Moreover, it runs emergency shelters, fostering families, houses of fraternity, cooperatives and day-care centres, therapeutic communities for drug users and centres for alcoholics.

APG23 carries out awareness campaigns, micro-credit programs, and it provides services for persons with disabilities, Roma and Sinti, homeless, prisoners, migrants, elderly, people infected and affected by HIV/AIDS, mothers in trouble and women forced into prostitution.

Furthermore, the Association has a nonviolent presence in war zones in order to guarantee the respect of human rights on both fronts, assist displaced populations, and carry out activities aimed to combat the trafficking of human beings and assist its victims.

The Associazione Comunità Papa Giovanni XXIII is committed to promoting the "society of Gratuitousness", a society based on the awareness that everything (earth, people, resources etc.) is a gift from God, founded on the values of being, sharing and relating, where the least, the disabled, the marginalized set the pace of the human family's march.

APG23 IN FRANCE

APG23 is present in France since 2010. It runs, at the moment, two Family Homes¹ that are welcoming structures in the Occitanie region, department 65 Hautes Pyrenees. In the last years, the Association has welcomed in its structures around 50 persons with disabilities for different reasons and for different length of time. We have tried to facilitate the inclusion of these persons in school, work and social life according to their age and type of disability.

¹ See our website: www.casafamiglia.apg23.org/en/125-APG23_Family_Home

APG23 has built networks with national and local agencies² in order to have a mutual collaboration, to face difficulties together and share solutions. Through these networks, we came in contact and helped more than 200 people with disabilities. APG23 is available to stand alongside with persons with disabilities and to be the voice of the voiceless.

The present report is also the result of direct interviews³ to parents of children affected by disabilities. The parents narrate the experience of their children in the school setting and their integration once the compulsory course of study is finished. However, the case studies cited in the report are not exhaustive. They are indicative of the patterns of violations of children's rights in France.

EXCECUTIVE SUMMERY

Disability in France is managed in such a way to respond effectively to the essential needs of the person with disabilities, attentive to medical and educational needs.

The report analyses the situation of children with disabilities at school. France has a not-integrated school system. The educational path of people with disabilities is, indeed, chosen by the typology of disability: if the disability impedes an efficient and quick learning, the child still has access to school but as part of special classes (ULIS), compromising his/her educational, and consequently working-path. Children are divided in different types of ULIS according to their disability following a medical logic (divided by pathology), instead of considering the learning needs or the compensation tools required. Actually, because of the high costs of maintenance, only one ULIS is present in school, which welcomes together and indistinctly all children with disabilities without a division by pathology or age. In this way, it is not possible for teachers to follow each child appropriately.

Moreover, the French school system has a strong focus on acquiring knowledge at the expense of socialization and personal development; students with disabilities do not always seem to be properly supported in the socialization with their schoolmates.

All children who cannot be placed in schools for their disability, are placed in IME (medical-educational institutions). IMEs present themselves as centres of excellence aimed at personal care in all its aspects, from health to education. However, the social requests are not

² Office Chrétien des personnes Handicapées, Association des Paralysés de France, AIGUE VIVE, Maison départemental des personnes handicapées, Difenseur des droits, Santuario Notre Dame de Lourdes, Centre d'Education Spécialisée pour Dysphasiques et Déficients Auditifs

³ Direct interviews involved 41 persons with disabilities, part of them are in Annex 1.

considered: people live in these structures without a contact with the world outside, with other people and children.

The second aspect analysed in this report is the inclusion of persons with disabilities at work. According to the France law, since 1987, companies with more than 20 employees are obliged to hire at least 6% of persons with disabilities. However, this obligation is not implemented because of the low level of qualification of persons with disabilities. Furthermore, more and more companies are choosing to take advantage of the possibility of subcontracting services, as hiring disabled staff requires a lot of bureaucracy and companies feel too much controlled. By subcontracting work to ESAT (Etablissement et Service d'Aide par le Travail) and EA (Enterprise Adaptée), disabled people, however, remain excluded from the able-bodied world and bound in a purely disabled system without the possibility of comparison and growth.

From this analysis emerges that France still lacks in the search for a system that is truly inclusive and attentive also to the needs of socialization of disabled people, that need a continuous comparison with able-bodied people for their educational and moral growth. The French government is required to undertake a different attitude, not only efficient towards persons with disabilities, but that manages to create an environment of true inclusion instead of the current segregation, as is evident from the testimonies and the perception of the population. Disabled people must be part of society, not bound in special classes or institutions dedicated to them. They must be able to live together with other people, to confront themselves also with today's society: even though this could lead to an apparent delay in the notional knowledge of able-bodied people, it actually translates into the acquisition of empathy and acceptance of the different. These skills are difficult to calculate according to efficiency's criteria, but are extremely useful to create an inclusive society.

RIGHT TO EDUCATION FOR CHILDREN WITH DISABILITIES (art.23)

The French Government, with the law n. 2005-102⁴, made enormous steps ahead towards a more inclusive school for people with disabilities. However, a condition of separation still exists in fact, bringing to consider France as a not-integrated school system.

The educational path of people with disabilities is, indeed, chosen by the typology of disability: in the case it does not interfere with the intellectual learning capacities, the child can have access to a normal class and complete his/her studies. On the other side, if the disability impedes an efficient and quick learning, the child has still access to school but as part of special classes (ULIS), compromising his/her educational -and consequently working-path.

ULIS (Local Units for Educational Inclusion)

Access to ULIS classes is for children with disabilities such as troubles DYS (dyslexics, dysphasia, dyscalculia, dyspraxias, dysorthographies, attention disorders), autism, anxiety.

According to the legislation⁵, ULIS are inclusive facilities which gradually include learners with disabilities in mainstream classes. Learners are encouraged to follow subject areas (e.g. physical education, mathematics, etc.) in their mainstream ‘reference class’ at their own pace and ability, allowing them to keep up with their peers’ learning rhythm. In truth, the ULIS are actually proper special classes inside ordinary schools, where children with disabilities follow all the subjects. Even though the assimilation in a traditional class should be guaranteed, it does not always happen. The decision of putting a child in a ULIS class comes from a culture that considers education as a system to acquire knowledge: those that are not able to keep the pace are inserted in these special classes with an educational path that fits better their intellectual capacities.

⁴ Law n° 2005-102 of 11th February 2005 “Pour l’égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées” (“For equal rights and opportunities, participation and citizenship for people with disabilities”)

⁵ Circular no. 2015-129, 21 August 2015 on Local units for education inclusion (ULIS), facilities for learners with disabilities’ schooling in primary and secondary education

The law establishes four types of ULIS⁶ where children are inserted according to their disability following a medical logic (divided by pathology), instead of considering the learning needs or the compensation tools required. It officially complies with an English classification of pathologies⁷.

A student with disabilities is associated in a school with the ULIS that is the closest to his specific needs. Actually, because of the high costs of maintenance, in schools are usually present only one ULIS that welcomes together and indistinctly all children with disabilities without a division by pathology or age. In this way, it is not possible for teachers to follow each boy at the same time and in an appropriate way trying to adapt the program to different ages and different disabilities. Therefore, the choice to include the child in an ULIS is not adequate for its purpose (encourage learning according to the child skills) because it is not possible to follow his educational path properly.

Due to the very strong focus of the French school system on acquiring knowledge at the expense of socialization and personal development, students with disabilities do not always seem to be supported in a good way in their socialization experiences, with a particular regard on the implications of their disability. Interaction's occasions of children from the ULIS with other children from the same school are limited only to common moments (recess, school parties, school trips), occasions that are not sufficient and that are not structured enough to place a child with disabilities in a group of children that are not familiar with their conditions. For some vulnerable pupils, integration into the ordinary environment can therefore constitute an ordeal, even a symbolic violence, exposing them to situations of failure or recurring obstacles. Despite students with disabilities are generally satisfied and feel good at school, they are less than the average of normal students. Children with disabilities are also more likely to feel moderately or little at ease at school.⁸

Over the years there has been an increase in the school integration of children with disabilities in ordinary school through ULIS, especially in college by 300% and in high school by 900%. Nevertheless, once a child is placed in an ULIS, it is exceedingly difficult

⁶ ULIS 1: students with issues related to mental and cognitive functions (language and speaking too); ULIS 2: auditory handicap, with/without related issues; ULIS 3: visual handicap, with/without related issues; ULIS 4: motoric handicap and pluri-handicap

⁷ FC: cognitive or intellectual function disorders; TSLA: specific language and learning disorders; TSA: autism spectrum disorders; TFM: motor function disorders (including dyspraxia); TFA: hearing disorders; TFV: visual disorders; TMA multiple associated disorders. <https://www.european-agency.org/country-information/france/systems-of-support-and-specialist-provision>

⁸ <https://www.cairn.info/revue-agora-debats-jeunesses-2016-4-page-79.htm>

for him to re-enter an ordinary class or to leave the ULIS path between the various school grades. Moreover, most of the time, his study path ends before his able-bodied peers: almost all children with disabilities from 3 to 5 years old are educated in a normal school; at the age of 12 they are 80%; at 15, just over 60%; and at 18, only 44%.⁹ Most of the children stop at college with the achievement of the DNB (National Diploma of Brévet); moreover, a study shows how students with cognitive/intellectual problems, which constitutes the largest casuistry, hardly reach this stage, also because of possible lack of ambition of the students themselves.¹⁰ Over the years there has always been a remarkably high school dropout from college to high school, although this percentage tends to decrease, setting for the school year 2018/2019 around 80%.¹¹

Finally, access to post-secondary school studies for children with disabilities is incredibly low: only 6% of young people with disabilities aged between 20 and 24 are graduates in higher education.¹²

Early school leaving also has a consequence on access to work: according to one study 7% of people of working age (15-64 years) are disabled, i.e. 2.8 million people; of these only 988,000 people are employed (35% of the total).¹³

IME (medical-educational institutions)

All children who cannot be placed in a school context because of their disability are placed in: IME¹⁴. In 2018, 104,519 children were enrolled in these medical care facilities, 76% of whom followed a schooling course for the 2018-2019 school period¹⁵. The majority of children placed in IMEs have serious disabilities not considered suitable for ordinary school education.

IMEs present themselves as centres of excellence aimed at personal care in all its aspects, from health to education. The costs are fully reimbursed by the health service, both in case of residency and semi-residency from morning to evening. The personnel present in a typical IME include the psychiatrist, the nurse, the rehabilitation doctor, the physiotherapist, the

⁹ https://www.lemonde.fr/societe/article/2016/02/12/handicap-a-l-ecole-peut-mieux-faire_4863978_3224.html

¹⁰ <https://www.versunecoleinclusive.fr/tag/dnb-reussite-des-eleves-ulis/>

¹¹ <http://scolaritepartenariat.chez-alice.fr/page30.htm>

¹² https://www.lemonde.fr/societe/article/2016/02/12/handicap-a-l-ecole-peut-mieux-faire_4863978_3224.html

¹³ <https://www.agefiph.fr/sites/default/files/medias/fichiers/2019-09/CHIFFRE-CLES-2018-AGEFIPH-WEB.pdf>

¹⁴ establishments for children with mental disabilities; establishments for children with multiple disabilities; establishments for conduct and behavioural disorders; establishments for children with motor disabilities; sensory education institutes (visual or hearing impairments).

¹⁵ <http://scolaritepartenariat.chez-alice.fr/page96.htm>

psychologist, the orthopaedist/logopaedics, the psychomotor, the social worker, the school educator, the team of educators, as well as the general services and the management.

In most IMEs there is a school unit, through a specialized teacher sent by the regional academy. The services offered concern the promotion of expression, communication, socialization, autonomy in the acts of daily life, the creation of individual paths, in addition to the diagnostic accompaniment, the hospitalizations of relief to lighten the families (e.g. during the holiday periods) .

Regarding the sociality offered to users of IMEs, there are rare cases in which a real inclusion in society is proposed, preferring to limit the exits of a whole group, divided by age or pathology, to some aggregating moments for the community such as the open-air market or a trip to the lake. In these moments, however, the young people welcomed into the IME do not have a real possibility of exchange with the people they meet as there is a tendency to keep the group closed and to limit interactions with society. In this way, the person with disabilities limits his/her interactions only with other people with disabilities or with specialized personnel, not being able to favour a social integration with able-bodied people in a normal social context that can also help him in his personal growth.

Questions:

- 1. How does the state intend to overcome this non-inclusive culture aimed only at the efficiency of the response towards the physical and educational needs of the person with disabilities?**
- 2. What measures does the state intend to take to limit early school leaving or encourage the achievement of diplomas (middle school diploma or BAC), which are currently indicators of a real flaw in the system of inclusion of the child with disabilities?**
- 3. How does the state plan to encourage greater interaction between children with disabilities in IME and peers in schools? In some schools, training by IME educators has been activated for teachers of ordinary schools, this has favoured mutual knowledge and gradual inclusion in ULIS classes of children welcomed in IMEs.**
- 4. How does the state intend to pass the ULIS classes by favouring a greater inclusive school that not only looks at the notional aspect of education, but also of an education that takes place in sociability and in the encounter of diversity?**

- 5. What measures does the state intend to take so that IME centres are not focused only on the medical development of children but also on their social development through interaction with society?**

WORK (art.27)

Working age persons with disabilities (from 15 to 64 years) are 2.8 million (7% of the total number working age people), among these only 988,000 are employed, that is 35%.¹⁶ Almost 20% of those able to work are unemployed, twice the average of working population (10%).¹⁷

TRAINING

As declared by the French Government in the report submitted to the Committee¹⁸, the low level of qualification of persons with disabilities seeking employment is the main obstacle to their preservation and access to the workplace: almost 80% of them have a qualification level lower or equal to the vocational training certificate. This lack of training is also the result of an inadequate education system, as explained in the previous chapter. Inadequate support for people in special classes, high school drop-out rate after DNB and a non-inclusive school system, do not encourage the growth of both knowledge and social skills that a person must have in order to enter the world of work.

Further problem is that children in special schools and ULIS are also people with behavioural problems, people with deafness, hyperactivity, dyslexia, mental weakness, problems in the affective sphere, and so on. These are not serious disabilities, and if they are adequately supported from the beginning, they should not create problems in job placement.

Over time, the French Government has tried to compensate for the lack of training through the work of the *cap-emploi* (agency set up to help people with disabilities to find a job). These bodies offer many training courses which, however, are unlikely to result in a work.

COMPANIES RECRUITMENT

Since 1987, companies with more than 20 employees have been obliged to hire at least 6% of people with disabilities. The 11 February 2005 law reaffirms this obligation and extends it to new categories of persons with disabilities: holders of the disability card and recipients of the disability allowance. This recruitment obligation is left out by companies that are divided

¹⁶ <https://www.agefiph.fr/sites/default/files/medias/fichiers/2019-09/CHIFFRE-CLES-2018-AGEFIPH-WEB.pdf>

¹⁷ https://www.unea.fr/espace-presse?field_publication_category%5B20%5D=20&field_publication_category%5B351%5D=351&form_build_id=form-CZ6Kf5Lh0DCQzV9118eV9Gz9yt1sOXQb1qVDBzH87DA&form_id=ecedi_list_filter_form

¹⁸ CRPD/C/FRA/1

into smaller enterprises, with less than 20 employees, in order not to be obliged to respect the recruitment obligation.

In addition, another system to avoid the people with disabilities recruitment is implemented by the subcontracting of certain services to employment assistance institutions and services (ESAT), adapted companies (EA) or home tasks distribution centres. This way may allow the company to meet the 50% limit on the obligation to hire people with disabilities. However, this partial exemption may not exceed 3% of the workforce of the establishment. In addition, there is a minimum purchase threshold that applies to employers, that for 4 years have not taken any positive action in favour of the employment of people with disabilities. If the company does not fulfil its employment obligation, or one of the alternatives, must pay an annual contribution to AGEFIPH (*Association de Gestion du Fonds pour l'Insertion Professionnelle des Personnes Handicapées*).¹⁹ According to an AGEFIPH data, in 2016 the companies tested with the obligation to hire disabled staff were 102,100: 34% fulfilled staff recruitment, 17% hired staff but also requested subcontracting to EAST or EA, 41% partially applied the law (with direct and / or indirect hiring) as they have had to pay the contribution to the state, and 8% did not take actions in favor of the labor inclusion of people with disabilities.²⁰

More and more companies are choosing to take advantage of the possibility of subcontracting services as the hiring of disabled staff requires a lot of bureaucracy and companies feel more controlled. By subletting work to ESAT and EA, people with disabilities, however, remain excluded from the able-bodied world and bound in a purely disabled system without the possibility of comparison and growth.

ESAT

People with disabilities who are not considered adequate to the world of ordinary work according to a visit by the handicap body (MDPH), are included in the Etablissement et Service d'Aide par le Travail (ESAT) which allow people with disabilities to access at work in a protected environment. People who access ESAT are at least 20 years old and have a working capacity of less than 1/3 of the earning or working capacity of a valid person or, a

¹⁹ <https://www.editions-tissot.fr/actualite/droit-du-travail/l-interview-du-mois-les-alternatives-a-l-obligation-d-emploi-de-handicapes>

²⁰ <https://www.agefiph.fr/sites/default/files/medias/fichiers/2019-09/CHIFFRE-CLES-2018-AGEFIPH-WEB.pdf>

person whose working capacity is greater than or equal to 1/3 of a person's ability valid, but which requires one or more medical, educational, social or psychological supports.

The ESAT are very often flanked by the *Foyers d'hébergement* structures aimed at welcoming people with disabilities. Users consequently find themselves living inside a large village where they have both hospitality and work, without however accessing the outside world, an example is the foyers of Lourdes.²¹

THE EA

The Enterprise Adaptée allows people with disabilities to pursue a paid professional activity in conditions tailored to their specific needs. Adapted companies employ at least 80% of employees with disabilities in their productive workforce. Adapted firms are part of the labor market. Their social mission is to employ people with disabilities who are in difficulty regarding access to work. The status of disabled workers employed by adapted businesses is that of full-fledged ordinary employees, thus strengthening their legitimacy as citizens in society. Their salary depends on the work they perform and their qualification, in accordance with the regulatory or conventional provisions applicable in their branch of activity. They therefore benefit, without discrimination, from the same rights and duties as any other employee. Their employment contract can be either temporary or permanent, as in the case of 86% of workers with disabilities in adapted businesses. They are even more likely to be hired with permanent contracts, since 21% of the adapted companies recruit their employees directly with permanent contracts, compared to 8% of the other companies. Two thirds of the French know these specific structures: 39% of the French say they know what it is and 27% have already heard of it, but believe they are not entirely sure what it is.²²

Questions:

- 6. What methods does the government intend to adopt to encourage the employment of people with disabilities by trying to evade the legislative obligation?**

²¹ <https://leruisselet.fr>

²² [https://www.unea.fr/espace-
presse?field_publication_category%5B20%5D=20&field_publication_category%5B351%5D=351&form_build_id=form-
CZ6Kf5Lh0DCQzV9118eV9Gz9yt1sOXQb1qVDBzH87DA&form_id=ecedi_list_filter_form](https://www.unea.fr/espace-presse?field_publication_category%5B20%5D=20&field_publication_category%5B351%5D=351&form_build_id=form-CZ6Kf5Lh0DCQzV9118eV9Gz9yt1sOXQb1qVDBzH87DA&form_id=ecedi_list_filter_form)

- 7. How does it intend to promote the integration of adults in institutions or large complexes that provide accommodation and work, without however encouraging contact with the outside world?**
- 8. How does the state plan to promote the knowledge of AE and the integration of people with disability?**

ANNEX 1

Some interviews to biological parents and/or fostering or adoptive parents of children with disabilities.

1st case: immigrant boy with psychological delay in the movements, difficulties in learning and behavioural disorders.

“He has repeated the first elementary class and it was immediately clear that he was in need of a support teacher. We made a request to the “Body for Disabilities” that obviously proposed a special class within an ordinary school called CLIS²³; to do this, the child would have had to change school; we had to fight, call many meetings and make appeals asking for a support teacher in class so that he would not have been included in a special class only formed by children with disabilities. Being a very intelligent child, he would have risked to become very soon a negative leader in the little class and not stimulated to improve in any way; they have supported us up to the fourth elementary class even if every year they continued to propose us to put the child in special classes”.

2nd case: immigrant girl with learning disability and emotional vulnerability

“In the previous State she attended school up the eighth grade; she worked a lot on herself, focusing on her ability to concentrate and on the choice of working hard. In France, we received the rejection of 4 schools and at the end the acceptance of a school that had no aid and no experience with people with disabilities. They had a lot of good will but this was not enough. Results: educational failure, regression, violence suffered, isolation. When she was forced by the situation to stay at home for a whole year without a reason to wake up in the morning she started to show such a restlessness that we were forced to accept the only proposal made by the Body for Disabilities, although we did not agree at all that an educational structure with 40 youths with mild cognitive delay and behavioural difficulties would have been a stimulating place for her to grow at a personal and formative level”.

“This structure although highly specialized and with a huge number of professionals has a very basic level aimed at keeping the youth calm; it is a structure with a high medicalization

²³ CLIS (Classes pour l'inclusion scolaire) was substituted by ULIS in 2015.

also for very simple things. For example: “I am a bit tired, - go and lie down in the infirmary” – the nurse, if you are bit stressed, will offer you some drops of drugs to stay calmer, drugs for the slightest pains, for every type of physical or psychological problem, drugs were immediately proposed as a solution. Regarding the school level, it was so basic that it has brought her to regress enormously compared to the knowledge already acquired; in the name of a tranquillity of the person, in the name of the lower possible level of stress and agitation, the work requested to her was absolutely inferior to her capacities. Moreover, the comparison with youths with similar or worst difficulties reassured her in achieving minimum goals that were surely inferior to her possibilities. Moreover, the attitude of the structure, that according to our knowledge is a widespread attitude in the public structures, is that of taking charge of the person completely excluding the family being convinced of having the solely responsibility for wellbeing of the person.

3rd case: immigrant girl with slight mental delay.

“We asked 4 different schools for her enrolment. They refused. At the end, a private school accepted to enrol her. It was immediately clear that without the mediations of someone her school attendance could not be productive; the other pupils were not at all used to have a relationship with a person in difficulty, they did not have the tools to understand how to relate to her; therefore, they were making fun of her. There have been also episodes of physical and verbal violence; the teachers too did not have the instruments to face or understand her difficulties.”

“The proposal from the Body for Disability crashed with the lack of effectively available places in the appointed structures. Therefore she at the age of 17 years has been forced to stay at home a full year without any possibility of inclusion. That’s why we choose to by-pass the French government and get the high school diploma for her in Italy thank to the good will of the Italian educational structure that has appointed her with a support teacher that was simplifying the subjects. Three times per year she was going to Italy to take exams and do practical exercises”

4th case: brothers and sisters with Down syndrome, and severe psychological delay in the movements.

“When our children were seven/eight years old, the coordinators of the schools openly declared that they could not deal with them anymore. The children were not even accepted in ULIS. The only alternative was an institute, in which they have been going for a while. For not suffering

in a passive manner, we candidate ourselves to become parent’s representatives and were selected. From this position, we tried to change things but without any results. In 2008, we took advantage of the law to organize a nice job around our children. We looked for people that could come and teach them how to read and write, to participate and express things in the social life; moreover, they have started different artistic and sporting activities; these activities are taking place in the city and in the middle of social life. From the moment they stopped school, they have been doing different activities at home which have been appositely adapted to them.”

5th case: Fragile X Syndrome

“Even if a specific law exists, there is a big gap between the law and the reality. The social inclusion depends rather on the good will of the people: educators, AVS (Auxiliaires de Vie Scolaire), even if it is not easy to find them. (...) There is, in fact, the tendency to leave the persons with disabilities among themselves, although I don’t know the reasons for this choice; and neither I know if there are dominant theoretical models of psychological nature”.

“They tend to point the attention on the medical needs of the child whit disability: it is for this reason that there are many specialized structures, but these structures segregate the persons with disabilities and therefore prevent people from asking themselves real questions on disability”

6th case: girl with Down syndrome

“Once I was in a hospital, I recognized a helper along the corridor and said to him: “Good day!” He looked at me and replied: “Ah yes! You are the mother of the little trisomic!” It hurt me a lot. It was a label. But this is madness! And especially for Down syndrome.

When reaching the school age, almost all the children with trisomy 21 are included in a ADAPEI that is an institute gathering different persons with disabilities, of different age, and where no one learns anything. They take them for a walk, that is it. Once, I have also heard the story of a child with trisomy 21, who was abandoned by the father and, in a short period of time, lost also the mother: this child was welcomed in a ADAPEI but they did not even

thought her how to read. Since we did not agree with this choice, I and my husband have decided to move in autonomy first by paying a private speech therapist and a physiotherapist, then calling all the schools in the territory to know if any of them would accept her. Many schools replied negatively thinking that it would have been detrimental to the child. Only one school accepted her for half day, because she did not have the AVS (Auxiliaire de Vie Scolaire) that was denied to us since we did not opt for the ADAPEI; after a year, she has been discharged because the school concluded that she was too behind in terms of learning capabilities in comparison with the other pupils.”

7th case: immigrant boy with Cornelia de Lange syndrome

“We introduced our son to the elementary school in our village/town and from the very beginning the director of the local corresponding diocesan structure was prone to the implementation of a reception project according to the 2005 well-known law , stating that it assured an undeniable right and that the school would do anything to guarantee it. This school did not and still does not have an ULIS class.

We started with the medical documentation needed to open the dossier and therefore submit the application to the MDPH. The application immediately created a rebound of jurisdiction between the school and the Provincial Offices for people with disabilities, as our son’s educational skills- who had attended 3 years of studies with educational support in Italy- were considered very low according to their skill standards. The determination of the director allowed a judicial hearing at the Province to present the project, that established with our agreement an alternated attendance at the IME and at school. He was granted the possibility to start and the full financial coverage, including about ten weekly hours of presence of an AVS assistant (Auxiliaire de vie scolaire). The school took some time for the admission, on the one hand to prepare the class and especially the parents (a previous case of a serious disability within the institute had caused strong resistance especially among adults), on the other hand to look for an AVS, which was quite difficult due to the seriousness of the case and because the academic year had already started and the staff was already defined. The first period was covered by the presence of the mother in the classroom.

At the end of the year, all the stakeholders were enthusiastic for the effective integration of the child in both environments, but above all for the opportunity to speak and reflect on diversity and live the experience of inclusion in an elementary school.

Nevertheless, this experience was concluded at the end of the elementary cycle, as everyone's opinion considered that the same organization for the collège would have not assured to him a positive and stimulating experience.”