

87th Pre-Sessional Working Group of the CRC LOIPR of France June 2020

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 CLIS¹; 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

¹ CLIS (Classes pour l'inclusion scolaire) was substituted by ULIS in 2015.

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 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 she 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 she 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 disabled child: 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 (Auxiliare 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."