

ANNEX 1

Some interviews to biological parents and/or fostering or adoptive parents

1st case: L.P. arrived in France when he was 6 years old. He has psychological delay in the movements, difficulties in learning and behavioral 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 CLIS; 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”.

“the support teachers are people with a contract “of aid” which means that they have been unemployed for some time and for this reason they are entitled to be proposed with few hours or few months contract with a minimum salary; therefore, they are not people prepared in any case to face the learning and behaviour difficulties, they have not done specific studies.”

2nd case: D.M. 58 years, affected with spastic quadriplegia; she came to France at the age of 52 years

“After the initial surprise for the fact that we were asking that she could continue to live in the family, they immediately gave to us all the financial aid to help her in her daily needs. It is very strange for the people around and for professionals, doctors, nurses, physiotherapists to know that she lives in a family and see that she comes with us everywhere: walks, trips, holidays, school performances, in a word the life of an ordinary family”

3rd case: J. C. has arrived in France when she was 16 years old. She is affected by learning disability and emotional vulnerability

“(....) Before coming to France she attended school up to the eighth grade; she worked a lot on herself, focusing on her ability to concentrate and on the choice of working hard. When we arrived 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 J. 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 (psychologists, social workers, psychiatrists, educators, nurses, speech therapists etc.) 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 J 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 J. was absolutely inferior to her capacities. Moreover, the comparison with youths with similar or worst difficulties reassured J. 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 sole responsibility for wellbeing of the person.

“ (...) They have proposed to J. to fill the documents to access the location “adult handicapé”. Once she obtained it, she refused the protected flat and went to live alone. She gets 807 euros of pension plus has to pay for a rent of 410 euros. The government gives her another contribution of 250 euros even is she has not tried to work a single day. J. is completely supported by the French government and lives as a retired woman in spite of being 21 years old. She has got no valid reason to wake up in the morning, is completely abandoned to herself. Would her not have a family that tries to stay near to her and motivates her, she would only risk to end in dangerous encounters or fall into depression.”

4th case: D.R. Slight mental delay. She arrived in France when she was 16 years old, after an Italian course of study in ordinary classes

“ (...) At our arrival in France, 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 D. 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 D. 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”

5th case: J.B.G. with Down syndrome, 28 years old; T.G. with Down syndrome, 24 years old; M.G. with severe psychological delay in the movements, 21 years old. All adopted children of the G. family.“

(...) 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 those French programmes (CLIS, ULIS) that allow spending some hours in the classes and other hours in separated places. 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.”

6th case: B.D. Fragile X Syndrome, actually an adult

“ (...) 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”

“ (...) Counsellors and psychiatrists have always looked for psychological causes to the problem of B., looking at me suspiciously. When B. was still small (in the years of the nursery school), we enrolled him in the “hospital de jour” (that is a psychiatric hospital for children, where you don’t learn anything). For four years, during that period, I was forced to meet the psychologist every week.“

7th case: C.S. girl with Down syndrome, 15 years old

“ (...) Once I was in Tarbes, a hospital where my daughter was often admitted. 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! and I replied to him: I am the mother of C.! 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 Lourdes 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 C. 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, C. has been discharged because the school concluded that she was too behind in terms of learning capabilities in comparison with the other pupils.

8th case: E.P. 14 years old and L.M. 8 years old. Situation of the family P. living in France since June 2016

E. P. 14 years old. Severe physical disability, moving only with the wheel chair

“ (...) In December 2015, after a medical examination, a dossier was opened in the district centre for handicap for an evaluation regarding the school admission for the next year. In March 2016, we participated to the weekend “ open schools” and found some schools absolutely inadequate in terms of accessibility; other schools were in the process of adjustment, and others without barriers. In June 2016, E. was examined by an occupational therapist and a social worker in the centre for handicap; they evaluated the knowledge of the French language, the ability of moving autonomously, and the needs. In July, the request of admission to a school in the territory was presented; in August, the centre for handicap decided that the admission was possible highlighting the generic need of a support person but without specifically mentioning the hours or the competencies of such a support person.

„ (...) In the occasion of a working stage, the experience of public transports, (on paper all fully adequate to the transportation of a wheelchair), resulted very disappointing, mainly due to the fact that the lifters of the buses are rarely used and the drivers show an insufficient training regarding their utilization. This has happened even if the transport company had been alerted few days in advance about the presence, in specific routes and hours, of E. and the wheelchair. (...). From a medical point of view, the specialised services to which E. has to go are centralized in the paediatric hospital of Necker of Paris, 800 km far away. In the necessity of a long term care, the activation of hospital courses to replace the absence from school has been proposed”