

INTRODUCTION

Associazione Comunita Papa Giovanni XXIII (APG23) is a catholic international association founded in Italy.¹ The Association is now present in thirty countries on the five continents. The Association has Special Consultative Status with the United Nations Economic and Social Council (ECOSOC)². APG23 has prepared the following submission for the Universal Periodic Review of the Republic of France with the intention to focus on the implementation of the recommendations accepted by France in the second cycle of the UPR, with regard to the rights of persons with disabilities. The information and the data provided have been collected by the members and volunteers of APG23 in France Occitanie region, department 65 Hautes Pyrenees, through direct interviews³, questionnaires proposed to the stakeholders, monitoring activities and from public documents and research material.

Rights of Persons with Disabilities

FOCUS ON: Recommendations n.120.34 - n.120.50 - n. 120.78 - n.120.144 (A/HRC/23/3)⁴ (CPRD)⁵

1. Sources

1.1 Our experience

APG23 is present in France since 2010. It runs, at the moment, two Family Homes⁶ 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.

APG 23 has built networks with national and local agencies such as OCH (Office Chrétien des personnes Handicapées)⁷, APF (Association des Paralysés de France), AIGUE VIVE, MDPH (Maison départemental des personnes handicapées), Difenseur des droits, Santuario Notre Dame de Lourdes, CESDDA (Centre d'Education Spécialisée pour Dysphasiques et Déficients Auditifs) in order to have a mutual collaboration, to face difficulties together and share solutions⁸.

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 interviews⁹ to parents of children affected by mental disabilities. The parents narrate the experience of their children in the school setting and their integration once the compulsory course of study is finished.

1.2 The steps made by the Country

From 2005, when the national law for persons with disabilities came into force, there have been many changes in the country. Many tools have been created to promote occupation, education and social inclusion for persons with disabilities. In 2013, within the Inter Ministerial Committee for disability, the government decided to include a specific section on disability in every new law.

1 Its activities in the world of poverty and marginalization brought to the direct sharing of the life with the poor in 1973 when the first family-home was opened. See www.apg23.org

2 Its commitment at the UN is the result of sharing the life with the poor and is the fruit of the international elaboration and synthesis of the action for the removal of the root causes, which create injustice.

3 Interviews to the OCH (Office Chrétien des personnes Handicapées) National Director, to the Delegate of the Defender of the Rights of Persons with disabilities of the department of Tarbes (06/02/2017) Mr Michel David, to the local Representative of APF (Association Paralysés de France) and more than 40 disabled. Some interviews are reported in the ANNEX I

4 Report of the Working Group on the Universal Periodic Review*France- Human Right Council 23rd Session-UPR -21 march 2013- A/HRC/23/3

5 Convention on the Rights of Persons with Disabilities (CRPD) and its international obligations ratify by France.

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

7 The OCH (Office Chrétien des personnes Handicapées) National Director has answered to our written interview on 23/02/2017. See <http://www.och.fr/actualite/1045421>

8 In 2015/2016, APG23 co-operated with FNSF through the services of a volunteer of the International Civil Service who was affected by hearing and speech impairment. They carried out a mapping on the school insertion and social integration of persons with hearing impairment in Occitanie. They also made a sensitization campaign in a college of the 65th department.

9 Direct interviews involved 41 persons with disabilities.

At the National Conference on Disability of the 14th December 2014, an effort was made to promote an inclusive society, in particular regarding issues pertaining education and occupation. Moreover, issues regarding disabilities are more addressed in the government's policies.

We welcomed the fact that in June 2016 the Ministry of Social Affairs and Health together with the Ministry of the Family and the Rights of the Children and Women has issued ministerial instructions

(Instruction n^o DGCS/3B/2016/207 du 23 juin 2016) for the transfer and inclusion of the didactic units, previously located in the premises of the medical social services (ESMS) for the disabled children, inside the ordinary schools: these measures already announced by the President of the Republic during the National Conference on Disabilities (CNH) on the 11th December 2014, in favour of a more inclusive school, have been also confirmed several times in the recent CNH of the 19th May 2016. Likewise, it is positive that the new Labour Act No. 2016-1088 of 8 August 2016 introduces accompanied employment for workers with disabilities. Its implementation also includes support and guidance from the employer. The legislation has come into force only on the 1st January 2017 and its impact evaluation is premature. The inclusion of persons with disabilities at work, even if it has gradually improved, has not yet reached the set goals.

2. Concerns

2.1 Income

Regarding the access to rights and to an income, still huge inequalities persist. Persons with disabilities have access to poorly qualify and less paid jobs, mainly part-time jobs.

Unemployment rate of persons with disabilities is twice the one of the population without disabilities and the percentage of persons with disabilities having a job is 36% against the 65% of people without disabilities employed¹⁰. This means that persons with disabilities are also the ones with lower income. Certainly, there is need of interventions to avoid that the people with a disability inferior to 80% might become at risk of poverty. If we look at the primary, secondary or higher education of persons with disabilities, it remains hugely inferior to that of the general population.

2.2 Education

The statistics show the growing role of the ordinary school in the education of children with disabilities, but attention has to be paid to the fact that far too many children are attending specialized classes instead of ordinary ones. According to the ministerial data in 2016¹¹ only 43,8% of disabled students going to school in an ordinary context can benefit from an adequate accompaniment. Moreover, the enrolment of children with disorders of the autistic spectrum (TSA) results to be increased by 30%, but it is not said where or with which modalities, and especially there are no data on the total population of children with autistic spectrum. Therefore, it is not known if the reported 29.392 disabled minors sent to school are to be considered a significant percentage. Regarding TSA minors, it is reported that among those children included in the ordinary school, only 67.8% are accompanied by an AVS (auxiliaire vie scolaire). This means that 32.2% is lacking accompaniment. In 2015, UNICEF stated that 20,000 children with disabilities and 80% of children with autism are not in school. The education system does not reduce inequalities between pupils and still places France in the lowest ranks in Europe in terms of equity¹².

France has decided to proceed in the gradual transformation of the AVS contracts¹³ in AESH contracts (Accompagnant des élèves en situation d'handicap), prepared by a specific training; in this regard, many people pointed out that the validation procedure of the competencies should be done through a new instrument different from the actual VAE (validation of acquired competencies) since the VAE has shown to be a very poor instrument in the selection of the staff. APG23 thinks that, at least, the VAE should be seriously revised.

The ambitious project of promoting the cooperation between the social-medical sector and the national education system for strengthening inclusive education¹⁴ carries visible difficulties in identifying the direct beneficiaries and a general lack of information exists regarding the real possibilities that a disabled person could benefit from it. The above-mentioned projects seem to experience difficulties in its implementation,

10 See: Agefiph-ouvrir l'emploi aux personnes handicapées- N.2016-4 Le Tableau de board available in the website: <https://www.agefiph.fr>

11 <http://www.education.gouv.fr/cid102157/conference-nationale-du-handicap-2016-un-point-d-etape-positif-pour-l-ecole-inclusive.html>

12 https://www.unicef.fr/sites/default/files/rapport_activite_unicef-2015.pdf

13 Of the 56.000 AVS contracts, France intends to transform 32,000 contracts of 35 weekly working hours into permanent contracts

14 CRPD/C/GC/4, General comment No. 4 (2016) Article 24: Right to inclusive education

at least at the local level. Regarding the extracurricular activities only 1 over 6 councils has received requests and only half of them has adopted instruments to make them effective. There are still important gaps regarding data. It would be useful to monitor and/or carry out a survey on specific disabilities. For example, the people with mental disabilities must face very difficult challenges and are mostly excluded from virtuous initiated paths. In the December 2016 report, the Human Rights Defender affirms that ten years after the adoption of the CRPD, much progress has been made but significant delays remain.

2.3 Social Inclusion

Regarding social inclusion, among the almost 110 associations present in the Annuaire sanitaire et social des Midi-Pyrénées, only 7 are reported to be structures devoted to the valorisation of the autonomy and self-determination of the person with the same principles confirmed in ad hoc ethical papers. These 7 agencies have locations in the whole region, and offer different types of services to different types of beneficiaries¹⁵. The remaining structures are divided in MAS, FAM (Maisons d'Accueil Spécialisées e Foyers d'Accueil Médicalisés) and home based care associations.

MAS and FAM include all the specialized residential structures in the region; these structures often don't have an internet website, but only highlight in the yearbook the type of service that is guaranteed, the telephone number and the number of beds available. Therefore, there is little public transparency on the services offered. As residential institutions, these structures take charge of the protection and care of the persons with disabilities in a totalizing manner, but don't refer to any accompaniment towards social integration; the high professionalism of the service looks like directly linked to the level of exclusion of the person that practically lives as a secluded person.

The home based care associations are limited at guaranteeing assistance to people at home, whenever their physical and mental capacities are challenged. Such associations have assistance rather than a development approach.

Lastly, there are some structures that are dealing with the working inclusion of persons with disabilities called ESAT (Etablissement et Service d'Aide par le Travail), that are places of protected work, therefore marginal compared to the rest of the society. These places have got very little to do with the working inclusion in a wider and diversified social context. From all this, we can assert that there is not yet a sufficient and adequate perception and representation of the disabled person as a right-holder at a social level.

It is then important to put emphasis on the formation of teenagers and adults with disabilities that could not benefit from the present progress on inclusive education. There is need to accompany them up to paths of employments.

2.4 Architectural barriers

In regard to the architectural barriers, a lot has been done but the target of total accessibility has not been reached within the 10 years time frame set by the government after the adoption of the national law for disabilities.¹⁶

2.5 Interviews

All the people interviewed underline the necessity of a cultural change towards the persons with disabilities. In fact, the mentality of focusing on assisting and relieving the disability rather than helping the person with disabilities in developing his/her own capabilities is deeply rooted in the French culture. A child affected with disability is considered to have a life that is unworthy and full of suffering. Therefore, children with disabilities live in an environment of hostility, mercy, fear, exclusion, discrimination and stigma because they do not fall into the eugenic standards determined by the dominant mentality.

Recently the Jerome Lejeune Foundation (that is named after the famous catholic doctor that discovered the genetic origin of the trisomy 21) has stated "France is a country leader in the elimination of children with trisomy 21 before they come to life and about 96% of these children is aborted¹⁷.

In the medical-social sector, the workers and the specialized professionals portray themselves as the only ones that know how to take care of the children with disabilities; this often leads them to have a neglecting attitude towards parents, that should instead always be involved in the educational project for their children. In regard to inclusive education, France has started different interesting projects (CLIS, classe pour

15 APF (Association Paralysés Français); AGAPEI (Association consacrée à la gestion de l'handicap mental); Solidarité Familiale (Association consacrée à la gestion des relations familiales); ASEI (Agir, Soigner, Eduquer, Insérer) ARSEAA (Association consacrée à la Sauvegarde de l'enfant, de l'adolescent et de l'adulte) ANRAS (Association nationale de recherche et d'action sociale) APAJH dans le Tarn (Association consacrée à la personne en situation d'handicap).

16 Officially stated by Interministerial Committee Handicap see CIHN <https://informations.handicap.fr/art-accessibilite-20-6345.php>

17 <https://www.fondationlejeune.org/depistage-prenatal-de-trisomie-21-sintensifie/>

l'inclusion scolaire, ULIS unités localisées pour l'inclusion scolaire), but the class, the teachers and the families should, first of all, have an emotional good disposition in welcoming children with disabilities.

On the issue of working perspectives, there are the ESAT that are very useful institutions for the insertion on the workplace of mild disabled people. Instead, only repetitive jobs that do not valorise in any way the person are proposed to persons with severe disabilities. Even if there has been an increase in the number of laws and accessibility to work and education, the coverage of the services still leaves out a lot of adult and minors with disabilities and is not uniform in the different regions of the country. Moreover, it is not possible to affirm that there has been a qualitative development that recognizes equal dignity to the person with disability.

It is necessary to promote with sensitization and training the adoption and/or fostering of the children with special needs or multiple disabilities since such children are often institutionalized. In fact, the right to a family or to a family-like structure remains an empty word for these children. In order to have an adequate implementation of these rights according to article 23 of CPRD and of the CRC, there is the need of a national legislation that can identify the placing in extra familial context only as a last resource.

Valuing a person means allowing him/her to make a path that leads to his/her self-determination and to acquire capacities in order to independently choose a project of life; valuing a person with disability means just this, bearing in mind what are his/her peculiar characteristics. On the other hand, for the disabled people to be able to choose, it is necessary an environment in which he/she can choose among the different possibilities that may be adequate to his/her desires and attitudes.

3. Recommendations

- It is necessary and urgent to make a greater effort for training, sensitization and education on the culture of diversity and disability with the aim to promote a real culture of equality, tolerance and reciprocal respect; for preventing and fighting the discrimination towards the disabled children and adults in all the sectors of the society and in particular in the public sector; and for the recognition in real terms and not just formally, of the equal dignity of persons with disabilities at every level of social life.
- In the educational context it is necessary a sort of cultural revolution, by shifting from a quantitative development to a qualitative development in order to adapt and adjust the educational activity to the real needs of the disabled child.
- Even if there have been some progress, there is need to proceed very fast in including in ordinary schools the too many children that are still excluded. All the minors in schools should be granted an adequate educational support.
- To introduce new procedures for the validation of the special teacher's competencies to guarantee an effective acquisition of the required specific formation.
- More punctual and systematic statistical research and collection of data have to be planned concerning the number of disabled in the country, the total rates of schooling, the quantity and quality of the services and educational support offered. Such data should also be disaggregated for different types of disability (mental, physical, etc.)
- In every attempt to adapting and applying new legislations on disability in the different contexts (educational, social and working), it is urgent to give greater attention to children and adult with intellectual disability since they are usually the most penalized.
- To adopt every measure even legislative for guaranteeing in every social or medical residential structure the valorisation and development of the autonomy and self-determination of the person with a disability as well as the transparency of the offered services.
- The interventions in the field of labour integration must be strengthened; business policies must put at the centre the development of the working dignity of the person with disabilities.

- To get rid of the disparities and differences among regions and provinces in terms of: architectural barriers, school treatment and scholastic support, home support and assistance, working inclusion possibilities and compensation and guarantee an uniform coverage.
- Adoption and fostering of disabled children in families and family-like structures should be supported and promoted. A new national legislation that forbids the placing of minors with disability in another type of institution (unless in the case of extreme ratio) should be adopted.
- The life of the disabled child has to be protected from conception. All the possible maternal support for the protection of the life of the disabled child must be adopted and even during intrauterine life.

*Finally, **on reporting and follow up of the third UPR Cycle**, we would like to recommend the following: Ensure the effective implementation of UPR recommendations through the establishment by the time of the mid-term review of the current cycle, **of a permanent governmental mechanism** to liaise with relevant ministries and consult with civil society, National Human Rights Institutions (NHRIs) and all relevant stakeholders.*