France Fact Sheet on Social Care & Support Services Sector for Persons with Disabilities

Part of a series of Country Fact Sheets available on the EASPD website

Written by: Aurore Flipo Coordinated and edited by: Policy Impact Lab





SUBSECTORS OF SOCIAL CARE & SUPPORT SERVICES AND THEIR CHARACTERISTICS

Early Childhood Intervention

Children from zero to six years old with any kind of disability can be received in centres for early care and support action (CAMSPs), which provide social and educational help in day care and support in mainstream childcare. CAMSPs provide the children with a multidisciplinary team (including pediatricians, physiotherapists, educators and social workers) in order to detect and undertake early actions to help children with disabilities. There are 293 CAMSPs in France, and they are funded by the National Health insurance and the Departments¹. The special needs education and home care services (SESSADs) are focused on education and provide services for children from up to 20 years old. The SESSADs are different for each kind of disability and are often part of other social support and care facilities (for example, IME: see Long-Term Institutional Care and Respite Care). Some of them also provide educational support (see Education Support). Safep (Early education and family support services) is a SESSAD that receives children aged 0-3 with severe auditive or visual disability. There are 890 SESSADs in France, funded by the National Health Insurance². They receive predominantly children with intellectual (44%), psychosocial (23%), sensorial (13%), physical (12%) disabilities, ASD (9%) and multiple disabilities (9%). The medico-psycho-pedagogical centers (CMPPs) receive children up to 18 years old with learning and psychosocial disabilities or disorders and ASD. The centers provide educational and therapeutic follow-up, a few hours per week, in order to maintain the children in their regular living environments. The 309 CMPPs are funded by the National Health Insurance and the Regional Health Agencies³.

Education Support

The 2005 law on equal rights and opportunities, inclusion and citizenship for persons with disabilities⁴ stipulates that mainstream childcare facilities must "participate in the integration of children with disabilities". However, there is no legal obligation for a childcare facility to accept a child with disability, and their integration depends on local childcare facilities' policies⁵. The law also stipulates that each child with disabilities is entitled to education and schooling in the mainstream system, the closest to his/her home, and in a continuous and adapted path. In order to apply this objective, the MDPH⁶ is responsible for the elaboration of a personnalised schooling project (PPS), entitling children with any kinds of disabilities⁷ to various support services, depending on their individual situations. Children can be received individually in regular classrooms with the help of school aids (AVS) and various SESSAD (see Early Childhood Intervention) services, in particular:

• SSAD (Home care and support services) provide home services for children with multiple disabilities (both physical and intellectual) up to 20 years old.

¹Since 2004, departments in France have become responsible for all the social care and support public services.

²The 'health' department of the French social security system.

³Regional health agencies are responsible for organising the healthcare system at the regional level. Local counties deal with social services but not with health. Since both are present in most of the social care and support services for persons with disabilities, it is sometimes difficult to know whether it depends on the local counties or the regional agencies. This is one of the issues the Senate commission will look into.

⁴The law n°2005-102 of the 11th of February, 2005, on equal rights and opportunities, inclusion and citizenship for persons with disabilities is the main law pertaining to persons with disabilities. It focuses on the right to compensation, accessibility (to employment, education, citizenship) and social inclusion. It provides a legal definition for the concept of disability and created a Commission for the Rights and Autonomy of Persons with Disabilities. It also set up the MDPHs (Departmental Houses for Persons with Disabilities), whose mission is to evaluate the needs of individuals and ensure that they have access to their rights, and provide them access to the social care and support services they need. The law also created new protections for workers with disabilities.

⁶Generally speaking, access to childcare facilities is not a right in France. Local authorities can choose to provide childcare or not. Children with disabilities often have priority access, but not always. Since each structure has its own (discrete) criteria to select the children they receive (there are always many more demands than places), one would have to prove that their child has been discriminated against. There is no case-law so far.

⁶Refer to footnote 4.

⁷The compulsory school age in France is currently 6, but 97% of children between 3 and 6 are enrolled in public pre-schools. The French Government announced, on 27 March 2018, that the compulsory age will be lowered to 3 years old as from the 2019 start of the school year. Children with disabilities are entitled to a PPS from the age of 3.

• Ssefis (Education and family integration support services) help children over three years of age with severe auditive disability in their daily lives.

• Saaais (Autonomy and School Integration Support Services) accompany children over three years of age with severe visual disability in their daily lives.

Schools can also receive children with disabilities in special classrooms with lower class size and professionals trained to work with children with disabilities (CLIS in elementary schools, ULIS in secondary schools). Education can also take place in residential care or day care facilities providing a Learning Unit (UE) such as IME and ITEP (see below). Children in UE can also attend mainstream school part-time. AVS, CLIS and ULIS are funded by the Ministry of Education and local authorities, while UEs depend on the budget of the facilities they are included in.

In 2014-2015 there were 48,361 students in CLIS and 36,060 in ULIS. There were 111,683 pupils with disabilities schooled in mainstream elementary schools and 82,875 in secondary schools, 43% of them being accompanied by an individual school help (AVS). There were 79,714 pupils in UE. However, some children are not provided with education⁸.

ITEPs (Therapeutic, Educational and Pedagogic Institutes) are therapeutic, educational and pedagogical institutes for children aged 3-20 with learning and psychosocial disabilities, and some forms of ASD. IMEs (Health and Care Institutes) are institutes designed for children with severe intellectual disabilities including ASD, as well as with multiple disabilities. IEMs (Physical Education Institutes) receive children with severe physical disabilities. Some of them are specialised in sensorial disabilities. There are 440 ITEPs, 1,256 IMEs and 148 IEMs in France, all funded by the National Health Insurance. Special education institutes provide education for children who cannot attend the mainstream schooling system but do not have a severe disability. They can also provide support in the mainstream system.

Employment Support

Since the law N°87-517 of 10th of July, 1987 for the Employment of Persons with Disabilities came into force, the Professional Insertion of Persons with Disabilities Funds Management Association (AGEFIPH) manages employers' contributions⁹ (EUR 404mn) and funds actions for the professional insertion of persons with disabilities in the private sector. Since 2005, the public sector also contributes through its own fund (FIPHFP, budget EUR 157mn). Both fund training and support actions for job seekers with disabilities¹⁰, through diverse partnerships: with mainstream training organisations and Capemploi, a public employment service and placement agency network dedicated to workers without severe disabilities and employers. The 2005 law on disability has reaffirmed the obligation for every +20 employer to have a minimum of 6% of their workforce being persons with disabilities, whether full-time or part-time. Non-compliance with this obligation results in the payment of heavier contributions to the AGEFIPH/FIPHFP.

Workers with severe intellectual disabilities can work in the sheltered sector in Working Support and Services Facilities (ESAT)¹¹. There are 1,350 such facilities in France, mainly run by the non-profit sector and funded by the National Health Insurance. Workers with less severe disabilities can be employed in adapted entreprises (EA) which are run by the private sector, which are made of for-profit businesses with at least 80% of employees with disabilities. Some of these companies, labelled home-based work distribution centers (CDTD), are specialised in home-based work which can be done as distance work. These services are all provided at a departmental level.

Supported employment is a measure that has been experimented in several regions before being generalised by the law n°2016-1088 of the 8th of August, 2016 on labour, social relations and safeguarding of career paths. It offers medico-

¹⁰This refers to job seekers with any kind of disabilities, as long as the person is officially recognised a worker with disability by the MDPH.

¹¹While the AGEFIPH / FIPHFP is a funding scheme designed to encourage employers to hire directly persons with disabilities, employers who subcontract part of their production to an ESAT also "counts" for not paying fees to the AGEFIPH.

⁸ There are 1,200 children enrolled in Belgium, partly because of the lack of solution in France (Piveteau report), mostly ASD cases. Officially there are no "zero solution" children, but in reality they exist, although there are no official numbers. According to NGOs, there is also a big inequality of access to the mainstream system: at age 6, 85% of children with disabilities are in the mainstream system, but there are only 48% at age 10 (La Croix, 2018).

⁹These are a sort of tax that employers pay, with the amount depending on the number of persons with disabilities they employ: the less they employ, the more they pay.

social care and employability support services, including job coaching, for workers with disabilities and their employers or job seekers all throughout their careers. Regional initiatives, managed by public or private partners, are co-funded by the AGEFIPH (EUR 2mn), the FIPHFP (EUR 0.5mn) and the State, through Regional Health Agencies (EUR 5mn¹²) on the basis of public tender procedures. Beneficiaries must be workers with officially recognised disabilities, with a project of working in the non-sheltered sector. Priority is set on young adults with intellectual disabilities, including ASD (Direccte, 2017).

Day Care

Diverse facilities provide day care for persons with disabilities. The special needs education and home care services (SESSADs, see Early Childhood Intervention and Education Support) can provide different kinds of day care for children aged 0 to 20, depending on their disability. ITEPs (Therapeutic, Educational and Pedagogic Institutes), IMEs (Health and Care Institutes) and IEMs (Physical Education Institute), and special education institutes also offer day care, depending on the children and their families' situation.

For adults (over 20), there are Homes or Occupational Homes ("Foyers"), which are structures designed for adults with disabilities that do not need continuous healthcare but are not able to work, whether in the mainstream labour market, the sheltered sector or adapted businesses. They provide diverse social and creative activities in order to help persons with disabilities exercise and maintain their capabilities (art, physical activities, physical therapy), and also often provide residential care (see Long-Term Institutional Care and Respite Care). There are over 1000 such centers in France, funded by the users depending on their financial resources, and also receiving public and private subsidies.

Living Support

SPASADs (Comprehensive social care and support home services) are home services designed to help adults (over 20) with disabilities that do not need residential care, to stay home by assisting them in their daily lives (grooming, meals, etc.) These services are delivered through medical prescriptions and funded by the National Health Insurance.

Long-Term Institutional Care and Respite Care

For children, ITEPs (Therapeutic, Educational and Pedagogic Institutes), IMEs (Health and Care Institutes) and IEMs (Physical Education Institute), and special education institutes also offer residential care, depending on the children and their families' situation. For adults, FAM (Nursing home) are designed for adults with disabilities needing continuous healthcare. There are 969 FAM, funded by the Health Insurance and departments. MAS (Specialised foster homes) receive adults with severe disabilities, including: severe intellectual deficiency (16%), multiple disabilities (44%) and ASD (12%). There are 683 MAS, funded by the Health Insurance. Both facilities include fully residential care or day care; although in the case of MAS, residential care is the most common (94%). All in all, there are 494,000 places in care and support services and facilities, including 157,000 for children. 89% of them have a private, not-for-profit status, 10% a public status and 1% a private, for-profit status. "Foyers" (see Day Care) also provide housing for adults with disabilities who cannot work but who do not need continuous healthcare either. NGOs running ESATs (see Employment Support) can also provide housing for ESAT workers.

There is a lack of adequate residential services options for ageing persons with disabilities.

Leisure and Social-Life Support

Created in 2005, the SAMSAH (social care and support services for adults with disabilities) has the mission to assist adults with disabilities¹³ in their integration in mainstream social life. SAMSAH's multidisciplinary team designs a life project with the person and a plan for adapted assistance in the realisation of this project (including SAVS). There are 392 SAMSAHs, funded by the National Health Insurance and the Local county. SAVS (Social Life Support) are social services aiming at providing support to adults with disabilities and ease their access to family, education, work and leisure mainstream services. They are also funded by the National Health Insurance and the Local county.

The SAVS is dedicated to daily life, while SAMSAH are multidisciplinary (including healthcare) and provide a whole path for support through the personnalised project. Both often provide living support.

GEM (Mutual help groups) are self-funded non-profit associations run by groups of persons with disabilities or their families in order to implement their mutual help projects.

FUTURE TRENDS

The academic experts interviewed for this fact sheet report that public policy concerning persons with disabilities have undergone a profound change since the 1970s, that has not yet come to an end. Fillion (Interview, 2018) has identified three long-term trends in public policies. First, policies tend to focus more and more on inclusion into mainstream society and the adaptation of its environment to diversity, rather than 'readaptation' of individuals to mainstream society. Second, policies are more and more transversal, challenging the highly sectorised organisation of the welfare state. This debate started with the publication of the Piveteau report (2014), that highlights the existence of breaks in the lifecourse caused by public policies' categories (including age categories) and resulting in departures to other Member States (mainly Belgium)14. Third, there is the growing importance of the translation of international regulations (UN CRPD) and debates into national law.

In a recent research study on the provision of social care and support services for persons with disabilities, Rapegno and Bertillot (Interview, 2018) also underlined the growing importance of the concept of a whole individualised pathway in the provision of services. This is reflected, for example, in the "A personal response for everyone" approach, put forward by the MDPH and adopted progressively by all stakeholders since 2015, and that has resulted in the adoption, by the law n°2016-41 of the 26th of January, 2016 (article 89, implemented in January, 2018), of the right for individuals to request the formulation of a comprehensive individualised support plan. This development has contributed to a reframing of the service offer in terms of schemes and benefits. Another current trend is the implementation of new public management rules in the field of social care and support services, that has forced the non-profit sector to change and adapt.

Experts have also underlined the development of policies in favour of self-determination, a demand promoted by NGOs, such as Trisomie 21 France (Down syndrome). This is reflected in an online decision-making tool designed for persons with intellectual disabilities, and a theoretical handbook (*C'est ma vie, je la choisis:* It's my life, I choose it) issued by the FIRAH (International Foundation for Applied Disability Research) and the CCAH, and piloted by Trisomie 21 France.

In September 2017, the Government unveiled the policy agenda of the Interministerial Committee on Disability. Disability has been set as a 'top priority' by the government invested in June, 2017. Five main objectives have been set:

¹³Age 20-60, depending on the individual situation and autonomy (to be assessed by the MDPH).

¹⁴The report says that 6,800 French persons with disabilities have left France for Belgium because of the lack of social care adapted to their situation in France. The problem is particularly important with adults with ASD.

- Guaranteeing a better access to rights.
- Guaranteeing access and support for education from kindergarden to university.
- Guaranteeing access to the labour market.
- Increasing the ability of staying home while accessing healthcare services.
- Access to leisure, sports and activities and promoting inclusiveness.

A first phase has been launched, consisting of a wide consultation of stakeholders, that should result in a policy agenda to be issued in 2018.

On 25 January, 2018, the Senate's Commission on Social Affairs mandated a working group on the issue of the financing of care and social support services for persons with disabilities, with an objective of simplifying the system to ensure continuity in their lifecourse. The Commission will in particular look into a new pricing system called Serafin-PH, that has been piloted and should be implemented at the horizon 2020-2022. It aims at financing care and social support facilities based on their users' individual characteristics, rather than on a fixed number of places and/or services, but the results of these experimentations are not known yet.

CONDUCTED INTERVIEWS

Emmanuelle Fillion, Sociologist. 5 February 2018. Noémie Rapegno and Hugo Bertillot, Sociologists. 5 February 2018.

CONCTACTED

UNAPEI, APAJH, APF.

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This fact sheet is prepared as part of the EASPD "Reaching Out" Work Programme 2017. With the financial support of the European Union Programme for Employment and Social Innovation "EaSI" (2014-2020)

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