

National Resource Centre for Rare Disabilities

Encompassing:

Deafness and concomitant disorders
Complex language disorders



La Ligue Fraternelle
des Enfants de France

Managing association: La Ligue Fraternelle des Enfants de France (LFEF)

La Ligue Fraternelle des Enfants de France founded the Centre for Children with Multiple Disabilities and the Robert Laplane National Resource Centre, which it also manages.

The charity, founded in 1895, was acknowledged as being in the public interest by Félix Faure on 23 March 1898.

In 1970, a new free clinic was opened at 33 rue Daviel in Paris' 13th arrondissement, along with a Physical & Mental Health and Education Centre (CMPP) for children with sensory disorders. Since 1974, the centre has been providing early screening for deaf children, and check-ups for visually impaired children. And it was on these same premises that the Centre for Children with Multiple Disabilities was opened in 1987.

In 1998, the French Ministry of Social Welfare entrusted LFEF with management of the Robert Laplane Resource Centre, which is one of the three national centres for rare disabilities. The centre is for deaf children and young adults with multiple disabilities and severe dysphasia.



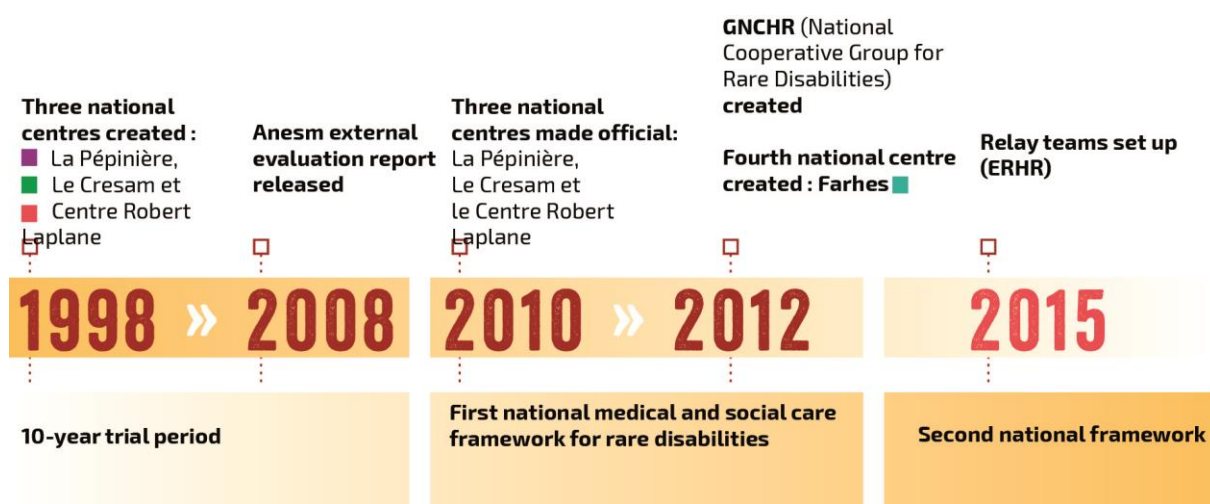
The Robert Laplane National Resource Centre for Rare Disabilities (CNRHR):

The Robert Laplane CNRHR was opened in 1998, at the same times as two other National Resource Centres for Rare Disabilities: CRESAM in Poitiers for deafblind people, and La Pépinière in Loos-les-Lille for visually impaired children with concomitant disorders.

These three centres were run as part of a trial until they were made official in July 2010.

The government decree of 4 December 2011 granted the National Cooperative Group for rare disabilities permission to carry out its own assignments as well as work on joint cross-disciplinary projects with the national resource centres for rare disabilities, in addition to their specific roles.

The GNCHR's work is carried out through contributions from a team of professionals from the four CNCHRs, and others employed directly by the GNCHR. The scope of its work is defined in the 2009-2013 first national medical and social care framework for rare disabilities. The second framework, for 2014-2018, incorporates new stakeholders: as of January 2015, relay teams joined the full programme.



Target population:

Deaf children with concomitant disorders:

We are very often contacted by healthcare professionals working with deaf children who present language and learning disorders that cannot be explained by deafness alone. Their overall development is complicated by sensory, cognitive, or motor problems.

We also work with children with complex disabilities who are deaf but treated in an establishment that does not specialise in deafness.

Children with complex language disorders (CLD) with concomitant disorders or diseases:

These are children who are not deaf, but who present language development disorders as part of a complex clinical profile. Comorbid factors may mean that these children are not classed as suffering from dysphasia. The diagnoses – autism spectrum disorders or intellectual deficiencies – puzzle professionals and do not provide enough information to develop suitable treatments.

As for children suffering from dysphasia, their language disorders may contrast with their interpersonal skills. Healthcare professionals or patient families identify and try to develop these skills.

Deaf or CLD adults with concomitant disorders due to congenital or acquired conditions:

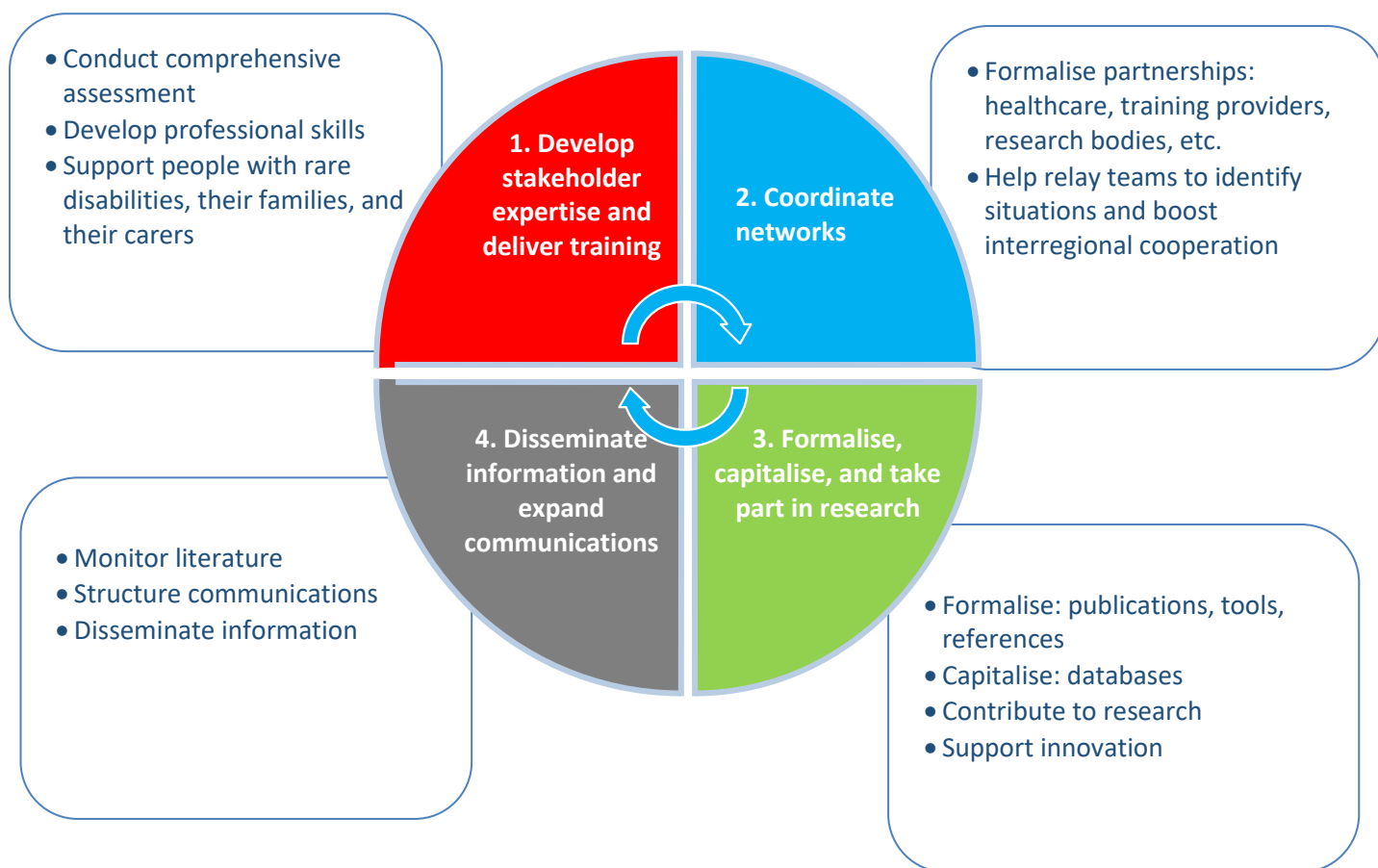
Patients that we have treated since childhood may consult us throughout their lives, in particular when trying to choose adult establishments and programmes.

We also receive new requests from individuals and their families in a variety of circumstances. These individuals may be isolated and excluded and experiencing significant psychological suffering, in particular due to communication problems and a lack of training for the people in their environment. To assist these individuals, we need to rely on the national network.

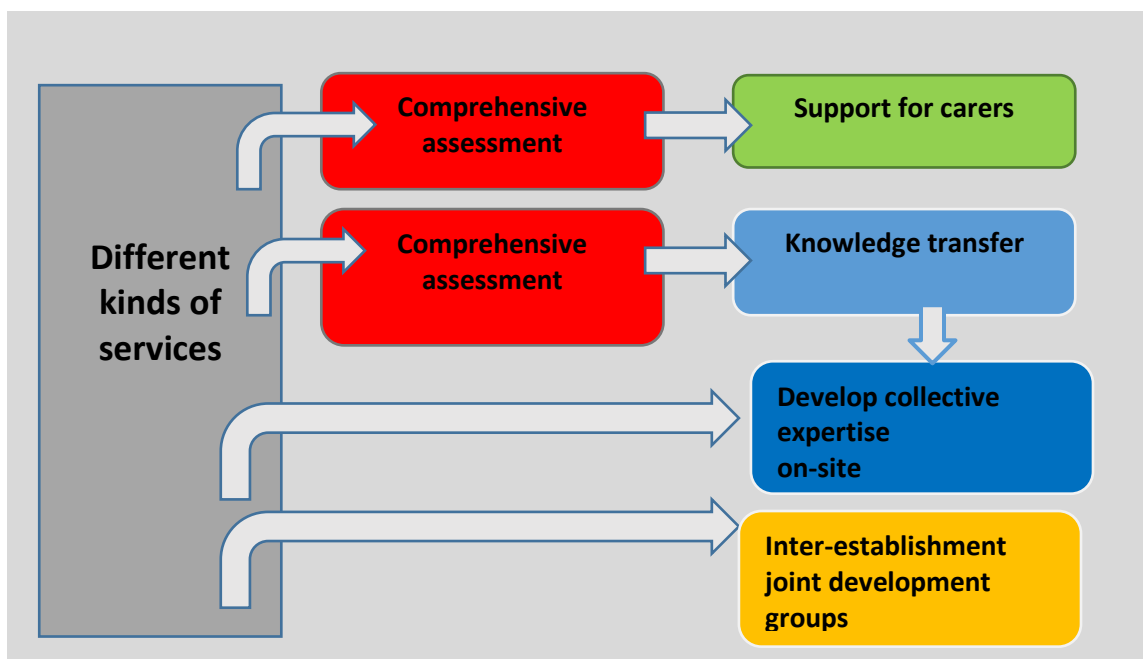
Our mission:

All of our missions are delivered within an overarching organisation and are intended to improve the

quality of life, treatment, and support for people with rare disabilities all over the region, in an effort to boost their independence and participation in society.



Services:

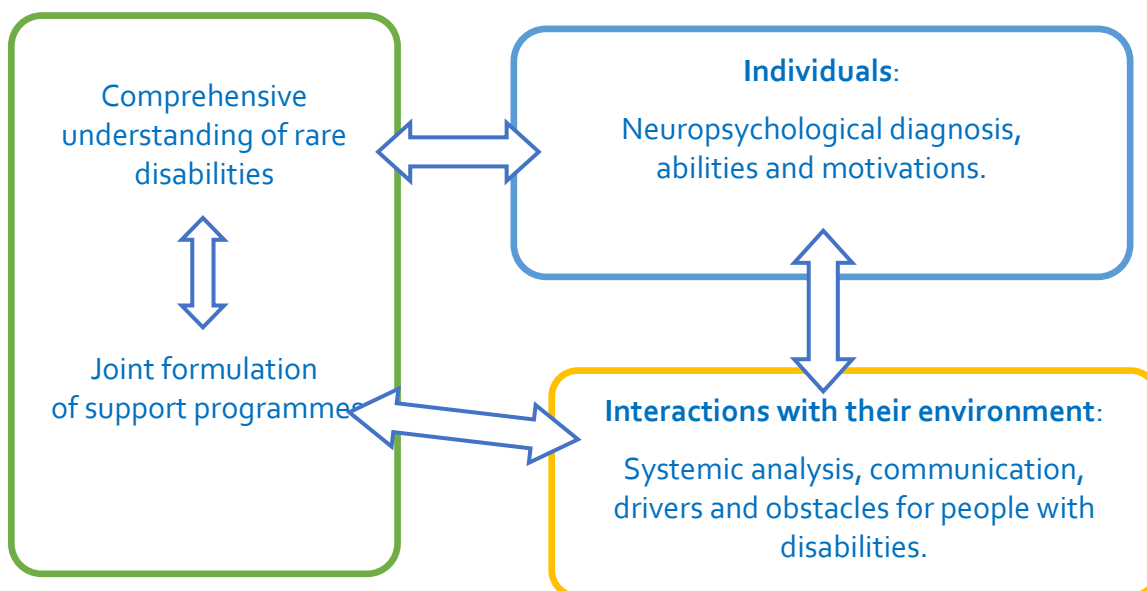


➡ Comprehensive assessment of rare disability cases: “Understand better to treat better”

The assessment takes the form of a functional appraisal of the disorders. Sensory, neurosensory, motor, neuromotor, and cognitive aspects are all taken into account, in their individual complexity as well as their interactions. Strictly speaking, we don't provide a report, but we do adopt a clinical assessment strategy based on the latest findings in neuropsychology and neurolinguistics

This is accompanied by an eco-systemic analysis: the individual's abilities and motivations are analysed with regard to environmental factors that will facilitate or hinder their social inclusion.

Together, this forms a comprehensive assessment, with the full spectrum of factors and stakeholders helping us to understand the rare disability. The aim is to reach a shared general understanding of the individual's functional and communication profile. This understanding will let us better tailor our responses to the environment the person with disabilities occupies.



This comprehensive analysis is followed by an intervention to adapt responses to the environment:

- For healthcare professionals to jointly establish a personal programme
- Or for parents, carers, and people with rare disabilities to tailor the support provided to the person with a rare disability

➡ **Interventions with people with rare disabilities, their families, and their carers:**

A key point in support is when parents or families/friends contact us for the first time.

We regularly meet with young people's families when assessing their situation, always accompanied by professionals from the partner team during our interventions on-site for the comprehensive assessment and knowledge transfer.

We support the families of individuals who are isolated due to the lack of local facilities to provide support. A few highly complex cases receive long-term support. The centre plays a role in monitoring these cases. However, as we are unable to offer long-term support, we work in partnership with one or more relay teams in order to find a solution.

Families that we have supported come back to us for further clarifications of the problem for themselves or various educational, medical, and paramedical stakeholders.

Young people who are now adults contact us to better understand their own rare disability.

The centre's staff are proficient in sign language. They can support deaf parents by meeting them face-to-face or via video-conferencing.

Knowledge transfer among several professionals, on-site for a particular case

The aim is to train them to identify disorders and deficiencies, to analyse how they interact, and to jointly develop support plans.

For problem cases with children or young people:

- Understand the difficulties the child or young person encounters in light of current knowledge in neuropsychology and neurolinguistics, and analyse how they interact and the effect this has on communication and language, learning capacity and behaviour, and in doing so develop their ability to observe, question, and form different levels of diagnostic hypotheses.
- Understand the child or young person's situation in their environment, and their skills so as to deliver appropriately adapted treatment.

We do this by:

- Holding joint observations (healthcare professionals and resource centre staff) and staff meetings before the team begins its investigation.
- Jointly proposing diagnostic hypotheses and avenues for treatment; joint treatment objectives are defined with the team. These objectives are broken down specifically for each professional, in relation to the work carried out by the establishment with regard to personal support plans.

The training may be followed by several more courses for the same professionals, and understanding of these complex interactions is disseminated by analysing and comparing different situations.

Developing the collective expertise of a team of professionals on-site

In establishments that treat a number of young people with rare disabilities that fall under the scope of our centre.

At the request of the establishment's management, we can work with them to develop an awareness-raising and training programme within the framework of a partnership. These training interventions are adjusted to the needs and requests that arise during various observations and appraisals.

They may take the form of practical training with people with disabilities, with the resource centre team contributing to groups, or even the production of films and videos. Collective expertise is developed through observations, team meetings, and video analysis.

Traditional training modules are also available, and include: drawing and symbols for language and communication, and various approaches to reading.

Management appoints a contact person for the project as part of the support agreement they sign. Some of the identification and remedial work is delegated to the team and supervised by staff from the national resource centre.

Implementation of a programme to develop skills in a partner health/social care establishment

The project manager at the partner health/social care establishment coordinates several of the establishment's teams at different times or all together, as they receive the various training initiatives developed with the support of the establishment's contact at the resource centre.

A certain number of rare disability cases can be treated in a face-to-face or telephone appointment with a resource centre professional. Internal knowledge transfer also occurs (e.g. setting up work groups, resource officers, resource teams)

➡ **Inter-establishment work groups: joint skill development.**

For several years now, the Robert Laplane CNRHR has been coordinating various work groups and inter-establishment training programmes on rare disability issues.

They involve professionals from all over France. They currently take place in our Parisian offices, but there are plans to also deliver them regionally with support from our relay teams and partner establishments.



1- Training group for deaf professionals on concomitant disorders:

Agnès Vourc'h (speech therapist, linguist) has delivered this course for many years, directly in French Sign Language. Each course runs for three years. Two classes run every year. 10 half-days per academic year.

It is intended for signing deaf professionals working with deaf children with concomitant disorders, and primarily those working in SEHAs (FSL teachers, FSL educators, medical and psychological assistants, maternity assistants, etc.).

Throughout the course, clinical case studies underpin and enrich the theoretical lessons and educational analysis. These clinical cases, provided by the participants themselves in video sequences, are a key component of the course.

2- Group for rehabilitation therapists in health/social care establishments:

A group has existed for many years now. It is coordinated by Elisabeth Lasserre, a neuropsychologist and executive assistant.

The group includes rehabilitation therapists working with deaf children for the first time and those with more experience, and its main aim is to share knowledge and best practices. The shared discussions and

presentations use clinical examples and themes to understand the how disorders concomitant to deafness interact, along with their consequences and how they can be overcome. Investigation also focuses on how tests can be adapted and delivered.

Five days per theme were scheduled in 2016.

3- Work groups for child language disorder specialists in the Paris area:

Elisabeth Lasserre, executive assistant and neuropsychologist, coordinates this group which has existed since 2006. On average, it involves eight professionals from four health/social care establishments in the Paris area: Directors, Social Care and Education Manager, Head of Department, Teachers, Doctors, Psychologists, Speech Therapists. This group's aim is to share knowledge through clinical cases, as well as to promote networking. The group did not reconvene in 2015 and we are currently considering setting up a national or regional work group.

4- Work groups for doctors in health/social care establishments:

Jeanne Cousin, head physician, and Elisabeth Charrière, ENT doctor, coordinate this group. It was launched in September 2014. Due to the number of registered participants, two groups were set up. Only one met in 2014. The other was scheduled for early 2015. The main aim is to train doctors in the diagnosis of young deaf people with concomitant disorders.

Establishment doctors: This group is made up of ENT doctors, generalists, and paediatricians from all over France.

5- Work groups for psychologists in health/social care establishments:

Audrey Constant, a neuropsychologist, coordinates this group which formed in January 2015. It is made up of clinical psychologists from our network of partner health/social care establishments, and other healthcare establishments that would like to learn about neuropsychology to better understand the problems encountered by certain young deaf people.

The aim is to provide support for psychologists in these establishments as part of a comprehensive, cross-disciplinary approach to children and adolescents with hearing difficulties and concomitant disorders or complex language disorders.

The work group is made up of 10 psychologists specialising in psychopathology or developmental psychology, coordinated by a psychologist/neuropsychologist.

Four or five one-day meetings every year (9:30am to 5pm), around every two months.

Contributions from professionals in various fields.

6- Nursery Rhyme Seminar

Deaf professionals from establishments share thoughts and practices on FSL nursery rhymes, in order to compile a teaching tool (album+DVD) that children can use to learn French Sign Language. The album is intended for anyone who might want to use it (professionals, parents, children).

Seven deaf professionals from partner establishments attended seminars/workshops for two years running (2016 and 2017), held every two months or so (dates in appendix). The seminars were led by Agnès Vourc'h, a speech therapist and linguist.

These seminars were also attended by Marion Blondel, a linguist specialising in formal FSL language structures, especially those in FSL nursery rhymes. She is a researcher at the CNRS in Paris.

Multidisciplinary team (7.2 FTE)



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Ligue Fraternelle des Enfants de France is a charity founded on 8 December 1895 at the Palais de l'Elysée. It was recognised as serving the public interest on 23 March 1898.

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The charity is made up of two establishments and one department, which includes:

The Robert Laplane National Resource Centre for Rare Disabilities (CNRHR), created by prefectural decree on 13 July 2010 (NOR: MTSA1018806A)

- FINES No. 75 004 452 1

- SIRET No. 784 543 456 00023 APE 8891B

- Category: 461 Resource Centres: two combinations of rare disabilities: Hearing disorders with one or more concomitant disorders and complex language disorders with or without concomitant disorders.

Authority: Regional, interregional, national

- Number of weeks open: 47