

POLICY AND ORGANIZATIONS

CRESAM, the national resource centre for deafblindness in France, was created in 1998. In 2009 the France government designed a national plan for rare disabilities, in which deafblindness was concluded.

Rare disabilities come from the association of very particular and uncommon impairments:

- Rare public
- Rare associations of impairments
- Scarce and complex technicities

These rare associations of impairments result in several interrelated difficulties that further complicate the person's life. The coordination between local players and additional available expertise is not sufficient in taking charge of care in an optimal way for people with a rare disability. Using an integrated system appears to be the adequate response.

Integration is a collaborative working method that has many objectives:

- An interdisciplinary approach to evaluate the needs and build a response strategy
- The interdependence between the players' actions and resources in the answer to the specific needs of the person
- The principle of subsidiarity in terms of expertise

As much as possible it is the local level that responds to the need of a person with a rare disability, when it has the expertise to do so. If there is difficulty or doubt, it refers to a more specialized level.

The integrated system relies on four principles:

- The integrated window to ensure uniqueness and consistency in the answer to the person irrespective of the entry point used to get in the system
- The players' co-responsibility in the creation, application and follow-up of the appropriate caring strategies
- Doubt and questioning instruction relying on the principle of subsidiarity to better build compensating strategies
- A system for sharing information facilitating information flow

The setting up of this integrated system relies on different players and structures that act at different levels:

- The CNSA (Caisse National de Solidarité pour l'Autonomie) and the DGCS (Direction Générale de la Cohésion Sociale) lead the rare disabilities schema at the national level
- The ARS (Agence Régionale de Santé) lead their policy on rare disabilities in their territory, organized around an interregional support network with 7 referring ARS

- Four national centers specialized in rare disabilities: CRESAM (deafblindness), la Pépinière (visual impairments and other impairments), Robert Laplane (Hearing impairments and other...), FAHRES (severe epilepsy).
- The GNCHR (Groupement National de Coopération Handicaps rares) drives the rare disability players at a national level
- Twelve relay teams, located at the interregional level, are the local key players of the integrated system.

These relay-teams have three missions:

- Gather the players to detect existing needs and resources
- Guide individually the situations among the evolution of a life pathway
- Offer their expertise

The local contributors such as sanitary, medical and social professionals, institutional contributors, and rare disabilities networks, associations and close family members intervene in the direct environment of the person with a rare disability.

With the arrival of the ER, the missions of CRESAM have changed. CRESAM has four missions:

- Evaluate the competences of a person with deafblindness
- Follow-up individual cases
- Training of professionals, care-givers, persons with deafblindness, others
- Research

CRESAM cooperates closely with the relay teams in order to answer the needs of persons with deafblindness.

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