

Study on the application of the right to respite for children in situation of polyhandicap in the France south-western



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Objective :

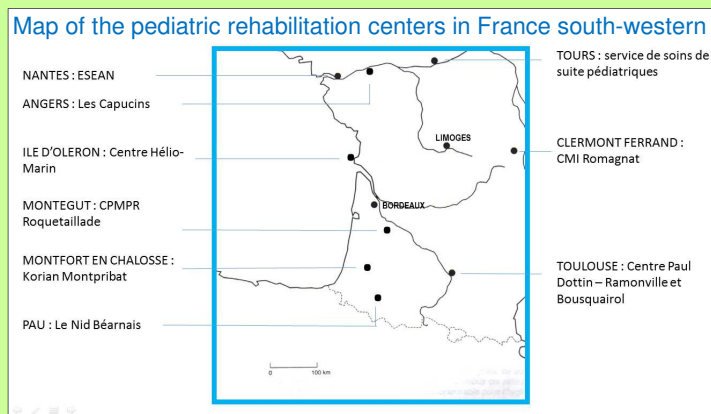
- ✓ In France, the respite is a right for any person in situation of disability.
- ✓ In the case of children suffering from polyhandicap, the heaviness of the nursing, the cares technicity and the existence of behavioral problems complicate the access to this right, even when it is all the more essential for the families.
- ✓ The network for childhood and disability in south-western (REHSO) leads this study to evaluate the implementation of the respite right in the territory.

Patients and methods :

- ✓ In France south-western, the number of children in situation of polyhandicap is estimated at **a thousand**.
- ✓ Questionnaires have been sent to the pediatric rehabilitation centers and the medicosocial establishments specialized into motor disabilities of this territory, between June and September 2017.

Results :

- ✓ On the 85 questionnaires sent, **44% of responses** were obtained.
- ✓ The all 9 pediatric rehabilitation centers accept children with polyhandicap, 6 of which with tracheotomy and 2 with parenteral nutrition.
- ✓ But the rate of **admission refusal can reach 50%** of the demands because of a lack of place.
- ✓ 28 medicosocial establishments receive polyhandicapped children.
- ✓ Only 6 maintain an accompanying all over the year, and only 3 propose temporary stays.
- ✓ **18 express needs** of respite stays.



| Responses to questionnaires | Pediatric rehabilitation centers | Medico-social establishments |
|------------------------------|----------------------------------|-----------------------------------|
| | N = 9 | N = 28 |
| Number of structures | All accept respite stays | 3 are authorized to respite stays |
| Number of children/year | 2-30 | 0-10 |
| Number of activity days/year | 0-800 | 0-670 |

Discussion :

- ✓ This study highlights the disequilibrium between the offer et the needs in respite stays for children in situation of polyhandicap.
- ✓ The needs of the more disabled children are the less covered needs.
- ✓ The reduction of the closing periods of medicosocial establishments may lighten this problematic.
- ✓ The development of alternative solutions to respite stays in conventional hospitalization seems to be necessary : hospitalization at home, specialized home-care services, specialized host families...

Conclusion :

The application of the right to respite for children in situation of polyhandicap is defective in the France south-western because of a lack of places in temporary stays, within rehabilitation centers as in medicosocial structures, and the absence of regional coordination.