

Feedback of the main impacts of Covid-19 for Caregivers



1. What are the main challenges faced by people with disabilities and their caregivers with the covid-19 epidemic and containment?

Continued care:

- Some treatments are stopped or postponed to an uncertain deadline, which creates risks of regression and an impact on long-term health.
- Difficulties in finding technical equipment for treatment from pharmacies as well as the necessary protective equipment (masks, hydroalcoholic gel)

Fear of contamination:

Some caregivers refuse the passage of professionals to people helped by fear of contamination, this generates:

- A real break in the care and support journey
- Increased isolation which is particularly impactful for people with mental disabilities
- An increase in the burden of the caregiver who takes over the tasks of the various professionals usually accompanying the person with a disability
- A significant emotional charge

Psychological difficulties:

- Reinforced isolation and increased feeling of loneliness
- Increased caregiver fatigue, a need for respite
- An increase in communication difficulties, more nervousness and / or uneasiness
- The loss of bearings for certain people with disabilities
- A significant mental load: certain situations are particularly difficult for people with behavioral disorders (the resulting aggressiveness is particularly difficult to live in everyday life, a fortiori in a confined everyday life) or mental handicap
- A risk of violence or mistreatment on both sides of the caregiver-supported couple

Support:

- The lack of training for carers on the pathology of their loved one in the field of disability, which generates mistreatment and generates suffering for the caregiver and the person supported.
- For parents of children with disabilities, the issue of home school is all the more difficult to provide.

In disabled establishment or retire home :

- Difficulties linked to the lack of meeting with their family and sometimes by a lack of "physical" contact between user and carer.

Administrative & financial:

- Significant administrative and financial issues (certain families do not wish to consider returning to an institution for fear of losing the money paid as part of human)
- Day reception accompaniments on our IMEs are subject to an exemption request from the ARS.
- Inequality in access to IT tools, which creates additional difficulties.

2. What is your assessment of the measures taken by the authorities (measures derogating from the confinement rules, extension of rights, adaptation of the functioning of the MDPH, etc.)? Have you identified any difficulties?

Positive points:

- the possibilities of additional ballads ("exit permission"): positive impact responding to a real need, especially for children with behavioral disorders or adults with mental disabilities
- Authorization to renew usual treatments without a prescription
- Maintaining appointments with treating physicians and local networks: nursing offices for example.
- The extension of rights , which had reduced anxieties on the budgetary aspect
- The flexibility of the confinement rules to maintain physiotherapy sessions with people whose state of health requires their intervention.
- The maintenance for the most vulnerable of home visits by professionals accompanying medical and social services
- The great reactivity on the part of the departmental house for the disabled (public service)

Difficulties :

- Difficulties in having protective equipment for professionals with the consequences of being unable to ensure sanitary rules or stopping care.
- Break in rights for some people and complication regarding new files that were being processed.
- Difficult conciliation between work and help given to loved ones when confinement is cohabitated. The sick paid leave for caregivers have been established 3 weeks after the beging of the criseis, itw as late , and we don't know if it will be extended.
- Lack of respite for caregivers

3) What measures would be necessary if the confinement of a part of the population - the most vulnerable people - is to last a long time?

Care:

- Maintaining medical and social support at home
- Have clear instructions on hygiene measures for these children who cannot wear masks and whose compliance with barrier rules is not possible.
- Have specific recommendations for people with disabilities (today the recommendations on medico-social are strongly oriented for nursing homes)
- Offer home support for families most in difficulty or in institutions (make 1 for 1).
- Creation of a place of reception for people with disabilities to set up stimulation with hygiene measures (1 for 1)

Exits :

- A priority card for shopping
- Maintain the possibility for caregivers to visit their loved one in an establishment
- Maintain and encourage accompanied outings for 2 or 3 people while ensuring compliance with barrier measures, in order to maintain a non-virtual social link
- Extend places to walk in « like park)

Respite:

- Time and respite arrangements for parents (allow professional teams to organize respite)
- To be able to offer daycare support within our establishments for children and families in difficulty
- Promotion of home offers. Relays proposed to compensate for lack of sleep, violence, the need to relax.

Administrative & financial:

- Immediate compensation for caregiver leave, so as to allow gradual deconfinement and the reinstatement of professional assistance, until the situation becomes stable again.
- A global assessment of the caregiver-assisted person situation for professionals