Supplement to the Parallel Report of German Civil Society "Human Rights Now!", presented by the Alliance of German Non-Governmental Organisations on the CRPD c/o German Disability Council (10.08.2023)

Factsheet: Intensive Care and Rehabilitation Strengthening Act (GKV-IPReG)

The GKV-IPReG came into force in significant parts on October 29, 2020 and brought about changes in the Social Code V (SGB V), which regulates statutory health insurance. The law affects around 22.000 people with a particularly high need for medical treatment care. These people are now entitled to out-of-hospital intensive care (AKI) under the newly introduced § 37c of the German Social Code, Book V (SGB V). As in the intensive care unit of a hospital, their state of health must be monitored around the clock and, in the event of life-threatening situations, rescue intervention must be possible at all times. Most of the patients concerned are artificially ventilated.

With the GKV-IPReG, the German government wanted to counteract the billing abuse that had become known in so-called ventilator living communities. Due to various implementation steps, the law will not take full effect until October 31, 2023.

Now, there are **two main problems** that endanger an independent life of persons in need of intensive care in their own homes:

- The first problem arises from the wording of the law in § 37c Para. 4 SGB V. According to this, AKI may in future only be provided by "qualified nursing professionals". However, many families and independent living adults have so far ensured their care in the personal budget or in individual case arrangements with mixed qualified teams, because already in the past not enough qualified nursing professionals were available. These care arrangements in the so-called skill mix have so far enabled the desired care in the own or family home. The use of "qualified nursing professionals", which will be required by law in the future, and the current shortage of skilled workers may result for those affected not being able to find a nursing professional, having to leave their home and move into an institution. This is contrary to the UN CRPD.
- Another significant problem arises from the so-called Out-of-Hospital Intensive Care Directive (AKI-RL), which, among other things, regulates certain qualification requirements for physicians who are authorized to care for AKI patients. There are currently not enough physicians available who fulfill the requirements standardized in the AKI-RL to be able to prescribe intensive care. There is also a lack of physicians who can carry out the potential assessment required for ventilated patients before a prescription is issued. This endangers the security of care for patients from October 31, 2023, when prescriptions may only be made on the basis of the AKI-RL (see also https://www.deutscher-behindertenrat.de/ID292627)

Proposals for recommendations to the German government

- Please change the provisions in SGB V as soon as possible so that people who are dependent on intensive care can continue to live in their own homes. There must be the possibility for them to be cared for by self-trained assistants and not only by nursing professionals.
- Please create the legal conditions for a transitional regulation to the AKI-RL in order to guarantee
 the establishment of reliable care structures and to ensure that in the future physicians with the
 qualifications required by the AKI-RL will be available in sufficient numbers.

Addendum

It is striking and amazing that the German government does not even mention the GKV-IPReG in its additional information, despite the many discussions and disputes surrounding it.