

CHAPTER 26

Quality of life and integration of care & education in children with complex and intensive support needs: Recommendations to policy makers

MIA NIJLAND, JO LEBEER, ADELINDA CANDEIAS, MARINA RODOCANACHI, MAGDALENA TSONEVA, ENIKŐ BATIZ & ERIC ZOLLA

From January 2014 to June 2017, we worked as partners from eight countries in the Enablin+ project, with the aim of contributing to a sustainable quality of life for children with complex and intensive support needs (CISN). This common ambition has both generic and “country specific” angles. In this report, we address the “umbrella” points of attention, which are common across all partner countries. Our work was guided by the principles underlying the UN Convention on the Rights of People with Disability, which has been signed by all eight partner countries.

During the collaborative project, our vision was aimed at:

- a) Enabling a better human life for children with CISN, based on equivalence and dignity, taking into account the necessary support, life-long and life-wide.
- b) Enabling them to be full members of the local community, having a good family home, a social network and space to flourish and learn.
- c) Enabling education and other meaningful activities for them, focused on well-being and development.

Making Quality of Life better for children with CISN requires a *continuous micro-, meso- and macro- support system*. It involves structural support in the daily practice of *child and family* (micro-level) and the practice of *childcare providers* (meso-level). At macro level, it is about *facilitating the necessary preconditions*: local, regional, national and international (policy makers and politicians).

Children with CISN rely on people who know and assist them well, day-to-day, 24 hours a day. First, it is the *family* to which the child belongs. In particular, parents, who as *experts in experience*, know their child completely, and support him or her unconditionally. They need *tailor-made support* from professionals who can contribute on various fronts to make