Collaborative Support for Parents and Operators of Disabled

Smart City: Social Innovation

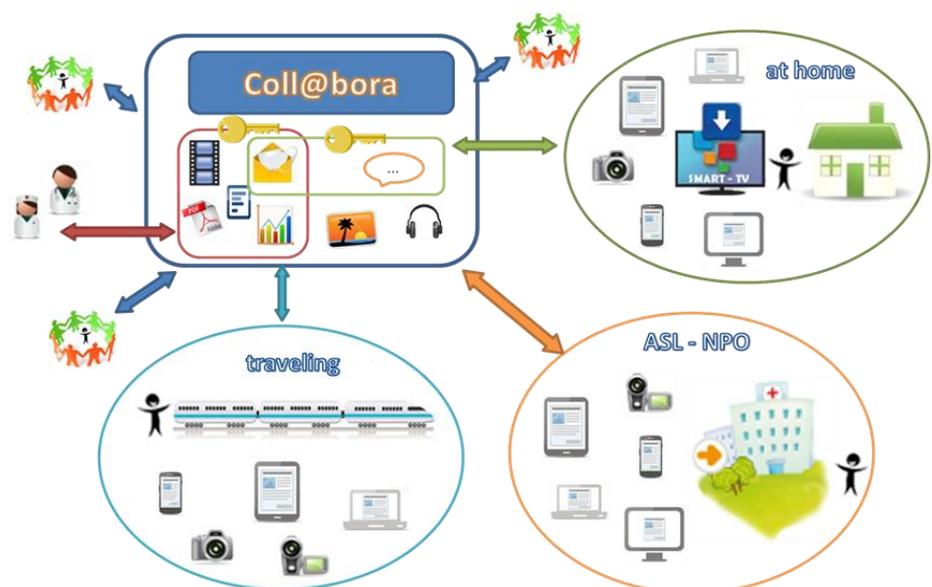Primary topics: Welfare Technologies and Inclusion, Healthcare

Coll@bora

Over 90% of disabled people live in the household, and most of them are followed by support team, which is built with the family along with specialist associations affiliated with ASL, offering support to disabled people and their families. These associations, NGO and ASL build a special relationship with families with disabilities by making available a team of doctors, speech therapists, therapists, volunteers. Creating a team that does not follow the disabled only during therapy sessions, but follows him at a distance when the disabled person is at home or on vacation. Particular disabilities require a lot of attention as **physical disabilities and learning**, and in situations where there are clear **communication problems** showing a strong inconsistency between expressive language, full of shortcomings, and the receptive. There are many causes that may affect the ability of learning and communication, some are congenital (Mental retardation, Angelman Syndrome, Autism), others due to a head injury, stroke, diseases such as Parkinson's and ALS (Amyotrophic Lateral). In these situations, as in others, **the family is the environment in which it is possible to detect the patient's most significant behaviors**: progress and issues. These environmental conditions are difficult if not impossible to replicate in the rooms of therapy. Doctors have enormous difficulties to understand and observe such behavior, the costs are high. In these situations, cooperation and dialogue between the family and the people of the support team is very important and often occurs at a distance, with great effort and high costs. Even describe a new problem or a little progress and/or a different attitude can become difficult, if not impossible; short distances can become unbridgeable.

Coll@bora aims to solve problems of management and protection of information needed to build effective and protected collaborations in the teams following the disabled. Coll@bora is based on technical ICT collaborative work, protection for the privacy of sensitive information, mobile computing and artificial intelligence.

In common practice, family produce **movies/photos to show to the support team the behavior of people with disabilities in the family**, to highlight problems and successes, and in reference to treatment. Similar solutions are practiced in places of treatment by doctors and assistants with the approval of family members. These videos and images can be shared with the support team, but only in respect of the privacy of the patient, of the child, of the disabled. The **audiovisual documentation** is not a mere

collection of digital media to support the medical record, but **a medical-family collaboration tool**, a tool for analyzing, understanding, reference, and training to new volunteers and young doctors, etc.. The experiences of the support team should be able to be shared to create complex strategies, new methods, in accordance with the patient. Often these images and/or video must be collected and sent to obtain a second medical opinion in a secure and confidential way by medical specialists in distant Europe; they are therefore a very important documentation of the state and evolution of the patient, the relationship with
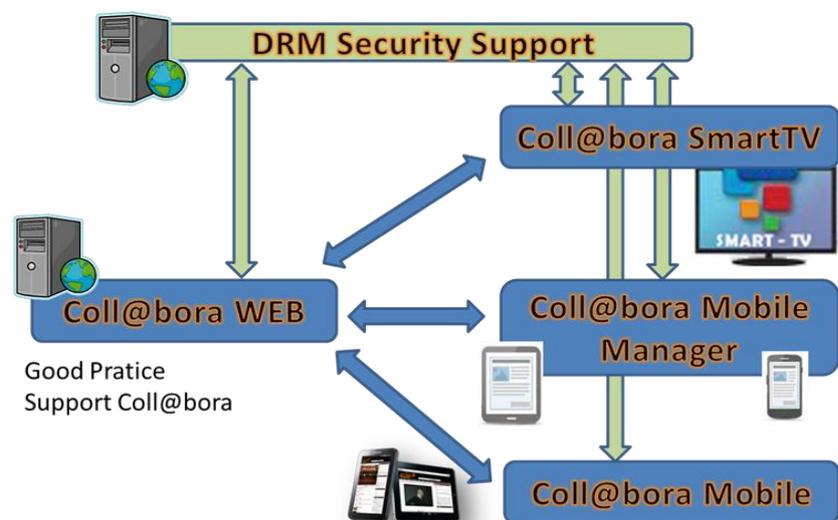
their parents and with the environment, etc., that simply cannot be conveyed by mail, uploaded on social networks, left on USB key, loaded in DVD, left on dropbox, etc.

The problems addressed by Coll@bora should not be confused and cannot be solved by modeling solutions and management of medical records. There are a lot of investment in the construction of electronic health records: tools to collect the information and analysis of the historical evolution of the clinical problems of each person; for the tracking of the disease, of the progress and actions taken to hospital with a focus on last event, for patient information collected over time, etc. None of the state of the art solutions allows the management of the daily care work in a collaborative and safe way, with cross-media information that are exchanged between the team that assists the disabled person and the family.

Coll@bora is providing strong advantages for: (i) relatives interested in facilitating relations with the management team, (ii) associations in order to offer a better service to the families and people with disabilities by providing a collaborative support to the involved teams, but also to manage the wealth of knowledge, to support the training of the staff, etc.

Coll@bora provides a secure collaboration tool for the teams and for the association to support the families and the disabled people.

Main results of Coll@bora will be: (i) a platform of collaboration and management for the teams (made up of parents, family members, physicians, physician assistants, volunteers, etc..) to support the invalids in accordance to privacy, (ii) web applications, SmartTV and mobile for the support to assistance and service operators, family, and impaired, (iii) validator of the solution is Modi di Dire team.

The *Modi di Dire* **Association and NPO/ASL is the primary trial of Coll@bora.** The possibility of using **Coll@bora** collaborative protected system solves several problems of social communication. For example, *Modi di Dire* applies models, tools and procedures for care and support for disabled young people with communication problems. The association encourages parents and the community, to use various approaches to collaborative and augmentative communication. Operators Association Ways to Say, local services, ASL, associations and day care centers, frequented by children who participate, collaborate for this purpose. This network is trying with difficulty to create formalized arrangements to establish a stable comparison of cooperation between the various figures of reference, involved with their specific role in the creation of a rehabilitation program, which sees players such as psychiatrists, psychomotor therapists, support teachers and parents of children with disabilities, creating for each disabled person a specific support team, which may change over time as needed and according to the parents and the doctor.