

# ACCESS: Accessibility to clinical care for people with ASD through anxiety management by using personalized applications and IoT<sup>1</sup>

## Extended Abstract

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### I. INTRODUCTION

Human rights include the right to access quality health services without any discrimination. Unfortunately, healthcare access for any person, regardless of their functioning and abilities, is still a broken right in many countries worldwide [WHO23].

Autism Spectrum Disorder (ASD) is a neuro condition that severely compromises the communication and socialization areas, and the ability to successfully decode and interact with the surrounding world. It is characterized by a deep heterogeneity at the behavioral level, with notable inter-individual differences and features [BON24]. Unfortunately, the number of adults diagnosed with ASD is rapidly increasing [NAR20]. This is leading to a growing population of adults with ASD in need of medical attention.

Persons with autism experience more health conditions and have a shorter life expectancy [TAY23]. Emotions such as anxiety, fear, discomfort, represent common access barriers to healthcare services [RAY17]. Without knowledge of functioning and peculiarities of people with autism, without the adoption of familiarization protocols and the ability to deliver anxiety-containing strategies, clinicians and healthcare professionals are limited in their actions and support for this population. The ACCESS project aims at improving care paths for this vulnerable group.

ICT represents an effective way to support people with autism in everyday life, including healthcare [DOH20, HAS21]. However, to be effective, efficient, and satisfactory ICT tools need to be: 1) accessible and usable for people with ASD and 2) seamlessly integrated in

clinical protocols, which have to be properly adapted to incorporate and exploit technology. This requires a codesign process involving all stakeholders from the early phase of the project, in order to understand the process, collect data, and discuss problems from a different perspective. Designing with users with ASD usually rely on feedback from caregivers, such as parents, teachers, and care workers [ROB21] but this practice, including a mediation, cannot exploit the full potential of the codesign approach. Sensorial and communication barriers can hinder participation of people with severe autism in codesigning tools. However environmental and physical devices for stress detection can offer very valuable data. More awareness and education of clinicians is another critical essential aspect. Without accessible ICT tools, healthcare professional education and clinical protocols adapted for dealing with this population the intervention can be limited [BON23].

### II. THE ACCESS PROJECT

ACCESS is a project funded by the National Research Program and for Projects of National Interest (PRIN-PNRR) that began on December 2023.

The project aims at developing technologies to support the management of anxiety of people with ASD when dealing with clinical treatment. These technologies will be integrated into a tool named ACCESS that will be tested and evaluated in two pilot studies, namely that of dental care and ENT care (Ear, Nose and Throat). The key of ACCESS is that people with ASD can be introduced into clinical treatment by following a personalized path, which takes into account their needs and timelines, and that makes use of a number of digital tools, like serious games to get accustomed to the clinical path, or tools to record, in the form of multimedia material, the patient's experience so that they can analyze and relieve it later.

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ACCESS builds over more than a decade of research conducted by the members of the teams on technological solutions for disability, and it extends their previous achievements under many different aspects. In particular, with ACCESS we plan to adopt a methodology of participatory design involving since the early stages a number of stakeholders for the design, test and assessment of the implemented tools. Secondly, ACCESS will use sensors for the assessment of the anxiety level and stress of the patient with ASD during clinical care in an innovative way, and finally, we will enrich ACCESS with real-time personalization that makes use of those sensors. Leveraging our network of connections with stakeholders that include associations for ASD, hospitals, caregivers, medical specialists and “Aziende Sanitarie Locali”, we will hence create focus groups assisting all the phases of design, development and assessment of ACCESS, and we will set up two pilot studies with real patients with ASD demonstrating the effectiveness of ACCESS in the cases of dental care and ENT care.

The team comprises the University of Pisa that develops the main ACCESS tools, Politecnico di Milano that develops the sensors to monitor anxiety level and stress of the patients, the University of Torino that develops the real time personalization capabilities of ACCESS, and the National Research Council that develops the participatory methodology for the design, development and assessment.

### III. CONCLUSIONS AND STATE OF THE PROJECT

The project has just completed the preliminary phases of reviewing the state of the art and analyzing and collecting an initial set of requirements for the next phase of design. In particular, the collection of requirements has been conducted by meetings with specialists and visits of technologists at the Audiology and Phoniatrics Clinics (OPC) at Azienda Ospedaliero-Universitaria Pisana (AOUP). The result was a detailed analysis of the environment, of the procedures (especially of the clinical path) and of the exams conducted in the clinical paths. This step will be next refined by a focus group with specialists, technologists and researchers that the project will set up in the next months.

A second set of collected requirements concerns the detection of the stress of the patient. This functional element of ACCESS will be implemented by means of a sensor developed by Politecnico di Milano specifically to this purpose.

From a point of view of the engineering of the system, the consortium is adopting an iterative model, and we expect the first version of the prototype to be available on the

short term in order to proceed through tests with end users (both patients and specialists), for the next step of development.

In parallel, as the validation of the system will necessarily involve end users, the consortium is engaged in the application to the ethical committee for the approval of the project, and in designing the system in compliance with the GDPR regulations.

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