Scientific synthesis

“Developing and implementing a framework for evidence-based practice for technology relevant for autism”

BETA
BUILDING EVIDENCE FOR TECHNOLOGY AND AUTISM

Foreword

Throughout this document, we use the term autistic community to refer to people who have a diagnosis of autism and autism community, to refer to the broader community affected by autism, including families and care-givers. Close collaboration between academic researchers and stakeholders from the autism community was crucial to our research project. We opted for a participative approach where experts from the autistic and autism communities were asked to co-construct a methodological framework with the research community to address issues related to digital technology for autism.

During the last two decade, parents, clinicians and researchers have noted the great benefit of digital technologies as therapeutic and educational tools for people with Autism Spectrum Disorders (ASD). The clinical and scientific literature emphasizes the assets of technology for supporting autistic individuals, such as offering a predictable environment, rich stimulations, reduced social demands and portability. There are however potential risks that need to be acknowledged, such as excessive use, risks of neglect or the rapid obsolescence rate of technology. Harm can also be caused by wasting resources, in terms of time and money, on interventions which do not deliver benefit and are not efficient.

Until now, the autism community lacked a mechanism whereby autistic individuals or their care-givers could easily gauge whether a technology was beneficial and assess possible harm. Due to the exponential proliferation of technological supports for autism, the current situation is one where commercially available digital supports are often not evidence based whereas technological supports with an evidence base are not commercially available. The autism community is therefore in need of a practical framework to be able to identify evidence-based practices in the field of technology-based supports. Expertise on the matter can be drawn from academic research, but should also be sought from the autism community itself.

With the autism community, we co-developed an accessible framework to enable an understanding of the evidence base for digital interventions. To enable the autism community to effectively contribute to the co-design of the EBP framework, we used an anonymous online participatory design that enabled experts originating from the autistic and autism communities to work with researchers on equal standing. Together, they were able to make recommendations for how digital technologies can facilitate inclusion and promote respect for autistic people.

Summary of the final report

Introduction: There has been an exponential increase in the availability of digital technologies to support the autistic community. However, there is no mechanism for users and their caregivers to easily access evidence demonstrating that such technologies are beneficial. According to recent scholarly reviews, digital technologies for autism with an evidence base are not commercially available, and commercially available technologies often lack a solid evidence base. Evidence-based practice (EBP) is central to medical disciplines and is increasingly being extended to psycho-behavioral interventions for autism. EBP has been instrumental in promoting and standardizing evaluation methods such as Randomized Control Trial methodologies. In the present project, we sought to co-develop with the autistic community a framework for assessing evidence supporting technology-based interventions.

Methods: Our methodology was twofold: (1) We developed a scale, called User-Centered Design for Support (UCDS), to assess the extent to which the design of a digital technology is informed by empirical data, autism domain expertise and the scientific literature. We evaluated our scale and an EBP scale specifically designed for autism interventions in a randomized sample of 211 relevant published reports. (2) We conducted a Delphi study to elicit recommendations from a panel of experts (researchers, developers, autism community) on digital technology interventions for autism.

Results: Inter-Rater Reliability for the two tested scales was good to excellent and the UCDS classification of weak and strong studies had high correspondence with an independent human expert. The majority of reviewed articles received a “weak” EBP rating and a medium to low score on the UCDS scale. The Delphi study yielded recommendations for improving the following three aspects of technology for intervention: reliability, engagement, and efficiency.

Discussion: The framework and scales we developed, and the resulting recommendations we received, can help members of the autism community determine the evidence base before adopting technology-based interventions.

Presentation of the application supports

A website (www.beta-project.org) has been developed to host the application supports, which are all openly accessible. Application supports (except videos) can be found in the accompanying documents. These documents are stored in three different folders according to their language: EN for English, FR for French and ES for Spanish. These documents are listed and described in the table below. This table uses serial numbers to identify the different application supports.