What we talk about when we talk about stakeholders in the Autism Spectrum Disorder case

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Abstract

Digital transformation in Health Care contexts is an emerging field still suffering from several limitations due to – among others – a not deep enough analysis of stakeholders' perspectives. This situation is particularly heavy in the Autism Spectrum Disorder realm, where the variety of stakeholders to be supported and the huge numbers of contexts to be considered make it difficult to outline a clear shared design goal that unites the interests and the activities of all stakeholders. In this position paper we address these issues by (1) overviewing design difficulties deriving by fragmentation, lack of coordination among the people involved in the care of ASD persons, and lack of ad hoc design approaches, and (2) outlining preliminary results as to the prioritation of stakeholders and the distribution of power, support, influence among them.

Keywords

autism spectrum disorder, digital transformation, socio-technical, value creation, stakeholders

1. Introduction

Digital transformation in Health Care (HC) contexts is still an emerging field seeking to health care process improvement. Notwithstanding the huge potential in ameliorating the overall HC operational effectiveness and efficiency, it has been observed that the work in the field tends to focus more on the technologies that are being introduced rather on a strategic or structural perspective [18, 23]. This is not to be considered really surprising, being coherent with the need-satisfaction curve of a technology showing an "unfilled need" area at the beginning of the curve [54,55]. Anyhow, the path towards technological innovation/transformation balancing the three legs of technology, user expectation/experience, and business/marketing is not to be taken for granted without some action.

Generally speaking, digital transformation can be described as "*a process that aims to improve an entity by triggering significant changes to its properties through combinations of information, computing, communication, and connectivity technologies*" [51]. One may observe that a process like this is in line with Clegg's view on new technologies offering *"opportunities to work in more interconnected ways, providing scope and catalyst for new working arrangements"* [11] under a socio-technical perspective. Among others, such perspective would properly consider the relationships between the organization, the people enacting business processes, and the systems supporting these processes [4, 51, 35]. In the HC case, however, the impact on the multiple involved stakeholders is recognized as being not yet adequately highlighted [23, 37], though a multi-stakeholders perspective would instead be critical to properly understand how, in practice, the various players of an HC

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ecosystem (e.g., patients, pharmaceutical companies, hospitals, public agencies) exploit technologies, experience improvements in the quality of care, and, overall, benefit of value creation. Actually, it has also been observed that value in HC is still not completely measured and understood, also due to the multiple and often conflicting goals of the huge variety of stakeholders involved, including access to services, profitability, high quality, cost containment, safety, convenience, patientcenteredness, and satisfaction [10, 43].

1.1. The Autism Spectrum Disorder case

This is for example the case of the Autism Spectrum Disorder (ASD) realm, a field in which the effectiveness improvement potentially provided by digital transformation processes would be crucial, given the dramatic increase of ASD prevalence [17] and the resulting costs on the society.

The multi-stakeholders perspective is particularly complex in the ASD case. The heterogeneity and the complexity of the condition and its impact on almost all the aspects of the life of an ASD person require an overall support involving multiple specialties and interventions, where the benefit of a single intervention may depend also on the effectiveness of other interventions throughout the care cycle and the care network. The support to ASD persons therefore involves a complex network of stakeholders that need to interact not only with the ASD person but also with each other, with a complex map of information flow and many-to-many communication channels [48]. The effectiveness of the care coordination impacts on the effectiveness of the whole ASD ecosystem and is therefore a crucial aspect deserving special attention within the context of digital transformation processes.

Convergence and contamination of knowledge and technologies coming from different fields may indeed provide for an acceleration of the process and lead to so far unexpected and somehow unimaginable results, allowing both to support existing value propositions and to create new value propositions. A combination of state-of-the-art technologies coming, e.g., from Information Systems, Big Data, Artificial Intelligence, Internet of Things, Sensors, Virtual Reality, Augmented Reality, Digital Twins (just to mention a few) would allow for (1) significant effectiveness improvements as to taking charge of the ASD person, testing, assessment, care management and network coordination, (2) significant increase in the efficacy of rehabilitation interventions, (3) innovative prosthetic intervention impossible otherwise, able to ease the social interaction of ASD person, (4) simulation and prediction capabilities, impossible otherwise, able to ease the intervention construction, to increase the probability of its success, and to support caregivers by anticipating the behavior of the ASD person in specific situations and help them in implement appropriate countermeasures, (5) approaches to crisis management unimaginable otherwise (we refer to [48] for a discussion on these points).

The last decades have indeed shown an ever-growing interest on ICT-based solutions for problems related to ASD, due, among others, to the continuous advances in technologies favoring the development of cognitive rehabilitation tools, education tools, and assistive technologies in general (see, e.g., [7, 19, 20, 40, 47]). On the other hand, the attention to care management and care network coordination has been so far definitely insufficient, making also extremely difficult to achieve longitudinal studies on large users' samples. We posit that digital transformation in ASD care should make some steps forward, guided by a shared goal that unites the interests and the activities of all stakeholders and by the vision of an all-round ICT-supported ASD care, resulting in substantial changes to the overall organizations of the ASD person's network [48]. Though there is a consolidated and shared view on which ASD stakeholders have to be involved [48, 52, 53], difficulties in the analysis arise due to (1) the great number of heterogenous contexts (families, health center and institutions, school settings, work settings, recreational contexts, and a huge variety of social settings) to take into consideration, (2) the great variety of groups with similar needs (from the ASD persons to various types of professional and not professional caregivers and professional operators in the above mentioned variety of settings), (3) the harmonization of their (sometimes) conflicting expectations [28, 29, 36] and (4) their prioritation in the design process given that all these perspectives are usually reported as lists or networks with associated needs and expectations and lack of salience information as to the digital transformation.

These issues must be addressed to pave the way towards the possibility of accurately measure the value resulting from the digitalization, given that, according to [43], determining value in HC requires to track the patient outcome and cost longitudinally, taking into account all services and activities that jointly success in meeting their set of needs.

1.2. Goal and structure of the paper

In this position paper we aim at outlining a possible contribution in this direction by analyzing the combination of issues that so far hindered the transition from "emerging" to "established" in the ICT-supported ASD care field. To this end, after highlighting in Section 2 stakeholder-related difficulties arising during the design of ASD centered ICT solutions, in Section 3 we sketch results from preliminary studies carried out within the framework of the activities of TetaLab (TechnologyEnhanced Treatment for Autism Lab), a multidisciplinary laboratory of the University of L'Aquila; this study aims at identifying stakeholders for all-round ICT-supported ASD care and classifying them according to a salience theory [31] to provide stakeholders' prioritation guidance. Finally, in Section 4 we draw the conclusions by outlining future research activities and by reflecting on the desirable evolution of the field and the necessary actions.

2. Issues in dealing with stakeholders of ASD oriented ICT applications

Autism Spectrum Disorders (ASDs) are characterized by fixated and repetitive patterns of behaviors, restricted interests, and social/communication deficit [1], which severely interfere with the processes of building social relationships, integrating into community, and functioning occupationally. The term spectrum suggests the multidimensionality and heterogeneity of the disorder, whose manifestations vary considerably in relation to the severity of the symptoms, the level of development and the chronological age [1, 24, 26].

Recent studies report that the increase in prevalence estimates up to 1-2% [17], with 1 in 68 in the USA [3] and around 1 in 100 children in Europe [2]. Such increase may be linked to a variety of factors: greater public and professional awareness, changes in diagnostic criteria and in the use of screening scales, increase in screening in children and adults, more accurate evaluation, and more accurate diagnostic procedures [17, 49]. Whatever the reasons, the growing number of people receiving the diagnosis, considering that the majority require continuous and lifetime assistance in diverse areas, entails significant costs for individuals with ASD, families, healthcare system and society in general [6, 45].

The "costs" refer both to the economic impact on public health and school system and to the burden on families and caregivers in terms of time, effort, money, stress and, more generally, of quality of life [26]. Support for ASD people and their families is particularly complex, especially if individual differences are considered [24], and requires shared and synergistic work between different professional figures.

2.1. Stakeholders' fragmentation and consequences on digital transformation

The scientific literature [8, 14, 25] highlights fragmentation and lack of integration between the different fields of intervention and care (e.g., medical, educational, recreational), which end up in further burden for the families. The lack of adequate collaboration between all the figures responsible for taking charge, management and rehabilitation of the person results in negative consequences on the quality of life and on the results of the intervention.

A shared decision-making and care-management system would certainly help in promoting a collaborative process for care planning through an ongoing dialogue between the ASD person, caregivers, doctors [5, 22] and local services, allowing to mitigate the negative effects of the fragmentation. Unfortunately, whereas ICT-based solutions could certainly boost such a collaborative approach, the lack of integration between fields of intervention resulted so far in a similar fragmentation of technology-based solutions and to the production of a variety of tools separately addressing, for example, psychotherapy, social skills and communication training, rehabilitation, vocational readiness training, just to mention a few areas of intervention [40].

It is worth noticing that the main interest has been so far on the so-called "technology-based treatment" rather than on health management and care network support, thanks both to rather consolidated literature results on the efficacy of the visual modality for ASD people [30] and to the continuous advances in computer graphics and input devices and the development of affordable devices offering "synthetic experiences" at various levels of immersion: the current technology makes it possible to shape synthetic worlds promoting role-play and replicating social situations, perceived as (predictable) "safe" environments by individual with ASD, where they can learn social skills to be later transferred into the real world [47].

Anyhow, notwithstanding the general consensus on the efficacy of Virtual Reality (VR), Augmented Reality (AR), and multimedia technologies in ASD treatment, scholars still underline (1) the lack of robust methods and techniques for assessing the effectiveness of the proposed approaches, (2) the lack of proof for generalization (in many cases proposals are at proof-of-concept level and generally evaluated with too limited clinical groups), and (3) the need for more research within real educational and clinical settings to make it possible to conduct longitudinal studies (e.g., [19, 20]). Therefore, even with state-of-the-art solutions, in many cases the value deriving from the digital transformation cannot be adequately measured even for a specific intervention.

In [48] we discussed the necessity of a radical change of perspective not only in the studies on technology-enhanced ASD treatment, but also – and beforehand – in the overall management of the ASD person, from testing/diagnosis to treatment/assessment and support on a daily basis in a variety of settings (e.g., home, school, working place, recreational contexts), to be re-designed under a SocioTechnical (ST) approach taking into consideration all stakeholders and their needs. This would lay the foundations for large-scale longitudinal studies in a variety of settings, as well as for an all-round support to the ASD person, taking into considerations all involved actors.

Given the resulting complexity of the overall ST system and the heterogeneity of its components in terms of activities, involved stakeholders, contexts of use (e.g., clinical setting, home setting, schools), and services (e.g., medical guidance, crisis management, real-time monitoring), the ambitious goal of ICT-based all-round support to ASD persons necessarily requires (1) an evolutionary vision of the system and its offered services and (2) adequate design methodologies based on the co-construction of knowledge by the variety of involved actors to maintain the focus on the different involved factors, to overcome the fragmentation issues, and to boost beneficial changes in ASD care processes.

2.2. Difficulties in the participation to the design process

Unfortunately, the problems deriving from the fragmentation between the different fields of intervention on the stakeholders' side have been so far amplified by the lack of clear methodological approaches on the system developers' side.

Researchers agree on the fact that engaging the perceived beneficiaries in the design process potentially facilitates social acceptability of the designed product (e.g., [38]) and that therefore the design process has to be based on the co-construction of knowledge by a variety of stakeholders who highlight the different contextual factors involved: psychologists, educators, computer scientists, parents, care-givers, and ASD people (often children) should all be involved with different roles in the design process, to achieve successful technology design (see, e.g., [9]).

Anyhow, though integrating research within real-world practices is mandatory for developing evidence-based therapeutic and educational interventions, such integration is not without challenges. There exists a gap between ASD researchers and computer scientists, who may have not only different working approaches but also different expectations on what the design outcome should be [7, 9]. Furthermore, while all stakeholders generally wish to contribute to design ideas and to provide feedback about relevance and usability, not all of them like to be responsible for definitive design decisions [28, 29]. Another difficulty is due to contrasting points of view among different group of stakeholders, as in the case of parents raising children with autism and autistic adults in the workplace, as discussed in [36]. Moreover, one should also remark the recent reflections of the scientific community about the inclusion of ASD persons in the design process with new roles [28, 56].

Furthermore, despite literature on ICT-based ASD treatment reports on a significant number of experiences based on participatory design (see e.g., [9]), the main endeavors have so far been in the engagement of the autistic community (ASD people and caregivers) with less concern for harmonization of the different professionals involved in the multidisciplinary design process.

Within such a complex design scenario, the lack of clear ad-hoc methodological approaches is viewed as a crucial issues by many researchers: in [42] authors observe that one of the challenges in developing ICT tools for ASD people is to coordinate the diverse and divergent perspectives of the involved stakeholders; in [7] the need for more structured approaches and well-established guidelines for design is advocated; in [39] authors observe that partnership with stakeholders requires a rethinking of how research is designed.

3. Supporting coordination and prioritation

The analysis of the issues discussed in the previous section reveals stakeholders' prioritation and coordination issues and the consequent necessity of adequate methodological tools to guide designers in addressing them. In this section we discuss some preliminary results that we achieved in this direction.

3.1. Stakeholders' prioritation

The study of stakeholder identification to connect it explicitly to value creation has received growing attention in the last decades [16, 21, 31, 32, 33]. Due to the economic importance of stakeholders in creating and distributing value [16, 32, 50], there is growing interest in theories that help to identify and classify organization's stakeholders. For example, starting from Freeman's general definition of stakeholder as "any group or individual who can affect or is affected by the achievement of the organization's objectives" [15], Mitchell et al [31] developed a theory of stakeholder identification based on the possession of the attributes of *power*, *legitimacy* and *urgency*, with respect to the process, mission and goal under consideration. Based upon this typology, they further proposed a theory of stakeholder salience for guiding designers in addressing prioritation issues.

According to Mitchell's *salience theory*, the different combinations of the three attributes result in seven classes of stakeholders, which can be grouped into three categories (see also Figure 1): three *low-salience* classes with only one of the three attributes, called "latent" stakeholders (areas 1, 2, 3); three *moderately salient* classes with two attributes, called "expectant" stakeholders (areas 4, 5, 6); and a *highly salient* class with all three attributes, called "definitive stakeholders" (area 7). An "expectant" stakeholder (whether "dominant," "dangerous," or "dependent") can achieve a "definitive" status by acquiring the missing attribute.

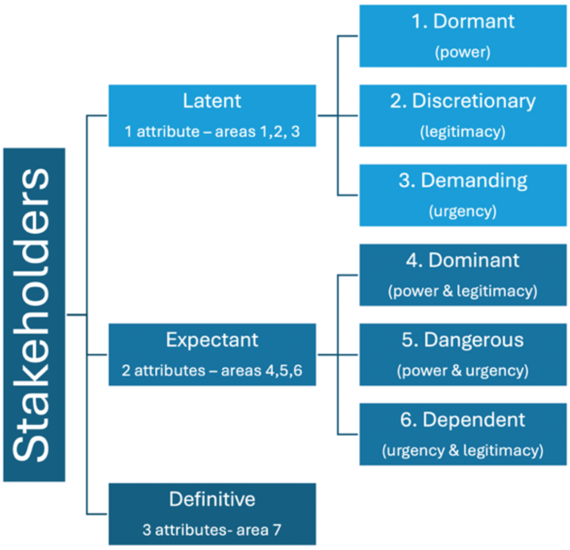

Figure 1: Stakeholders classification according to Mitchell's theory of salience.

Building on the results of interviews with operators and families [42] combined with observational studies [48] carried out within the framework of the activities of TetaLab in cooperation with the Regional Reference Center for Autism of the Abruzzo Region (involving medical doctors, psychologists, families and caregivers), we identified the stakeholders of an all-round ICT-supported ASD care, presented in Table 1.

Table 1

Expected stakeholders of all-round ICT-supported ASD care

General type	Stakeholder group
Users	*ASD persons*
	High-impact caregivers, who in most cases correspond to parents;
	Medium/low-impact caregivers
	National Health Service (NHS) /Regional Health Service (RHS) workers, such as pediatricians, general practitioners, child neuropsychiatrists, psychiatrists, healthcare professionals (psychologists, social workers, rehabilitation therapists), and other NHS specialists in consultation (outpatient, hospitalization, and emergency care)
	Sector-specific workers (rehabilitation facility workers and local social workers)
	Teachers (regular and support)
	Company Tutor
Others	*Regional Health System*
	Social Security System
	School System
	Associations
	Companies
	Agency for Digital Italy (AgID), coordinating all Italian public administrations as to the achievement of the objectives of the Italian digital agenda

We then classified identified stakeholders according to the concept expressed in Mitchell's theory (see Figure 2), based on their possession of one, two, or all three of the following attributes:

- the stakeholder's *power* to influence the process of taking charge and caring for the ASC individual,
- the (moral) *legitimacy* of the stakeholder's relationship with the process of taking charge and caring for the ASC individual,
- the *urgency* of the stakeholder's claim regarding the process of taking charge and caring for the ASC individual.

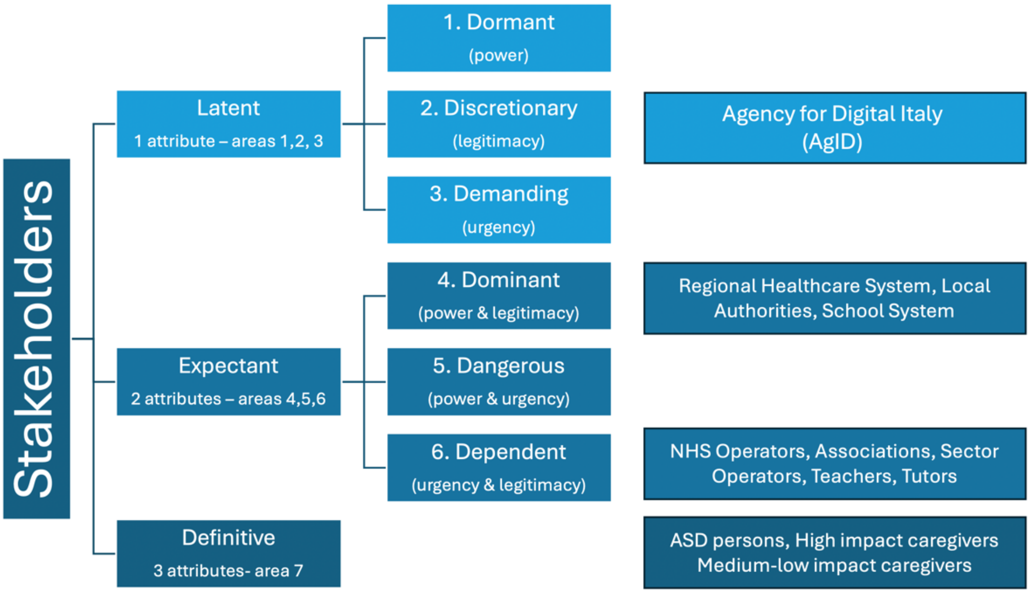

Figure 2: Mapping of identified ASD stakeholders onto the Mitchell's theory scheme.

Based on this result, one may observe that the engagement of the autistic community (ASD people and caregivers) pursued so far by ICT-driven projects as primary goal was indeed methodologically correct (being them high-salient definitive stakeholders). On the other hand, the saliency scheme also shows that it is time to include in the digital transformation process:

- the different professionals of the ecosystem (dependent stakeholders with *urgency* with respect the process of taking charge and caring for the ASC individual), and
- local authorities such as Regional Health System School System (dependent stakeholders with the *power* of influence the process of taking charge and caring for the ASC individual), within the framework of (hopefully coordinated and harmonized) multidisciplinary design processes.

3.2. Stakeholders' coordination

As to coordination, at least in the case of ICT-based solutions for ASD *treatment* one may benefit from results achieved in other fields where multidisciplinary teams must conceive, implement, and validate novel learning methods.

In this direction, in previous studies we proposed a structured iterative methodological framework denoted "*deejay*", based on Action Research and aimed at providing a general guideline for organizing the activities of a multidisciplinary team. The approach, deriving from our Action Research experiences in learning-oriented projects, blends the Susman and Evered AR cyclical process model

[46] and the tandem approach proposed in [27], and provides an additional level of detail about the design of the overall process in terms of time scheduling, information exchange, actors involved, emphasizing roles and responsibilities of involved actors. In particular, the deejay framework provides guidance in the tricky case in which the outcome of the research cycle is the problem-solving method of the real-world problem (a common situation in projects aimed at developing innovative learning approach).

The framework, originally developed in Technology-Enhanced Learning contexts, has been afterwords successfully adopted for a project carried out by TetaLab in cooperation with the Regional Center of Autism and aimed at developing a personalizable ASD-oriented Augmentative and Alternative Communication tool [12]. While for details on the framework we refer to [13], here we observe that this design tool is adequate for addressing single technology-enhanced treatment interventions but does not provide a general unifying solution for our vision of all-round digitalized ASD care services.

4. Conclusions and future work

In this position paper, we overviewed fragmentation, coordination and prioritation difficulties arising in the analysis of the stakeholders for ASD centered ICT solutions in general and for our ambitious vision in particular, aiming to an ICT-enhanced all-round support to ASD persons. A socio-technical system of this kind is necessary for enable longitudinal studies not only to validate technologyenhanced solutions for ASD treatment, but also to lay the basis for evaluation of values created by the digital trasformation.

As first steps in this direction, we reported here preliminary results of studies carried out in cooperation with the Regional Reference Center for Autism of the Abruzzo Region (involving medical doctors, psychologists, ASD persons, families and caregivers) aimed at addressing two specific design issues revealed by the analysis of stakeholders:

- lack of saliency information, causing insufficient support to stakeholders' prioritation,
- insufficient engagement and harmonization of the professionals involved in the ASD care.

More specifically, as to the former point we reported results about classification and prioritation of stakeholders in the Italian organizational situation according to a salience theory [31], while, as to the second point, we sketched the main characteristic of a methodological structured framework providing a general guidance for the organization of the activities of a multidisciplinary team.

These contributions are still in a preliminary stage, also due to the fact that digital transformation in the ASD case is still a quite immature field. The next steps in our research in this direction will be carried out in the near future by TetaLab projects, in particular within the framework of the Research and Development programs for "Innovative applications of virtual and augmented reality for people with an autism spectrum condition (ASC)" handled by the Ministry of University and Research and the Agency for Digital Italy (AGID)-Smarter Italy.

As to the limitations of present results, it must be observed that the ASD case may be regarded as paradigmatic for application domains in which promising ICT solutions are still at their infancy. This may imply the need of downsizing some experiment parameters considered standard otherwise, e.g., in terms of technological maturity of results (in many cases still at the stage of proof-of-concepts) and of size of users' groups involved in the evaluation. While these limitations might suggest that preliminary results are not of interest for the scientific community, we believe that the relevance of the problem (in terms of increase of prevalence, needs and expectations of the ASD community, and high costs on the society) must suggest that the scientific community takes actions for encouraging and favoring studies of this kind in the mainstream of scientific research *notwithstanding the initial limitations*, while the involvement of stakeholders with the power and the legitimacy of boosting digital transformation deliver desired results. For example, agreements with Health Care Systems and

Health Care associations, along with the digitalization of ASD care management, are among the most powerful weapons to lay the basis for, among others, the recruitment of large groups of homogeneous participants in evaluation studies and the possibility of conducting longitudinal studies, which would lead to mature studies, as the ASD community deserves.

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Declaration on Generative AI

The author(s) have not employed any Generative AI tools.

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