Implementing Intervention Studies with Autistic People and Digital Technologies in Natural Settings: a Guide to Best Practice

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Abstract

With the rapid advance of technological developments and the ongoing increase in the number of studies that evaluate the efficacy of its use in autistic people, the need arises to do so with increasing scientific rigor and provide researchers and participants (e.g., professionals and families) in these studies with a framework that guides them in this practice. This chapter presents a ten-steps best-practice guide to successfully implement intervention studies that are aimed at improving skills in autistic people and use digital technologies. Key aspects such as selecting the most appropriate technology or applying the most suitable research design are included in the guide, which is based on the authors' perspective to empower autistic people and professionals who work with them, with the ultimate aim of bridging the gap between science and practice. This guide is especially valid for studies aimed at autistic people who also have intellectual disability, as in every step, the needs of this vulnerable collective are considered.

Keywords: Intervention Studies; Autistic Individuals; Digital Technologies; Natural Settings; Best Practices.

With the rapid advance of technological developments and the ongoing increase in the number of studies that evaluate the efficacy of its use in autistic people, the need arises to do so with increasing scientific rigor and provide researchers and participants (e.g., professionals and families) in these studies with a framework that guides them in this practice. This chapter presents a ten-steps best-practice guide to successfully implement intervention studies that are aimed at improving skills in autistic people and use digital technologies (e.g., tablet applications or augmented reality games). By intervention study we refer to any psychoeducational action which implies the implementation of a series of sessions with one or more improvement targets. This guide is based on the authors' perspective to empower autistic people and professionals who work with them, with the ultimate aim of bridging the gap between science and practice.

1. *Purpose of the intervention.* It is of paramount importance to have a clear objective of what the intervention is for. What is the skill that needs improvement? What do we and what do we not know about this skill? What kind of change would be considered clinically significant? Previous intervention studies as well as systematic reviews and meta-analyses available in the field can be highly informative (e.g., Soares et al., 2021). One should also have a good understanding of the social validity component: Is the chosen target skill really needed for the participant? For instance, would an improvement in this skill actually help their development or social inclusion? Besides, given the time and possible other costs associated with the implementation of an intervention, there is an important ethical component: Is my intervention purpose important enough to justify participation instead of other activities that could be equally beneficial? This question calls for a cost-benefit analysis. Finally, given its potential contribution to the validity of the technology-mediated intervention (TMI) study, one should consider involving autistic people in the cocreation of the intervention and study design, following well-established principles of participatory design research (Benton, Johnson, Ashwin, Brosnan, & Grawemeyer, 2012).

2. *Technology selection.* In line with the previous, a proper technology selection is always necessary, and this should be done in the context of an appropriate person-technology matching. As suggested by Odom

et al. (2015), researchers should check if there is a good fit between stakeholders involved (autistic participants as well as practitioners and caregivers who are supporting these participants in their technology use), the technology selected, and the activity in which that technology is to be used. If a particular technology is going to be used as the central element of the intervention, its usability needs to be tested prior to the start of the intervention study, as a low usability score would negatively affect the desired intervention effect (Mazon, Fage, & Sauzéon, 2019). Finally, the Technology Readiness Level (TRL; European Commission, 2014) of the digital technology should be compatible with the research questions formulated, with the setting where it will be tested and with the research design to be followed (see the next step: '3. Research design').

3. *Research design.* To evaluate the effect of a TMI, a wide range of research designs can be applied. Traditionally, randomised controlled trials (RCT) have been considered the gold standard for effectiveness research as it allows for establishing a cause-effect relation between the intervention and outcomes of interest. However, a high-quality RCT requires many resources including samples of sizes that in the context of autism intervention research are not always feasible. For example, in a simple experiment with an experimental treatment group and a control group in which participants undergo individual intervention and have one outcome measurement at the end of the study, to have an 80% chance of detecting a moderate effect, one would need a total of N = 128 participants equally divided over the two groups (Leppink, 2019). One can considerably reduce the number of participants in an experiment by increasing the number of measurements per participant (Leppink, 2019, 2020). Besides, designs that include series of measurements both before and after intervention, can help to establish trends in outcome variables of interest prior to intervention (e.g., practice effects) and after intervention (Maric & Van der Werff, 2020) and can help researchers to study non-linear trajectories in skill development (Leppink & Pérez-Fuster, 2019). For these and other reasons, single-subject designs (SSDs, also called single-case designs, SCDs; Parker & Brossart, 2003; Tanious & Onghena, 2021; Van de Schoot & Miocevic, 2020), such as reversal or multiple baseline designs, have become more and more popular in the field as an alternative to traditional group-based experiments with one or two measurements per participant (Leppink, 2020, 2022; Maric &

Van der Werff, 2020). SSDs allow for analysing data both at group level (as in traditional experiments with larger groups but fewer measurements) as well as individually, and the latter is highly desirable in many TMI studies. If well conducted, applying all possible controls, SSDs do not necessarily offer less methodological rigor than traditional experiments and can still contribute to the establishment of evidence-based practices (Reichow, Volkmar, & Cicchetti, 2008). In any case, it is the research question that should guide the selection of the research design, and what constitutes the 'gold standard' method should be the one that reliably provides the information needed, and what can be done in the context and individual situation at hand (Cartwright, 2007).

4. *Autistic participants.* To select the autistic individuals who are participating in the study, it is necessary to establish inclusion and exclusion criteria. These criteria, which in our field often include aspects related to age, sex, a specific diagnosis, the lack of a skill and the presence or absence of previous technology use, should be carefully selected according to the research question and then applied to the potential participants to get the final sample. For the criteria to be adequately applied, it is fundamental to previously gather information from participants directly, using standardised assessments, for instance, and/or indirectly interviewing the people who know them best, such as their family or the professionals who work with them. Obtaining information with regard to their strengths and weaknesses, desires and fears, interests and needs, sensory issues and communication system, among others, is important not only for sample description purposes but also to make all the necessary adaptations, especially when using highly adaptable or customised technologies.

5. *Other study participants.* In line with the previous and based on the Person Centred Planning (PCP) approach (Sanderson, 2000), the intervention study should consider the participation of all the agents who can positively contribute to the success of the intervention, including family and community members, professionals and/or peers. For example, it is very common to include teachers as participants in TMI studies aimed at improving skills in schools. This is because the children's teachers are the ones who most likely know how to teach them best so they first get trained by the researchers on how to deliver the intervention and then

the teachers implement the study sessions to the children (Pérez-Fuster, Herrera, Kossyvaki, & Ferrer, 2022). This situation can be facilitated by implementing the intervention in natural settings such as a school where teaching-learning situations generally take place rather than in non-natural settings such as a university laboratory, which generally require a familiarization process and can make generalization more difficult.

6. *Study materials.* A part from the digital technology formed of hardware (e.g., smartphone, personal computer) and software (e.g., mobile app, augmented reality technology game) that is used to deliver the intervention, there are many other materials that can be used in this type of intervention study. For instance, a social validity questionnaire can be addressed to families and professionals to evaluate the importance of the target skill as mentioned previously. In addition, a procedural fidelity protocol (Ledford, & Gast, 2014) and a study calendar can be created to help the interventionists to meticulously follow the study sessions as planned. When neither standardised nor non-standardised assessments are available for what we aim to measure, ad hoc assessments can also be created, although the associated limitations also need to be considered. A satisfaction questionnaire addressed to participants can be a valuable tool for the researchers to learn about their experience interacting with the technology beyond the effects of the intervention on the target skill. All these materials, together with the participant inclusion and exclusion criteria discussed in step 4, the intervention procedures and the consent forms that participants – or legal guardians in case of children or individuals with disability – need to sign, should be submitted to acquire approval from an official Ethics Committee or Institutional Review Board, which may be part of the institution at which the study is to be carried out.

7. *Interventionist training.* To aim for the highest ecological validity, the intervention is best delivered by someone who knows the autistic participant well, such as the teacher in a school setting. For this, researchers need to implement specific training to teach the interventionist (e.g., teacher) how to use the study materials, including the procedural fidelity protocol, how to conduct the sessions with the technology, as well as how data should be collected (e.g., video recording, written notes) and safely stored according to official standards typically required for the corresponding ethical

approval and including laws and regulations such as the European Union's *General Data Protection Regulation* (2016).

8. *Technology experience.* Previous exposure to technology in general and to the particular technology used in the intervention should be documented and accounted for. Technology safety is also important and some technologies (e.g., immersive virtual reality) may require some exclusion criteria to avoid possible side-effects (e.g., not including participants with a personal or family history of epilepsy, migraines, or vertigo). In any case, safety should always be top priority and can be guaranteed with the close supervision of those who know the autistic participant well, with the support of after-session safety questionnaires and interviews via which possible adverse effects can be easily identified and reported.

9. *Effective communication.* In intervention studies, many agents are generally involved, including the autistic participants, the interventionists, other professionals from the centres where the studies are being conducted, and families. For an intervention study to be successful, it is necessary to establish a communication system that allows all stakeholders involved to effectively communicate throughout its implementation. Special attention needs to be given to autistic participants who use alternative communication systems (e.g., Picture Exchange Communication System) as they should be able to communicate at all times during the study sessions. Having a continuous information exchange across all agents allows for faster solutions when there are implementation issues. Also, facilitating a communication channel, the researcher gets valuable information which can complement other data collected and inform future studies.

10. *Dissemination.* The researchers should communicate the results obtained to all stakeholders involved in the study. This can be done in different modalities, from a written research report to an oral presentation with visual aids, but preferably using plain language and as accessible as possible. They should also be informed of other publications such as scientific conference papers or journal articles that have been created as a result of the study in which they have participated. When the TMI results are positive because there has been an improvement in the target skill, this practice allows teachers and other professionals to spread the work done

among other colleagues and facilitate its replication with other participants in other places, increasing the chances for the establishment of evidence-based practices in the field (Reichow et al., 2008).

To conclude, although the ten steps in the above guide need not be followed in the exact order presented in this chapter, it can help researchers to design effective TMIs for autistic people. This guide is especially valid for studies aimed at autistic people who also have intellectual disability, as in every step, the needs of this vulnerable collective are considered. Finally, it is recommended that researchers who design TMIs to improve a given skill in autistic people do so considering the life cycle perspective prioritizing their empowerment and what can help to promote their independence and wellbeing.

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