Educational psychology research on children with developmental disabilities
using expensive ICT devices
Larah van der Meer* · Dan Weijers
Victoria University of Wellington

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Abstract
Some expensive ICT devices, such as iPods and iPads, have been shown to have
developmental and educational benefits when used in the right environment and with
the right software. The resulting expansion of research in educational psychology that
uses expensive ICT devices with children, and particularly children with developmental
disabilities, raises an important ethical issue: it seems negligent and unfair to withdraw
an expensive ICT device from a child with a developmental disability at the end of the
study if the child has made considerable progress with the device and wouldn’t be
supplied with a replacement from elsewhere. We discuss an example of this issue and
provide several recommendations for sourcing ICT devices for participants after the
study as well as planning mechanisms so as to avoid the predicament in the first place.

The research context of the study
The research evaluated the effectiveness of new information and communication
technologies (such as iPods and iPads) to enhance the social and communicative
functioning of children with various developmental disabilities. Specifically, the
research compared the effectiveness of teaching several children with autism spectrum
disorder (ASD), who had little or no spoken language, to use three alternative
communication systems for functional communication skills (such as requesting
preferred items). The three systems included: (1) no-tech sign language (Makaton New
Zealand/Aotearoa, 1998-99), (2) low-tech picture exchange communication systems
(Frost & Bondy, 2002), and (3) high-tech iPod-/iPad-based speech-generating devices

*Larah.vanderMeer@vuw.ac.nz
Research using expensive ICT devices

van der Meer & Weijers

(Lancioni, et al., 2007). No-tech sign language is a communication system that is always accessible to the individual, low-tech picture exchange is more readily understood by communication partners, and high-tech speech-generating devices can be viewed as integrating these aspects by being both portable and a more readily understood mode of communication with the voice-output feature. Still, many such speech-generating devices are expensive, bulky, and stigmatising for the user (Shane et al., 2012). This research provided some of the first empirical evidence for the successful implementation of new high-tech iPods and iPads with the software application Proloquo2Go (Sennott & Bowker, 2009) to create an alternative communication system with voice-output, that is smaller, more affordable, easy to transport, readily available, and socially acceptable (Shane et al., 2012)

Who was involved with the study?

The government funded research was approved by the University's Faculty of Education Human Ethics Committee. Further, the research complied with the ethical standards of the American Psychological Association and the New Zealand Psychological Society. The research was led by a professor of educational psychology whose research specialises in communication interventions for children with autism and other developmental disabilities. The research was primarily undertaken by a postgraduate student, whose role included the development of study protocols and training manuals, undertaking parent/teacher interviews and adaptive behaviour assessments for participants, implementation of interventions for single-case experimental design (Kennedy, 2005), training parents/teaching assistants in implementation of intervention, data collection and analysis, preparation of manuscripts for publication, training and supervision of research assistants in implementation of interventions and data collection and analysis.

The study and the seed of the ethical issue

Because up to 50% of children with ASD do not develop the ability to speak (Peeters & Gillberg, 1999), they are commonly taught to use alternative modes of communication. Under budgetary constraints, the research team was responsible for developing effective communication interventions using both low-tech and innovative-ICT-device-based communication systems for such children. The research was funded to establish whether children could learn to communicate with both low- and high-tech
communication systems and whether incorporating each child’s preference for using one system over the others would lead to improved intervention outcomes.

It was unknown prior to implementation of the empirical interventions which communication system the children would prefer to use and therefore require for continued use after the research ended. Therefore, funding was only given to purchase three iPods and two iPads as well the Proloquo2Go software application for use by four research participants for the duration of the intervention. Furthermore, after completion of the intervention it was intended that the iPods and iPads be used as communication systems for new research participants in the on-going series of studies. Although it was not considered during the initial planning of the series of studies, these budgetary constraints meant that if children showed proficiency in, and preference for, using the iPod-/iPad-based speech-generating device they would be left without a means of using their newly developed communication skills after completion of the research.

The results of the study and the researchers’ response
After the participants had used each communication system for approximately three months, the results of the research indicated which system was most effective for, and preferred by, each participant. One participant preferred using the low-tech picture exchange communication system. Since this is a low-cost communication option, funding was not required for this child to receive continued intervention with the system, and thereby a means to communicate with others. Three of the participants preferred using the iPod-/iPad-based speech-generating devices. Fortunately the families of two of these participants already owned both iPods and iPads and could therefore continue to provide their child with this expensive ICT-device-based means of communicating. However, one participant, Ian (pseudonym), did not have access to his preferred, and most effective, system of communication (the iPad-based speech-generating device) post intervention. This charismatic young boy with autism, had the desire to communicate with others, but his speech was mostly unintelligible. The iPad-based speech-generating device enabled him to finally express himself and be understood by others. Taking away the iPad-based speech-generating device was therefore thought to inhibit the development of his communication skills and his chances for successful interactions with those around him. The postgraduate student
Research using expensive ICT devices
van der Meer & Weijers

responsible for implementing the research perceived this withdrawal of the ICT intervention as ethically challenging. After several months she raised funds through Sober October—an initiative which involved people sponsoring her to not drink any alcohol for the month of October—and used the money to purchase an iPad and the software application Proloquo2Go to serve as a speech-generating device for Ian.

The success of this fundraising effort and the Ian’s adoption of the iPad-based speech-generating device as a means of communication was picked up by media resulting in a news story aired on national television. Ian’s family explained that having the iPad was “just wonderful” because it has enabled Ian to communicate with them more easily.

In another study, in which participants also demonstrated proficiency with, and a preference for, using the ICT device, an agreement was reached where the school provided the iPods and iPads for continued communication and academic intervention after the research was completed. In this case the parents of one of the research participants raised enough money for the school to purchase the iPods and iPads as well as the Proloquo2Go software application. The postgraduate student provided professional development for the teachers on how to programme the iPod-/iPad-based speech-generating devices and how to successfully implement them into communicative and academic tasks for the students.

The ethical issue

It cannot always be known, prior to the implementation of this kind of study, that most of the participants would demonstrate higher levels of proficiency with, and a preference for using, expensive ICT devices. Therefore, in cases where such devices will be used to teach fundamental life skills (e.g., functional communication) it would seem to be a moral requirement that the researchers ensure budgets or plans are in place to enable all of the research participants to have continued access to the device after the research is completed. Taking away devices, which the participants were dependent upon to exhibit their newly learned skills, can be viewed as ethically unacceptable because it would re-expose them to negative circumstances (Kennedy, 2005). In this case the participants’ ability to express themselves and be understood by others would have been taken away from them, thereby inhibiting the development of their communication and potentially making them feel discouraged to an extent that might
lead to further problems. In addition to these potential setbacks, it also seems unfair that participants who give their time and energy to help test innovative ICT devices, and who do not have the resources to obtain the required ICT device through other means, would then encounter further setbacks and dashed hopes in return.

In terms of Kantian moral theory, taking away these expensive devices from research participants who have benefitted, and would continue to benefit, greatly from their use is a clear case of using the research participants as means to the ends of the researchers and not as ends in themselves (Kant 1959). Indeed, taking away these expensive devices from disadvantaged children is effectively exploitation of the disadvantaged, albeit to a less worrying extent than some commercial practices and other forms of research. Consequentialists view the morally best action as the one that brings about, or seems likely to bring about, the best consequences (Sinnott-Armstrong 2012). Consequentialists might argue that the best possible outcome would arise if the researchers kept the expensive ICT devices and used them in future research. However, this research team has shown that fundraising and careful planning allows for future research and happy and respected research participants, showing that withdrawing the expensive devices does not result in the best possible outcome after all. Furthermore, by ensuring that disadvantaged research participants will not have beneficial interventions discontinued after the research has concluded, the researchers will be acknowledging that the research participants are valuable in and of themselves and that they have their own goals in life (that might not perfectly align with those of the researchers).

Taking back expensive ICT devices from research participants who were benefitting from them in an important way is an example of a wider set of moral issues concerning post-intervention effects on research participants. As such, the ethical concern raised here also applies to any kind of research that discontinues valuable interventions, especially when the research participants are already significantly disadvantaged (e.g., the elderly or disabled adults). But, taking back expensive ICT devices from children with developmental disabilities is certainly a special case of this wider set of moral issues because of the uncommon coincidence of confounding factors. Most notably, expensive ICT devices are out of financial reach for many families caring for children with developmental disabilities, not only because they are expensive but also because they tend to fall outside the purview of governmental funding agencies and insurance companies (often because the best ICT technologies are new and do not fit
within the established funding rules). In the case of Ian, his mother explained that neither the school nor the Ministry of Education would fund insurance for the iPad-based speech-generating device and personal insurance would only cover its use in school when a protective case was used, which had to be sourced from overseas. These insurance issues took several months to resolve.

**Recommendations**

To prevent such ethical predicaments, future research of this type should incorporate one or more of the following actions (in order of preference): (a) allocate money in the research proposal to fund an ICT device for each participant to keep personally (if the trial is successful for that child), (b) negotiate with other organisations to allocate funding for the ICT device for each participant to keep personally (if the trial is successful), (c) negotiate with the school to allocate sufficient funding to continue the intervention with the ICT devices within the school environment, (d) if there isn’t enough funding for all participants to keep the ICT device, develop a hierarchical system where the ICT devices are given to those participants most in need (which shouldn’t be difficult if the study assesses the participants’ levels of achievement before and after intervention with the ICT device), (e) arrange with an ICT device supplier to provide participants with the option to purchase a device at a discounted price at the end of the experiment, and (f) if there is not a confirmed budget or solid plan for participants to keep the ICT devices, then make it clear to all involved (e.g., participants, parents/carers, teachers) that participants will not get to keep the ICT device and that this may have some negative effects on their development.

In future research of this type, the budget should also incorporate sufficient funding for insurance to be taken out on the devices to ensure that no promises to provide the devices to participants will be broken as a result of unforeseen circumstances. If this is not possible, then participants, parents/carers, and teachers involved in the research should be made aware of the cost and benefits of taking out insurance on the devices themselves.

Finally, before granting ethical approval for such research, Human Ethics Committees should try to manage the situation by alerting the principal investigators to the ethical concerns of withdrawing a successful intervention (the ICT device) from a research participant, especially from a child with a developmental disability. If this
ethical concern is not addressed by the Human Ethics Committee, the principal investigators should manage it themselves.

References


Response to Reviewers

Thank you very much to the reviewers for their comments; they have enabled us to substantially improve the paper.

----------------------- REVIEW 1 ---------------------

I would suggest that the paper includes far too much information regarding the study’s methodology, e.g.: single-case experiment, multiple-baseline design, theoretical perspective of self-determination. Although, important for your research these may not be relevant to the specificity of this paper - reflections upon the withdrawal of ICTs in interventions with children. I would recommend reducing the descriptions to your study’s methodology (there is quite a lot of description) and focus much more on the personal experiences of the researchers, parents and children in relation to handling ICT interventions and withdrawals with children.

- This is an excellent suggestion. Specific information regarding the study’s methodology has been removed, such as details about the multiple-baseline and alternating-treatments design, and theoretical perspective of self-determination. In total, 8 lines of unnecessary methodological detail were removed. (These sentences were removed from the first three sections).
- Furthermore, inclusion of the personal experiences of the researchers, parents, and children has been added to in the section (newly) entitled ‘The results of the study and the researchers’ response’. More detail on the personal experience of those involved was added to the new section, ‘The ethical issue’ (mainly concerning the difficulties of obtaining insurance for the iPad).

Also, there is a significant error on page 4 when the authors state that: "In this case the participants ability to ... was taken away from them...”. In fact, you state that each child, in the end, did retain access to the expensive ICT, so this sentence needs to be changed to reflect this.

- Thank you for pointing this error out. The sentence now reads: “In this case the participants’ ability to express themselves and be understood by others would have been taken away from them, thereby inhibiting the development of their
communication and potentially making them feel discouraged to an extent that might lead to further problems.” (Emphasis added to show change).

In the conclusion the authors could generalise the recommendations beyond research with children to both the elderly and the adult disabled. Also, might these recommendations also hold true for able-bodied research participants? It would be worth reflecting on this as well.

- Another great point. We have added a paragraph that discusses the wider implications of the core ethical issue (e.g., for the elderly and disabled adults too) and makes it clear what is different about this specific example. (The paragraph is in the new section, 'The ethical issue').

----------------------- REVIEW 2 ---------------------

The paper is good enough to be included in the repository. It addresses an ethical issue not limited to ICT research, but certainly of interest to HREs and ICT researchers. The paper is well-written and the methodology clear, although a brief comparison of the different modes of communication may be helpful.

- Thank you for this suggestion. A brief comparison of the different modes of communication has been included in the first section (where the different modes of communication are first introduced).

More discussion of the ethical issue itself would improve the submission--why is it ethically unacceptable to not provide funding for expensive ICT post-research? Removing ICT devices from research participants is posed as an ethical problem:

"Taking away the device, which the participants were dependent upon to exhibit their newly learned skills, can be viewed as ethically unacceptable because it would re-expose them to negative circumstances (Kennedy, 2005)...In addition to these potential setbacks, it also seems unfair that participants who give their time and energy to help test innovative ICT devices, and who do not have the resources to obtain the required
ICT device through other means, would then encounter further setbacks and dashed hopes in return."

What would be helpful is a normative theory or concept to support the judgment of removing the ICT devices as "unfair"—e.g., justice, equity, capabilities approach, etc. A link could be drawn between the ethical issue and those arising in research undertaken in third world countries, as both suggest 'exploitation' of research participants which demands restitution.

- This is a great suggestion. In response, we created a new section, entitled ‘The ethical issue’, to enable us to add more detail and theory. The new section pulls some material out of other sections, but also includes 2 new paragraphs, one on extra morally relevant details and one on relevant moral theory.