Co-Designing Digital Technologies to Support Minimally-Verbal Children on the Autism Spectrum

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ABSTRACT

This doctoral work considers how to best co-design with minimally-verbal children on the autism spectrum in classroom contexts. It focuses on 1) leveraging personal interests and individual strengths to foster engagement, social interaction and self-expression through novel technologies and 2) child-centred, holistic methodological approaches to co-design work. This research questions how integrating these may better engage and include minimally-verbal children on the spectrum in the co-design of digital technologies.

CCS CONCEPTS: • **Human-centered computing** → **Empirical studies in HCI**

KEYWORDS

Co-design; Autism; Methods; Child-centred; Minimally-Verbal; Non-verbal; Strengths; Interests

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Findings from Phase 1

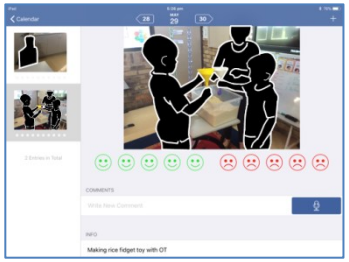

Figure 1 MeCalendar in use in an autism-specific classroom

Figure 2 A teacher using MeCalendar to record a social activity

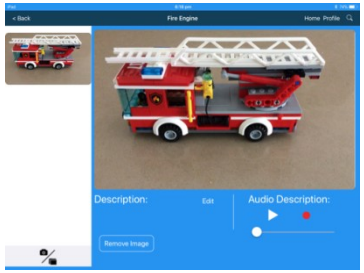

Figure 3 A MyWord dictionary entry - 'Fire Engine'

1 CONTEXT

I undertake my doctorate at Queensland University of Technology in Brisbane, Australia, under the principal supervision of Professor Margot Brereton, in the Design Participation Lab, School of Electrical Engineering and Computer Science, Science and Engineering Faculty. I am in the second year of my PhD, having begun in February 2017 and am on track for completion in February 2020.

2 BACKGROUND, AND MOTIVATION

Both the concept of 'having a voice' and the concept of 'being verbal' are heavily relied upon in the design process, but, this work questions, how does one have a *voice* in design if one is not *verbal*? [20]. It is estimated that around 30% of children on the autism spectrum are *minimally-verbal*, which means individuals may communicate with; no spoken language at all; atypical non-speech sounds only; a few words or phrases in limited contexts; or echolalic language, i.e. the child repeats language of others but does not generate it [15]. However, despite the high proportion of children on the autism spectrum who are minimally-verbal, these children are very seldom catered to in existing co-design a) methods or b) technologies [1, 20].

Individuals on the spectrum typically have challenges in social communication and interaction, as well as restricted, repetitive patterns of behaviours, interests or activities [2]. There is increasing research in this area [6, 11, 14], however, many current technologies focus on measurable academic outcomes [16], instead of encouraging the individual's own interests, strengths and abilities to be understood and supported. In education-specific contexts, technologies designed for children on the spectrum who are described as 'high functioning' [2] or children on the spectrum who are verbal [6, 7]. The technologies developed are often targeted towards teaching very specific, pre-defined skills, such as emotion recognition [14], social skills for specific situations [11] or specific behaviours [16]. However, if the learner is not interested in or motivated by this pre- defined content, it can present a barrier to learning [21]. Since children on the spectrum often have very specific areas of interest and knowledge, which can provide a great source of motivation [21], it seems there is an opportunity to springboard learning through their known interests and to find ways to incorporate these into simple, digital technologies.

Further, many classic co-design techniques (e.g. Cooperative Inquiry [4]) rely heavily on verbal communication and high cognitive load (such as brainstorming and group discussion), and fine motor skills (such as crafting). These typically require broad metacognitive and social skills to be able to participate, as well as requiring the child to be able to focus on design activities for long periods, something which often does not align with their skillset. This doctoral work builds on the notion that it has come time to think beyond assistance and intervention [7] in designing with minimally-verbal children on the spectrum, and instead to think towards holistic technological support from a person-centred, child-led and ability-based perspective. Further, it looks to investigate how to use child-led approaches from Speech and Language Therapy to follow the child's lead [9] during the co-design process, rather than adult-driven research agendas.

Explorations in Phase 2:

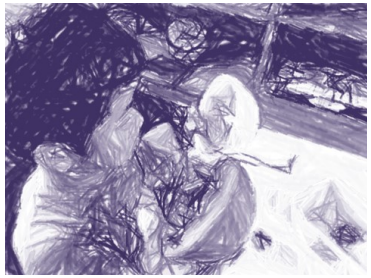

Figure 4 A child inspecting the inside of a ball-based tangible prototype

Figure 5 A child showing us his favourite things during co-design sessions e.g. the alphabet

3 PROBLEM STATEMENT AND RESEARCH AIM

This research seeks to approach co-design from a new perspective, asking how to build on children's own interests, abilities, and motivations, in order to support engagement, social interaction and self-expression. This work will address these perceived gaps in knowledge through exploring two main concepts. Firstly, how technologies can leverage minimally-verbal children on the spectrum's unique interests and strengths in order to encourage engagement, social interaction and self-expression in autism-specific classroom contexts. Secondly, how to best co-design with minimally-verbal children on the spectrum through child-led approaches from adjacent disciplines, such as Speech and Language Therapy. The research aim is therefore to determine how co-designed digital technologies can support minimally-verbal children on the autism spectrum express, engage and interact through leveraging individual interests and strengths in autism-specific classroom contexts.

Research Question 1: How do existing strengths- and interests-based digital technologies (MeCalendar and MyWord) support minimally-verbal children on the spectrum in autism-specific classroom contexts?

Research Question 2: How can minimally-verbal children on the spectrum be best supported to engage, express and interact in co-design practice?

2a). Which methods and approaches best support minimally-verbal children on the spectrum during this process?

2b). Which design concepts for novel co-designed technologies emerge during this process?

Research Question 3: What are the overall theoretical and practical design perspectives which arise from this work and how can these be developed into a guiding framework for use across disciplines?

4 RESEARCH APPROACH AND METHODS

This research is carried out in an autism-specific primary school, with up to 24 children, aged 4 to 8 years old, and their teachers, parents and therapists. Qualitative data is collected at the participating school through ethnographically-inspired methods such as participant observations and semi-structured interviews, and analysed through thematic [3] and interaction [13] analyses. As this study is exploratory in nature it will draw from a Participatory Design (PD; [5]) mindset, using Cooperative Inquiry (CI; [4]) and Reflective, Agile, Iterative Design (RAID; [10]) approaches. Initial work will be carried out using an existing suite of tablet apps called MyPortolfio, which includes an audio-visual calendaring app (MeCalendar [18]) and an audio-visual dictionary app (MyWord [17, 19]). The methods will be based on "a continuously deepening understanding of the context and the [research] target" [8, p. 230] and are employed flexibly.

5 RESULTS TO DATE - Phase 1: Exploratory Study of Existing Prototypes

In Phase 1 (completed), the use of existing child-centred audio-visual apps was explored in classroom contexts and addresses RQ1.

Publications to date:

Paper 1

Co-Design Beyond Words: 'Moments of Interaction' with Children on the Autism Spectrum
CHI 2019, Forthcoming Full Paper, (Wilson et al., 2019 [20])

Paper 2

MyWord: Enhancing Engagement, Interaction and Self-Expression with Minimally-Verbal Children on the Autism Spectrum through a Personal Audio-Visual Dictionary
IDC 2018, Full Paper
(Wilson et al., 2018 [19])

Paper 3 (Best Paper Nominee)

Digital Strategies for Supporting Strengths- and Interests-based Learning with Children with Autism
ASSETS 2017, Full Paper
(Wilson et al., 2017 [18])

Paper 4 (WiP - Honourable Mention)

MyWord: Supporting the Interest-based Learning of Words through a Personal Visual Dictionary
DIS 2017, Work-in-progress Paper, (Wilson et al., 2017 [17]).

Two audio-visual apps were evaluated (MyWord, a digital dictionary (Fig. 3), and MeCalendar, a digital calendar (Fig. 1)) in classroom contexts. Overall, our findings demonstrate that simple digital technologies which celebrate and support individual strengths and interests can result in enhanced engagement in class tasks, social interaction with peers, and self expression (Fig. 2). This phase has resulted in three peer-reviewed publications [17, 18, 19] which provide a more detailed account of the findings to date. Further to the evaluation of MeCalendar and MyWord, Phase 1 enabled us to define opportunities for new or extended technologies to be designed. Importantly, it brought to light the perceived lack of specific methods of co-designing with minimally-verbal children on the spectrum. Moving forward, this work will address opportunities which arose from Phase1, such as; supporting social interaction with technologies; supporting creativity and play with technologies; supporting movement and dynamic action with technologies and; opportunities for tangible technology use.

6 DISSERTATION STATUS AND NEXT STEPS

6.1 Phase 2: Developing Co-design Methods with Minimally-Verbal Children on the Autism Spectrum

Phase 2 (current) addresses RQ2 and will explore methods for co-design with minimally-verbal children on the spectrum. Projected outcomes include: (a) a greater understanding of using child-led methods from Speech and Language Therapy when co-designing with this group and (b) novel or extended or adapted technologies which address the gaps identified in Phase 1. It investigates how to better enable our child participants to become design partners and indeed design protagonists [12] through translation of e.g. child-led approaches from Speech and Language Therapy. Crucially, it focuses on following the child's unique interests (e.g. Fig. 6). Thus far, an approach to co-design - Co-Design Beyond Words (CDBW) - has been developed. This has resulted in a full paper publication at this year's CHI conference [20]. This involved the co-designing of a playful prototype, the VoiceBall, using the three iterative phases of CDBW; the Foundation Phase (preparation for interaction), the Interaction Phase (designing and-reflecting in the moment) and the Reflection Phase (reflection-on-action). This contributes a novel co-design approach and presents 'moments of interaction', the micro instances in design in which minimally-verbal children on the spectrum can convey meaning beyond words, through their actions, interactions, and attentional foci. This can shape design insight and direction, and reveal unique strengths, interests and abilities.

6.2 Phase 3: Evaluative Study of Emergent Designs and Methods

Phase 3 (proposed) addresses RQ3 and will build on the designs developed in Phase 2. It will evaluate use in classroom contexts of the emerging tangible technologies, paying particular attention to their ability to support minimally-verbal children on the spectrum to self-express, socially interact and engage. Part 1 of this phase will involve the building of the technology which emerges from the co-design sessions.

Part 2 will involve evaluating the use of this technology in classroom settings with our child participants and design partners through detailed interaction analysis [13] and through using and refining the Co-Design Beyond Words approach [20]. Continuing longitudinal co-design work with child collaborators will help hone these methods, leading to the development of a framework on design with those who communicate without words.

7 CURRENT AND EXPECTED CONTRIBUTIONS

Beyond the published contributions of this project so far [17, 18, 19, 20], it is expected that the three phases will be analysed so as to develop a guiding framework for co-design work with minimally-verbal children on the spectrum, presenting a methodological approach to work with this group. It is hoped this will be of benefit to other researchers in this area and in adjacent fields. Further, this work looks to build an understanding of how to translate our findings from research to practice contexts, such as extension into the Education and Disability fields. Most importantly, this research aims to continuously trial and evaluate our methods and technologies with our child collaborators, ensuring their unique strengths and interests are represented and supported.

8 ACKNOWLEDGEMENTS

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8 REFERENCES

[1] Meryl Alper. 2017. *Giving Voice: Mobile communication, disability, and inequality.* MIT Press, Cambridge, Massachusetts
[2] American Psychiatric Association (2013). Diagnostic and statistical manual of mental disorders (DSM-V). American Psychiatric Publishing, Arlington, VA.
[3] Virginia Braun and Victoria Clarke. 2006. Using thematic analysis in psychology. *Qualitative research in psychology* 3, 2, 77-101.
[4] Allison Druin. 1999. Cooperative inquiry: developing new technologies for children with children. In Proceedings of the SIGCHI conference on Human Factors in Computing Systems (CHI '99). ACM, New York, NY, USA, 592-599.
[5] Pelle Ehn. 1989. *Work-oriented design of computer artifacts.* Hillsdale, NJ: Lawrence Erlbaum Associates
[6] Christopher Frauenberger, Judith Good, Alyssa Alcorn, and Helen Pain. 2012. Supporting the design contributions of children with autism spectrum conditions. In Proceedings of the 11th International Conference on Interaction Design and Children (IDC '12). ACM, New York, NY, USA, 134-143
[7] Christopher Frauenberger, Judith Good and Narcis Pares. 2016. Autism and Technology: Beyond Assistance & Intervention. In Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems (CHI '06), ACM, New York, NY, 3373-3378.
[8] Christopher Frauenberger, Marjo Rauhala and Geraldine Fitzpatrick. 2017. In-action ethics. *Interacting with Computers,* 29, 2, 220-236.
[9] Stanley Greenspan, Serena Wieder, and Robin Simons. 1998. *The child with special needs: Encouraging intellectual and emotional growth.* Addison Wesley.

[10] Clint Heyer and Margot Brereton. 2010. Design from the everyday: continuously evolving, embedded exploratory prototypes. In Proceedings of the 8th ACM Conference on Designing Interactive Systems (DIS '10). ACM, New York, NY, 282-291

[11] Juan-Pablo Hourcade, Natasha E. Bullock-Rest and Thomas E. Hansen. 2012. Multitouch tablet applications and activities to enhance the social skills of children with autism spectrum disorders. *Personal and ubiquitous computing,* 16, 2, 157-168.

[12] Ole Sejer Iversen, Rachel Charlotte Smith, and Christian Dindler. 2017. Child as Protagonist: Expanding the Role of Children in Participatory Design. In Proceedings of the 2017 Conference on Interaction Design and Children (IDC '17). ACM, New York, NY, USA, 27-37

[13] Brigitte Jordan and Austin Henderson. (1995). Interaction analysis: Foundations and practice. *The journal of the learning sciences* 4, 1, 39-103.

[14] Peter Leijdekkers, Valerie Gay and Frederick Wong. 2013. CaptureMyEmotion: A mobile app to improve emotion learning for autistic children using sensors. *Computer-Based Medical Systems*. IEEE, 381-384.

[15] Helen Tager-Flusberg and Connie Kasari. 2013. Minimally Verbal School-Aged Children with Autism Spectrum Disorder: The Neglected End of the Spectrum. *Autism research* 6, 6, 468 – 478

[16] Tracy Westeyn, Gregory Abowd, Thad Starner,Jeremy Johnson, Peter Presti and Kimberley Weaver. 2012. Monitoring children's developmental progress using augmented toys and activity recognition. *Personal and Ubiquitous Computing,* 16, 2: 169-191.

[17] Cara Wilson, Margot Brereton and Bernd Ploderer. 2017. MyWord: Supporting the Interest-based Learning of Words through a Personal Visual Dictionary. In Proceedings of the 2017 ACM Conference Companion Publication on Designing Interactive Systems (DIS '10) ACM, New York, NY, 132-137

[18] Cara Wilson, Margot Brereton, Bernd Ploderer, Laurianne Sitbon, and Beth Saggers. 2017. Digital Strategies for Supporting Strengths- and Interests-based Learning with Children with Autism. In Proceedings of the 19th International ACM SIGACCESS Conference on Computers and Accessibility(ASSETS '17). ACM, New York, NY, USA, 52-61

[19] Cara Wilson, Margot Brereton, Bernd Ploderer, and Laurianne Sitbon. 2018. MyWord: Enhancing engagement, interaction and self-expression with minimally-verbal children on the autism spectrum through a personal audio-visual dictionary. In Proceedings of the 17th ACM Conference on Interaction Design and Children (IDC '18). ACM, New York, NY, USA, 106-118.

[20] Cara Wilson, Margot Brereton, Bernd Ploderer, and Laurianne Sitbon. 2019. Co-Design Beyond Words: 'Moments of Interaction' with Minimally-Verbal Children on the Autism Spectrum. In *CHI Conference on Human Factors in Computing Systems (CHI'19), May 4–9, 2019, Glasgow, Scotland, UK.* ACM, New York, NY, USA

[21] Mary Ann Winter-Messiers, 2007. From tarantulas to toilet brushes: Understanding the special interest areas of children and youth with Asperger syndrome. *Remedial and Special Education* 28, 3, 140-152.