Considering Disabilities in Autoethnographic Research

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1 INTRODUCTION

First-person research methods continue to gain traction as a significant way to collect data in Human-Computer Interaction (HCI). According to the recent special issue of ACM Transactions on Computer-Human Interaction, firstperson research helps researchers explore the "mundane, ongoing and ubiquitous presence of technology" and rely on "first-hand experience as a mode of knowing" to inform the design [5, p. 1]. From autobiographical design research to understand the lived experience of the researcher [9, 10] to the investigation of a specific phenomenological experience of a group of participants [3, 11], there are many ways to conduct first-person research. The method gives us opportunities to understand different perspectives, and multifaceted data collection methods bring new insights to understand nuances in the experience that might not have been visible without using the first-person method.

Nonetheless, there has been little exploration of opportunities on how the method could inform the work in HCI disability research. Having a disability is complicated, and they are often over-simplified for the able-bodied [8]. This position paper showcases initial thoughts from our third study using the autoethnographic workbook titled the *Inside-Out Probe Workbook*. The workbook takes research through three phases that inform the design of a wearable prototype to support their mental health. Though previously the workbook collected data from able-bodied researchers, we have transitioned to design wearable technology to support the mental health of the second author who has a disability. It is important to note that the first and second authors share learning disability (LD) Dyslexia. Along with the LD, the second author also uses an Anaphylaxis Service Dog. Using the service dog in public sometimes causes mental and emotional stress due to discriminatory ill-informed public interactions.

2 MENTAL HEALTH AND DISABILITIES

LDs make it significantly more difficult to understand new information, learn new skills, and can even affect one's social relationships [6]. The stigma around LDs, including being misunderstood in school, work, and their daily lives, can be stressful and often, people with PD need to work harder than their peers around them [7, 13]. Similar to other disabilities, there is an increased chance for people with LDs to be diagnosed with mental disorders such as anxiety and depression [4]. Mindfulness exercises such as deep breathing lessen the stresses and challenges of dealing with a text-heavy society and give people the ability to have a clear mind to deal with the stresses of daily life [1].

3 INSIDE-OUT PROBE AND DESIGN PROCESS

The original intention of the *Inside-Out Probe Workbook* and design process was to understand the first-person experience of group walking meditation [3] than later translated to collect autoethnographic information to inform the design of a scarf to assist with emotional regulation [2]. Different from our previous studies, we began the project with open conversations to understand the complexities of the second author's disabilities. From early conversations with the

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research team, both the first and second authors felt comfortable and in a safe space to disclose their disabilities. Within the initial conversations, we realized that modifications needed to be made in the data collection method to make it accessible for the researcher. The most significant change in the workbook was around the journalling data collection method. With an LD, writing by hand can become a considerable burden, including cramping, which can be very uncomfortable [12]. Therefore, we used alternate ways to collect data, including using a computer to fill out the workbook or recording the answers verbally depending on how the researcher felt. Secondly, we had limitations in the design. To use the prototype in public environments, she needed to be able to use her service dog with the prototype, the prototype needed to be comfortable and hide the electronics in the fabric.

Similar to the previous iteration, we split the process into three phases: the initial data collection phase, the design of the prototype, then testing the prototype in real-world environments. During the initial phase, the researcher spent 16 days journaling, filling out body maps, drawing, and abstract sculptures to describe the experience with both stressful daily activities (such as going to the grocery store) and relaxing activities (breathing exercises). We emphasized alternating between stressful and relaxing activities to take care of the researcher and ensure she was not overstimulated. After each activity, she would fill out the *Inside-Out Probe Workbook* to document her experience in a textual and visual way. Then in the second phase, we built and designed a prototype and finally, for the last 16 days, she alternated through stress daily activities and breathing exercises where we documented the experience in a similar process to phase one.

3.1 Movement Band Prototype

The final band (Figure 1) consisted of two servo motors, an Arduino and a galvanic skin response sensor. As a hobby, she enjoys embroidery; therefore, similar to previous prototypes, we encourage any craft-making skills in the design process. Despite that prototype was worn under clothes, and the embroidery was not visible to the public, she liked knowing it was there to support her. Preliminary analysis and reflection of the data indicate that for our design researcher, the data from the visual elements were more meaningful and helped inform the design of the final prototype more than the journaling elements in the workbook did.



Fig. 1. Left Image: Sketch of the movement band. Middle: Close-up of the embroidery. Right: The second author is wearing the prototype.

4 FUTURE WORK

In future iterations, we plan to translate the workbook into a toolkit with multiple options on how to collect autoethnographic data, which will encourage more exploration and creativity for different disabilities. For instance, our current workbook is very visual (except for voice recording for the journal element). Is it possible to translate body maps or sketches into a form that blind or visually impaired researchers can use? The more accessible we can make the workbook, the more helpful it will be to design meaningful wearable technology for everyone.

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REFERENCES

[1] James Beauchemin, Tiffany L Hutchins, and Fiona Patterson. 2008. Mindfulness meditation may lessen anxiety, promote social skills, and improve academic performance among adolescents with learning disabilities. *Complementary health practice review* 13, 1 (2008), 34–45.

Manuscript submitted to ACM

- [2] Karen Cochrane, Yidan Cao, Audrey Girouard, and Lian Loke. 2022. Breathing Scarf: Using a First-Person Research Method to Design a Wearable
 for Emotional Regulation. In Sixteenth International Conference on Tangible, Embedded, and Embodied Interaction. 1–19.
- 110
 [3] Karen Cochrane, Lian Loke, Matthew Leete, Andrew Campbell, and Naseem Ahmadpour. 2021. Understanding the first person experience of

 111
 walking mindfulness meditation facilitated by EEG modulated interactive soundscape. In Proceedings of the Fifteenth International Conference on

 112
 Tangible, Embedded, and Embodied Interaction. 1–17.
- [4] Sherva Elizabeth Cooray and Alina Bakala. 2005. Anxiety disorders in people with learning disabilities. *Advances in psychiatric treatment* 11, 5 (2005), 355–361.
- [5] Audrey Desjardins, Oscar Tomico, Andrés Lucero, Marta E. Cecchinato, and Carman Neustaedter. 2021. Introduction to the Special Issue on First-Person Methods in HCL. ACM Trans. Comput.-Hum. Interact. 28, 6, Article 37 (dec 2021), 12 pages. https://doi.org/10.1145/3492342
- [6] Eric Emerson and Pauline Heslop. 2010. A working definition of learning disabilities. Durham: Improving Health & Lives: Learning Disabilities
 Observatory (2010).
- [7] Faye Ginsburg and Rayna Rapp. 2013. Entangled ethnography: Imagining a future for young adults with learning disabilities. Social Science &
 Medicine 99 (2013), 187–193.
- [8] Megan Hofmann, Devva Kasnitz, Jennifer Mankoff, and Cynthia L Bennett. 2020. Living disability theory: Reflections on access, research, and
 design. In *The 22nd International ACM SIGACCESS Conference on Computers and Accessibility*. 1–13.
 - [9] Kristina Mah, Lian Loke, and Luke Hespanhol. 2021. Towards a Contemplative Research Framework for Training Self-Observation in HCI: A Study of Compassion Cultivation. ACM Trans. Comput.-Hum. Interact. 28, 6, Article 39 (nov 2021), 27 pages. https://doi.org/10.1145/3471932
 - [10] Carman Neustaedter and Phoebe Sengers. 2012. Autobiographical Design in HCI Research: Designing and Learning through Use-It-Yourself. In Proceedings of the Designing Interactive Systems Conference (DIS '12). Association for Computing Machinery, New York, New York, USA, 514–523. https://doi.org/10.1145/2317956.2318034
 - [11] Corina Sas. 2019. First person HCI research: Tapping into designers' tacit experiences. In ACM Designing Interactive Systems Conference: 1st Person Research Methods in HCI Workshop.
 - [12] DL Sparkes, GL Robinson, TK Roberts, and RH Dunstan. 2006. General health and associated biochemistry in a visualperceptual sub-type of dyslexia. Learning Disabilities: New Research (2006), 81–98.
 - [13] Jack Trammell. 2009. Postsecondary students and disability stigma: Development of the postsecondary student survey of disability-related stigma (PSSDS). Journal of Postsecondary Education and Disability 22, 2 (2009), 106–116.