

Making as Expression: Informing Design with People with Complex Communication Needs through Art Therapy

Amanda Lazar^{1,2}, Jessica L. Feuston², Caroline Edasis³, Anne Marie Piper²

¹University of Maryland, College Park, MD; ²Northwestern University, Evanston, IL;

³Mather LifeWays, Evanston, IL

lazar@umd.edu, {jes.feuston@u., ampiper@}northwestern.edu, cedasis@matherlifeways.com

ABSTRACT

There is a growing emphasis on designing *with* people with diverse health experiences rather than designing *for* them. Yet, collaborative design becomes difficult when working with individuals with health conditions (e.g., stroke, cancer, abuse, depression) that affect their ability or willingness to engage alongside researchers and verbally express themselves. The present paper analyzes how the clinical practice of art therapy engages these individuals in co-creative, visual expression of ideas, thoughts, and experiences. Drawing on interviews with 22 art therapists and over two years of field work in a clinical setting, we detail how art therapists view *making as expression* for people with complex communication needs. Under this view, we argue that art therapy practice can inspire collaborative design engagements by understanding materials as language, creating space for expression, and sustaining expressions in a broader context. We discuss practical and ethical implications for design work involving individuals with complex communication needs.

Author Keywords

Art therapy, collaborative design, communication, health.

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

INTRODUCTION

Human-centered design methodologies that emphasize user involvement, such as participatory design and co-design, often rely on participants engaging alongside researchers throughout the process of co-creation. The ability of participants to verbally express ideas, thoughts, and needs is often an implicit aspect of the design process; yet, many individuals have a limited ability or willingness to communicate in this way. Prior work details the complexities of conducting design work with individuals with stigmatizing or emotionally sensitive experiences

[14,65,66], speech-language impairments [72], and cognitive or developmental disabilities [59,62]. Much of this work offers strategies to mitigate the impact of an impairment on the design process by avoiding open-ended prompts and offering limited alternatives [115] or having a proxy speak on the individual's behalf [9,40]. These strategies are useful modifications; however, they can constrain an individual's involvement as well as limit what is achieved through co-design, where the goal is to open up participants' creative potentials, fluidly support a wide range of conversation topics, and collaboratively envision new design futures. Further, limited work has questioned the dominant and implicit role of verbal discourse in collaborative design, which stands to marginalize the viewpoints of people with complex communication needs.

An enriched understanding of making can contribute to more intentional research designs, practices, and analyses. The present paper analyzes the discipline of art therapy as a way of understanding how to support people with complex communication needs in generative, co-creative design engagements. Our analysis is grounded in interviews with 22 art therapists who work with populations with complex communication needs and over two years of field work in a clinical art therapy setting. Art therapy is a profession in which clients, guided by the art therapist, use art materials, the creative process, and the resulting artwork to express their feelings, reconcile emotional conflicts, foster self-awareness, and achieve other goals [116]. We call attention to the ways in which art therapy, situated within clinical practice and alongside biomedical views of health, eschews verbal discourse and positions making as interpretive, non-reductive expressions of the self.

This paper makes three primary contributions. First, we contribute an analysis of a clinical practice that views making as a valued form of expression, which expands how researchers can understand interaction and co-creation with people with complex communication needs. Second, we detail how therapists construct and enact this worldview by (1) understanding materials as language, (2) creating a space for expressions to emerge, and (3) sustaining these expressions in a broader societal context. The third contribution is a discussion of the lessons HCI researchers can draw from clinical art therapy practice to guide formative, co-creative design engagements involving people with complex communication needs.

Permission to make digital or hard copies of all or part of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for components of this work owned by others than the author(s) must be honored. Abstracting with credit is permitted. To copy otherwise, or republish, to post on servers or to redistribute to lists, requires prior specific permission and/or a fee. Request permissions from Permissions@acm.org.

CHI 2018, April 21–26, 2018, Montréal, QC, Canada

© 2018 Copyright is held by the owner/author(s). Publication rights licensed to ACM.

ACM 978-1-4503-5620-6/18/04...\$15.00.

<https://doi.org/10.1145/3173574.3173925>

RELATED WORK

There is a growing literature that describes design involving individuals with complex communication needs, including individuals with emotionally distressing experiences, severe speech-language impairments, cognitive impairment, autism and other developmental disabilities, trauma, and mental health conditions. The present paper builds on existing strategies for adapting design methods for people with complex communication needs and power dynamics in designing with these populations. Beyond this, we examine literature on making as a way of broadening possibilities for co-creative design engagements involving these individuals.

Strategies for Adapting Research Methodologies

Research involving individuals who have difficulty speaking fluently (e.g., due to stroke, cognitive impairment, developmental disabilities) emphasizes the ways in which typical design methods – which often involve verbal expression – must be modified [43,90]. Work by Moffatt et al [72] and Brereton et al [12] note that using low-fidelity prototypes can be challenging for individuals with language, sensory, or cognitive impairments who have difficulty expressing and interacting with abstract concepts. Concrete prototypes, on the other hand, yield opportunities for participants to interact directly with interfaces [12]. This work and that of others [9,34,90,101,112,114,115] provides useful strategies for engaging individuals with speech-language or cognitive impairments in design through the use of physical and visual artifacts, such as storyboards and pictures, and avoiding open-ended questions.

These strategies emphasize the use of prepared design artifacts and closed prompts as a way of structuring interaction so that communication is achievable between researchers and participants. Yet, even when researchers use methods that do not require participant verbalization, challenges still arise from the use of language (e.g., explaining prototypes to participants) and difficulties interpreting non-verbal interactions [43,87]. Further, these strategies may not open up the creative potential of participants. In the context of participatory design with children with autism, Makhaeva et al. [62] assert that “the challenge of meaningful participation is a challenge of configuring structures and freedoms for a gradual unfolding of the creative potentials of participants.” While this work acknowledges that co-creative processes occur within a socio-material context, many practical questions remain concerning how researchers should select materials, arrange environments for design, and interact in these contexts.

Another approach involves the use of proxies, or another person who speaks on the behalf of an individual with complex communication needs. In prior work, proxies are often parents, teachers, or caregivers (e.g., [12,36,44,71]). Researchers often use proxies when participants are seen as unable to contribute to design discussions or when the burden of participation is seen as too high for a participant [32,44]. Yet, proxies may have goals and values that

conflict with those of the individuals for whom they speak [43]. Further, this approach neglects the fact that people with complex communication needs can still participate meaningfully in design engagements, particularly when provided with a supportive social and material environment [42]. Some have noted, however, that creating a supportive environment requires long-term relationships with participations through regular sessions [59] or training for designers and researchers [65,101]. Existing approaches involving the use of proxies leave open questions around our expectations for interaction and how to engage alongside participants with complex communication needs.

Power Dynamics and Ethics

In addition to the challenges of adapting methods to support collaborative design engagements, researchers are beginning to understand the ways in which power dynamics affect participation. Collaborative design methods aim to empower people by democratizing the design process [17,27,86,100]. Some researchers, however, question what it means to participate in design work, inspiring reflection on who initiates, directs, and benefits from user participation as well as how participation occurs [8,108]. This ongoing discussion reflects on values in participatory design [47], how people negotiate and voice conflicting views, and what constitutes a result [10]. This discussion is particularly relevant to work involving people who are not often included in the design process on the basis of age (e.g., young children [26,33], older adults [105,107]), socio-economic factors [21,35], or ability [2,4,37,59,62].

Prior work describes power imbalances between researchers and participants as unavoidable [43]. Additional power dynamics may emerge when individuals confront their own abilities and experiences as part of the co-creative process [11,109], particularly when the focus of design is an individual’s emotionally distressing or stigmatizing experience. For example, prior work acknowledges the feasibility of conducting design work with individuals with mental health conditions (e.g., bipolar disorder [66], psychosis [110], depression and anxiety [50]) but rarely unpacks how participation in design activities introduces new vulnerabilities or how researchers navigate power relations and interpret individuals’ mental health experiences (see [51] for an exception). Other design projects involve health concerns of women immigrants [14], who may face traumatic separation and distress, and mothers and children at a homeless shelter [21]; politics and power relations are central to these engagements. Even encouraging older people to speak about aging as part of formative design research can be emotionally complex and sensitizing [57], particularly in the context of pervasive age-related stereotypes around technology use [13,53]. While researchers often view collaborative design as empowering participants [34,105], we must consider how participation can be a sensitizing experience and identify strategies for shifting these power imbalances.

Broadening the Scope of Design Engagements

Power dynamics also play out in how researchers conceive of what constitutes co-creative design engagements. The maker movement, with its roots in art and technology design, has helped shape what it means to engage in design. Some have even said the maker movement is more about meaning making than producing actual products [99]. In HCI, making has been proposed as democratizing technological practice, shifting how people engage with technology from user-as-consumer to user as creator, artist, and co-designer [103]. Studying both the practice and products of making among marginalized groups, such as people with disabilities, can provide insight into these individuals' values, experiences, and needs [16,70,89].

While making has been lauded for empowering and democratizing technology design, critics have pointed out its inaccessibility in the West to people who are not privileged (i.e., male, white, middle or upper class, able-bodied) [1,70,103]. Some critiques note that there are individuals who are involved in making but are not conceptualized as makers in public discourse (e.g., elderly hackers in China) [60,102,103]. According to this line of thinking, researchers participate in discursive formulations of making, which encourage certain kinds of making and makers [60]. Thus, researchers can identify forms of making that are not being discussed widely as a way of expanding the scope of who is participating in design [102]. The present study of clinical art therapy extends discourse on who is considered a maker and sites in which making occurs while calling attention to making itself as a form of expression for people with complex communication needs.

METHODS

This paper draws on semi-structured interviews with art therapists, extensive field work in an art therapy setting, and ongoing collaboration with practicing art therapists. Our analysis also draws on theorizing in the field of art therapy and the historical perspectives of this discipline.

Interviews and Field Observations

We conducted in-depth interviews with 22 art therapists who have worked with a variety of populations, including individuals experiencing addiction, child welfare, immigration, domestic violence, mental illness, traumatic brain injuries, physical disabilities, dementia, aphasia, and cancer. Interview participants have practiced art therapy for 11 years on average (1-37 years) and regularly lead individual and group therapy sessions.

We have also conducted more than two years of field observations at a residential facility for older adults located in the Midwestern region of the United States. This community offers art therapy to its residents. The majority of the adults we interacted with in art therapy live in the skilled nursing portion of this community and have language, cognitive, and sensory impairments from a range of conditions, including dementia, stroke, and Parkinson's disease. Our field work involved ongoing weekly

observations (1.5-2 hours) of art therapy sessions at this community. Our protocol was informed by a collaborating art therapist and we obtained human subjects approval from both the community organization and our university to conduct this research. Before we studied participation in art therapy in detail, we obtained consent from legally authorized representatives, and the collaborating art therapist obtained consent from art therapy participants.

Data Analysis

Our approach to data collection and analysis largely follows a constructivist grounded theory approach [18]. Our process of analysis emerged through interactions at our field site, with our data, and between members of our research team, one of whom is an art therapist. Specifically, as themes emerged from data collected at our field site (e.g., field notes, transcripts, audio/video data), we supplemented our initial understandings with interviews with art therapists, by attending art therapy conferences, and reviewing related theories of art therapy as a way of understanding and interpreting our data. We continuously adjusted our interview sampling and questions to probe various areas until reaching saturation. We report three primary themes below, which emerged through this iterative process of data collection and analysis. First, however, we provide background on the field of art therapy that informs how we view our data and our overall analytic perspective.

Art Therapy as a Context of Study

In the 1940s, individuals began practicing art therapy as a type of psychotherapy [78], which draws on the fields of art and psychology to include the addition of visual art practices to talk as a treatment modality [106]. Medical models have heavily influenced Western psychotherapy, and in turn, art therapy utilizes concepts such as diagnosis, disease, and treatment [106]. Art therapists typically conduct sessions with one participant or with a small group of participants, who are also referred to interchangeably as "clients" or "artists." Like other forms of therapy, therapeutic goals are diverse and include confronting trauma, having a platform for social expression, working through decisions (e.g., deciding whether to take a new job), and building skills such as self-esteem, frustration tolerance, and social skills. Art therapists practice diverse theoretical orientations, including psychodynamic, humanistic, feminist, and postmodern approaches [74,106]. These different approaches indicate the diversity of perspectives within the field, resulting in a variety of stances towards art therapy participants, the process of art therapy, and the art that is created in art therapy.

Art therapy practices have shifted along with attitudes towards art and psychotherapy [79]. For example, art therapists vary in how they interpret and relate to art created by participants, summarized in [73]. While some therapists ascribe psychological meaning to artwork or relate it to a diagnosis (e.g., taking up a small portion of the page as indicative of depression), most therapists in our study



Figure 1. Range of materials and artifacts created in art therapy include fibers or fabrics, clay, aluminum foil, and glass mosaics.

viewed images less as objects of inquiry to determine pathology and more as “messengers” from which they can learn. With this view, restricting an image through a classifying label can lead to “imagicide,” or the death of an image [75]. The present analysis, along with most of our study participants, embraces the latter, more contemporary branch of art therapy. Thus, our analysis attends to the process of creation and expression—rather than reductively interpreting the product of creation—as a way of informing how researchers can approach design engagements with individuals with complex communication needs.

FINDINGS

The field of art therapy recognizes “that there are many people in the world who cannot or will not express their feelings verbally” [76]. Art therapy is one approach, along with dance movement, music, and drama therapies, that emphasizes nonverbal (or non-talking) modalities. Art therapy is distinguished from other nonverbal therapies through its focus on “*art making and art product*” [AT2]. In art therapy, creative art making is regarded as an important and valued form of communication [63]. In the sections below, we unpack how art therapy practice views *making as expression*. While we return to each of the themes below in the discussion section, here we briefly connect each with the literature on collaborative design.

Understanding the Language of Materials

To understand making as expression, the first lesson art therapy offers is through its nuanced view of materials as language. This view of materials resonates with prior work in collaborative design, which often involves engagement with materials as part of the process of co-creation [84,113]. Ehn points out the ways that objects play a role in language-games and, consequently, design [28]. Similarly, prior work engages Schön’s concept of materials “talking back” [38,94] to analyze how material configurations shape collaborative design work [19,41,48,54,92,104]. Analyzing art therapy extends this theorizing of the “meaningful role” that materials play and their centrality to the unfolding process of creation through their individual “functions and uses... [that] often result in changed designs and revised plans on the part of the client and art therapist” [75].

Becoming an Expert in Materials

Art therapists understand that their choice, presentation, and expectations around the use of materials shape the

possibilities for interaction. As such, they employ a range of materials (see Figure 1), such as paints (oil, watercolor, acrylics), fibers (wool, silk, needle felting, yarn), mosaics, clay, household items (aluminum foil), and found supplies. Relying on their own facility with materials, art therapists support participants’ creative expression through interaction with these supplies [52]. Therapists also incorporate music, visual media (e.g., video recordings), and embodied interactions (e.g., gestures) into the art making process. Art therapists explained that an important part of their role was being “*an expert in materials*” [AT2]. Therapists utilize their expertise to “*find the right medium for the individual so that they can just express themselves...*” [AT7]. In co-design, the researcher’s role is described as “providing tools for ideation and expression” [93]. Art therapists described the importance of selecting materials with “intentionality” by reflecting on what materials enable and constrain for each individual. In art therapy, finding the “right medium” for a particular participant at a particular time involves considering the expressive properties of materials and sociocultural associations with materials.

Different Materials have Different Expressive Properties

As part of being an expert in materials, art therapists recognize that materials have various expressive properties. AT2 described how art materials are “*the language of art – so they’re like the verbs and nouns and things of visual art.*” AT1 explained, “*A particular material can say something that another material can’t for someone...*” AT1 compared broken windshield glass, which one person brought to a session, with tulle: “*[the materials] say something automatically different to the viewer, just in terms of brokenness and sharpness and potential harm, and softness and flexibility.*” Continuing, she described how material selection is “*the sort of language that artists use when they create.*” One framework some art therapists use is based on the idea that materials exist on a spectrum from “resistive” to “fluid” [61,80]. Fluid materials, such as watercolors, support certain affective and sensory states while resistive materials, such as pens, support structure and boundaries [80] (see Figure 2).

Selecting materials depends on an understanding of what type of expression should be supported in a particular art therapy session. AT7 explained:

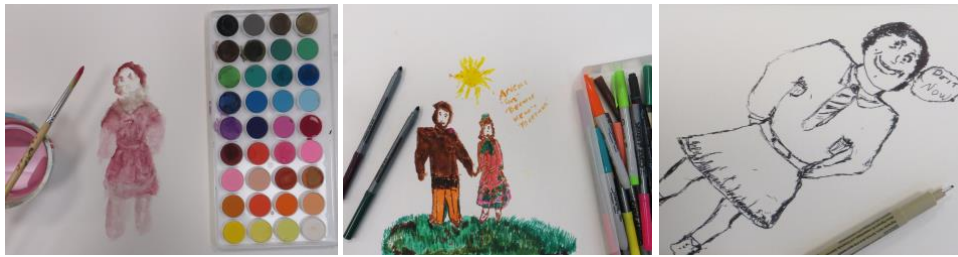


Figure 2. Art therapy participant created soft figures using water colors (left), more defined figures with markers (center), and rigid figures when drawing with a fine tipped pen (right).

“not feel satisfied communicating big swirls of emotion.” The therapist contrasted this with another person who would not enjoy communicating precise detail *“mainly because she can’t create that sort of realism with her disease process.”* Thus, therapists attend to the communicative needs of each individual when offering materials during a session.

“What are you trying to accomplish? What do you want them to communicate to you?... Really fluid materials are great for free, big movements, emotional things, letting out, a sense of release... If you want somebody to communicate a specific structure, object, or words, you can’t give them a big paintbrush and paints. But on the other hand, if you want somebody to loosen up and relax... typically giving them a sharpie and piece of paper is not going to do it.”

Therapists described situations where they intentionally avoided *“certain materials [that] would escalate certain conditions of the client’s”* [AT4] (e.g., avoiding fluid materials for clients with anxiety). Another perspective encourages therapists to, over time, guide participants towards materials that enable therapeutically valuable states (e.g., from resistive to fluid), without requiring therapists and participants to verbally acknowledge this change [61,80]. For example, AT3 described a series of sessions with a boy in residential care due to behavioral issues:

“He came to art therapy in the beginning and he drew these really harsh edged military weapon, like swords and bombers with a fine tipped black marker ...And he starts looking up and seeing what I’m doing. And I’m doing these watercolor drawings that are much softer...he said I’d like to try that. So he starts making these weapons and military vehicles out of watercolor and they’re softened. And over time he started fooling around more with the watercolor as he’s talking about why he’s there, what’s going on... And as he started to loosen up and soften and talk about more what his feelings were, his behavior got better...” [AT3]

In this example, the art therapist selected materials intentionally to guide the participant towards engaging with difficult emotions. In our field work, we observed therapists learning over time how various materials support expression for each individual. A therapist described one client who alternated between fluid water colors, defined but fluid markers, and rigid pens. The therapist said, *“the tight, restrictive [materials] give her an opportunity to be more detailed,”* and explained that these materials lead the client to communicate about specific people or ideas. The client titled a drawing with a fine tipped pen as *“her inner critic”* and with it offered a detailed story about her older sister (Figure 2, right). Pointing to acrylic paints, the therapist said this particular client would lose all detail and

Materials are Situated in a Sociocultural Context

Beyond the expressive properties of materials, art therapists recognize that the sociocultural context affects how participants interpret and use materials. One therapist explained that *“every material is loaded with meaning...”* A key figure in art therapy writes, *“[a material’s] significance and meaning are the result of a complex interplay of personal, historical, social and cultural contexts...”* [80]. Further, the relationship between these factors emerges during an individual’s interaction with materials in a specific context [80]. An example is the conception of certain materials as related to “high art.” Several art therapists described selecting high quality art materials to convey the importance and worthwhileness of art therapy as well as to position art therapy participants as artists. At the same time, a perspective in art therapy recognizes that when art therapists unreflectively select certain materials as “fine” art materials, they may be inadvertently positioning individuals who do not regularly have financial access or a relationship to these materials as unrefined [79]. Recognizing the distance that some art therapy participants may feel from “high art,” other therapists discussed finding less intimidating materials such as aluminum foil as opposed to clay: *“there’s something intimidating about a material that’s recognized as something that, ‘that’s what artists do.’”* [AT9]. AT9 also explained that she liked to bring household materials with which participants were familiar, describing how participants may have interacted with materials such as wood to build a birdhouse or fabric to make their own clothing. This connects with research on sense-making, which recognizes the ways that people select technologies based on a “self” they are interested in becoming [67]. Therapists are mindful of the diverse sociocultural associations participants have with materials and adapt material choices to support each person.

Creating a Space for Expression

The second lesson we can draw from art therapy practice involves the therapist’s role in creating a space for expression to emerge through the process of making. Ongoing debates and theorizing in design research examine the role of the researcher or facilitator in design work (e.g., [12,96,108]). Light and Akama question how our current research culture anonymizes facilitation and its agency and draw attention to the importance of understanding the designer’s participatory practice [58]. Here we analyze the participatory practice of

art therapists in constructing a space for expression to occur through making.

Shifting the Terms of Communication

The notion of making as expression shifts the terms of communication away from verbalization and focuses attention on the process and product of creation. Art therapists explained that working with materials was often more suitable and less threatening to clients than verbal communication alone. AT18 explained how relying on verbal language “creates a barrier.” Therapists used materials to find “a different way in,” [AT14] or a way to connect besides verbal language, with participants. AT15 compared engaging with materials to “having a conversation,” albeit “through a different medium” than verbal language. AT12 mentioned how this was helpful because “the art becomes this outlet that takes some of that pressure off of directly communicating with another person.” Participants may use artwork as a way of externalizing and getting distance from difficult topics, with AT14 saying “It can be a lot easier to talk about a piece of artwork than to talk about yourself.” AT18 explained:

“I had one woman, a patient who really had a hard time dealing with her mother... she (the client) was hospitalized with depression. She came to my session and she said, ‘I want to draw a portrait of my mother.’...As she draws the image, she kept telling me that her mother is one of the best mothers in the whole world... ‘She’s wonderful. I love her dearly.’ That’s what she’s verbally saying to me. But I’m observing the way she draws. She’s grabbing the pastel and really aggressively drawing her image, the woman. The facial expression of the portrait is quite angry and aggressive...When you see that kind of incongruency...you begin to feel that this woman has tremendous anger and resentment toward her mother. It’s a hard fact to admit – ‘I really hate my mother, she’s so controlling.’ It’s very difficult to say... That is the kind of things we get to see. The glimpse of real, inner feelings come in visual expression.”

Under this view, the process of creating artwork and the artwork itself tells you “what is important to that person and what the main point of connection is,” said AT7. She continued, “With one client, all of her work is about nature and memories of her family.... If you’re just talking to her, she probably won’t tell you that she loves nature, and green things, and was married to a man named Peter, but that comes through in her art.” This therapist provided another example of what a participant’s artwork can communicate:

“I assumed that everybody knew that [the client] loved to talk about the house she raised her kids in...and the dog that was always running around...because all of her art depicts her backyard. When I talked with her caregiver and CNAs in memory support, nobody had heard this story and it seemed so strange to me...because that is clearly the most important thing to her absolutely above all else. The story that brings her joy and fuels her identity is raising her kids, in this house,

and watching them play. That only comes out because that is the art that she makes every single week...”

Although at times verbalization happens through the art making process, verbalization is not the central goal. Bruce Moon, a scholar in art therapy, explains that “... I believe it is possible that our most significant work takes place without speaking at all” [73]. AT12 explained, “Something that we put a lot of weight in the field is letting the art speak for you and taking some reliance away from verbalizing things.” AT1 further confirmed this perspective through her explanation of how she has learned the most from people who rarely speak: “...they’ve really forced me to believe in that material language, forced me to believe that art is intelligible in it of itself and to not have to get that verification about what’s going on.” Continuing, she discussed a client in a private psychiatric hospital:

“[He] told me ‘I want to build a fire today’... We had a wood room and I started pulling out some pieces... pretty soon he’s joining me and then he found these balls of clay and started making sort of rock shapes, and he took the paper off the crayons and put it up on top like it was flames... he never said why he wanted to make the fire, I never really asked him either, and then after it was all done we just stood back and looked at it... all I asked was ‘hm, wonder what we’re gonna burn today.’ And he said ‘evil’. And I was like ‘hm. I wonder where we can find evil’. And he just went [gestures pulling something out of the mouth] and just dropped it in the fire, and that was all that was said. I never asked him to explain anymore, I felt like he had said plenty through what he did there.” [AT1]

This participant’s interaction with the material workspace and with his therapist is treated as an acceptable and insightful form of communication. Prior work recognizes the ways that our physical experience in the world and bodily engagement is central to interaction [25,46,85]. Aligned with this perspective, art therapy’s reframing of interaction not only shifts the terms of communication away from purely verbal discourse but also helps foster a safe space for multimodal, multimedia expressions to emerge.

Creating a Safe Space

Therapists aim to create a space where participants feel comfortable engaging in the process of creation, exploration, and expression of thoughts and feelings [75]. One way that therapists contribute to a “safe space” [AT4] and a “very accepting, comfortable environment” [AT1] is by making art alongside participants. As AT3 said, this was helpful because “people don’t like to be watched... Especially when they’re talking about things that are difficult, and you sit there and stare at them while they’re drawing, it makes them uncomfortable...” The act of making alongside a participant can help shift this dynamic and create a more comfortable and safe space for creation.

Therapists are aware of the dynamics between participants and others outside of therapy. They have different

perspectives on the degree to which other individuals (e.g., staff, family members) should be involved in the process of art therapy. Though some art therapists described involving family members and staff in sessions with people with complex communication needs, AT18 said that she discouraged family members and staff from joining sessions because it was important to have a space where participants “*can express themselves freely and spontaneously without being judged.*” Therapists recognized that others sometimes attempt to influence a participant’s art making process or product, disrupting the safe space that the therapist worked to construct.

Another aspect of creating a safe space involves bearing witness to expressions as they unfold [68]. The therapist’s role is not to provide directives or interpret art; rather, it is to witness participants as they “*discover what that [artwork or material] means for them*” [AT1]. Bearing witness means to be “*a follower instead of a leader*” [AT2]. Witnessing and following, however, do not imply passivity. Therapists respond to participant expressions verbally, through response art, or with thoughtful silence to demonstrate a participant is “*accepted and affirmed*” [AT1].

Negotiating Goals

As part of creating space for expression to unfold, therapists reflect on their own expectations for interaction during the process of making. Art therapists believe in “*trusting the process*” [69] and that, given the right materials, the participant “*ultimately and instinctively knows where they need to go... the artistic process will work things out for people...*” However, trusting the process does not mean that the participant is assumed to understand everything ahead of time and be able to convey it to the therapist. Rather, participants’ “*artworks may reveal feelings and issues the client is not consciously aware of at the time the artwork is created*” [75]. An understanding of these feelings emerges over time and through interaction with materials. Further, trusting the process does not mean that the therapist provides no structure or feedback. Instead, the therapist thoughtfully selects and arranges materials, suggests a mode of exploration (whether focused or open), and responds in ways that further affect the process of art making (e.g., staying silent, making art in response) [77].

Therapists acknowledge that their interactions with participants occur within existing clinical settings and institutions, which often have pre-defined goals for clients (e.g. court ordered therapy for anger). Art therapists believe that the participants’ goals matter as a social justice issue [75]. AT2 said, “*I think it’s a social justice issue for me that I shouldn’t determine what somebody else needs to work on in their life.*” Further, art therapists described ongoing reflection as a way to mitigate the assumptions that seep into their understanding of participants’ needs. AT2 described doing so by, “*... really being in touch with what I think should happen...versus what they (participants) think... knowing that that’s our human tendency to feel like we know what’s*

best for somebody else.” AT4 stressed the importance of not coming to participants with “*preconceived notions,*” explaining that, “*sometimes I might go to the session and think that I’ve tried this with this particular population and since this is [a] similar population, I’ll do the same thing as well. But [it] doesn’t necessarily work that way.*” Nevertheless, art therapists negotiate therapeutic goals for and with participants, taking into consideration the larger system of health care and insurance. Therapists explained that at times institutional goals were at odds with individual goals, but they worked to “*connect with clients to figure out what it is that they need and want*” [AT2]. That is, therapists aimed to conduct therapy in a way that satisfied institutional goals while still supporting their client’s desires and goals for expression.

Supporting Expression in a Broader Context

The notion of making as expression highlights multiple underlying power dynamics—from the privileged position of verbal discourse to hierarchies inherent in art and therapy as disciplines to who makes decisions around sharing artwork. The work of art therapists includes negotiating these power dynamics to sustain clients’ expressions in a broader social context. Art therapists are aware that outside of the art therapy practice, clients are often marginalized due to their position in society, disability, or stigmatizing experiences. To help counter this, they are advocates for the perspective of making as expression and aim to dismantle hierarchies that arise within the domains of health and art.

Deconstructing Hierarchies

Therapists’ reflexive practice attends to the hierarchies inherent in therapy and art, and through this, they aim to shift power imbalances across both cultures. Therapists acknowledge that their interactions occur within a larger context of care, in which patients are positioned as in need of help and therapists as those providing help. Similar tensions exist between researchers and the researched [91]. AT1 explained that, “*Whenever you have a hierarchy, it reinforces a power differential.*” Some therapists described trying to eliminate the distinction between therapist and participant (e.g., by avoiding the labels of patient and therapist), aiming for a more “*collaborative*” relationship [AT17]. Prior work has identified the ways in which hierarchies and clearly demarcated roles in healthcare contexts (e.g., clinician, patient) affect the design process [24], and in our field work, we observed therapists positioning themselves as “*assistants*” and “*helpers*” in the creative process as one effective strategy (also see [52]).

Beyond hierarchies reinforced by the health care system, the field of Art can esteem certain work and materials (e.g., high art, fine arts) and disparage others (crafts as “*low arts*”) [81]. Therapists are aware that participants come to art therapy with assumptions of what makes something ‘art’ and who can take on the role of an ‘artist.’ Therapists described crafting a social environment that did not encourage one ‘right’ way of making art. AT1 described this as, “*the art*

here is not hierarchical... there's an atmosphere that's cultivated of 'whatever you choose to do, that's great...' Further, therapists emphasized that all forms of engagement and “being” during therapy are valued. For example, an ornate painting is not seen as a more successful outcome than a careful arrangement of oil pastels on a piece of paper [55]. Therapists explained to participants that everyone, including the therapist, had the potential for creative exploration and personal and artistic growth, and that reciprocal exchanges took place within the group. AT4 said that he would tell participants “*We are here to learn together. Each one of you has a lot to offer. And that's how I try to position it.*” The work of deconstructing hierarchies and forming a co-creative partnership is essential in collaborative design as well.

Serving as an Ambassador of a New “Shared Language”

Understanding that verbalization is a dominant form of communication, therapists work to ensure that others can receive expressions created in therapy. AT17 described the importance of using a “*shared language*” to convey interactions that take place in an art therapy so others (e.g., family, care providers) can understand. In other words, therapists acknowledge the need to use verbal language to some extent to communicate with others. When possible, therapists facilitate participants in sharing their artwork, whether by bringing the participant to a care meeting or bringing artwork and relaying descriptions exactly as the participant said them (at times using audio recordings). Therapists have participants title their work and compose “*artist statements*,” or provide other modalities of expression (e.g., arranging word tiles on an art piece).

Therapists are mindful advocates and adjust the way they share artwork depending on the audience. In care meetings, therapists used artwork to share participant’s functional and emotional states, as well as preferences as they impacted health care [20]. With family and caregivers, artwork was shown to support emotional connections or to challenge perceptions of participants as unable to engage in activity or with others. Art therapists may also use artwork to convey to staff the possibility of using multisensory expression to interact with residents without speaking to them [55]. Further, therapists model what it means to “witness” artwork for others, and step in when they perceive others attempting to interpret participant artwork in a way that does not reflect what the participant intended [54].

Sharing Expressions to Advocate for Societal Change

Though art therapy usually takes place behind closed doors, therapists see value in sharing the expressions embodied in artwork more broadly to engender positive societal changes. AT12 said, “*There is only so much two people [a participant and therapist] can do together.*” She continued that if the participant takes the art “*into a wider audience, then it might become an issue that's actually handled...*” Therapists supported participants in sharing artwork in exhibits, zines, self-published books, and YouTube videos. Often the purpose of sharing with a wider audience was to challenge

stigma associated with a health condition, disability, or position in society. Therapists explained that sharing artwork “*changes people's concept of you*” [AT10] and can “*create more empathy*” [AT15]. When others view participants’ work, they are able to view these individuals as “*capable of doing things that contribute to society.*”

Sharing artwork also helps participants build a receptive audience that they may not have otherwise, as the artwork is “*so concrete and so visible, powerful and expressive, that it's a different way than verbally saying 'I am here'...*” [AT15]. Therapists recognized that many participants face challenges that are significantly heightened by their positioning in society [45]. Similarly, another therapist said that “*as therapists we have to be social activists,*” and saw art shows as advancing her advocacy. Prior design research has also begun to challenge perceptions (e.g., around dementia) [90]. Yet, therapists described reflecting on their reasons for sharing the work of participants, particularly those with cognitive impairments who do not recognize it is their art being shown. AT7 questioned “*Whose agenda is that serving... mine, cause I'm an art therapist and I want to show that I work with people with dementia? Is it in that person's benefit, because they're a person, and sometimes they are not perceived as people?*” We argue that these are pressing questions for collaborative design work as well.

DISCUSSION

Drawing from the clinical discipline of art therapy, this paper calls attention to the notion of making as a valued form of expression for people with complex communication needs. Below, we discuss the practical ways in which researchers can adopt insights from art therapy practice in their own work as well as ethical issues and responsibilities that come to light based on our analysis of art therapy.

Insights for Practice

Analyzing art therapy practice provides insights for collaborative design engagements, and here we revisit our findings to inform co-creative design projects involving people with complex communication needs.

Consider What Materials Say

As research begins to unpack materiality in design (e.g., [41,104]), art therapy calls attention to the nuances of materials as language. Above all, therapists spoke of the importance of intentionally selecting materials by attending to their physical, sociocultural, and expressive properties as well as the kinds of participation and states materials encourage. For example, therapists think about how “*a brush full of paint has more limited possibilities for action than a jar full of finger paint*” [49]. Others described how a shared piece of paper for a group session changes interaction compared to individual canvases. While Makhaeva et al. assert that material selection is central to unlocking participants’ creative potential [62], we can look to art therapy for a nuanced view of the “*possibilities for action*” that various materials afford (see [80] for a review). With a richer understanding of materials, we can take advantage of

different qualities of materials for different stages of a project. Post-It notes and markers, often provided during early brainstorming, can be rearranged flexibly but require succinct, written thoughts and reinforce boundaries. How might more fluid materials (e.g., acrylic or watercolor paints) change participants' creative potentials? Further, researchers can consider which materials support certain individuals. As an example, researchers working with individuals with anxiety may wish to avoid fluid materials, particularly early in the design process [80].

Another way researchers can better attend to the language of materials is to understand that material selection, arrangement, and social expectations reflect a wider value system. Crayons and printer paper may evoke child-like comfort for some and give others the impression that their ideas will not be taken seriously. Researchers who introduce high quality brushes and paints may convey to some that their work (and time) is valuable and alienate others who perceive fine art as for the elite. Similarly, selecting materials that are traditionally associated with particular groups but are devalued by the dominant group (e.g., women and knitting; subcultures and tattoos) further reveal values and expectations around participation. As digital tools for making become more accessible to the general population, they are likely to take a more central role in formative design work. It will become increasingly important for researchers to consider what these materials say in terms of empowerment (i.e., signaling to a population that they are joining the maker movement) and balance this against how these tools reinforce hierarchies that prize technology and technological know-how over other creation skills. This critique extends to how and why we introduce electronic making kits to various groups, such as sociocultural implications of fabric-based kits for women (e.g., LilyPad [15]). Though instructors and shop managers make decisions about resources and the environment, the ways in which tools for making affect participation are less understood. For example, how CAD tools look and feel, the width and refinement of the extruder, the materials (plastic vs pancake batter), and the colors of acrylic or ABS plastic (primary or neutrals) all stand to influence participation and have their own sociocultural associations for various participants. The therapist, as well as the researcher, “wields enormous influence... simply by deciding what materials to provide...” [80]. As researchers, an important area for future research involves thinking critically about how material selection, arrangement, and expectations for interaction shape collaborative design engagements.

Creating Space for Expression

Art therapy also helps set expectations of what is accomplished within a co-creative session and considered an outcome. The concept of “trusting the process” means that the therapist approaches participants' expressions with “attentiveness, openness, curiosity, a nonjudgmental attitude, and a sense of wonder,” rather than “the intention of finding hard-and-fast interpretive truths” [77]. The therapist is

willing to be in a state of “not knowing,” acknowledging that this can be an unsettling position [77]. This suggests that the key role of the researcher is not one of facilitator who issues prompts and directives. Rather, the researcher acts as a witness, taking in the participants' work and selecting an appropriate response, which can take the form of a held gaze and a thoughtful silence or a gently probing question. This aligns with Light and Akama's description of the performative nature of facilitation, which involves embodied knowing, moment-to-moment shifts, and fluid negotiation around formal processes [58]. In terms of practical applications, researchers can practice witnessing rather than directing, and creating alongside participants rather than observing them, as ways of shifting the dynamics of collaborative design sessions.

The notion of creating space for communication also resonates with prior work discussing how researchers may be most useful in an “infrastructuring” role in participatory design [5]. That is, rather than facilitating participants in responding to known issues or improving existing technologies (e.g., asking participants to design a better medication container), researchers can be involved in “identifying, designing, and supporting social, technical, and spatial infrastructure” [29]—providing an environment where participants can discover and respond to issues that matter to them [22]. Similarly, the concept of response art, or art created to respond to an interaction during therapy, helps re-envision how researchers could respond to participant interaction through modalities other than speech or written text. Often the focus in formative design work is on articulating insights and plans to move design forward; yet, the results of formative design work may not be best, or even possible to express, through words. Conveying design work through newer publication and presentation formats, such as the visual thinking gallery [6], art exhibitions [30] and Pictorials [7] at conferences expands the range of possibilities and sustains these new forms of expression (see [111] for an excellent example).

Ongoing Reflection of Power Dynamics

Reflexivity, particularly with respect to positions of power, is not a new topic within design [3,23,95]. Art therapy lends insights into why ongoing reflection on power dynamics is essential to sustaining the expressions of people with complex communication needs more broadly in society. As discussed earlier, individuals are confronted with their own abilities and experiences as part of the process of sharing (through art therapy or research [11,109]), and sharing emotionally distressing or stigmatizing experiences poses additional considerations that researchers are just beginning to recognize [14,21]. Art therapists understand that power dynamics underlie the entire process of making and sharing. They receive extensive training on how to reflect on and account for their positionality in the therapeutic relationship and learn to practice reflexivity through oversight from experienced colleagues [31]. This suggests that our research training and mentoring practices should better attend to

positionality and promote reflexive practice, particularly when working with these populations. Art therapy can serve as a model for how to incorporate “ongoing self-questioning” [3] in technology design, a key priority of Feminist HCI [3] and Social Justice-Oriented Interaction Design [23]. Therapists describe a dual role as activist, and we should attend to similar identities as we understand and report on the “designer using the method” [58].

Ethics and Responsibility

While art therapy provides an instructive lens for envisioning collaborative design work, art therapists are skilled professionals who are trained to work with and nurture long-term relationships with individuals with complex communication needs. Therapists thoughtfully create spaces for participants to express sensitive thoughts and emotions that they may have never expressed before. Therapists understand risks involved: disclosing something too soon can be harmful; participants may at first feel worse when they begin communicating these thoughts and feelings; and therapists must know “*how to wrap somebody up in a way that they are not walking around out in the world after a therapy session completely wide open*” [AT2]. Additionally, art therapists draw on networks of health care professionals, who can provide continuity in care, help deal with crises, and address other aspects of the participant’s wellbeing. In agreement with prior work [65,82], an effective strategy is to create design teams that include health care practitioners or professionals who are trained to work with individuals with complex communication needs (e.g., art therapists, occupational therapists, social workers).

The point here is not to propose researchers should embody the role of therapist; rather, that drawing out experiences and desires of individuals with complex communication needs is serious work. There is depth and nuance to working with individuals with complex communication needs that research often glosses over. Power relations with participants and their position in society are rarely brought to the forefront of design work. Yet, these issues exist the moment researchers enter an engagement [22,58]. We can learn from art therapists, who integrate an awareness of power relations into their practices and work to reduce power differentials (e.g., by cultivating spaces without a “right way” to engage). Though this paper draws largely on the perspectives of therapists, other work unpacks power dynamics between researchers and people with complex communication needs (e.g., [64,83]).

Further, the case of art therapy makes it clear that expression through any modality changes people: “we make our art and our art makes us” [77]. Recognizing the potential for change through participation is a particularly salient issue when research aims to engage individuals in discussions of discrimination, stigma, or social acceptability [56,97,98]. In our own work, we have benefited from long-term partnership with therapists, who bring their own ethical attunement and sensitivities to the research practice. These collaborations

revealed how researchers can enable participants to set the terms of communication while being mindful of the privileged position of verbal discourse and its isolating effects on certain people. Collaboration with therapists has also revealed how pursuing certain topics without a participant being ready or the space being ‘safe’ can be damaging. As researchers, we must develop practices or engage experts to help “*wrap somebody up*” after a session that leaves them “*completely wide open*.”

Finally, as we shift our practices to value and convey expressions of people with complex communication needs to the larger research community, we must consider our responsibility in terms of the ways we represent these populations. We can turn to the history of “outsider art,” or artwork created by people considered to be “other”—those who cannot or do not adhere to dominant forms of expression and being (e.g., individuals with mental health conditions) [88]. The ways this work has historically been valued, presented, and discussed are now seen as exploitative. That is, the art is treated as special because the population who created it is seen as so different from the viewers—which further highlights differences and solidifies stigma and negative positioning in society [88]. We, too, must question whether we are doing “outsider research.” While collaborative design aims to empower those who may be invisible or weaker in power [39], we must remain aware of how research may inadvertently disempower. As researchers, we need to consider the ways we frame research and present findings, which can end up magnifying or sensationalizing differences between the studied group and others. The ways in which we describe populations and articulate the need for research in a particular area can reveal underlying values and power dynamics.

CONCLUSION

There is a growing interest in involving individuals with complex communication needs in design work, particularly around the creation and use of new technologies. Current strategies for engaging these individuals often focus on bridging gaps in communication left by an impairment or stigmatizing experience. At times, we narrowly scope and limit the conversational space so that we, as researchers, can understand. We argue that art therapy provides a model for how the research community can view *making as expression* and shift the terms of communication to understand what is most important to participants and points of connection for future design work. Further, art therapy provides a lens on the privileged position of verbal discourse in collaborative design work and opens up new avenues for fostering supportive and experience affirming co-creative design engagements.

ACKNOWLEDGEMENTS

We thank the individuals who participated in this study. This work was supported in part by NSF grant IIS-1551574 and the Delaney Foundation.

REFERENCES

1. Morgan G. Ames, Jeffrey Bardzell, Shaowen Bardzell, Silvia Lindtner, David A. Mellis, and Daniela K. Rosner. 2014. Making cultures: Empowerment, Participation, and Democracy – or Not? *Proceedings of the extended abstracts of the 32nd annual ACM conference on Human factors in computing systems - CHI EA '14*: 1087–1092. <https://doi.org/10.1145/2559206.2579405>
2. Lisa Anthony, Sapna Prasad, Amy Hurst, and Ravi Kuber. 2012. A participatory design workshop on accessible apps and games with students with learning differences. *Proceedings of the 14th international ACM SIGACCESS conference on Computers and accessibility (ASSETS '12)*: 253–254. <https://doi.org/10.1145/2384916.2384979>
3. Shaowen Bardzell and Jeffrey Bardzell. 2011. Towards a Feminist HCI Methodology: Social Science, Feminism, and HCI. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '11)*, 675–684.
4. Laura Benton, Hilary Johnson, Emma Ashwin, Mark Brosnan, and Beate Grawemeyer. 2012. Developing IDEAS: Supporting Children with Autism within a Participatory Design Team. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '12)*: 2599–2608. <https://doi.org/10.1145/2207676.2208650>
5. Erling Björgvinsson, Pelle Ehn, and Per-Anders Hillgren. 2012. Agonistic participatory design: working with marginalised social movements. *CoDesign* 8, 2–3: 127–144.
6. Eli Blevis. 2016. The Visual Thinking Gallery : A Five Year Retrospective. *Proceedings of the ACM Conference on Designing Interactive Systems (DIS '16)*: 1096–1110.
7. Eli Blevis. 2016. Being Photo-Visual in HCI and Design. *Proceedings of the ACM Conference on Designing Interactive Systems (DIS '16)*: 983–995. Retrieved from <http://doi.acm.org/10.1145/2901790.2901863>
8. Claus Bossen, Christian Dindler, and Ole Sejer Iversen. 2012. Impediments to user gains: experiences from a critical participatory design project. *Proceedings of the 12th Participatory Design Conference: Research Papers - Volume 1*: 31–40. <https://doi.org/10.1145/2347635.2347641>
9. Jordan L. Boyd-Graber, Sonya S. Nikolova, Karyn A. Moffatt, Kenrick C. Kin, Joshua Y. Lee, Lester W. Mackey, Marilyn M. Tremaine, and Maria M. Klawe. 2006. Participatory Design with Proxies : Developing a Desktop-PDA System to Support People with Aphasia. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '06)*: 151–160. <https://doi.org/10.1145/1124772.1124797>
10. Tone Bratteteig and Ina Wagner. 2016. What is a participatory design result? *Proceedings of the 14th Participatory Design Conference on Full papers (PDC '16)*: 141–150. <https://doi.org/10.1145/2940299.2940316>
11. Bas Brederode, Panos Markopoulos, Mathieu Gielen, Arnold Vermeeren, and Huib de Ridder. 2005. pOwerball: the design of a novel mixed-reality game for children with mixed abilities. In *Proceedings of the Conference on Interaction Design and Children (IDC '05)*, 32–39.
12. Margot Brereton, Laurianne Sitbon, Muhammad Haziq Lim Abdullah, Mark Vanderberg, and Stewart Koplick. 2015. Design after design to bridge between people living with cognitive or sensory impairments, their friends and proxies. *CoDesign* 11, 1: 4–20. Retrieved from <http://www.tandfonline.com/doi/abs/10.1080/1571088.2.2015.1009471>
13. Robin Brewer and Anne Marie Piper. 2016. “Tell It Like It Really Is”: A Case of Online Content Creation and Sharing Among Older Adult Bloggers. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '16)*, 5529–5542.
14. Deana Brown, Victoria Ayo, and Rebecca E Grinter. 2014. Reflection Through Design: Immigrant Women’s Self-reflection on Managing Health and Wellness. *Proceedings of the ACM Conference on Human Factors in Computing Systems*: 1605–1614. <https://doi.org/10.1145/2556288.2557119>
15. Leah Buechley and Hannah Perner-Wilson. 2012. Crafting technology: Reimagining the processes, materials, and cultures of electronics. *ACM Transactions on Computer-Human Interaction* 19, 3: Article 21. <https://doi.org/10.1145/2362364.2362369>
16. Erin Buehler, Stacy Branham, Abdullah Ali, Jeremy J. Chang, Megan Kelly Hofmann, Amy Hurst, and Shaun K. Kane. 2015. Sharing is Caring: Assistive Technology Designs on Thingiverse. *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems - CHI '15*: 525–534. <https://doi.org/10.1145/2702123.2702525>
17. John M. Carroll and Mary Beth Rosson. 2007. Participatory design in community informatics. *Design Studies* 28, 3: 243–261. <https://doi.org/10.1016/j.destud.2007.02.007>
18. Kathy Charmaz. 2014. *Constructing Grounded Theory*. Sage Publications, London.
19. Amy Cheatle and Steven J. Jackson. 2015. Digital Entanglements: Craft, Computation and Collaboration in Fine Art Furniture Production. *Proceedings of the*

- 18th ACM Conference on Computer Supported Cooperative Work & Social Computing (CSCW '15)*: 958–968. <https://doi.org/10.1145/2675133.2675291>
20. Raymundo Cornejo, Robin Brewer, Caroline Edasis, and Anne Marie Piper. 2016. Vulnerability, Sharing, and Privacy: Analyzing Art Therapy for Older Adults with Dementia. In *Proceedings of the ACM Conference on Computer-Supported Cooperative Work & Social Computing (CSCW '16)*, 1572–1583.
 21. Christopher A. Le Dantec. 2012. Participation and Publics: Supporting Community Engagement. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '12)*: 1351–1360. <https://doi.org/10.1145/2207676.2208593>
 22. Christopher A Le Dantec and Carl DiSalvo. 2013. Infrastructuring and the Formation of Publics in Participatory Design. *Social Studies of Science* 43, 2: 241–264.
 23. Lynn Dombrowski, Ellie Harmon, and Sarah Fox. 2016. Social Justice-Oriented Interaction Design: Outlining Key Design Strategies and Commitments. *Proceedings of the Designing Interactive Systems Conference (DIS '16)*: 656–671.
 24. Sara Donetto, Paola Pierri, Vicki Tsianakas, and Glenn Robert. 2015. Experience-based co-design and healthcare improvement: Realizing participatory design in the public sector. *Design Journal* 18, 2: 227–248. <https://doi.org/10.2752/175630615X14212498964312>
 25. Paul Dourish. 2001. *Where the Action is: The Foundations of Embodied Interaction*. MIT Press.
 26. Allison Druin, Jason Stewart, David Profit, Ben Bederson, and Jim Hollan. 1997. KidPad: A Design Collaboration Between Children, Technologists, and Educators. *Proceedings of the Conference on Human Factors in Computing Systems (CHI '97)*: 463–470. <https://doi.org/10.1145/258549.258866>
 27. Pelle Ehn. 1989. *Work-oriented design of computer artifacts*. Doctoral Dissertation. Arbetslivcentrum.
 28. Pelle Ehn. 1993. Scandinavian Design: On Participation and Skill. In *Participatory Design: Principles and Practices*, Douglas Schuler and Aki Namioka (eds.). 41–70.
 29. Pelle Ehn. 2008. Participation in design things. In *Conference on Participatory Design*, 92–101. <https://doi.org/10.1145/1795234.1795248>
 30. David England, Celine Latulipe, Nick Bryan-Kinns, Ernest Edmonds, and Sean Clark. 2016. Art.CHI II: Digital Art in a Post-Digital World. *Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems (CHI EA '16)*: 3477–3483.
 31. Barbara J. Fish. 2017. *Art-Based Supervision: Cultivating Therapeutic Insight Through Imagery*. Routledge, New York, NY.
 32. Christopher Frauenberger, Judith Good, and Alyssa Alcorn. 2012. Challenges, opportunities and future perspectives in including children with disabilities in the design of interactive technology. In *Proceedings of the 11th International Conference on Interaction Design and Children (IDC '12)*, 367–370. <https://doi.org/10.1145/2307096.2307171>
 33. Christopher Frauenberger, Judith Good, Wendy Keay-Bright, and Helen Pain. 2012. Interpreting input from children: a designerly approach. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI'12)*: 2377–2386. <https://doi.org/10.1145/2207676.2208399>
 34. Julia Galliers, Stephanie Wilson, Abi Roper, Naomi Cocks, Jane Marshall, Sam Muscroft, and Tim Pring. 2012. Words are not enough: Empowering People With Aphasia In The Design Process. *Proceedings of the 12th Participatory Design Conference on Research Papers (PDC '12)*: 51–60. <https://doi.org/10.1145/2347635.2347643>
 35. Chiara Del Gaudio, Alfredo Jefferson de Oliveira, and Carlo Franzato. 2014. The influence of local powers on participatory design processes in marginalized conflict areas. In *Proceedings of the 13th Participatory Design Conference: Research Papers - Volume 1 (PDC '14)*, 131–139. <https://doi.org/10.1145/2661435.2661440>
 36. Katie Gaudion, Ashley Hall, Jeremy Myerson, and Liz Pellicano. 2015. A designer's approach: how can autistic adults with learning disabilities be involved in the design process? *CoDesign* 11, 1: 49–69. <https://doi.org/10.1080/15710882.2014.997829>
 37. Kathrin Gerling, Kieran Hicks, Michael Kalyn, Adam Evans, and Conor Linehan. 2016. Designing Movement-based Play With Young People Using Powered Wheelchairs. *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*: 4447–4458. <https://doi.org/10.1145/2858036.2858070>
 38. Elisa Giaccardi and Elvin Karana. 2015. Foundations of Materials Experience: An Approach for HCI. *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems (CHI '15)*: 2447–2456. <https://doi.org/10.1145/2702123.2702337>
 39. Joan Greenbaum and Daria Loi. 2012. Participation, the camel and the elephant of design: A introduction. *CoDesign* 8, 2–3: 81–85. <https://doi.org/10.1080/15710882.2012.690232>
 40. Foad Hamidi, Melanie Baljko, and Isabel Gómez. 2017. Using Participatory Design with Proxies with Children with Limited Communication. In

- Proceedings of the SIGACCESS Conference on Computers and Accessibility (ASSETS '17)*.
<https://doi.org/10.1145/3132525.3132527>
41. Nicolai Brodersen Hansen and Peter Dalsgaard. 2012. The Productive Role of Material Design Artefacts in Participatory Design Events. In *Proceedings of the Nordic Conference on Human-Computer Interaction (NordCHI '12)*, 665–674.
<https://doi.org/10.1145/2399016.2399117>
 42. Ingrid Hellström, Mike Nolan, Lennart Nordenfelt, and Ulla Lundh. 2007. Ethical and Methodological Issues in Interviewing Persons With Dementia. *Nursing Ethics* 14, 5: 608–619.
<https://doi.org/10.1177/0969733007080206>
 43. Niels Hendriks, Karin Slegers, and Pieter Duysburgh. 2015. Codesign with people living with cognitive or sensory impairments: a case for method stories and uniqueness. *CoDesign* 11, 1: 70–82.
<https://doi.org/10.1080/15710882.2015.1020316>
 44. Sen H. Hirano, Michael T. Yeganyan, Gabriela Marcu, David H. Nguyen, Lou Anne Boyd, and Gillian R. Hayes. 2010. vSked: Evaluation of a System to Support Classroom Activities for Children with Autism. *Proceedings of the 28th international conference on Human factors in computing systems (CHI '10)*: 1633–1642.
<https://doi.org/10.1145/1753326.1753569>
 45. Dan Hocoy. 2005. Art Therapy and Social Action: A Transpersonal Framework. *Journal of the American Art Therapy Association* 22, 1: 7–16.
<https://doi.org/10.1080/07421656.2005.10129466>
 46. Edwin Hutchins. 1995. *Cognition in the Wild*. MIT Press.
 47. Ole Sejer Iversen, Kim Halskov, and Tuck Wah Leong. 2010. Rekindling values in participatory design. *Proceedings of the 11th Biennial Participatory Design Conference (PDC '10)*: 91–100.
<https://doi.org/10.1145/1900441.1900455>
 48. Giulio Jacucci and Ina Wagner. 2007. Performative roles of materiality for collective creativity. *Proceedings of the 6th ACM SIGCHI conference on Creativity & cognition (C&C '07)*: 73–83.
<https://doi.org/10.1145/1254960.1254971>
 49. Sandra L. Kagin and Vija B. Lusebrink. 1978. The Expressive Therapies Continuum. *Art Psychotherapy* 5, 4: 171–180. [https://doi.org/10.1016/0090-9092\(78\)90031-5](https://doi.org/10.1016/0090-9092(78)90031-5)
 50. Anne Marie Kanstrup and Pernille Bertelsen. 2016. Bringing New Voices to Design of Exercise Technology: participatory design with vulnerable young adults. In *Proceedings of the 14th Participatory Design Conference: Full papers - Volume 1 (PDC '16)*, 121–130.
<https://doi.org/10.1145/2940299.2940305>
 51. Sarah Kettley, Richard Kettley, and Matthew Bates. 2015. An Introduction to the Person-centred Approach As an Attitude for Participatory Design. *Adjunct Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing and Proceedings of the 2015 ACM International Symposium on Wearable Computers (UbiComp/ISWC'15 Adjunct)*: 1101–1104.
<https://doi.org/10.1145/2800835.2807945>
 52. Amanda Lazar, Raymundo Cornejo, Caroline Edasis, and Anne Marie Piper. 2016. Designing for the Third Hand: Empowering Older Adults with Cognitive Impairments through Creating and Sharing. In *Proceedings of the 2016 ACM Conference on Designing Interactive Systems (DIS '16)*, 1047–1058.
<https://doi.org/10.1145/2901790.2901854>
 53. Amanda Lazar, Mark Diaz, Robin Brewer, Chelsea Kim, and Anne Marie Piper. 2017. Going Gray, Failure to Hire, and the Ick Factor: Analyzing How Older Bloggers Talk about Ageism. In *Proceedings of the ACM Conference on Computer-Supported Cooperative Work & Social Computing (CSCW '17)*.
<https://doi.org/10.1145/2998181.2998275>
 54. Amanda Lazar, Caroline Edasis, and Anne Marie Piper. 2017. Supporting People with Dementia in Digital Social Sharing. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '17)*: 2149–2162.
<https://doi.org/10.1145/3025453.3025586>
 55. Amanda Lazar, Caroline Edasis, and Anne Marie Piper. 2017. A Critical Lens on Dementia and Design in HCI. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '17)*, 2175–2188. <https://doi.org/10.1145/3025453.3025522>
 56. Amanda Lazar and David H. Nguyen. 2017. Successful Leisure in Independent Living Communities: Understanding Older Adults' Motivations to Engage in Leisure Activities. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI)*, 7042–7056.
<https://doi.org/10.1145/3025453.3025802>
 57. Tuck Wah Leong and Toni Robertson. 2016. Voicing values: laying foundations for ageing people to participate in design. *Proceedings of the 14th Participatory Design Conference*: 31–40.
<https://doi.org/10.1145/2940299.2940301>
 58. Ann Light and Yoko Akama. 2012. The Human Touch: Participatory practice and the Role of Facilitation in Designing with Communities. *Proceedings of the 12th Participatory Design Conference (PDC '12)*: 61–70.
<https://doi.org/10.1145/2347635.2347645>
 59. Stephen Lindsay, Katie Brittain, Daniel Jackson, Cassima Ladha, Karim Ladha, and Patrick Olivier.

2012. Empathy, participatory design and people with dementia. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '12)*, 521–530. <https://doi.org/10.1145/2207676.2207749>
60. Silvia Lindtner, Shaowen Bardzell, and Jeffrey Bardzell. 2016. Reconstituting the Utopian Vision of Making: HCI Ater Technosolutionism. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems - CHI '16*, 1390–1402. <https://doi.org/10.1145/2858036.2858506>
61. Vija B. Lusebrink. 2010. Assessment and Therapeutic Application of the Expressive Therapies Continuum: Implications for Brain Structures and Functions. *Art Therapy: Journal of the American Art Therapy Association* 27, 4: 168–177. <https://doi.org/10.1080/07421656.2010.10129380>
62. Julia Makhaeva, Christopher Frauenberger, and Katharina Spiel. 2016. Creating Creative Spaces for Co-Designing with Autistic Children - The Concept of a “Handlungsspielraum.” *Proceedings of the 14th Participatory Design Conference (PDC '16)*: 51–60. <https://doi.org/10.1145/2940299.2940306>
63. Cathy A. Malchiodi (ed.). 2003. *Handbook of Art Therapy*. The Guilford Press.
64. Jennifer Mankoff, Gillian R Hayes, and Devva Kasnitz. 2010. Disability studies as a source of critical inquiry for the field of assistive technology. In *Proceedings of the 12th international ACM SIGACCESS conference on Computers and accessibility (ASSETS '10)*, 3–10. <https://doi.org/10.1145/1878803.1878807>
65. Mark Matthews, Geri Gay, and Gavin Doherty. 2014. Taking part: role-play in the design of therapeutic systems. *Proceedings of the 32nd annual ACM conference on Human factors in computing systems (CHI '14)*: 643–652. <https://doi.org/10.1145/2556288.2557103>
66. Mark Matthews, Stephen Volda, Saeed Abdullah, Gavin Doherty, Tanzeem Choudhury, Sangha Im, and Geri Gay. 2015. In Situ Design for Mental Illness: Considering the Pathology of Bipolar Disorder in mHealth Design. *Proceedings of the 17th International Conference on Human-Computer Interaction with Mobile Devices and Services (MobileHCI '15)*: 86–97. <https://doi.org/10.1145/2785830.2785866>
67. John McCarthy and Peter Wright. *Technology as Experience*. MIT Press.
68. Shaun McNiff. *Integrating the Art in Therapy: History, Theory, and Practice*. Charles C Thomas Publisher, LTD, Springfield, Illinois.
69. Shaun McNiff. 1998. *Trust the Process: An Artist's Guide to Letting Go*. Shambhala Publications, Inc.
70. Janis Lena Meissner, John Vines, Janice McLaughlin, Thomas Nappey, Jekaterina Maksimova, and Peter Wright. 2017. Do-It-Yourself Empowerment as Experienced by Novice Makers with Disabilities. *Proceedings of the 2017 Conference on Designing Interactive Systems (DIS '17)* 1: 1053–1065. <https://doi.org/10.1145/3064663.3064674>
71. Laura Millen, Sue Cobb, and Harshada Patel. 2011. A method for involving children with autism in design. In *Proceedings of the 10th International Conference on Interaction Design and Children (IDC '11)*, 185–188. <https://doi.org/10.1145/1999030.1999057>
72. Karyn Moffatt, Joanna McGrenere, Barbara Purves, and Maria Klawe. 2004. The Participatory Design of a Sound and Image Enhanced Daily Planner for People with Aphasia. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '04)*, 407–414. <https://doi.org/10.1145/985692.985744>
73. Bruce L. Moon. 2004. *Art and Soul: Reflections on an Artistic Psychology*. Charles C Thomas Publisher, LTD.
74. Bruce L. Moon. 2008. *Introduction to Art Therapy: Faith in the Product*. Charles C Thomas Publisher, LTD.
75. Bruce L. Moon. 2015. *Ethical Issues in Art Therapy*. Charles C Thomas Publisher, LTD.
76. Bruce L. Moon. 2016. *Art-Based Group Therapy: Theory and Practice*. Charles C Thomas Publisher, LTD, Springfield, Illinois.
77. Catherine Hyland Moon. 2002. *Studio Art Therapy: Cultivating the Artist Identity in the Art Therapist*. Jessica Kingsley Publishers.
78. Catherine Hyland Moon. 2010. A History of Materials and Media in Art Therapy. In *Materials & Media in Art Therapy: Critical Understandings of Diverse Artistic Vocabularies*, Catherine Hyland Moon (ed.). Taylor & Francis, 3–48.
79. Catherine Hyland Moon (ed.). 2010. Introduction. In *Materials & Media in Art Therapy: Critical Understandings of Diverse Artistic Vocabularies*. Taylor & Francis, xiii–xxxi.
80. Catherine Hyland Moon. 2010. Theorizing Materiality in Art Therapy: Negotiating Meanings. In *Materials & Media in Art Therapy: Critical Understandings of Diverse Artistic Vocabularies*, Catherine Hyland Moon (ed.). Taylor & Francis, 49–88.
81. Catherine Hyland Moon. 2010. *Materials & Media in Art Therapy: Critical Understandings of Diverse Artistic Vocabularies*. Taylor & Francis.
82. Argyro Moraiti, Vero Vanden Abeele, Erwin Vanroye, and Luc Geurts. 2015. Empowering

- Occupational Therapists with a DIY-toolkit for Smart Soft Objects. *Proceedings of the Ninth International Conference on Tangible, Embedded, and Embodied Interaction (TEI '14)*: 387–394.
<https://doi.org/10.1145/2677199.2680598>
83. Kellie Morrissey, Gavin Wood, David Green, Nadia Pantidi, and John Mccarthy. 2016. “I’m a rambler, I’m a gambler, I’m a long way from home”: The Place of Props, Music, and Design in Dementia Care. *Proceedings of the 2016 ACM Conference on Designing Interactive Systems (DIS '16)*: 1008–1020.
<https://doi.org/10.1145/2901790.2901798>
84. M.J. Muller. 2003. Participatory design: The third space in HCI. *Human-Computer Interaction Handbook 4235*: 1051–1068.
<https://doi.org/10.1145/153571.255960>
85. Rafael Núñez and Walter J Freeman (eds.). 1999. *Reclaiming cognition: the primacy of action, intention and emotion*. Imprint Academic, Thorverton, UK. Retrieved from
<http://books.google.com/books?id=G01LhJnzUWMC>
86. Kristen Nygaard. 1979. The iron and metal project: Trade union participation. In *Computers Dividing Man and Work – Recent Scandinavian Research on Planning and Computers from a Trade Union Perspective*, A. Sandberg (ed.). Utbildningsproduktion, Malmö, Sweden.
87. Cian O’Connor, Geraldine Fitzpatrick, Malcolm Buchanan-Dick, and James McKeown. 2006. Exploratory prototypes for video: interpreting PD for a complexly disabled participant. In *Proceedings of the 4th Nordic conference on Human-computer interaction: changing roles (NordiCHI '06)*, 232–241.
<https://doi.org/10.1145/1182475.1182500>
88. Hester Parr. 2006. Mental health, the arts and belongings. *Transactions of the Institute of British Geographers* 31, 2: 150–166.
<https://doi.org/10.1111/j.1475-5661.2006.00207.x>
89. Halley P. Profita, Abigale Stangl, Laura Matuszewska, Sigrunn Sky, and Shaun K. Kane. 2016. Nothing to hide: Aesthetic customization of hearing AIDS and cochlear implants in an online community. In *Proceedings of the 18th International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '16)*, 219–227.
<https://doi.org/10.1145/2982142.2982159>
90. Paul A. Rodgers. 2017. Co-designing with people living with dementia. *CoDesign*.
<https://doi.org/10.1080/15710882.2017.1282527>
91. Yvonne Rogers and Gary Marsden. 2013. Does he take sugar? Moving beyond the rhetoric of compassion. *interactions* 20, 4: 48–57.
<https://doi.org/10.1145/2486227.2486238>
92. Daniela K. Rosner. 2012. The Material Practices of Collaboration. In *Proceedings of the ACM 2012 conference on Computer Supported Cooperative Work (CSCW '12)*, 1155–1164.
<https://doi.org/10.1145/2145204.2145375>
93. Elizabeth B-N. Sanders and Pieter Jan Stappers. 2008. Co-creation and the new landscapes of design. *CoDesign* 4, 1: 5–18.
<https://doi.org/10.1080/15710880701875068>
94. Donald A. Schön. 1983. *The Reflective Practitioner: How Professionals Think in Action*. Basic Books, New York, New York, USA.
95. Phoebe Sengers, Kirsten Boehner, Shay David, and Joseph “Jofish” Kaye. 2005. Reflective Design. In *Proceedings of the 4th decennial conference on Critical computing: between sense and sensibility (CC '05)*, 49–58. <https://doi.org/10.1145/1094562.1094569>
96. Nima Herman Shidende and Christina Mörtberg. 2014. Re-visiting design-after-design: reflecting implementation mediators connectedness in distributed participatory design activities. In *Proceedings of the 13th Participatory Design Conference on Research Papers (PDC '14)*, 61–70.
<https://doi.org/10.1145/2661435.2661437>
97. Kristen Shinohara and Jacob O Wobbrock. 2016. Self-conscious or self-confident? A diary study conceptualizing social accessibility of assistive technology. *ACM Transactions on Accessible Computing (TACCESS)* 8, 2.
<https://doi.org/10.1145/2827857>
98. Kristen Shinohara and Jacob O. Wobbrock. 2011. In the shadow of misperception: assistive technology use and social interactions. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '11)*, 705–714.
<https://doi.org/10.1145/1978942.1979044>
99. Jay Silver. 2015. The Maker Movement is about Making Meaning. *Medium*. Retrieved from
<https://medium.com/@wakeupsilver/the-maker-movement-is-about-freedom-25ef8a323022>
100. Jesper Simonsen and Toni Robertson (eds.). 2013. *Routledge International Handbook of Participatory Design*. Routledge.
101. Wina Smeenk, Janienke Sturm, and Berry Eggen. 2017. Empathic handover: how would you feel? Handing over dementia experiences and feelings in empathic co-design. *CoDesign* 882, March: 1–16.
<https://doi.org/10.1080/15710882.2017.1301960>
102. Yuling Sun, Silvia Lindtner, Xianghua Ding, Tun Lu, and Ning Gu. 2015. Reliving the Past & Making a Harmonious Society Today: A Study of Elderly Electronic Hackers in China. In *Proceedings of the 18th ACM Conference on Computer Supported*

- Cooperative Work & Social Computing (CSCW '15)*, 3933–3942. <https://doi.org/10.1145/2675133.2675195>
103. Joshua G. Tanenbaum, Amanda M. Williams, Audrey Desjardins, and Karen Tanenbaum. 2013. Democratizing technology: pleasure, utility and expressiveness in DIY and maker practice. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*: 2603–2612. <https://doi.org/10.1145/2470654.2481360>
 104. Jakob Tholander, Maria Normark, and Chiara Rossitto. 2012. Understanding agency in interaction design materials. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '12)*. <https://doi.org/10.1145/2207676.2208417>
 105. Stephen Uzor, Lynne Baillie, and Dawn Skelton. 2012. Senior designers: empowering seniors to design enjoyable falls rehabilitation tools. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '12)*: 1179–1188. <https://doi.org/10.1145/2207676.2208568>
 106. Randy M. Vick. 2003. A Brief History of Art Therapy. In *Handbook of Art Therapy*, Cathy A. Malchiodi (ed.). The Guilford Press.
 107. John Vines, Mark Blythe, Paul Dunphy, Vasilis Vlachokyriakos, Isaac Teece, Andrew Monk, and Patrick Olivier. 2012. Cheque Mates: Participatory design of digital payments with eighty somethings. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '12)*: 1189–1198. <https://doi.org/10.1145/2207676.2208569>
 108. John Vines, Rachel Clarke, Peter Wright, John McCarthy, and Patrick Olivier. 2013. Configuring participation: on how we involve people in design. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '13)*, 429–438. <https://doi.org/10.1145/2470654.2470716>
 109. Jonathan Waddington, Conor Linehan, Kathrin Gerling, Kieran Hicks, and Timothy L Hodgson. 2015. Participatory Design of Therapeutic Video Games for Young People with Neurological Vision Impairment. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems (CHI '15)*, 3533–3542. <https://doi.org/10.1145/2702123.2702261>
 110. Greg Wadley, Reeva Lederman, John Gleeson, and Mario Alvarez-Jimenez. 2013. Participatory design of an online therapy for youth mental health. In *Proceedings of the 25th Australian Computer-Human Interaction Conference: Augmentation, Application, Innovation, Collaboration (OzCHI '13)*, 517–526. <https://doi.org/10.1145/2541016.2541030>
 111. Jenny Waycott and Hilary Davis. 2017. Sharing the housebound experience through visual storytelling. In *Proceedings of the 2017 ACM SIGCHI Conference on Creativity and Cognition (C&C '17)*, 2–14. <https://doi.org/10.1145/3059454.3059487>
 112. Kristin Williams, Karyn Moffatt, Denise McCall, and Leah Findlater. 2015. Designing Conversation Cues on a Head-Mounted Display to Support Persons with Aphasia. *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems (CHI '15)*: 231–240. <https://doi.org/10.1145/2702123.2702484>
 113. Stephanie Wilson, Abi Roper, Jane Marshall, Julia Galliers, Niamh Devane, Tracey Booth, and Celia Woolf. 2015. Codesign for people with aphasia through tangible design languages. *CoDesign* 11, 1: 21–34. <https://doi.org/10.1080/15710882.2014.997744>
 114. Mike Wu, Ron Baecker, and Brian Richards. 2005. Participatory design of an orientation aid for amnesics. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '05)*, 511–520. <https://doi.org/10.1145/1054972.1055043>
 115. Mike Wu, Brian Richards, and Ron Baecker. 2004. Participatory design with individuals who have amnesia. In *Proceedings of the eighth conference on Participatory design: Artful integration: interweaving media, materials and practices - Volume 1 (PDC 04)*, 214–223. <https://doi.org/10.1145/1011870.1011895>
 116. <http://arttherapy.org>.