Learning from research on creative involvement of people with a communication difficulty: A book chapter review of Seldom heard voices in service user involvement- Creativity in public involvement: supporting authentic collaboration and inclusive research with seldom heard voices

Mostafa Hatem

1Architecture and Built Environment at UWE, University of the West of England) Bristol

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F.A. (First Author) Faten Mostafa Hatem, Architecture and Built Environment at UWE (University of the West of England) Bristol.

Corresponding Author
Faten Hatem, is the corresponding author of this paper.

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The authors cited in the article are the only authors of the work. Author contributions relate to all aspects of the work including research, analysis, revision, and final presentation.

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Communication difficulty, Augmentative and alternative communication, AAC, Public involvement, PI, governance and planning.

Abstract
This paper reviews a chapter of the book “Seldom heard voices in service user involvement”, the chapter was also published in a peer-reviewed paper under the title Creativity in public involvement: supporting authentic collaboration and inclusive research with seldom heard voices. Research Involvement and Engagement. The review also combines material from the speech given by the co-author of the book in a collective workshop in Bristol on authentic engagement of people in the city. This is done with the aim to expand and build on the lessons learned in terms of enhancing the governance and engagement in the city. This stems from the significant experience of integrating creative methods in involving participants who have communication difficulties as the focus was to enhance Augmentative and Alternative Communication (ACC) services in the health care system of the UK. The review makes it clear that the impact of establishing such mechanisms benefits research in various fields, especially in terms of interdisciplinary cooperation among design and science disciplines when designing and conducting research. Also, the paper shows how and why communication can be essential to improve using unconventional engagement methods.
Introduction

Augmentative and Alternative Communication (ACC) is a term for strategies that are used to get through the difficulties of communication and speaking. These could be unaided (e.g. gestures, signs and movement codes like an eye blink for yes) or aided with external devices or systems for communication. The number of people who could find these techniques useful in the UK alone was estimated by 300,000 people from various backgrounds and age groups (Creer et.al, 2016, Volkmer and Broomfield, 2022). The general expectation is that 536 people per 100,000 UK population (about 0.5%) could benefit from AAC (Creer et.al, 2016).

As part of the Unspoken Voices Project, a 15 years’ long of clinically experienced therapist led research on ACC as part of her clinical doctoral fellowship. The project was motivated by the fact that ACC users feel quite detached and excluded from participation in decision making on choosing and issuing ACC devices by health services in the UK (Lynch et al., 2019, Volkmer and Broomfield, 2022).

According to Volkmer and Broomfield (2022), the research aimed to establish the outcomes that are essential to ACC users and to define existing means of support and obstacles of their engagement. Public involvement (PI) in this case was seen as a significant integration of people who depend on ACC to contribute not only to the integrity of the project outcomes, but also to its value, acceptability and accessibility. To provide guidance and contribution, service users were approached through various means, the main preference was to meet in person. However, the main challenges to such PI were namely due to time, COVID-19 restrictions, location and -given the nature of the project- language/communication. The latest was a prominent aspect to focus on, which was sometimes accommodated through communication partners as well as consideration of a variety of cognitive, physical and communication abilities instead of a ‘norm’.

Authentic engagement

Volkmer and Broomfield (2022) asserted that an alternative was needed to achieve a more meaningful involvement and noted a low level of interaction between participants of the project as the main feedback loop occurred with her as the conductor, which made her look for an alternative. The researcher (Katherine Broomfield) was also a distinguished speaker at the workshop conducted by the Association of Collaborative Design (ACD) Conversation lab, in Bristol, under the title; “How to Ensure Authentic Engagement?”. She mentioned that it was a main goal in -the sought after- alternative to turn this aspect of transferring a direct feedback loop, restricting collaboration to participant-researcher (session facilitator), into a wider set of loops including participant-participant. She also emphasized the use of objects to convey emotions and ideas and emphasized the role of the facilitator in empowering participants to take ownership of discussions. It was also important to identify each person's perceived role in the engagement process, such as being a “navigator,” “supporter,” “leader,” or “listener” in the room. The ACD workshop was a collective brainstorming on two fundamental questions: “What constitutes authentic engagement, and how can we ensure it?”.
In addition, integrating nature into our processes and thinking was explored. The outcome of the workshop concluded that ‘authentic engagement’ depends on meaningful, transparent and inclusive dialogues built on trust and clarity. It also recognizes the importance of nature, uses diverse methods of engagement, and invites ongoing feedback, community expertise, and unbiased narratives.

The online report on the workshop comprised a few key and additional insights listed below.

- **Key Insights:**
  - **Meaningful Engagement:** Going beyond surface-level interactions to create significance for all parties involved.
  - **Transparency and Honesty:** Authentic engagement thrives on open communication, sincerity, and genuine intentions.
  - **Inclusivity and Representation:** Emphasis on diverse perspectives, including Nature's voice, and employing varied engagement methods.
  - **Trust:** Recognised as the bedrock, establishing trust demands time and consistent dedication.
  - **Due Diligence:** Engagements should be rooted in evidence-based practices supported by thorough research and data.
  - **Clarity of Language:** Clear, accessible communication is indispensable, especially for complex subjects.
  - **Effective Engagement:** Asking pertinent questions, utilising diverse mediums, and having a defined purpose are critical.

- **Additional Insights**
  - **Openness, Care, and Curiosity:** Fostering an open environment encourages better engagement.
  - **Sense of Ownership:** Clearly defining outcomes and ownership in engagement is imperative.
  - **Authenticity Assessment:** Prioritising quality over quantity in engagements should be the focus.
  - **Third-Party Review:** An unbiased review can serve as a gauge for authenticity.
  - **Two-Way Dialogue:** Active conversations and ongoing feedback loops enhance authenticity.
  - **Bias and Agenda Awareness:** Recognising and addressing biases and agendas is crucial.
  - **Physical Visibility:** Engaging the community through physical presence, for example, through a shop front.
  - **Balancing Human and Nature Engagement:** Treating nature as a participant, ensuring its voice is heard and represented.

**Figure 1: Key and additional insights (ACD Conversation Lab 18, 2023), generated by the researcher.**

The inspiration is expressed to have come from her attendance of Design for Health conference at Sheffield University, where several projects and research works were conducted implementing creative ways and techniques closer to design discipline than healthcare, presenting dialogues among academics, artists and healthcare workers. As part of using collaborative methods, the researcher focused on learning through experience, adopting principles of “enacting, seeing and doing” to sustain the co-creation of meaning through engaging participants in creative activities. These principles are part of the participatory design aspect that was used as the main framework for using creativity in PI as part of the Unspoken Voices project (Broomfield et al., 2021; Volkmer and Broomfield, 2022).
Participatory design is a general notion for how people are directly engaged in the advance of information technologies (Simonsen and Robertson, 2012). It was recognised that consultation with end-users is essential to the usability of the product for whom it was intended, and that collaborative approaches should integrate reflective practices, advocating mutual learning to balance the designer-user relationship (Broomfield et al., 2021; Volkmer and Broomfield, 2022).

**Process of preparation and knowledge production; enacting, seeing, doing, seeing again and reflecting**

Preparing for the main event

In preparation for the event, a venue was chosen since it is accessible to the target group. Conference and meeting rooms had access to internet and display screens. Ease of travel was also taken into consideration, as the venue was within walking distance for some participants, was also suitable for parking if arriving by car and was accessible by train. Time was chosen to be early afternoon according to the participants’ convenience (e.g. arrival time and morning schedule). Communication facilitators such as speech therapists and support personnel joined the meeting with participants to overcome difficulties of communication. Additionally, simple or plain English was used in the preparation material that was provided to participant prior to and during the event. This was prepared cooperatively with the participants in an initial meeting and according to the INVOLVE guidance (i.e. INVOLVE, 2012) and they resulted in a set of a core agenda, roles, responsibilities and reference. This initial event enhanced quality of the latter main even, for example in terms of considering comments on the materials that were “text-heavy” or sometimes incoherent. Also, the researcher noted that there was little interaction among the participants and instead the main feedback loop was with her as a conductor, asserting that despite her long experience, an alternative is required to deliver a more successful and meaningful cooperation (Broomfield et al., 2021; Volkmer and Broomfield, 2022).

Enacting:

Simple text material and sum-ups in the early-stage meeting were improved to adopt an audio-visual mode in the second meeting. where presentations included a voice over (i.e. a PowerPoint presentation with an audio-narrator) and the resulted video was added on YouTube. This not only increased the participants satisfaction but also allowed third parties to have an insight into the project. As a series of images indicating project themes were displayed, the group was asked to rate them using a simple exercise of allocating a bigger number of Lego bricks to those they agree to, which enabled a discussion on their logic afterwards and interaction among the participants and their supporters or the facilitator sometimes. This activity produced an enhanced annotated version of the participants information material that is also supported with a recruitment video that was well received by the group members. Providing various media and active engagement methods allowed participants to have a common meaning and understanding of the project and encouraged the research investigator to continue working with creative ways of involving them.

Seeing:

In the second meeting visuals were proven useful and an artist joined in to illustrate the content of that meeting graphically. New terms of vocabulary was also represented visually to
the group and evoked their interest to discuss. However, the response was varied among the group (e.g. reaction and preference) and this diversity was appreciated as a way to learn about a different perspective or experience.

Doing:

A co-designed visuals and text tool; The Talking Mat, targets those who require communication help and is employed to get the participant’s input in clinical, scientific or service development setting (Murphy, 2010 cited in Volkmer and Broomfield, 2022). This was used in the project to express the level of agreement to certain topics and provide a context for the debate. Participants could interact not only with their communication supporters, but also with their peers as they told each other stories on how they handled this task/activity. For instance, they could reflect on the meaning of the topic to them, degree of the difficulty doing the task, critique of certain images or terms, as well as what is missing from the tool (e.g. when they could not find something to express their opinion). Key concepts, definitions and discussions on project themes resulted from data collected using this tool.

Reflecting:

The group was given a range of objects or a supporting ACC device to select, to assess the impact of using such participatory design or creative methods, and whether it achieved its aim in terms of making the participants recognise their role and value of the group. They were asked an open question; “what the group means to you?” Hence, a narrative on the group’s meaning to the member developed. Another object-facilitated exercise followed to answer another question; “What is your role in the group?” Using metaphors to express their opinions, the participants were engaged in the discussion and provided insight into their own perceptions on one hand and explore others’ while relating and positioning themselves to each other’s roles within the dynamic of the group.

Seeing again:

As Covid-19 restriction were introduced, the reflective and evaluative preparation meetings were the last to be conducted face to face. The group’s support and awareness of each other’s needs in terms of communication encouraged progressing with online trial of PI meetings.

Whereas email communications took place, online meetings using sponsored video platforms were conducted individually and allowed testing the accessibility and acceptability of the online platforms, defining any problems (i.e. troubleshoot). A checklist of functions was used to guide and document these meetings.

After familiarity was established, a collective meeting was conducted. To maintain the use of creative methods, participants were asked -prior to the meeting- to bring visuals that express their experiences during the summer. Images were shared in the meeting (on-screen) as the members told their stories, while using a bright-coloured border line to recognise the chosen image. The researcher also used several representations that indicate the themes and data analysis she developed during that time. This activity allowed the group and researcher to remain connected with exploration of creative methods, also online.
Impact, reflections and top tips

The therapist and researcher recognise the difference such engagement makes can be noticed in the ways in which it helped boosting collaboration among participants and making them aware of their purpose and role, since they were able to clearly describe them. She also noted that challenging nature of engaging people who experience communication difficulty, sometimes can be mitigated not through clinical skills but through another lens to this problem.

“Looking beyond professional boundaries and seeking inspiration from other discipline can widen the toolbox of resources available and provide different perspective on group interactions and individual contributions. Employing creative practices, using a framework of participatory design…. helped to create a project that is both accessible and connected to priorities of population it aims to represent”.

(Volkmer and Broomfield, 2022; 126).

Also, it is evident that establishing these principles and ways of involving ACC users is one of the main meaningful contributions of her research.

“Once productive methods for group members to participate had been established, the group has contributed to The Unspoken Voices project in a number of ways. The shared understanding about the aim of the research, which was established through the use of audio-visual materials, resulted in one group member attending a meeting of the Research Ethics Committee to advocate for the importance of the research project and the use of the adapted, accessible recruitment materials.”

(Volkmer and Broomfield, 2022; 124-125).

- Using images and graphics (produced by Smizz) in this project was to redefine research-related terms and produce important outputs such as easy access summaries (e.g. systematic review), visual representations of the meetings content and communication of certain aspects of the project in papers and conferences. Two members of the PI group worked with the researcher to co-produce, use and present vignettes from PI meetings into a conference presentation.
- Discussing and conducting The Talking Mats™ activity which involved PI members in data analysis, made the researcher able not only to better recognise the important contents of initial themes produced but also not overlook aspects of their experience that are not readily available in data collected.
- Reflective activities in meetings made the group aware of their stand towards and role in the project. Replacing questions with activities offered, made the focus to be on participation in creations of common understanding rather than response. Also, developing metaphors shaped by attention to objects or relevant features of objects allowed group members eliminated the demand to direct language and thought to questions, which enabled exploring interpretations of the group “without having to direct their thoughts and language toward the question” (Volkmer and Broomfield, 2022; 125).
The top recommendations or tips listed in the figure were also important outputs of this research and provide guidance for planning and implementing interdisciplinary research activities and methodology, especially in projects focused on inclusive engagement of people.

Figure 2: Top tips by Volkmer and Broomfield (2022; 127), generated by the researcher.

<table>
<thead>
<tr>
<th>Recommendations</th>
<th>Details</th>
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<tbody>
<tr>
<td>Embrace creativity</td>
<td>- If you lack confidence in your own creative powers, enlist the support of someone who has what you need. There are always willing artists and art students around who would be delighted to support your creative endeavours.</td>
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<td>Redistribute control</td>
<td>- Have one or two general themes for a meeting, rather than a specific set of agenda items. Embrace the direction that the group members want to take and be ready to receive their wisdom with an open mind.</td>
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<tr>
<td>Flexibility</td>
<td>- Bring along creative activities but also be prepared to adapt them if necessary. Respond to the verbal and nonverbal feedback that the group provides in terms of their ability to engage in your activity. They may need help to be creative too.</td>
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<tr>
<td>Look beyond the dialogue</td>
<td>- Co-production occurs between agents and therefore, potentially, between their explicit contributions. Seek out the implicit meaning. This may be found in the way they engage with the activity, the process of conducting the activity, or in the story that is created from the activity. All have value and potential meaning for your project.</td>
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References


