
Amplifying Voices: Co-researchers with Learning Disabilities Use a Co-designed Survey to “have a conversation with the public”.

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Abstract

The concept of ‘giving voice’ in research and in the design of accessible technologies involving people with learning disabilities (LDs) has been often used to highlight the necessity for careful consideration of their opinions and needs. Those who ‘communicate differently’ are often portrayed as the beneficiaries of the technological advancements rather than

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contributors to the technology that can benefit everybody. Here, we present a case study whereby people with LDs co-designed an inclusive survey platform and created an online survey to “have a conversation with the public” and to challenge attitudes towards LDs. Over 800 participants with and without disabilities or impairments completed the survey and reflected on their learning experience. Using qualitative and quantitative methods, we found that the co-created platform enabled all – the co-researchers and the respondents – to have their ‘voices amplified’ and to be listened to in a meaningful way – just as in ‘a conversation’ between people.

Author Keywords

disability; survey; design; co-production; inclusion.

CSS Concepts

• **Human-centered computing~Human computer interaction (HCI).**

Introduction

In research involving people with learning disabilities (LDs), here referred to as ‘inclusive research’, the

Using videos as the main medium for asking the questions in the survey, the co-researchers ask the following questions:

1. Question No.1 (Lizzie):

- a. Hi, my name is Lizzie. I've got a question for you... People stare at me all the time. What do you see when you see me? (video)
- b. How do you feel when I ask you that question? (video)

2. Question No.2 (Pino):

- a. My name is Pino, and I would like to ask you a question. Are you frightened of people with learning disabilities? I want you to answer that question. And I want you to tell us what you really think. (video)
- b. Can you tell me why you chose that answer? (text)
- c. How does it feel when I ask you that question? (video)

3. Question No.3 (Pino):

- a. Alright then. I've got another question for you... Do you trust us? (video)
- b. Can you tell me why you chose that answer? (text) (video)

concept of 'giving voice' is often used to highlight the necessity for careful consideration of their opinions and needs and is a way of empowering them [2] [4]. For example, the aim of the study by Correia et al. (2017) was to "give voice to people with intellectual disabilities [here LDs], and to explore their perspectives about their family quality of life". In this and other 'inclusive research' studies, 'the voices' of people with LDs are "included" [2], "being heard" [2] [5], "represented" [6], "preserved" [2] and "promoted" in the research process with the aim to change lives for people with LDs [5] [6]. Participants with LDs voice their views and opinions so that researchers can learn about the lives of people with disabilities from an "insider perspective" [3] and "to have their voices heard by policy and legislative organizations" [5].

Similarly, in the context of the design of mobile and communication technologies for those who 'communicate differently', the underlying premise is that these devices 'give voice to the voiceless' highlighting 'personal liberation via technology' [1]. This further highlights the power imbalance whereby those who need the assistance are passive recipients of technological advancements. Very rarely is there a discussion of how those who 'communicate differently' may, in addition to benefiting from, contribute to the technological advancements in a way that is beneficial to everybody and can in turn capture 'the voices of many' (including those who do and do not 'communicate differently').

Here, we present a case study whereby people with LDs co-designed an inclusive survey platform and created an online survey to challenge public attitudes towards LDs with the aim to provide a platform for the public "to

have thinking experience, a different mind-set!". As part of this study, we evaluate its significance and relevance to the concept of 'giving voices'.

Methods

Heart n Soul Asks Survey

Our case study is embedded within a larger study as described in detail in Chapko et al. (2020)¹. In short, working with *Heart n Soul*, a London-based creative arts organization which believes in the power and talents of people with learning disabilities (LDs), we established a team of co-researcher with LDs who co-designed an accessible survey platform and created the [first multimedia online survey](#) to challenge public understanding of LD in the form of "*having a conversation with the public*"². The aim was for co-researchers to derive and ask questions in ways that are important and meaningful to them, and representative of their lived experiences ([see Side Bar](#)). In addition to the questions created by co-researchers, the survey includes demographic and feedback-related questions. The final survey was launched in December 2019 and can be found at www.heartsoulasks.com.

Feedback-related Question

Here, using currently received 900 responses at the time of writing (the survey remains open), we evaluated one open-ended feedback-related question: *Thank you for answering our questions. What did you learn about yourself from this experience?*

¹ <http://ualresearchonline.arts.ac.uk/15342/>

² Co-researchers wanted to ask the public whether they have any questions to them and they framed this idea as "a conversation with the public".

4. Question No.4 (Lizzie):

a. Hi, it's me Lizzie again. I would like to know, what would you do in this situation? ... Would you cross over to the other side of the road if you saw me coming? (video)

b. Can you tell us why you chose that answer? (text)

c. How do you feel about that question? I know it could be awkward. Do you know what? Just be honest. That's all I'm asking - to be honest. (video)

5. Question No.5 (Mark S):

a. How would you feel, and what would you do, if you were in our shoes? (video)

6. Question No.6 (Donald):

a. My name is Donald and I've got a question for you: Do you have any questions for me or the other people? (video)

Data Analysis

We performed analysis using the combination of a quantitative data analysis software Stata 15 and a qualitative data analysis software NVivo 12 Plus. First, we used Stata to manage and clean the data and to derive descriptive statistics. Second, we auto-coded the emerging themes and sentiments in the responses to the question using the 'automated insights' feature³ in NVivo. Finally, the text search query was used to position the emerging themes in context and to evaluate the term 'voice' from the participant's perspective after taking part in the survey.

Results

Heart n Soul Asks Survey Respondents

By January 2020, 877 respondents have completed the survey and provided a response to the feedback-related questions (n=877). Most of the respondents identified themselves as a woman or female (82%), with no disability or impairment (70%), living in the UK (88%) in Greater London (30%), with the average age of 43.3 (SD=12.8). Out of those, 665 (n=3 audio responses) provided a full response to the question of interest.

Auto-coded Themes

The phrases 'learning disabilities' followed by 'learning difficulties' were identified as the main auto-coded themes with the total of 190 references⁴ (17.5% coverage) and 34 references (3.3% coverage) respectively. Using the text search query for the phrase

³<https://help-nv.qsrinternational.com/12/win/v12.1.90-d3ea61/Content/coding/automated-insights.htm>

⁴ The coverage percentage indicates how much of the response content to the question is coded at an auto-coded theme (here 'learning disabilities' and 'learning difficulties').

'learning disabilities', the respondents mostly wrote '**about** (people with) learning disabilities'. In this context, the respondents emphasized how much they do not / did not know about LDs and expressed their willingness to know more about LDs.

Sentiment Analysis

As the result of the sentiment analysis, a total of 45 references (3.8% coverage) were identified as 'very positive' and 75 references (6.20%) as 'very negative'. At these extremes of opinions, in the 'very positive' content, the respondents appreciated the fact that the questions come directly from people with LDs (e.g. "*I think I've known my own prejudices already, but the questions being asked in video [form] by a person with learning difficulties did help me to be a bit more honest in my answers*") and that 'inclusive research' of this type exists (e.g. "*I learnt some really inspiring ways of making research more accessible for people with a learning disability*"). Two respondents articulated very personal reflections over the role of freedom and trust in their relationships with their children:

- "*Made me question how much freedom I should give my son with autism*".
- "*I need to work harder at trusting my adult son and not be so scared about him making mistakes*".

In the 'very negative' content, the respondents expressed their frustrations about how people with LDs are treated (e.g. "*[That] I am more angry about the way people with learning disabilities are sometimes treated than I remember.*"), with 6 references mentioning Lizzie's story in Question No.4 (e.g. "*Lizzie's story about the woman crossing the road made me cry and feel angry at the same time.*"). The reference to "*prejudice*" appeared 9 times, with 5 respondents

confirming their own prejudice towards people with LD, with 3 indicating their willingness "to change".

'Voice' Using the Text Search Query

In response to the *Feedback-related Question*, there were 7 references including the word 'voice'. Here, 'the voices' of people with LDs are "strong", "important", and "real", and it is important "to keep raising up", "to listen", and to "support" these voices. Importantly, one of the respondents framed the concept of 'the voice' in the following way: "That these sorts of questionnaires, with **real voices, resonate deeply with me!** And that I have lots to learn."

Discussion

In this project, co-researchers with LDs created an inclusive survey platform for the public "to have thinking experience" and to be able to "have a conversation" with them. Over 800 participants with and without disabilities or impairments completed the survey and reflected on their learning experience. While the term 'voice' was used in a more standard way [2], the full reflections of the respondents were more revealing and meeting the aims and expectations of the co-researchers. The survey sparked curiosity about the lives of people with LDs with many indicating that they would like to or need to know more about LDs. Among the more emotionally-charged answers, several respondents had reflections beyond the world of LDs indicating the impact of the questions designed and directly asked by the co-researchers. Many respondents were clearly frustrated and personally touched by the stories with several acknowledging that they are 'part of the problem'. Therefore, the co-researchers actively **amplified the voices** of the public and were no longer the passive recipients of technology but active co-

creators of technology with wider impact. The co-created platform enabled all – the co-researchers and the respondents – to have their voices heard and to be listened to in a meaningful way – just as in 'a conversation' between people.

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