ORIGINAL ARTICLE

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In the physical to digital transition with friends—A story of performing inclusive research together no matter what life throws at you

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Accessible summary

- We are members of an arts organisation who support the creative talents of people with learning disabilities and autistic people.
- We have been working on a research project at "The Hub" at Wellcome Collection in a team consisting of academic and nonacademic professionals with diverse abilities.
- Because of coronavirus, we all had to stay home to stay safe. To carry on with our research project, we participated in 28 creative research meetings on Zoom.
- In this paper and accompanying video, we will tell you how we did it. We will also tell you how we felt about moving away from "The Hub" and trying to do research remotely from home.
- We hope our project has shown that people with learning disabilities can transition well to working online when there is trust and mutual respect.

Abstract

Background: As part of "The Hub" project at Wellcome Collection, a team of eight co-researchers with learning disabilities along academics created an online survey to challenge public understanding of learning disabilities. Using creative and arts-based methods, co-researchers remotely co-analysed the survey results amid COVID-19 lockdown challenges. Here, we explore our unexpected "transition" journey from the physical "Hub" to the digital space.

Methods: We organised 20 sessions at The Hub and used audio/video/photo recordings to capture key moments. With the lockdown, we ensured that every co-researcher had access to and support for digital technologies. Throughout 2020, we organised 28 Zoom meetings involving all co-researchers. In June, Lilly (a multi-media journalist and she lives by the motto striving for equal opportunities for people with disabilities and fairness throughout) and Sue (an independent Leadership Coach and Mentor) conducted Zoom interviews with the co-research team to reflect on our transition

journey. In this creative video-form submission accompanied by an accessible report, Lilly puts together a story of how we transitioned and felt throughout this process.

Findings: We identify that trust and the social bonds established at The Hub are the key components of our transition to the digital environment. There is the tension between longing for in-person contact and trying to make the most out of the situation to maintain these relationships. At the heart of this is the motivation to "change the world" and strive for social justice. Having time and opportunity to improve, and co-researchers' steady growth in confidence are equally important.

Conclusions: The determination for maintaining friendships among co-researchers and the motivation to "change the world" overcome COVID-19-related challenges in continuing co-research.

KEYWORDS

digital inclusion, inclusive research, learning (intellectual) disability, participatory research, research design

1 | EASY READ

1.1 | Summary

Heart n Soul is an arts organisation who support the creative talents of people with learning disabilities and autistic people.

We have been working on a research project called Heart n Soul at The Hub at Wellcome Collection.
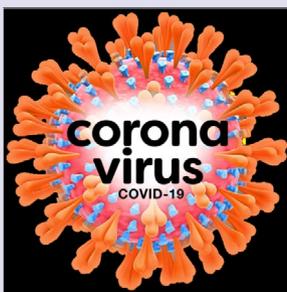
But because of coronavirus, we all had to stay home to stay safe.

To carry on with our research project, we participated in 28 research meetings on Zoom.

Along with a video, this is an easy read to tell you about how we did it and how we felt about it.

2 | BACKGROUND

2.1 | Introduction

Heart n Soul is an arts organisation that believes in the power and talents of people with learning disabilities and autistic people.

In 2018, we started a research project called Heart n Soul at The Hub at Wellcome Collection.

At The Hub, we worked with researchers, artists, clinicians, computer scientists and designers to do research.

We did a type of research together called "inclusive research."

This means research is done in a way that includes people with learning disabilities. We want to lead research and be listened to.

2.2 | What we did at The Hub

We found that in academic writing attitudes towards people with learning disabilities are generally positive and inclusive.

But, this did not fit with the experiences of everyone on our project. They did not feel like society has mainly positive feelings towards them.

As a team of diverse people, we wanted to know why this was happening.

To try and find out more about how people really feel about learning disability and autism, we created a new kind of online survey.

We felt a survey would be a good way to ask questions, but only if we could make it accessible and ask our own questions directly to the public in a creative way.

8 co-researchers who enjoyed coming to The Hub the most worked on the survey questions in detail. They were Pino, Robyn, Lizzie, Mark S, Ifeoma, David, Michaela and Donald.

We co-designed our questions and survey together. We wrote a paper about this too! https://dl.acm.org/doi/abs/10.1145/3313831.3376278

- People stare at me all the time. What do you see when you see me?
- Are you frightened of people with learning disabilities?
- What's it like to have a learning disability? Some people don't understand us. Some take the mickey. And I don't like it. How would you feel if you were in our shoes?

We collected more than 1500 responses to our first survey!

2.3 | Transitioning to working from home

As we were trying to find out what the responses to our survey meant, a lockdown happened. This meant we could no longer visit The Hub.
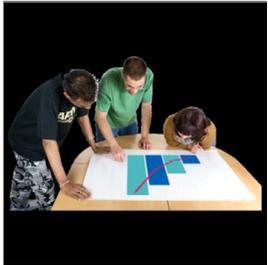
But the lockdown did not stop us from co-analysing our survey responses. Co-analysis means evaluating information together, so everyone can contribute.

We used creative ways like singing, drawing, painting, plasticine, creative writing to co-analyse the information. All remotely at home!

In the next section, we will tell you how we did it. We will also tell you how we felt about moving away from The Hub and trying to do co-research remotely from home.

3 | METHODS: HOW WE DID IT

We needed access to computers and the Internet. It took some time and team effort to make sure that all of us are comfortable with using Zoom. We tell a story about this is in a different article! https://doi.org/10.1145/3461778.3462010

Throughout 2020, we organised 28 Zoom meetings involving all co-researchers.

In June, Lilly and Sue conducted a series of Zoom interviews with the team to reflect on our "transition" journey from working at The Hub to online.

Lilly

Lilly is a multi-media journalist and a trustee for Heart n Soul.

Sue

Sue is an independent leadership coach and mentort.
Lilly and Sue asked all members of the research team what they thought of and felt about co-research at that time.

Lilly then made a video using these interviews along with videos filmed when we were working at The Hub. In our film, we share some of our experiences of the transition journey as well as the research that we created.

The video is nearly 30 minutes long. You do not need to watch it all in one go. You can pause it and come back to it.

You can watch the video if you type this link into your browser:
https://drive.google.com/file/d/1Z67LdJrSyt3Kz9m1_YJaV854QmdiqUOO/view

4 | FINDINGS: WHAT WE FOUND OUT

We came up with 9 themes. We found these important in thinking about our transition journey.

1. Creative Research

In the video, you can see us singing and dancing—these are some of the methods we used for our research at The Hub and when working from home.

2. Space in Transition

We miss The Hub! You will hear all of us in the video talk about how important the space was. Happy memories of The Hub kept us motivated, and we cherished our friendships.

3. Trust

Our research project could carry on outside of The Hub because we built trust with one another and tried to grow it over the course of the remote sessions.

4. Social Bonds

We are not only co-researchers but we are friends too! During the remote working, we wanted to meet to do research together but also to catch up as friends.

5. Staying Connected
Staying connected was the key priority for us! None of the team members could stay behind, and we made sure that everybody had access to the computer and the Internet.

6. Changing the World
At the heart of this transition is the motivation to "change the world" and strive for social justice.

7. Growing in Confidence
Having the time and opportunity to improve and grow in confidence were important to developing and improving the project.

8. Power Dynamics
Co-researchers took ownership of the project!

9. Artwork
Co-researchers created artwork to creatively think about our survey responses and show our research findings in exciting ways!

5 | CONCLUSION: FINAL THOUGHTS

Two things that really kept us going when our research became hard because of the coronavirus were as follows:
1. Our friendships across the team
2. Wanting to "change the world"

We hope our project has shown that people with learning disabilities can transition well to working online when there is trust and mutual respect.

It is also not often that people with learning disabilities have the opportunity to take a detailed look at research results.

We created new ways of looking at the information from our surveys, so that everyone could take part in finding out what the results mean.

Jargon Buster

This part of the easy read helps to explain some of the words we used:

Accessible: If something is accessible, it means it is easily used by lots of different people.

Academic: Academic is used to describe things or people that relate to schools, colleges or universities.

Attitudes: Attitude means the way you think or feel about something. For example, "Her attitude towards work is very good".

App: An app is a small computer programme.

Co-analysis: Co-analysis means evaluating information together so everyone can contribute.

Co-research: Co-research is when professional researchers work with people from different backgrounds to do research together in a way that everybody can meaningfully contribute.

Data: Data is another word for information collected during research.

Research: Research is careful study and investigation to discover or explain new things.

Survey: A survey is a set of questions you ask a large group of people to find out about their opinions.

Find Out More

You can find out more at:

www.heartnsoulatthehub.com

Even though our project has come to an end, you can still get in touch with Heart n Soul if you have a question or would like to know more.

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