



Finding a way to work ... young people with intellectual disabilities learning in work

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Information for family and friends

I am seeking participants for this research study. If you are family, a friend or ally of a young person with a learning disability, I would like to let you know why this research is being done and what it will involve. Please take time to read the following information carefully and discuss it with the young person involved.

What is this study about?

It can be hard for young people with learning disabilities to find employment after school and college. Purposeful and engaging occupations of other kinds may also be hard to find following changes in social care budgets. As a result, young people may not have opportunities to participate in the kind of life experiences shared by most adults – of going to work, learning from others and contributing to shared goals.

Some eligible people have a personal budget that can be used to support work aspirations as well as care, leisure and social needs. This study aims to investigate the experiences of young people who have found a form of work – paid or unpaid - that fits their strengths and interests and are employing a personal assistant or 'buddy' to make their participation possible.

I will explore the experiences and aspirations of such young people, asking how far they are developing their capabilities by taking this route.

The study is being conducted for my doctoral research at the University of Southampton and is funded by the Economic and Social Research Council.

What is the point of the study?

The study will examine an employment and occupation possibility that is open to young people in the current funding context. I aim to explore how far this form of participation in work deserves to be more widely adopted.

The study should contribute to understanding of the significance of learning at work for young people with learning disabilities, and to academic and policy debate about work in relation to adult identity and social inclusion.

I hope that young people with learning disabilities may benefit in the longer term from research that considers an innovative way to access and support participation in work when quality employment is inaccessible.

Who can participate?

I want to collaborate with young people with learning disabilities who have found a workplace matched to their strengths and motivations, and who are employing a buddy or personal assistant to make their participation possible.

I am keen to find young people working in places where people with learning disabilities are not usually found.

I want to look at the experiences of people who are not able to access a workplace without support, at least in the short term. I'm interested in what difference having the support of a personal assistant might make.

What do I want participants to do?

The study is designed to be inclusive and collaborative, with an important role for young people.

I want to video young people at work and ask them to watch and talk about the video. They will be able to refer to the video throughout discussion. Other visual supports will be available to clarify questions.

I will need them to consent to filming and to work with me to help me to understand what they are learning and what it means to them.

I will need the consent of key personnel at the workplace for filming to take place, and I would also like to interview one co-worker for their perspective.

A short video is available to give information to young people about the project and participating in it.

What will happen if a young person decides to participate?

These are the steps of the research process following consent:

1. I will meet the young person to talk to them about their aspirations, their work and what they would like to be filmed.
2. I will visit the young person at work up to three times to make the video. I will film as unobtrusively as possible to avoid distracting them.
3. I will give a copy of the video to the young person to watch and think about in their own time.
4. I will arrange to meet the young person – wherever they like - and ask them to point out the parts of the video they think show important parts of the work experience.
5. I will edit the video to make a set of clips of these moments.
6. I will meet the young person to review their clips in detail and ask questions about what is happening in them. I will also video the meeting, so that the both video clips and discussion are recorded.
7. I will ask the PA and a work colleague, in separate meetings, to review the chosen video clips and ask them questions about what is shown.

8. I will write a short accessible report putting together the perspectives of participants. I will send this to everyone who took part for feedback.
9. I will discuss what people have said and the feedback they have given in the writing up of my PhD thesis.
10. I will send a revised accessible report to all participants.

About privacy

In published work and presentations, participants will be identified using agreed pseudonyms. Only the researcher will have access to real names.

It is important that young people choose and approve the video of themselves to be used in the project. I will delete footage if asked.

I may want to use the video when I present findings of the research. Young people will be recognisable to people who know them in video clips.

Film made for the project will be kept in secure storage at the University of Southampton for a period of 10 years after the end of the project.

What if the young person changes their mind about taking part?

Young people can withdraw consent without giving reasons at any time up to four weeks after the end of filming.

Family and friends and young people can ask questions and get more information at any time. I am available by email, by phone or in person.

My number is 07463 878777 My email is a.e.croydon@soton.ac.uk

Are there any risks involved?

I do not believe that participating in this project involves risk, but participants are free to withdraw if they have any concerns.

What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researcher who will do their best to answer your questions.

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

Thank you!

Thank you very much for taking the time to find out about this project.

Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data

protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the researcher if you have any questions or are unclear what data is being collected about the young person concerned.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses personal data when someone takes part in one of our research projects and can be found at <http://www.southampton.ac.uk/assets/sharepoint/intranet/Is/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf>

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about the young person until the award of the PhD, after which time any link between you and your information will be removed.

To safeguard the rights of participants, we will use the minimum personal data necessary to achieve our research study objectives. Their data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).