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Developing a training course to teach research skills to people with learning disabilities: "It gives us a voice. We CAN be researchers!"

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Accessible Summary

- We are eight people with learning disabilities. We did a training course at a university in London. It was called "Learning how to do research." We learned about the 10 steps in research, and we practised how to do research.
- Part of the course was doing our own research project. Then, we presented it to an audience.
- In this article, our tutors describe the course. We say what it was like for us. Most of us were nervous about doing the course, but we learnt a lot from it.
- There are not many opportunities for people with learning disabilities to learn about research. We think more people with learning disabilities should have the chance to do it. We hope this article helps other teachers to start a research course.
- We *can* be researchers! Being involved in research gives us a voice.

Abstract

Background: Within learning disability research, it is important to involve people with learning disabilities at all stages, but there are limited opportunities for them to learn about the research process or to gain research skills.

Method: An eight-session research training course for people with learning disabilities was developed and piloted at a university in London. The focus was on understanding the research process and gaining practical skills in collecting, analysing and presenting research data. Training methods were experimental, with an emphasis on learning by experience in a "fun" way.

Results: Ten people with learning disabilities completed the course, showing great enthusiasm and commitment. During the final sessions, students developed and conducted their own research projects, choosing "Employment" as their research topic. The training methods were well received. Benefits included an increase in confidence

and new work opportunities for several of the students. This paper was co-authored by the tutors and most of the course graduates.

Conclusion: It is possible for people with learning disabilities to become skilled researchers, but in order to do so, it is important that they have adequate training opportunities. Funding should be made available for more such courses.

KEYWORDS

inclusive education, learning (intellectual) disability, research

1 | BACKGROUND

1.1 | Inclusive research

Over the past few decades of learning disability research, there has been a strong interest in emancipatory, participatory and inclusive research designs (Chappell, 2000; Kiernan, 1999; Rodgers, 1999; Ward & Simons, 1998; Williams, 1999). In inclusive research, people with learning disabilities are not merely subjects for research; as Walmsley and Johnson (2003) explain, they are instigators of ideas, research designers, interviewers, data analysts, disseminators and users of research. The principles upon which inclusive research is based are (a) that research must address issues that really matter to people with learning disabilities, and which ultimately leads to improved lives for them; (b) that it must access and represent their views and experiences; and (c) that people with learning disabilities need to be treated with respect by the research community (Walmsley & Johnson, 2003).

There have been numerous published accounts of research studies and research processes that involved people with learning disabilities as co-researchers (Brookes et al., 2012; Herron, Priest, & Read, 2015; Holman, 2013; Nind & Vinha, 2012; O'Brien, Mcconkey, & García-Iriarte, 2014; Salmon, Barry, & Hutchins, 2018), including accounts written or co-written by researchers with learning disabilities themselves (Flood, Bennett, Melsome, & Northway, 2012; Schwartz & Durkin, 2020; Tilly, 2015; White & Morgan, 2012; Williams, Ponting, & Ford, 2015). This journal has been at the forefront of promoting and publishing papers about inclusive research. The first author (Irene) has worked with people with learning disabilities as co-researchers for over a decade, mostly on qualitative studies around topics involving cancer, dying, death and bereavement. They have contributed to all stages of the research process, from formulating the research question to data analysis and dissemination, and have co-authored papers on these processes (Butler, Cresswell, Giatras, & Tuffrey-Wijne, 2012; Tuffrey-Wijne & Butler, 2010).

1.2 | Advantages and difficulties of co-researching

The published literature and our own experiences of inclusive research show that involving co-researchers has clear benefits and advantages, but also difficulties and challenges. Co-researchers can help to ensure that the research is relevant to the lives of people with learning disabilities. We found that co-researchers with learning disabilities can act as catalysts and role models when interviewing people with learning disabilities or facilitating focus groups of people with learning disabilities, helping participants to share their feelings, experiences and ideas much more freely and thus improving the quality of the data (Butler et al., 2012). Other authors have reported similar advantages (O'Brien et al., 2014). The benefits go beyond the actual research: most co-researcher accounts speak of the impact on the co-researchers' confidence, leading to personal growth and increased levels of autonomy and independence, not just at work but in their personal life (Salmon et al., 2018; Tilly, 2015; White & Morgan, 2012).

The challenges of co-researching, however, are also significant. For research to be fundable and publishable, it must not only be practical and useful to the people it is for (in this case, people with learning disabilities), but it must also be academically rigorous (Walmsley & Johnson, 2003). This creates a tension, as academic rigour requires a high level of abstract thinking, which can be particularly difficult for people with learning disabilities. In order to be able to participate in the entire research process, they will need extra support (Williams & Simons, 2005), and by implication, more time and increased levels of funding. One team of co-researchers explained how they would not have been able to do the job without employing a personal assistant for each co-researcher (Flood et al., 2012).

1.3 | Training for researchers with learning disabilities

Strnadová, Walmsley, Johnson, and Cumming (2016) assert that if people with learning disabilities are to become researchers, knowledge of research methodology and research processes is essential. They raise the question whether research training should be generic or project specific.

The literature on research training for people with learning disabilities is largely anecdotal. Overall, there is a recognition in the literature that research skills are gained not just through formal training, but also through experiential learning, role modelling, discussions and reflection. Nind, Chapman, Seale, and Tilley (2016) explored the issue of training, which had emerged as a major theme in a series of

seminars on inclusive research. They set out a number of models for training and capacity building. In the "Apprenticeship model," the novice researcher works alongside more experienced researchers who model and mentor, whereas in the "Formal model" the novice is taught by a teacher following a curriculum. Other models include the "Lifelong learner model" where the novice identifies their own training need and seizes opportunities to address them; the "Challenging inequality model" where researchers with and without learning disabilities learn together; and the "Addressing deficits model" which has a focus on focusing training on the novice's specific gaps in skills and experience.

Most academic researchers will have acquired a significant part of their knowledge of research processes and the development and application of research skills through formal training, in the form of generic courses (rather than specific training connected to a particular research project). In contrast, it seems that co-researchers often develop these skills through "on-the-job" training, using an apprenticeship model with elements of the other models described by Nind et al., but not formal training involving a curriculum. Training typically involves some sessions at the beginning of a project where co-researchers learn about research, with a focus on practising specific data collection methods such as developing questionnaires and interviewing skills (Butler et al., 2012; Flood et al., 2012; White & Morgan, 2012). As Williams and Simons (2005) explain about a team of *People First* researchers:

> When we started out on this project, there was no particular reason why any of the members should have an idea of what research was. (p.10)

In another paper (Flood et al., 2012), three co-researchers explain:

> At the beginning of the research, we knew what research was. However, we had not done any research ourselves. It was important that we had the chance to learn more about the different ways we could ask people for information. We also needed to have the chance to practice. (p.289)

Strnadová, Cumming, Knox, and Parmenter (2014) described a 15-week training programme for a group of researchers with and without learning disabilities working on a particular project, which covered generic research skills such as problem formulation, interviewing skills and dissemination, as well as specific skills related to their project such as using an iPad as a research tool. Skills that were not needed at their particular project stage were omitted, such as data analysis.

Johnson (2009) noted the need for support resources that are specific to the research projects people with learning disabilities want to undertake, and described the use of role plays, practice sessions and easy-read materials.

There is a lack of opportunities for formal research training for people with learning disabilities, and in particular, research training that is not linked to a particular research project. As a result, it is difficult for people with learning disabilities to learn about research

prior to applying for jobs as co-researchers or members of research advisory groups. This is striking, given the importance of the paradigm of inclusive research and the fact that most research funders have made user involvement at all stages of the research process a prerequisite for funding. It may be that formal training is offered by research teams, at colleges or universities, but we found very little literature or descriptions of such courses or programmes. An exception is a course offered at the University of Limerick in Ireland, aimed at enabling self-advocates to learn how to do research (Salmon & Carey, 2013). An eight-session pilot curriculum was delivered to 14 students, leading to an online open-source 12-week curriculum (University of Limerick & Trinity College Dublin, 2013).

We agree with other authors (Strnadová et al., 2016) that having lived experience of learning disabilities is important, but it is not a sufficient qualification to become a researcher. Not everyone wants to be a researcher or is suited to it. On-the-job training is important, but recruiting people without previous research experience, training or understanding of what research involves can lead to problems if it turns out being a researcher is not, in fact, right for the person. We therefore identified a need for a formal research training course for people with learning disabilities.

1.4 | Developing and piloting a research training course

This paper describes the development, delivery and evaluation of a pilot course for people with learning disabilities, titled "Learning how to do research," delivered in eight weekly two-hour sessions at Kingston & St George's University in London, UK (April–June 2019). Our aim was to set up a course that would enable people with learning disabilities to get a taster of research and develop some basic research skills, which could help them to decide whether they were interested in becoming researchers themselves. We thought it would also help those who want to recruit people with learning disabilities as co-researchers and members of research advisory groups. In our experience, it can take a long time for people with learning disabilities to settle into such roles, understand what is required and indeed discover whether they are interested and suited to doing research. The capacities and limitations of potential co-researchers are not easily assessed through standard interviewing procedures. A secondary aim in developing a research course, therefore, was to widen the pool of suitable candidates for future co-researcher roles, to experiment with innovative training methods and to assess the extent to which generic research training sessions could help people with learning disabilities to understand and conduct research.

1.5 | How was this article written?

This article was written by the three course tutors (Irene, Claire L and Daniel) together with eight of the 10 course graduates. We wanted to write it for other researchers who are interested in developing a

similar course and hopefully convince researchers and funders of the importance of research training. Irene wrote most of it. Because we think the readers of this article will be researchers without learning disabilities, Irene did not write the whole article in easy-read or plain English. However, in describing and evaluating this course, it is very important to include the experiences and opinions of the course graduates. The words of the people with learning disabilities who completed the course are given in the sections headed "Graduates," whilst the perspectives of Irene, Claire L and Daniel are headed "Tutors."

Graduates:

We had a meeting in September 2019. We talked about ideas and about different ways of writing the article. Irene told us about lots of articles that other people had written. In some articles, people with learning disabilities wrote about being a researcher or getting research training. There were hardly any articles about research training for people with learning disabilities, so we wanted to write this one. Irene and Daniel wrote down what people in the group said about the course. When Irene had written the first draft of the article, she sent it to us. We then had another meeting in November 2019. This was like a focus group. The course graduates were in the focus group, and Irene and Daniel were like researchers who ask the questions. It was tape-recorded. Irene then looked at everything we said and added it to the article. We had another meeting in January 2020. We took it in turns to read parts of the article out loud, and we talked about changes we wanted to make, until everyone was happy with all the words.

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2 | THE RESEARCH TRAINING COURSE

The course was run at the Joint Faculty of Kingston & St George's University of London. We were able to offer the course free of charge, thanks to a grant from the National Institute for Health Research which paid for the course materials and 12 days of Claire L's time. Irene and Daniel contributed their time free of charge. The venue was also free of charge. Irene and Claire L developed the curriculum and taught on all the sessions; Daniel was an additional guest tutor on some of the sessions.

The first half of the course was aimed at giving students a basic understanding of the research process, broken down in 10 steps (see Table 1); and getting to grips with the data collection methods that, in our experience, co-researchers were most likely to be directly involved in: questionnaires, interviews, focus groups and Nominal Group Technique. During the second half of the course, students put their learning into practice by developing their own research questions and data collection tools, gathering data and presenting their findings.

The sessions were as practical and "fun" as possible, with a strong emphasis on learning by experience. An example was the very first "getting to know each other" session, where students were given a simple questionnaire to administer to each other in pairs, like a structured interview. They then each presented the "data" they had gathered, which were typed up on an Excel sheet (projected onto the wall) on the spot. This allowed us not only to get to know each other, but also, at the end of the round, to analyse the group's data (discovering, for example, that there was a good mix of ages and genders, that none of the students had a pet and that all students had travelled to the university by public transport). It made the explanation of the 10 steps of the research process less intimidating, as the students were daunted by words like "analysis" but delighted to discover that they had actually already done it! They also understood that Irene's *hypothesis* was wrong – she had expected that quite a few students had pets.

2.1 | Getting a place on the course

Graduates:

Some of us heard about the course because we work with Mencap [*a UK charity working to improve the lives of people with learning disabilities*]. Staff at the Mencap office (where Bernie, Dan and Diane work) arranged a meeting for about seven people with learning disabilities. They told us about the course and asked who would like to go. We thought it looked interesting. We had already been involved in some research projects at Mencap, and we thought it would be good to learn more about how to do it. Most of us applied and some of us got a place. Others heard about it from their support workers. Claire H's mum saw it and told her about it. Three of us (David, Leon and Michelle) know Irene and Claire L. We helped her with her research before. Irene asked us if we wanted to do the course and we said yes. We all had to tell the teachers why we wanted to do the course. Some of us made a video and some of us wrote it down.

2.1.1 | Tutors

We had no idea where we might find potential students, apart from the three people who had already been involved in our research advisory groups. We developed a flyer (see Figure 1) and tweeted it once. This led to 22 applications and a number of enquiries from organisations and groups of people with learning disabilities (including self-advocacy groups) who asked if we could run a similar course with them, for all their members. The selection process was somewhat arbitrary and unsatisfactory. Most applicants had given valid reasons for wanting to do the course (see Figure 2), but some applicants did not seem to understand what the course was about, and applied (encouraged by their support staff) because it was simply "something to do." This demonstrated a challenge, as it excluded

people who might have needed more explanations or time to understand what this was all about. This created a bias towards people with mild (rather than moderate) learning disabilities. We selected students more or less at random, ensuring a balance of genders and ages. We were unprepared for the level of disappointment for applicants who were not offered a place. It was perhaps difficult for them not to consider themselves as having "failed." One unsuccessful applicant telephoned Irene on receiving the news, explaining how much he had wanted to come to the university, and how hard it was to be "always turned down for things."

2.2 | Being nervous

> ### Graduates:
>
> We didn't say it at the time, but most of us were really quite nervous about coming here. It was nice to hear afterwards that we weren't the only one! Here is what some of us said about it.
>
> **Claire H:** I was really nervous coming here. I've never been to uni before. Both my sisters went to university, but I didn't think I could go, because I couldn't cope with the work load. So I was worried. Could I do it? Would I be able to keep up? I am usually quite nervous. I clam up. I can be nervous about putting up my hand. I sometimes don't speak, because I think, when I do, I'm going to be criticised for what I say. I'm often quite hard on myself up for saying something wrong.
>
> **Michelle:** I think we all do that. I have a mild learning disability. I beat myself up because I think I didn't do it right. I was also nervous about meeting new people. Knowing what to expect. Will I understand it? Each week I was petrified. I might not have shown it, but I was. Can I do the homework? Am I doing it right? Even though I knew Irene and we've worked together before, I was still nervous. But it was also exciting. We're not all perfect, but we all learn. And at the end of it, we all got our certificate! (see Figure 3).
>
> **Bernie:** I was nervous too. I didn't know what to expect.
>
> **Dan:** I was nervous about coming to a new place. Trying to get here on the first day. We went the wrong way round. I thought, are people going to judge you?
>
> ### We have some tips for helping students to be less nervous
>
> - It would have been good to have an ice breaker at the beginning.
> - What was good was that in the first session, the teachers said that there is no wrong or stupid question. There was a slide about that. We found that really, really helpful.
> - Teachers should reassure the students all the time.
> - Now that we finished the course, we could help to reassure future students about it! Perhaps we should make a video to tell people about it, and put it on YouTube…

2.2.1 | Tutors

It was somewhat surprising to hear how nervous the students had been, including those who had seemed quite confident. We had underestimated the impact of holding this course at a university. This was rather daunting, but also gave the students a real sense of achievement and confidence. We treated them as serious students, with the explicit expectation that they did their best. They rose to this, taking the course extremely seriously, always arriving in good time and paying careful attention throughout the sessions.

2.3 | The lessons

> ### Graduates:
>
> We really liked all the lessons. We talked about ground rules in the beginning. Phones off, be interested and listen to each other, and come to all the sessions. Some of us missed one or two sessions but we tried to catch up. That was quite hard, because there was lots in every session.
>
> How the course is taught is important, because if it's all serious, people lose interest. The best one was when we learned about how to do interviews. Irene and Claire L did *The Very Bad Interview*. Irene did everything wrong when she was interviewing Claire L. She kept talking about herself, and she wasn't interested in Claire L's answers. And she looked at her phone. You mustn't have your phone on when you are doing and interview. We laughed so much! It was good fun but also informative. It shows you how to present yourself for a job interview. How to answer questions and how to put yourself across. Interviewing skills are important.
>
> We also liked learning big and difficult words. We learned the word HYPOTHESIS. It means that you *think* something is true, but you're not quite sure.
>
> We were given a folder with all the slides and the homework in it. That was very helpful. The folders were really smart, with the university logo on it. We are very proud of them!

2.3.1 | Tutors

A breakdown of course content is given in Table 2. Focused sessions and homework task were related to the research process steps 1 (asking a question), 3 (formulating a hypothesis), 4 (planning), 5 (action – data collection) and 8 (presenting) (see Table 1). Step 6 (data analysis) was incorporated in most sessions but we did not include a specific focus on this. Student feedback showed that they enjoyed the approach of keeping the "lecturing" brief, and letting the students learn mostly through experiencing the different

TABLE 1 The 10 steps of the Research Process

1. Start with a question
2. What do people know about this already? (*literature review*)
3. Hypothesis (*what do we think MAY be true about this?*)
4. Planning (*how will you find out?*)
5. ACTION! (*finding out*)
6. Analysis (*what did we find?*)
7. Conclusion (*what does it all mean?*)
8. Presenting (*tell people about it*)
9. Make changes...
10. ...ask a new question

aspects of the research process. We wanted to make the course as interactive and hands-on as possible and experimented with several different teaching methods. For example, teaching interview skills involved a role play demonstration ("*The Very Bad Interview*,"

see Tuffrey-Wijne & YouTube, 2019) where students were given large buzzers to press every time they spotted something the interviewer could improve on. This was followed by a homework task of writing their own list of *Tips for Interviewers* (Figure 4). Focus group facilitation was taught by asking two students to facilitate a group discussion (the group was role-played by Claire L and three colleagues from the faculty, brought in for the purpose and unknown to the students). The students who were observers could interrupt at any point to make suggestions; those who did would then be asked to take the facilitator place. Students discussed the challenges afterwards, including the difficulties of preventing one group member to dominate the discussion and go off on a tangent, and encouraging another to speak at all. Other teaching methods included the use of flash cards, small group discussions and practising research methods in pairs.

FIGURE 1 Flyer to advertise the course [Colour figure can be viewed at wileyonlinelibrary.com]
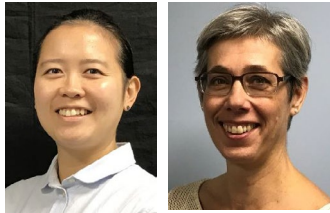
Who are the teachers?
We have lots of experience of doing research together with people with a learning disability.
- **Claire Lam** will lead the lessons.
- Professor **Irene Tuffrey-Wijne** will make sure everything goes well.
  She will also teach on some afternoons.
- Other people will help with the teaching, including people with a learning disability.

Claire   Irene

We have 10 free places available.
The course is paid for by the National Institute for Health Research (part of the NHS), because they want more people with learning disabilities to be involved in research.

How do I apply?
The course leaders will decide who gets a place. To help us decide:
- Tell us **why** you want to do the course.
- Tell us anything else about your life that you think we'd be interested in.
- You can do this in a letter, email, video, in person, or in whatever way you find easiest.
- You can ask someone to help you.
- Please apply **before 31 January 2019.**

We want to tell you more about the course.
Get in touch and ask us!

Contact Irene Tuffrey-Wijne

Email: i.tuffrey-wijne@sgul.kingston.ac.uk

Phone: 020 8725 0116 *leave a message.*
Don't forget to say your phone number

Address: Kingston & St George's University
6th floor Hunter Wing
Cranmer Terrace
London SW17 0RE

FIGURE 1 (Continued)

2.4 | Homework

Graduates:

We all found the homework hard. For example, one week we took home some questionnaires about "How can a visit to the GP be made better?" Leon tried to take the questionnaire to his GP practice, but people there were busy. Others had given the questionnaire to their family or support workers and that was easier. Another week, we had to interview someone. Some of us found it difficult to find someone to interview.

We think it was good to get homework though. Practice makes perfect! Research is about finding things out, but also putting it into practice. If you make a mistake, you can learn from it. You can turn it into something positive. Feedback is also research. You are finding from your colleagues what they think about things. They give you more ideas.

It helped that you did it in quite a nice comfortable environment. Irene and Claire L were perfect and outstanding, there was no pressure. Of course you had to be here on time, but we didn't get our work thrown at us, like they do at a university, *"there, you got to do that by tomorrow."* It was done in a relaxed way. We didn't feel pressured if we couldn't do the homework, as long as we could talk about it and use some of the information that we knew.

2.4.1 | Tutors

An example of a completed homework task (week 3, on conducting research interviews) is given in Figure 4. We underestimated how seriously the students would take their homework, and how hard it was for them when they struggled to complete the tasks or when they were not sure whether they were doing it right. In future courses, we will spend more time discussing the homework tasks, both beforehand and afterwards.

2.5 | Doing our own research project

> *Graduates:*
>
> We chose our own research topic. We did it like this: We made a list of all our ideas for research. We put it on a board. We narrowed it down. Then we voted. We had lots of topics. Health, violence, gangs, public toilets... The one that ended up with the highest scores was *Employment, Jobs and Benefits*. It is important because not enough people with a learning disability have a job. It would be good to see more people having a job, being given a chance to prove what they can do. We wanted to do research about that.
>
> The teachers put us in groups. One group had to do a questionnaire. One group had to do an interview. One group had to do a focus group. They helped each group to prepare. It was hard but we found out some interesting and surprising things.

2.5.1 | Tutors

It was exciting for us to see how innovative the students were with regard to generating their own research questions and producing data collection tools. Their questions demonstrated the importance of exploring issues from their own perspectives, and by implication, including people with learning disabilities in setting the research agenda, as well as be involved in research design and analysis. We decided to allocate the students to one of the three groups in accordance with their demonstrated interests and strengths, as we wanted them to be as successful as possible in the short time available. Most students found the session of focus groups the hardest (e.g. one student clearly struggled to understand that the facilitators were not required to answer the questions themselves; another was extremely shy and found it hard to ask questions out loud) so we did not allocate them to the focus group. Students who clearly enjoyed getting to grips with questionnaire development were allocated to that group. Whilst the students learned not only from their own groups but also from observing and the others, a longer course would have given them more opportunities to explore and practise the different data collection methods.

2.6 | Doing a presentation on the final afternoon

> *Graduates:*
>
> On the final day, we had to do a presentation. We could bring our family, friends and support workers. The room was full of people. We had to stand up in front of them, and tell them about the research project we had done. It was nerve-racking! None of us liked doing it. We were on shaky ground! But it was useful, and we all think that it was important. On future courses, this shouldn't be left out. It's good to figure out how to do it.

2.6.1 | Tutors

Doing presentations for the first time is indeed nerve-racking for most of us. However, the benefits of helping people with learning disabilities to stand up and speak in public go beyond "information transfer"; it gives a powerful message to the listeners of the importance and benefits of inclusion, and it gives the speakers a significant confidence boost. We were impressed with all the students, but perhaps most so with the student who had been too shy to say their name in class, yet stood up and talked about their questionnaire results in front of a room full of invited guests, including relatives, support workers and academic staff from the faculty.

2.7 | Why is this course important?

> *Graduates:*
>
> - A course like this gives people a voice. Having a voice is one of the most important things.
> - It helps people broaden their future ambitions.
> - It's a way of meeting new people.
> - It builds up our confidence. If your confidence is up, you can do research and find things out.

2.7.1 | Tutors

Some of the benefits of this course were anticipated – such as broadening horizons and ambitions, and learning new skills. We had also anticipated some secondary benefits that would have a wider impact on the graduates' lives, such as increased self-confidence and self-esteem. We were surprised, however, by the extent

FIGURE 2 Extracts from student applications [Colour figure can be viewed at wileyonlinelibrary.com]

"Why would you like to do the course?"

People with learning disabilities may have different views to those who don't have a learning disability, they may think things that others don't, and it's really important to include those, because sometimes you can find out things that you may not have known.

In this course, I will have an opportunity to learn how to do interviews, making a questionnaire, meeting other people in the course and working with them.

I want to develop my confidence within research and where and how to get information in the right way not the wrong way.

I am really interested in using research to find out more about peoples experiences and people's opinions on Learning Disability

I hope the course will help me to be more confident in giving my opinion because I will be able to practice working out what the answers mean.

I know the course will be a challenge but I would like to have the chance to do it.

I've been to two special needs schools. The headmaster said that I couldn't be taught. I would like to know a bit more about the older generation of people with learning disabilities who ended up in psychiatric hospitals. It's an important subject to talk to other people with learning difficulties who might need a voice. If I can do a good job, that would be good.

FIGURE 3 The graduates and their certificates [Colour figure can be viewed at wileyonlinelibrary.com]

to which being on this relatively short course impacted positively on students' lives. Several of the students' relatives (who attended their presentations and award ceremony on the final day) reported a significant increase in confidence in the students' daily lives; one parent said that the student had a different posture, standing more upright than before.

TABLE 2 Curriculum

Date	Session content	Homework
Week 1	**Introducing research: What is it?** • Setting ground rules for the course • What do we already know about research? • Get to know each other in pairs: a. Use "get to know each other" interview questions" sheet and report back to group what each pair learnt about each other b. Collect data whilst introducing each other using Excel Sheet • Research in 10 steps	Step 1–3: Start with the research question "How can a visit to the GP be made better?" and hypothesise possible answers to this question. Bring back answers next week
Week 2	**Research methods 1: Questionnaires** • Ground rules recap + say hello again! • Examples of different questionnaires: a. Who were they for? • Types of Questions: Open and Closed • Demo interview from two teachers: a. Students raise cards depending on whether teachers asked closed or open questions to each other • Qualitative and Quantitative Research: a. What types of questions are used? • Homework Review: a. List all hypotheses shared on flipchart • Step 4: Planning to find out using questionnaires a. Create a questionnaire using hypotheses • Step 5: Action! Discuss using questionnaires: a. Type up questionnaire and print for students to take home as homework	Step 5: Action! Each students to receive six copies of questionnaire created in session today; to ask at least 5 people to fill in their questionnaire and bring back next week
Week 3	**Research methods 2: Interviews** • Ground rules recap • Research Step 1–5 review using examples from Session 1 and 2 • Homework review: Step 6: Data collection and brief analysis a. Students lay all questionnaires in front of them and report back to group whilst teacher inputs data onto excel sheet on big screen b. Analysis: briefly summarise and discuss findings • Demo interviews from two teachers: a. Round 1: A very bad interview b. Round 2: A very bad interview replay- students given buzzers to stop interview and suggest improvements • Interview skills group discussion • Try interviewing someone for homework! Bring back top tips to share with group next week	Step 5: Action! Part 1: Interview someone for 5 min using the question listed Part 2: Think about what was helpful and not helpful in your interview, write it down and bring back next week
Week 4	**Research methods 3: Focus Groups** • Homework review: top tips for interviews • Focus Groups: a. Why use a focus group? b. Who is it good for? • How to run a focus group • Students try to run a focus group: Bus company has hired you as researchers, find out why people do or do not take buses • Students can take turns asking questions	Begin thinking about own research interests: Step 1: What do I want to know? Bring back topics of research project next week
Week 5	**Own research project** • Make a list of all students' proposed research topics • Decide on a final topic, using Nominal Group Technique • Divide into three sub-groups. All will design their own study in relation to the chosen topic, using one of three allocated data collection methods: questionnaire; face-to-face interview; focus group	Think about what questions you'd like to see answered in your research project. Bring back for discussion with your sub-group next week
Week 6	**Own research project** • Preparing for data collection: Each sub-group meets with one allocated tutor. Planning: specific research questions; sample (who are the participants/interviewees?); data collection tool (develop the questionnaire or interview schedule); who will collect the data? *NB Data must be collected within the group, so only students or tutors can be participants*	

(Continues)

TABLE 2 (Continued)

Date	Session content	Homework
Week 7	**Own research project** • Finalise the preparations (in the sub-groups) • Conduct the study: a. Questionnaire completed by fellow students b. Interview conducted (in front of the whole group) c. Focus group conducted (in front of the whole group) • Discuss the findings together	
Week 8	**Showcasing/presentation** (invited audience for the final hour) • Preparation for public presentation of findings • Students present their findings • Celebrations and certificates	

2.8 | After the course

> **Graduates:**
>
> We found that the course has helped us in lots of ways. We have used some of the things we learned on the course. It has given us more confidence in ourselves. It has also helped some of us in our jobs. Some of us got new roles because of the course. Here are some examples.
>
> **Dan:** I had a job interview and I was thinking of the things that I learned in the course, about good interviews and bad interviews. Then Mencap asked me to come to Northern Ireland with them and help carry out some focus groups and surveys. I've also spent a few days helping Mencap staff to analyse the findings.
>
> **Bernie:** I went to Worcester. Like Dan, I am part of the research team at Mencap. We did some focus group interviews with trainees. It was called the Employment Cohort Study. We asked them questions like, how did they join the Trainee-ship? What things did they want to do when they were at school? What kind of jobs would they like to do? In the focus group was people with learning disabilities interested in getting a job. I was helping it, co-delivering it. Dan did one in Northern Ireland. I think the reason they asked me and Dan and Diane to do it was because we did this course.
>
> **Diane:** I have volunteered with the Mencap Research Team a couple of times, to get more experience with research.
>
> **Richard:** I went for a job interview this year. I used the things we learned here. How to present things when you go for an interview. I didn't get the job but I got to the last three. So I did quite well. Also, I am on the Transforming Care Partnership Board for the south east. I went to a conference where we all did different workshops and I did a workshop on transforming care. I suppose we did a bit of research there because I asked them questions. I asked if they knew about it.

2.8.1 | Tutors

It is clear that this course has filled a gap and met a need. Six months after completing the course, the graduates reported that they had better knowledge of research and had increased their skills. They demonstrated a significant increase in confidence, not only in their jobs and activities but also in their lives in general. They were extremely proud of having completed the course. Four of the graduates had been involved in research-related projects as a direct result of having completed the course, and most had used the newly learned skills in some practical way. They found the session on interview skills particularly helpful and reported on using it when attending job interviews or being on interview panels for new staff. They were also more confident in being involved in advocacy meetings with peers, with one student taking on a new leadership role in this.

2.9 | Ideas for future courses

> **Graduates:**
>
> We hope there will be more courses like this. It really helps people with their jobs and employment. There was quite a lot of information to take in, in two hours. Perhaps the sessions could be longer, with a tea break in the middle. Or more sessions. Because research is such a huge spectrum and there is a lot to learn about research.
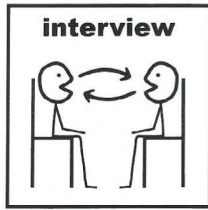>
> *This is what we would say to other people with learning disabilities who are thinking of doing the research course*
>
> Just give it a go! You will find out more about research. You might get a bit nervous at first, but we think you will enjoy it. Do the course, nothing might happen straight away, but if you do the course and they see you're taking it all seriously, you will get something out of it. People will notice you. It is important to build up your confidence and be a leader in the world, not just sitting back and waiting for someone to do something. Because we are all leaders. We must go out there and lead the world.

FIGURE 4 Example of homework [Colour figure can be viewed at wileyonlinelibrary.com]

2.9.1 | Tutors

Given the success of the course, we would like to run it again. We are currently looking into ways of getting funding for it, as we think the course should continue to be offered free of charge. The basic content and structure of the course seem to have been successful, although we would agree with the graduates that it would be better to have longer sessions or more sessions. Ideas for future developments include the following:

- Pairing students with learning disabilities with learning disability nursing students, so they can learn about research together. We think that the enthusiasm of students with learning disabilities could inspire enthusiasm for research in student nurses; it would also encourage and teach student nurses to become inclusive future researchers. When we talked about this idea to the graduates, they liked it very much.
- Setting up an inclusive university-based research and education group, which could be a forum for developing research ideas and informing education.

3 | CONCLUSIONS

3.1 | Tutors' conclusion

An eight-session pilot course aimed at developing research skills for people with learning disabilities, developed and delivered at a London university, has led to tangible benefits for the students. They demonstrated that it is possible for people with learning disabilities to become skilled researchers. If inclusive research is taken seriously, it is important that people with learning disabilities have opportunities to learn about research in a way that is tailored to them. We believe that it is essential to invest in such training, and we urge research funders, universities and colleges to consider this.

We believe that formal training according to a curriculum is an important part of developing an inclusive research environment, as it can provide people with learning disabilities with a basic understanding of the research process and help them assess whether they would like to become researchers. Once people with learning disabilities are part of inclusive research teams, formal training will still be important, but other approaches will also be of significant value. This may include, for example, working alongside a mentor and role model; researchers with and without learning disabilities learning together; and addressing specific gaps in knowledge and skills.

The training course we have described is only one way of addressing the lack of formal research training opportunities and has by no means addressed all training needs. Along with the inclusive research described in the literature, it could include only students (or researchers) with mild and moderate learning disabilities who had a certain degree of verbal ability and understanding. Certain aspects of the research process were not sufficiently addressed, including literature reviews, data analysis and research ethics. We think there is scope for a much wider programme of research training, addressing the needs of beginners as well as those in need of more in-depth training.

We would like to encourage future course leaders and students to share their experiences and resources, so others can learn from

it and build on it. Our course materials are available on request from the first author.

> **Graduates' conclusion:**
>
> We want to put into this article that we say *Thank you* to Irene and Claire L for coming up with the idea for doing a course like this for people with learning disabilities, and seeing the confidence that people could have, to be able to go out and do research.
>
> We just want to say that people with learning disabilities CAN do research. Because we can! We broke through the barriers! We've gone out there and we've achieved something special.
>
> It is right for people with a learning disability to be heard and to be seen, and not just to be walked over. To be able to take part in doing things. It's like a book, don't always judge a book by the cover. Always look inside to see what a person can do. It is good for people to get the opportunity to go out in the world and to do normal things that other people do.

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