JARID Journal of Applied Research in Intellectual Disabilities
bild Published for the British Institute of Learning Disabilities
Journal of Applied Research in Intellectual Disabilities 2016

Evaluating a Research Training Programme for People with Intellectual Disabilities Participating in Inclusive Research: The Views of Participants

Judit Fullana, Maria Pallisera, Elena Català and Carolina Puyalto
Institute of Educational Research, University of Girona, Girona, Spain

Accepted for publication *9 May 2016*

Background This article presents the results of evaluating a research training programme aimed at developing the skills of people with intellectual disabilities to actively participate in inclusive research.
Methods The present authors opted for a responsive approach to evaluation, using a combination of interviews, questionnaires and focus groups to gather information on the views of students, trainers and members of the research team regarding how the programme progressed, the learning achieved and participants' satisfaction with the programme.
Results The evaluation showed that most of the participants were satisfied with the programme and provided guidelines for planning contents and materials, demonstrating the usefulness of these types of programme in constructing the research group and empowering people with intellectual disabilities to participate in research.
Conclusions The evaluation revealed that the programme had been a positive social experience that fostered interest in lifelong learning for people with intellectual disabilities.

Keywords: inclusive research, intellectual disability, programme evaluation, research training

Introduction

The International Convention on the Rights of Persons with Disabilities (United Nations, 2006) establishes a set of measures that ratifying states must implement to guarantee that people with disabilities can access their rights under equal conditions and opportunities. Although considerable progress has been made with regard to the social inclusion of people with intellectual disabilities in recent decades, research shows that they encounter numerous obstacles to exercising their rights, not least with regard to access to professional training to provide them with adequate resources and enable them to cope with working life (Beresford 2004; Clarke *et al.* 2011; Pallisera *et al.*, 2014), living independently and being included in the community (European Commission, 2009; Emerson & Ramcharan 2010; FRA-European Union Agency for Fundamental Rights 2013). Furthermore, in many cases, they are not satisfied with the services they receive (McConkey *et al.* 2004; Deguara *et al.* 2012).

Social and educational research, understood as an activity that serves people and society, should aim to give a voice to people with disabilities. The inclusive research model, developed from the 1990s onwards, argues that people with relevant personal experience on an issue being investigated should participate actively in the research process (Walmsley 2001, 2004; Walmsley & Johnson 2003). This adds value to the process by including the views and experiences of those object of the research, in our case people with disabilities, increasing their opportunities to influence political and social change through the defence of their rights (Koenig 2011; Johnson *et al.* 2014; O'Brien *et al.* 2014).

There are different ways for people with disabilities to participate in research (Ward & Simons 1998;

10.1111/jar.12262

Walmsley & Johnson 2003; Bigby *et al.* 2014): the *advisory approach*, in which people with intellectual disabilities participate as advisors or counsellors; the *leading approach*, whereby people with intellectual disabilities exercise control in initiating, leading and conducting their own research on topics that are important to them; and the *controlling and collaborative groups approach*, when people with and without disabilities work together on a research process in which each contributes their skills and experience to generate new knowledge together.

Whatever the mode of participation, in order to actively participate in the various phases of the investigation, people with disabilities need to have specific technical and procedural knowledge of this process (Ward & Simons 1998; Walmsley & Johnson 2003; Walmsley 2004; Bigby & Frawley 2010). However, few research training experiences have been conducted with people with intellectual disabilities (Johnson 2009; Cumming *et al.* 2014; Salmon *et al.* 2014) and there is no agreement on what such training should cover. Training people with intellectual disabilities is therefore one of the challenges of inclusive research (Johnson 2009; O'Brien *et al.* 2014; Nind *et al.* 2015).

In spite of the above, a review of what scarce literature there is addressing the issue of training people with disabilities does offer some guidance on such processes. This includes recommendations of working on comprehension of the research concept, determining which issues it is important for the team to address, accessing written materials and managing tasks (Strnadová *et al.* 2014). It is suggested that practical activities be employed to apply relevant aspects (Abell *et al.* 2007; Flood *et al.* 2012) and sufficiently accessible materials be used for participants (Burke *et al.* 2003; Flood *et al.* 2012). There are also recommendations to include ethical issues related to research (Burke *et al.* 2003; Abell *et al.* 2007) and allow participants to interact with groups of people with disabilities performing joint research in order to share experiences (Flood *et al.* 2012).

Existing training experiences are an important point of reference, although there are few systematic evaluations of these experiences. One such evaluation is the pilot Research Active Programme (RAP) (Salmon *et al.* 2014), developed at the University of Limerick (Ireland). The course consisted of 12 4-h sessions and had 14 participants. Based on this evaluation, which focused primarily on the views of participants with disabilities, Carey *et al.* (2014) concluded that participants considered it a good opportunity to access a wider social network within a university setting, participate as joint researchers and be more critical and improve research. The authors made the following recommendations: offer individualized learning guidance on the use of computers and other instruments necessary for research; include students on the course from professions related to caring for people with LD, or organizations that provide care for these people, in order to lay the groundwork for future partnerships for inclusive research; allow participants to evaluate each session; and ensure that participants have means of transport to access the course (Carey *et al.* 2014).

Another experience was conducted as part of an investigation into the transition to adulthood and working life of young people with intellectual disabilities, carried out between 2011 and 2014 by the Research Group on Diversity at the University of Girona. An Advisory Committee was set up comprised of people with intellectual disabilities who actively participated in research activities. This was the foundation for the launch of a Research Training Programme in 2014.

The Research Training Programme was aimed at developing participants' skills to actively participate in various activities related to conducting educational research. It was taught to the 12 people who had served on the Advisory Committee during the 2012–13 academic year and was structured in eight sessions. Table 1 outlines the topics of each training session, the activities carried out and the learning outcomes.

This article presents the results of evaluating this research training programme designed for people with intellectual disabilities. The aims of the evaluation were to identify the strengths and weaknesses of the programme so as to offer some guidelines for planning and implementing this type of programme and evaluate its usefulness as a support and training strategy for people with intellectual disabilities participating in inclusive research.

Method

A programme evaluation approach was chosen which aimed to obtain useful data to evaluate its relevance and identify elements for its improvement. The novelty of the programme and its low number of participants and training sessions led us to choose a qualitative approach to evaluation, in line with the tenets of *responsive evaluation*, which, according to Stake (2004), means being guided by the experience of being personally present on the programme, feeling the activity and the tension and

Table 1 Overview of sessions, topics, aims and activities

Session	*Topic*	*Learning outcomes*
1	The research process	• Learning about the phases involved in the research process. • Identifying reasons for conducting research.
2	The interview (I)	• Learning the basic steps for conducting an interview. • Identifying good and bad practices in interviewing.
3	The interview (II)	• Learning key aspects in preparing an individual interview. • Practice doing an interview.
4	Visual methods as a support for data collection (I)	• Learning about potential uses of drawings and photographs in data collection.
5	Visual methods as a support for data collection (II)	• Using photographs and drawings in a research project on independent living.
6	Focus group (I)	• Learning the main characteristics of focus groups.
7	Focus group (II)	• Learning the main characteristics of focus groups.
8	Course review	• Review content learnt on course.

basing the evaluation above all on personal interpretation. The evaluation collected the views of participants with intellectual disabilities (henceforth 'the students'), researchers – who carried out the role of facilitators – and trainers, using data collection and analysis strategies designed to ascertain their views in some detail.

The present authors focused the evaluation on analysing the programme's development and results. Within programme development, data were collected on the following topics:

- The suitability of the content, materials and methodology used in each training session on the programme, and the role played by the trainers in each session.
- The accessibility of the materials used and degree to which they were understood by participants.
- The suitability of the sequencing of activities and strategies used.
- The role of facilitators and members of the research team in providing adequate support to the participants with intellectual disabilities.
- The level of participation of the people with intellectual disabilities and their level of motivation and interest shown in the sessions.

With regard to the results of the programme, data were collected on:

- Learning outcomes with regard to research methods and strategies.
- The general level of satisfaction of those involved in the programme, their perception of its usefulness, fulfilment of expectations and satisfaction with the learning achieved.

A combination of in-depth interviews, focus groups and adapted questionnaires for people with intellectual disabilities were used. An assessment activity was carried out in some of the sessions to ascertain what learning had taken place. All of the training sessions were recorded on video after obtaining the informed consent of all participants, students and trainers. The focus groups with participants were also recorded on video. The interviews with trainers and focus group with the research team were recorded on audio. Below, the present authors provide details of the programme participants, instruments used and data analysis. Data were collected on an ongoing basis throughout the programme, as shown in Table 2.

Participants

The programme participants comprised 12 people with intellectual disabilities (eight men and four women aged between 24 and 53) who participated on an Advisory Committee linked to a research group at the University. Eight were working in sheltered employment and four in supported employment. Seven people lived with their parents, four on their own with home support and one person lived alone. They all had a sufficient level of autonomy to come to the University where the programme was run on their own and participate actively in the 60- to 75-min training sessions.

They signed an informed consent document explaining the aims of the study and were asked their permission to video sessions, guaranteeing data confidentiality. Three researchers from the research group and a master's degree student provided support

Table 2 Data gathering during the programme sessions

	Programme sessions							
Data-gathering strategies	*1 The research process*	*2 The interview (I)*	*3 The interview (II)*	*4 Visual methods (I)*	*5 Visual methods (II)*	*6 Focus group (I)*	*7 Focus group (II)*	*8 Programme review*
Interviews with trainers (TI)	TI1		TI2	IT3				
Focus groups with students (SFG)	SFG1	SFG2	SFG3	SFG4	SFG5	SFG6		
Student questionnaire (SQ)	SQ1		SQ2					SQ3
Assessment activity with video recording (EA)			AA1		AA2		AA3	
Research team questionnaire (QE)	RTQ1	RTQ2	RTQ3					
Researchers' focus group (GFE)								RTFG1

TI, trainer interview; SFG, students' focus group; SQ, students' questionnaire; EA, assessment activity; RTQ, research team questionnaire; RTFG, research team focus group.

and acted as facilitators in the different sessions. These four people were also in charge of evaluating the programme. The programme trainers comprised five professors from the same university. Programme participants, members of the research team who acted as facilitators and support staff during the sessions and the session trainers themselves were all informants in the evaluation process.

Instruments

A combination of questionnaires, interviews and focus groups were used to collect information on the different sessions. Table 3 lists the evaluation topics and instruments used. The crosses indicate which topics data were collected about for each instrument.

Questionnaires allow information to be obtained quickly for each person in the group, provide information focused on the object of analysis and involve simple data processing (Corbetta 2007). As Table 3 shows, the students answered a questionnaire at the end of sessions 1 (SQ1) and 3 (SQ2), consisting of seven questions in an accessible format. The questions were accompanied by images for ease of interpretation, and students had to respond by marking one of the following options: *very good*, *good*, *could improve* or *I didn't like it*. They could add written comments, with the support of a member of the research team if required. The questions were designed to ascertain whether they had found the session understandable and evaluate the content and materials used, the role of the support staff and participants' own participation, interest and general satisfaction with the session.

The questionnaire for session 8 (SQ3) obtained information on the learning acquired and satisfaction with the programme. In this case, the questions were open. Four members of the research team wrote down the answers of those participants who preferred to respond orally. The questions about what they had learnt included, for example, asking participants whether they could say something about what research is for and how interviews visual methods and focus groups are used as research tools. Finally, they were asked about their satisfaction with the programme and to provide an overall evaluation of its usefulness and whether they would like to do more research training.

Four members of the research team completed a questionnaire of open questions at the end of session 1 (RTQ1), two at the end of session 2 (RTQ2) and one member completed the questionnaire at the end of session 3 (RTQ3). The questions required that each member of the team who had attended the session individually evaluate it and the students' degree of satisfaction and learning (Table 3).

Focus groups complete and enrich information obtained from questionnaires, while also facilitating interaction between participants and allowing opinions and experiences to be discussed and contrasted (Krueger & Casey 2000). According to Cambridge & McCarthy (2001) and Barr *et al.* (2010), the focus group is a non-threatening environment that helps participants with intellectual disabilities gain confidence through the support they receive from other participants. The students participated in six focus groups, one each at the end of sessions 1–6 (SFG1 to SFG6). One member of the research team led each group. The researchers

Table 3 Evaluation topics and instruments used

	Students				*Research team members*		*Trainers*
Evaluation topics	*Questionnaires SQ1, SQ2*	*Questionnaire SQ3*	*Focus groups SFG1, SFG2, SFG3, SFG4, SFG5, SFG6*	*Assessment activities AA1, AA2, AA3 Session transcripts*	*Questionnaire RTQ1, RTQ2, RTQ3*	*Final focus groups RTFG1*	*Interviews TI1, TI2, TI3*
Training programme development							
Aims of programme and sessions			X		X	X	X
Sessions							
Content							
Materials							
Methodology			X		X	X	X
Role of trainers							
Accessibility							
Materials used							
Participants' perceived level of comprehension	X				X		X
Activities: sequencing and strategies employed			X		X	X	X
Role of facilitators and team members providing support	X				X	X	X
Student participation in sessions	X				X	X	X
Student interest and motivation	X		X		X	X	X
Results							
Learning outcomes on research methods and strategies		X	X	X			
Satisfaction with programme							
Perception of usefulness							
Related to prior expectations							
Satisfaction with learning	X	X	X		X	X	X

themselves participated in a focus group at the end of the programme (RTFG1), their views being collected on the planning, development and results of the programme. Table 3 shows the topics addressed in the focus groups with students and the one with the research team.

The evaluation plan allowed for an activity at the end of sessions devoted to a specific topic in order to obtain information on learning outcomes. These activities (AA1, AA2 and AA3) were carried out at the end of sessions 3, 5 and 7, which were related to doing interviews, using visual methods and doing focus

groups. Video recording the sessions and the subsequent transcription of the recordings allowed analysing students' answers to the questions posed by trainers with the aim of evaluating the learning that had taken place.

Interviews with trainers were conducted at the end of sessions 1 (TI1), 3 (TI2) and 4 (TI3). The topics were similar to those mentioned in the research team focus group, but with special emphasis on their views regarding planning and running the sessions, students' participation and interest and the resulting learning outcomes.

Data analysis

The videoed sessions, focus groups and interviews with trainers were transcribed in full. Transcripts, together with the questionnaire administered to members of the research team, were analysed using thematic content analysis, by means of structural coding (Saldaña 2009), a method in which the phrases used as codes are based on the subject of research. Thus, an initial list of codes was linked to the topics addressed in the evaluation, summarized in Table 3. One researcher encoded the material using structural codes. Two other researchers then reviewed a sample of the encoded material – one of the focus groups conducted with students, one interview with the trainers and the transcribed material from the assessment activities carried out in the sessions – to verify whether the encodings matched. The criteria and codes were agreed upon and the first researcher reviewed all of the material again. The final structural codes were as follows: programme aims, how the sessions were run, the role of trainers, session materials and content, session activities, the role of support staff, student participation, student interest and motivation, learning outcomes and student satisfaction.

The three researchers carried out a second encoding of the material, which consisted in identifying strengths, weaknesses and proposals for improvement for each of the structural codes. Each researcher encoded part of the material, which was then pooled in a working session. Finally, one of the researchers carried out a joint analysis of the questionnaires, interviews, focus groups and assessment activities.

Results

The results obtained refer to strengths, areas for improvement and proposals regarding the development of the programme and its results. With respect to the development of the programme, the following issues were analysed: programme aims, the methodology used in the sessions, role of trainers, accessibility of materials and content, sequencing of activities undertaken, role of team members providing support, students' participation in the sessions and their interest and motivation. With regard to programme results, the following were addressed: students' learning outcomes and overall satisfaction with the programme with regard to perception of its usefulness, fulfilment of expectations and satisfaction with what they had learnt.

Programme development

The data analysis revealed that the trainers and researchers evaluated all aspects related to programme development and the sessions themselves, while the contributions of students mainly focused on evaluating the materials and content, the activities, the role of support staff, their participation in the sessions and their motivation and interest.

All of the trainers and members of the research team agreed in highlighting that the programme aims had been met and were appropriate for the characteristics of this group, and that there had been a notable effort to link the content of each session with the previous ones. However, members of the research team considered that other important aims beyond those related to learning research methods had not been sufficiently taken into account, such as group building and teamwork. In relation to the issue of achieving aims, Researcher 1 said:

> Yes they were met in the sense of a minimum amount of knowledge regarding what constitutes an interview, a focus group, and also being aware of what a research process is or what it involves (...) I think this was achieved. (...) In terms of strengthening the group I would say that we did not propose that as an aim, which was a mistake because I think we should have made it one of the objectives (Researcher, (RTFG1))

Evaluating how the sessions were run included the role of trainers. The trainers were university professors who had adapted the content of the sessions to the aims and simplified the information presented. They had taken into account the fact that the students were adults training to participate in research:

> It's about finding a balance, I suppose, that is adapted, so that what you explain has coherence and meaning, but not falling into the trap of treating participants like children. I admit that was difficult because I had no experience with this group (Trainer, TI3)

All the trainers thought that the structure of the sessions had been more suitable when a first part had been dedicated to a brief theoretical presentation accompanied by images and examples, and a second part to creating a participatory dynamic:

> Do an activity where they can do something, be active and take a central role, yes. This does not mean that there should not be twenty minutes of explanation, which is also very interesting, in fact. And it also fosters a type of ability that's useful to foster: attention, abstraction, (. . .), I think it's good to sometimes create some challenge, you know? (Trainer TI3)

The research team valued collaboration with professors from other research groups very highly because it helped them to expand their knowledge of the programmes taught at the university and allowed them to see that people with intellectual disabilities can do important work in the field of research:

> I think it's also a way of giving visibility (. . .), of changing people's mindsets about the potential of people with intellectual disabilities in relation to research. If you see that a person with disabilities is able to understand concepts and processes related to research you can also understand that they can do other things in life (Researcher, GFE1)

The research team used different strategies to make the session materials and content accessible to the students, providing a printed copy of each trainer's presentation and accessible summaries of each session. The trainers used video, adapted presentations, drawings and photographs and designed accessible practical activities to facilitate learning. Most students said they had been able to understand the sessions well: in questionnaire SQ1, 11 of them rated it 'very good' or 'good' and only one said it could be improved. In questionnaire SQ2, of the eight participants, seven indicated that they had understood the session very well and one well. The materials were also rated positively by students. Visual material received the highest score, such as photographs and drawings, as well as audiovisual presentations that used little written text.

An effort had been made to ensure that the materials provided and used in the different sessions were accessible. However, the research team acknowledged that although accessibility had been improved, it had not been performed in a very personalized way:

> . . .we (the research team) say that the material is accessible but what we do is to try and develop material that is not too complex, contains images, and has large writing, and for the sessions not to be too long. But we did not at any time speak with them individually to ask: "So, to follow a presentation. . . what would you like the content to be like?" (. . .) We should take the necessary time to have individual meetings with them and get a clear idea about what they need (. . .) (RTFGI)

Regarding the activities, the students and research team felt that the presentation activities had been clear and understandable, highlighting the use of everyday examples, presented in the form of video, photographs and drawings as a way of facilitating understanding of the content. Most of the activities carried out during the sessions fostered students' active participation.

The students rated the role of those providing support during sessions positively. According to the results of questionnaire SQ1, nine of them rated it 'very good' and two 'good'. In questionnaire SQ2, the eight participants chose the 'very good' option. The trainers deemed support people necessary to assist in the group activities, give the trainer confidence and contribute to continuity between sessions. The members of the research team who had provided the support stressed that more attention must be paid to supporting trainers and students from the very first session:

> I think it gives confidence to the external trainers who collaborated. As well as the fact that they showed us the materials before presenting them so we could review them. In some cases we were able to say: this should be presented differently, less text. . . We could give advice. (Researcher, RTFG1)

The students evaluated their opportunities to participate in the sessions as quite good. When responding to the question of whether they believed they had been able to participate as much as they would have liked, in questionnaire SQ1, only three of the 12 students considered they did not participate very

much. In questionnaire SQ2, eight of them considered that they had participated 'quite a lot' (five people) or 'a lot' (three people). The trainers also deemed it necessary to plan spaces for participation.

As for the student's interest and motivation, the trainers and research team agreed that these had been higher when students had been able to relate the content to their own experiences. When asked about participants' interest, the researchers said:

> When they were doing the exercises you could see they were involved, and that they were motivated and showed interest. The fact that the sessions were not very long helped maintain the level of interest, attentiveness... (Researcher RTFG1)

Programme results

Data on the learning achieved by students was obtained from questionnaire SQ3, which was administered at the end of the final session. It contained open-ended questions where participants indicated whether they could remember different aspects of the content covered on the training programme. Data on this learning were provided via the analysis of video transcripts from the different sessions, selecting information related to the activities that trainers had planned to gather information on learning, as well as transcripts from the focus groups conducted at the end of each session. Table 4 contains the topics and some examples of student responses in questionnaire SQ3.

The students understood that the interview is a method for collecting information and its preparation and implementation must take into account different aspects which are not always easy. The clearest learning was related to what you can do and what you should not do when interviewing a person. The following quote is from a student referring to the interview simulation activity carried out by the trainers in order to evaluate learning in sessions 2 and 3:

Table 4 Student responses to the questionnaire on learning achieved

Question	*Responses to questionnaire SQ3*
What is the purpose of research?	• A small group of people come together to talk about a particular topic. The presented project is analysed thoroughly from different perspectives to have a base, because later you have to interview a person, and to have a wider range of things that people talk about and ways of talking. • To find out our opinions and know what people think about us. Research means looking for answers to something or some project and presenting it. Depending on what it is about it may be more or less useful. I think that research is useful for learning more new things.
What did you learn about how to conduct interviews?	• Many things: to look smart and be polite and have questions prepared. • Personally, I knew how to do it, but it helped me to get better at doing one. How to look at people, body language, the way the interviewee acts... • Gestures, eye contact, naturalness, not to be nervous, and it is very helpful when looking for work. • Interviewing with another person to listen and learn from the other person. • How to start, ways of addressing the other person... different ways I had not seen.
What do you remember about visual methods as support for data collection? What did you learn?	• The drawings of other countries such as Chile or Chiapas, drawn by people from there and taken across the Atlantic, and putting them with drawings drawn by people from Europe and comparing them. The drawings were different because people from different countries have different ways of drawing or thinking. • It is useful to know how the person sees and what they want to present. • Seeing things very differently and approaching them from another point of view. • To know other people's opinions.
What is a focus group?	• It is a small research and working group that analyses different research projects. • A group that explains things. • Small groups of people, between 6 and 8 and they all look at the situation and give their opinion. • You set up a group and present a topic and you have to discuss it.

> That we have to bear in mind, when we do an interview, not only to have it prepared but also when doing the interview, to go into more detail, so the person sees we are interested about what they are saying, you know? That we are listening to them and we have prepared it. And above all, be punctual. (Student, transcript AA1)

With regard to visual methods, at the end of sessions 4 and 5, students had talked about some of their learning following an activity using drawings on the same topic by people from different countries and of different ages, where significant differences were observed in the content:

> - You could see different cultures, ... people who have drawn things, from different countries, from South America or from here... some of the things are nothing like each other.
>
> - You saw that the drawings can be very different.
>
> - They vary a lot, they think about things that we don't see here, ... that it's different.
>
> (Student, transcript AA2)

The trainer from session 4 pointed out in interview IT3 that the students had learned and been able to correctly identify the use of visual methods. She considered visual methods to have a wide range of possibilities for people with intellectual disabilities, although they also have an abstract component that should be complemented by storytelling about the pictures.

With regard to the focus groups, which were addressed in sessions 6 and 7, the responses to questionnaire SQ3 indicated a certain level of understanding of this strategy of data collection allowing the free expression of opinions and views.

Although data were collected on student learning throughout the programme, students' satisfaction with this learning was difficult to evaluate as many of them saw successfully learning new things about research as satisfying, but did not identify what specific learning they believed they had achieved.

Information on the students' overall satisfaction with the training programme was obtained via questionnaire SQ3 and the focus groups (SFG1 to SFG6). The trainers expressed their degree of satisfaction in the interviews (TI1, TI2 and TI3) and the researchers via the questionnaires (RTQ1, RTQ2 and RTQ3) and the final focus group (RTFG1).

At the end of the final session, the students were asked to evaluate whether they had enjoyed participating in the programme: five answered 'a lot', three 'quite a lot' and one person 'not much', because he had found it difficult to understand the explanations. Students generally said it had been an interesting experience. Some said the programme had helped them to 'learn new things'; others gave more specific answers, saying it was useful to 'know how an interview is prepared', 'learn what research is', 'learn to talk to people' or even 'have more self-confidence'. Three people emphasized its usefulness for the future: 'to know things for later on', 'I learned a lot and it will be very useful', 'it might help me in the future'.

The trainers were satisfied with their participation on the programme. They emphasized that it was a challenge to adapt the training sessions on research to a group with intellectual disabilities. The experience had been more positive than expected in terms of students' participation and understanding:

> That was the most interesting part, that perhaps you were expecting more simple reflections and they weren't. (Trainer, TI2)

The research team also viewed the usefulness of the course as positive, and not only for the students:

> It was useful for them (the students) (...) and has been useful for us because we have had an experience which we have planned from the beginning, its implementation, evaluation... We have collected data and that provides us with knowledge about what we have done. And we have seen that the people were happy, and therefore it has worked. (Researcher, RTFG1)

Nevertheless, they still stressed the need to improve the accessibility of content from the first session onwards. Overall, the research team was satisfied with the results.

> At first I had many doubts about what the session would seem like to participants and after seeing how some of them participated, I was pleasantly surprised. Still, I think we should improve the accessibility of content and materials so that everyone can give their opinion. (Researcher, RTQ1)

> I think it went well and if at any point I had had any expectations they would not have been as high as the impression I have now. We now also have the perspective of having done the program and seen how the group evolved… there is more group awareness, that they are working together with us, what research entails… and they feel more involved and that their opinion is valued, you know? In this respect I think it went very well (Researcher, RTFG1)

Discussion

Although it is widely acknowledged that research training constitutes an important element in involving people with intellectual disabilities in inclusive research processes (Strnadová *et al.* 2014), few experiences have been instigated in this area and there is no agreement on what this training should comprise. The evaluation of the research training programme presented in this article has allowed us to reflect on what might be strengths and areas for improvement on such programmes.

The results of the evaluation process provide us with some guidelines, which coincide with the proposals made by Carey *et al.* (2014) and Salmon *et al.* (2014): ensure the use of plain language, combine images and written text and avoid presentations with too much written text; do practical activities such as role playing, representations or simulations, group discussions and short presentations; link training activities with topics and tasks relevant to the research in which they are participating as coresearchers and work in small groups.

The main aims of the training programme were to facilitate understanding of the concept of research and its stages and to develop skills related to data collection. Research training for people with intellectual disabilities is a way of providing support for and facilitating the inclusive research process. The results of our study coincide with those of Johnson (2009), namely that it is essential to link training with the topics and strategies that will appear in the research the people with disabilities are participating in, and that it is important to plan in advance which tasks the coresearchers will collaborate on in order to carry out training related to these activities. Some authors suggest the inclusion of topics such as ICT training, particularly in mobile technologies (Cumming *et al.* 2014), making questionnaires (Salmon *et al.* 2014) and doing data analysis (Stevenson 2014); however, these were not covered on our programme.

Beyond research training, the programme has demonstrated its usefulness in fostering group awareness, cohesion and teamwork, which were not initial aims, but were identified as outcomes of the programme. Strnadová *et al.* (2014) suggest that support for people with disabilities should not be related only to research training, but also the cohesion of the group which is to collaborate on the research. Training thus takes on relevance as a process that contributes to the *construction of the research team*, that is, to forming a working team capable of successfully carrying out the various tasks of research.

With regard to areas for improvement, the present authors can point to the format and scheduling of the sessions, adapting the content and materials and evaluating the learning achieved. The availability of participants and their means of accessing the university by transport are factors that condition planning of the format and scheduling of the programme. In our case, fewer hours were dedicated to training, and less continuously, than with other experiences. However, this was the best option available. This kind of logistical constraint must be taken into account when planning these programmes and shorter sessions designed or breaks planned between sessions (Salmon *et al.* 2014).

It is recommended that the particular needs of each participant be taken into account when adapting content and materials. The evaluation suggested conducting individual interviews prior to the start of the programme to determine what kinds of strategies facilitate understanding and learning for each individual participant.

Evaluating learning was one of the difficulties encountered. As in the experience conducted by Carey *et al.* (2014), after the course, the students had clearer ideas about the concept and usefulness of research and knew how to identify several important tasks such as data collection through interviews or focus groups. However, evaluating learning is an issue that requires improvements in the future and should make use of complementary strategies to obtain evidence on the learning achieved. As Salmon *et al.* (2014) suggest, clearer ways of collecting objective data on learning need to be incorporated, with a much clearer definition of what type of learning is expected and using systems that fit with the characteristics of the participants. Learning the relationship between the dimensions involved in research and knowledge construction can be complex for many people with disabilities because it involves a high level of abstract thought. However, it should not be forgotten that one of the aims of such programmes is to empower them

to feel able to participate, with the necessary support, in research addressing issues that affect them. For people with intellectual disabilities, this means gaining confidence, understanding that research is an important and useful activity, feeling able to participate by carrying out various tasks related to data collection and analysis, understanding that group work can provide significant results and understanding that they themselves can suggest issues that may lead to research processes. All of the above are necessary in motivating people with disabilities to participate in inclusive research.

Another relevant aspect in terms of learning is related to the social situation created: building a group space where people communicate through dialogue and debate, where they feel safe and free to express their ideas and concerns and where they expand their role by participating in formal activities within an adapted format, allowing them to interact, develop a role and improve their opinion of themselves (Carey *et al.* 2014). In short, it is a positive experience that promotes interest in learning and an opportunity to involve people with intellectual disabilities in lifelong learning via training activities that represent a positive experience.

The study presented here suggests, therefore, that research training programmes are of interest to people with intellectual disabilities who have the opportunity to participate in inclusive research. Some guidelines to consider are:

- Select contents carefully and try to link them to the research or daily life experiences participants are familiar with.
- Keep presentations brief and plan practical activities that allow students with intellectual disabilities to participate through dialogue and group work.
- Plan specific activities that can be used to observe the student's learning process.
- Carefully plan the timing and sequencing of sessions, leaving time between sessions and planning breaks during them. It is important to remember the logistical issues of transportation and access to the site where the programme is being held when planning the sessions.
- Use plain language and visual materials combined with simple text in presentations. Work with participants individually to identify what adaptations they need.
- Ensure to create a working environment that helps develop group cohesion, especially if participants are taking part in inclusive research as advisors or researchers. In this respect, it is recommended that activities represent positive experiences for participants to promote their interest in learning.

On the basis of the programme carried out and the results of its evaluation, the present authors would agree with the words of Williams & Simons (2005: 11) who, referring to training undertaken by the Swindon People First project team, stated that training 'had a significance far beyond the learning of skills on a course. This significance had to do both with their own identity as researchers, but also with their identity as people with learning difficulties. Both identities were essential to the work they were doing, and their strength lay in the fact that they could be both a researcher and a person with intellectual disabilities'.

Acknowledgments

The present authors would like to express our gratitude to the members of the Advisory Committee, professors at the University of Girona who worked selflessly on the training course and MINECO, the Spanish Ministry of Economy and Competitiveness, for giving financial support through two research project grants (Reference grant numbers: EDU2011-22945 and EDU2014-55460-R).

Correspondence

Any correspondence should be directed to Judit Fullana, Institute of Educational Research, University of Girona, C/Sant Domènec 9, 17071 Girona, Spain (e-mail: judit.fullana@udg.edu).

References

Abell S., Ashmore J., Beart S., Brownley P., Butcher A., Clarke Z., Combes H., Francis E., Hayes S., Hemmingham I., Hicks K., Ibraham A., Kenyon E., Lee D., McClimens A., Collins M., Newton J. & Wilson D. (2007) Including everyone in research: the Burton street research group. *British Journal of Learning Disabilities* **35**, 121–124.

Barr O., McConkey R. & McConaghie J. (2010) Views of people with learning difficulties about current and future accommodation: the use of focus groups to promote discussion. *Disability & Society* **18**, 577–597.

Beresford B. (2004) On the road to nowhere? Young disabled people and transition. *Child: Care, Health & Development* **30**, 581–587.

Bigby C. & Frawley P. (2010) Reflections on doing inclusive research in the 'Making Life Good in the Community' study. *Journal of Intellectual Developmental Disability* **35**, 53–61.

Bigby C., Frawley P. & Ramcharan P. (2014) Conceptualizing inclusive research with people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities* **27**, 3–12.

Burke A., McMillan J., Cummins L., Thompson A., Forsyth W., McLellan J., Snow L., Fraser A., Fraser M., Fulton C., McCrindle E., Gillies L., LeFort S., Miller G., Whitehall J., Wilson J., Smith J. & Wright D. (2003) Setting up participatory research: a discussion of the initial stages. *British Journal of Learning Disabilities* **31**, 65–69.

Cambridge P. & McCarthy M. (2001) User focus groups and best value in services for people with learning disabilities. *Health and Social Care in the Community* **9**, 476–489.

Carey E., Salmon N. & Higgins A. (2014) Service user's views of the research active programme. *Learning Disability Practice* **17**, 22–28.

Clarke S., Sloper P., Moran N., Cusworth L., Franklin A. & Beecham J. (2011) Multi-agency transition services: greater collaboration needed to meet the priorities of young people with complex needs as they move into adulthood. *Journal of Integrated Care* **29**, 30–40.

Corbetta P. (2007) *Metodología y Técnicas de Investigación Social*. McGraw Hill, Madrid.

Cumming T. M., Strnadová I., Knox M. & Parmenter T. (2014) Mobile technology in inclusive research: tools of empowerment. *Disability & Society* **29**, 999–1012.

Deguara M., Jelassi O., Micallef B. & Callus A. M. (2012) How we like to live when we have the chance. *British Journal of Learning Disabilities* **40**, 123–127.

Emerson E. A. & Ramcharan P. (2010) Models of service delivery. In: *Learning Disability: A Life Cycle Approach* (eds G. Grant, P. Ramcharan, M. Flynn & M. Richardson), pp. 59–72. Open University Press, Berkshire.

European Commission (2009) *Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care*. Directorate-General for Employment, Social Affairs and Equal Opportunities.

Flood S., Bennett D. & Melsome M. (2012) Becoming a researcher. *British Journal of Learning Disabilities* **41**, 288–295.

FRA-European Union Agency for Fundamental Rights (FRA) (2013) *Choice and Control: The Right to Independent Living. Experiences of Persons with Intellectual Disabilities and Persons with Mental Health Problems in Nine EU Member States*. Publications Office of the European Union, Luxembourg.

Johnson K. (2009) No longer researching about us without us: a researcher's reflection on rights and inclusive research in Ireland. *British Journal of Learning Disabilities* **37**, 250–256.

Johnson K., Minogue G. & Hopkins R. (2014) Inclusive research: making a difference to policy and legislation. *Journal of Applied Research in Intellectual Disabilities* **27**, 76–84.

Koenig O. (2011) Any added value? Co-constructing life stories of and with people with intellectual disabilities. *British Journal of Learning Disabilities* **40**, 213–221.

Krueger R. & Casey M. A. (2000) *Focus Groups: A Practical Guide for Applied Research*. 3rd edn. SAGE Publications, Thousand Oaks, CA.

McConkey R., Sowney M., Milligan V. & Barr O. (2004) Views of people with intellectual disabilities of their present and future living arrangements. *Journal of Policy and Practice in Intellectual Disabilities* **1**, 113–125.

Nind M., Chapman R., Seale J. & Tilley L. (2015) The conundrum of training and capacity building for people with learning disabilities doing research. *Journal of Applied Research in Intellectual Disabilities*. doi: 10.1111/jar.12213.

O'Brien P., McConkey R. & García-Iriarte E. (2014) Co-researching with people who have intellectual disabilities: insights from a national survey. *Journal of Applied Research in Intellectual Disabilities* **27**, 65–75.

Pallisera M., Vilà M. & Fullana J. (2014) Transition to adulthood for young people with intellectual disability: Exploring transition partnerships from the point of view of professionals in school and postschool services. *Journal of Intellectual and Developmental Disability*. doi:10.3109/13668250.2014.938032.

Saldaña J. (2009) *The Coding Manual for Qualitative Researchers*. Sage Publications, Los Angeles, CA.

Salmon N., Carey E. & Hunt A. (2014) Research skills for people with intellectual disabilities. *Learning Disability Practice* **17**, 27–35.

Stake R. (2004) *Standards-Based and Responsive Evaluation*. Sage, London.

Stevenson M. (2014) Participatory data analysis alongside co-researchers who have Down syndrome. *Journal of Applied Research in Intellectual Disabilities* **27**, 23–33.

Strnadová I., Cumming T., Knox M., Parmenter T. & Welcome to Our Class Research Group (2014) Building an inclusive research team: the importance of team building and skills training. *Journal of Applied Research in Intellectual Disabilities* **27**, 13–22.

United Nations (2006) United Nations Convention on the Rights of Persons with Disabilities. Retrieved in http://www.un.org/disabilities/convention/conventionfull.shtml (accessed on 14 July 2014).

Walmsley J. (2001) Normalisation, emancipatory research and inclusive research in learning disability. *Disability & Society* **16**, 187–205.

Walmsley J. (2004) Involving users with learning difficulties in health improvement: lessons from inclusive learning disability research. *Nursing Inquiry* **11**, 54–64.

Walmsley J. & Johnson K. (2003) *Inclusive Research with People with Learning Disabilities: Past, Present and Future*. Jessica Kingsley Publishers, London.

Ward L. & Simons K. (1998) Practising partnership: involving people with learning difficulties in research. *British Journal of Learning Disabilities* **26**, 128–131.

Williams V., Simons K. & Swindon People First Research Team (2005) More researching together: the role of nondisabled researchers in working with people first members. *British Journal of Learning Disabilities* **33**, 6–14.