

# Co-researching with People who Have Intellectual Disabilities: Insights From a National Survey

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**Background** Inclusive research with people with intellectual disabilities is growing internationally but with few studies examining its feasibility.

**Methods** In undertaking a national study exploring what life was like in Ireland for people with intellectual disabilities, a community of practice was developed involving a core group of co-researchers: five people with intellectual disabilities, four university researchers and three service support staff. An additional cadre of 15 co-researchers with intellectual disabilities was recruited to undertake data gathering and analysis with 23 focus groups involving 168 participants. The research experience was documented through oral feedback, progress reports, minutes and a project review.

**Results and conclusions** The key learning is documented arising from the setting up of an inclusive advisory group and implementation of each of six research steps. The study demonstrates feasibility and the added value of university co-researchers recruiting and developing skills together with co-researchers with intellectual disabilities. Topics for further research and development are identified.

**Keywords:** collaboration with people with intellectual disabilities, community of practice, co-researching

## Accessible Abstract

This paper tells you about how people with intellectual disabilities worked with a group of university researchers. Both groups were called co-researchers and together they ran 23 focus groups across Ireland. People with intellectual disabilities talked about their lives and what could make them better. They said they needed to have a good place to live; a job; enough money; relationships; and acceptance as respected citizens.

The university co-researchers wrote about what it was like doing research together and how people with intellectual disabilities joined the advisory group; decided on the questions; ran focus groups; and presented findings.

Together they grew into a community of researchers where the university co-researchers shared their research skills and people with intellectual disabilities shared what it was like living with a disability. They both saw great value in working together and plan to work more to make this type of research happen.

## Introduction

The United Nations Convention on the Rights of Persons with Disabilities (UN, 2006), under Article 31, requires States to collect research data that addresses the barriers faced by persons with disabilities in exercising their rights under the Convention. The World Report on Disability (WHO 2011) recommends more

qualitative research on the lived experiences of people with disabilities in order to understand their present quality of life and the shortcomings that need to be addressed. However, only a handful of such studies have been conducted with people who have intellectual disabilities at the national level: notably in New Zealand (Logan *et al.* 2003), England (Emerson *et al.* 2005), Scotland (Curtice 2006), Croatia (Association for

Self-Advocacy, 2007) and Ireland (Garcia-Iriarte *et al.* 2009a,b).

In line with the ethos of 'nothing about us without us', research into the lived experiences of people with disabilities requires their participation in the research process. There is growing evidence that their involvement results in more relevant research questions, ensures the appropriateness of data collection methods, provides a more comprehensive analysis of data and better dissemination of study findings (Garbutt *et al.* 2009; Tuffrey-Wijne & Butler 2009; Bigby & Frawley 2010; Kramer *et al.* 2010; Turk *et al.* 2012). Inclusive research is a growing discipline with people with intellectual disabilities undertaking various roles, such as being members of advisory groups (Walmsley & Johnson 2003), advising on and piloting the content of interview questions (Emerson *et al.* 2005) and co-facilitating focus groups with more experienced researchers (Logan *et al.* 2003). Several accounts exist of the contributions that people have made as paid research assistants (Bigby & Frawley 2010; Turk *et al.* 2012). However, relatively little documentation exists on the specifics of more experienced researchers working in partnership with people with intellectual disabilities to maximize their participation throughout the whole research process from setting the research questions through to the dissemination of the findings.

A particular challenge has been to find mechanisms that allow for co-researchers to exercise control within the research process and not just to act as advisers or to take on the role of a paid research assistant. To date, the issue of control has been explored more within advocacy contexts and the style of support that is provided to members of self-advocacy groups (Garcia-Iriarte *et al.* 2009a,b). However, the balance between support and control within a research process involving experienced researchers and people with intellectual disabilities as co-researchers has rarely been systematically examined and not in the context of a national research study involving more than one group of people with intellectual disabilities for an extended period of time. While participatory, emancipatory and inclusive research approaches provide principles and frameworks for planning and conducting such research projects (Zarb 1992; Walmsley & Johnson 2003; Barnes 2006), they do not necessarily address the particular needs of persons with intellectual disabilities in acquiring the knowledge and skills to become active research team members. The concept of 'communities of practice' emerged as an attractive model throughout the study reflected upon within this article. Wenger

(1998) introduced the term 'communities of practice' where groups are characterized by a common identity and where through repeated interactions develop a set of resources, tools and strategies within their chosen domain; in this instance researching the lives of Irish persons with intellectual disabilities.

Hence, the purpose of this study was to examine the process of conducting research with people with intellectual disabilities at a national level, analysing the support strategies and practices developed by a community of practice consisting of groups of people with intellectual disabilities, local supporters, and experienced university researchers. Two main questions are addressed within this study:

To what extent can people with intellectual disabilities be involved as co-researchers in all aspects of the research process from inception to dissemination?

What adaptations are needed to maximize their participation and control in each element of the process?

The reporting of such strategies will add to the debate and understanding of the who, what and how of developing co-researching in the field of intellectual disability although there would be implications for other marginalized groups.

## Method

### The context

The National Institute for Intellectual Disability (NIID) Trinity College Dublin obtained funding for a 4 year Transfer of Knowledge Study on *Doing Disability Research* funded through Marie Curie Action, European Union. An overall advisory committee was established to cover three related research strands: the *All We Want to Say* project; an *Inclusive Family Study* and a *Life Story Project*. The membership consisted of 23 members that represented people with intellectual disabilities as well as family members, university researchers, service organizations and government representatives.

Members of the advisory committee divided into one of three core groups for the respective projects. These core groups were specifically responsible for making decisions about the direction and implementation of the respective project and several members within each core group became co-researchers. The core group for the *All We Want to Say* project consisted of five co-researchers with intellectual disabilities, four university co-researchers, and three disability agency members, two of whom acted as supporters for the co-researchers. As a group, they worked together to define the questions to

be specifically addressed within the theme *What is life like for adult persons with an intellectual disability on the island of Ireland?* and to make decisions about the ways in which the inclusive research strategy would be implemented. University co-researchers sought ethical approval for the study which was granted by Trinity College, Dublin.

In summary, the project engaged a further cadre of 15 co-researchers with intellectual disabilities recruited mostly from advocacy groups in Northern Ireland and the Republic of Ireland. After a series of training and consultation sessions, the co-researchers co-facilitated 23 focus groups involving 168 people with intellectual disabilities throughout the island of Ireland using both scheduled and probe questions. The focus groups were transcribed verbatim and an initial thematic analysis was undertaken by university staff prior to the co-researchers with intellectual disabilities identifying the core themes that would result in improved lives: money management, relationships, employment, house ownership, leisure, communication, respect and self-advocacy (see Garcia-Iriarte *et al.* 2009a,b). The co-researchers helped to guide the development of an accessible report with accompanying DVD that summarized the findings. They gave presentations at local and international conferences.

### Assessing the research process

The *All We Want to Say* study took place over a 48 month period and its progress was documented in various ways. First oral feedback was collected from co-researchers at national and local meetings along with feedback from the focus group participants. Second, regular progress reports were presented to the Advisory Committee and the minutes were kept of members' discussions and comments (15 reports in all). Third, an end-of-project review was conducted involving all members of the Advisory Committee. A panel of five 'critical friends', all who had been involved as Marie Curie Fellows or university co-researchers commented on the report of this review.

These various records were reviewed by the three authors to identify the main learning on co-researching. Each stage of the *All We Want to Say* research project is discussed in this study in relation to three reflective questions: What worked well? What did not work so well? What needs to happen in the future? It is important to note that the project was designed primarily to gather data on what life was like for people with intellectual disabilities living in Ireland and not

specifically to evaluate the co-researching process. Thus, two cautions should be noted. No independent evaluation was available and the evidence gathering was largely *post hoc* rather than prospective.

## Results

The lessons from undertaking the project are presented within the various phases of the research process using a common structure of describing what happened, what worked well and not so well, and what needs to happen in the future. First though, the role of Advisory Committee is reviewed.

### The project advisory committee

Although the research funding had been sought by university researchers and they retained responsibility for ensuring the research was completed, they were eager to share ownership of the project with other stake-holders drawn from advocacy groups and service provision along with individuals who had expertise in inclusive research. The committee's major responsibility was to ensure that all projects were inclusive of people who had lived experience of disability and to involve them in one or more parts of the research process and to assist with the recruitment of co-researchers. It also was to provide a forum where progress reports would be received and constructively discussed thereby providing a measure of internal validation of the outcomes. A further role was to link the three proposed projects supporting them to be inter-dependent and to share mutual learning.

### What worked well and what could have worked better?

Membership and attendance at the advisory committee was consistent over the 4 years; serving to bond the co-researchers with intellectual disabilities to other members of the group. A community of practice (Wenger *et al.* 2002) began to emerge exemplified by the relationships that developed among committee members and which were sustained over the 4 years of the project. A shared vision and belief that research needed to be inclusive of people with the lived experience of disability drove the agenda, reinforced in turn as the feasibility of doing the study became evident. The meetings provided co-researchers with intellectual disabilities with the opportunity to participate in the presentation of progress reports and to contribute to discussions. Team building occurred through use of reflective rounds and the formation of three project-specific subgroups. The latter

provided further time for co-researchers with intellectual disabilities to brain-storm issues and share opinions with their university co-researchers and agency supporters. The minutes of the advisory committee revealed how members of the different core groups were prepared to give both positive and constructive feedback to one another while also celebrating the progress made.

A major failing of committee meetings was that often the intended agenda was not covered due to time constraints. Presentations from core groups took longer as additional time was needed to explain issues. Discussion had to be curtailed and participation by co-researchers with intellectual disabilities was initially slow but grew as people became more confident to speak up at meetings. In retrospect, more time could have been spent in smaller discussion groups in preparation for decision making with the whole group.

#### *What needs to happen in the future?*

One of the original intentions of the project was that there would be a co-chair with the lived experience of disability at both the overall advisory committee and core group levels. Although this was discussed at the start of the study, the complexity of managing the committee agenda led to it being submerged as a priority. In any future project, it needs to be built into the project management along with longer time for meetings. Also, use of group teleconferencing through free communication software is an option for overcoming travel problems as well as a means of following up on issues between meetings. This was trialled towards the end of the project with some success.

#### **Identifying the research questions**

The broad area of research had been identified as part of the funding application. Hence, when co-researchers with intellectual disabilities joined the core group for this project, they knew the overall direction but the detail in terms of the research methods and specific questions remained to be worked out. Different types of methodologies were presented to the core group by the university members and through discussion focus groups emerged as the preferred option for gathering data (Kroll *et al.* 2007). The first two authors then worked with the co-researchers with intellectual disabilities to develop a set of questions to be asked in the focus groups. This was done by first talking about what were the important things in their lives and the questions they might ask if they wanted to find out how

life was like for other people with intellectual disabilities. These were then grouped into thematic areas and the first two authors compiled a set of questions based on each and introduced the idea of piloting the questions. The members of the core group invited the students with intellectual disabilities studying at the National Institute for Intellectual Disability (NIID) to join with them in a focus group to pilot the questions. Based on this experience, changes were suggested by the co-researchers with intellectual disabilities, notably also asking how they thought their life could be made better to counter the negative responses that tended to dominate. The area of relationships was also added at their suggestion plus having visual prompts for use during the focus group discussion to make the questions more accessible for the co-researcher facilitators. At this stage, two part-time research interns joined as university co-researchers and worked alongside those with intellectual disabilities to choose and trial relevant pictures with accompanying prompt statements. The research interns were also responsible for managing the setting up of the focus groups around the country.

#### *What worked and what could have worked better?*

In keeping with Walmsley & Johnson's (2003) criteria of what constitutes inclusive research, the questions represented a set that covered what people with intellectual disabilities in the co-researcher group and pilot focus group saw as important in their lives most of which are reflected in the current quality of life literature (e.g. Schalock *et al.* 2008), such as, housing, work, friends and relationships, education, health and social life. This process also provided further validation of their relevance to an Irish context and confirmed the ownership of co-researchers to the process. However, the framing of the questions was largely done by university co-researchers as was the design of the graphics used, although both were developed and adapted following feedback by the co-researchers with intellectual disabilities.

The partnership of how the questions were developed was a learning curve for all, requiring new skills for both groups. For the co-researchers with intellectual disabilities up skilling in how to prepare non-leading questions and prompts was evident, whereas for the university co-researchers their learning included deep listening to the opinions of the co-researchers, as well as accommodating suggested changes in an accessible manner.

### *What needs to happen in the future?*

If university co-researchers are to partner people with intellectual disabilities more equally in the research process, they need skills of facilitation as well as opportunities to deepen their background knowledge of people's lives in the area under exploration. Likewise co-researchers with intellectual disabilities need to gain insights into how research is conducted and information about past studies needs to be available to them in accessible formats. This is foundational to inclusive research if they are to benefit from the existing research literature on methods and results. Hence, a community of practice setting out to investigate the potential of a new research topic could use various activities for mutual learning, including inviting guest speakers with experience of the topic; presenting the most relevant research reports in an accessible manner, and brainstorming the importance of the topic and its meaning for people with intellectual disabilities. Sessions on how to formulate research questions would also be valuable.

### **Recruiting co-researchers**

Ownership over the process was also evident in the way that co-researchers with intellectual disabilities on the advisory committee strongly suggested more people be recruited as co-researchers to enable more focus groups to be run across Ireland, and that training be made available for people with intellectual disabilities on how to run a focus group. The original group of co-researchers invited other members from their advocacy group or service organization to come to the training if they were interested in becoming a co-researcher. A flyer was also sent out to organizations by the university co-researchers in particular to self-advocacy groups within service organizations and those that were independent. These groups were chosen as their members were more likely to have experience of speaking up for themselves and an interest in the research topic.

New organizations interested in participating in the project were either visited by the university interns to explain the project or spoken to over the phone. If they wished to participate, the organizations would then invite two to three interested people with intellectual disabilities to the training sessions accompanied by a staff member as a supporter. The response was so high that four training sessions were held, two in Dublin, one in Galway and one in Northern Ireland involving nearly

40 persons although not all went on to become co-researchers.

### *What worked and what could have worked better?*

Recruitment of co-researchers through personal contacts, targeted invitations and self-selection elicited a good response from a wide geographical area with a balance of gender, age and varied experiences of using services. That said, it was hard to assess the extent to which service staff determined who attended which reflects the broader difficulty of gaining access to people with intellectual disabilities through service agencies. This was not an issue where flyers or emails went directly to self-advocates who were usually accompanied by supportive staff members. Indeed, the support that local services needed to provide was one that had not been sufficiently addressed in planning the study. Co-researchers with intellectual disabilities often needed assistance, for example, to get to meetings, to read documentation and to carry out the tasks assigned to them. Reliance on service staff meant that different personnel with varying levels of interest came to the training sessions or were unavailable because of other work commitments. It would have been preferable for support staff to volunteer or be selected for their support role and for them to be considered members of the evolving community of practice. However, this would have required a definite commitment from service agencies which was only negotiated informally.

### *What needs to happen in the future?*

Recruitment procedures that include support persons for potential co-researchers need to stress that inclusive research is an experience where there is a different way of being around people with intellectual disabilities, taking time to listen deeply and respecting their ability to formulate their ideas. An information session run by co-researchers with intellectual disabilities before people buy into the project would be illustrative of the shift in power within this type of research where research is done *by* people with intellectual disabilities and not *on* people with intellectual disabilities. This would also give people with intellectual disabilities a practical demonstration of what they would be committing to do.

### **Training co-researchers**

Training sessions were held in four locations to reduce travel time, with around 10–16 persons attending each

one. They were led by the first two authors with assistance from other university co-researchers and followed a common format. The training covered the following: how to open up a focus group through using rounds; how to ask questions using prompts provided; how to listen carefully before responding; how to cope with people who dominated; how to electronically record the dialogue; the need for ethics and how to use information sheets and consent forms. The training was based around power point presentations but mainly it was interactive with role plays demonstrating both good and poor practice. Accessible handouts were provided and each person was given a personal portfolio to store them. Support staff from advocacy or service agencies were considered full participants in the training sessions although they were not expected to be involved in the running of the later focus groups. Some played a vital role at the training, for example, acting as an interpreter for the co-researcher.

#### *What worked and what could have worked better?*

The training content and delivery was decided on largely by the university co-researchers who drew upon their research expertise and their experience of working with people with intellectual disabilities although not specifically within an inclusive research paradigm. Adjustments were then made in light of reflections and feedback received.

A gap that emerged at the time of training related to the role of the support person being played out as a *director* and not as a supporter of the research process. This was observed in the way some supporters spoke on behalf of the organization, announcing that this area of research would not be ethically approved and on other occasions that staff could not be released to transport co-researchers. However, learning through doing was a feature of the project arising from there being no blueprints for how to conduct inclusive research (Bigby & Frawley 2010), which includes how to train supporters for their role.

#### *What needs to happen in the future?*

At a minimum, an orientation session on inclusive research would be valuable to offer to managers and support staff. Ideally, this should be led by experienced co-researchers with intellectual disabilities who could spell out with examples the type of support that might be needed and how it could be provided.

During the training, it also became evident that most co-researchers would require support with the more technical aspects of the process, notably time keeping, making audio recordings and issuing invitations to participants and arranging venues. With further training sessions allied with practice, it is possible that co-researchers could master these functions although some form of technical support will likely be required.

#### **Information gathering through focus groups**

Twenty-three focus groups were run, 16 in the Republic of Ireland and seven in Northern Ireland. In total, 168 people with intellectual disabilities participated in the focus groups. The groups were run by two co-researchers using one of following three formats: the co-researchers with intellectual disabilities ran the focus group independently; the university co-researcher with intellectual disabilities and the university co-researcher shared the asking of the questions; the university co-researcher coached their partner with intellectual disabilities by sitting behind and giving support where reading was difficult or where responses were not forthcoming. The majority of groups were co-shared in terms of asking the questions with the overall intention that the discussion was framed in terms of the things 'we' experience rather than the things 'you' experience. The university co-researcher took responsibility for audio recording the session that was then sent out for transcription. On occasions, the university co-researcher also recorded the responses on a flip chart in an accessible manner such as drawing pictures. The sessions lasted around 60 min and the co-researchers held a debriefing after the group ended to summarize their impressions and note any issues that had arisen.

#### *What worked and what could have worked better?*

The techniques that the co-researchers with intellectual disabilities had learned through training on how to structure both the opening and closing of the focus group were routinely and successfully used. Likewise, the structured questions with visual referents ensured the content was covered in an accessible manner and they were able to answer most of the queries that arose. However, during the running of the focus groups, the co-researchers looked to the university partners for guidance and coaching across a range of issues, such as when to move from question to question; prompting in areas where the response was limited and following up on new ideas emerging in the focus group. It was also a

two way learning activity requiring the university co-researcher not to rush their partner in moving from one question to another and allowing time for follow-up questions to be framed.

#### *What needs to happen in the future?*

For co-researchers to have more control over the data collection (Sanderson & Lewis 2011), they need more practice in asking questions, using prompts and following up a comment with questions not scripted. Most found it hard to adopt a conversational style. Additional benefits would accrue if further practice sessions could be organized to cover the different skill sets required to become an inclusive researcher and leading to them being more *in control* of the data collection. Also for co-researchers with high communication needs, electronic devices such as electronic tablets may be of use in pre programming questions. The investment in training time is justified if the co-researchers get involved in further projects.

#### **The analysis of the data**

A two-stage process was adopted for the data analysis. First, the verbatim transcripts of the focus groups were thematically analysed by two of the university co-researchers checking for confirmability across the different groups. In all, 19 preliminary themes were identified and it was evident that data saturation had been reached in that no new themes were identified in the later groups that were analysed (E. Garcia-Iriarte, P. O'Brien, R. McConkey, M. Wolfe and S. O'Doherty, unpubl. data).

A second stage aimed to identify the core factors that underpinned the 19 preliminary themes and to make this a shared endeavour with the co-researchers with intellectual disabilities. Most of the co-researchers who had participated in the running of the focus groups came together with their supporters for a 3-h data analysis session. They were divided into two groups with 10 co-researchers in each. Co-researchers were presented with the 19 themes (one at a time) and given a large sheet of A3 paper with a square drawn in the centre. They were then asked to think back to the focus groups they had facilitated and assess how important each of the themes was based on participants' comments. Those themes which were deemed to be more important went into the centre square; those that were less important were placed outside of it or towards the outside of the sheet. Throughout, the group

had to give reasons for their decisions and come to a joint agreement. Once all 19 themes had been placed, they were asked to reduce those in the centre square to four or five key themes, either by considering whether some could be moved out of the square because they were not as important as others or whether any themes could be combined, because they were part and parcel of the same thing. The resulting distribution of themes from the two groups was then compared and eight core themes were agreed: money management, relationships, employment, house ownership, leisure, communication, respect and self-advocacy.

For each of these themes, the university researchers had identified the sub-themes arising from examining the relevant open and axial codes. These too were written on flash cards and the groups were asked to place the sub themes in order of importance from the most to least. This proved to be a more difficult task as several of the subthemes were thought to be of equal importance. However, this exercise broadly verified the critical subthemes within each core theme and these were largely verified later through a thematic content analysis of the focus group transcripts by independent university researchers (E. Garcia-Iriarte, P. O'Brien, R. McConkey, M. Wolfe and S. O'Doherty, unpubl. data). Finally, this form of analysis was repeated separately with eight co-researchers in Northern Ireland with similar findings which gave further evidence of internal validity for the main themes.

#### *What worked and what could have worked better?*

The co-researchers readily understood the task and engaged with it. The justifications they gave for their ratings were a rich data source that in retrospect the authors regret not having audio-recorded to enrich the data analysis. The use of the flash cards exemplifies how each stage of the research process can with lateral thinking be made accessible for co-researchers with intellectual disabilities. The analysis of the data was made more authentic by the co-researchers being engaged in a manner that is in keeping with Lincoln & Guba's (1985) concept of member checking. The technique was similar to some of the strategies suggested by Strauss & Corbin (1998) to mine the data where the relationship between themes is drawn diagrammatically.

#### *What needs to happen in the future?*

Qualitative data analysis can be challenging but arguably it can be made meaningful and accessible for

persons with intellectual disabilities. The challenge is for more experienced researchers to think more creatively on how the wisdom of people with intellectual disabilities can be marshalled to guide data analysis through using the same techniques as in traditional research but making them accessible for understanding without losing the integrity of the outcomes. This is worthy of further investigation particularly in the context of the statistical analysis of quantitative data.

### Presenting the findings

The project findings were written up initially only as an accessible report with minimal text and many illustrations. This summarized all stages of the research process but concentrated mostly on the core themes and subthemes prioritized by the co-researchers. Early drafts were prepared by the third author and the publication was refined through discussion with the core researchers who took pride in seeing their photographs in the authors' page (a copy is available at: [www.tcd.ie/niid/](http://www.tcd.ie/niid/)).

The core group of co-researchers also prepared oral presentations on the project for use at a public meeting in Dublin attended by over 80 persons including government officials, politicians and senior managers from services. Public expressions of support were made for the inclusion of co-researchers with intellectual disabilities in the research process. They also presented papers at the 2008 World Conference and the 2010 European Congress of the International Association of the Study of Intellectual Disabilities (IASSID) and at a national disability conference in Ireland in 2009.

For the IASSID conferences, it was decided that only the co-researchers with intellectual disabilities would present, with the university co-researchers being on hand for support if needed. The first author worked with the group on two weekends to practice their presentation skills which illustrated the developing community of practice. Three co-researchers with intellectual disabilities each took one aspect of the presentation and spoke to power point slides. An accessible handout on the presentation was co-developed between the presenters and the first author.

### *What worked and what could have worked better?*

The co-researchers were credible presenters although they required a great deal more preparation and practice for undertaking a task that university researchers could easily assume better suited their backgrounds. But having completed the research project and reported on

it, one of the co-researchers with intellectual disabilities made the point that although the findings were right in describing how people experienced their lives she said, 'but nothing changes'. This led the core group to decide to work on identifying ways to see if the project findings could be used to bring about change. The idea of making a DVD was discussed and accepted by the group. This media would present the findings in an accessible format for reaching people with intellectual disabilities and service agency staff. Five groups of co-researchers agreed to participate in a further phase of the project by selecting the most important study findings and doing their own presentations which were subsequently recorded. They went on to organize local presentations aimed at forming local committees to bring about changes in the services with which they were associated. This is described more fully in Garcia-Iriarte *et al.* (E. Garcia-Iriarte, P. O'Brien, R. McConkey, M. Wolfe and S. O'Doherty, unpubl. data).

### *What needs to happen in the future?*

Co-researching is a process that does not end with the production of a research report. The personal investment of co-researchers with intellectual disabilities brought greater emphasis on ensuring the findings had an impact on policy and practice. If university researchers are unable or unwilling to engage in this endeavour, then bridges need to be built with organizations such as advocacy groups who will do so.

### Overall reflections

The added value that the co-researchers with intellectual disabilities brought to the research process was evident in their identification of the content of the questions and then in the analysis as they helped to deepen the discussion associated with identified themes of importance. Also, focus group participants who were intellectually disabled commented that they felt they could be more open when a peer with similar lived experiences asked them for their opinions. The co-researchers helped also to ensure that the findings were reported in an accessible, concise and coherent manner that resonated with how they saw their lives as opposed to the reports and interpretation that in the past traditional researchers may have put on their lives.

A further aspect of added value that was evidenced in minutes and project reports was the ongoing respect that the university co-researchers had for their co-researcher partners. This was often expressed in

terms of their experience of the unexpected wisdom that the co-researchers brought to their involvement in the research process.

The added value of having people with intellectual disabilities as co-researchers did not come about merely by their being physically present. Their understanding of the process and active participation had to be nurtured. In retrospect, we as university researchers would identify the following as key drivers to this. We needed to work at the pace of the co-researchers; taking the time to repeat and revise. We had to become better at listening to one another; of appreciating what was not being said as well as what was said. The use of small group activities assisted in this. We strove to make our oral and written communications accessible with plenty of visuals and active learning approaches. Preparation of materials was time-consuming but a set of resources are now available for future use. We had to be flexible and adjust the plans to what was feasible to do in the time and with the resources available to us. We had to trust the co-researchers with intellectual disabilities to take the lead; notably in introducing the study to others, responding to questions and speaking at conferences.

Finally, some of the co-researchers went on to work on other projects as part of a newly formed Inclusive Research Network (Tierney *et al.* 2009). Hence, this investment has spawned a cadre of co-researchers with growing experience of and confidence in undertaking research projects.

Finally, the concept of a community of practice (Wenger *et al.* 2002) provides an adequate framework for inclusive research through providing a space where learning about the chosen research topic can be facilitated, as well as acting as a catalyst for learning to do better through repeated practice.

## Discussion

This study demonstrated the feasibility of recruiting a community of co-researchers with intellectual disabilities from across the island of Ireland and of inducting them in the basics of the research process from defining the research question through to the presentation of findings. Admittedly, the descriptions and analyses are predominantly those of university researchers albeit with many years experience of undertaking research projects in Australasia, USA, UK and Ireland.

Co-researching raises fundamental questions about the nature of research within the field of disabilities and particularly intellectual disabilities. First, who is qualified to undertake research? As university staff, we might have

come to the study knowing the findings from previous international and local research alongside an awareness of the policy and theoretical debates in the literature, and experience in using various research methodologies. But these faded in significance as the lives of people with intellectual disability in modern Ireland became the principle focus of the research project. At each stage of the study, the presence of the co-researchers kept us rooted in their realities. Their lived experiences became our lived experience. As university researchers we gained a much deeper appreciation and insight into their daily lives as they exchanged anecdotes of past and present experiences in which their hurt, isolation and helplessness was evident as well as the joys, achievements and improvements that they had witnessed. These insights were especially valuable when the university staff undertook the initial data analysis of the focus group audio-recordings as it helped them to appreciate better the deeper meanings underlying participants' contributions that may have been incompletely expressed verbally. But acquiring such 'inside knowledge' may be seen by some as jeopardizing the impartiality of research. However, this simplistic argument is best countered by ensuring that all research studies incorporate safeguards to minimize researcher bias and we have illustrated how we attempted to do this within this investigation (e.g. Strauss & Corbin 1998). Moreover, the coalition of interests inherent in the community of practice approach provides a further safeguard that can be absent in studies that are solely led by researchers.

It could be assumed that the need to involve co-researchers will vary according to the research questions being investigated. Yet, the move internationally towards greater public and user involvement in determining the research that is funded through public monies suggests that strong arguments need to be marshalled for *excluding* persons whose lives are likely to be affected by the research rather than having to argue for their inclusion (Walmsley & Johnson 2003; United Nations 2006). Hence, the research teams of the future are likely to include a range of co-researchers. In this respect, a particular issue relates to payments. The expenses of co-researchers were covered in this study but unlike university staff, they received no wage. This was partly defensible on the grounds of it being a feasibility study which evolved as a 'community of practice' approach (Wenger *et al.* 2002). There was also the danger that payments would have limited the numbers of co-researchers employed on the project as happened in previous research (e.g. Turk *et al.* 2012). Even so, our preference would be to move towards

funding bids that allowed for co-researchers to be recompensed for their time and expertise.

A second challenge relates to demystifying research. Inducting the co-researchers into the research process forced us to give clear and concise explanations at each stage and to focus only on the essential elements of what constituted research and why they were important (Garbutt *et al.* 2009; Kramer *et al.* 2010). This level of clarity was not easily achieved but it helped to eliminate ambiguity and ensured consistency in the approaches adopted across the data gathering and analysis. Although we relied mostly on oral communication, this was supplemented by accessible typed notes that together formed a personal portfolio that co-researchers could share with others, such as family or service staff and also use as a reference source for themselves.

Arguably, this approach is somewhat easier to adopt with qualitative methodologies to which people can more readily relate although rigour still needs to be maintained in sample recruitment, data gathering, data analysis and presentation of findings. Once again, the complementary expertise of the research team can contribute to this. For example, in relation to sample recruitment, on the positive side the engagement with co-researchers extended the reach of the project throughout the island. There was little difficulty in recruiting participants to focus groups possibly because of the novelty of an invitation coming from co-researchers with intellectual disabilities with whom they could identify. It also negated to some extent the gate-keeping function of service agency staff that can constrain recruitment. A possible negative thought is that co-researchers may seek to recruit people already known to them with a resulting bias in response. The expertise of university-based researchers should help to ensure rigour is maintained in sampling while also increasing their colleagues' understanding of the research methodologies in a meaningful way.

The third challenge arises if the foregoing arguments are accepted; namely, how can co-researchers with intellectual disabilities be developed and sustained so that inclusive research becomes more widespread? Our study did little to address this issue. The leadership came from university researchers and although this function was increasingly shared as the project unfolded, university personnel were key co-ordinators and managers of the various administrative functions that were required. It is likely that co-researchers with intellectual disabilities will require particular supports but they do not necessarily need to come from professional researchers. Future studies could explore

the potential of advocacy groups taking on overall responsibility for undertaking research studies with university personnel as advisers and supporters. Similarly, the co-researchers required ongoing support at a personal level to undertake their duties; for example, in travel to/from venues and assisting with the running of the groups. These roles were fulfilled largely by existing support staff who had varying degrees of commitment to the research process. In retrospect, we should have been more proactive in recruiting and sustaining support staff as part of a broader community of practice. Nonetheless, the continuing challenge is how people eager to be co-researchers can be best supported by persons other than service agency staff. One appealing prospect is that of co-researchers offering peer support to one another and further research could usefully identify the processes that facilitate this.

We also failed to fully involve co-researchers in certain aspects of the research process; notably, in preparing the funding bid and seeking ethical approval. The judgement of peers is central to both and the credibility of the research team is a critical factor in their assessments. In our defence, we were initially caught in the paradox of needing funding and seeking ethical approval before we could embark on a study involving co-researchers with intellectual disabilities. Indeed, this is an illustration of how existing systems are designed to promote a particular approach to research (Zarb 1992). But change could come in time; for example, if co-researchers were to sit on funding panels and ethics committees (Boxall & Ralph 2010). In subsequent projects we undertook, co-researchers were involved in preparing applications to ethics committees and we recommend this as an essential element in future studies.

Finally, during the study, we failed to document in a detailed and systematic way the contributions and experiences of all members of the research team. In retrospect, a parallel research process utilizing personnel independent of the project researchers would have been a helpful addition to the study and it is one we would commend to future researchers if we are to arrive at a fuller understanding of how inclusive research can be realized and the added value that it brings.

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## References

- Association for Self-Advocacy, Croatia Association for Promoting Inclusion and Inclusion Europe (2007) *Human rights of persons with intellectual disability*. Country report Republic of Croatia. Available at: <http://www.inclusion-europe.org/documents/HR-FinalReport-EN-web.pdf> (accessed on 10 November 2009).
- Barnes C. (2006) "What a difference a decade makes": reflections on doing 'emancipatory disability research'. In: *Overcoming Disabling Barriers* (ed. L. Barton), pp. 346–361. Routledge, Oxford.
- Bigby C. & Frawley P. (2010) Reflections on doing research in the "Making Life Good in the Community" study. *Journal of Intellectual & Developmental Disability* 35, 53–61.
- Boxall K. & Ralph S. (2010) Research ethics committees and the benefits of involving people with profound and multiple learning disabilities in research. *British Journal of Learning Disabilities* 39, 173–180.
- Curtice L. (2006) *How is it going?: A survey of what matters most to people with learning disabilities in Scotland today*. Available at: <http://www.sclde.org.uk/library-publications/how-it-going-a-survey-what-matters-most-people-with-learning-disabilities-scot/> (accessed on 15 November 2011)
- Emerson E., Malam S., Davies I. & Spencer K. (2005) *Adults with learning difficulties in England 2003/4: Full report*. Available at: [http://www.lancs.ac.uk/staff/emerson/FASSWeb/Emerson\\_05\\_ALDE\\_Main.pdf](http://www.lancs.ac.uk/staff/emerson/FASSWeb/Emerson_05_ALDE_Main.pdf) (accessed 15 November 2011)
- Garbutt R., Tattersall J., Dunn J. & Boycott-Garnett R. (2009) Accessible article: involving people with learning disabilities in research. *British Journal of Learning Disabilities* 38, 21–34.
- Garcia-Iriarte E., Kramer J. C., Kramer J. M. & Hammel J. (2009a) "Who Did What?": a participatory action research project to increase group capacity for advocacy. *Journal of Applied Research in Intellectual Disabilities* 22, 10–22.
- Garcia-Iriarte E., O'Brien P., McConkey R. & co-researchers (2009b) *All we Want to say: Report of National Survey*. National Institute for Intellectual Disability, Dublin.
- Kramer J. M., Kramer J. C., Garcia-Iriarte E. & Hammel J. (2010) Following through to the end: the use of inclusive strategies to analyse and interpret data in participatory action research with individuals with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 24, 263–273.
- Kroll T., Barbour R. & Harris J. (2007) Using focus groups in disability research. *Qualitative Health Research* 17, 690–698.
- Lincoln Y. S. & Guba E. G. (1985) *Naturalistic Enquiry*. Sage Publications, Newbury Park, CA.
- Logan R., Fougere G., Hague K., Holloway L., Kiro C. & Moore A. (2003). *To have an 'ordinary' life*. Report to the Minister of Health and the Minister for Disability Issues from the National Advisory Committee on Health and Disability (New Zealand). Available at: <http://www.nhc.health.govt.nz/resources/publications/have-ordinary-life-kia-whai-oranga-noa> (accessed on 15 November 2011)
- Sanderson H. & Lewis J. (2011) *A Practical Guide to Delivering Personalisation: Person-Centred Practice in Health and Social Care*. Jessica Kingsley Publishers, London.
- Schalock R. L., Bonhamb G. S. & Verdugoc M. A. (2008) The conceptualization and measurement of quality of life: Implications for program planning and evaluation in the field of intellectual disabilities. *Evaluation and Program Planning* 31, 181–190.
- Strauss A. & Corbin J. (1998) *Basics of Qualitative Research: Grounded Theory, Procedures and Techniques*. Sage Publications, Newbury Park, CA.
- Tierney E., Curtis S. & O'Brien P. (2009) *The Inclusive Research Network: A Participatory Action Research Project*. National Federation of Voluntary Bodies, Galway.
- Tuffrey-Wijne I. & Butler G. (2009) Co-researching with people with learning disabilities: an experience of involvement in qualitative data analysis. *Health Expectation* 13, 174–184.
- Turk V., Leer G., Burchell S., Khatram S., Corney R. & Rowlands G. (2012) Adults with intellectual disabilities and their careers as researchers and participants in RCT. *Journal of Applied Research in Intellectual Disabilities* 25, 1–10.
- United Nations (2006) *Convention on the Rights of Persons With Disabilities*. United Nations, New York.
- Walmsley J. & Johnson K. (2003) *Inclusive Research With People With Learning Disabilities: Past, Present and Futures*. Jessica Kingsley Publishers, London.
- Wenger E. (1998) *Communities of Practice: Learning, Meaning and Identity*. Cambridge University Press, Cambridge.
- Wenger E., McDermott R. & Snyder W. (2002) *Cultivating Communities of Practice. A Guide to Managing Knowledge*. Harvard Business School Press, Massachusetts.
- WHO (2011) *World Report on Disability*. Available from: [http://whqlibdoc.who.int/publications/2011/9789240685215\\_eng.pdf](http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf) (accessed on 12 December 2011)
- Zarb G. (1992) On the road to Damascus: First steps towards changing the relations of disability research production. *Disability and Society* 7, 125–138.