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## A critical reflection on accessing women with learning disabilities to participate in research about sensitive subjects through organisational partnerships

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# **A critical reflection on accessing women with learning disabilities to participate in research about sensitive subjects through organisational partnerships**

## **ACCESSIBLE SUMMARY:**

- This article is about reaching people with learning disabilities to take part in research on sensitive topics, like contraception. Contraception is a way to prevent pregnancy.
- The article shows that working with organisations can help to find and support people with learning disabilities to take part in research.
- The article explores what research teams need to do when working with organisations to find and support research participants.

## **Abstract**

**Background:** Contraceptive use by women with learning disabilities differs from that of non-disabled women of a similar age. Women with learning disabilities start contraception earlier and often use it when they not sexually active. Hence there is a need to hear directly from these women about their experiences of contraceptive decision-making. But accessing women to discuss a sensitive topic such as contraception poses significant challenges to researchers.

**Methods:** The study was qualitative in nature and involved conducting semi-structured interviews with nineteen women. This paper reports on the methodological challenges and findings from the project which have wider implications for research on sensitive topics with hard to reach groups. It reflects critically on the challenges of accessing women with learning disabilities to participate in research on contraception.

**Results:** Twelve of the 19 participants in our project were recruited through two organisations. Working in partnership with organisations who had a keen interest in the research and endorsed it at senior level enabled us to overcome recruitment challenges. But working in this way raised gatekeeping issues that impacted upon data collection and may have affected our substantive findings.

**Conclusion:** Working in partnership with organisations can be an effective and practical way of recruiting participants that researchers may otherwise find hard to reach. However, organisational partnerships can be hard to develop and take time. We argue that it is important to reflect openly and honestly about the methodological and ethical issues that may arise when working closely with organisations in sensitive research.

## 1. INTRODUCTION

This paper reports on the process of recruiting and interviewing participants for research into the experiences of women with learning disabilities who use contraception. It reflects upon the experience of developing partnerships with two organisations to facilitate access to participants when researching ‘sensitive’ topics. It highlights methodological challenges encountered during the project, particularly the need for pragmatism. It has implications for research with people with learning disabilities on topic areas that might be regarded as sensitive, taboo or ethically complex; and it sheds light on the reasons adults with learning disabilities are excluded from research (Iacono 2006; Lai et al. 2012).

The research project<sup>1</sup> that informs this paper was conducted by an all-female research team, one of whom has learning disabilities. We set out to interview a minimum of 15 women with learning disabilities who used specialist disability services and who were using, intending to use, or had previously used contraception. Ethical approval was granted by the Open University Human Research Ethics Committee. By the end of the project we had interviewed 19 women, including four women with high support needs<sup>2</sup>, and three women from Black and Minority Ethnic (BAME) communities. All names of organisations and individuals have been anonymised. This paper focuses specifically on working in partnership with organisations to include people with learning disabilities in research, and on the methodological issues that arose during the project. The substantive findings have been discussed elsewhere (Ledger et al. 2016).

## 2. LITERATURE REVIEW

Recent years have seen a growing emphasis – through government policy, the academy and the self-advocacy movement - on the importance of hearing people’s experiences and views in research (DH 2015; Nind 2014; Walmsley et al. 2018). There is increasing evidence that adults with learning disabilities value participating in research, experiencing personal and social benefit as a result (Ledger, 2012; Crook et al. 2016), and, that people want researchers to use their experiences and perspectives to improve quality of life for other people with learning disabilities (Calvely 2012; McDonald et al. 2012). But involving people with learning disabilities in research continues to be hindered by a number of complex and intersecting factors, beginning with the process of reaching people who may wish to take part. Previous studies have highlighted the ways in which gatekeepers (either family members, practitioners or organisations) can create barriers to participation for a host of reasons. These include lack of time to support the research; lack of understanding about the purpose, risks and possible benefits of research; concerns about organisational risk, prioritizing other tasks and activities above the research; and a general lack of enthusiasm about it (Crook et al. 2016; Lennox et al. 2005; Nicholson et al. 2013). Practical issues also serve to make recruitment of people with learning disabilities particularly complex: travelling to and from research venues can be expensive and difficult to organise because people who cannot travel independently will often need staff support to participate; support workers may not be able to attend due to other commitments; and family carers may be overstretched (Crook et al. 2016; Ellis 2015). Ethical concerns have sometimes created additional barriers to involving people with

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<sup>1</sup> The research was funded by Open Society Foundations

<sup>2</sup> The study adopted the definition of Beamer and Brookes (2001): ‘High support needs describes people who have learning disabilities and extra needs. Some have physical disabilities, other health needs and ‘challenging’ behaviours’ (p.10)

learning disabilities in research, as researchers or research organisations conclude that the process of securing ethical approval and obtaining informed consent will be too complex, time consuming and resource intensive (McClimens and Allmark 2011; Boxall and Ralph 2011).

While these recruitment issues cut across learning disability research more generally, there are additional challenges when conducting research that might be described as ‘sensitive’. Definitions of what constitutes sensitive research varies between texts (Mallon and Elliott 2019), but it is frequently identified as research that is accompanied by a level of risk or threat, because it invites participants to reflect on deeply personal experiences that fall within the private sphere, or because it may expose forms of stigma or deviance (Lee 1993). Dickson-Swift et al. (2008) argue that research can be defined as ‘sensitive’ in relation to the potential impact it may have on participants, for example, evoking distressing emotions. Tuffrey-Wijne et al. (2008), discussing their research on cancer and end of life care, outlined how it was difficult to identify people with learning disabilities who had (or were affected by) cancer. Personal contacts and networks were often the most fruitful ways of finding people, but ethical safeguards around the project prevented people from being approached directly through these more informal channels. As researchers, they spent considerable time and energy investing in relationships with staff and carers, explaining why the research was important, and reassuring them that participants would be treated well throughout the process.

However, while gatekeepers can create barriers to people’s involvement in research, they can also serve to facilitate participation. Some research projects are almost entirely dependent upon securing the enthusiasm and support of organisational leaders, who play an active role in supporting the recruitment process (Tilley 2007; Ledger 2012). Researchers need to guard against the danger of ‘over-rapport’ with such gatekeepers who may bestow important ‘gifts’ upon them, for example, disclosing information that would otherwise be unavailable, or providing access to people and other data that enriches the study (Bosk 1979). Nevertheless, developing these relationships with organisational gatekeepers is sometimes the only practical way to get a piece of research off the ground. Indeed, much innovative inclusive research has been enabled by the relationships that academics have developed with self-advocacy organisations and services (Nind 2014). Adhering to ethical guidelines such as those developed by the Social Research Association (SRA) can support researchers to consider the impact of these relationships and develop strategies to help manage dilemmas that arise in practice. Reflecting on the implications of partnership working, Williams and Tarleton (2015) argue that close associations with organisations throughout the research process can serve to increase the impact of the research, as mutual interests are served. Pondering on whether or not close associations with external partners risks unacceptable levels of research bias, they highlight the importance of ‘maximum reflexivity’, so that ‘the final results take into account and develop our own thinking in a transparent way’ (2015: 151). Williams and Tarleton acknowledge that all social research is interpretative, and the researcher’s positioning matters. However, they argue that the benefits of partnership working to support research in learning disability outweigh the risks. The interdependencies between academics and collaborating organisations are often neglected in discussions about research design and methodology. And yet it is often the case that research could simply not be realised without the creation of such partnerships. While academics may require the input of external organisations to broker relationships, contribute to research design or provide essential contextual information, community partners will have their own motivations for supporting the research (Facer and Enright 2016).

### 3. METHODS AND METHODOLOGICAL FINDINGS

This section discusses the research methods and outlines the process we followed to recruit participants through working with two organisations – an advocacy group (Connect<sup>3</sup>) and a service provider (Zamma)<sup>4</sup> on a qualitative project exploring women’s contraceptive choice and use. It explains why the organisations were selected, how they were initially approached, the recruitment and interview methods used in each and how these were adapted to respond to the needs of individual women and different organisational settings as the research unfolded. During the study the research team also approached other organisations and individuals using existing networks and snowballing, but recruitment was less successful.

This paper focuses on the methodological challenges of working specifically with these two organisations to include people with learning disabilities in research on sensitive topics.

#### 3.1 Methods, consent and pilot

The team developed an accessible information sheet and consent form to inform potential participants and their supporters about the research. Both were piloted with a woman with learning disabilities known to one of the research team and who had volunteered to help. Minor amendments were made after this. Amendments included edits to the words and images used.

Questions and accompanying photographs and images (e.g. of contraceptives) were piloted with five women prior to finalising their content. This pilot phase feedback, combined with good practice guidance on promoting the involvement of people with learning disabilities in meetings and decision-making (NICE 2016), led to the team developing an accessible ‘Getting ready for Interview Tool’ which comprised of a set of accessible questions about contraception presented in PowerPoint format. These were sent to potential participants with the easy read information sheet two to three weeks in advance of the interview. This easy read interview schedule enabled women to make informed consent about participation and helped them prepare for interview.

#### 3.2 Participants

In total, 19 women were interviewed. Women were included if they:

- had a label of learning disability, and had been users of specialist services for people with a learning disability
- were able to consent to take part without undertaking a formal assessment of capacity
- were using, intending to use, or had previously used contraception.

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<sup>3</sup> pseudonym

<sup>4</sup> pseudonym

Table 1 provides a brief profile for each research participant giving their age and ethnicity and an indication of their support needs. The table also gives information on method of recruitment and further information on the type and location of interview.

**Table 1 Participant profiles (n=19)**

Please note that some interviews at Zamma were designed to resemble a relaxed ‘cafe’ style environment with refreshments, either in the participant’s living room or the supported living unit lounge. For other interviews that were not arranged through organisations, meetings took place at the request of the woman involved. If a participant asked to meet in a cafe, steps were taken to ensure that privacy and confidentiality were maintained.

Participant numbers	Age/ethnicity	Method of recruitment	Interviewer, Method and location of interview	High Support Needs Y/N
<b>RECRUITMENT THROUGH CONNECT</b>				
1.	51; White British	Organisational partnership	Researcher; 1:1 interview; Connect Office	N
2.	28; White British	Organisational partnership	Connect Director; 1:1 interview; Connect Office	N
3.	25; White British	Organisational partnership	Researcher; 1:1 interview; Connect Office	N
4.	22; White British	Organisational partnership	Researcher; 1:1 interview; Connect Office	N
5.	37; White British	Organisational partnership	Researcher; 1:1 interview; Connect Office	Y
6.	26; White British	Organisational partnership	Researcher; 1:1 interview; Connect Office	N
7.	46; White British	Organisational partnership	Connect Director; 1:1 interview; Connect Office	N
8.	24; White British	Organisational Partnership	Researcher; Interview supported by Connect worker; Skype	N
<b>RECRUITMENT THROUGH ZAMMA</b>				
9.	28; White British	Organisational partnership	Researcher; Interview supported by keyworker; In woman’s own flat	N
10.	40; Philippian	Organisational partnership	Researcher; Two women interviewed together; Informal café style with refreshments; Lounge of supported living unit	N
11.	32; Black British	Organisational partnership	Researcher; Interview with two women supported by home manager, with accessible interview questions sent in advance; Lounge of supported living unit	N
12.	36; Black British	Organisational partnership	Researcher; 1:1 interview; In woman’s own home	N
<b>NON-ORGANISATIONAL RECRUITMENT</b>				
13.	43; White British	Research Team networks	Professional Advocate; 1:1 interview using accessible interview questions sent in	Y

			advance; Café	
14.	56; White British	Research Team networks	Researcher; 1:1 interview; In woman's own home with refreshments	Y
15.	54; White British	Research Team networks	Researcher; 1:1 interview; Café	N
16.	49; White British	Research Team networks	Researcher; 1:1 interview; Local advocacy office	N
17.	19; White British	Research Team networks	2 researchers; Interview with participant and her parents together; In the family's home	Y
18.	29; White British	Research Team networks	2 researchers; Interview; Local advocacy office	N
19.	61; White British	Self-nominated	Researcher; 1:1 Interview; University Office	N

### 3.3 Organisational partnerships

Twelve of the 19 women interviewed were reached through close partnership working between members of the research team and the two organisations, 'Connect' and 'Zamma'. These organisations were different in their size, purpose and management structures and systems. The advocacy agency (Connect) is in a rural location serving a predominantly white British user group. The service provider (Zamma) is in an inner city and supports an ethnically diverse population. The discussion below presents an overview of how members of the research team worked with each organisation.

#### ***Connect: Approaching the organisation***

Connect had previously expressed interest in taking part via an online survey in which families and staff supporting contraceptive decision-making were asked about their views and experiences (REF). It had not been possible to interview members of Connect at that stage because ethical approval had not been granted to include women with learning disabilities. The Research team re-contacted Connect when ethical approval was secured for this project, and they agreed to ask members if they would like to take part.

#### ***Connect: Access, recruitment and interviewing***

Connect had recently run a course on women's health. Sexuality, including contraception, were significant elements of the course, which aligned with the focus of our project. Researcher JW worked closely with Connect's Director to recruit women. The easy-read interview schedule was sent two weeks before the interview date, so that women knew what questions they would be asked. Sending the questions in advance was intended to support women to answer questions on a complex topic and to assist them to make an informed decision about participation.

Interviews were scheduled over two days in a rural part of the UK that was difficult to access by public transport. Forty-eight hours prior to the scheduled date Connect's Director informed the research team that 12 women, not the expected six, wanted to take part.

Consent forms had been circulated, and of the 12 women who attended on the day, eight arrived with completed consent forms. JW led a group session where she went through the interview questions with the women attending, to establish that they did understand the topic, and were making an informed decision to be interviewed. Following this session, eight women said they

would like to be interviewed, although one was then excluded because her experience of contraception was not sufficiently recent.<sup>5</sup>

The women were then interviewed individually in turn in private offices, while Connect staff undertook activities with the other women present. Because there were more women than anticipated, the Connect Director offered to undertake some interviews simultaneously. The researcher made a pragmatic decision that this was the only way all seven interviews could be done in one day. Although not ideal, neither the budget nor the project timetable allowed for a return visit. Hence two of the seven Connect interviewees were interviewed that day by Connect's Director. She had not been formally trained in administering the interview, and the women already had a relationship with her. However, the alternative was to exclude those women as JW would have been unable to conduct all seven interviews in one day. It was also clear to the team that the research could not have taken place without Connect's willingness to actively support the research process.

### ***Connect: The added value of participating in the project***

Following completion of the research, Connect's Director reported that the project had helped them to understand more about the issues faced by their members, and to take steps to address them, including providing more information about contraceptives as the research showed how little women knew; and by supporting one woman to write to her GP requesting a consultation to change her contraceptive.

### ***Zamma: Approaching the organization***

Zamma is a housing and social-care charity providing supported living, nursing care and employment support to approximately 120 people with learning disabilities in an inner-city location. The organization had a long-standing interest in supporting tenants with sexuality and relationships and, for this reason, we decided to approach them. SL initially approached the Chief Executive and was invited to a meeting to discuss research aims and methods. The research team was then requested to make an accessible presentation to the Board to seek their approval.

This presentation raised further questions about the research project (for example, recruitment, anonymity and confidentiality) and new questions about Zamma practice (for example, how many women supported by Zamma used contraception and how was it monitored?). Board members with learning disabilities endorsed the idea of sending interview questions in advance – emphasising that this practice was helpful for their own work on the Board.

### ***Zamma: Access, Recruitment and interviewing***

Following Board approval, Zamma's Care Service Manager (CSM) wrote to all female tenants asking if they would like to take part and briefed residential and supported living managers about the research. In response, managers and keyworkers set time aside to talk to women who met the research criteria about the project. Information about the research was headed with Zamma and University logos to make it clear to staff and residents that this was a trusted project with the

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<sup>5</sup> Another young woman who met the criteria but had been unable to attend (ironically due to period pains) was interviewed by the researcher the following week via Skype. She was supported on the call by a Connect worker. This brought the total number of participants recruited through Connect to 8.



organisation's endorsement. Zamma managers introduced the researcher to four women who had expressed a clear interest in being interviewed and reported that three other women who were eligible had declined to be interviewed. A further three women appeared unsure or inconsistent in their responses and so were excluded. A further six women with high support needs, who communicated non-verbally, were initially put forward by Zamma keyworkers for inclusion but subsequently excluded, as it was not possible to trace their former case records to confirm their historical use of contraception (remembered by staff) and as a result did not meet the research selection criteria.

Because participants were initially approached by Zamma managers it was important to ensure that women reliant on the organisation for support, were giving free and informed consent and not agreeing to participation to please staff. This risk was openly discussed between the researcher and Zamma staff who confirmed they would make it clear to all that participation was their choice and that it was fine to decline – as three women clearly did. Zamma senior managers explained that they often visited projects to inform residents of such opportunities and invite their participation. There was evidence that residents were familiar with saying no in this context. Three weeks before the interview date researchers sent easy read information, consent forms and interview questions to the four confirmed participants via managers and frontline staff.

Each woman worked with her keyworker, family or support circle to prepare for the research interview. All interviews were informal and the woman herself chose who she wanted to support her and where/how the interview would take place. At the start of every interview the researcher re-visited the consent form. At the end of each interview Zamma staff left the room, consent was re-visited and the women were asked again to sign by the researcher.

#### ***Zamma: The added value of participating in the project***

As with Connect, the active participation of Zamma was essential to the research. In turn, Zamma recognized the research as an opportunity for their organisation to focus on a complex issue which had not previously been discussed at Board level, in particular, the need to collate information on contraception as part of their health action planning. The Zamma CSM, a member of the senior management team, described her involvement in the project as '*humbling and educational*'.

## **4. DISCUSSION**

In this paper we have highlighted that research on 'sensitive' topics with people with learning disabilities can be a 'messy' (Sparrman 2014) and resource-intensive business that requires creative approaches to recruitment and other aspects of the research process. However, these approaches bear methodological and ethical consequences which we discuss below.

Recruiting women with learning disabilities for research purposes can be extremely challenging (Iacono 2006). Our research highlights how researchers in this field cannot rely on advertisement, social media or other 'pull' methods of accessing respondents (Walmsley 1993), even though they have been found to be successful with other 'hard-to-reach' groups (Topolovec-Vranic & Natarajan 2016). Rather, they have to work hard to foster trusting relationships with individuals and

organisations where there is the possibility of mutual benefit using an ‘active and personal approach’ (Crook et al. 2016: 136).

Two significant organisational relationships made this research possible. Both were interested in women’s reproductive and sexual health. In Connect, contraception decision-making was a strong fit with their advocacy campaigning role. At Zamma, the research was an equally good fit with their commitment to practice development in supporting people with learning disabilities with sexuality, relationships and sexual health. The research project was successful because of the alignment of our research goals with their organisational priorities. Both partner organisations felt that their participation in the project had been beneficial and supportive of their organisations and of individuals within it, adding ‘value’ to the original aims of the research. Engagement in the research prompted both organisations to review the information and support they provided to women on contraception, and informed health action planning at Zamma.

However, there are limitations to this approach and it is possible that our substantive research findings are not typical of the experiences of women with learning disabilities. Every method of recruitment in research has its strengths and weaknesses. For example, relying on pull methods might attract participants with particularly strong views.

Research teams conducting similar types of work should be mindful of the additional time that can be needed to carry out such work successfully. We used a number of techniques to access participants including working with new organisations and individuals as well as those that were already known to us. Not all of our strategies were productive. If there was no obvious benefit to the organisation or the individuals working directly with the women, it is perhaps not surprising that many found reasons to decline the opportunity. The time and resource required to establish new relationships should not be under-estimated.

It is also worth noting that when working in partnership, organisations and individuals act as gatekeepers (Walmsley 1993; Nicholson et al. 2013; Crook et al. 2016). Gatekeeping meant that we were able to recruit successfully to the project but it also raised a number of issues. For example, Connect recruited women who did not meet our inclusion criteria and had to be excluded on the day. Ideally, this would not have happened. In contrast, Zamma chose to exclude some women because they were not able to determine their reproductive histories. We cannot be certain that there were no other women who might have met the criteria for inclusion, but – for other reasons – were not invited by our gatekeepers to participate in the research. All of these gatekeeping issues may have influenced our substantive research findings.

Twelve of 19 participants were recruited via partner organisations. In the case of Zamma, the participants were tenants and the research information bore the Zamma and University logos. Although we feel sure that no participant was coerced to participate and that consent processes were appropriate, it is always possible that some participants felt obliged to participate because of their relationship with the organisation and/or gatekeeper. As a research team we felt that there were sufficient examples of women declining to participate to indicate that the risk of coercion was minimal.

Working in partnership with individuals and organisations in research can also impact on the process of data collection. A number of unforeseen issues arose during this time. Connect organised interviews in a rural area and, because of their involvement, we were grateful that participants were able to reach that location and participate. However, the research team was expecting to interview six individuals and twelve were invited. This meant that seven interviews had to be done within one day rather than an anticipated lower number. Arguably, this may have affected the quality of the interviews and the richness of the research data generated. It also allowed less time for reflection between interviews and it was difficult to write field notes. Furthermore, pragmatism dictated that the Director at Connect conducted two interviews which otherwise could not have taken place. This may have compromised rigour – though there is no evidence that it did.

We had originally planned to interview women on a one-to-one basis, with support if required. In practice, the process of interviewing was much more varied than this. Our priority was ensuring that women were able to share their experiences of contraceptive choice and use in a safe environment but these differences in interview method will have influenced the data. In responding flexibly to the women's requests on where they wanted to be interviewed and with whom, some methodological rigour was lost but this is arguably compensated for by the fact that in both organisational settings the support of friends and long standing staff may also have enabled the women interviewed to contribute more fully in a relaxed setting. These methodological and ethical dilemmas are often present in sensitive research, and we hope our discussions about them here will support other researchers to reflect and plan accordingly when drafting proposals and ethics applications.

## **5. CONCLUSION**

The purpose of this article has been to provide a transparent account of how researchers developed organisational partnerships to enable them to hear directly from women with learning disabilities about their experiences of using contraception. Accounts given by the women in our project created opportunities for more nuanced understandings of how contraception for this population is prescribed and reviewed. But we argue that the potential benefits of recruiting people from hard to reach groups must be openly discussed alongside the possible compromises in methodological rigour and the additional time required for reflexivity and relationship-building that we identified.

Focusing on our methodological findings, we argue that fostering strong organisational partnerships can support the inclusion of people with learning disabilities in research when organisational interests align, and the partnership can be mutually beneficial. When working in partnership with organisations and with people with learning disabilities, our research highlights that flexibility is required to ensure that participant information, consent forms and interview schedules are fully accessible. However, this approach requires considerable investment in time and other resources to address potential ethical concerns and, in particular, to ensure that research participants give informed consent. Embedding reflexivity is also essential to ensure that the welfare, rights and wishes of the participants remain central. We acknowledge that our approach to including people with learning disabilities in research raises questions of methodological rigour and we have explored these above. However, research methods are not neutral; they are 'productive' and they produce the reality that we come to understand (Law, 2004). Without organisational partnerships,

and a creative approach to research, this important project would not have been possible.

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