
NATIONAL FEDERATION OF VOLUNTARY BODIES

Providing Services to People with Intellectual Disability

Using Focus Groups as a Research Method in Intellectual Disability Research: A Practical Guide

Organisation

**The National Federation of Voluntary Bodies
Providing Services to People with Intellectual Disabilities**

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Introduction

Focus groups are commonly used as a research method for conducting research with people with intellectual disability (e.g. National Federation 2007; Nind 2008; McCallion and McCarron 2004; Fraser and Fraser 2000; Perry and Felce 2004; Barrett and Kirk 2000, etc.) This is because focus groups are time efficient; they include a greater number of opinions, suggestions and ideas; they capture lived experiences; they allow for deep exploration of topics, including sensitive topics; and participants do not require written language skills.

Focus Group Definition:

From collective focused exercises or group discussions, focus groups provide a rich and detailed set of qualitative data,

- *based on group interactions;*
- *which is inductive and naturalistic;*
- *about perceptions, thoughts, feelings and impressions of group members;*
- *who are selected and assembled by researchers;*
- *based on personal experiences;*
- *in participants' own words;*
- *on the topic that is the subject of the research (Freeman 2006)*

Focus groups with older adults and people with intellectual disabilities as participants appear to be more of a test of the design, organisation of the questions and facilitator's (Can also be called the moderator) skills. Therefore, more detailed preparation is advisable particularly when including participants with intellectual disability.

Focus Groups are invaluable for 'grounded theory' development - focusing on the generation rather than the testing of theory. They are often perceived as more 'cost effective' than traditional methods and adaptable to a range of research approaches and designs. To prepare for using a focus group as a research methodology, as with any research method, the investigator must identify the rationale for using focus groups as opposed to other methods, and outline the strengths and the limitations of the method for the specified purpose.

Aim

This paper has been prepared as a user-friendly 'how-to' guide on the best way to conduct focus groups with people with intellectual disability. It has been prepared from an extensive review of the literature (See the Bibliography, essential and additional reading lists). This practical guide has been divided into 4 sections, each dealing with separate stages of preparing for, conducting the focus group, analysis of data and write up.

1. Sampling, Group Size and Number of Focus Groups

- Identify who your participants will be. They may be chosen on the basis that they share a common geographic location; or are a group of people who receive a service, or who have a certain topic in common or share some common experience e.g. people who have the same medical concerns.
- Even within groups try to get the correct balance between homogeneous and heterogeneous i.e., try to get the diversity of opinion within groups. If group members are very homogeneous, the lack of different viewpoints or lack of conflict of interests may reduce the scope of the information gathered, as well as reduce group interaction. With some heterogeneity in the group mix opinions are challenged and there is more debate on issues. Therefore a kind of momentum is generated which allows underlying opinions, meanings, feelings, attitudes and beliefs to emerge alongside descriptions of individual experiences (Parker and Tritter 2006, p27).

- Be aware of the role of 'gatekeepers' (those whose role it is to protect the rights and interests of potential participants). Researchers will need to communicate with them and seek to reassure them where needed. Who are the gatekeepers and how can you best involve them and communicate with them?
- Groups can be recruited using purposive or theoretical sampling, i.e., by approaching people and asking them to be potential recruits or by choosing participants from a sampling framework. Alternatively participants can be chosen via a 'snowball' sampling technique (This is a method where you recruit one person and then this person recruits others that they have access to, giving you access to a larger group). Another effective method of recruiting people is by 'piggy-backing' an already formed group. This could be where you might join a committee meeting's agenda and invite the committee members to be participants in the research.
- Ideally there should be 5 to 6 in each focus group. If the group is too large participants with intellectual disabilities may find it difficult to take part. This could be because of a fear to speak out in a crowd or because of cognitive impairments and distractions from other group members or speech and hearing difficulties (Barrett and Kirk 2000; Fraser and Fraser 2000). "Although Morgan and Schannell (1998) recommend group size of between six to ten, we agree with Balch and Mertens (1999) that where speech and hearing difficulties are present, small groups are needed to achieve better results (Fraser and Fraser 2000, p228). However larger groups have been used successfully too (See Andre-Barron, Strydom and Hassiotis 2008). Group size will depend on people's cognitive ability, the environment and on the skills of the facilitator.
- Usually between 3 and 5 groups are sufficient to gain the diversity of views towards saturation (Bloor et al 2001). "We also agree with Morgan and Schannell (1998) that between three and five groups lead to gaining the diversity of views towards saturation, without the possibility of repetition of ideas" (Fraser and Fraser 2000, p228).

2. Organising the focus group:

For a focus group to be successful the researcher must be well prepared and this will be evident in the organisation of the focus group

- When choosing a location, choose one that the participants regularly attend and at a date and time that they are usually there or is convenient for them. This will make it easier for people to attend. Be aware however that this could also effect or bias the responses of participants too
- Support persons may be required to accompany participants, plan for this in organising your focus group.
- Provide participants and their support persons if they have one with appointment cards and reminder phone calls or letters or emails prior to attendance
- In correspondence prior to the focus group ask participants to consider and think about the topic(s) before attending the focus group.
- Avoid starting the focus group too early if people are travelling and stick to the times you give people, including the planned duration of the group.
- To increase focus group attendance, meet with participants beforehand to chat informally with and to answer questions also.
- Welcome participants at the entrance. This will be a big aid to reducing unease in some participants and the use of small talk is important also.
- Participants need to be reassured that any data they provide will be kept confidential and private within the research team. However, there are significant limitations on this issue as other participants may talk about what they hear in the setting. Placing a do not disturb sign on the door and asking participants to respect the privacy of all other participants' focus group opinions after the focus group has ended could be helpful.
- Always consider consent issues prior to the focus group. Consent will need to be gathered prior to and start of the focus group
- Capacity is a fluid concept and therefore at the time of giving consent, the researcher needs to check that the participant will be giving informed consent. (National Federation 2009)

- Try to gather socio-demographic details, along with initial attitudes or viewpoints on the focus group topic of each individual. This will help create groups that will have the right balance. This can be done by getting people to complete a pre-group self completion questionnaire, which could be filled in and returned by post or could be done at a pre-focus group ice-breaking and information meeting for example or even at the beginning of the actual focus group to help settle people and reduce awkwardness. Try to ensure the person has support completing this questionnaire and/or privacy and ensure accessible versions of documents are used. Again consider the issues of informed consent
- Where possible it is recommended to recruit 20 percent more participants than is required to account for drop out rates.
- To improve recruiting and avoid attrition (drop out) incentives or compensation can be offered for participation i.e. food and drinks during the focus group, out-of-pocket expenses, a prize, information and education, even curiosity and interest could be enough to motivate people to participate. This needs to be balanced with undue incentives e.g. payment which could bias results. Often the use of compensation or incentives will depend on the organisation's policy on incentives.
- Have a assistant facilitator to help you for conducting the focus group on the day
- Extra training may help facilitators facilitate participation by individuals with different types of disability.
- Refreshments provided at a mid-point can help if group members seem to be tiring or to allow people use the bathroom. This can disrupt the group dynamics already established though and it may be difficult to re-establish the group interaction. It could be helpful to have the refreshments at the beginning of the focus group or to leave refreshments on the table during the focus group, especially if you are aiming for a long focus group of an hour to 90 minutes.
- Make sure the breaks are long enough to allow people to get to the bathroom and eat and drink.
- Everyone will need a name badge with the name they like to be called on it, in large letters.
- Ensure lighting is appropriate i.e. look out for too much glare or dimly lit rooms, etc.
- Ensure you are in a quite environment, maybe placing a "Do Not Disturb" sign on the door.
- The room should be easily accessible, with no stairs used to gain access to it and the room should be warm with comfortable seating.
- Where possible a seating pattern should resemble a circle to enhance greater interaction.
- The use of an inviting, colourful room to help elicit discussions can be helpful.
- The focus group environment should allow a participant to feel part of a group, participants should not feel alone or unique in the group.
- The environment should reduce anxiety as much as possible.
- Ask the people you are inviting whether they have access needs such as; Braille; documents on tape; an induction loop; large print documents; wheelchair access; sign language interpreter; parking for disabled people; Makaton; and food that meets any dietary requirements.

To conduct the focus groups you will need some tools of the trade. The following checklist should be consulted:

➤ **Check-list for Audio recorder: One way to record notes and document the focus group is to use an audio recorder**

- Ask permission for the focus group to be recorded and ensure that participants feel comfortable about this
- Audio recorders with microphones containing automatic volume control should be avoided, if you are unhappy with the built-in microphone. In that case an external multi-directional microphone should be used.
- Ask each participant to identify their names with their own voices, which will aid in the transcription.
- Put in new batteries
- Check time and date
- Delete old recordings
- Check that the recording is set at the highest quality
- Plug in external microphone if you are using one

- Make a practice recording and play it back
- **Check-list for Camera:**
 - Ensure that participants have given their consent and are comfortable with you using a camera to record their responses. Look for evidence of discomfort and be aware of signs that a person is not happy with being recorded.
 - Check that there are good batteries in the camera
 - Check that there is sufficient memory

3. Running the focus group

3. A. Initial tasks

The following checklist will help to introduce the topic and establish some ground rules for the focus group to take place. Remember it is important to get off to a good start and build rapport with the group before in-depth discussion takes place.

- 1) The welcome
- 2) The ice breaker
- 3) The overview of the topic
- 4) The purpose of the study
- 5) The ground rules
- 6) Background and context for first sub group of questions or exercises
- 7) First question

3. B. Using Focusing Exercises

When discussion gets under way on the topic it is important for the facilitator to keep the discussion on track and avoid rambling, or awkward silences.

- Some techniques to do this include: (i) open questioning, give e.g. Barrett and Kirk 2000, (ii) loose word associations, (iii) 'ice breakers' or 'warming up' exercises, (iv) ranking exercises, (v) vignettes (Andre-Barron, Strydom and Hassiotis 2008), (vi) news bulletin exercises, (vii) asking participants-"what is happening in this photo?" (viii) role playing (Wituk et al 2003), (ix) narrative elaboration (Saywitz and Snyder 1996) and (x) Q-methodologies (Van Exel and De Graaf 2005; Kreuger, Van Exel and Nieboer 2008). For examples of exercises ii-vi check out (Kitzinger 1994) and for exercises iv-vii check out Bloor et al 2001.
- Explain the focusing exercise. This will take several minutes and may include accompanying materials e.g., drawings, overheads etc.
- Facilitators will need to clarify any questions so that all participants understand the activity. Role play can be an effective means of explaining the activity

3. C. Accessible Information and Designing Questions

For information on accessible information and events check out Dennis 2002; NIID 2008; SCIE 2005; EASPID 2005; NALA 2005; etc. more available on the additional reading list.

- The use of illustrations or visual aids is important for people with intellectual disabilities.
- The use of augmentative and alternate communication (AAC) is a strategy that will increase communication effectiveness for everyone and include more people who have speech or comprehension difficulties.

- Recognition of self-developed non-symbolic, non-linguistic and behavioural communication methods used by people with intellectual disabilities is vital in analysing data from focus groups.
- Develop simple, easy-to-understand questions for the focus group with the aid of a person with an intellectual disability as expert stakeholders.
- Ensure the questions are conversational, clear, short and open-ended.
- Split the questions into topics with each topic holding 2 – 6 questions.
- Each topic will be introduced to the participants before the questions will be asked, to establish the context of the next few questions.
- Context cues may be required possibly before every question to facilitate participants.
- Serendipitous, or off the subject or chance questions from the facilitator and assistants will be allowed at the end of each topic of questions, as not to distract from the topic at hand
- Progress Questions within each topic from general to more specific. For example:
 - ✓ Q1: *What do you think about the support you are getting from your service provider?*
 - ✓ Q2: *What parts of the support are good and what parts are bad, in your opinion?*

3. D. Role of Support person

- The addition of an interpreter familiar with the participants' communication can be important. Participants may require a support person to attend the focus group with them and you must consider their role in advance
- Have support persons also completed a consent form prior to the focus group; there are examples of consent forms now used clarifying the role of the support person during the focus group. (Tierney et al. 2009). Some highlights of these forms are to explain that the supporter's role is simply to support the person to participate in the focus group and not to speak for or on behalf of the person with an intellectual disability.

3. E. Role of the Facilitator

The role of the facilitator is vital in conducting the focus group and in pulling together the diverse opinions of the groups. To do this the facilitator must be multi-skilled and aware of the dynamics of the group and have a good understanding of the nature of intellectual disability.

- The role of the facilitator is in the background and non-directive and to tap into group life, not to change it.
- The facilitator must be enthusiastic, a good listener, empathetic, understanding and culturally aware
- The facilitator needs to highlight that there are no correct answers to the questions
- Ask participants to speak one at a time only
- Speak slowly and clearly and allow participants time to think about the question and respond
- Interruptions should also be prevented and a participant allowed to complete a comment/response rather than allowing the interruption and returning to the interrupted participant later on
- It is important to remind individuals who avail of services that the researchers are not working for any agency providing services. If this is not the case the person must be informed as to what effect their input may have on the services they avail of
- Ground rules need to be laid out at the beginning of the focus group indicating how people will participate and how people will respect each other in the focus group
- Avoid choosing the most talkative in the group always to offer a response. Notice the non-verbal behaviour of some participants also e.g., "You seem to be nodding, are you agreeing with what was said?"
- Try to look for consensus and variation in opinions and statements.
- Highlight at the beginning that if a person does not agree with an opinion then that person will need to voice their own opinion.
- When people speak, look to the other members to see if there is agreement or disagreement and if

neither is visible ask the other group members do they agree or disagree with the statement.

- If someone has an supporter make sure that when you are talking, you continue talking to the person with the intellectual disability, not to the supporter
- Traffic light cards are a great asset, where red cards represent 'I do not understand' or 'no', amber cards represent 'slow down' or 'repeat' and green cards represent 'yes' or 'I understand'.
- Make sure all group members have an opportunity to debrief at the end of a focus group on their experience and ask any questions that they have.
- A summary sheet about the confidentiality and the purpose of the study and other ethical considerations could be distributed to all individuals that will include your phone number if people have questions afterwards.
- Offer to send the findings of the study to participants if they are interested
- Thank them for their participation and effort.
- If somebody needs to talk afterwards and the topic is a difficult one, offer a non-judgemental, active listening, ear and do not give advice on the matter. If you feel the person needs some further support; supply the person with contact details of organisations that apply to that topic.

3. F. Important points for the facilitator to note:

- The environment cannot be too service-orientated or having an overwhelming teaching, testing or custodial ambiance as the environment holds a lot of power.
- From prior visits and small talk at the door, try to ascertain dominant talkers, self-appointed experts, shy people and rambler. This will allow you to arrange seating, putting those who may need more control closer to you and also try to position people with hearing impairments closer to you.
- Consider the communication style of persons with severe intellectual disabilities: a nurturing relationship can be assistive in these discourses.
- Pay attention to behaviours such as eye gaze, vocal sounds, body movements, facial expressions, and tactile gestures. This will help to build trust and maintain momentum in an interactive exchange.
- It is vital to leave enough time to increase the opportunities for communication.

3. G. Possible pitfalls during a focus group

- Be wary of using a flipchart or taking notes as this could potentially turn the facilitator into a teacher type role within the group; could this be done by an assistant or a group member?
- Think about the different biases that could potentially corrupt the data at this level of the study e.g. acquiescence, nay-saying and recency bias.
- Factors which may influence response rates include; issues of permission and autonomy that impede spontaneous sharing; learned silence or learned compliance responses; consequences of medication may interfere with genuine interactions also.
- Also social desirability may be a consequence of a perceived imbalance in the status of the interviewer and interviewee. However it can help by remembering to focus on the participants as experts on the topic at hand.
- Over dominant participants may block quieter members.
- Bias can also be introduced through the manner of questioning and the facilitator's verbal or non-verbal reactions to statements by participants e.g. expressing surprise.
- Lack of training is a major pitfall. Facilitators need to consider training and prepare themselves sufficiently before focus groups to cut down on these biases.

4. After the focus group

When the focus group has been completed there are a number of tasks to be completed including transcription and analysis, follow up with participants and report of the focus groups and dissemination of its findings.

4. A. Transcription and Analysis

- You could have a coordinating committee if there are many focus groups with different facilitators. This committee would help keep all facilitators on the same track and also would be able to ensure that the analysis and reporting are consistent and valid with all group data collected.
- Analysis can be broken into 4 types 1: Transcription-based analysis, 2: tape-based analysis, 3: note-based analysis, 4: memory-based analysis. The analysis of focus group data is dependent on your design, epistemology and practical considerations such as time and resources. For further detail on these methods read Kitzinger 1994; and Bloor et al 2001; and Madill Jordan and Shirlie 2000.
- Every effort should be made to transcribe all recorded speech”, including all speech when there are multiple voices, all unfinished and interrupted speech, brief extracts of speech, and in the cases of inaudible speech the analyst needs to transcribe as much as possible, even writing down a suggestion for what was said where useful. If there is no available cue to indicate what is being said, then the analyst needs to indicate there is a piece of the data missing which is normally done with an ellipsis.
- Speech should not be tidied up, including grammar, pronunciation, other oral communication and body language such as laughter and nodding one’s head should be noted.
- During the focus group, the facilitator needs to use people’s names as much as possible to help the transcribers. However be sure to reassure participants that this will be anonymised.
- Where it is not possible to recognise a voice or a short utterance on a tape mark the extract as unidentified, including the gender of the voice though.
- The analyst needs to be systematic and rigorous, reflecting the views of all participants.
- The data storage and retrieval needs to be decided on at the transcribing level. Do you want to analyse the transcripts manually or using a software package? If there are big transcripts or numerous groups, software packages are much faster and reliable, than manual storing and retrieving.
- The process of indexing then involves the analyst reading and re-reading the text and assigning index codes, which relate to the content of the data and are of interest to the researcher’s analytic framework.
- Coding categories reflect the content of data collected rather than the questions on the interview schedule or focus group topic guide and often use concepts or vocabulary borrowed from respondents.
- Have one or more independent analysts To achieve a reduced level of subjectivity by the analyst, acceptable inter-coder agreement will help and improve the quality of the work this can also provide extra or more in-depth insights to some of the themes.
- This is costly and time consuming and it could be difficult with multiple coding of entire datasets. One idea is to have another person cast an eye over segments of data or emergent coding frameworks, and this is a core activity of supervision sessions and research team meetings. Ultimately what is of value is the content of disagreement and the insight that discussion can provide for refining coding frames.

4. B. Follow-up with participants

- Feedback Groups can be held at the end of a study to check back with participants about the preliminary analysis, to see if you understood the discussions fully and accurately, and also to broaden the depth of participants' views. It is important to note that these cannot be considered 'validation exercises'
- Often participants can have an emotional response to reading their own speech in a transcript. It is important to reassure participants that the information they have provided will be kept private and confidential and to thank them for their contribution to the discussion/ data. Feedback data will contribute to the data already collected, but be careful about discounting data previously collected due to subsequent feedback data (Bloor et al 2001), as the feedback data may be received in a very different context from the original data.

4. C. Reporting and dissemination of findings

- Finally in the write up of the report it is important not simply to add up all the sentences that represent a theme or support the hypothesis.
- Context needs to be provided with quotes.
- Phrases reported in the write up are part of a discussion between at least two people often times, therefore sometimes showing one person's responses and excluding the other half of an extract can cause the quote to lose some richness.
- It is important that only at the final stage of reporting an extract is cleaned up and made more easily readable.
- Include a rigorous and detailed account of the methods and context of the focus groups to stand by your chosen design and to let others decide for themselves the level of quality of a piece of work..
- Make sure your aims and objectives are clear. Make sure you established the methods through reference to a body of literature, detailing the sampling techniques and clearly establishing the rationale and theory behind it. Also describe changes in the technique if there were any, use an explicit analytic framework and cross-reference your findings in the conclusion with the transcript.

Focus groups using participatory or emancipatory research methodologies:

The collective nature of the focus groups can, according to the literature, empower the participants and validate their views and experiences. They can also create awareness. This awareness may stem from the recognition that problems are not just individual but structural and shared. Participatory techniques which can be employed to deliver emancipatory results include:

- The Use a 'bag of tools' to help with the research relationships. This bag unpacked as part of the scene setting routine in the field, includes physical objects or props that act as reminders that 'as we build rapport and develop relationships we are there as researchers.
- Include co-researchers in the planning by including them in developing the focus group questions and their make-up and order. Find out what topics and issues are important to people with intellectual disabilities on the research topic and develop questions on these for the focus groups using people's own vocabulary and ideas.
- Include co-researchers in the data collection by training people to become focus group facilitators or supporters in facilitation. Support people with intellectual disabilities to run the focusing exercises and to facilitate the data recording where possible.
- Include co-researchers in the analysis by getting people to co-ordinate data collection and to, with support, determine which findings are most important and relevant to them and their services for reporting.
- Involve co-researchers in the reporting and dissemination of findings by having people with intellectual disabilities provide presentations, have them decide which methods of data

presentation are to be used and by having co-researchers involved in the decisions in where the findings need to be disseminated.

Conclusions on focus group methodologies

The use of focus groups has many implications for the participants who take part as the group process is not only about consensus and the articulation of group norms and experiences. Differences between individuals within the group are equally important.

- By participating in a focus group, participants can become more actively engaged in determining the future direction of services.
- Partnerships between service providers and those who use services can be strengthened.
- Focus groups can be viewed as an approach that not only provides useful information to stakeholders, but empowers consumers of services to become more active agents in designing and improving services.

Final Word

By equalizing the power relationships between researchers and people with intellectual disabilities, researchers can get better and more comprehensive data and make studies more reliable and valid. All power, as Foucault recognized, provokes counter-vailing resistance and the most successful technique of subordinate resistance is concealment (Bloor et al 2001).

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Appendix1:

Virtual Focus Groups

Some areas that can include virtual focus group methodologies are instant messaging, discussion threads in fora and board rooms, comment sections, video messaging, emailing to-and-from within a mailing list including the email history, chat rooms, purpose-made software etc. These avail of multimedia and could potentially increase understanding and facilitation for people with intellectual disabilities. There is a gap in the literature on these methods as modes of qualitative research methods with people with intellectual disabilities, even though most of these communicative means are well-established and some at this stage old-fashioned methods of online communication.

- They are fast, low cost and convenient
- People from multiple locations can be accessed
- Greater participant diversity
- They give us access to people who are immobile and dispersed. As well as to sensitive topic discourse
- The data is already transcribed
- There are population biases of pc owners in that it may restrict access to people who have no access to computers and to people who can only use computers through their gatekeepers or support staff or service providers
- It is difficult to detect deceit, difficult to probe and the rapport is difficult to establish
- The data lacks non-verbal cues and information
- There is sparse information regarding the use of virtual focus groups with people with intellectual disabilities (Bloor et al 2001; Burton and Brnening 2003)

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Appendix 2:

How to make events and information accessible, including websites with pictures to help make materials more accessible

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