

# **REFLECTIONS ON CONDUCTING FOCUS GROUPS WITH PEOPLE WITH LEARNING DISABILITIES: THEORETICAL AND PRACTICAL ISSUES**

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## ABSTRACT

*This paper examines the use of focus groups as a methodological approach when undertaking research with people with learning disabilities. This is presented within the context of an ongoing research project that has principally adopted a participatory research approach and that is seeking to understand how people with learning disabilities conceptualise and understand their mental health. As such this paper may be seen as a critical case study of the ongoing methodological challenges of using focus groups, as well as exploring some of the thornier practical issues such as recruitment, attendance, data collection, ethical issues and matters of consent, facilitation, venue and payment in adopting this approach when undertaking research with people with learning disabilities. The paper concludes that the focus group approach is a legitimate methodological approach within the research process in the field of learning disabilities.*

**Key words** focus groups, learning disabilities, theoretical and practical issues for research.

## INTRODUCTION

The role of people with learning disabilities within research has changed over the past twenty years. Historically people with learning disabilities have had research done to them— they have been subjects to the researcher, the studied, the analysed but never the participant (Kiernan 1999, Walmsley 2001, Dye et al 2004). However with the development of the concepts of participatory research (Northway 2000, Tetley, Hanson 2000, French et al 2001, Soltis-Jarrett 2004) leading to emancipatory research (Zarb 1992, Oliver 1992, Hanley 2005) within the general disability field, the natural progression has been to incorporate these principles into research with people with learning disabilities (Stalker 1998, Kieran 1999, McClimens 1999, Chappell 2000, Walmsely 2001, Gilbert 2004, Walmsley 2004). This initially was demonstrated by the use of personal narrative to illustrate life experience (Goodley 1996, Atkinson and Walmsley 1999, Gray and Ridden 1999, Atkinson 2005), one to one interview (Booth and Booth 1996, Knox, Mok, Parmenter 2000) and recently has developed into the formation of research groups (Richardson 2000, Chapman and McNulty 2004, Townson et al. 2004, Williams and Heslop 2005). Now researchers are charged with the responsibility of making their research accessible and inclusive to people with learning disabilities; but this is not without problems (Stalker 1998). Arguably the use of focus groups as a mediator of participatory approaches would seem an appropriate methodological approach and it is this particular approach that this paper is concerned with. Therefore, the remainder of this paper moves away from a general discussion of the role of people with learning disabilities in research, to consider the more specific theoretical and practical issues of using focus group approach with this group of people. McCallion and McCarron (2004) have said;

*‘The approach used [focus groups] was found to be particularly helpful in reconciling diverse researcher and consumer perspectives, considering both basic and applied research issues, and yielding both national-specific and internationally relevant recommendations.’*

## **FOCUS GROUPS THEORY AND BACKGROUND**

Focus groups were first described in 1926 (Jackson 1998) but they have become increasingly popular for research from the 1940s onwards (Puchta and Potter 2004). The basic concept is that a group of people with a shared interest for example, gender, age, ethnicity, religion, life experience, expertise, are brought together (Bloor et al. 2001). Having brought a number of individuals together the groups *raison d'être* becomes one of discussing/examining a particular issue for example, cars, (Puchta and Potter 2004, Government Policy (BBC 2005), support for people with learning disabilities from the Asian community (Raghavan, Waseem, Small, Newell 2005). The number in the group should be determined by the nature of the topic being discussed for example, how personal it is, the more sensitive the subject the smaller the group. The recommended group size is between six–eight people, (Beyea and Nicoll 2000a) but in practice it can range from between three to fourteen. Recruitment to the group can be achieved in various ways for example, advert, and word of mouth (Beyea and Nicoll 2000b). The aim here, in sampling terms, is to produce a group that is as representative of the parts of society who would be interested in the topic presented that could practically be made (Beyea et al 2000a, Bloor et al 2001, Puchta et al 2004). Groups can be formed from already established groups (Owen 2001), or brought together for a particular study (Webb 2002). Group members may be paid for their time (Cote- Arsenault and Morrison-Beedy 1999).

Focus groups are facilitated by a moderator or facilitator whose task is to keep the conversation flowing and 'focussed' on the topic (Sim 1998, Cote-Arsenault et al 1999, Bloor et al 2001, Lane et al. 2001). One of the most important principles of focus groups is that the conversation is encouraged and facilitated between group members. It is this interaction between members that is crucial to this type of group, examining the group dynamics enables the researcher to weight the importance of what is said and unsaid (Bloor et al 2001, Owen 2001, Mansell et al 2004). To use an analogy of exploration the facilitator is not so much the expedition leader rather a combination of navigator and cartographer ensuring that the group head in the

right direction but happy to investigate new paths if relevant to the purpose of the expedition. This can be achieved by different means for example, prompt questions and rating scales (Cote-Arsenault et al 1999, Bloor et al 2001). As the group dynamic is important there should to be a second researcher present to observe and capture the interaction between group members (Cote-Arsenault et al 1999, Beyea and Nicoll 2000c). The groups are recorded through various means for example, note taking during and after the group, audio recording, video recording, direct observation (Beyea et al 2000c). The environment within which the group is held should be carefully considered before conducting any focus groups (Beyea et al 2000b). The setting needs to encourage discussion that will enable the participants to feel comfortable and able to talk freely. Individual's homes can be used (BBC 2005), as well as community centres, university rooms, schools and hospitals. The data gathered is analysed using a range of qualitative methods for example, looking for themes and assessing interactions between group members.

Evidently as a research method focus groups have both advantages and disadvantages. The advantages are located around the accessibility of groups (Owen 2001), the breadth of knowledge, experience and views within the group to produce a range of themes for analysis (Jackson 1998), the opportunity for group interaction which can provide insights into group dynamics (Sim 1998 Jackson 1998, Fraser and Fraser 2001), and groups can be inexpensive to run (Jackson 1998, Sim 1998). The disadvantages may include dysfunctional group dynamics for example, levels of trust within the group can vary considerably and that may influence people's discussion (Jackson 1998), the facilitator can become the focal point for the group with all comments addressed to him/her rather than a conversation occurring within the group (Owen 2001). Also the group may gain little from the experience with potentially all of the benefits going to the researchers (Mansell et al. 2001) and finally analysis of data can be time consuming (Beyea et al 2000a).

### **A context for this paper: a case study**

Late in 2003 Berkshire Healthcare NHS Trust in collaboration with Thames Valley University-London, decided to undertake a small scale investigation to explore how, if at all, people with learning disabilities accessed mainstream mental health services. 'Valuing People' (DoH 2001) the governments white paper for England had set out an agenda for learning disability services that advocated that people with learning disabilities should have all of their health needs met by mainstream health services and this should include mental health. In keeping with the participatory approach to research, and following discussion between the University, Trust and a number of self advocacy groups it was decided that the most appropriate way to investigate how people with learning disabilities accessed mainstream mental health services, and to find out people's views of mental health and the services they use and would like to use in the future was to ask them. And in asking them it was felt that the most suitable methodological approach that would enable us to work within the participatory tradition was to adopt a series of focus groups that would be undertaken across the county. As there are six Unitary Authorities [UA] in Berkshire it was decided that that there should be a corresponding number of focus groups to match each of the authorities, and that given the nature of the individuals' (dis)abilities that the groups should run over a period of six weeks. In England UAs refer to a single tier unit of local government that is responsible for most local government functions, and has geographical boundaries that are co-terminus with local Primary Care Trusts. Evidently this was to be a much larger project than the small scale study that was originally anticipated by Berkshire Healthcare Trust and the University, and this was responded to by a successful submission of a detailed research proposal to the Health Foundation in 2005 that sought funding for a two year study.

### **Theoretical and practical issues of conducting focus groups in learning disability research.**

#### **Recruitment**

In line with participatory research the aim of the research project used in this paper as a case study, was to recruit to the focus groups primarily from self

advocacy groups. The very first hurdle encountered was that of finding sufficient people who wanted to take part in such groups. It might be assumed that in the brave, new, post-‘Valuing People’ (DoH 2001) world there would be a surfeit of advocacy groups blooming all over Berkshire. Of the six unitary authorities, one had a well established group (its own community office and staff run by group), two had groups that have been more recently established (they have their own staff) and three had groups which were still relatively new and in the formative stage of development (still supported through statutory agencies or a citizens advocacy service). After locating where each of the groups were located followed the next challenge: that of making contact and organising face to face meetings and this proved extremely problematic. In one case merely arranging to meet the support worker for one self-advocacy group took months. Next having made contact we found that some of the self advocacy groups were reluctant to become involved. Of the groups that were finally identified five volunteered to become involved in the research project.

The recruitment process necessarily led to the establishment of a non randomised purposeful sample. Therefore we established broad inclusion criteria that required participants to have learning disabilities and be able to contribute to a discussion in a group on mental health issues. We secured 85 people with varying degrees of learning disabilities, 37 were male and 48 female. All participants were interested in being involved in the research but few had much lived experience of mental health problems. This meant at times that the facilitator had to provide detailed explanation, and as such this had the potential to be construed as leading informants and at times the researchers had to actively steer away from providing an educational service rather than undertaking exploratory research. Notwithstanding this one day centre helped establish a group of people who had learning disabilities and mental health problems and this proved very beneficial to the study.

Where self-advocacy groups proved elusive in becoming involved then other services were approached for example, day centres and Further Education colleges. We found that both support staff and people with learning

disabilities were keen to be part of the project when groups were run within their college or day service. Of the five established groups who were engaged with this research project the involvement of each was for a six week period.

**Insert table 1 about here.**

The numbers in each of the focus groups members were highly variable. The largest group had nine members as well as three to four staff supporting them; the smallest had two members with two support/carers. The majority of groups had between five to eleven members. Table 1 provides summary data on all of the individuals who attended the focus groups through the data collection phase of this study. Experience in this study related to both recruitment of and securing a representative sample of the population being studied, has led us to question about how representative self-advocacy groups are of the wider learning disabled population. This is raised as problematic because self-advocacy groups are often the first to engage in research such as this, and this is often because they present as a relatively accessible group of people.

### **Attendance**

Attendance at the focus group sessions was also extremely variable. Holidays and sickness caused some attrition to the number of people involved. Clashes between commitments did occur for example, a double booking between a focus group and a college course caused a dilemma for one group member who eventually opted for college as she had already '*paid her money*'. Of the focus groups that were conducted in 'community settings' we identified an added complication and that was one of transport. Despite initiatives to develop the skills of people with learning disabilities to access and use public transport people in this study were in the main dependent upon others for transportation. And even those who could use local public transport were entirely reliant on the vagaries of the bus timetables. Those wary of buses or unable to catch them were dependent on the good will of others for example, family, care/support staff, which in turn depended on staff



who were able to drive being in the employ of a caring agency. Map reading and punctuality were also found to be necessary skills equally both for people with learning disabilities and their supporters. On one occasion deficiency in both these areas resulted in one group member with Autistic Spectrum Disorder having to wait a considerable time for his very 'late' lift and this served to cause considerable distress whilst waiting. Taxis may seem a solution but carry with them a significant cost implication. Many people with learning disabilities are in receipt of one or more benefits and the mobility component rarely covers the cost of more than two taxis a week. Therefore researchers can inadvertently become competitors to other dimensions of a person's life that sometimes for example, means people with learning disabilities making decisions between shopping and a social life or attending a focus group.

Offers to help with meeting costs of fares were made but these were never taken up, possibly demonstrating the dedication of members to attend the focus groups. Only one of the four groups conducted within community settings has failed to work and a specific issue related to attendance issues caused this. The time, day and venue were not the most appropriate and did not fit in with the usual timetable and, or, interests of this group.

Within one day service 'dropping' in and out of groups appeared to be standard practice; wandering off for toilet breaks, returning late from lunch or just engaging in seemingly distracting behaviour. These unforeseen and unhelpful behaviours were often commonly accepted behaviours in learning disability settings but nonetheless had to be accommodated within the focus groups. Taking into consideration the nature of learning disability and its potential impact on concentration we found there was a need to sensitively manage groups at the member's pace whilst establishing clear parameters for conduct.

### **Ethical issues and matters of consent**

Arguably all research will encounter a range of ethical issues including matters relating to consent and in this respect focus group methodology is no

different. Focus group research has the potential to explore areas that may be deeply personal to group members. Therefore researchers need to establish clear and ethical methods of working that identifies what can be said within the group and what may or may not be discussed outside of the group situation. The relationship between the facilitator and participants should be one of mutual respect and interdependence, for example, participants may rely on the researcher's knowledge of the research process and the researcher on the knowledge that the participants hold which will enable them to inform the researcher in addressing research questions (Walmsley 2001, Walmsley 2004). It therefore beholds the facilitator to establish rapport with participants and develop a relationship built on trust (Northway 2000a). Ethics within the project is an ongoing process (Northway 2000b). This produces a challenge to the researcher to ensure that they do not take control over the process (Chappell 2000) and that power is held equally between all parties (Chapman et al 2004). The nature of the relationship between researcher and participants will have bearing on the data generated. People are unlikely to disclose important information to those they do not trust or who they perceive do not respect them. This ethical relationship lasts throughout the research process including the writing up and dissemination (Stalker 1998). As Tetley and Hanson (2000) have written:

*'The essential issue for researchers contemplating participatory research, therefore, is to recognise the power dynamics, skills and knowledge of all stakeholders and explore the ways in which those who are once the subjects of research can, if they wish, be empowered to participate, contribute and have control throughout the project.'* (Tetley and Hanson 2000, 3)

As this research project was being undertaken jointly between a University and a Health Trust and that we were using health care practitioners to locate at least some of the participants this project required Local Research Ethics Committee (LREC) approval. We found that the language, value base and assumptions about the nature of research, of this particular LREC, conflicted strongly with the more dominant social model approach more commonly adopted in learning disabilities. The social model that now dominates learning

disability is not easily reconcilable with the medical model, seemingly adopted by the LREC, and other commentators have also noted this (Ramcharan et al 2001).

With eventual ethical approval this necessarily led to a consideration of issues of consent and the complexities of capacity to consent. An 'accessible' brief was devised for the project that used simple language that was supported with pictures from Change (Change 1999). At the first meeting of each focus group for each of the series of groups that were conducted a briefing paper was given and explained to each of the participants. An 'accessible' consent form was also developed which was used conjointly with the briefing paper and all participants were given an option to sign it, or offer their verbal consent and for this to be recorded by their supporters or the researchers. Two people expressed reluctance but this was thought to be due to the language used, rather than expressing a wish not to be part of the group and thereby involved in the project. At some of the venues we also encouraged support staff to sign the consent forms and this seemed to assist in producing a feeling of camaraderie.

It is worth spending some time reflecting on whether consent was given as consequence of truly understanding the research project – informed consent? We would argue that on balance the answer is that participants did understand the research project. Whereas, the concept of the research itself may have been difficult to comprehend, we believe that group members did understand what was important about the project, and that they did understand that what they would say would be taped, and that it would then be analysed and subsequently an anonymised report would be written and then sent to them about what had been discussed. As importantly they knew that what they said, their views were pivotal to the entire project and as such we believe that all participants demonstrated capacity to consent.

### **Facilitation**

The focus groups were conducted using trigger questions developed from a county-wide workshop held in 2004 at Thames Valley University. These

trigger questions enabled the facilitator to enable discussion of a number of related themes that included an exploration with each group of what participants understood by health, mental health, the differences between good and poor or bad mental health, who offered them support and what their dreams and aspirations were for future services. The over arching aim within each of the focus groups was for the facilitator to focus the members' attention and to promote fluent discussion. There was an ongoing tension between fidelity to the principles of participatory research and the need to offer direction to the group in order to keep the group 'focussed'; although arguably this is an artefact of the facilitator's role. Proponents of participatory research have consistently argued that people with learning disabilities should direct research (Walmsley 2001, Chapman et al 2004). Whereas we attempted to fulfil the participatory ethos we have found a need for the facilitator to be directive at times otherwise we found that many hours could be spent on obscure topics by people who 'took the floor' and therefore dominated discussion of specific topics of interest to those particular individuals. Two examples of this were the oppression of people with Aspergers Syndrome by society and on another occasion all the different types of food that everyone liked or disliked. This we found caused a dissonance between the methodological commitment of participatory research with the practicalities as to how directive and how much information the facilitator should give to participants.

Within the context of this case illustration we found it necessary, in order to fulfil the role of facilitator, to develop a fairly extensive methodological 'tool kit' comprising different strategies and activities to attempt to keep different groups focussed. This means when running focus groups for people with learning disabilities, the activities offered need to reflect the different abilities of group members. One of the biggest challenges we have found for the facilitator has been to run the first session for each of the series of focus groups that we conducted completely 'cold', that is with no idea of group members' skills and abilities for example, communication, concentration, or the group dynamics for example, who usually dominates. In response to this we adopted flexible strategies to cope with this and always had at our

disposal a large box of resources and these were often required to facilitate ongoing discussion. In this box we made sure that we had a range of materials that included for example; pens, paper, scissors, pictures, magazines, books, easy to read material that had been developed elsewhere concerning health and or mental health. A full list of items used, their purpose, advantages and disadvantages to the process and outcomes of the focus groups is provided in table 2.

**Insert table 2 about here.**

As the sessions progressed informal assessment of ability dictated how to approach the various themes that were being explored in the research being undertaken. The group dynamics within each group situation was also problematic for successful facilitation. For example, those who dominated the quiet but deep thinkers as well as those too shy to speak up, have all at times proved challenging to the facilitator.

Booth and Booth (1996) on writing about interviewing people with learning disabilities have highlighted four main obstacles to discussion:-

- Inarticulateness
- Unresponsiveness
- Concrete frames of reference
- Problems with time for example, chronology of events.

Of these we found that the major obstacle for facilitation was that of needing to establish a concrete frame of reference, and we believe that this impacted on the ability to articulate, respond and make sense of events within a temporal dimension.

Arguably mental health is a complex concept for anyone to grasp, it is abstract. Whereas it is easier to discuss aspects of physical health for example, hearts, lungs because these can be concretised relatively easily-one can feel the heart beat or the lungs expand and if nothing else there are

'bodies' which can be taken apart to illustrate the case. By way of contrast mental health is concerned with abstract concepts such as thoughts and feelings this for some made it inaccessible area to talk about and this proved challenging. We found there was a need to decrease the abstract as much as possible but in such a way that the group were not being lead or manipulated into what the researchers wished to hear.

### **Data collection**

We have found that the use of pictures as a medium to assist in data collection has proved to be invaluable. Asking people to identify emotions from pictures; what makes them happy, sad and, or, frightened, who would support them in such situations, and using this as a cue to name local resources for example, hospitals, were all central to enabling us to assist participants focus their discussion. Equally we found that asking participants to produce their own pictures for example, to draw to who they would go for help, their General Practitioner, their ideal person for support was also very helpful. We have found that this 'concretising' and anchoring of discussion in lived experience facilitated discussion enabling it to take on some reality when expressed in at least two dimensions – participants being able to say 'this is 'x' and I like them because .....

An additional advantage of using pictures was having something for participants to 'take home', one participant was particularly proud of being able to show her mother the picture she had drawn of her. Another participant from a different group liked to have something tangible to take from the sessions and colour printed pictures met their needs in this respect.

We also experimented with video vignettes from popular television soap operas but our experience was that participants were keener to identify and engross themselves in episodes of 'Casualty' or a 'Touch of Frost' [both popular English television programmes] than the emotions that we thought were being portrayed. Additionally a board game was devised. Whereas this required a lot of concentration throughout the game, using chocolates as counters certainly assisted in focussing the attention of participants; but unfortunately this strategy did not facilitate much discussion. Cards with

statements about services adopted from the Green Light to Mental Health (DoH 2004) and Our Mental Health by the Tuesday Group (2004) also proved helpful for participants in deciding what was important to them and why; although we found the latter far more accessible to the participants that we worked with. The former from the Department of Health proved somewhat cryptic and inaccessible to our participants. A selection of mental health resources from a variety of sources for example the British Institute of Learning Disabilities, the Estia Centre, the Department of Health and the Elfrida Society were all incorporated into facilitating discussion by our participants in talking about different aspects of mental health.

We have learnt that having two audiotape recorders at different ends of the table(s) ensured that the quiet word to a support worker was not missed even if it was not actually heard during the group session. Often it was the quiet words that were most revealing. We also found that promoting turn taking activities enabled the quiet to be heard and to speak with confidence.

### **Venue**

As described already the focus groups were conducted in a multiplicity of settings that has included community halls, day centres and Further Education Colleges. Producing an environment that was conducive to discussion has proved difficult on a number of occasions. One college room was long and thin with a formal desk arrangement for the 'students' in a single line with space for their tutor at the front and at a very practical level this meant that seeing the entire group at once was in this instance impossible. In one day centre there was a variety of chairs and as the group gathered around the table some could be seen and others not due to mix of seat heights. Entering a day centre or college to run a group had the added disadvantage of the researcher walking into another's territory. There are rules that are set out and must be obeyed for example, lunch is at 12.15pm and the session will then end no matter where the group is in the discussion. We have learnt that the researcher has to approach each venue with a degree of wariness for in those settings participants and support staff seem to feel that they are on home territory and their original commitment to the research

project sometimes became lost in the familiarity of the sameness in which they are located. So on the one hand a familiar setting may assist participants to relax and feel comfortable but conversely we found that it could also hinder discussion in the focus groups. For example we found that whereas some behaviours were tolerated in some settings as unproblematic they compromised the researcher when establishing ground rules for the conduct of participants in the focus group.

Venues within community settings have an advantage of making the focus group new and exciting. There is an advantage for the researcher of being able to control the layout of the room and also build in flexible tea and coffee breaks. However, as might be expected such venues frequently come with their own challenges too. We encountered problems with keys and for example, the lock at one hall was broken, we also experienced poor attendance by care takers, chairs and tables were sometimes locked away and this could necessitate further journeys for extra keys. In one setting there was the distraction of the weekly line dancing session which began as the focus group ended and this caused much amusement with some attempts by participants of the focus group to join in.

### **Payment**

Paying people with learning disabilities to participate within focus groups is highly contested. Should researchers make such payments, we believe that they should and there is precedence for this (Cote-Arsenault et al 1999). It is their unique knowledge and specific information from them, and only them that the researcher is seeking and we would argue that this has value, and in our society we pay for items of value. Notwithstanding this we found payment of individuals to be almost impossible within the financial regulatory systems of a University. Therefore we made clear from the onset that we were not in a position to offer payment and that their involvement represented an altruistic interest in the work being undertaken and subsequent outcomes. However, at each of the focus groups all participants were offered tea, coffee and chocolate biscuits. This should not be dismissed as trivial or unimportant we learnt that the value of tea, coffee and chocolate biscuits in research should



not be underestimated. The importance of being rewarded and this reward, no matter how humble, being offered simultaneously with what was being said respected and valued was important. And whether that was achieved by weekly tea, coffee and biscuits or chocolates at the end of the six week series of focus groups we have learnt was immaterial, that it was achieved was of primary importance. Would money have proved a greater incentive and been a more powerful inducer of discussion? Possibly so and certainly it would be equitable with other groups of participants involved in similar focus group methodology. But often those participants to whom money is important are the people who are aware of the precarious nature of income to the benefit system and so they may well prefer 'goods to cash'. The promise of, and the eventual realisation of a commitment to acknowledge the contribution of participants to the work being undertaken appeared as tangible and important a reward to the participants of this study as any material reward.

## **Conclusion**

It may appear from this paper that running focus groups with people with learning disabilities is fraught with methodological and practical issues and we would argue that these have not always been reported on fully in the research literature. Additionally we would argue that other researchers in the field have not written about practical strategies that might usefully be employed to overcome some of the difficulties that might be encountered in the field. We have tried to counter these difficulties by adopting a wide range of strategies and recounting these challenges that other researchers should try and avoid. The strategies we found of particular use included having a range of activities for participants that made the topic being discussed as concrete as possible. We have learnt that facilitators and researchers in using this methodological approach need to be flexible and this will include using breaks when participants need them and avoiding persevering with a topic when they either don't understand or have personal experience of it. The facilitator needs proceed at the group's pace as much as possible and ensure that the environment remains familiar and comfortable. We would advocate the importance of ensuring all are seated around a table together this gives the group purpose and a focus. It is important to allow participants space to come

and go as they chose. It is of paramount importance to keep the group's interest and this we achieved through a variety of different activities/tasks that enabled the group to remain focussed on the topic, and this will require the facilitator to offer activities at appropriate level for the group and individual participants. From our experience we learnt that no two groups reacted in the same way to any given topic – much of what is discussed will depend on the life experiences of the individuals. Self evidently if a topic has no relevance to participants or their life they will not be interested in discussing it, any more than anyone else would. We would suggest that running groups over a period of time encourages rapport and trust. And that this element of the research was supported by the researchers joining participants at more informal times for example at tea breaks or sharing lunch with them. The facilitator should allow participants to be in control as much as possible for example in positioning tape recorders, changing over tapes and even turning tapes on and off. It is important to establish group rules at the first meeting and this should include issues such as interrupting others, turn taking and the use of mobile phones. We would advocate that facilitators should be honest and open about their own knowledge and experiences and if asked a question then it should be answered truthfully. This methodological approach also demands that their views and opinions are all valued and treated with respect. Finally on closure it is important to thank participants at the end of the group, congratulating all on the hard work of the group and where appropriate to offer some form of tangible reward – in our experience chocolate was always well received. Notwithstanding the challenges and strategies necessary to overcome them we are of the opinion that such frustrations can be found in a range of alternative methodological approaches that could have been used. Further that the use of focus groups in this present study has enabled us to establish unique and original insights into how people with learning disabilities understand and construct mental ill health and other methodological approaches may not have surfaced these insights.

It is the case that for many years the emotional needs of people of learning disabilities have been ignored, subverted or disregarded. There are those who in the past who would even deny that people with learning disabilities had

feelings (Hatton et al 2005). In the context of this present study we have noted that as the focus groups progressed it became apparent that people with learning disabilities care deeply and are hurt as deeply when degraded, stigmatised and abused as is the rest of society; that they have important stories and experiences to tell especially with reference to their mental health, and at the very least they deserve to be listened to. We believe this methodological approach is enabling us to construct unique ways of understanding how people with learning disabilities understand their mental health and what kinds of support they would like to receive; paradoxically the clearer the picture becomes the level of detail makes its interpretation ever the more challenging to understand.

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**Table 1 for focus group article**

Group	Recruitment	Location	Group Composition				Ethnicity			Diagnosis					Level of Learning Disability	No of Sessions
			Total	average	gender		W	A	B	DS	ASD	CP	VI	MHP		
					M	F										
A	Advocacy group	Community hall	8	5.3	3	5	8			2				3	Mild-moderate	6
B	Advocacy group	Community hall	11	7	3	8	11			4	1		2		Mild - moderate	6
C	College	College	8	6	6	2	6			1	1			3	Moderate-severe	6
D	Advocacy group	University	7	5.3	4	3	4	3		1				2	Mild-moderate	6
E	College	College	9	8.3	4	5	8		1	4				1	Moderate-severe	6
F	Day centre	Day centre	6	4.8	4	2	6			1	2		1		Severe	6
G	Advocacy group	Community hall	7	1.75	0	7	7			2					Moderate - severe	4*
H	Day centre	Community hall	12	7.5	6	6	12			1		1			Moderate-severe	6
I	Day centre	Day centre	5	4.6	1	4	4	1		1		1			moderate	5☞
J	Day centre	Day centre	6	4.16	1	5	6							2	moderate	6
K	Advocacy group	Community hall	6	4.4	5	1	6			1					Mild-moderate	5☞
Total			85	5.5	37	48	80	4	1	18	4	2	3	11		62

\* 2 sessions no one attended and group cancelled after 4<sup>th</sup> session – clashed with day service programme and there were transport difficulties

☞ 1 session cancelled due to heating problem at day centre

☞ 1 session cancelled due to support worker not being available

KEY: Gender; M= Male, F = female, Ethnicity; W = white British, A = Asian British, B = Black British, Diagnosis; DS = Downs Syndrome, ASD = Autistic Spectrum Disorder [including Aspergers syndrome], CP= Cerebral Palsy, VI = visual impairment, MHP = know history of mental health problem e.g. on medication, seeing psychiatrist or psychologist.



Table 2 Items used, purpose, advantages and disadvantages to the process and outcomes of the focus groups.

ITEM	USE/ROLE/PURPOSE	ADVANTAGES	DISADVANTAGES
<p>Pictures:  Things that may make people happy or that they enjoy doing  Things that may make people sad  Things that may make people frightened</p>	<p>To encourage discussion of a particular theme  To provide some concrete prompts</p>	<p>Enabled group members to make selection of items that meet the theme under discussion  Engaged group members in activity  Encouraged group members to talk about the theme in feedback session  In general group members appeared to enjoy selecting pictures especially for the first theme</p>	<p>Selection of pictures limited to what had previously been chosen by facilitator  Activity dependent on visual-perceptual skills of group members</p>
<p>Single picture from Change CD of depressed person – sitting with head in hands</p>	<p>To encourage discussion of how the person felt and then what would happen if the group members felt the same</p>	<p>Provided insight into group member's perceptions of feelings  Enabled some group members to identify with the picture  Promoted discussion</p>	<p>Varied interpretation of the picture for example, horror that the person was wearing not shoes, concern that they might have measles</p>
<p>Support cards – sets of cards depicting three support groups:  Family and friends  People paid to be there for example, GP, psychiatrist, CTPLD member, day service worker  General public including religious leader, senior managers within services, self advocacy groups (usually local group named) – Change Picture bank used</p>	<p>To look at the different groups of people who might provide support – the cards were used as a memory prompt as well as to encourage group members to think about the different people they encounter</p>	<p>Fulfilled purpose  Promoted discussion</p>	<p>Pictures on cards not always clear about who the person actually was</p>
<p>Statement cards – statements from Lewisham Tuesday Group Paper and Green Light for Mental Health (DoH 2004)</p>	<p>To encourage discussion about services and rights pertaining to people with learning disabilities and mental health problems  To examine some of the</p>	<p>Encouraged discussion and enabled group members to think about what was important to them in both sets of statements</p>	<p>Statements from the Green Light for Mental Health (DoH 2004) often too long and complex for people to understand. They were also quite repetitive at times.</p>

	statements from the Green Light for Mental Health (DoH 2004) and see how people with learning disabilities responded to them		Hospital statements difficult for people to understand if they had not receive inpatient treatment for mental health problems On one occasion collecting the card became more important than listening to the statements
Photographs of local hospitals	To introduce the topic of hospitals and inpatient care to the groups To establish local knowledge To encourage the telling of personal stories regarding hospital To show what and where the different in-patient services were	Promoted discussion Encouraged story telling – many people were able to relate their own experiences of local hospital services Provided some information for group members for example, about the newly built mental health hospital Was a concrete reference point for discussion	Concentration from the group members was on physical rather than mental health
Pens and paper for drawing for example, favourite person – such as their GP	To enable group members to produce their own picture for the topic under discussion	Flexible activity could be done as a group or as individuals also people could draw or write as they preferred Perceived as a fun activity Encouraged discussion Enabled everyone to participate Provided supplementary data to support tape recordings	Individual activity when being performed and therefore most of the discussion was concentrated in the feedback sessions
Selection of different information sources for example, books, leaflets, about mental health, local services, - these were both locally and nationally produced	To examine different types of information and decide which ones the group members thought were the best	Encouraged discussion Enabled everyone to participate within the activity Promoted choice Educational for both group members and support staff	Individual activity when being performed and therefore most of the discussion was concentrated in the feedback sessions