Looking Into Abuse: Research by People with Learning Disabilities

Study Protocol (Stage Two)

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This protocol provides further details concerning the origins of the study, the study design and the management of the project. It complements the information provided within the easy read ethics form and study plan which have been developed to promote greater access for all members of the research team.

The original idea for this research came from people with learning disabilities who were concerned about abuse and who felt the need to develop ways of keeping people safe. They also wished to develop and be involved in a research project. The overall approach is thus one of participatory research which:

Recognises that in the past the views of people with learning disabilities have not been sought in research. Research has tended to be undertaken ‘on’ rather than ‘with’ them (Kiernan, 1999)

Recognises that people with learning disabilities are the best people to comment on their lives and experiences (Richardson, 2000)

Facilitates the active involvement of people with learning disabilities in the research process (see for example Abel *et al*, 2007; Ham *et al*, 2004).

The three year project and the application for research funding were developed in a participatory manner with the active involvement of people with learning disabilities. The project commenced in May 2010 at which point both the three co-researchers and the project research assistant were in post. Since this time work has focused on developing the skills of the research team, developing the information sheet, data collection tools and practicing data collection. The process has been overseen by the Research Advisory Group who meet on a 2 – 3 monthly basis. Over 50% of the members of this group are people with learning disabilities with other members representing parents of people with learning disabilities, the three organisations collaborating in the project, and supporters of self advocates who are attending the meetings. The group is chaired by Lynne Evans who is a woman with learning disabilities. Fuller details of how people with learning disabilities have been involved in the development of the project are included in Appendix 1 and are illustrated throughout this protocol.

Project development has also been supported by a Specialist Interest Group. This group comprises representatives of a range of agencies including local authorities, the Police, health services and the voluntary sector. This group provides advice, acts as a source of information concerning current practice issues and also acts as a route for disseminating information regarding the project. It provides the project team with access to a range of experience and expertise including that relating to psychology, health and social policy, criminal justice, the Independent Mental Capacity Advocacy Service, self advocacy, counselling, speech and language therapy, social work and nursing. A number of group members also have extensive experience in relation to the development and implementation of vulnerable adults policies.

The project is being funded to a total grant value of £417,633 by the Big Lottery Fund. It is a collaborative study which is being undertaken by the Unit for Development in Intellectual Disabilities (UDID), University of Glamorgan, in partnership with New Pathways (an organisation which provides post sexual abuse counselling) and Rhondda Cynon Taff People First (a self advocacy organisation of people with learning disabilities). New Pathways are the grant holders.

An initial application was made to the HESAS Ethics Committee in December 2009 for outline approval for the project. This was granted and funding was released. It was stressed that no data would be gathered until approval for the process of data collection had been obtained and that this could only occur once the research team were in post and had had the opportunity to develop the data collection tools and other relevant processes. It is this level of ethical approval which is now being sought. Khanlou and Peter (2005) note that the need to return to ethics committees for approval on more than one occasion is a reflection of the nature of participatory research which by definition requires discussion and agreement with all members of the research team before decisions can be taken. However, it is also argued that participatory research can promote greater ‘ethical acceptability’ since it gives people more control over the research process (Thomas and O’Kane, 1998). Since prospective participants for this study will be approached via community groups rather than via the Health Service no external (NHS / ADSS) research ethics approval will be sought.

# Background and Rationale

People with learning disabilities are acknowledged as one of the most vulnerable groups in society. Studies give estimates of abuse ranging from 30 – 50% (McCarthy and Thompson, 1997; Mencap, 1998; White *et al*, 2003). Identification of abuse is recognised as problematic since not all abuse is recognised as such, recognised abuse is not always reported and even where it is reported further action is not always taken. The issue could thus be greater than these figures suggest. It is normally staff who are asked to report abuse with little involvement of the people who have been affected (Sobsey, 1994; Moss, 1998; Brown, 1999; DoH, 2000; White *et al*, 2003). People with learning disabilities have, however, stated that when they do report abuse they are often not kept informed or are not believed (Magill *et al*, 2010). It is probable that such a lack of response will make them less likely to report abuse in the future should it occur.

Adult protection investigations often start with ‘very little reference to the feelings and attitudes of the victim’ (Lawson, 2001). Government guidance has focused attention on this issue and services have developed adult protection / abuse policies (Department of Health, 2000; National Assembly for Wales, 2000; Mathew *et al*, 2002). However, policies themselves do not protect – it is how people act differently as a result of the policy that protects (Cambridge, 1999; Northway *et al*, 2004). People with learning disabilities are rarely consulted on policy and often not know what is available to protect them. They may not know how to keep themselves safe from abuse (Bruder and Stenfert Kroese, 2005). 70% of organisations surveyed in one study (Northway *et al*, 2004) did not provide information for service users in their adult protection policy.

Research has often failed to ask people with learning disabilities what they think and feel about abuse although it is acknowledged that they are the best people to comment on their own lives and experiences (Ward, 1999; Richardson, 2000). Equally little is known about what matters to people with learning disabilities after abuse; what they do to keep safe and what they think needs to change. There is thus a gap in the literature. Research after abuse tends to focus on lack of convictions and ensuring justice although there is growing evidence that psychological therapies are beneficial for people with learning disabilities (Corbett *et al*, 1996; Hollins and Sinason, 2000; Royal College of Psychiatrists, 2004; Willner, 2005; Peckham *et al*, 2007).

Too often people with learning disabilities have been the subject of research with no control over what is researched, how it is done or what happens to the outcomes. Academics and policy makers often decide the agenda (Kiernan, 1999; Ward, 1999). Participatory research aims to give power back to disabled people and to bring about change both in research and wider society (Zarb, 1992; Finn, 1994). It involves people with learning disabilities working as co-researchers and being actively involved at all stages of the research process (Northway, 1998; Northway, 2009).

This research aims to address both the concerns of GRAB[[1]](#footnote-1) Members and the important gaps in the literature identified above by undertaking a participatory study. We have made enquiries but are not aware of similar work being undertaken anywhere else. Furthermore, the information gathered from the study will be used to directly inform the development of counselling provision for people with learning disabilities via New Pathways. At present such a service does not exist in South Wales. This commitment to the production of knowledge in order to bring about action and change are key elements of the participatory research approach (Northway, 2010a).We also aim to reflect upon the process of working together in the context of this project in order that we may learn more about the practice of participatory research and also so that we can share this information and further progress the development of this research approach. The need to gather such information regarding both the process and findings of participatory research has previously been noted (Royal College of Nursing, 2007).

# Study Aims and Research Questions

This project aims to:

Develop better ways for people with learning disabilities to find support after being abused and to prevent abuse.

Develop more detailed information on how participatory research works for all concerned.

Disseminate research findings to people with learning disabilities and professionals

The specific research questions it seeks to address are:

What do people with learning disabilities understand by abuse?

What are their views about abuse?

What help and support do they need to keep safe?

When someone has been abused what are the best ways to help?

# Core Research Team

Three people with learning disabilities have been appointed to work as co-researchers (Samantha Flood, Melanie Melsome and Davey Bennett). They are employed by RCT People First to work 3.5 hours each per week on the project. Prior to interviews for these posts a research information day was held to introduce prospective applicants to the research process and this specific project. The co-researchers were also involved in the interview process for the full time project research assistant (Joyce Howarth) who is employed by the University of Glamorgan.

Each of the co researchers has a personal assistant who supports them in a range of activities such as reading and understanding key documents, developing research tools, preparing for meetings and undertaking practice data collection. They also provide support with travelling to appointments as required.

Within RCT People First both the co researchers and their personal assistants are supported and supervised by Emma Alcock who has taken on the role of Participation Officer. Emma meets with them on a regular basis. In addition Victoria Jones (University of Glamorgan) acts as participation advisor and in this role provides support in areas such as ensuring accessibility of information, promoting participatory approaches and collating the reflective accounts completed by team members. Ruth Northway (University of Glamorgan) provides support as the research manager which includes participation in project planning and providing advice regarding research approaches and ethical requirements.

In the first year of the project there has been a strong emphasis on team development and training. This is an important component of participatory research (Northway, 2010b) and seeks to promote an ethical approach by ensuring that all involved are provided with adequate support to develop their skills and to feel confident in their role. All team members attended two half day team building sessions in August 2010. In January 2011 the team met to plan the activities which need to be completed during 2011 with an emphasis on preparing for this ethics submission and ensuring that everything is in place for data collection. Further training has also been provided for the core team in relation to each of the three data collections methods (see below). In each instance this has involved discussion regarding the approach, participating in the approach as a research subject and practising the approach. Opportunities for practice are being provided on a regular basis to ensure that skills learnt are maintained in readiness for data collection. Throughout this process we have also discussed ethics on a regular basis and have talked about what needs to be in place to keep participants and the research team ‘safe’.

# Study Design

One activity which is continuing throughout the study is the development of an accessible literature review relating to the four study questions. Key literature has been identified and this is being converted into easy read versions so that the co researchers can then consider what has been said and how it relates to the questions. In addition other media such as DVDs are being identified and reviewed. The aim is to produce an accessible literature review by the beginning of 2013 and to thus provide access to up to date information in formats which can be used by people with learning disabilities.

## Data Collection Methods

Before discussing the specific methods of data collection it is important to note some general principles which were considered both to ensure that the research team receive the appropriate support to facilitate their role as researchers and to ensure that participants are able to understand what is being asked of them. Key to this is the need to ensure that information is provided in formats which are accessible to those who use them. It will be noted throughout, therefore, that all written information has been developed in easy to understand formats which use larger fonts and colour, pictures to reinforce written language and language which is as simple as possible. All of the materials have been reviewed by people with learning disabilities to check their accessibility and acceptability and changes made where necessary. Where an activity is referred to in a number of different materials (for example the information sheet and the consent form) then the same picture / symbol has been used to promote consistency and aid understanding. Data collection activities have also been developed to actively engage participants rather than just posing questions which may otherwise be rather abstract.

In developing the interview and focus group schedules attention has been paid to meeting the specific support needs of the individual co-researchers and thus some variation will be noted. For example in some instances different coloured fonts have been used as an additional cue as to who should be saying what. The co-researchers will continue to practice using these schedules between now and the time of data collection.

To ensure that as many people as possible are enabled to participate we intend to use three methods of gathering information – focus groups, individual interviews and questionnaires. These have been mapped to the research questions to ensure that all questions will be addressed by at least one of the methods of data collection (see Table 1 below)

|  |  |
| --- | --- |
| **Research Question** | **Method of Data Collection** |
| What do people with learning disabilities understand by abuse? | Focus group  Individual interviews |
| What are their views about abuse? | Focus group  Individual interviews |
| What help and support do they need to keep safe? | Questionnaire |
| When someone has been abused what are the best ways to help? | Questionnaire |

**Table 1: Methods of data collection mapped to research questions**

Each of the data collection methods is now explored in more detail:

### Questionnaire

This is a simple, anonymous way to take part. Short questionnaires have been used in other research involving people with learning disabilities. For example in one study (Townsley and Gyde, 2007) 16 short questions were used each accompanied by appropriate illustrations. Thirteen of the 16 questions could be answered by ticking a box although space was left for people to make comments if they so wished.

The survey tool for this study (Appendix 2) has been designed in an accessible format which mostly requires only a tick box response (although there is opportunity for further comment if desired). The focus in this aspect of data collection is on research questions 3 and 4. This was decided upon as these questions are more general in focus and the risk of someone being emotionally upset is less. This is important since some participants may wish to complete this activity independently. The front sheet of the questionnaire provides information concerning the project and how it will be used.

The questionnaire has been tested with people with learning disabilities from outside of Wales and achieved a good response and favourable feedback. No major changes were required as a result of this feedback.

### Focus Groups

Focus groups have been used in other studies involving people with learning disabilities (see for example Barr, *et al,* 2003; Fraser and Fraser, 2001; Gates and Waight, 2007). They are seen as an important way of including people in research who might otherwise be excluded due to limited skills in relation to reading and writing although it is acknowledged that they can still exclude those with limited verbal communication (Barr *et al*, 2003; Cambridge and McCarthy, 2001). To maximise participation it is essential that group moderators are well prepared, that informed consent is achieved and that accessible information is used (Barr *et al*, 2003).

Some people in this study may wish to join such a small group discussion (about 4 – 8 people). This way they can say as much or as little as they want. The format of the focus group and the topic guide for the group are appended (see Appendix 3). It will be noted that the groups will commence with introductions in order to put participants at their ease and get them used to speaking within the group (see Appendix 4) . The ‘ground rules’ for the group will then be discussed and checked with everyone (see Appendix 5). Following this formal consent will be obtained (see Appendix 6) and participants will be reminded that it is OK for them to leave at any time.

In developing the format for the group the key challenges were trying to facilitate discussion of an abstract question (what do you understand by abuse?) without leading participants into a particular way of answering. Furthermore we wanted to structure the group such that the focus was not on them as people who may potentially be abused but rather on what they think abuse is. After much discussion it was agreed that photographs of people would be used (see Appendix 7) and that participants would be asked how they thought the people in the photographs might be abused. If then a particular form of abuse is identified an ‘object of reference’ would be put on the table to signify that form of abuse (see Appendix 8 for examples of such objects). Objects of reference are objects which assist communication. They are used to represent events, ideas, people etc. and provide a ‘bridge’ to more complex forms of communication such as words (Park, 2003). In this instance they will be used firstly to provide a more tangible reminder of a particular form of abuse (for example a walking stick indicating physical abuse) so that participants have an additional prompt to aid memory. Secondly, they will be used in the second part of the group to facilitate comparison between one form of abuse and another. The inclusion of a range of activities within such groups has been found to be helpful (Gates and Waight, 2007) and this particular format was tried with a group of people with learning disabilities from outside of Wales and was found to be both acceptable and to gather the information we are seeking. At the end of each discussion a reminder of the availability of the counsellor will be given.

The focus groups will take place during the residential workshop (see below) and we anticipate that up to 7 groups may be held. Each group will be moderated by the research assistant and a co-researcher. The groups will be audio or video taped according to the consent and preference of the group. A ‘stop’ card (see Appendix 9) will be given to participants to hold up should they wish to withdraw from the group at any time.

### Individual Interviews

Not everyone feels comfortable in groups so we will speak with people one-to-one if they prefer. Some people may wish to be video recorded or the interview can be audio recorded if they prefer. The interviews will be conducted by one of the co-researchers and their personal assistant. Over the course of the residential (see section below) we have planned for up to 14 to take place.

The interviews will focus on the same research questions as the focus groups and some participants will take part in both activities. Where possible, therefore, the individual interview will take place before the focus group for that individual concerned and where this is not possible then a gap between the two activities will be scheduled to avoid contamination of data as much as possible. However, despite the focus in the interviews being on the same two research questions the approach taken will be different. Appendix 10 contains details of the interview schedules for the interviews. It will be noted that there are two schedules and that there are some differences – this is to allow for the individual needs of the co-researchers as previously discussed. Interviews will commence with introductions and completion of the consent form (Appendix 11). The main part of the interview will then focus on the sorting of photographs (Appendix 12) according to whether the participant feels they depict abuse, they don’t depict abuse or they are unsure and discussion arising from this activity. As with the group interviews participants will be provided with a ‘stop card’ (Appendix 9) to hold up should they wish to terminate the interview at any stage.

These interviews have been practised with people with learning disabilities from outside of Wales and they were found to be appropriate and acceptable. Only minor changes were made as a result of this activity.

These methods of data collection will be used in two ways:

### The research residential

In preparing this proposal we talked to other projects that work with people with learning disabilities to get ideas as to how to collect data. Because people with learning disabilities need to trust the researchers a research residential was suggested as providing the best opportunity to get involved. This approach has been used successfully by other voluntary groups who have wanted to gather information.

Over the course of the three day research residential people will have the opportunity to:

Learn more about the project, what we are doing and why we are doing it

Ask questions about their participation

Attend an informed consent session where people can learn about their rights as participants and can give consent to participate (see Appendix 13 for the general residential consent form) If they choose not to participate in the data collection they can still take part in the social events.

Get to know the research team, other support staff and the specialist counsellors as well as making new friends with people with learning disabilities from other areas.

Participate in focus groups, video or audio interviews and the questionnaire

Enjoy a series of relaxation and fun events these could include walks, music sessions, guided relaxation, drama and disco

The hotel for the research residential has been booked for November 16th – 18th 2011. The criteria for choosing the hotel were developed by members of the Research Advisory Group and a small group of RAG members undertook visits to three hotels and made a final choice based on these criteria. The facilities the hotel will offer include a large room for leisure activities and the initial introductory session and closing sessions. Some smaller rooms for activities and for the focus groups and individual interviews will also be available and a private room for counselling.

A provisional plan for the residential is attached (Appendix 14). It will be seen that it will commence with a large group session which will facilitate introductions, housekeeping arrangements and information sharing regarding the project (see Appendix 15). It is also intended that this will provide the opportunity for seeking initial consent and for completion of the questionnaire if participants are willing to fill this in. Consent will be sought again before any further data is gathered via individual or group interviews. The programme has been arranged to provide a balance of research (work) activities and leisure based activities. Throughout members of the research team will be on hand to deal with any queries and volunteers (who have been CRB checked) have also been recruited to assist with manning a central information point, assisting with orientation and leisure activities.

### Postal Survey

We want to ensure that people who are unable to attend the residential workshop are still able to contribute. In addition to seeking the participation of people attending the residential we will therefore send copies of the survey to groups of people with learning disabilities across Wales for anonymous postal return (please see Appendix 16 for letter of invitation). We will use our networks of contacts (for example All Wales People First) to identify where we can send them. We will include a reminder that if individuals have already completed a survey at the residential then they do not need to complete another one. Questionnaires will be returned to us using a Free post address.

Postal surveys have been used in other research involving people with learning disabilities. For example in one study self advocacy groups in England were surveyed using a short questionnaire which used appropriate illustrations to support each question (McNally, 2002; 2003). This postal survey achieved a positive response rate of 53%.

## Participants

We want to give lots of people with learning disabilities the chance to take part. However, we realise that it is often difficult for people with severe learning disabilities to take part in research or give informed consent. Most of the people who take part will probably have mild or moderate learning disabilities. However, within the focus groups we have included some questions relating to people with more severe disabilities as we think there might be some different issues and they may suffer some different abuses. We have to consider these but cannot presume what people think. We discussed this with people with learning disabilities in GRAB to see what they thought about this. One said ‘we probably have more idea what it’s like for them (people with severe learning disabilities) than other people do.’

All participants in this study will be over 18. In relation to the residential then we have 50 places available for people with learning disabilities and 25 places for their accompanying supporters. We will recruit participants via People First Groups and Social Enterprise Groups within South Wales. Initially a letter of invitation (Appendix 17) participant information sheets (Appendix 18) will be sent out to groups along with the DVD (Appendix 19) which has been developed to provide information in an alternative format to promote accessibility. If the groups so wish then members of the research team will also visit to provide information and to address questions. Members of the groups then have the opportunity to decide whether or not they wish to take part and to discuss it with relatives or carers if they choose to. Should they then wish to participate we will ask that they complete and return to us (via Freepost) a pro forma (Appendix 20) which provides demographic information and contact details. This information will be used (anonymously) to demonstrate to funders that diversity issues have been considered in relation to the sample. Also it is impossible at this stage to determine what the level of interest will be. If we receive over 50 applications then this information will be used to ensure that we include people from a range of geographical settings, genders, support needs, ethnic backgrounds etc. Anyone who expresses an interest in participating but who we are not able to offer a place to will be thanked for their interest and invited to complete the questionnaire. Acceptance letters will be sent out to those people for whom a place is available (Appendix 21) and they and their supporters will be asked to confirm acceptance of the offer of a place (see Appendix 22)

In relation to the postal survey we will distribute 500 surveys via People First Groups and other groups identified by our networks across Wales. We hope to get a good response rate by making the survey quick and easy to complete and by giving information via an information sheet (Appendix 23) that answers questions people might have. Based on a low estimate of a 10% response rate we would have collected data from 100 people with learning disabilities (combined residential weekend and postal survey). We hope, however, that this number will be higher.

## Data Analysis

We will find ways to analyse data which are useful to our co-researchers on the project. For this reason it is still difficult to be precise at this stage regarding data analysis as it will depend upon their particular strengths and support needs. We will also use the experience of people who have undertaken analysis in other participatory studies. For example one group (Kramer *et al,* 2011) found that all group members with learning disabilities were able to participate in the initial data analysis but there was greater variability in relation to participation in data interpretation. Approaches which they found helpful included reducing data into ‘chunks’, using visual representations, using a modified focus group approach to facilitate group analysis and group members familiarity with the questions.

Most of the data gathered will be qualitative (from interviews and focus groups) but some will be quantitative (from the questionnaire). In relation to the qualitative data we will make use of visual tools so that we can make maps between different ideas and see how things fit together. The aim will be to find common themes and messages in the information people give us. In relation to the quantitative data we will count frequencies and calculate percentages. We will make use of N Vivo and SPSS or Excel to assist us in data analysis.

Before we analyse the data gathered in the project we will practice data analysis using other information so that the team can develop the necessary skills.

## Researching the Process of the Project

Participatory researchers have been criticised for failing to provide sufficient details about their studies to enable others to fully understand the approach which has been taken (Reason, 1998). Also, within participatory research, the process of working together to undertake research can be as important as other things which are learnt during a study. For these reasons the project team keep reflective diaries of their experiences of working on the project. We will use this information to tell other people about what worked well and what was not so good. Already we are in the process of drafting two articles for submission to journals one of which relates to getting funding and one which relates to what it is like to become a researcher. In addition an article has recently been published concerning the process we used to select a hotel (Evans et al 2011).

Already the team feel that they have learnt a great deal as a result of working together on the project. Such learning includes how we can work together in more inclusive ways and how we can challenge systems to be more inclusive. Development at a more individual level has also taken place which includes aspects such as increased confidence and enhanced creativity.

# Ethical Issues

The subject of this research (abuse) is one which might be considered to be sensitive and the participants (people with learning disabilities) are one group which have often been considered to be ‘vulnerable’ in the context of research. A number of complex ethical issues may thus arise. However, these need to be balanced against the fact that not undertaking such research also has ethical implications such as depriving ‘vulnerable’ groups of the benefits of research (Smith, 2008) and continuing the historical situation in which the voices of people with learning disabilities were not sought or heard. Indeed it is argued that some questions can only be answered by members of ‘vulnerable’ groups and that only when they are provided with the opportunity to engage in research will standards of care and quality of life be improved (Weaver *et* al, 1999). As Liamputtong (2007) has observed a failure to undertake such research may thus increase vulnerability which would appear to be the antithesis of policy and practice in relation to the abuse of people with learning disabilities. The challenge is thus to develop ways of working which facilitate valid consent and which achieve an appropriate balance between benefits and harms. Members of the group who developed this proposal have previous experience of gaining ethical approval for a participatory research study (Ham *et al*, 2004).

## Consent

We recognise that people’s capacity to consent may be enhanced by the provision of information in appropriate formats and at appropriate times. For this reason a staged approach to seeking consent will be adopted. It will be an on going process of ‘review and negotiation’ (Abrahams, 2007). First information in accessible formats (written and DVD) will be sent to groups of people with learning disabilities (Appendices 18 and 19). Next, if the group is willing, members of the research team will visit to talk about the project and answer any questions. Potential participants will have the opportunity to discuss the project with others if they so choose before making a decision. If individuals then choose to go to the residential weekend they will attend another session which will discuss the project and ways in which they can participate before seeking their consent. However, as previously discussed this consent will again be checked before the commencement of interviews and focus groups and it will be stressed that it is OK to withdraw consent at any time.

It may be that some individuals, despite using the process outlined above, are unable to provide valid consent. The Mental Capacity Act 2005 stresses the need to start from a presumption of competence, that capacity can fluctuate and that it is situation specific hence the need to recheck consent at the beginning of each data collection activity. Furthermore the Mental Capacity Act states that for consent to be valid the individual needs to be able to:

* Understand information which is relevant to the decision
* Retain the information
* Have the ability to use or weigh the information in order to make a decision
* Communicate their decision (whether by talking, sign language or other means)

Should it be deemed that an individual does not meet these criteria then they will be thanked for their interest in the study but data will not be gathered from them.

In relation to the postal questionnaire then return of completed questionnaires will be taken as informed consent.

## Confidentiality

All personally identifiable data (for example consent forms and application forms) will be kept securely and separately from the transcripts of focus groups and interviews. All data entered on to computer will be password protected. The questionnaires do not require participants to enter their names and so are anonymous. Any direct quotes used in either reports or publications will be assigned a pseudonym. It is hoped that these measures will ensure anonymity and confidentiality. However, it is possible that participants may disclose that either they or another person is being abused or that they themselves have committed abuse. In such circumstances there may be a need to break confidentiality in order that appropriate action is taken. Participants will, however, be made aware of this (see risks below).

## Potential Risks

Please see Appendix 24 for a risk assessment in relation to the residential workshop. In addition it is recognised that it is important to ensure that members of the research team and volunteers do not present a risk to participants and thus everyone has had a CRB check.

When talking about keeping safe and abuse it may be that someone discloses that they have been abused, that someone else is being abused or that they have committed abuse. If they tell us about abuse which has not been investigated then we will have a duty to advise them as to how they can report it. However, in some instances the nature or extent of the abuse may be such that we would have a duty to report it to the appropriate person / agency. We will make sure that everyone involved in the research is aware of this before they consent to take part in the study (see Appendices 6, 11, 13 and 18) In addition in order to ensure an appropriate response we have drafted a form of words (Appendix 25) which will be used by researchers in such circumstances and opportunities to practice this will be provided prior to data collection. In addition colleagues from New Pathways will be present throughout the residential and they are very experienced in dealing with such disclosures.

Even if someone has not been abused they may still find that talking about it brings some powerful emotions to the fore. New Pathways counsellors will thus be attending the residential workshop to provide support as required. Indeed part of the rationale for holding the residential workshop is that it will provide a safe space within which to discuss the difficult topic of abuse. Furthermore should participants be distressed as a result of participating in data collection it will allow time following the interview or focus group to provide support. New Pathways staff will be undertaking specialist training provided by Respond (a specialist provider of training in relation to psychotherapy with people with learning disabilities) which will enable them to provide counselling support and this will be available to participants between the hours of 8am and 11pm. In addition two other members of New Pathways staff (who are also trained counsellors) will be present and will provide additional input if required. Where on going support is indicated then with the individual’s permission contact will be made with the local Community Support Team.

It is recognised that difficult issues may arise for members of the research team and that they will require support. Undertaking such research may bring with it an emotional cost to the researchers (McGarry, 2010) who may themselves feel vulnerable (Davison, 2004). It is for this reason that on going team building, group and individual support has been happening throughout the project and will continue. The research team has also been supported by the Research Advisory Group and the Specialist Interest Group and meetings of both groups have provided a forum for discussion of key issues as they have arisen and will continue to do so throughout the life of the project.

Finally it is recognised that whilst every effort has been made to identify potential risks which may arise it is not always possible to easily predict all risks since sensitivity or distress may only become apparent during the research process (Davison, 2004). It is thus essential that the research team are sensitive to changing situations in order to remain ethical (Abrahams, 2007). This has been achieved to date via a process of constant reflection and discussion amongst members of the research team. During the residential event it will be facilitated via the debriefing sessions and this process will continue throughout the remainder of the project.

## Benefits

As with all research studies it is important that benefits outweigh or at least justify the potential risks. Within this study it is anticipated that there will be both direct and indirect benefits. For those attending the workshop there will be the opportunity to raise their personal awareness of abuse and of the support which is, or should be, available if they experience abuse. This will hopefully empower them to protect themselves more effectively and, should the need arise, to seek appropriate forms of support. Attendance at the workshop will also provide them with the opportunity to network with other people with learning disabilities and also to learn more about research. More indirectly it is planned to disseminate the findings of the project as widely as possible so that people with learning disabilities, their families and carers, and professional workers will have increased awareness of what people with learning disabilities understand by abuse and the support they feel they need if they are abused. This in turn will hopefully facilitate the development of better support for people with learning disabilities who have been abused. Specifically New Pathways will use the findings of the study to develop the provision of supportive and therapeutic services for people with learning disabilities across South and West Wales. Such services are currently difficult to obtain.

By developing strategies which support the active involvement of people with learning disabilities at all stages of the research process it is also hoped that this study will demonstrate how people with learning disabilities can make an important contribution to research in this area. This will hopefully benefit not only other people with learning disabilities who wish to undertake research but also the wider development of research methodology.

## Dissemination Strategy

It is proposed that both the study findings and information regarding the process by which the research has been undertaken will be disseminated as widely as possible. To this end the following activities are planned:

* Dissemination of both the study findings and the accessible literature review to people with learning disabilities in a range of formats. This will include written information and presentations at appropriate conferences.
* Dissemination via professional journals and conferences which will target a range of audiences including therapists, police, social care, health and education staff
* Dissemination via academic journals and conferences which will include those focused specifically on learning disabilities, those focused on health and social care, those focused on research and those focused on violence and abuse
* Dissemination to policy makers

Other activities will be developed as appropriate and the focus will be on local, national and international levels.

# Project Timeline

June 2011 Submission to ethics committee

New Pathways staff attend Respond training

July 2011 Continue to practice use of data collection tools

Send out invitations to residential

August 2011 Continue to practice use of data collection tools

Start to prepare information for residential

September 2011 Follow up invitations to residential

Allocate places

Continue to prepare materials for the residential

October 2011 Inform participants they have been allocated places

Visit Hotel to make final arrangements

November 2011 Residential

December 2011 Start transcription

January 2012 Send out postal questionnaires

Continue work on accessible literature review

February onwards Data analysis

Literature review

Commence dissemination

January 2013 Disseminate accessible literature review

February 2013 Completion of project report

Completion of papers for publication

May 2013 Project ends

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# Appendix 1

# Involvement of People with Learning Disabilities in Developing the Research Project

|  |  |
| --- | --- |
| Stage of Project | Involved? |
| Choosing which topic to study | ✓ People with learning disabilities decided that we should look at abuse |
| Writing the research questions | ✓People with learning disabilities decided what we wanted to find out about abuse |
| Deciding how we should find things out | ✓People with learning disabilities decided how we should find out what we want to know |
| Applying for money to do the research | ✓People with learning disabilities were involved in writing the forms |
| Interviewing for the research assistant | ✓People with learning disabilities were involved in the interviews for the research assistant |
| Seeing what other people have written about abuse | ✓People with learning disabilities are involved in the literature review |
| Developing the interviews, focus groups and questionnaire | ✓People with learning disabilities have been involved in deciding what should be asked and how it should be asked |
| Choosing the hotel for the residential | ✓People with learning disabilities have been involved in deciding what type of hotel they wanted. Also in visiting hotels and choosing which one we will use |
| Developing the information sheets, DVD and consent forms | ✓People with learning disabilities have been involved in developing and commenting on the information sheets, dvd and consent forms |
| Providing advice regarding the project | ✓More than 50% of our research advisory group are people with learning disabilities. They have provided advice about things such as the hotels, the information sheets and consent forms and who we need to tell about the project. The group is chaired by a colleague who has learning disabilities |

# Remaining Appendices Submitted as Separate Files

Appendix 2 Questionnaire

Appendix 3 Focus Group topic guide

Appendix 4 Introductions for focus group

Appendix 5 Ground rules for focus group

Appendix 6 Consent form for focus group

Appendix 7 Photographs of people for focus groups

Appendix 8 Examples of objects of reference for focus groups

Appendix 9 Stop card

Appendix 10 Individual interview schedules (x2)

Appendix 11 Consent form for individual interviews

Appendix 12 Photographs for individual interviews

Appendix 13 General consent form for research residential

Appendix 14 Provisional programme for research residential

Appendix 15 Introductions for research residential

Appendix 16 Invitation for participation in postal questionnaire

Appendix 17 Letter of invitation for research residential

Appendix 18 Information leaflet for research residential

Appendix 20 Application form for research residential

Appendix 21 Letter giving offer of a place at research residential

Appendix 22 Letters from participants and supporters confirming acceptance of place at research residential

Appendix 23 Information sheet for postal survey

Appendix 24 Risk assessment

Appendix 25 Procedure for dealing with disclosures of abuse

1. GRAB (Group Research About Abuse) were a group of people with learning disabilities who met regularly over a number of years at the University in order to identify an area for research and to develop the proposal for funding in collaboration with University based staff and staff from New Pathways. Some members of GRAB are now members of the research advisory group for the LIA project thus providing continuing opportunities for active involvement in the project. [↑](#footnote-ref-1)