

Looking into Abuse: Research by People with Learning Disabilities

Looking into Abuse Research Team

March 2013

Project Funded by:



'So what you're saying is it doesn't matter what condition people got, they're still the same people. They should live their lives, normal lives, like they should live. And they shouldn't have to be afraid to speak up for themselves or anything like that. And should be free to live as normal people'

(Participant in Study)

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ISBN: 978-1-84054-251-6

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Special thanks must also go to the participants in the study who have shared their thoughts and experiences in order that the abuse of people with learning disabilities may be better understood and appropriate support provided.

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Project Summary

This three year participatory research project has been a collaborative venture between the University of Glamorgan, Rhondda Cynon People First and New Pathways, and has been funded by the Big Lottery. The idea for the research came from people with learning disabilities and they have been actively involved at all stages of the research process.

The aims of the project were 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 were:

- 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?

The Research Project

Data was gathered from people with learning disabilities in Wales by means of individual interviews (n= 14), focus groups (47 people in 7 groups) and questionnaires (n=107). In November 2011 47 people with learning disabilities attended a three day residential event at a hotel and during their stay the interviews and focus groups took place and questionnaires were distributed. The remaining questionnaires were distributed and returned via the post.

The data gathered was analysed by the research team and indicated that participants were aware of a wide range of different types of abuse. However, whilst some had received education about the nature of abuse others had learnt about it via the media or via friends who had been abused and through personal experience. When asked how they felt about abuse a wide range of strong emotions were expressed including anger, embarrassment and a loss of self confidence. However, some participants stated that abuse can make people feel like harming themselves and as though life is not worth living.

A range of potential ways of helping people to stay safe were presented to participants in the questionnaire and they were asked to indicate whether they felt each strategy would be helpful. Most strategies attracted a high rating but the ones attracting the highest scores included having someone you can talk to, making sure someone knows where you are, learning to speak up, staying away from nasty people and telling people with learning disabilities what the law says. When asked what support people need when they have been abused the highest ratings were given to people being there for them, being believed and having support to live their life. The research team noted, however, that whilst these strategies were felt to be helpful the reality of people's lives is that they are not always listened to and believed.

Learning About Researching Together

The second aim of the project related to learning more about how we could work together as a team to undertake the research. The things we found important to think about here included building and maintaining relationships, issues relating to how people are employed, practical issues such as money and accessibility and time. We also developed some new approaches to working together such as using a residential event to gather data, working with a Research Advisory Group (RAG) where more than 50% of the members were people with learning disabilities, and promoting inclusion in the process of seeking and obtaining ethical approval. Reflecting on the project we felt that we had all learnt a great deal from each other and that we had all benefited although in different ways. Throughout the process people with learning disabilities were involved in all key decisions and in many instances they were the decision makers. However, while we managed to change the usual balance of power within the research process towards people with learning disabilities having greater power, there were some things such as the fact that the co-researchers worked part time whereas University staff worked fulltime that meant some imbalances remained. The reason for doing this research is to try and understand and improve the situation of people with learning disabilities but we have also learnt that trying to work with other people to change things takes a long time especially at the end of a project when time is limited.

Conclusions and Recommendations

From this study it can be concluded that people with learning disabilities have a valuable role to play in developing, undertaking and disseminating research. It can also be concluded that they are aware of abuse and the negative effects it can have on people but whilst they can identify strategies that could help to keep people safe and support them if they are abused, there seems to be a lack of education regarding personal safety issues. In addition they do not always feel that they are listened to and/ or believed.

The following recommendations are therefore made:

- That people with learning disabilities should have greater access to personal safety/ abuse awareness courses and that they should be involved in the development of such courses
- That when people with learning disabilities disclose abuse other people must **listen** to them, **believe** them, **act** appropriately and provide support
- That people with learning disabilities who have been abused should have greater access to counselling
- That further research is undertaken regarding the relationship between suicidal thoughts and abuse of people with learning disabilities and concerning the effectiveness of various post-abuse therapeutic interventions for people with learning disabilities.
- That people with learning disabilities should be involved in raising awareness amongst others about the impact of abuse on people
- That in future participatory research careful attention is given as to how people with learning disabilities can be employed for more hours and also that induction is given in relation to employment issues
- That co-researchers have personal assistants were appropriate to support them in their work

Looking Into Abuse: Research By People With Learning Disabilities

Introduction

The origins of this project lie back in 2003 when a group of people with learning disabilities attending the Teaching and Research Advisory Committee (TRAC) meeting at the Unit for Development in Intellectual Disabilities (UDID) stated that they wanted to undertake some research. The area they wished to focus on was abuse since they felt that this is something people with learning disabilities often experience. There followed a lengthy period of developing a funding proposal together and this was finally submitted only to be turned down. A subsequent proposal was also rejected but eventually, some seven years later, funding was obtained. This proposal had been developed as a collaborative venture involving RCT People First, New Pathways and UDID: the three year project finally commenced in May 2010 funded by the Big Lottery.

Structure of the Report

This study has used a participatory research approach and within participatory research both the substantive findings of the research and the learning which occurs as a result of finding ways to work together. As the use of participatory approaches is growing in the field of learning disability research this knowledge of how to develop a research project together is important: it allows researchers to learn from the experiences of others. Within the context of this study we wanted to share not only what we have found out about research but also what we have learnt about working together: what has worked and what has not worked so well. However, this presented a challenge in terms of writing the report – should we seek to weave these two strands together or should we separate them but include them in one overall report. We discussed this with the Research Advisory Group (RAG) and they felt that the latter option would be clearer. The report thus has two main sections: the report of the research project and then a report about learning about researching together. Finally overall conclusions are drawn and recommendations made for future developments.

1. Part One: The Research Project

1.1 Literature Review

This project started from recognition on the part of people with learning disabilities that they, their friends and acquaintances, may often experience abuse. That their perception reflects wider experiences can be seen within the research literature.

The history of people with learning disabilities reveals that they have long been subjected to various forms of abuse (Ryan and Thomas, 1987; Pring, 2011). However, recognition of this as a social issue requiring a response has only been relatively recent. The Ely Inquiry (DHSS, 1969) brought to the attention of the general public the unacceptable and abusive conditions people with learning disabilities experienced within long-stay institutions. Whilst this did bring about a policy response in the form of the White Paper Better Services for the Mentally Handicapped (DHSS, 1971) this did not prevent subsequent inquiries taking place (see for example Burgner *et al*, 1998; CSCI and Healthcare Commission, 2006; Healthcare Commission, 2007). Indeed, whilst this research project has been in progress a further scandal in the care of people with learning disabilities has occurred since in 2012 the BBC Panorama programme exposed abuse at Winterbourne View, a privately run hospital unit in Bristol. In this televised account of abuse episodes of physical and psychological abuse were seen and staff have subsequently been tried and imprisoned. A serious case review has also been undertaken (Flynn, 2012) and a Government response has been published (Department of Health, 2012).

That the abuse at Winterbourne View occurred is extremely concerning as both England (Department of Health, 2000) and Wales (National Assembly for Wales, 2000) have policy guidance designed to raise awareness of abuse and the procedures that should be followed should it occur. Once again policies have been in place but they have not always protected people with learning disabilities from abuse (Northway *et al*, 2007).

That change needs to occur as a result of Winterbourne seems to be generally accepted but a central theme within these recommendations is that units such as Winterbourne should close and people with learning disabilities and challenging behaviour should be protected in smaller units in their own communities. Whilst this may be a partial solution it does not fully address the issue of the abuse experienced by people with learning disabilities (Northway and Jenkins, 2012) since abuse also occurs within community settings. For example in the study undertaken by Reiter *et al* (2007) most physical abuse was reported as occurring in the local neighbourhood and McCormack *et al* (2005) identified the most common location of abuse as being the family home followed by day services and public places. In addition recent years have seen growing concerns regarding hate crimes (part of the wider experience of abuse) experienced by people with learning disabilities with one study suggesting that almost 9 out of every 10 people with learning disabilities have been harassed or bullied, that 2/3 are bullied at least once a month and that just under 1/3 are bullied on a daily or weekly basis (Mencap, 1999). In a more recent study (Gravell, 2012) 67 people with learning disabilities were interviewed and the most frequent types of incidents reported were name calling or verbal abuse (27%), attacks on property, uninvited entry, burglary or destroying possessions (23%), borrowing or stealing money or being made to buy things (20%), and physical abuse, threats or assaults (18%).

One of the difficulties regarding abuse is determining the true extent to which it occurs. Two recent systematic reviews undertaken under the auspices of the World Health Organisation programme relating to violence and disabled people have indicated that disabled children (Jones *et al*, 2012) and adults (Hughes *et al*, 2012) are at greater risk of experiencing abuse and violence than their non-disabled peers. An earlier review of published studies focused specifically on the situation of people with a learning disability (Horner-Johnson and Drum, 2006) and suggested that they are more likely to be subjected to abuse than non-disabled people and possibly at greater risk than other disabled

people. All three reviews note methodological weaknesses within the studies included. Nonetheless a similar picture is noted elsewhere since Lan-Ping *et al* (2009), in their review of reports of sexual assault in Taiwan, found that the rate of sexual assault was 2.7 times higher amongst disabled people than amongst the general population. Moreover, within the group of disabled people those with intellectual disabilities accounted for more than 50% of the reported cases.

In a relatively early study of sexual abuse Turk and Brown (1993) reviewed the previous studies (n=7) they could find and these suggested prevalence rates amongst people with learning disabilities of 8% - 58%. Some of the issues they note as giving rise to methodological difficulties were the reluctance to disclose sexual abuse, differing definitions, and the reliability of the information gathered. Turk and Brown (1993) thus report on their study of new cases of sexual abuse within a two year period occurring within the area covered by one regional health authority. One hundred and nineteen useable questionnaires were returned for analysis and in 84 (70.6%) cases it was deemed that abuse was either proven or highly suspected. However, they note that this figure is likely to be an underestimation of the true extent of sexual abuse that was occurring. In a subsequent study using the same approach Brown *et al* (1995) found that 85 (77.9%) of 109 responses reported sexual abuse that was either proven or highly suspected. It must be remembered, however, that these studies were examining only reported allegations of sexual abuse and that at the time they were undertaken the subsequent policy framework for supporting vulnerable adults had not been introduced (DH, 2000; NAW, 2000). As a consequence current systems and structures were not in place to deal with allegations of abuse in a systematic manner.

A number of studies have used routinely collected data to try to determine both the nature and extent of abuse. For example Beadle-Brown *et al* (2010) examined the adult protection data from two local authorities and found that one third of all referrals related to people with learning disabilities. Physical abuse was the most common form of abuse in this group but sexual abuse was more prevalent than within other client groups. Within Wales (Care and Social Services Inspectorate, 2011) data indicates that whilst older people comprise the largest number of adult protection referrals in 2009 – 10 people with learning disabilities are second having more referrals than people with mental health problems who comprise a larger group within the population. Cambridge *et al* (2006) highlight a similar picture in their review of the data collected by Kent and Medway local authorities where 60% of alerts were raised relating to older people but a third of the alerts related to people with learning disabilities suggesting either a higher level of abuse or a greater likelihood of reporting in relation to people with learning disabilities. Sexual abuse was more commonly reported in relation to people with learning disabilities but within this client group 33% had experienced multiple forms of abuse with the most common combination being physical combined with psychological abuse.

In the review undertaken by Cambridge *et al* (2006) at least 5% of the cases relating to a person with a learning disability involved multiple perpetrators and they were significantly more likely to be abused by a man rather than a woman. The largest number of alerts was raised regarding abuse by another service user (26.4%) and then abuse by family/ partner/ carer (23.3%). Elsewhere Cambridge *et al* (2011) note that in their analysis of adult protection referrals that just over half of the referrals for alleged sexual abuse the perpetrator was another service user. This compared with other forms of abuse where the alleged perpetrator was a service user in only a fifth of referrals.

Whilst official data provides us with an insight into the abuse experienced by people with learning disabilities there are limitations and caution needs to be exercised when interpreting this data. For example does a rise in the number of allegations reflect an increase in abuse or increased awareness of policy and the confidence to use it? In addition there can be a problem with missing data (Cambridge *et al*, 2011) and some allegations are withdrawn for fear of the consequences (Joyce, 2003) and thus this data may be omitted even if abuse did occur. It is also suggested that within service settings the true incidence of physical abuse is not known as client to client aggression can be recorded as challenging behaviour rather than as abuse (Joyce, 2003). Whilst definitions of abuse are provided within policies these definitions can be interpreted in different ways and it has been suggested that different professionals and different agencies use different thresholds when deciding what action should be taken (Collins, 2010). This leads to inconsistency as to what is recorded as an allegation of abuse and hence appears within the official data as such.

Few studies have asked people with learning disabilities themselves as to whether they have experienced abuse. One exception is the study undertaken by Ward *et al* (2010) that examined interpersonal violence. In their sample of 47 people with learning disabilities 40 indicated that they were currently, or had been, in romantic relationships and of these 60% said that they had experienced some form of interpersonal violence. One third said that they had experienced abuse with one partner and the other two thirds with multiple partners with emotional abuse being the most common form of abuse followed by physical abuse. It is interesting to note, however, that 9 of the 24 participants who indicated to researchers that they had been abused said that they had not sought help at the time thus further supporting the argument that official data concerning abuse is likely to be an under-representation.

Despite the difficulties with obtaining a true incidence rate of the different forms of abuse what evidence we do have indicates that it is a significant risk for people with learning disabilities. This being the case it is important that efforts are made to reduce such risks and, where possible, to prevent neglect and abuse. One factor that has been identified as increasing vulnerability to abuse is a lack of sexual knowledge and Eastgate *et al* (2011) interviewed nine women with learning disabilities concerning their relationships, their sexual knowledge and their self-protection skills. They were found to have a lack of sexual knowledge which in turn reduced their ability to self-protect. Similarly Murphy (2003) undertook a study comparing the sexual knowledge of 60 adults with learning disabilities with 60 non-disabled 16 – 17 year olds. On average the people with learning disabilities had poorer knowledge than the non-disabled young people and higher levels of vulnerability in relation to sexual abuse. Where the participants with learning disabilities had received sex education they did significantly better on the sexual knowledge and vulnerability assessments.

Khemka *et al* (2005) evaluated the effectiveness of a curriculum designed to improve safety by increasing the effectiveness of decision making skills. Thirty six women with learning disabilities were randomly allocated to either the intervention or the control group. The results demonstrated an improvement in knowledge, decision making and empowerment amongst the intervention group. From this the researchers conclude that women with learning disabilities are able to improve their decision making skills and also that they can apply them in situations of abuse. Bruder and Stenfert Kroese (2005) undertook a review of interventions aimed at protecting people with learning disabilities from abuse and, in keeping with the previous study, conclude that preventative and

protective skills can be learnt. However, they also conclude that the knowledge does not always readily transfer to day-to-day situations and thus interventions need to include both the transmission of knowledge and the opportunity to practice skills in situ. This approach was used by Egemo-Helm *et al* (2007) who evaluated the use of behavioural skills training combined with in situ training to prevent sexual abuse. Seven women with mild to moderate learning disabilities commenced the programme but only four completed. Generalisation of skills to day-to-day settings occurred in 3 of 5 women after only one or two sessions but one participant required 12 such sessions. Three out of 4 participants interviewed one month following the training had maintained the skills. The authors note, however, that a limitation of this study is that assessment only took place within the home setting which means that true generalisation of the skills to social settings was not assessed. A further limitation linked to sample size and dropout rate also need to be taken into account when considering the usefulness of the study findings.

In Australia Frawley *et al* (2012) developed a peer led programme designed to counter violence and abuse of people with learning disabilities. People with learning disabilities were involved in the development and delivery of the programme to 41 participants. In total over 20 people were trained as peer facilitators and at the end of two years most programmes were still running with funding being sought to facilitate continuation.

Collins and Walford (2008) report on a course designed to help people with learning disabilities to keep safe. Delivered in a college setting the course ran one afternoon a week for the academic year with support available should participants wish to disclose abuse. As a result of the course those attending developed strategies for keeping safe in different situations including personal safety plans and identification of who they would turn to if they needed to disclose that they had been abused. This initiative seems to have led to some promising developments but unfortunately the paper does not include a formal evaluation or provide details as to whether the courses have been continued and/ or extended to other areas.

Taking a somewhat different approach McGrath *et al* (2009) assessed the effectiveness of an anti-bullying intervention with three groups of people with learning disabilities. One group received psychosocial intervention, another received psychosocial intervention and the involvement of community stakeholders, while the third group acted as control. Before the intervention 43% of the participants reported being bullied in the previous 3 months while 28% self-identified as bullying others. Post intervention reports of being bullied decreased significantly in the two intervention groups but not in the control. However, no significant reduction was recorded in relation to self-reported bullying. This might suggest that different interventions are required for those who bully others.

Despite the development of some strategies designed to protect people with learning disabilities from abuse it is unlikely that all abuse will ever be eradicated. It is therefore important to consider the impact of abuse on people who have been abused and how support may best be provided. Speaking specifically of sexual abuse van Nijnattan and Heestermans (2010) argue that people with learning disabilities have fewer cognitive coping strategies to deal with dramatic events such as this and at the same time people around them often inhibit rather than support discussion concerning such issues. As a consequence their emotions can be ‘...buried beneath feelings of shame, guilt and confusion...’ (p404). Such feelings can last for many years as in one life story an adult with learning

disabilities recounts how physical and sexual abuse in childhood led to feelings of not being able to engage in adult sexual relations (Roberts and Hamilton, 2010). In the same paper reference is made to workshops involving people with learning disabilities that focused on abuse where participants shared experiences of 'humiliation' and 'shame'. The authors argue that such experiences challenge the 'still prevalent view' that people with learning disabilities are not affected by abuse. Understandably such feelings are going to limit the extent to which victims of abuse feel able to report this abuse to others.

The effects of abuse on people with learning disabilities are also reported elsewhere. Marsland *et al* (2007:19) argue that such effects are 'distressing, traumatic and enduring' whilst Lewin (2007) points to the psychological effects including post-traumatic stress disorder (PTSD). Murphy *et al* (2007) explored the experiences of 18 people with learning disabilities who had allegedly been abused through interviewing their parents and carers. Compared with 3 months prior to the alleged abuse a negative impact on adaptive behaviour and an increase in challenging behaviour was noted following the alleged incident. At a later stage 'some' recovery was seen. Such limited recovery is commented upon elsewhere along with the fact that therapeutic support is both limited and generally provided by primary care services than by specialists with expertise in PTSD and learning disabilities (Rowell *et al*, 2012). Reiter *et al* (2007) found in their study that abuse had more emotional impact on young people with learning disabilities than on the young non-disabled participants. Brown and Beail (2009) conducted semi-structured interviews with 9 people with learning disabilities who self-harm who were living in secure accommodation. A strong theme to emerge from the data was the impact of previous abuse on the current meaning of self-harming behaviours.

Sequeira *et al* (2003) undertook a matched case control of 54 adults with learning disabilities who had a history of sexual abuse and 54 adults with learning disabilities without such a history. Those with a history of abuse were found to have higher rates of mental illness, behavioural disturbance and PTSD. These responses reflect those amongst the general population but in addition an increase in stereotypical behaviours was observed. The severity of the effects was related to the severity of the abuse.

Elsewhere hate crime is reported as having a 'devastating effect' that reinforces negative feelings of being different and isolated from others (Mencap, 1999). Such victimisation can also result in individuals having to move home to escape from harassment and abuse (Whittell and Ramcharan, 2000). Terms used to describe feelings in such situations include being afraid, being angry, being upset, ashamed and humiliated, and disappointed and lonely if they lose friends (Gravell, 2012).

Sometimes people with learning disabilities choose not to report abuse as they fear that doing so may make the situation worse (Gravell, 2012). One study reported that most disclosures of abuse were made to those whom the victims had most contact with and that this was usually known people within their living situation (Joyce, 2003). When they do report it is important that they receive an appropriate response but disclosures are not always acted upon quickly (Joyce, 2003) and participants in another study (Hollomotz, 2012) stated that when they had made disclosures they had not always been taken seriously. In addition even when abuse is disclosed to a trusted person such as a family member their attempts to raise concerns may be dismissed (Flynn, 2012). Sometimes changes in behaviour may be the only indication that someone has been abused but this

requires that not only are the behavioural changes observed but also that abuse is recognised as a potential contributory factor. Unfortunately it is suggested that services may fail to make such links and hence fail to respond in an appropriate way (Marsland *et al*, 2007)

Sequeira and Hollins (2003) conclude, from their review of relevant research, that following sexual abuse people with learning disabilities may experience a range of psychopathological effects similar to the non-disabled population. Elsewhere Brakenbridge and Morrissey (2010) found a high level of trauma (including abuse) related symptoms but a lack of recognition of conditions such as PTSD, poor recording of information and lack of screening for trauma related symptoms. A significant level of work is thus required to support victims of abuse (Joyce, 2003) but the limited availability of post-abuse support has already been referred to (Rowell *et al*, 2012) and the need for increased clinical and psychotherapeutic services noted (Sequeira, 2006). Razza *et al* (2011), however, point to what they call the 'inverse relationship' whereby people with learning disabilities experience higher rates of trauma and interpersonal violence and yet have lower than average rates of access to treatment. Furthermore, since not all abuse is recognised or disclosed it is likely that many more people with learning disabilities are living with the after effects of abuse and not receiving appropriate support.

Some people with learning disabilities are offered specialist support services and in a retrospective study of case notes relating to 100 sequential referrals to one specialist psychotherapy service, 35 referrals were found to be for trauma and abuse (Parkes, 2007). However, the authors of that study note that the true prevalence of abuse and trauma amongst the sample was likely to be higher since those referred for other issues often disclose abuse. Such information was, however, recorded in the detailed therapy notes and the research team did not have access to these.

Referring specifically to sexual abuse Sequeira (2006) has argued that there is evidence to support early intervention post abuse since this can assist in minimising adverse effects before they become established as long-term, chronic symptoms. In addition she warns that if symptoms are either overlooked or attributed to causes other than abuse then treatment is only going to be palliative, and abuse that is on-going may not be detected. Nonetheless it is important to exercise some caution since not all behavioural and emotional disturbances will signify that abuse has occurred and some individuals may not show such disturbances even when abuse has occurred (Sequeira, 2006).

Peckham *et al* (2006) provide an account of a post abuse survivor group for people with significant learning disabilities. These sessions ran alongside parallel educational groups for their carers over a period of five months. At the end of these sessions improvements were noted in relation to sexual knowledge, trauma and depression but neither self-esteem nor anger showed such improvement for most participants. In relation to challenging behaviour deterioration was seen before any improvement.

It can thus be seen from the literature that there has been a tendency to focus on sexual abuse rather than other forms of abuse, that some work has been undertaken in relation to abuse prevention but this is limited, and that whilst the after effects of abuse are acknowledged the provision of appropriate support may not always be forthcoming. What is also evident from the research reviewed is that with very few exceptions (for example Hollomotz, 2012) the data has generally comprised routinely collected data, the views of carers and professionals, or the assessment of people with learning disabilities by others. The views and experiences of people with learning disabilities are seldom heard.

Given the suggestion that there is a need to question whether policies such as *In Safe Hands* (NAW, 2000) and *In Safe Hands* (DH, 2000) have led to a more adequate response to the abuse experienced by people with learning disabilities (Rowse *et al*, 2012) this is a significant omission. Whilst significant it is perhaps not entirely unexpected since Robinson and Chenoweth (2011) comment on the absence of people with learning disabilities from research, policy and practice development aimed at improving their safety. Similarly McDonald *et al* (2012) note the restricted opportunities that people with learning disabilities have to give their opinions concerning research that focuses on their experiences. Such an omission is viewed as important as understanding and responding to such views is important if policies and practice are to develop in ways that treat people as they would wish to be treated (McDonald, *et al*, 2012). This is particularly significant when policies and practice relate to the prevention of abuse and the provision of support when someone is abused. This then presents a challenge not only for what is research but also how it is researched. An alternative research approach that facilitates the active involvement of people with learning disabilities at all stages of the research process, and that is grounded in their experiences and concerns, is participatory research.

Participatory research (PR) is said to have 'emerged' as a research approach in the 1970s in Tanzania (Hall, 1992). Central to PR is the belief that key groups of people have been marginalised within the research process and that this marginalisation adds to their wider feelings of powerlessness and oppression: their views and experiences are not heard and their expertise concerning their day to day living is not recognised. To change this situation PR seeks to develop partnerships between academic researchers and communities so that they can learn from one another, work with each other, and undertake research together. The issues to be researched are rooted in the concerns of the 'community' who are involved in all stages of the research project from identification of the area for examination, through the designing the research, gathering and analysing the data, and disseminating the findings. It aims to produce 'useful knowledge' (Khanlou and Peter, 2005) and is focused on using the research to achieve change: action is an integral part of the participatory research process. The approaches used within PR vary widely from more traditional use of questionnaires and interviews (for example Kramer *et al*, 2011; Inglis and Swain, 2012) through to the use of techniques such as Photovoice (for example Booth and Booth, 2003; Lopez *et al*, 2013) and drama presentations (Schneider *et al*, 2004). No two PR studies are alike since they are shaped by the team working on each individual project. What is common is the value base that underpins PR which includes the commitment to challenging existing power relations (Northway, 2010a), the willingness to work in partnership, and the desire to respect each other's experience and expertise. It has therefore been argued that PR is an 'attitude' rather than a specific research design (Cornwall and Jewkes, 1995).

Within disability research debates took place regarding existing research in the 1990s. Such research was criticised for not addressing concerns of importance to disabled people, for failing to involve them as other than subjects, and for failing to have a positive impact on their quality of life (Oliver, 1993). Emancipatory research (in which disabled people controlled all aspects of the research process including the funding) was therefore promoted by members of the disability movement (for example Oliver, 1992; Zarb, 1992; Barnes and Mercer, 1997). Such research, it was argued, would transform power relations and promote research that was based in the social rather than the individual model of disability. Included in such debates was consideration of how such research

related to PR with some authors dismissing PR as failing to change the power relations to any significant degree (Oliver, 1997; Zarb, 1997).

What is interesting, however, is that within such debates little reference is made to wider literature concerning PR where the stated aim is one of transformation and empowerment (for example Park, 1993; Israel *et al*, 2013). In some instances it thus appears that the terms ER and PR are used interchangeably whilst others argue that perhaps the relationship is better viewed as a continuum of changing power relations rather than as two distinct entities (Northway, 2003). Chappell (2000) argues that whilst ER and PR have similarities they diverge in two main areas. First she states that whereas ER has used the social model of disability as the basis for understanding disability it is rarely mentioned within PR. Second she states that within ER disabled people rather than researchers are in control of the research process. Neither of these two areas is, however, precluded within PR. In the context of this report, therefore, the terminology used will be PR and readers may judge for themselves the extent to which they feel power relations have been transformed such that people with learning disabilities have had control over the research process and have been empowered within this process.

The mainstream disability literature also fails to take account of the situation of people with learning disabilities who have perhaps been at the greatest risk of marginalisation within the research process. Nonetheless participatory research approaches have increasingly become more evident within the learning disability research literature. Chappell (2000) argues that PR provides the opportunity to work in partnership with researchers and to have greater influence over the research process: both of these opportunities have previously mostly been denied. Kiernan (1997) similarly argued that the development of PR meant a change from research *on* to research *with* people with learning disabilities. However, Kiernan (1997) also indicated that since the research process relies on the use of intellectual skills this suggests that people with learning disabilities may require significant levels of support to participate. This then gives rise to the need to consider the role of the supporter and the influence they may exert (Kiernan, 1999; Williams, 1999).

Participatory research aims for active involvement of people with learning disabilities at all stages of the research process. To date involvement in the process of identifying priorities for research has not been widely reported in the literature. One exception to this is the study undertaken by Nierse and Abma (2011) who provide an account of how people with learning disabilities and family members were involved in identifying research priorities before proceeding to participate in other elements of study design and implementation. They argue that such participation was crucial to provide real opportunities to exert control. Another stage of the participatory research process that is not widely reported is that of seeking and securing ethical approval although Ham *et al* (2004) discuss how participation was facilitated in this process.

Participatory research involving people with learning disabilities has explored a range of topics including advocacy (Chapman *et al*, 2011; Garcia-Iriarte *et al*, 2009), Quality of Life (Bigby and Frawley, 2010; Haigh *et al*, 2013) and the experience of being a man with a learning disability (Inglis and Swain, 2012). To date, however, there does not appear to have been a study that focuses on the abuse of people with learning disabilities that has taken a participatory approach. This project therefore seeks to address this gap.

1.2 Research Aims and 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?

1.3 Data Collection

The data were collected using three approaches: focus groups, individual interviews and questionnaires. Table 1 below maps the different research questions to the relevant means of data collection.

Table 1: Research questions and methods

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

Before discussing the specific approaches to data collection it is important to briefly discuss the research residential event that was held in November 2011. Given the sensitive nature of the topic being explored the research team felt it was essential that participants should not be expected to take part in interviews or focus groups that could raise distressing interviews and then be left unsupported. For this reason funding was obtained to facilitate a three day residential event in a hotel for participants. This event enabled data collection to take place whilst ensuring that both counselling support and more general support was available (see section below concerning ethics). It

also allowed for social and recreational events that were important to balance the difficult nature of the research topic.

1.3.1 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).

The format of the focus group and the topic guide for the group are appended (see Appendix 1). The groups commenced with introductions to set people at their ease and then the 'ground rules' for the group were discussed and checked with everyone. After formal consent was obtained participants were reminded that it was OK for them to leave at any time. A 'Stop' card was provided for participants to use if they wished to stop the discussion at any stage. Each group was facilitated by a co-researcher and the research assistant.

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 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' was then put on the table to signify that form of abuse. 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 were 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 had an additional prompt to aid memory. Secondly, they were 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 were seeking. At the end of each discussion a reminder of the availability of the counsellor was given.

Seven focus groups were held. Six of these were audio recorded but in the 7th one participant indicated that he did not wish this to happen and so an additional facilitator recorded key responses.

1.3.2 Individual interviews

The interviews focused on the same research questions as the focus groups and some participants participated in both activities. Where possible, therefore, the individual interviews took place before the focus group for that individual concerned to avoid contamination of data as much as possible. Despite the focus in the interviews being on the same two research questions the approach taken

was different. Appendix 7 contains details of the interview schedule for the interviews. To allow for the individual support requirements of the co-researchers slightly different versions were developed. These asked the same questions but the information was presented in a slightly different manner and with different prompts to assist those involved. The interviews were 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 that activity.

The interviews commenced with introductions and completion of the consent form. The main part of the interview then focussed on the sorting of pictures (see Appendix 2 for examples) according to whether the participant felt they depict abuse, they don't depict abuse or they are unsure and discussion arising from this activity. Participants were provided with a 'stop' card they could use to end the interview at any stage if they so wished. At the end of the interview participants were reminded of the availability of the counsellors and supported to access them if desired.

1.3.3 Questionnaire

Questionnaires provide 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 (Townshley 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 3) was designed in an accessible format which mostly required only a tick box response (although there was opportunity for further comment if desired). The focus in this aspect of data collection was 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 might wish to complete this activity independently. The front sheet of the questionnaire provides information concerning the project and how it would be used.

The questionnaire was 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.

The questionnaire was administered in two different ways. First all participants at the residential event were invited to complete the questionnaire. Second, following the residential event questionnaires were sent out to People First groups across Wales inviting participation. Return of questionnaires was via pre-paid postage.

1.4 Data analysis

As part of the training the research group participated in before starting data analysis the analogy of completing a jigsaw puzzle was used to assist with understanding. Just as when completing a jigsaw the first stage is to find the corner pieces, then the straight edges, then you sort pieces into similar colours before putting it all together to complete the picture, so data needs to be sorted into categories of similar information and then put together to form the complete 'picture'. This process of putting the picture together may, of course, involve trying things a number of ways until things fit

together in a logical way. A similar approach was taken to data analysis in this study with each of the co-researchers taking responsibility for the initial sorting of one of the data sets before they were discussed by the core research team as a whole in order to determine meaning(s).

With the *focus groups* each transcript was read and relevant sections were highlighted and cut and pasted into a separate file headed with each of the key questions asked. A different colour was used for the text coming from each individual focus group to allow for ease of identification. With the *individual interviews* a similar approach as taken to all of the questions with the exception of the question that asked participants to decide whether the photographs shown to them were abuse, not abuse or they were not sure. Here a recording form was devised by the co-researcher to allow responses both from individuals and those relating to individual photos to be seen. With the *questionnaires* a recording form was again devised by the co-researcher to collate responses from individual questionnaires in batches of 10. These were then further collated to bring all of the responses together.

Once this initial sorting had taken place numerical data were transferred into graphs with subsequent group discussion focussing on both the meaning(s) of the results and the best way to present them in a graph. In relation to the qualitative data the key themes arising from responses relating to each question were presented in diagrammatic format but group discussion was supplemented by illustrative quotes from the actual transcripts. This process of sorting data followed by discussion involving the entire group proved invaluable as the co-researchers were able to ground the data we had gathered in the reality of lived experience (Kramer *et al*, 2011).

1.5 Ethical Issues

People with learning disabilities are often considered to be 'vulnerable subjects' in the context of research (McClimens and Allmark, 2011) and abuse is viewed as a 'sensitive' topic. In addition whilst participatory research is viewed as offering an ethical approach to research it also raises particular ethical issues (Perez and Treadwell, 2009; Khanlou and Peter, 2005). Each of these areas presented particular challenges to securing ethical approval for this study. Further information regarding this process is provided in a later section of this report (see Section 2.5.3) but here the key ethical considerations are outlined.

The nature of participatory research is such that the precise nature of the study develops as the research team come together to share ideas and experiences. In this study the proposal for funding had been developed in partnership with people with intellectual disabilities acting in a voluntary capacity; their views had shaped the study design. The proposal for funding included monies to employ the co-researchers and the research assistant and it was important that they were also able to shape the development of the study. However, (as with many research funders) funding for the study could not be released until ethical approval was obtained and yet we could not employ the key members of the team until funding was released. A pragmatic approach was therefore required.

Since none of the participants in the study were recruited via health or social services ethical approval was sought from the Faculty Ethics Committee within the Faculty of Health, Sport and Science at the University of Glamorgan. The ethics committee were approached to determine whether they would provide 'Stage 1' approval based on the information we had submitted for the funding application on the basis that we would not recruit or collect data until we had returned to

them for 'Stage 2' approval once further study documentation had been developed. At the same time we approached the funders to see if they would be prepared to accept such Stage 1 approval. Both parties agreed, Stage 1 approval was granted, the funding was released and the core members of the research team were appointed. Further work was then undertaken to develop all the study documentation such as the full protocol, letters of invitation (Appendix 4), information leaflets (Appendix 5), consent forms (Appendix 6), and data collection tools (Appendices 1,3 and 7). Full ethical approval was obtained in May 2011.

As noted above the subject of this research is sensitive and one of the key issues that needed to be considered was how to minimise any harm and distress and, should distress occur, then to ensure that support was available. Given that abuse is unfortunately a common feature of the lives of people with learning disabilities there was obviously the potential for discussion of abuse to remind people of negative and harmful experiences. However, not to research abuse and to hear the voices of people with learning disabilities also has ethical implications since it denies their personal experiences and silences their voices. In addition it has been suggested that excluding 'vulnerable' groups from research can increase their vulnerability since harmful practices to which they are exposed remain undetected (Juritzen *et al*, 2011). Risks thus need to be balanced against potential benefits and a number of strategies were put in place. First all participants were recruited via People First or other organisations of people with learning disabilities. This meant that on-going peer support was available for them. During the residential event counsellors were available throughout and participants were regularly made aware of their availability. For example reminders were provided at the end of each interview and focus group. Should on-going support be required mechanisms were also put in place for this to be arranged. In relation to the postal questionnaire it was decided that the focus should be on those questions relating to support rather than thoughts and feelings regarding abuse since this would be less likely to cause distress. However, once again these questionnaires were distributed via People First groups to ensure the availability of some support and information regarding other sources of support was included with the questionnaires.

A second important consideration was how best to ensure that consent to participate was freely given on the basis of information that was understood, retained and used to arrive at a decision. Information leaflets were developed using an easy read approach supported by photographs. These leaflets were trialled with the RAG and amended in light of their constructive feedback. In addition a DVD was produced for use by people who prefer their information in that format. These were sent out to People First groups and people were invited to respond with an expression of interest in taking part in the residential event. At the residential event the first session again set out what the research was about and what people were being asked to do in the study. The voluntary nature of participation was stressed as was the right to withdraw consent at any stage. Following this session the consent form was discussed with each individual, further information provided as required and the consent form was signed. Before each focus group and individual interview the voluntary nature of participation was again stressed and continued consent was checked at the end. Consent was thus viewed as an on-going process of 'review and negotiation' (Abrahams, 2007) rather than a one off event. In relation to the postal questionnaire an information leaflet was sent out giving details of who to contact for further information if required. Return of completed questionnaires was taken as an indication of consent.

Given the sensitive nature of the subject it was important to assure participants regarding confidentiality. They were therefore informed that all personally identifiable data (for example consent forms and application forms) would be kept securely and separately from the transcripts of focus groups and interviews and that all data would be entered on to computers that are password protected. The questionnaires did not require participants to enter their names and so are anonymous. Any direct quotes used in this report have been assigned a pseudonym.

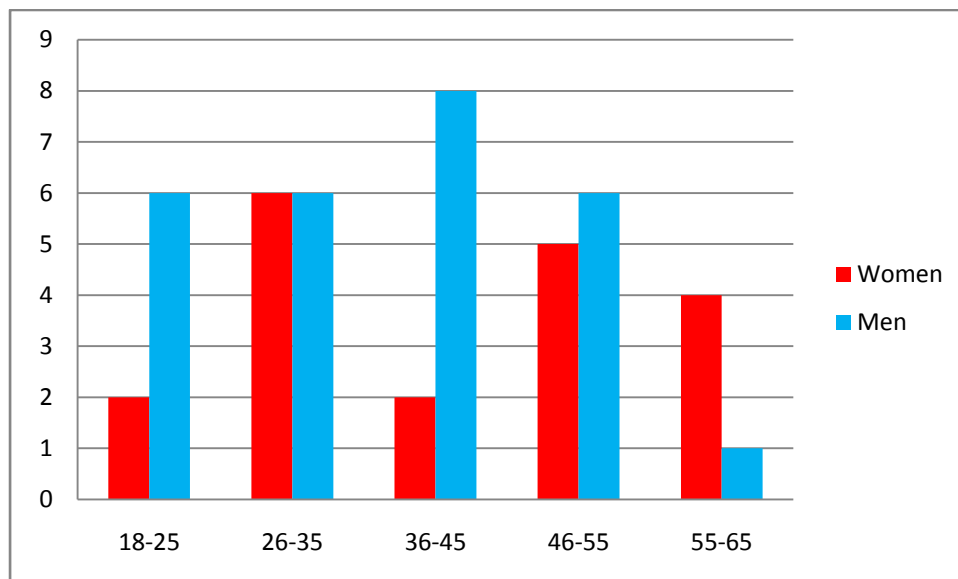
There are, however, limits to confidentiality in a study exploring abuse since as a research team we had a duty to ensure that if participants had been / were being abused and action had not been taken then we had a duty to report it via the appropriate channels. This was clearly stated in the information provided and participants were reminded before the focus groups and interviews that if they told the researchers that they or someone else was being hurt then we would need to report it. However, participants were reassured that this would not be done without their knowledge and involvement. It was important that this had been clearly stated as disclosures were made during the residential that required further action.

1.6 Findings

1.6.1 How many people took part?

Forty seven people attended the residential event of these 19 were women and 27 were men (one person did not indicate gender). The ages of participants are included in Table 2 below.

Table 2: Ages of people attending the residential event



All those attending the residential participated in one of the seven focus groups.

Fourteen individual interviews were undertaken. Interview participants were selected to reflect a balance of genders, a range of ages, and differing levels of learning and physical disabilities. Participants from differing ethnic / cultural backgrounds were also included.

In total 110 questionnaires were returned of which 107 were included in the study (3 excluded due to insufficient data). The number of participants responding to the questionnaire includes those who attended the residential event and details of all respondents are given in Table 3 below. All participants at the residential completed the questionnaire and of the 150 sent out by post 63 were returned giving a postal response rate of 42% and an overall response rate of 56%. Not all respondents indicated the area of Wales in which they lived but of those who did responses were received from 14 of the 22 local authority areas in Wales.

Table 3: Characteristics of those completing the questionnaire

Characteristic and overall number of responses	Responses
Gender (n=107)	Male= 56 Female = 51
Age (n=106)	18–25= 16 26-35= 23 36-45= 29 46-55=21 56-65= 14 66- 75=3
Living arrangements (n= 107)	With family = 40 With partner= 8 By themselves = 19 By themselves with support = 6 With other people= 3 With other people and staff=30 With children and partner = 1
Member of People First (n=103)	Yes = 91 No = 12

1.6.2 Focus Groups

In one focus group (FG1) one participant did not consent to the discussion being audio-recorded and thus only key responses were noted. For this reason it will be seen below that fewer quotes from this group are included. The group in which specific comments were made is noted after each quote by 'FG' followed by the group number.

Participants in the focus groups were asked **what abuse meant to them**. A range of responses were offered as shown in Figure 1 below.

Figure 1 : Focus group participants' views as to what abuse is



One participant provided their definition of abuse:

'Abuse to me is hurting someone or being hurt. Causing someone discomfort and it could be in a lot of different ways' (FG2)

Across the groups participants demonstrated an awareness of a wide range of forms of abuse including:

- Physical
 - *'He beats me, threw stones' (FG2)*
 - *'...and they hit them don't they, slap them?' (FG6)*
 - *"he kicked my legs. I was like, I was bleeding...I had a deep cut here, and that took a month to heal' (FG2)*
 - *'Push him' (FG3)*
- Financial
 - *'Take money off you. If you've got staff some of them are bad, some are good. You've got to really trust them' (FG1)*
 - *'Financially...it's where people take your money off you' (FG4)*
 - *'Where they like go into people's houses and nick money and stuff that don't belong to them' (FG6)*
- Domestic
 - *'I've gone through domestic violence' (FG2)*
 - *'Where a partner will hit the man or husband or wife' (FG4)*

- Neglect
 - *'Yes they can take your food off you' (FG4)*
 - *'They're left soaking wet or they're left in soiled sheets. And I can tell you what hospital it is....' (FG2)*
- Sexual
 - *'Somebody raping somebody' (FG4)*
 - *'I agree with what K said as well on sexual abuse. I think it's wrong 'cos forcing someone against their will, it's you know, it could be rape as well, and it's not nice 'cos that gives that woman a physical, mental, abuse' (FG7)*
- Emotional
 - *'I got called a ugly child and a frigging idiot on the bus' (FG2)*
 - *'Calling him names'....'Like idiot'....'Like ugly' (FG3)*
- Child abuse
 - *'I used to be in a children's home. And this lady didn't want to go to bed one night and the staff kept on pushing her' (FG2)*
- Bullying
 - *'Like, err, being abused, now it might be that children in school are bullying each other' (FG7)*
 - *"I got bullied in school and I had my jewellery taken off me' (FG2)*
- Violence
 - *'I was going to say it's violence, but hitting you with a car's abuse isn't it?' (FG3)*
 - *'They might come along and stab him or summat' (FG6)*
- Elder abuse
 - *'Old people and people who work in old people's homes, the carers and that can take advantage' (FG7)*
- Antisocial behaviour and hate crime
 - *'I been on the bus, coming home from college. I've been dissed by a woman I didn't know....' (FG2)*
 - *'Maybe gays abused' (FG6)*
- Racism
 - *'Talking about racial abuse and at the moment it's in the news is the Stephen Lawrence case' (FG6)*
 - *'I knew someone, right, he was in his school and he was a little boy and all his class were all white and he's the only one who's dark and his teacher helped the others but left him out' (FG3)*

When shown the photos of different people and asked why they might be abused participants readily suggested a range of potential reasons. Some of these related to the person having a disability:

'Being bullied coz of what you've got' (FG1)

'I think they do it because you've got something wrong with you' (FG1)

'She looks like, she looks she has Downs Syndrome. Pick on her' (FG4)

'And 'cos she has Down's Syndrome she could be easy picking.' (FG4)

'I think he could be abused for his disability' (FG5)

'because they do say people with learning disabilities is more of an easy target to be abused' (FG5)

However, other personal characteristics were also noted as potential causes:

'It could be about her weight...' (FG2)

'It gets to me cos people laugh at me and in school I been called names cos of my looks. I've been called names and I suffered for years and years.' (FG2)

'...what, what, what about racism, is that abuse?' (FG3)

'She might be abused cos she's elderly person. Cos she's got thin and looks old.' (FG4)

'By his religion, by his turban' (FG5)

'He could have a load of abuse cos like the children, and his religion as well, he's Muslim' (FG5)

'her gender' (FG5)

'Because she's Indian' (FG7)

It was interesting to note that other views were also expressed by some participants:

'And also because of her clothes which she's wearing they could be provocative...Well, she's old enough to say Ok and someone could take it like a come on then.' (FG4)

(Regarding the way a woman is dressed) 'It was some boy thing. Some of them might think that she erm, they can do anything' (FG6)

When asked **how abuse made them feel** participants identified a range of feelings and emotions (Figure 2 over page).

Figure 2: Focus group participants' feelings about abuse



Figure 2 is presented to provide an overview of the key feelings to emerge from the focus groups. However, it is also important to note (in their own words) some of the things that participants said regarding their feelings about abuse:

'It's not, it hurts' (FG2)

'I think it makes a person lack confidence, lack of doing anything' (FG2)

'Oh god it's horrible' (FG2)

'I felt really embarrassed' (FG2)

'very paranoid' (FG3)

'I feel cross, really angry about it' (FG4)

'Shaking inside' (FG4)

'All that suffering, it's not fair' (FG4)

'Somebody could, when somebody pushes them too much they could harm themselves' (FG4)

'Yeah, well it makes me feel really sort of angry that somebody, another human being with a soul like can do that to someone' (FG5)

'...is life worth living sometimes? People you know could do away with themselves. You may think this, you may have this idea, but would you carry it out?' (FG6)

'You can get nightmares when people abuse you. Nightmares about it. I always have that when people abuse me and take advantage' (FG6)

'Like a headache, you just can't get it out of your head' (FG6)

'It's wrong, 'cos its wrong because you're not abusing someone else and you're not doing no wrong at all and somebody comes and starts abusing you, well why?' (FG7)

'She might take her own life cos she might get fed up with it and think that there's only one way of doing it' (FG7)

One theme that emerged from the data but which not asked as a direct question related to the experience of abuse either at a personal level or through witnessing or hearing about abuse. This was coded under the heading '**Abuse happening for real**'. Some of the examples provided here related to abuse within the family:

'I been abused, from my father, when I was living in...He was wrong for touching me' (FG2)

'Oh no, no, no. I went through domestic violence and it was my own fault...You know, because I dunno, maybe I done something to him, I dunno. And I'd just say to him hit me again if you want, it's just one of those things that happen, I'm afraid in families' (FG2)

'Yep then afterwards he went against my mother and hit my mum then he went and hit him again' (FG2)

'I had abuse done to me. I felt awful sore with my father for hitting my mother' (FG3)

'I was in my family, I was emotionally abused. I'm not going to say the other, but my father said to me Do you know you'll never grow up to be anything, you're so stupid.' (FG2)

Others did not specify the context:

'I had sexual abuse when I was 14. That's how I knew about abuse' (FG3)

'I went through something not very nice. No I hear children every day they go through that and it makes me so bloody angry' (FG2)

'...I have been pushed out through the door and punched in my back, so it's...I'm getting fed up with it' (FG3)

'It's happened to me. I've had first-hand of it' (FG1)

'I didn't realise, the people who done financial abuse to me it were done in a sneaky way. But fortunately there is an investigation going on about it at the moment' (FG5)

'Every time I went out, people used to throw cans at me and call me fatty. People in cars used to throw chips at me' (FG2)

'Beaten up and been burnt on my backside by matches' (FG5)

'From the age of 11, I been bullied all the way through ... no, sorry younger than that ... been bullied all the way through and only 2/3 years ago I got out of it and I've just blanked it out of my mind, but it's still in there' (FG5)

For some the effects of abuse happening to them led to them resorting to violence:

'One day it got too much. One day he was on his own and he come after me and I just, I swunged around and I kicked him, kicked his, kicked him, and that's it then.' (FG2)

'...Then guess what happened? He got his jaw broken by my fist' (FG2) (different participant to above)

It was also acknowledged by participants in FG6 that abuse can occur within supported living and that as well as carers committing abuse people with learning disabilities can also sometimes abuse other people with learning disabilities.

Within the focus groups discussion took place as to whether one form of abuse is worse than others. Not everyone felt able to decide upon this but nonetheless some views were expressed:

'I know neglect is really really bad and physical isn't that bad but it is bad if you know what I mean.' (FG3)

'I think rape is worst to me' (FG4)

'Well, that all depends on the individual because what can be abuse to you might not be abuse to me' (FG4)

'I'd say emotional abuse is worse than any of them because you're showing, you're hiding signs away in your head and you're not sharing them and that to me seems ... really really hard.' (FG5)

'sexual is the worst I think' (FG6)

'Well, it depends. Some abuse is worse than others isn't it?...Well, physical abuse when someone kicks you...Well, you feel it don't you then?' (FG6)

'I was thinking about sexual abuse, 'cos they might feel dirty inside or they might be afraid to tell somebody that they, that it's happened and they're just too afraid to speak out.' (FG6)

'Sexual...because you can be forced into sex and you could turn out and have a baby or something and then it's not your fault because you don't want it anyway.' (FG7)

'Yeah, I agree what K said as well on sexual abuse. I think it's wrong 'cos forcing somebody against their will, it's you know, it could be rape as well, and it's not nice 'cos that gives that woman a physical, mental, abuse' (FG7)

Discussion took place as to **what participants did / would do if abuse occurs** and the key responses are set out in Figure 3 below:

Figure 3: What do people do about abuse?



Some people reported taking positive action in response to abuse:

'I had to make a hate crime report, and I had to write it down, the police lady had to come to pick it up' (FG2)

'I made a complaint to (local AM) and she says she's going to contact me soon' (FG2)

Sometimes this could be via people who were already known and trusted by them:

'I know with especially people with learning disabilities right, that they wouldn't go to the police but wait till the People First office.'(FG4)

However, such action did not always result in others following it up with action as shown in this exchange between two participants in FG3:

'I told staff about it, so they reported it to the what-do-you-call people innit'(FG3)

'I did, and no-one did nothing about it'(FG3)

A similar lack of action was noted in another focus group:

'Also when children tell their parents it all happens in the school and they try to have a talk with the headmaster. The headmaster don't take no notice, the parents must try' (FG7)

Elsewhere a participant reported not taking action:

'I didn't do nothing. I just pressed the button and come off the bus and just walked home' (FG7)

'Nothing, just let it go over my head' (FG5)

Even when participants felt able to tell other people about abuse occurring some difficulties in disclosing were also voiced:

'I explained to my mum what was going on and my dad but didn't tell them everything' (FG5)

When asked **what** they thought **should happen about abuse** they suggested that abusers should be reported and that they should be *'put away for good'*. However, in this exchange in FG7 it was also noted that sentences could be reduced:

'But when some people say for good, they only do two years. I reckon when they say for life, it should be for life' (FG7)

'Yeah, yeah I reckon that. Not to be told 25 years and come out in 12 years. Should sentence how long it should be' (FG7)

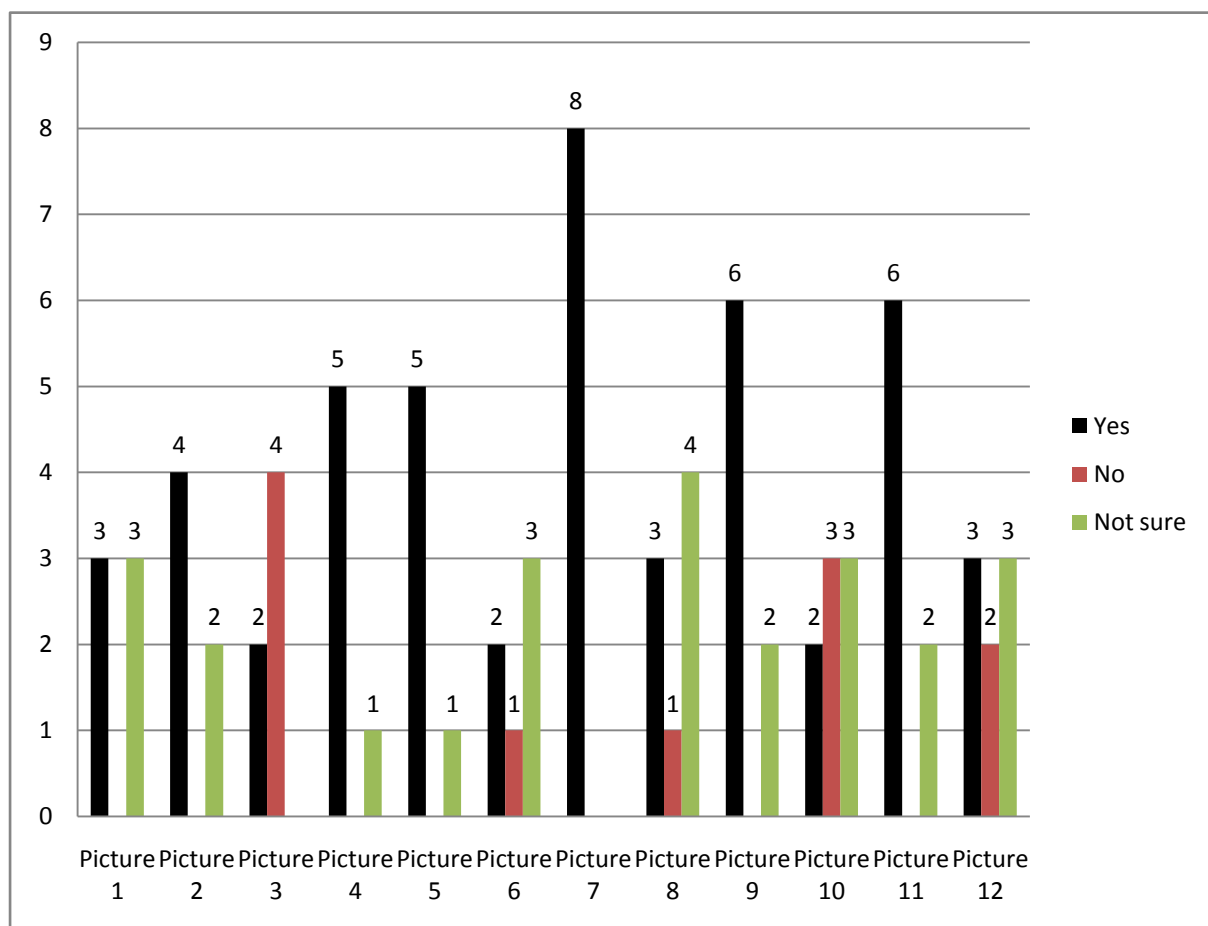
More plain clothes police were also suggested as helpful. If abuse occurs then participants indicated that people should tell their parents or the police and again having more police walking about was suggested. It was stressed that people should be free to live their lives.

To help keep people with learning disabilities safe participants suggested the need for the police to be involved and that care staff should lose their jobs if they abuse someone. To help people who have been abused being able to tell someone about the abuse and providing them with support to move to a safe environment were offered as useful strategies. Being able to stand up for yourself was also viewed as a helpful self-help strategy.

1.6.3 Individual Interviews

At the beginning of the interview participants were each asked to look at six pictures and to decide whether they thought each picture showed abuse happening, whether they weren't sure, or whether they thought there was no abuse in the picture. They were asked to place each picture on one of three cards indicating 'yes', 'no' and 'not sure'. Having made their decision they were then asked why they had made the decision they had. In total twelve pictures were used but participants were shown either numbers 1 – 6 or 7 – 12 and this is reflected in the number of responses indicated in Figure 4 below.

Figure 4: Does this picture show abuse?



In each instance participants were asked about why they felt each picture showed abuse, didn't show abuse or they weren't sure. As can be seen in Figure 4 there was only one picture (7) where there was total agreement. However, in contrast picture 8 shows 3 people felt it was abuse, 1 person that it wasn't abuse, and 4 were not sure. Reasons given included:

Ceryn said 'Yes'	<i>'He is going to touch her breast'</i>
Doris said 'No'	<i>'he's being friendly and putting his arms around her'</i>
Afan was 'not sure'	<i>'It could be sexual harassment. It could be that they are in a relationship and she doesn't really mind.'</i>

Another example of such differences of opinion is seen in picture 3:

Sean said 'Yes'	<i>'That's kind of abuse isn't it, if not like being touched.'</i>
Annabel said 'No'	<i>'Right now these two are happy and they help one and other.'</i>

Participants were also asked what abuse meant to them. Their responses demonstrated awareness of a range of different forms of abuse as can be seen below:

'Well, there's sexual abuse, there's physical, there's forced marriages, that's abuse as well. Being forced to marry when you don't want to.' (Sean)

'It could be sexual, it could be rape. It could be financially. I know another 2 but I can't think of them at the top of my head at the moment.' (Afan)

'Well, people hitting people, being nasty. I can't think of nothing else mind. I know it's abuse when somebody hits somebody, cos it happened.' (Doris)

'To me abuse is where someone gets hurt or physically. That's what it means to me. They're all sorts of abuse. There is financial. There is abuse where your friends might be sort of using you. Of course there is sexual abuse.' (Elliott)

'Well it covers, .. well. I always thought abuse meant people using bad language. Whereas there's different version of abuse isn't there? Abuse can mean you get verbal abuse, someone using abusive language at you. Abuse can ... they can go round shouting names at you' (Gareth)

'Abuse is having something happen to someone they don't want. So it could be sexual abuse, financial abuse, emotional abuse, physical abuse.' (Ceryn)

'When somebody is bullying you, and kicking or punching you or taking money off you. They can rape you, be abuse. Forcing sex. Threatening police for something you haven't done. Could tie you up or lock you somewhere' (Wanda)

Each participant was asked how they learnt about abuse. For some this was via training provided by organisations such as People First. Sean and Gareth reported attending conferences about abuse, and Ryan mentioned information from the social worker. Some reported that they had educated themselves through reading books (Sean) or through watching the television (Charles and Owain). Some participants learnt about abuse via friends who had been abused:

'Being a friend of someone that had been abused in their childhood' (Elliott)

'But actually found out abuse because a friend of mine was sexually abused when she was 2 years old' (Sean)

For others, however, their learning had taken place as a result of direct personal experience:

'I've been abused in the past so I know how it feels.' (Dionne)

'When I was younger, I had things happened to me that shouldn't have. I ended up going into care because of it. That is how I sort of knew it was wrong' (Ceryn)

'Cos I been abused myself.' (Wanda)

For Ajit and Angharad attending the residential event was the first time they had really learnt about abuse.

Participants were asked why they thought people are abused to which a number of potential reasons were offered:

- Because of their disability
 - *'Because they've got learning disabilities'* (Wanda)
 - *'Because they've got a disability. They think they're dull, they're boring they can't learn. If they do anything they can't say, nobody will believe them.'* (Joanne)
- Because they are different
 - *'Unfortunately the public eye does not take people with learning disabilities very lightly. They think they are different to someone else'* (Elliott)
 - *'Because we don't seem to be what you call 'normal'. Don't look right, the same as everybody else'* (Afan)
- Other people don't like them
 - *'Because they don't like them'* (Charles)
- Easy targets
 - *'because they cannot stick up for themselves'* (Gareth)

Nonetheless some participants also indicated that they didn't know why abuse occurs. They suggested a number of groups of people who abuse people with learning disabilities including professionals, the public, families, strangers and also people they had met before. They also

indicated that abuse can take place in settings such as playgrounds and the workplace. As Ceryn said:

'It could be anyone. It could be a carer, it could be a friend of the family, it could be a family member, and it could be anyone. Who knows? Oh yes they would the person. A stranger could do it but 9 times out of 10 they would know them.' (Ceryn)

Sean also comments on the range of potential abusers:

'Anybody who deals with people with disabilities basically.' (Sean)

The effect of this range of potential sources of abuse was noted by Joanne:

'...you can't trust people in the world' (Joanne)

Deciding whether abuse has occurred is core to detecting and responding to incidents of alleged abuse and whether or not support is support and provided. In the interviews participants were asked who they felt decides what abuse is. Responses included social workers, parents and the law/ police. However, it was also suggested that it should be the individual who has been abused:

'individuals. Comes to individual person can decide what abuse is.' (Sean)

In a comprehensive response Elliott (despite originally stating 'don't know') highlights how not everyone is able to report abuse themselves and so other people have to decide:

'I don't know. Maybe it is the 'law' or... I myself have a good understanding of what is right and what is wrong so I can tell myself what is right and what is wrong. But you know if someone is unfortunately not to have the ability of doing that then who is to say who decides what is right and what is wrong. I would then assume it would be the person's carer or the authorities.' (Elliott)

As in the focus groups participants in the interviews were also asked how they feel about abuse. The key responses are set out in Figure 5 below:

Figure 5: Interview participants' feelings about abuse



For Sean there is a certain resignation that even though abuse is wrong it will occur:

'I just feel it shouldn't happen, but it does. And there's nothing you can actually do about it, it just happens...makes me feel angry, it's such against, it's actually abusing your human rights basically, and we all have human rights' (Sean)

Others, however, talked about the profound effect it can have on an individual and their psychological well-being:

'I felt like I had been turned inside out and gone through the mangle' (Elliott)

'it's Well not very nice. It makes you feel – sometimes it makes you feel, it's like is life worth living for' (Gareth)

'Well, I feel it's such a terrible thing for anybody to go through Sometimes people who get abused continuously feel like taking their own lives.' (Ajit)

Participants were also asked what they thought could happen to someone who abuses people with learning disabilities (Figure 6)

Figure 6: What can happen to people who abuse people with learning disabilities?



Gareth was very clear as to what should happen if care staff abuse:

'If they're abusing someone who's in residential care, they should be struck off, they should lose their job. They should be sacked and their job taken away from them. In other words, what I'm trying to say is they are not fit to do the job. They should be struck off. They should never be carers 'cos the idea of them being carers is to be there to care for that person, not to be uncaring.' (Gareth)

Whilst most participants felt that there should be some form of punishment Elliott expressed a different view suggesting that the abuser may reflect on what they have done:

'Nothing. He is just left with the thought that he has done it. That is not enough to justify that he won't do it again' (Elliott)

However, there was some concern that nothing might happen to the abuser:

'They get off free don't they? They get away with it. Sometimes they get away with it sometimes they get caught' (Ajit)

It was also noted that it can be difficult for people to report abuse which then means that abusers are not punished:

'You got to have guts to back to the police and tell them.' (Joanna)

If people are to report abuse then safeguards need to be in place to protect them:

'they could go to the police station and report in confidence. In other words the police would take it further. I mean that person would be prosecuted and likely go to prison. As long as the police could assure that that person that reported the matter, they wouldn't know that the matter had been reported by name.' (Gareth)

Participants were then asked what they felt should happen to people who abuse. Again a range of responses were offered including:

'If they're taken to court and they're found guilty, they won't be allowed to abuse people again. They wouldn't be allowed to work again.' (Sean)

'If they do something like that they shouldn't be in the job.' (Afan)

'Tell their parents They should take him to the police, and he should own up. Well, they should put him away to learn him a lesson' (Doris)

'But if it came to a carer their job should be taken away, they're not suitable to do the job' (Gareth)

'Well, I want them to be erm (silence) I want them to be behind bars. Punished, yeah' (Ajit)

For others a feeling of wanting abusers to understand the impact of their behaviour on people with learning disabilities was important:

'I want them to understand how they feel about it. And why do you want to do it cos it's not fair' (Wanda)

'I think they should see how we are treated and see how they feel' (Joanna)

'Sent to jail. They should be made to go on a course about abuse and things to see how it affects the people they abuse' (Ceryn)

At the end of the interview participants were asked if there was anything else they wanted to say. Only Elliott and Ceryn took this opportunity:

There are more and more people prosecuting. There are more and more people being punished and let us keep it that way (Elliott)

I think there should be more POVA training for adults with learning disabilities to know the different kinds of abuse because unfortunately some people might be abused but don't know. (Ceryn)

'I think it should be taught in schools as well, that would be quite helpful. Teaching from a really young age' (Ceryn)

1.6.4 Questionnaire

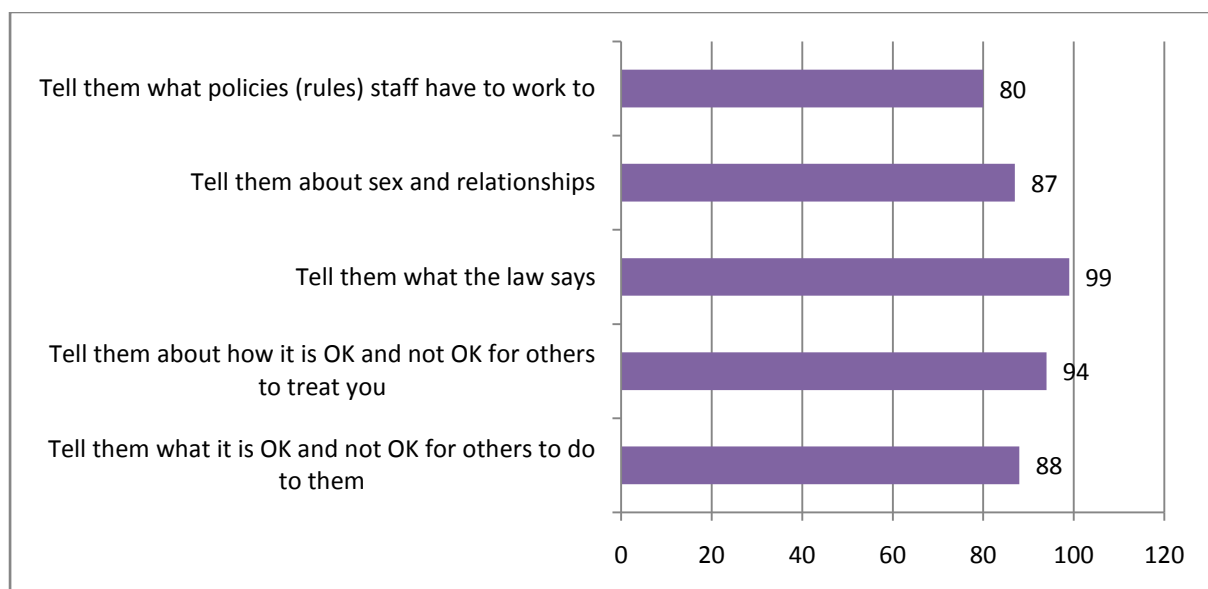
One hundred and seven questionnaires were included in the analysis but it should be noted that some participants did not answer all.

The responses to the question asking how people with learning disabilities can keep themselves safe are presented below as those actions that they can take themselves (Figure 7) and those actions that other people can do (Figure 8)

Figure 7: Actions people with learning disabilities can take to keep themselves safe

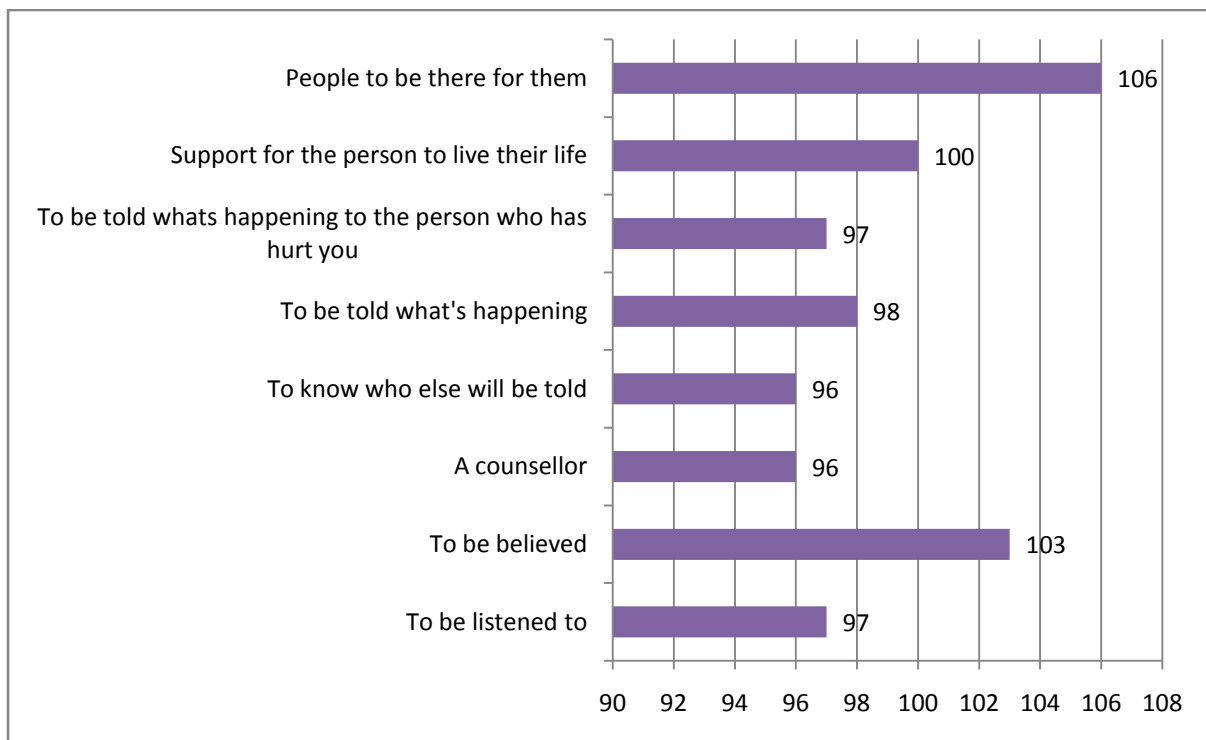


Figure 8: Actions other people can take to keep people with learning disabilities safe



The responses participants gave when asked what can help someone who has been hurt (abused) are set out below in Figure 9.

Figure 9: What support can help people who have been hurt (abused)?



Almost half of those completing the questionnaire (n=50) took the opportunity to make further comments in the spaces provided. Some of these related to things that people could do themselves to keep safe (the number following each statement refers to the participant number):

'Make sure you have good support behind you and people you can trust' (5)

'By locking front and back doors. If someone knocks at the door don't let them in unless they have id' (11)

'Tell someone where you are going at all times and keep their number so you can ring them up if you are followed you to keep safe' (35)

'Carry a panic alarm or card with your emergency contact numbers eg relatives incase the person needs help' (47)

In addition a range of other people were cited as being important sources of support such as family, social workers, support workers, advocates and the police. The importance of education and training was recognised with one participant suggesting a need to educate the public (10), another suggested a need for people with learning disabilities to receive POVA training (76), and another the need for people with learning disabilities to attend other courses (40). When people are abused it is important that they speak to others about this:

'Being aware of your surroundings, don't get into awkward situations, always tell people when something is wrong' (94)

'Make sure you speak up, talk to someone who has been abused or knows how to handle abuse' (92)

However, one participant (90) stressed that it was important that people with learning disabilities are taken seriously when they speak up suggesting that this may not always be the case. Indeed another participant said:

'Write a diary on paper and burn it , write on a stone and throw it into the sea or river' (39)

Perhaps suggesting that the information is best left unshared and somehow 'disposed' of.

In relation to supporting someone who had been abused participants in the questionnaire again identified the importance of telling someone and the range of people suggested included family, police, teacher, support worker, doctors and advocates. It was important to find someone you could trust (57). However, the nature of the support required was also commented upon:

'Someone to be there for the person for as long as it takes' (6)

'Talk to other people who have been hurt (15)

'Maybe find out if there is a group they can go to' (42)

'Sort out the problem keep an eye on them' (79)

'Someone to talk to, out of hours numbers eg Samaritans, support staff and family members' (99)

Specific activities such as training, music and other activities were suggested but listening, supporting and being there were the most common forms of support noted. One participant (62) said that they wanted support but also for their supporter to be angry on their behalf about what has happened. Unfortunately, however, another comment was made that suggested disclosures may not always be taken seriously:

'To be understood and believed- what they are doing is right' (72)

When asked if they would like to make any further comments some participants again stressed the importance of telling other people and of sticking up for your rights. Interestingly some of these comments took the form of advice to other people with learning disabilities:

'Speak to people more' (3)

'To make sure you tell someone all about what happened, you will regret it later if the people who hurt don't get punished properly' (5)

'To stand up for your own rights because we should not be abused in any shape or form from anybody' (72)

'If you have been hurt, don't be on your own – get help get support' (76)

'Don't be abused or abuse others' (79)

1.7 Discussion

The discussion will be structured in relation to the four research questions since data for some questions was gathered via more than one method.

1.7.1 What do people with learning disabilities understand by abuse?

In the individual interviews participants were asked how they learnt about abuse. Some had attended conferences or training provided by People First and others had educated themselves through reading books or watching television programmes. However, a number indicated that they had learnt about abuse either through direct experience of being abused, having friends who had been abused, or witnessing abuse (such as abuse within the family). Nonetheless it is also important to note that two people indicated that the residential event was really the first time they had learnt about abuse. Given that participants in the residential were from organisations of people with learning disabilities who are perhaps those most likely to have been provided with such information this is worrying but what of the wider population of people with learning disabilities? These findings raise concerns as to how they are to safeguard themselves from abuse if they are not told what abuse is or what they can do to reduce / avoid it.

The participants in both the interviews and the focus groups were able to name a wide range of different types of abuse that go beyond those set out in current policy guidance (NaW, 2000). Reference was made to elder abuse, racial abuse and domestic abuse with some participants discussing how they had experienced abuse due to multiple personal characteristics such as having a learning disability and belonging to a minority ethnic group. This interaction between personal characteristics and abuse is one that could usefully be researched further.

Domestic abuse is an under-researched area in relation to people with learning disabilities and the occurrence of domestic abuse amongst this population is said to be under-reported (Taggart *et al*, 2010). One study, however, explored the experiences of 5 women who had experienced a range of different types of domestic abuse (Walter-Brice *et al*, 2012). One participant in the current study spoke of how she had experienced domestic abuse and reflected that '*it was all my fault*' (FG2). This reflects the theme of 'self-blame' that emerged from the work of Walter-Brice *et al* (2012). However, it is also important to draw parallels with wider domestic violence reports that highlight how non-disabled victims can often blame themselves. This raises the question of whether, within that particular context, women with learning disabilities have more in common with other abused women than with other people with learning disabilities. This is perhaps an area worthy of exploration in future research.

This reflection of wider societal views was also evident in one of the focus groups where participants engaged in discussion as to whether what a woman wears can lead others to assume that she is inviting sexual attention. However, given that some participants in this study indicated that they had learnt about abuse via the media this discussion is perhaps not surprising.

Whilst one participant in the individual interviews did not know why abuse occurs, others in both the interviews and the focus groups suggested a range of reasons including race, religion, and personal appearance. A number were very aware of how people are abused because they are different and that one of the differences other people see as significant is having a learning disability. For Joanna this means that other people abuse people with a learning disability because they feel the person

will not be able to speak up as no-one will believe them. Similarly Gareth suggested that they are unable to stand up for themselves.

Whilst participants could name a wide range of abuses there was less clarity / agreement as to whether the photographs shown to those participating in the individual interviews showed examples of abuse or not. Indeed only one photo elicited total agreement. This perhaps reflects wider difficulties within services as to deciding upon thresholds for abuse (Collins, 2010). However, participants did think carefully before making their decisions and considered a range of factors. Nonetheless the same behaviour can be interpreted differently as shown by picture 9 where Ceryn felt it was abuse as one person in the picture was touching the breast of another, Doris interpreted this as being friendly whilst Afan suggests that it could be sexual harassment or they could be in a relationship. This illustrates the complex range of visual, contextual and social factors that need to be taken into account and also highlights how it may be difficult for people with learning disabilities to distinguish between acceptable and unacceptable behaviours.

The challenges involved in relation to deciding whether abuse has occurred are fundamental to achieving justice for people with learning disabilities who have been abused. In the interviews participants identified a number of people who they felt should decide what abuse is: social workers, parents and the law/ police. One person (Sean) however, indicates that it should be the individual who decides. This might be viewed as a positive position to take: if the individual says abuse has occurred then it has. Nonetheless, people with learning disabilities may have been socialised into accepting abuse as part of everyday life and/ or may not recognise abuse when it occurs. In addition Elliott in his interview notes that not everyone with a learning disability is able to understand what's right or wrong and so other people may need to decide. Where possible people with a learning disability should, therefore, be supported to recognise and report abuse but this does not negate the importance of others being vigilant particularly on behalf of those who are unable to speak up. This may include vigilance in relation to behavioural changes that may be indicative of abuse (Murphy *et al*, 2007; Brown and Beail, 2009).

1.7.2 What are their views about abuse?

Participants in both the interviews and the focus groups expressed a range of views when asked how they felt about abuse. Unsurprisingly their views were overwhelmingly negative but some of the comments provided extremely vivid descriptions of personal feelings such as stating that abuse is '*like a headache*' that you cannot get out of your head (FG6) and reporting feeling as though they had been '*turned inside out and gone through the mangle*' (Elliott). Such descriptions convey a sense of both physical and psychological pain.

Anger was an emotion identified by a number of people and this is reflected in comments made by some participants in the focus groups who told of how they sought to contain such feelings for a time but eventually they '*got too much*' resulting in the individual hitting out at their abusers. Within such a situation it is evident that people with learning disabilities may themselves be viewed as perpetrators of abuse, and potentially faces sanctions, because they have not been able to contain their anger at their abuse.

For others their views reflected very different emotions such as embarrassment and lacking self-confidence. These emotions can be particularly difficult in the context of abuse since they can lead

to self-blame and to reluctance to report. This lack of reporting then leads to a lack of support and a sense of justice that can lead to longer term negative effects. It can be seen how easily a cycle of abuse leading to low self-esteem leading to further abuse may occur.

What was particularly disturbing, however, is that a number of participants in both the interviews and the focus groups indicated that abuse can make someone feel like killing themselves. Whilst research examining suicide and people with learning disabilities is limited Merrick *et al* (2006) examined the existing literature and one risk factor for suicide identified in their review was a history of abuse. Other studies have found experiences of abuse and neglect to be factors that contribute to mental ill health in people with learning disabilities (for example Smiley *et al*, 2007; Taggart *et al*, 2010). In another study abuse was found to lead to psychological distress amongst people with learning disabilities and that whilst there was some improvement over time psychological difficulties remained (Rowell *et al*, 2012). One participant in the focus groups referred to nightmares as something that they '*always have...when people abuse me and take advantage*'. The presence of such nightmares as a response to abuse is noted in the literature where it is linked to Post Traumatic Stress Disorder (PTSD) (Stenfort Kroese and Thomas, 2006). Both the findings of the current study and those of other studies point to the need for appropriate, timely and effective support where abuse does occur. This issue is returned to below where support is discussed.

Within the focus groups discussion took place as to whether one form of abuse is worse than another. While little consensus was achieved a number of participants suggested that sexual abuse is particularly bad. It is not possible to tell from this study whether this response is a reflection of the fact that sexual abuse has been a particular focus when abuse of people with learning disabilities is discussed but this may be one contributory factor. Another explanation could be the particularly personal nature of such abuse that makes it both difficult to experience and embarrassing to report. In reality, of course, many people who are abused experienced multiple forms of abuse and so it may be difficult to separate one form of abuse from another. Finally, as one participant remarked, what one person feels is abuse is not viewed as abuse by another and thus there is inevitably a subjective, individual element in any assessment.

Participants were also asked their views regarding what should happen to people who commit abuse. As might be expected some expressed a view that people should be charged and imprisoned but voiced concern that often prison sentences are reduced. There was also agreement that if people in positions of trust (such as care staff) commit abuse then they should lose their jobs. Alternative views included the suggestion that nothing should happen to abusers as the knowledge that they have committed abuse may deter them from repeating such behaviour. Other participants suggested that abusers should be made to understand what it is like to be abused and how people with learning disabilities feel. Such an approach might perhaps involve people with learning disabilities providing awareness raising sessions for those who have committed abuse in a manner similar to restorative justice schemes that bring victims and perpetrators of crimes together.

1.7.3 What help and support do they need to keep safe?

When asked what people with learning disabilities can do to keep themselves safe the number of responses ranged from carrying a personal alarm (n= 75) to learning to speak up (n = 105). These

responses were discussed by the research group and we considered whether the lower numbers identifying a personal alarm as useful were due to a lack of awareness about this facility. However, some group members reported that a lot of work had been undertaken with People First Groups regarding use of personal alarms and they had been distributed by the Police. Unfortunately the alarms were found difficult to use and because of this they were not seen as useful. We also discussed how so many alarms are now heard in everyday life (for example burglar and car alarms) that often other people do not take any notice of them. These reasons might explain why fewer people felt personal alarms might be helpful (although 75 out of 107 people are still the majority of participants).

Almost all participants (n= 105) indicated that people with learning disabilities should learn to speak up concerning abuse. That this was recognised as important can be viewed as a positive sign that people with learning disabilities know that abuse should be reported. However, as previously noted, all participants were members of organisations of people with learning disabilities which means they are more likely both to have discussed abuse, and to have had support to learn to speak up. Nonetheless whilst participants in this study may recognise the importance of this whether they would feel able to do so if abuse had occurred or was threatened is another matter. Indeed in a study undertaken by Mencap (1999) it was found that 25% of the 904 participants were too scared to speak up about the bullying they were experiencing, that they had experienced it for so long that they saw it as just an inevitable part of having an intellectual disability, and that before that survey they had never had any discussion with anyone concerning bullying. Repeating the current study with other groups would therefore be interesting, but even without further research the need to provide support and opportunities for self-advocacy for people not attending self-advocacy groups is evident.

Another response that was rated very highly (n= 104) was making sure that someone knows where you are at all times. At one level this seems a very sensible measure to take in order to promote self-protection. However, it also means that people with learning disabilities may experience levels of surveillance and supervision not experienced by other adults. This could be a particular issue where people are supported by services that are overly risk adverse. When we discussed this as a research team we felt that this could be annoying for people with intellectual disabilities and one member suggested that it helps families and staff but not the individual with intellectual disabilities. A tension between protection and empowerment, and between autonomy and paternalism is thus evident.

A large number of participants (n= 101) indicated that staying away from 'nasty' people is a helpful strategy. Once again this seems to be a pragmatic approach to promoting self-protection but it imposes limitations on the freedom of people with intellectual disabilities when they are the victims. It can be difficult to know who the 'nasty' people are and it is important to note a significant number of allegations of abuse relate to family members and carers. For example, in one study (Cambridge *et al*, 2006) 23.3% of alerts regarding abuse related to abuse by family/ partner/ carer. In such circumstances staying away from abusers may be (or seem) impossible. It may also be difficult to achieve in cases such as hate crime. In a recent study examining hate crime experienced by people with learning disabilities 29% of incidents happened within the home, 28% out and about in the community, and 27% around the home (Gravell, 2012). In such circumstances avoiding abusers may again be virtually impossible and in some situations people with learning disabilities have had to move house whilst their abusers remain free to live their lives (see for example Whittell and

Ramcharan, 2000). Finally many people with learning disabilities live in group settings and attend day facilities where they may be exposed to the challenging behaviour of other people with learning disabilities. In such circumstances it may be difficult, if not impossible, to stay away from their abuser and client on client abuse may be viewed as 'challenging behaviour' rather than abuse (Joyce, 2003). One member of our research team commented even if you complain to staff that other clients have abused you no-one does anything about it. Despite this, in one study, 26.4% of alerts concerning abuse of people with learning disabilities related to client on client abuse (Cambridge *et al*, 2006).

Not giving personal information to strangers (n = 95) and knowing safe ways to behave (n = 92) were identified by the majority of participants as being important but fewer identified them as being helpful compared with other strategies. This is interesting given that strategies such as these are often included in personal safety programmes for people with learning disabilities such as those described by Khemka *et al* (2005). This could suggest that people with learning disabilities place less value on such strategies than do professionals and whilst their inclusion within personal safety programmes is important, perhaps we also need to consider how other strategies they perceive as helpful can also be included.

Comparing the responses in Figures 7 and 8 it is evident that participants were less likely to identify actions by others as being as important as the actions that people with learning disabilities should take themselves. This may suggest an awareness of personal responsibility for safety and/ or a reluctance to rely upon others. Nonetheless the lowest response to things other people can do was 80 people (75%) and thus a clear majority of participants also view the actions of others as important.

The largest response (n= 99) identified the need for people with learning disabilities to be told about the law. Previous research (Murphy *et al*, 2007) compared the understanding of adults with learning disabilities and young people without learning disabilities of the law relating to consent, personal and sexual relationships. Significant differences were found between the two groups with people with learning disabilities having lower levels of understanding. The researchers conclude that given the higher level of sexual abuse within this group it is important that they understand the protection that the law can offer to them. It would seem that the participants in the current study recognise the importance of understanding the law but when this was discussed by the research team it was felt that people with learning disabilities are not always given this information and helped to understand it. This point is also relevant in relation to people with learning disabilities as perpetrators of abuse: if they are unaware of the law they will not be aware that they are breaking it and run the risk of offending. Indeed the relationship between abuse and offending is a complex one and when the life histories of offenders with learning disabilities are examined a high incidence of abuse is found (Lindsay *et al*, 2004; Hayes, 2009; Lindsay *et al*, 2012). The reasons for this relationship remain unclear and further research is needed. However, it is possible that those exposed to abuse come to view this as normal behaviour and engage in such behaviours themselves only to find at a later stage that they are illegal. The importance of ensuring that people with learning disabilities know about the law lies, therefore, not only in assisting them to guard against illegal behaviours but also (since some of their potential victims will themselves be people with learning disabilities) in reducing the incidence of abuse.

Telling people with learning disabilities how it is OK for other people to treat them (n = 94) and about what it is OK for other people to do to them (n = 88) could be linked to a knowledge of legal issues but encompasses wider, perhaps less clear social norms and conventions. If you are unsure as to what is acceptable and unacceptable behaviour the unacceptable may come to be accepted as the norm. This could lead to people with learning disabilities accepting abuse as part of their lives: it is 'just how things are'. Reiter *et al* (2008) argue that enabling people with learning disabilities to become aware that they are being abused and that this behaviour is illegal is an important first step in countering abuse. Discussing this as a research team we felt that telling people with intellectual disabilities about these things is important not only to protect them from abuse, but also to stop them from breaking the law by abusing others.

Much of the self-protection work with people with learning disabilities to date has tended to focus on sexual abuse prevention (see for example Egemo-Helm *et al*, 2007). In our study 87 people said that it is important to tell people about sex and relationships. It is not possible from our data to say whether this response is based on experience of receiving such training or whether it is based on the experience of not receiving such training yet still recognising it as important. Studies elsewhere suggest that people with learning disabilities may lack sexual knowledge and that this increases their vulnerability to abuse (Murphy, 2003; Eastgate *et al*, 2011). Peckham (2007) found that attending a support group post abuse resulted in improvements in sexual knowledge suggesting the presence of a deficit that needed to be addressed but one that is amenable to change. It would seem that despite this being the focus on many abuse prevention programmes there remains much work to be done in the area of personal and sexual relationships. Moreover, providing such education solely in the context of abuse prevention strategies would risk personal and sexual relationships being viewed as something to be avoided rather than as a positive aspect of adult life.

Telling people about the policies staff have to work to was viewed by 80 people as being important. It could be that this response is lower than others because people with learning disabilities are not often told about policies and their contents. However, it can sometimes be the case that staff knowledge may also be limited and/or there is limited focus on their implementation (Northway, *et al*, 2007). As one of our research team commented during analysis staff often complain that policies are constantly changing and this could also be a reason why people with learning disabilities are not told about their content.

Although the word 'resilience' is not used in the questionnaire or in any of the comments it is apparent from the responses participants gave that they recognise the importance of both personal responsibility and support by others in developing resilience in the context of abuse. Ideally abuse would not occur and much needs to be done to reduce its incidence. However, it is also important that efforts are focused on assisting people with learning disabilities to understand how best to keep themselves safe. In an editorial for a special journal edition on resilience Broberg *et al* (2009) define resilience as:

'...an interactive concept that refers to relative resistance to environmental risk, or the overcoming of stress or adversity' (p955)

However, despite acknowledgement that both people with learning disabilities and their families / carers may need resilience to cope with adverse events each of the papers included relate to family resilience rather than resilience and people with learning disabilities. To date resilience has tended

not to be an approach that has been widely used in either practice or research relating to people with learning disabilities and abuse. The responses to the questionnaire in this study, however, suggest that it might be a useful way forward.

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

The findings of both the individual interviews and the focus groups highlight the range of emotions experienced by people with learning disabilities in relation to abuse. Whilst some of these comments were made regarding abuse in general some participants were speaking from direct experience of either being abused personally or witnessing the abuse of close friends and family. It is also important to remember that whilst some were speaking from recent experience others spoke of strong feelings in relation to abuse that had happened some years ago. Reading their comments is distressing particularly as some speak of how it can make you question whether life is worth living and hence lead you to consider self-harm. Such feelings are also noted elsewhere such as in the study undertaken by Brown and Beail (2009) where interviews with 9 people with learning disabilities who self-harmed revealed the impact of past abuse on current self-harming behaviour. Research relating to people with learning disabilities and suicide is limited but Merrick *et al* (2006) reviewed available studies: a history of abuse was highlighted in a number of studies as a precursor of suicide. All of these comments speak to the need to ensure that appropriate, acceptable and timely support is available where abuse does occur and yet this is an area that has not been widely explored within the context of research.

One hundred and six people out of 107 responding to the questionnaire indicated that when people are abused it is important that people are there for them. Having someone to talk to might also be expected to rate highly but a slightly lower number (n=97) indicated that this was helpful. Whilst still accounting for 91% of respondents this slightly lower figure could, potentially, be explained by previous experience on the part of those taking part. For example, van Nijnatten and Heestermans (2010) argue that the environments in which people with learning disabilities live often limit rather than facilitate discussion concerning abuse. Elsewhere Strike and McConnell (2002:53) comment that 'Sometimes support workers or so-called professionals don't *really* listen to people with an intellectual disability. They assume a lot'. Opportunities for discussion with trusted confidantes may thus be limited leading people with learning disabilities to view this as a less effective means of support.

One hundred and three people completing the questionnaire indicated that when someone is abused it is important that other people believe them. However, when we discussed this finding as a research group some members indicated that this does not always occur. As Joanna indicated in her interview '*You got to have guts to go back to the police and tell them*'. Worryingly similar experiences have been reported elsewhere such as the women in the study undertaken by Walter-Brice *et al* (2012) who wanted to be listened to and believed but had not always received such support. Participants in the study by Hollomotz (2012) also spoke of reporting abuse but others failing to act. If this reflects a widespread experience it would suggest that the recorded prevalence of abuse (which is already higher than for non-disabled people) may be an underestimation. Indeed it is also perhaps worth noting here that during the residential event some participants disclosed abuse that they had not previously shared with anyone further suggesting that current prevalence figures are likely to be an underestimation.

Other support that was viewed by questionnaire respondents as being helpful was for people with learning disabilities who had been abused to be kept informed as to what is happening (n = 98), to be told what is happening to the person who has hurt them (n = 97), and to be told who else is going to be informed (n= 96). These findings reflect those of Gravell (2012) in her study of hate crime against people with learning disabilities. Once again, however, it has been suggested elsewhere that people with learning disabilities are not always kept informed (Magill *et al*, 2010) and a gap between their self-defined needs and practice is apparent.

One hundred respondents to the questionnaire indicated that people who have been abused should be given support to live their lives suggesting that assistance is required to maintain daily living and to be able to move on. However, the number indicating that a counsellor might be helpful (whilst still comprising the majority of participants) was 96. This slightly lower number may be a reflection of the limited availability of counsellors providing support for people with intellectual disabilities, and a lack of awareness of what they can offer. Nonetheless Sequiera (2006) identified that therapeutic support post abuse can be effective and the fact that the majority of participants indicated that counselling could be helpful suggests that such support would be acceptable. In addition it is important to note that during the residential event held as part of this research all available sessions with the counsellors were taken.

The questionnaire specifically asked about whether counselling is helpful for people who have been abused and 96 participants indicated that it was. As a research team we considered carefully whether this relatively large figure reflected the fact that we had made it evident that counsellors were available during the residential event. However, only 47 of the 107 people completing the questionnaire attended the residential. Within the transcripts of the interviews and focus groups it is evident that some participants indicated that they wished to speak with a counsellor: it appears that they felt that this was a source of support they might find helpful. However, elsewhere comments were not volunteered about counselling. This is perhaps a reflection of the fact that counselling services for people with learning disabilities are very limited and whilst they may have heard of them they may not have experienced them. Such limited availability of support was seen in a study by Sequiera *et al* (2003) where 61% of the participants who had been abused had not been offered formal psychological support. Elsewhere it is suggested that such support should be offered as soon as possible after an adverse event such as abuse (Smiley *et al*, 2007), a point also made by Sequiera (2006) who suggests that if interventions are not made soon after abuse then adverse effects may become established as long term conditions. This is interesting when considered against some of the literature relating to offending behaviour amongst people with learning disabilities since there it is noted that both individual and group psychological support and therapy is provided (Lindsay *et al*, 2004; Lindsay *et al*, 2012). Whilst not denying the importance of such support for those who have offended the earlier provision of support could potentially avoid such offences. This is, however, an area that requires further research.

1.8 Conclusions

Before drawing conclusions it is important to note the limitations of this research. First it must be noted that participants came from self-advocacy organisations and this meant that they were probably better informed about abuse and the surrounding many issues than other people with

learning disabilities might be. Whilst this must be acknowledged it needs to be balanced against the fact that even though participants were probably better informed than others there were still examples of difficulties being experienced. Nonetheless, accessing wider populations would be a useful focus for future research. A second limitation is that participants tended to fall within a group often referred to as having mild or moderate learning disabilities. The experiences of those with severe and profound learning disabilities are not, therefore, represented despite the fact that they may be at particular risk of abuse. To find ways of accessing their experiences was beyond the resources of this project but could usefully form the basis of future research.

Balanced against these limitations is the fact that the survey achieved a positive response rate and the participant group was diverse in terms of age, gender, locality, ethnicity and disability. Through the use of different means of data collection the study has elicited the views and experiences of people with learning disabilities and has thus begun to address the knowledge deficit in this area. A number of conclusions may therefore be drawn and recommendations made.

It is evident from the findings of this study that abuse is, unfortunately, often a feature of the lives of people with learning disabilities as they witness abuse, hear about abuse from their friends, or through direct personal experience. Moreover, they are aware that abuse may take many forms and conscious of a number of factors that can make people more vulnerable to abuse. Nonetheless, while a few participants indicated that they had received information regarding abuse most had learnt via the media, through hearing the experiences of their friends or through personal experience of abuse. In addition it was apparent that sometimes the behaviour of other people can be open to different interpretations. Participants identified a number of areas where the provision of information/ education would be helpful in keeping people with learning disabilities safe namely understanding policies, legislation, how it is OK / not OK for other people to treat you, what it is OK/ not OK for people to do to you and having information about personal and sexual relationships. Other aspects of personal safety awareness were also identified as helpful. Some (but not all) of these areas are addressed within existing personal safety programmes but some of these programmes focus specifically on sexual abuse prevention and (given the findings of this study) it is evident that programmes are not always available. **It is thus recommended that personal safety courses be more widely available for people with learning disabilities, that they encompass more than just sexual abuse, and that they include the areas identified by participants as being helpful. Such courses should be part of a wider aim of helping people with learning disabilities to develop increased resilience.**

The range of responses provided by participants concerning their feelings about abuse reflected some very strong emotions and the significant emotional/ psychological effects that abuse can have. Of particular concern is the acknowledgement by participants that it can lead to suicidal thoughts. It can thus be concluded that people with learning disabilities experience psychological effects as a consequence of abuse and some can express these very vividly. If someone has been abused having the support of others and being kept informed as to what is happening were viewed as important by participants. However, whilst the importance of being listened to and believed were also stressed discussion within the research team highlighted that such a response is not always received when someone discloses abuse. It can be seen that such an inappropriate response may lead to the adverse psychological effects noted above. **A key recommendation is therefore that when people with learning disabilities disclose abuse they must be listened to, believed, appropriate action**

should be taken and support given. In relation to support **it is recommended that people with learning disabilities who have been abused should have greater access to counselling and other therapeutic interventions.** Ideally this should be provided as soon as is appropriate after the abuse but it also needs to be available to those who disclose abuse many years after the event. In relation to research **it is recommended that further research be undertaken regarding the relationship between abuse and suicidal thoughts in people with learning disabilities and concerning the effectiveness of various post-abuse therapeutic interventions with people with learning disabilities.**

Where abuse had occurred it was evident that many participants had very strong ideas as to what should happen to the abusers. While some of these reflected more common forms of justice such as imprisonment others demonstrated a very different approach suggesting that abusers should be helped to understand the impact of their behaviour on their victims. **It is therefore recommended that consideration is given as to how such understanding can be achieved and the role that people with learning disabilities should play in raising awareness.**

2. Part Two: Learning About Researching Together

The second aim of this project was to:


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

In keeping with this Part two of this project report will focus on the learning that has taken place as we worked as a research team from the point of identifying the original idea for research through to the dissemination of findings and plans for action based on those findings. Central to participatory research approaches is the creation of opportunities for active participation at all stages of the research process thus changing the balance of power from academic researchers to the 'community'. In this instance the 'community' being people with learning disabilities. As noted earlier PR has been criticised for failing to change power relations sufficiently such that whilst there is participation control remains with the academic researchers. To allow readers to judge for themselves the nature and extent of participation in this project Appendix 8 sets out key stages of the research project and provides evidence of how people with learning disabilities were involved throughout.

It will be noted from the aim stated above the intention has been to explore how PR works for all involved. For that reason the information discussed in this section has been gathered from a variety of sources including:

- Reflections completed by team members
- Group discussions
- Training events
- Research Advisory Group meetings
- Participation in events such as seminars and conferences

- Papers written by team members

The information will, therefore, be presented under a series of headings that have been identified by the research team and that recur as themes within the PR literature. Inevitably many issues are closely related and thus one section may cross reference to another. Where we feel that there have been key learning points then these will be identified by  **Learning Point** as we hope that other researchers reading this report will be able to learn from our experiences of what worked well and what we might do differently.

2.1 Building and Maintaining Relationships

Much of the literature concerning PR stresses the importance of building and maintaining relationships (for example Becker *et al*, 2013) indeed Plumb *et al* (2004) argue that funders need to understand that in PR they are funding not only the research but also the development of the partnership required to undertake the research. Strong relationships are required in PR studies since working together in this way demands a high degree of trust and this is only achieved after a period of getting to know and understand each other. It has also been suggested that developing a strong relationship is not something that is achieved and then ticked off: it is something that has been described as a 'never-ending process' (Christopher *et al*, 2008).

In the context of this project one advantage we had was that the team was not brought together initially to undertake a project that had been identified by other people. Instead it grew out of an existing relationship in which TRAC (the Teaching, Research and Advisory Group that meet at the University of Glamorgan) members expressed a wish to undertake this research. Some of the relationships in this project were thus long standing. However, New Pathways became involved at a later stage in the development and came from a non-learning disability background. They brought to the project an extremely valuable perspective but nonetheless we all had to come to understand each other's backgrounds and contributions. In addition some members of the project team such as those appointed to work specifically on the project joined later in the process and hence new relationships had to be developed. Two levels are important to consider here: the relationship between organisations and the relationship between team members.

This project involved two third sector organisations and one public sector organisation working together. What became evident early on in the project was the very different systems and structures these different types of organisation have. Whereas the third sector have much more flexibility in terms of systems and are therefore able to respond to issues more quickly the public sector has a more bureaucratic structure where decision making can be much slower and much less discretion is possible. One example early in the project where this caused difficulties was in getting the legal agreement signed by each organisation. In the third sector organisations this was straightforward but within the University it had to be determined as to who could sign and then when they would be available for signing. It was difficult for colleagues to understand this process and team members had to work hard to try and respond to the needs of the project whilst also staying within the requirements of their organisation. However, despite these structural challenges it was also recognised that the different organisations each had something important to bring to the project whether in terms of experience, access to resources, or contacts. This recognition that the project was stronger through every organisation's contribution provided the impetus to find ways of working with, round and through the differences in systems and structures despite our frustration at

times. With many decisions discussions took place as to which organisation would be the best placed to take the lead since different actions required different approaches. At times we were able to use the differing organisational strengths to the advantage of the project which would not have been possible were we working on a single agency basis.

At a team level different strategies were used to try and develop good working relationships. Within the first few months of the project we had two team building workshops that provided the opportunity to both get to know each other better and to share our hopes and wishes for the project. Unfortunately not everyone was able to attend but for those who did it was a useful experience. 'Team' has been a word commonly used in the course of the project as seen in the following comments:

'I am finding more and more that this project is about teamwork and that is what makes it all work'

'My experience of working in the team has been inspirational'

'The strength of this team is its belief in what we are trying to achieve'

As these comments indicate, however, 'team' within this project has been more than a label used to describe a group of people working together: it has been a way of working founded on the shared belief that people should not experience abuse and that things must change. Undertaking this research was seen by all as an important part of achieving such transformation. This is a good example of how participatory research requires commitment to an explicit value base (Cocks and Cockram, 1995) and a commitment to action (Northway, 2010a). Why the research is done is as important as what is discovered and both of these factors provide the motivation for research teams to work together to achieve change.

Nonetheless the concept of a team does not demand that everyone plays the same role. Indeed if the example of a sports team is used then everyone playing the same role would be viewed as being dysfunctional: a team of goal keepers is as ineffective as a team of strikers. Within this project the co-researchers were actively involved in all stages of the research whereas in many research teams some people are involved in the data collection but perhaps not so involved in data analysis. Inevitably we all have preferences for certain activities and the co-researchers in this project were no different. Perhaps if the project were repeated we would provide opportunities for involvement in all aspects of the research along with support to take advantage of these opportunities if so desired: choice and control would rest with the co-researcher. Having the opportunity to participate but deciding not to is very different to not being offered the opportunity and individuals being able to focus on those aspects of the research that best utilise their skills and interests may be a better approach.

☑ Learning Point It is important to recognise different organisational structures and to identify the best ways of working with these

☑ Learning Point Including a team building event is helpful in developing team approach and understanding of each other.

✔ Learning Point Provide opportunities for involvement at all stages and support to take these opportunities if desired. However, also consider whether using skills and talents of individuals at different stages of the research may make best use of the experience and expertise within the team.

2.2 Employment Issues

Some members of the research team were already in post prior to the project and commencement of the research for them just meant the allocation of some of their existing hours to this activity. However, a number of new posts were created specifically for the project namely the co-researcher posts, their personal assistants, and the research assistant. One important issue that had to be agreed was who would be the employer(s). The research assistant post, it was agreed, would be based in the University and employed by them. For the co-researchers and their personal assistants it was agreed that it would be better for RCT People First to be their employer. Whilst there are precedents of Universities employing people with learning disabilities the standard job specification for a University based research assistant would require a first degree (minimum) as an essential qualification for the post. This would, of course preclude most, if not all, people with learning disabilities. It was therefore more expedient for RCT to employ the co-researchers since they had experience in this area and to pursue employment by the University would have required protracted discussions.

We wanted to appoint the post holders in a manner such that the co-researchers would be able to influence the other appointments which, in turn, meant staggering the appointments process. A job description for the co-researcher post had been developed and submitted as part of the application for funding. This was updated and the posts were advertised. Information sessions were held and support to complete applications identified. The interviews were conducted by a member of staff from RCT and one from New Pathways. Reflecting on this experience the co-researchers felt this process had been helpful to them:

'It gave us the chance to think about what we can do, and to "sell ourselves"' (Flood et al, 2012)

Two of the co-researchers were supported to apply for their posts by a specialist employment agency. They found this support helpful but towards the end of the project commented that they felt they had not fully understood the nature of the post they applied for because whilst the agency had expertise in relation to employment they did not have an understanding of what research involved. Perhaps, therefore, if similar posts were to be advertised in the future some more in depth discussion could usefully take place with the employment agency before the posts are advertised.

Once the co-researchers were appointed it was then possible to appoint the research assistant. Development of the person specification and role profile here proved interesting since we initially we were told that it had to be advertised at a lower grade than the one we had funding for. The rationale provided was that the grade we had requested required more leadership and management than we had specified. However, from our perspective what was required for participatory research was facilitation and enabling. After providing a brief overview of the principles of PR for the Human Resources Department it was agreed that our role profile could stand at the grade we had requested. This example provides a useful reminder of how structures and systems can work against

making PR a reality and how important it is not to assume that other people have an understanding of its principles and values.

The co-researchers were involved in part of the interview process as they attended the presentations that candidates gave. Their contribution in terms of candidates approach and ability to make information accessible was invaluable. They were not, however, involved in the one to one interviews which is something that could possibly be approached differently in future.

The final team members to come into post were the personal assistants since we wanted the co-researchers to be fully involved in this process. The co-researchers all had different support needs and so they worked with student nurses to develop person specifications for the support they required as an individual. They were then involved in interviewing for, and appointing, their PA. It was important to appoint people in this sequence but this did delay the start of the project a little. In addition other requirements that had to be satisfied such as CRB checks also took time especially in getting some of the documentation required together for the co-researchers.

During the project there have been some changes in personnel as you might expect within a three year project. One of the co-researchers left after a few months and so the process of recruitment had to be repeated. Having someone new come into the team was difficult both for the existing members and the person having to come in to a project that had already been going for some months. Even though it was still relatively early in the project there was a lot to catch up with. Later two of the PAs also left due to other work pressures. This is perhaps very understandable given that few people are able to work for just a few hours per week (as required by this post) and therefore they inevitably have to have other employment. However, because each co-researcher requires individual support they each require their own PA for the hours they work. Were we planning the project again one thing that would perhaps be considered is to add in some hours for the PAs that are not tied into to providing one-to-one support which would then both increase their hours and enable them to provide other support to a project such as administration or transcribing. Within this project we were able to appoint one PA who was someone who already had some awareness of the project and who was known to the team and the other PA extended their hours to provide additional project support with the one-to-one support for the other co-researcher being provided by other members of the research team. It was felt that this was preferable to introducing yet another new member into the team.

In terms of providing support, however, it has been important to ensure that additional cover is available to provide the support required. During a period of extended sick leave of one staff member the co-researchers said how important it had been to them to have someone else who could stand in. They felt that this was advice that should be passed on to other people thinking about doing research.

Another important aspect of employing people is the provision of on-going support and supervision. RCT People First provided this for both co-researchers and their PAs. The reflections written by PAs identify this as an important form of support particularly in the early days of the project when it was very useful to talk through queries and concerns with someone.

Throughout the project training has been provided in relation to data collection, data analysis and other aspects of research. However, reflecting upon the project as a whole one area the team has

identified that we feel should be addressed in any future projects is to provide some training in what it means to be employed. The co-researchers had to take on a lot of new requirements in a short space of time such as observing hours of work, booking leave, completing time sheets and informing people if you are off sick. As they observe:

'Working as a co-researcher...means that we each have to make other decisions because we are employed to do a job' (Flood et al, 2012)

These are perhaps skills that many people take for granted but which people with learning disabilities may not have had the opportunity to develop. Some training in this area may, therefore, be helpful.

Within this project funding was sought and obtained to provide each co-researcher with a personal assistant. Whilst this inevitably added to the costs of the project this support has proven to be invaluable. They have provided practical support such as transport, filling in time sheets as well as supporting the gathering and analysis of data. However, the emotional support they have also provided has been greatly valued by the co-researchers who have said that without them they would not be able to do their job, that they have helped to build confidence and that:

'They have been there for us to talk to when we have been down and have also made us laugh' (Flood et al, 2012)

☑ Learning Point It is important that co-researchers have the opportunity to be fully involved in the appointments process particularly in relation to their PAs

☑ Learning Point While providing a personal assistant to support each co-researcher does add to the project costs this is a worthwhile investment both in terms of project completion and in relation to supporting the personal development of people with learning disabilities.

☑ Learning Point When planning a project careful consideration needs to be given to the hours worked by PAs to make such posts a viable option for people who possess the required values and skills.

☑ Learning Point Training concerning employment practices should be provided for co-researchers who have no previous employment experience.

2.3 Practical Considerations

Two key areas of practical considerations will be considered here: managing budgets and promoting accessibility.

2.3.1 Managing budgets

The management of the financial aspects of research has been a contentious issue within disability research with some authors arguing that research should be emancipatory and that this cannot be achieved until both the social (decision making power) and material (control of the budget) relations are transformed (Zarb, 1992). In practice this would mean disabled people having control not only the research design and delivery but also holding the budget and employing researchers. This debate has not really been mirrored within participatory research involving people with learning disabilities.

Within this project one organisation (New Pathways) acted as the grant holders but the budget was then shared with both RCT People First and the University of Glamorgan. A positive aspect of this is that some funding at least was controlled by an organisation of people with learning disabilities. However, there were a number of logistical problems with managing the budget in this way not least the different accounting systems of the three organisations. In particular key differences in terms of accessing funding and reporting spending were apparent between statutory and third sector organisations. At times this caused frustrations, misunderstandings and the need to spend a great deal of time clarifying things.

If planning a similar project in future we would calculate individual organisational budgets in terms of salaries, travel and consumables for example and then bring them together very carefully as the wider team to ensure that there were no items of expenditure that had been missed due to one organisation assuming another had included it. Thankfully we have been able to manage this in the context of this project by working very closely together. Nonetheless it has made us very aware of the potential for gaps to appear if individual budgets are not then carefully reviewed in terms of overall project requirements.

Whilst not having control over the overall research budget people with learning disabilities have, wherever possible, made decisions regarding how some monies were spent. Examples of this include deciding on how the monies for the residential event should be spent by identifying what they wanted from a hotel and then choosing the hotel to be used. This was quite a significant activity since people with learning disabilities are not often in the position of being customers with a considerable amount of money to spend. Other decisions have included the choice of bags for the residential, the design of the polo shirts worn by the research team and where the launch events should be held.

☑ Learning Point When planning a participatory project involving more than one organisation plan individual budgetary requirements but then review them together in terms of the project as a whole to ensure that areas requiring funding are not lost

☑ Learning Point Where possible support people with learning disabilities to take control over decision making in relation to expenditure.

2.3.2 Accessibility

For many the term accessibility conjures up images of ramps and wheelchair access. This has been important for us to consider in the context of this study, particularly in relation to the residential event. However, the need to promote accessibility is much wider than this alone. In deciding the venue for the residential the RAG were very clear that there had to be good wheelchair access, ground floor bedrooms and disabled toilets. Whilst the hotel we used did not have a lift to the second floor they agreed to provide us with a majority of ground floor rooms and the RAG felt this was acceptable given that the staff at the hotel had had such a positive attitude to people with learning disabilities (another dimension of accessibility).

Most RAG meetings were accommodated at the University and there access has usually not been a problem as we have been able to book specific rooms. What has also been significant about meeting there is that many of the RAG members are familiar with the setting having attended meetings there over a number of years. They therefore had confidence in finding their way around and in using

facilities such as the canteen (again accessibility). On a few occasions we had to use off site venues and here finding a room of an adequate size that had good access for people with limited mobility and adequate parking has been a time consuming challenge.

Finding venues for meetings is one thing but people need transport to get there as well. This can, at times, mean that taxis have to be used and this can be a considerable expense. Within this project we have been lucky to have some volunteer drivers that have been able to assist with transporting the co-researchers to various locations. With the residential event, however, a variety of forms of transport including train, bus, car and taxi were required dependent upon people's individual needs. All of this had to be costed into the original bid.

Another important aspect of accessibility has been the need to produce information that is easy to read (Northway, 2010b). This is essential and the RAG has been a great source of support in critically reviewing materials to improve accessibility. On a practical level, however, it is important to consider the cost implications of this when preparing research budgets. For us there was an initial outlay to purchase a software programme to enable us to use pictures in our documents. There then followed additional costs in terms of needing to photocopy documents in colour to make them more easily understood. Another cost that took us a little by surprise is allocated memory on the computer server. Each folder has an allocated memory that is usually more than sufficient for a project. For us, however, each document required multiple pictures and this soon used up this allocation of memory and more had to be purchased. Whilst the cost on this was small it is, we feel, an important learning point for others to consider in terms of setting up computer systems for projects.

☑ Learning Point Careful thought needs to be given to venues for meetings to include physical access, confidence, and availability of transport.

☑ Learning Point Producing easy read information takes up a lot of memory on computers and this needs to be considered when choosing and setting up computer systems for participatory projects.

2.4 Time

The time required to undertake PR is perhaps one of the most frequently recurring themes in the PR literature and there is a relationship between the time required/ available, the level of participation desired/ possible, and the scope of the research (Northway, 1998; 2010b). If any of these three factors is fixed then there is an impact on the other two. For example, if funding for a project means that the time available is fixed then this will influence the extent to which participation can be facilitated and/ or the scope of the research. Macaulay *et al* (1999) note that sometimes the time required can be more than researchers are able to give.

The time demands arising from PR relate to a number of factors such as the need to build and develop relationships as previously discussed. However, it can also be due to factors such as working together and joint decision making can take longer than one person making a decision in isolation. Maguire (1993) therefore refers to collective working as being 'messy' and 'time consuming'. An example of such lengthy decision making is the issue of authorship for this report. Usually in the context of writing a project report this is relatively straightforward. However, issues such as who is included and in what order they are listed can (particularly in academic circles) convey issues of power. Not wishing to do this it was felt important to discuss this issue in the context of a RAG meeting. A lengthy discussion took place, votes were taken and in the end it was not possible to

achieve agreement. The result has been a compromise in choosing to cite the authorship of this report as being the team in recognition that everyone has played an essential role.

Perhaps the first point to reflect on in relation to this particular project is the time it has taken to get from the initial idea to project completion: nine years. Over this period there have inevitably been a number of people who have joined and who have left the core group but there others (some of whom work in a voluntary capacity) who have remained committed to making this project a reality. Indeed, when we were earlier turned down for funding for the project it was largely due to the persistence of some team members, who themselves have learning disabilities, that further applications for funding were developed. Over this period of time it has been helpful to have new members join the group since they have brought with them fresh perspectives and differing experiences and expertise. However, as the project comes to the end it is also invaluable to have some group members who have travelled the entire journey together and who are able to remember the original reasons for wanting to do this research. The level of commitment they have shown over a long period of time must not be underestimated.

At a more micro-level the hours to be worked by those employed on the project were determined during the process of developing the application for funding. It was agreed that a full time Research Assistant would be required and the need for such a post has more than been borne out by our experience. It has been essential to have someone whose sole focus is on this project and who can therefore keep a day-to-day overview of what is happening. In relation to the co-researchers, however, there were concerns that too many hours employment per week could lead to difficulties in relation to any benefits they were claiming. For this reason the number of hours per week was set at 3.75 hours. In practice this has generally meant that co-researchers have worked one half day per week but when we held the residential event and when conferences have been attended, they have worked additional hours and then taken time back. This has, however meant that sometimes there have been periods of two to three weeks without them working.

A recurring theme in the co-researchers' reflections is the need for more time and this has been discussed as a group. As well as only having a very limited time each week to work on the project they also feel that having a gap of at least a week between sessions means that they have to spend the first part of each session reorienting themselves which further reduces the time for new work. They feel that were we to repeat the project then additional hours and perhaps also more than one day a week would be helpful. This should (funding permitting) be possible given that it has subsequently emerged from discussions with a specialist employment agency for people with learning disabilities that there are ways of addressing the benefits issue.

Within this project there has been a lot to do and so therefore time had to be carefully managed. However, the concept of a three year project with different activities being required at different stages was initially difficult to grasp. Therefore we have developed easy read time planners that show on a month by month basis what we need to do. This was completed for the first few months of the project and then, in January 2011, 2012 and 2013 we have held a planning day where the team have all come together to plan out what needs doing. This has been facilitated by using a large room, laying out on the floor a piece of flip chart paper for every month and then discussing as a group the activities required. As each activity is agreed we have then written it on a 'stick-it' and placed it on what we felt to be the relevant month. We found this helpful as if certain times of the

year looked too busy then we could look to see if anything could be moved round. It also helped us to understand that if we had a deadline we had to carefully plan what needed to be done to achieve it. For example we wanted to submit the project for ethical approval in May which meant that we needed to produce all the documentation earlier so that we also had time to test it with other people and make changes if necessary. As the co-researchers noted:

'We had a lot of discussion but in the end agreed as a team what should happen when'

(Flood *et al*, 2012)

Following these planning meetings the flip chart sheets were taken away and typed up in an easy read format so that everyone could have a month by month time planner. These planners have also been very helpful as a basis for reporting back to RAG meetings and also the completion of project reports for our funders.

Learning Point When planning PR studies think carefully about the scope of the research, the level of participation desired and then the time that will be required to complete this before calculating the funding required.

Learning Point When planning PR studies involving people with learning disabilities consult a specialist employment agency for advice as to the number of hours it is possible for people to work.

Learning Point When planning PR studies aim to increase the number of hours people with learning disabilities work and spread the work over more than one day per week.

Learning Point Having an easy read monthly planner is helpful in planning work and monitoring progress.

2.5 New Ways of Researching Together

As has already been discussed in this report PR approaches involving people with learning disabilities have become increasingly more common. However, there are some aspects of our study that, we believe, are new. Three specific areas will be discussed here namely the use of a residential event to undertake data collection, the contribution of the RAG, and a participative approach to seeking and securing ethical approval.

2.5.1 The residential event

The primary reason for deciding to gather data during a residential event was the nature of the subject we were studying. We felt that asking people to talk about something such as abuse that could be distressing and then leaving them alone would not be ethical. Instead we felt it would be better to provide an environment in which support could be provided should it be required. Accordingly a three day event was planned with the decision of which hotel to use being made by members of the RAG (Evans *et al*, 2011).

The programme was arranged such that everyone had the opportunity to take part in a focus group and complete a questionnaire whilst a smaller number were asked to participate in one to one

activities. This meant that some of the time was spent being involved in the research whilst other periods of time were free for participants to use the hotel leisure facilities, take part in a range of on-site and off-site activities organised by student nurse volunteers, or to simply relax. For members of the research team, however, work continued throughout and this did prove to be extremely tiring especially for the co-researchers who were not used to working a long day. When the nature of the subject is factored in to this along with the very difficult and emotional experiences people shared with us it is easy to see how it was physically, psychologically and emotionally draining.

Thankfully we had other members of the research team who were able to step in and take over if anyone needed a break (which they did). In addition work had been undertaken prior to the residential regarding stress management and keeping safe. The co-researchers each had, therefore, a personal safety plan that could be used to enable them to receive the support they required. In addition to this regular checks were made to see how people were feeling as well as holding a team meeting at the end of the day.

Since the residential the research team have discussed their feelings about the event. Everybody agreed that it had been a great event that overall it had been enjoyable, but that data collection had been very intense. We did not feel that extending the length such an event would be feasible due to the costs involved and also the fact that it might be difficult to ensure people had appropriate support for a more extended period. Given this it was agreed that were we doing this again we would have a larger group of people to do the data collection which would mean that individuals were not overloaded and had sufficient breaks in between work. This we felt could be achieved whilst maintaining the participatory nature by employing some further co-researchers specifically for data collection.

In addition to the supports already noted we also had counsellors on site at all times and their availability for both participants and the research team was stressed at regular intervals. In the event all of the time slots available for counselling were used either as a consequence of someone disclosing abuse and requiring support or someone being upset by a discussion. In some instances on going counselling support has been provided. It is also important to note that reactions can be delayed. In one instance a team member contacted a group after the residential to enquire as to how someone was. That person was OK but another, having time to reflect upon the issues, had later required support but difficulties had been experienced in securing such support in a geographically accessible location. This underlines the need for greater provision of counselling support for people with learning disabilities.

☑ Learning Point Residential events do offer a 'safe' space in which to collect data but appropriate supports, leisure activities and free time need to be built into the programme

☑ Learning Point Gathering data in this way is intensive for the research team and where team members are not used to working long hours it is important to limit the workload and provide adequate breaks. Employing additional co-researchers to collect data may be one way of achieving this.

☑ Learning Point Where difficult subjects such as abuse are being explored it is essential that counselling support is readily available and that there is follow up where required.

2.5.2 The Research Advisory Group (RAG)

Throughout the project the research team has been supported by a Research Advisory Group (RAG). Whilst the existence of such a group in the context of research studies is not new the way in which the RAG have worked in this project is, we believe, innovative. Meetings of the group have usually been attended by about 20 people (including members of the research team) over half of whom are people with learning disabilities. The group has also been chaired by Lynne Evans who is herself a woman with learning disabilities. Throughout the course of the project they have met on a two monthly basis. Their function has been to monitor the progress of the project, to advise the research team, and to take an active part in the making of key decisions.

Each meeting has taken the same format of starting with introductions reminding everybody of who we are and our role in the group. The next section of the meeting has been used to receive progress reports from the research team, especially from the co-researchers. Following a refreshment break the group would then split in two to work on specific activities. After a period of time the groups would swap so that everyone had the opportunity to contribute to each activity. Finally the large group would reconvene to address any other business.

The RAG advised regarding many areas and made decisions concerning key issues. Some examples include:

- Agreeing the criteria for identifying the hotel to be used for the residential event. These were then translated into a checklist that was used by three members of the RAG to visit and inspect two hotels (Evans *et al*, 2011). The RAG made the final decision as to which venue should be chosen.
- Choosing the design, colour and logo to be used on the bags provided for participants at the residential event.
- Identifying potential dissemination routes including both key people and key journals.
- Critically reviewing the materials developed for submission to the ethics committee.
- Deciding what members of the research team should wear when presenting at conferences.
- Identifying who should be invited to the project launch
- Identifying key learning points for inclusion in this report.

It is important to note that group members gave a great deal of consideration to these issues and were not afraid to voice their thoughts. For example when asked to review the information sheets to go to the ethics committee they were very clear as to what needed to change in order to make them easier to understand. Involving people with learning disabilities in this was invaluable. When discussing the bags for participants at the residential it was felt that having 'Looking into abuse' would not be a good logo to use as people might want to use the bags afterwards. However, group members felt that having 'Research by People with Learning Disabilities' would send out a positive message about the abilities of people with learning disabilities.

The discussion concerning what the research team should wear when presenting at conferences arose after a conference where three members of the team had presented wearing the polo shirts we had used for the residential event. We had felt that this reinforced our roles as members of our research team. However, at the conference some other presenters with learning disabilities had taken a great deal of trouble to dress formally leading us to wonder whether our decision had been

appropriate. The RAG members discussed this and it was finally agreed that we should continue to wear our polo shirts but that we should try to wear smart dark trousers and dark shoes. Later discussion, however, revealed that this could be challenging for co-researchers on limited incomes as whilst most full time paid researchers are likely to have dark trousers and smart shoes this may not be the case for people with learning disabilities.

It can thus be seen that the RAG played a major role in decision making and in many instances they were the decision makers rather than contributing to decisions made by others. They have also been invaluable in enabling us to complete the work to time. As we stated elsewhere:

'...if we did not have the RAG, we would not have been able to get all the work done' (Flood et al, 2012)

☑ Learning Point Structuring meetings so that they involve small group work of an interactive nature can be helpful in enabling greater participation in discussion and decision making

☑ Learning Point It is important to take account of the constraints imposed on people with learning disabilities by their limited incomes.

2.5.3 Ethical approval

PR requires that participation is facilitated at each stage of the research process. Nonetheless, to date, the reports of PR involving people with learning disabilities have not examined how participation in securing ethical approval can be supported. One exception to this is the work undertaken by Ham *et al* (2004). In this study we took the view that there should be opportunities for involvement in this stage of the research as with any other stage but at the same time recognised that barriers to such participation also existed. Two key barriers were the nature of the form that had to be completed (this was not written in an accessible format) and the detailed study protocol that would be required (this would be too long and complex to be useful to the research team). It was agreed, therefore, that rather than taking a traditional view of people with learning disabilities being viewed as 'unable' we would look to see how 'reasonable adjustments' could be made to the ethics process that would ensure the committee received the information they required but at the same time enabled all members of the research team to participate.

We needed to secure ethical approval from our Faculty Ethics Committee and so we decided to work with them from the beginning of the project and to present solutions rather than problems. We therefore gained agreement for two key changes:

1. To amend the existing ethics application form to ensure that it provided the information required by the committee whilst at the same time being easy read.
2. To produce a full study protocol to enable the committee to understand the nature of the project but also to produce an easy read version of the protocol that could be useful to the research team.

By taking this approach it was possible to meet the needs of the committee whilst at the same time facilitating participation.

Obviously a great deal of documentation had to be prepared for the committee. Where this was documentation that needed to be used by people with learning disabilities we asked RAG members to act as critical friends and to review our drafts. They made a variety of comments regarding

aspects such as wording and photos where the meaning was, they felt, unclear. As a result of this we made a number of changes but this was invaluable when it came time to meet with the committee as they felt the documentation had already been reviewed by the experts (RAG) in terms of its accessibility and acceptability.

When applications go to the committee there is the opportunity for two members of the research team to attend the meeting to discuss their study. Previous experience led us to believe that this would be helpful since any minor misunderstandings can often be more easily addressed by face to face discussion. However, we felt that we wanted three members of our team (RN, JH and LE as Chair of RAG) to attend as they all had important roles to play in commenting on aspects of the study. Once again we negotiated this with the committee and secured agreement. We also asked if we could receive any queries they had a couple of days before the meeting so that we could discuss them and prepare. This was agreed on the basis that we would submit our application slightly earlier to allow for it to be read. Reasonable adjustments were thus made by both parties.

The day of the ethics meeting was quite nerve racking: we knew that we were submitting a proposal for research relating to a 'vulnerable' group that was focusing on a 'sensitive' topic. The committee was quite large (about 15 people) but we were all treated with respect and were able to address the questions. As Lynne stated:

'Going to the ethics committee meeting was a new experience for me. Ruth and Joyce were nervous. I was nervous inside but didn't show it. When they opened the door and called us in, I was nervous then. 15 people! But it was alright. The committee talked to me'

Afterwards we were told that the study had been approved with no amendments – something that is very rare. When we expressed our surprise we were told that it was evident that we knew we were dealing with a difficult subject and because of this we had taken time to consider all of the issues very carefully. Where there were likely to be risks we had acknowledged then and had put strategies in place to address them.

☑ Learning Point Where possible work with the ethics committee in a proactive manner from the beginning of the project to identify potential barriers and the adjustments required to overcome them.

☑ Learning Point Try to offer solutions rather than problems: identify how things can be done differently to enable participation

☑ Learning Point Anticipate and do not try to ignore potential areas of risk but instead carefully consider and present strategies for their management.

2.6 Participatory Research?

Promoting the active participation of those traditionally denied opportunities to take an active role in research is a fundamental characteristic of PR. However, there are also some other important dimensions and the extent to which they have been achieved in this project are discussed here.

2.6.1 Who benefits?

Traditionally many of the benefits of research have been enjoyed by the researchers in terms of employment, promotion and publications. In the context of this project it is true to say that the co-researchers have also enjoyed the status of paid employment, learning new skills to build their CV's and promoting their work through publications and conference presentations. Having papers published was a particular source of pleasure although it is interesting to see that it also provoked some anxiety. As one co-researcher reflected they were concerned about getting things 'wrong' in a paper that a lot of other people would read and that if readers knew that they have a learning disability they '*might think that it's a joke and not take my article seriously*'.

An important area of learning for all the research team has been, however, the wider benefits experienced that may not immediately be thought of in relation to working as a researcher. For the co-researchers one of the most frequent observations was how they felt they had increased their self-confidence as a result of their work on the project. Such observations were confirmed by colleagues who saw people develop from being too nervous to speak in meetings to people who not only gave conference presentations to 50 or so people but who were described by those listening as being 'professional' and 'inspirational'. Other benefits derived from the project mentioned by co-researchers include learning to use the bus independently in order to come to work. Sam said that having to learn this to do her job meant that she had become more independent and able to travel to visit family and friends (Flood *et al*, 2012). Coming to the University, meeting new people, and visiting new places have also been mentioned as beneficial experiences.

Members of the RAG also noted benefits they felt they had gained by acting as advisors (and in many cases decision makers) for the project. Their comments included:

'It's nice talking. I feel happy when I'm asked for my ideas and opinion.'

'...forming new friendships and lots of hard work. I've enjoyed seeing the results at the end of it.'

'It was hard work at the beginning, but now it's coming to an end, I'm seeing the results of that hard work. It's been good being part of all the decisions that have made the project'

'It feels like a real democracy'

'It has challenged my attitudes, and others'

'It's great to be a part of something that everyone's passionate about and everyone wants to make people's lives better'

Just focusing on the benefits of research to the researchers and the full research team could, however, be seen as simply repeating and reinforcing traditional practices within research. Examination of wider benefits is therefore important and one important group to consider are those people who attended the residential event. As was noted in the first part of this report some participants did disclose abuse during the course of the event. Whilst this process was distressing for some people support was offered (including counselling) and new disclosures were followed up through the appropriate channels. It may sound strange to consider this a benefit but it needs to be placed in the context of people being offered a safe space in which they feel able to disclose abuse

and seek support. Had this not been the case these individuals may have kept painful and distressing experiences to themselves for a long time and potentially have suffered adverse physical and/ or mental health problems.

The final level of benefit that needs to be considered is the wider benefit to people with learning disabilities. The starting point for the project was that people with learning disabilities felt that research should be undertaken concerning abuse and that people with learning disabilities should take an active role in this process. The aim throughout has been to seek the views of people with learning disabilities concerning abuse and, based on the analysis of these views, make recommendations for the development of policy and practice. With New Pathways being a partner in the research a direct link to the development of therapy support informed by what people with learning disabilities feel is important a direct route for the translation of research into practice. It is thus hoped that a significant number of people with learning disabilities will eventually benefit from this research either through the elimination of / reduction in abuse or, where abuse does occur, receive timely support that they find helpful.

✔ Learning Point It is important to recognise that different people will benefit in different ways through involvement in PR projects.

✔ Learning Point Exploring ‘sensitive’ topics in the context of research may lead to distress and it is important to ensure that appropriate support is available. However, not to undertake such research means that the difficult and painful experiences of people with learning disabilities are unheard and not addressed.

2.6.2 Learning together?

Israel *et al* (2013) suggest that PR is a process of co-learning that facilitates the exchange of skills, knowledge and capacity between all those involved. It also recognises that partners bring different experiences, skills and knowledge to the research endeavour. For example within the context of this project some of us brought knowledge and experience in relation to research, others specific expertise in relation to counselling, some brought experience of supporting people with learning disabilities and, most importantly, others brought experience of what it means to be someone considered to have a learning disability. Learning has taken place both in the context of specific training sessions and through the informal, on-going process of working and learning together. We have all been challenged to think differently and to try to find alternative ways of achieving goals.

2.6.3 Changing the balance of power?

Historically people with learning disabilities have been assigned a very passive role within the research process often being the subjects (or even objects) of other people’s studies. In contrast PR seeks to challenge and change power structures both within the research process and within wider society. In assessing the current study, therefore, it is important to reflect on the extent to which this was achieved.

A key aspect of power is the power to make decisions and to have those decisions supported. Appendix 8 details the involvement and decision making of people with learning disabilities within this project. The decision to research this subject came from people with learning disabilities. The co-researchers identified that working in their role meant that they needed to make decisions (Flood *et al*, 2012). The RAG took a number of key decisions regarding the direction of the project not least

the decision concerning which hotel to use for the residential. In this respect it can therefore be seen that decision making power did rest with people with learning disabilities in many aspects of this study.

Decision making, however, is only one dimension of power and in other respects it has to be acknowledged that whilst the desire was to change traditional power imbalances some difficulties remained. The first area relates to the fact that whilst the research assistant was employed on a full time basis the co-researchers only worked 3.75 hours each week. The decision to structure the team in this way had been taken (as previously indicated) in order to avoid any adverse impact on benefit payments the co-researchers might be receiving. However, this inevitably meant an imbalance in power due to the time each team member had available to work on the project and some decisions and actions had to be taken at times when the co-researchers were not present.

A further consequence of this disparity in hours was that inevitably the research assistant earned considerably more than the co-researchers and this was a further inequality in power. As Joyce (research assistant) observed:

'...the power balance can never be equal while I am working longer hours for more money'

☑ Learning Point Power in the research process includes decision making power but other aspects such as time and financial reward are also relevant. If power relations are to be changed then attention needs to be given to all dimensions of power.

☑ Learning Point Consider carefully the hours that team members are going to be working on the project and try to achieve parity in terms of salary.

2.6.4 Leading to action?

A further feature of PR is that it aims to produce knowledge in order to bring about change: as Khanlou and Peter (2005) observe it aims to produce 'useful knowledge'. Within the context of this project the desired change is to try and reduce the abuse experienced by people with learning disabilities and, where it does occur, to ensure that they receive appropriate and timely support. Change can, however, take a long time and at the point of writing this report it is only possible to reflect on developments to a certain point. Nonetheless, some aspects are worthy of discussion since they reflect the commitment within the project to produce and communicate useful knowledge.

Although research concerning the abuse of people with learning disabilities has been published they are often the very people who are not able to access this information. It is published in journals they do not usually have access to and, even if they did, the language used is often complex and not easily understood. A key part of this project has, therefore, been to produce an accessible literature review which will be available on line. This has been produced by producing easy read versions of papers, discussing these with people with learning disabilities and recording their views. The aim is to make knowledge concerning abuse available to people with learning disabilities in a format they find useful.

An extensive dissemination strategy has been planned in order to ensure that the findings and recommendations (both regarding abuse and regarding researching together) reach a wide range of people. Some elements of this strategy have already been implemented with presentations being given at local, national and international events. In addition papers have been published concerning some aspects of the research process. A series of launch events are planned across Wales and England, as are further papers and conference presentations. People with learning disabilities, their families and supporters, professionals, politicians and other key decision makers will be invited.

It has been decided, however, that dissemination needs to continue beyond the end of the project and therefore a campaign is being launched based on key messages from the research. This will include a range of strategies including awareness raising activities and the use of social media.

☑ Learning Point It is important to consider the dissemination strategy from the beginning of a project taking account of the changes/ action desired as a result of the research

☑ Learning Point While change may take a long time some changes can be started during the life of a research project

2.7 Conclusions

Perhaps the most important conclusion from this project is that people with learning disabilities, given the right support, wish to be actively involved in research and have the capacity to do so. It is possible to support active involvement in all stages of the research project and such participation enhances the project since researchers who themselves have learning disabilities bring to the research project direct personal experience of what it is to live with a learning disability. Such experience can be invaluable in relation to understanding the data and its significance: it grounds the data in the reality of living with a learning disability. However, the study also confirms the observations of other researchers namely that PR is time consuming and that this means that additional funding may be required. Nonetheless the benefits of PR can justify the additional cost.

Another conclusion to be drawn from this study is that despite a real commitment to changing power relations (and to some extent achieving this) power has many dimensions. Whilst decision making power was shared, and in some instances key decisions were taken by the RAG, other aspects of power relating to pay and hours worked were felt to restrict power sharing.

A number of learning points are identified above and these are offered as recommendations to help other research teams develop their participatory research projects.

3. Overall Conclusions and Recommendations

The aims of this project were twofold: to learn more about what people with learning disabilities understand about abuse and the support they require, and to learn more about how we can undertake research together.

From the research undertaken it can be concluded that people with learning disabilities, with the right support, are more than able to actively engage in all stages of the research process and bring to it a wealth of life experience lacking in many other researchers. This is important when seeking to understand the life experiences of people with learning disabilities and how any difficulties may best be addressed.

It can also be concluded that people with learning disabilities are aware of a wide range of different types of abuse. However, whilst some have received education regarding abuse others have had to 'self-educate' using the media, by hearing of abuse via the media, by hearing of abuse from friends or through personal experience of abuse. Whilst we did not ask participants about their experiences of abuse it was evident from their responses that many had had such experiences which suggests that unfortunately abuse is a common feature in the lives of people with learning disabilities. The need for education and support to address this issue was recognised by participants.

Abuse understandably gives rise to strong feelings and anger, embarrassment and recurring negative thoughts were all mentioned. Most worryingly, however, was the fact that a number of participants said how abuse can make people consider suicide. Such an observation points to the need for people with learning disabilities to receive timely support if they are abused but whilst participants recognised that the support of someone you trust, having someone to talk to, and being believed are all important discussion amongst the research group and in the wider literature indicates that such support is not always available.

The two main sections of this report have outline recommendations arising from the study and it is not the intention to simply repeat them here. However, it is important to state the key messages arising from this study and then to identify where we feel responsibility should lie for taking the actions set out in the recommendations of this report. It is also important to state that whilst specific areas of responsibility are identified here the project team strongly feel that every citizen has a responsibility to take some action to address the abuse experienced by people with learning disabilities and therefore these messages apply to everyone:

- We need to ***listen*** to what people with learning disabilities say about abuse. This may be said through words or through behaviour.



- We need to ***believe*** them when they say they have been abused.



- We need to ***do something*** if they tell us they have been abused. This needs to include both an immediate, appropriate response as well as on-going support.



Recommendations for Policy Makers:

- The effectiveness of current and future policies aimed at responding to the abuse of people with learning disabilities should be regularly monitored and this monitoring should include the views of adults at risk of harm as to whether they feel safeguarded.
- Resources need to be invested to ensure that people with learning disabilities receive appropriate education regarding abuse, the law, and how they can keep safe.

Recommendations for Services

- Education regarding abuse should be provided for people with learning disabilities and they should be involved in developing such education.
- Services should be alert to potential signs of abuse, have clearly identified strategies for responding to abuse, and ensure that a person who discloses abuse is listened to, believed, and that appropriate action is taken. Such action needs to include making sure that there is someone who can provide on-going support for the individual.
- Therapeutic support services for people with learning disabilities need to be further developed so that support is available, accessible and acceptable. It also needs to be provided in a timely manner to facilitate early intervention.

Recommendations for Research

- Participatory research that facilitates the active participation of people with learning disabilities should play a greater part in the research undertaken in this field.
- Research should be undertaken that explores how different personal characteristics such as gender, race and sexuality interact with being identified as a person with learning disabilities in relation to abuse
- The relationship between abuse and suicidal feelings should be further examined

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Appendix 1: Focus Group Topic Guide

Focus Groups

Introductions and consent forms

This is a stop card. If you don't want to answer a question, or want to completely stop, just show it to me. It is fine to stop whenever you want.

If anyone wants to leave now or at any time, that is ok.

1. This research is about abuse. What do you think abuse is?

Any other thoughts?

Anybody else?

2. How do you feel about abuse?

(Get out the pictures. Give everyone the same photo.)

3. We would like you to look at the photo with the person sat next to you.

We would like you to talk together about how the person in the photo may be abused.

4. Can you now tell us all how you think this person may be abused?

Who wants to start?

If someone mentions a specific abuse, David put the object representing that on the table.

This is to help people remember the sorts of abuse they have talked about. This one is for ...

Use the questions below to help people think a bit more. Use 1 or 2 extra questions with each photo.

What if this person in the photo can't speak?

This person in the photo lives in supported house.

This person in the photo goes to college.

This person in the photo goes to a day centre.

This person in the photo lives alone.

This person in the photo lives with their family.

5. How do you feel about the person doing this to them, who hurts them?

Repeat with 3 pictures. Sam and Joyce take it in turns to give out the photos and ask the questions

If any object has not been used, get them out of the bag.

6. Do you think this can show or may be a kind of abuse?

How?

Explain that the objects show 5 different sorts of abuse. Put the sheets with their names underneath.

7. Does anyone have anything to say about this?
Are there other kinds of abuse that are not here?

8. Now we want you to think about if 1 sort of abuse is worse than another.

There is no right or wrong answer.

We are just interested in what people say.

Anything you say is ok.

In pairs, talk about what you think is the worst abuse.

9. Now can you tell us all if one of these worse than another?

(Check with each pair what they think)

10. What makes it worse?

11. Does anyone have any more things they want to say about abuse?

You may have talked about things that upset you. You may have heard things you did not like. We have a counsellor here who you can talk to if you want to. David can make you a time to see them.

Before you go, will you all say one thing that you are looking forward to?

Appendix 2: Examples of Pictures Used in Interviews



Appendix 3: Questionnaire



Looking into abuse: research by people with learning disabilities.

Questions.

We are finding out :



- **What help and support people with learning disabilities need to keep safe**



- **What are the best ways to help when someone has been hurt by somebody else.**

Your answers to our questions will help us to understand what needs doing.



We will do a report on what we find out. We will send this report to the same people we sent the questionnaires to. We hope this means you will be able to see what we find out.



We will tell as many people with learning disabilities, carers and staff as we can about what we find out. We will use magazines, the internet and conferences to tell people.



- We want to make sure everyone has a chance to see what we find out. We want to make sure that people with learning disabilities understand about abuse and are heard.



Thinking about abuse upsets some people. You may want to think now about who you can talk to.



You may want support to fill this form in.





People with learning disabilities are sometimes hurt by other people. Please tell us how they can keep themselves safe.

✓ Tick the ideas you think help



• If you don't know someone well don't give them personal information



• Stay away from nasty people



• Learn to speak up



• Have someone you trust to talk to, like a friend, family or worker.

•



- Have someone to talk to who can sort things out.



- Knowing safe ways to behave



- Carry a personal alarm



- Make sure someone knows where you are at all times.



- Tell people with learning disabilities about:



- What is ok and not ok for others to do to you





How it is ok and not ok for

others to treat you.



○ What the law says



○ Sex and relationships



○ What policies (rules) staff have to work to

Can you think of any other ways people with learning disabilities can stay safe? Please tell us here



2

If a person with learning disabilities is hurt by other people they may need support. What would be helpful?



Tick the ideas you think help



- To be listened to



- To be believed



- A counsellor



- To know who else will be told



- To be told what is being done/what is happening



- To be told what is happening to the person who has hurt you



- Support for the person to live their life – to carry on with the things they have always enjoyed



- People to be there for the person who has been hurt



Anything else you think might be helpful for people who have been hurt, please tell us here.

Is there anything else you would like to tell us?



About you

Please can you tick : ✓



•

Are you a man ?

or



•

Are you a woman?



• Do you belong to a People First group?



Yes

No





- **What age group are you?**

18 – 25

26 – 35

36 – 45

46 – 55

56 – 65

66 – 75

76+



- **Can you tell us the county you live in?**

.....

We need to know about your **Ethnic background**.

This is how you identify yourself, such as what country you and your family come from, the language you speak, the food you eat, your culture and the colour of your skin.

This is so we can make sure that everyone is having their say.

Please ✓ tick one of the following:



I am white



I am black



I am

Chinese
Korean
Japanese
Vietnamese



I am Asian

I have a mixed ethnicity



White and Black Caribbean
White and Black African
White and Asian

How do you describe your ethnic background?

I am _____



I do not want to say

Who do you live with?



Family



Partner



With other people



By yourself



By yourself with staff support



With other people with staff support



We will keep anything you tell us safe. We will not tell anyone else these things about you.



Thank you



Appendix 4: Letter of Invitation



Invitation to a residential.

Looking into Abuse: research by people with learning disabilities



We have been given money to find out what people with learning disabilities think about abuse. The research is being done by people with learning disabilities.

Please see the information leaflet that will tell you more about the project.

We are inviting people with learning disabilities who live in South Wales to take part in our research.



We are asking people to come to the Hilton Hotel in Newport. It will be 3 days and 2 nights:

16, 17 & 18 November 2011.

This letter is to ask if you want to take part.

This is what's going to happen at the hotel...



- A questionnaire.



- A small group interview that we will tape record.



- An interview on your own that we will tape record.



It's up to you if you want to take part. You can leave an interview any time if you feel unhappy with anything.



There will be counsellors and helpers at the hotel. They are there for people who may be upset. Or who need to talk to someone.



You can bring a support person with you. There will be fun activities as well as the work.



With this letter there are:



- an application form on yellow paper
- an information leaflet on blue paper
- a leaflet about the project on white paper

Please fill in this application form if you want to come to the research residential 16, 17 & 18 November 2011.

1. Your name
2. Your address

If you want to take part please fill in the application form that comes with this invitation.

We hope you want to take part in this research.

Thank you for your time.

From the research team.



Davey Bennett



Mel Melsome



Samantha Flood



Joyce Howarth



'Looking into abuse: research by people with learning disabilities'



Information about the research residential



We are inviting people with learning disabilities who live in South Wales to take part in our research.



It is up to you to decide whether or not you want to take part.



If you do want to take part, we are asking you to come to the Hilton Hotel in Newport. It will be for 3 days and 2 nights. It is all free but not the bar. We will pay your travel costs.



This is some information about the research to help you to decide if you want to take part.





The research will look at what people with a learning disability know and think about abuse. We will not be asking if you have been abused. We are not collecting stories about abuse that may have happened to you.



There will be 50 people with a learning disability at the hotel with their supporters.



You can do:
A questionnaire.



A small group interview that we will record.



An interview on your own that we will record.



You can stop doing the research any time if you want. You do not have to give a reason. This is fine.



Abuse is a hard subject. It can upset some people.



There will be counsellors and helpers at the hotel. They are there for people who may be upset. Or who need to talk to someone.



We will keep anything you tell us safe. No one outside the project will see or hear what we have talked about. Unless you tell us that you or someone else is being hurt. Then we will talk with you about who we need to tell.



We will do a report on what we find out. We will not use anyone's name in the report. We will send this report to the same people we sent invitations to. We hope this means you will be able to see what we find out.



We will tell as many people with learning disabilities, carers and staff as we can about what we find out. We will use magazines, the internet and conferences.



If you want to know more you can phone
Joyce Howarth:
01443 483881



Or email:
jhowarth@glam.ac.uk



Or write to:
Looking into Abuse
HESAS
University of Glamorgan
Glyntaf Campus
Pontypridd CF37 1DL



Appendix 6: Example of a Consent Form



Consent form: interviews, 'Looking into abuse: research by people with learning disabilities'

Name.....



Please tick the boxes where you agree.



I understand what the research is about.



I agree to be interviewed by a researcher.



I agree to have what I say recorded.



I understand that all the information I give will be kept private. It will not be shared with anyone outside the research team.



I agree that anything I say can be used in the research report. My name will not be used. No-one will know I said anything.



I agree to have my photo taken or be filmed. My face will not be seen when we are telling people what we have found out.

Date

Sign/mark.....



Appendix 7: Interview Schedule

Davey Bennett: Interview questions

My name is Davey. I am a researcher on this research project.

I am Karen. I am Davey's personal assistant. My job is to support Davey.

Can you tell me who you are?

What have you enjoyed here at the hotel?

Please can you fill out this **Consent Form** to say that you are happy to be interviewed.

We need to record what everyone says. We can use a camera to video or a recorder just to get your voices. Which do you want us to use?

All the information you give us will be kept private. No one outside the project will see or hear what we have talked about. Unless you tell us that you or someone else is being hurt. Then we will talk with you about who we need to tell.

We will not ask if you have been abused. We are not collecting stories about abuse that may have happened to you.

This is a stop card. If you don't want to answer a question, or want to completely stop, just show it to me. It is fine to stop whenever you want.

I've got about 10 questions to ask you, so take your time.

- We have a lot of time, so you can think about things.
- Don't worry if you cannot answer some questions.
- There are no right or wrong answers, we are interested in everything you have to say.
- Are you ready to start the interview?

1. I just want you to say what you think, there is no right or wrong answer.

What do you think abuse means?

What do you mean by ...

Can you tell me what ... is?

Can you give me an example?

Can you tell me a little bit more about what you think abuse means?

I will be using some pictures now. Are you OK with that?

I have got a few to show you. You have 3 possible answers:

Yes

No

Not sure

There is no right or wrong answer, it's just what you think.

[Show 1 picture at a time.]

Is the picture about abuse or not? Or maybe you are not sure.

[When they have put a picture in Yes]

Can you tell me about why that is abuse?

Can you tell me any more about that?

In what way is it wrong?

[When they put a picture in Not Sure]

Can you tell me about why you are not sure?

Can you tell me any more about that?

[When they put a picture in No]

Can you tell me about why that is not abuse?

Can you tell me any more about that?

3. How did you learn about abuse?

- Can you tell me a little bit more?
- Did anybody talk to you about it?
- Who was that?

4. Some people with learning disabilities are abused. Can you think of any reason for this?

- What do you mean by ...
- Can you give me an example?
- What makes you say that?
- Can you tell me any other reasons?

5. If we think about the people who abuse people with learning disabilities.

How do you think they know them? Who may they be?

- Can you give me an example of the kind of people?
- Who do you mean?
- What makes you say that?

- You have given me an example of the sort of people who abuse people with learning disabilities. Anyone else you might think of?
- If they don't know the person they abuse, who may they be?
- Anybody else?

6. Who do you think decides what abuse is?

- What makes you say that?
- Can you give me an example of who decides?
- Can you think about who someone might tell about abuse?
- Why do you think they would tell them?
- What do you think they would do?

- What do you mean by?

7. How do you feel about abuse?

8. What do you think does happen to someone who abuses people with learning disabilities?

- What makes you say that?

9. What do you think should happen to someone who abuses people with learning disabilities?

10. Is there anything else you would like to say?

You may have talked about things that upset you. You may have heard things you did not like. We have a counsellor here who you can talk to if you want to. Me or Karen can make a time for you to see her. Do you want to see her?

Karen to hold this sheet and give it to Davey if needed. If they tell you that someone is hurting them or hurting someone else...

You have told me that someone is hurting you or doing things you do not like, or is hurting someone else or you are hurting someone

Have you already told someone about this?

Have they done something about it?

If they haven't told anybody else or something has not been done about it...

I have to tell someone about it.

We want to try to do something about it.

I have to tell Emma, and she will need to tell a social worker.

Is there someone that you would like to tell about it?

Do you want to tell them or do you want us to tell them?

We can help you to do this.

Would you like to speak to a counsellor about it?

Would you like me to arrange this for you?

Appendix 9: Participation in the Research Process

Stage of the Process	Evidence of Participation
Identifying the research subject	The idea for the research project came from people with learning disabilities.
Developing the research proposal	People with learning disabilities were involved in identifying the research questions, deciding how the research should be undertaken and completing the application for funding.
Appointment of staff	People with learning disabilities were involved in the presentation stage of the interviews for the research assistant. Co-researchers drew up the person specification for their own personal assistants and were involved in their interviews.
Development of data collection tools	The co-researchers developed the interview and focus group schedules and the questionnaire.
Development of participant information	This was developed by the research assistant and co-researchers but then scrutinised by the Research Advisory Group (RAG) who suggested a number of changes.
Choosing the hotel for the residential	The RAG drew up the list of criteria for selecting the hotel. Members of RAG visited the hotels and scored them against these criteria. The RAG made the final decision as to which venue to use.
Securing ethical approval	The co-researchers and the chair of RAG were involved in completing the application for ethical approval and the Chair of RAG attended the meeting of the ethics committee with the research assistant and research manager.
Piloting the data collection tools	These were piloted by the co-researchers with other people with learning disabilities who then provided feedback.
Data collection	The three co-researchers were involved in data collection along with their PA or research assistant.
Data analysis	Each co-researcher took responsibility of sorting one data set. These were then discussed and analysed by the core-research team (with co-researchers taking a key role)
Report writing	RAG members decided on the overall structure of the project report. Various aspects of the reports have been discussed with co-researchers and sections checked with them. They have been involved in preparing the easy read version of the project report.

Dissemination	A number of conference presentations have been given, four papers have already been published and a series of launch events have been planned. All of these have involved co-researchers and RAG members in decision making, writing and delivery.
Development of action plan	The key messages were identified by the co-researchers and they have contributed to discussions as to how best to take forward the actions identified.