

Looking into Abuse: Research by People with Learning Disabilities

Executive Summary

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.

Aims and Research Questions

This project aims to:

- Develop better ways for people with learning disabilities to find support after being abused and to prevent abuse.
- Develop more detailed information on how participatory research works for all concerned.
- Disseminate research findings to people with learning disabilities and professionals.

The specific research questions it seeks to address are:

- What do people with learning disabilities understand by abuse?
- What are their views about abuse?
- What help and support do they need to keep safe?
- When someone has been abused what are the best ways to help?

This summary is presented in two key sections: the research project and the learning that has taken place regarding participatory research.

The Research Project

Three people with learning disabilities were employed to work on a part-time basis as co-researchers each supported by a personal assistant and working alongside a full time university based research assistant. In addition further support was available from the research manager, the participation officer and the participation advisor. The whole project team was supported by the Research Advisory Group (RAG) whose membership comprised over 50% people with learning disabilities. People with learning disabilities were, therefore, actively involved at all stages of the research process.

Ethical approval for the project was given by the Ethics Committee within the Faculty of Health, Sport, and Science at the University of Glamorgan. The project commenced in May 2010.

Data were gathered by means of individual interviews, focus groups and questionnaires. Forty seven people with learning disabilities attended a three day residential event at a hotel and during that event everyone took part in 1 of 7 focus groups and completed a questionnaire. Fourteen people also took part in individual interviews. Further questionnaires were distributed and returned by post leading to a total of 107 useable questionnaires. Each of the co-researchers took responsibility for sorting one of the three data sets. These were then presented to the research team and analysis undertaken by means of group discussion.

Key Findings

Participants were aware of a wide range of different types of abuse including domestic and racial abuse. Some had learnt about abuse through formal training sessions but others indicated that they had had to 'self-educate' through media such as television programmes, through talking with friends who had been abused and through direct personal experience of being abused. Understandably when asked about abuse participants expressed a range of strong emotions including embarrassment, loss of self-confidence and anger. Most worryingly, however, some participants said how abuse can lead people to feel like taking their life as they feel their life is not worth living.

In the questionnaires participants were given a number of strategies that might help keep people safe from abuse and asked to tick those they felt would be helpful. Participants were more likely to tick those strategies they could do for themselves than those that required other people to assist but all strategies were rated highly (range 75 – 105 out of 107 responses). Those rated most highly included:

- speaking up for yourself (n= 105)
- making sure someone knows where you are at all times (n = 104)
- having someone who can sort things (n = 101)
- stay away from nasty people (n = 101)
- tell them what the law says (n = 99)
- talk to someone you can trust (n= 99)

Participants were also asked to tick which forms of support they felt would help people who had been abused. Those rated most highly included:

- people being there for them (n = 106)
- to be believed (n = 103)
- support for the person to live their life (n = 100)

From these findings it is concluded that people with learning disabilities are aware of different types of abuse but may not receive formal education regarding abuse and keeping safe. Such education is important if people are to protect themselves from abuse and, should they experience abuse, that they are confident to disclose this to someone. People with learning disabilities also identify that there are a number of strategies that could be used to help keep people safe and these could

usefully be used as a basis for educational programmes aimed at assisting people to safeguard themselves from harm. Lastly, if people are abused, then it is important that they receive appropriate, acceptable and timely support and participants particularly identified the need for others to be there for people who have been abused and for others to believe them if they disclose abuse. Unfortunately the wider literature and discussion amongst the research team suggests that such supports are not always available.

Recommendations

On the basis of these findings the following recommendations are made:

- 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 in this study as being helpful. Such courses should be part of a wider aim of helping people with learning disabilities to develop increased resilience.
- That when people with learning disabilities disclose abuse they must be listened to, believed, appropriate action should be taken and support given.
- That people with learning disabilities who have been abused should have greater access to counselling and other therapeutic interventions.
- That further research is 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.
- That consideration is given as to how awareness of the impact of abuse on people with learning disabilities can be raised and the role that people with learning disabilities should play in raising awareness.

Learning About Research Together

The second aim of this research project was to develop a better understanding of how participatory can best be developed. Throughout the project, therefore, team members have been encouraged to reflect on the process of working together to undertake research and discussions have taken place with the RAG. The following are the key issues that we noted as being significant in relation to how the project progressed.

The project brought together not only three different organisations each with their own systems and structures but also a team of people some of whom had not previously worked together. It was therefore important that time was taken to both build and maintain trust and effective working relationships. Some challenges were encountered in relation to the employment of co-researchers and in future projects we would seek to enable co-researchers to work more hours and (for those who have not previously been employed) ensure that training is given in relation to employment issues. Practical considerations such as ensuring accessibility (both physical and in relation to information) and managing different budgets were challenging and, along with the participatory nature of the research, meant that time considerations were important. Participatory research is time consuming if active participation is to be achieved.

We felt that within this project we developed some new ways of working within participatory research such as using a residential event to gather data. Also having a Research Advisory Group

where the majority of members were people with learning disabilities and using this group both in an advisory and decision making capacity was innovative. Finally working with the ethics committee to adjust systems to enable people with learning disabilities to take an active role in the process of ethical approval, whilst still demonstrating both ethical and scientific integrity, was an important learning process for both the research team and the ethics committee.

In terms of participatory research a key question that researchers should consider is who benefits from the research. In the course of the project the research team feel that they have all benefited albeit in different ways: we have worked together and have learnt from each other. Ultimately, however, the research team want to achieve wider change whereby people with learning disabilities are helped to keep themselves safe, that abuse is reduced, but that where abuse does occur support is available in both a timely and on-going manner.

Another key aim of participatory research is for the traditional power relations within research to be changed such that people with learning disabilities are supported to take power traditionally held by researchers. Within the context of this project we believe that this was achieved in some ways but that power imbalances arose due to the part time nature of the co-researcher posts alongside the full time research assistant post. The imbalance in availability of time led to an imbalance of power since some decisions had to be made between the times when the co-researchers were in work.

The following are the key learning points we would offer to others considering undertaking a participatory research study:

- ☑ **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.
- ☑ **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.
- ☑ **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.
- ☑ **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.
- ☑ **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.
- ☑ **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.
- ☑ **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.
- ☑ **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.
- ☑ **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.
- ☑ **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.
- ☑ **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.

Overall Conclusions

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.

Some recommendations arising from the study have been noted above 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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Members of the Special Interest Group (SIG)

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