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Responding to the needs of people with learning disabilities who have been raped: co-production in action

Angela Olsen and Catherine Carter

Abstract

Purpose – The purpose of this paper is to discuss a project that explored why mainstream rape support services are still failing to meet the needs of women with learning disabilities. Principles of co-production and action learning enabled a group of women, including women with learning disabilities, to share knowledge and skills and develop easy-read information leaflets.

Design/methodology/approach – The project included representatives from a university, a third sector organisation and a rape crisis centre. Action learning methods were used to bring together a broad range of experience and expertise. The project was co-led by a woman with a learning disability and a lecturer in social work with people with learning disabilities.

Findings – Three organisations had been toiling with a similar issue, that of responses to women with learning disabilities who had been raped. All had previously examined the problem from their own perspectives. An action learning process enabled them to explore the issues from a range of experiences, sharing knowledge and expertise and enabling them to begin to develop better service responses. While co-production may highlight competing priorities in and between organisations, it can also provide the means of managing these tensions.

Social implications – The project demonstrated the importance of co-production. Working together led to a shared understanding of the barriers experienced by women with learning disabilities who had been raped. All had previously examined the problem from their own perspectives. An action learning process enabled them to explore the issues from a range of experiences, sharing knowledge and expertise and enabling them to begin to develop better service responses. While co-production may highlight competing priorities in and between organisations, it can also provide the means of managing these tensions.

Originality/value – The project demonstrates the importance of working with people with learning disabilities in order to develop services that truly meet their needs.

Keywords Learning disabilities, Domestic violence, Intellectual disability, Co-production, Action learning, Easy-read information

Paper type Case study

Introduction

This paper will discuss an action learning project instigated by a group of women with learning disabilities. What started as a relatively simple plan to improve the quality of literature available to women with learning disabilities who had been raped, turned into a more far-reaching project. The results included creating more accessible literature, staff training and raising awareness of the issue locally and nationally. It would be impossible to discuss all of these things in sufficient detail in one paper, so this paper will focus on the process of coming together to identify and begin to address the issues.
While it is acknowledged that men with learning disabilities experience rape, this paper will concentrate on violence against women as the original project was based on issues raised by a group of women with learning disabilities.

**Context**

First, it is important to understand how people with learning disabilities learn about sex, sexuality and relationships. A lack of knowledge about what makes a good relationship appears to be a major reason for people with learning disabilities engaging in dangerous sexual relationships (Dukes and McGuire, 2009; Tullis and Zangrillo, 2013). It has been suggested that many non-disabled people learn as much about sex from friends, family and social networking sites as they do from formal education (Jahoda and Pownall, 2013). This is not the case for people with learning disabilities who tend to have much smaller social networks and appear to gain much of their sex education from what they observe in their own families and mainstream media (Jahoda and Pownall, 2013). A person with a learning disability who is sexually assaulted by a relative or "friend" is less likely to have real friends to compare experiences with.

Research repeatedly finds that many parents and carers mistakenly believe that the best way of protecting people with learning disabilities from sexual abuse is to restrict their access to sex education. However, this is likely to leave the majority of adults with learning disabilities with a limited understanding of sexual behaviour (McCarthy, 1999; Futch, 2011; Fitzgerald and Withers, 2013; Jahoda and Pownall, 2013). Thus, the lack of formal education (McCarthy, 1999; Dukes and McGuire, 2009) combined with narrow social networks and extreme caution in information giving by parents and carers leaves people with learning disabilities ill-prepared to embark on healthy sexual relationships. As a result people with learning disabilities often do not recognise when they have been assaulted or abused (including when they have been raped) and have complex relationships with their abusers (Healy et al., 2009; Northway et al., 2013).

**Prevalence of rape and sexual assault**

It is difficult to assess the prevalence of rape of people with learning disabilities. Studies have used varying methods of data collection. Some studies include men while some are women only. Many conflate rape, sexual assault and other abuse. Most conclude that the prevalence of rape is likely rather higher than figures currently show. Withers and Morris (2012) suggest that between 25 and 50 per cent of adults with learning disabilities have been sexually exploited with almost 1,400 new cases occurring in the UK each year.

Sexual violence against women with learning disabilities is, of course, not only an issue in the UK. Petersilia (2000) states that 70 per cent of women with learning disabilities in the USA have been sexually assaulted, this figure being 50 per cent higher than that for women who do not have learning disabilities. She goes on to report that sexual assaults on people with learning disabilities in Australia are 10.7 times higher than in the general population. Other reports indicate that women with disabilities appear to experience abuse at greater rates than non-disabled women (Healey et al., 2013). However, services for women with learning disabilities who have experienced abuse are few and far between.

A national study of 20 service providers in the USA found that the major barriers cited for failure to provide services included providers’ inability to cope with the multiple issues often experienced by women with learning disabilities (Zweig et al., 2002). Poverty, lack of community presence, unemployment, communication difficulties and isolation are often experienced together when a woman is seeking help following rape. These findings were replicated in Victoria, Australia (Healey et al., 2013), although this study included men and women with all disabilities rather than just women with learning disabilities.

Attempts to improve responses in the UK have tended to be localised. For example, the first refuge for women with learning disabilities in England, Beverley Lewis House (BLH) in East London, established in 1985, remains the only such resource in the UK. While acknowledging that BLH accepts referrals from across the UK, none of the women with learning disabilities nor the service providers who contributed to the current project, were aware of its national reach.
Academic papers on the subject are few, with isolated projects as far apart as Tyneside and Devon (Howlett and Dandby, 2007; Palmer, 2009), both of which discuss pilot schemes directed at supporting women with learning disabilities. While these reports reveal the benefits of mainstream counselling and support for women with learning disabilities, they do little to explore the reasons behind the typical lack of availability of mainstream services in the treatment and support of women with learning disabilities following domestic and other abuse.

**Research by people with learning disabilities**

Given the apparent paucity of research, a group of 12 women from CHANGE, with experience of rape and learning disability, decided to undertake their own research on local experiences of support. CHANGE describes itself as a Human Rights Organisation (HRO), stating in its publicity material: “CHANGE is a leading national human rights organisation led by disabled people. We work inclusively. We campaign, run projects and research issues that affect the lives of people with learning disabilities” (www.changepeople.org/).

The group was facilitated by CC, who went on to participate in the project reported in this paper. Group participants were women with learning disabilities who did not receive social work support. The group’s unpublished findings included that none of them had felt adequately supported following experiences of rape or domestic violence. Most had initially sought help from the Police. Responses by the Police were generally unsatisfactory because the women could not prove that they had not wanted to engage in sex. Some had not realised that an offence had occurred until friends had told them that they were allowed to say “No” to unwanted sex. The group felt that they might have benefitted from leaflets that showed people with learning disabilities that they “did not have to put up with bad sex”. They thought that these could be available in GP surgeries, Police stations and shops.

Coincidentally, a lecturer in learning disability studies (AO) contacted the HRO to ask them to critique a participant information form. She was about to embark on a piece of research with women with learning disabilities who had experienced sexual violence, and wanted to ensure that participants had the best chance of understanding what they were potentially participating in. The HRO and the lecturer agreed that there were many areas of similarity in their work and decided to apply for Higher Education Innovation Funding (HEIF 4). HEIF 4 specifies that grants are made with the intention of developing and sharing knowledge between higher education institutions (HEIs), industry and society to promote social and economic benefit.

**Approach**

The project utilised principles of action learning (Revans, 1982). Terminology is chosen carefully here in response to Marsick and O’Neil’s (1999) challenge to the seemingly widespread adoption of the term action learning by groups that claimed to use the approach but had no formal structure or framework.

Action learning is a staged approach to learning or problem solving. It enables a small group of people, usually referred to as a “Learning Set”, to develop knowledge and expertise through a system of mutual questioning and problem exploration. The set is led by a facilitator who assists in problem exploration and reflection.

**Learning set composition**

Our set comprised four women, AO, PB, CC and KC. AO is a social worker and lecturer in learning disability studies with 35 years’ experience of supporting people with learning disabilities.

PB and CC are workers from the HRO. PB was one of the co-founders of BLH, CC has a learning disability and personal experience of rape. CC uses her experience and subsequent research to train groups of people with learning disabilities about sexuality and women’s issues. She also trains groups of staff in statutory and third sector services in the UK, Romania and other countries. CC had instigated and facilitated the research project in the HRO. KC is a volunteer.
from a local rape crisis centre (RCC); she is also an activist in women’s rights and a lecturer in law. Between us we had knowledge, drive and commitment to raising the profile of our topic. We also had useful networks that we could call on as and when necessary during our work.

AO and CC were the only members of the core set to attend all meetings and they co-ordinated the event to launch the accessible leaflets produced by the set once the process was completed. They were viewed as co-leaders by the rest of the set.

Action learning process

Following the usual tenets of action learning (see Figure 1), the set identified problems and turned them into questions about information that could be gathered from other organisations by set members. Findings were reported back to the set and led to actions to address the original problems. Reflection on these actions led to further problem identification.

The primary problem identified by the set was that women with learning disabilities did not feel well supported following rape. CC invited a group of eight women with learning disabilities to explore their experiences of support following rape. Some of these women had participated in CC’s previous research, while others had contacted CHANGE seeking help for other things and subsequently disclosed being raped, either recently or historically. The women highlighted a spiralling story of referral and re-referral between services. Typically, this would include referral to Police, Sexual Assault Referral Centre and learning disability services often without benefit for the woman. They were rarely referred to generic counselling services such as RCCs. None of them were aware of the RESPOND counselling service. CC found that participants preferred to access local “face to face” services where possible but that these were not always available. Participants who had been referred to “out of area” services, such as refuges, reported feeling unable to manage the additional problems that relocation created. These included accessing schooling for those who had children. Relocation also meant loss of familiarity with shops and services, further isolating the women in times of emotional need.

Some women thought that they could not seek help because they had been assaulted in the past and would no longer have evidence, so would not be believed. Others simply did not know where

**Figure 1** Action learning cycle

![Action learning cycle diagram](image-url)
to turn for help. Some went to the Police, hoping to prosecute the offender. Most had not sought emotional or medical help.

Those who had sought support said that they wanted to be listened to, be understood, believed and to be offered practical advice about what to do next. Some group members recognised that they struggled to speak coherently over the telephone. They thought that people were sometimes too embarrassed to seek clarification if they misheard words more than twice, so conversations quickly became difficult. They also thought that people made assumptions about their lives, generally assuming that they had a social worker to call on for help. They also thought that “helpers” believed that they (the women) would not possess the resilience or personal resources to promote change for themselves. Perhaps most distressingly of all, some of the women never reported their rape because they failed to get through automated telephone services, e.g. “if you are calling to discuss ‘a’, press 1 or ‘b’ press 2”.

This initial work helped us to identify and prioritise key tasks for the rest of the project. The first of these was the need to develop and publicise information for women with learning disabilities. Alongside the need to improve the information available for people with learning disabilities, there was a need to train staff teams to support them better. Space prevents full exploration here of this aspect of our work. Briefly, the RCC volunteers identified communication difficulties as a barrier to working with people with learning disabilities. Two trainers from the HRO delivered bespoke training in learning disability awareness. This included dispelling some of the myths about people with learning disabilities, such as always having a social worker or support worker in their lives, and their lacking personal agency. This resulted in volunteers asking callers for more detail about the types of support that they had and exploring and accepting their reasons for rejecting statutory services if the caller had made that choice. Volunteers began to value and encourage informal support networks rather than making assumptions that social work services were available or wanted. They also enquired about the caller’s previous coping mechanisms. These were skills that volunteers were accustomed to using with non-disabled callers. It was interesting to note that the presence of a learning disability prompted volunteers to assume caller reliance on a specialist learning disability service, rather than to recognise the caller’s need for “specialist” rape support services. Trainers also delivered a session on effective communication exploring complex words and phrases.

As the work progressed we co-opted other people into the learning set. At the busiest period the set comprised the original core members, another trainer with learning disabilities from CHANGE, a member of the CHANGE “words to pictures” team (an integrated group of workers some of whom have learning disabilities that advises non-disabled illustrators about the complexity of documents), a volunteer from a women’s aid service and the support of the conference team from the university to help host the final event.

The set worked well due to the levels of trust and respect between all members. For example KC brought one of the RCC information leaflets to the set. The RCC and local police liaison officers had spent weeks developing a potential leaflet that could provide information for people with learning disabilities who had been raped. CC and PB took the leaflet to the “words to pictures team”, who discussed all of the complex themes contained within the three page leaflet. The RCC had tried to avoid the use of jargon and complex concepts in an attempt to make the leaflet as user friendly as possible; however it was apparent that it was almost incomprehensible for people with learning disabilities. It was too long and too complicated. The words to pictures team identified how to simplify and then illustrate each point of the document. Complex themes were broken down into more easily understood short sentences, resulting in an “easy read” version of the original document, a process discussed further in the next section.

**Development of an easy-read leaflet**

Initially, the proposed RCC leaflet included a lot of technical information about sexual assault. For example, Version 1 contained the following text:

> Sexual assault is an offence involving non-consensual touching, under sections 3 and 7 of the Act. Sections 4 and 8 concern “causing a person to engage in sexual activity without consent”. This could include forcing you to perform oral sex. There are many other offences under the Sexual Offences Act.
2003, which is the Act used where the offence was committed after May 2004. These are a summary of a few of the most common offences, but if you hear about others and want to understand them then we will aim to find out more, on your behalf.

It was agreed that CHANGE members would read the leaflet and propose a simplified version for the next meeting. In this version (Version 2) the previous text was replaced as follows:

If you are a woman who has been raped, had unwanted sex, or been touched in a sexual way, without being asked, today, last month, or when you were younger then we are here to support you while you sort things out.

Once this simplified version was agreed the words to pictures team turned it into an accessible format.

The accessible leaflet was launched at a workshop for women with learning disabilities and agencies supporting people who have experienced sexual violence. The leaflet was viewed positively. An unintended benefit was found by female migrants who did not speak or read English but could understand the pictures. The workshop revealed a wealth of data in respect of the lack of preparedness of mainstream services, with some expressing shame and distress at their lack of expertise. We plan to share the findings of the workshop in another paper.

Co-production, knowledge sharing and knowledge development

The inclusion of people with learning disabilities throughout the process was the most important aspect of our work. However, it meant that the process took more time than funders wanted. Each part of the process took several weeks because most of the workers with learning disabilities worked part-time and took longer to process information than group members who did not have learning disabilities.

However, as the set grew in size, it became apparent that set members with learning disabilities were key to ensuring that the process never veered from its original intent. CC was joined by J, another female worker with a learning disability from CHANGE. Both women were professional, often arriving first at meetings, always prepared for the work ahead. At times the work progressed quickly and set members “forgot” that CC and J had disabilities. At these times CC would challenge non-learning disabled members about the use of complex words or ideas. On other occasions CC and J would ask for help to read a document. Both women brought energy and authenticity to the meetings. They not only spoke from personal experience but also from the experience of working and researching with different groups of people with learning disabilities. CC’s participation in external focus groups enabled other learning disabled women present in those groups to share their experiences without feeling fearful of being judged. As an insider researcher she was considered to be “one of us” by other people with learning disabilities in the group, rather than as “a professional”. Her networking skills outside the set enabled her to contribute a wealth of information.

Discussion

Learning across organisations: priorities and challenges

Co-production of knowledge is becoming increasingly popular as organisations realise the benefits of shared learning. It can provide a platform for knowledge generation, knowledge exchange and service development (Knight and Pettigrew, 2007; Bovaird, 2007; Gillard et al., 2010), and can contribute to the development of a learning organisation (Fenwick and McMillan, 2013). This was certainly the case with our project as it highlighted some competing priorities within the academic organisation; revealing differences of organisational cultures between semi-autonomous departments in a large institution.

Organisational culture is predicated on behavioural norms, values and attitudes as well as established patterns of work (Davies et al., 2000). However, it is also socially constructed, reflecting personal and team ideologies (Cameron and Quinn, 2011). The danger to a large organisation, that incorporates many diverse departments, is the development of competing organisational cultures. Our project revealed tensions between the increasingly business-
finance-focused approach of the central University and the Human Rights Based Approach (DH and British Institute of Human Rights, 2008) of the School of Social Work, which hosted the project.

Challenges were experienced in terms of both corporate branding and the negotiation of deadlines. For example, the marketing department of the University initially insisted that a specific format should be used to promote the workshop that launched the leaflet. CHANGE rightly insisted that the format was inaccessible for people with learning disabilities. A compromise was reached using the University branding colours and the CHANGE format. Set members had entered the project with an agreed timescale of 12 months. The HEIF funding was strictly time-limited, ending in July, however the launch event was scheduled for September to fit with the University calendar of events. The mismatch of timelines meant that work had to continue and invoices were issued by all set members after the funding deadline had passed. Happily, the University agreed to meet the ongoing costs, reflecting a commitment to co-production. This was a learning experience for us all. Our individual value bases meant that we were all committed to contributing to the project until we had achieved results that we were all happy with, despite imposed deadlines. The realities of this however were that the needs of the large organisation took precedence over those of the smaller organisations. The smaller organisations had to be more adaptable than the large and undertake a significant amount of work in good faith and in some instances without payment.

Unfinished work

One of the frustrations of the project was the limitation of its scope. Although the work was intended to be about knowledge production and service development, we would have liked to have developed it into a research project. Indeed the launch of the leaflet afforded us the opportunity to explore levels of support offered to a larger group of women with learning disabilities who had experienced sexual violence. The launch also included representatives from a wide range of women’s services, including those working with sex workers. The launch event provided an opportunity for people to come together to explore experiences from different perspectives. An overarching theme was that all services present, from hospital accident and emergency nurses to learning disability outreach services, thought that supporting a person with a learning disability after rape was someone else’s problem. Without exception all workers present said that their most likely course of action would be to take some details then refer the person on to what they believed would be a more appropriate service.

Many of those present took away ideas for improving their services but to date we have been unable to secure any funding to undertake follow-up surveys to gauge whether or not the learning has been put into practice and/or made any difference to people with learning disabilities.

Conclusion

Co-production of knowledge can promote respectful integration of ideas. If designed in partnership, resources developed are more likely to be supportive and empowering of people with learning disabilities.

Action learning can be a slow process if it is done thoroughly. Our work involved three core organisations, all of whom benefitted from the process learning a lot about each other as well as the intended problem during the iterations of the leaflet design. The process was not always comfortable. Our experience mirrors those reported by Fenwick and McMillan (2013) and Roberts et al. (2012), who acknowledged that partners in co-production do not always fully realise what they are agreeing to at the beginning of the process. We took great care to ensure that the project met the stated needs of all parties. However, in hindsight, we should have had a clearer agreement for meeting deadlines and a contingency plan for submitting invoices in the event of any delays. All of the agencies involved have now refined such contract and financial agreement practices. The project concluded with an easy-read leaflet and better-trained rape crisis staff. Beyond this, it also produced an e-resource of accessible pictures that are available for all RCCs across the country.
The benefits of working together included authenticity and a deepening commitment to co-production. We were all able to share expertise from our own field and learn a lot about the work of others. We were able to explore problems from a range of stances and develop a deeper understanding of issues than if we had attempted the work as individual organisation.

References


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