

Executive Summary – Central Advocacy Partners Survivors Project – Year 1 Report (November 2019)

Introduction and Background

The relationship between disability and abuse is relatively well established, particularly that between women with disabilities and domestic violence. The European Union Agency for Fundamental Rights (2014) suggests that 50% of disabled women have experienced domestic abuse at some point in their life. The experience of adults with learning disabilities who have or who are experiencing sexual abuse and/or intimate partner violence is, however, not so well documented in academic literature and there appear to be limited resources available to support them overall (Guardian, 2015). Existing research suggests that not only do adults with learning disabilities have limited knowledge of the services that might be available to them but also that agencies and professionals have limited knowledge of how to support adults with learning disabilities who are survivors of abuse (McCarthy et al, 2015).

In response to these issues and their own local experience, Central Advocacy Partners (CAP) developed a Survivors' Advocacy Project to support adults with learning disabilities who have or are currently experiencing such abuse to receive advocacy support. The project is funded for three years (from 2018) by The National Lottery Community Fund. The main focus of the work with survivors is to support them to remain safe, link them into existing services and support their access to such services as well as raising awareness of the key issues for adults with learning disabilities experiencing these forms of abuse.

The key outcomes for the project are as below:

- People (usually women) with learning disabilities/difficulties learn to recognise abuse, to end violence in their lives and to understand their rights.
- People (usually women) with learning disabilities/difficulties are more aware of the options and services available to them and are using those services to seek help.
- People (usually women) with learning disabilities/difficulties understand information, and are empowered to make decision in their lives.

The project is currently being evaluated by Dr Gillian MacIntyre and Dr Ailsa Stewart. The key questions being explored within the evaluation are:

- To what extent do referrers believe that adults with learning disabilities who are experiencing/ have experienced abuse have been supported by the survivors' project and in what way?
- What benefits do adults who have been referred to the service report?
- What have been the key challenges and opportunities for those delivering the service?

- What are the range of outcomes reported for those who have received support from the project at the end of the study period?

Methods

A multi-method qualitative approach has been adopted. This has involved undertaking a review of relevant literature, face to face interviews with staff involved (n=4 x 2) in the project both formal and informal, creation and distribution of an online survey to referrers to the project (n=7, 54%), face to face interviews with survivors (n=12), detailed case reviews for each survivor (n=12) interviewed and telephone interviews with referrers and professionals (n=3) with detailed knowledge of the project.

Evidence from the literature

The findings from the 1st year literature review suggest clear gaps in the evidence base. There are particular gaps in research involving adults with learning disabilities who have experienced domestic violence and sexual abuse. Whilst there is evidence correlating disability and an increased likelihood of experiencing a range of different types of violence and abuse, much of this evidence is not robustly generated and does not focus on learning disability.

Interventions to support those with learning disability who have experienced violence and abuse appear limited and under-evaluated, however, what does exist has a focus on the promotion of developing individual self-defence mechanisms to increase protective factors. More broadly it is evident that work is required to increase the understanding and awareness of professionals in justice, health and social care of the needs of those with learning disabilities experiencing violence and abuse. There are barriers to accessing existing supports due to a range of factors including clarity over what constitutes abuse and limited knowledge and understanding over what type of support might be suitable and available.

It is evident from the literature review that the aims and objectives of the Survivors Project are appropriate and relevant for increasing support to this group of survivors. It also provides evidence of a gap in knowledge about the impact of services such as the Survivors Project where they do exist and therefore the additional value of undertaking the evaluation.

Findings from the data collection process

The following findings are drawn from an analysis of the evidence drawn from across the data collected; that is the interviews with key stakeholders, the on-line survey and the case file reviews.

Referrals

During the first year of the project April 18 to April 19, 32 referrals were received by the project 13 were from external agencies (some made more than one referral so this represents 10 external agencies), e.g. third sector, health and social work organisations, eight were self-referrals and the balance, 11, were from staff within the broader CAP service, principally the

Parents Project. Twelve either did not choose to take up the service, did not fit the criteria or lived out-with the relevant geographical area. Thirty-one referrals were for women and a significant number, (n=9) had a dual diagnosis of learning disability and a known or suspected mental health issue, e.g. unstable personality disorder or anxiety and depression. A small number were pregnant at the time of referral. There was one male referral during the first year and he was referred onto another service due to the specific issues related to his case. A service was therefore provided to 20 survivors on an ongoing basis.

Who are the survivors?

Of the twelve women interviewed each had their own unique story however there were a number of features that were common across the cases:

- All of the women identified as having a learning disability or a learning difficulty of some kind, although they did not necessarily have a formal diagnosis.
- Women often had a dual diagnosis including an autism spectrum condition or mental health problem such as: depression, anxiety, post-traumatic stress disorder and unstable personality disorder.
- There was a broad spread of ages ranging from early to mid-twenties through to mid-sixties.
- The majority of the women interviewed had children and several of them had more than one child with the highest number being seven.
- Often the make-up of the family was complex and there were many blended families; where the children were not living together or necessarily with a birth parent.
- The majority of the women had experienced child protection processes and/or custody and access issues.
- A significant number of the women had had more than one abusive partner and cycles of abuse appeared common.
- The women experienced a variety of challenging issues alongside domestic violence and/or sexual abuse including poverty, debt, homelessness, substance abuse and problems accessing supports in a range of agencies including education, social care, health and housing.
- Loneliness and isolation due to a range of issues including fear of their abuser and mental health problems associated with their experiences featured.
- Many survivors expressed a desire to develop their social networks.

Contextualising the abuse experienced

All of the women had experienced abuse of one kind or another with the most common being physical, sexual, financial and psychological abuse or a combination thereof. For many of the women the abusive relationship had lasted for many years. Although none of the women reported currently being in a relationship with that partner they had on-going difficulties regarding contact with their former partners and a great deal of work was done to support women to develop strategies to keep themselves safe. There was a sense of normalcy around

abuse identified by the participants. Many had no experience of a positive relationship and it was difficult, therefore, for them to identify abuse. Several had limited awareness that they had been abused prior to working with the project.

All of the women could remember the reason for ending the relationship, for example; arrest and imprisonment of their partner, feeling great fear for their safety or that of their child, child protection concerns and the risk of losing their child. Historic abuse was prevalent in the sample group, for many the abuse started in childhood and often progressed to a series of abusive relationships in adulthood and the impact of this was significant in the support being provided by the project.

What has the response been?

The support provided by the staff team has been comprehensive and reflected the complex range of issues presented by the women. On average the women were seen once a week but this intensified around specific events such as court cases or child protection proceedings, therefore support provided was flexible. Issues such as poor housing, poverty, poor health, isolation and legal concerns often exacerbated the situations that the women found themselves in. These contextual issues had to be dealt with before any work could take place on the key issues related to the abuse, e.g. identification of abusive behaviours, post-traumatic health concerns and strategies for keeping safe and moving on. The support provided by the project is relationship-based. This allows staff to spend enough time with survivors to ensure their understanding is enhanced and relevant contextual issues are considered. A range of different types of support have been provided as noted below.

- **Advocacy** – Supporting survivors to navigate their way round different agency processes, develop better relationships with professionals, co-ordinate and attend meetings, translate complex and inaccessible material they received, attend court hearings and give evidence and refer them onto other relevant support.
- **Education** - Providing education about abuse to share knowledge, information and experience to empower survivors to make more informed choices in the future, with a focus on the features that make safe and positive relationships. Easy-read material was used to good effect. Survivors indicated that they felt much clearer about what constituted abuse and were able to provide examples when asked.
- **Keeping safe and ending abusive relationships** - Working with the women to develop safety plans so that they could keep safe now and in the future. This involved a range of practical tasks such as liaising with the local police to ensure that the women's property was marked or flagged to ensure local community police kept a closer eye on things when carrying out their local patrols and on-line safety advice.
- **Developing social networks** – For many of the survivors their relationship with their advocacy partner was their first experience of a trusting, positive relationship, again this reflects the relationship based advocacy model adopted in the project. Staff also supported survivors to identify a range of opportunities within their own community.

- **Practical support** – Support was provided with a range of very practical tasks such as to develop cooking or home-making skills or offering support with budgeting or referring onto local services for support.

What makes the support different?

The trusting relationships developed between the advocates and their partners is a highly skilled role and building these relationships has taken hard work, persistence, flexibility and understanding. Time was required to develop these relationships and an important feature of the project was that there was no pressure to close cases after a pre-determined period of time and a period of non-engagement by a survivor did not result in their support being withdrawn. There was clear acknowledgement that the level of support and intervention needed required longer-term and often intensive support. Other services in the local area acknowledged that they did not have the capacity to work with women in this intensive way. The staff bring together a unique combination of knowledge and expertise of both learning disabilities and gender-based violence and in doing so support women to increase their ability to protect themselves by increasing their confidence as well as their awareness of and knowledge of gender-based violence.

Ongoing need for the project

The evidence overwhelmingly suggests that there is an ongoing need for the service. The unique combination of the relationship based model of advocacy, staff expertise and the type of intensive and long term support that is provided fills a clear gap in service provision for women with learning disabilities in the Forth Valley area. The staff from the Survivors project have highlighted the lack of available, suitable service provision to refer women onto alongside a lack of accessible and transparent information that creates additional barriers for women with learning disabilities. Raising awareness of these issues is viewed as crucial in ensuring greater equality of access and support for survivors with learning disabilities.

Model of Advocacy

The model of advocacy within this project goes beyond standard advocacy support into something that could be termed advocacy plus. The lack of services to refer survivors onto who have sufficient skills and knowledge in working with those with learning disabilities has meant that the project staff have had to fill this gap themselves by providing that bridge and supporting other services to work with survivors, e.g. in promoting good communication and raising awareness of good practice and key issues. The intensity, complexity and long-term nature of the work undertaken by the project is also out-with standard advocacy parameters.

Staff Support, Workload and Future Development

The intensity, longevity and complexity of the cases explored within this evaluation has meant that the number of cases taken on by each staff member has been lower than anticipated 10 instead of 15. The staff and the project manager/s have worked together to ensure clear

support for each other to maximise effectiveness at the same time as protecting both survivors and staff. Peer support and appropriate training, e.g. Safe and Together, were identified as crucial in ensuring that staff within the project were able to work safely and efficiently in a non-discriminatory manner. Regular supervision sessions also take place to ensure the opportunity to unpack any issues identified by staff.

Aside from the obvious concern that the project continued to be funded securely on a long term basis, other suggestions for future development were made. The most consistent suggestion was for the project to offer group work support in the future, this was thought to provide the opportunity for survivors to share their experience and to begin to see the value of their experience in shaping others journey to recovery and perhaps developing a peer advocacy model. It was also felt that the job of increasing awareness of the needs of this group of survivors in other services should be further developed, perhaps with a specific post.

Conclusion

It is evident that much has been achieved to date. The evaluation has identified the value of the project's role in a number of areas but particularly with regard to increasing awareness of the specific issues faced by survivors with learning disabilities, promoting self-protective strategies with survivors and supporting survivors to deal with a range of issues in their lives. The data suggests a high level of satisfaction with what it has achieved for survivors referred. Whilst referrers found it difficult to quantify exactly how much progress survivors had made they were comfortable noting an increased awareness of abuse within survivors and a consequent increase in their self-confidence and self-esteem to speak out for themselves. Positive experiences of working with the project overall were noted; highlighting the high level of skills and experience of the staff in working with people with learning disabilities and the learning for others generated from this experience.

Survivors note a number of clear benefits from working with the project in particular, an increase in their self-confidence and self-esteem, greater understanding of abuse and its impact. This has been linked to increased feelings of self-worth. Having their voices heard is a key theme, particularly in formal settings, e.g. meetings with lawyers, social workers and other professionals. The advocate/partner relationship was also identified as a key benefit for survivors in aiding to break down isolation and loneliness.

An ongoing challenge for the delivery of the service is the sheer complexity and intensity of the work that requires to be undertaken over a long-period of time. Often the project staff are working with survivors who have little or no understanding of abuse and little confidence in their ability to maintain their life without support. Bringing survivors to a point where they are able to live without advocacy support will be a challenging aspect of the project in the future. There have, however, been real opportunities for the project to make a broader impact, particularly in raising awareness of the issues facing survivors with learning disabilities with other services and this is a further area for development in the coming years.