

# Central Advocacy Partners – Survivors Project

## First Year Evaluation Report 2018/2019



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## **1. 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). McCarthy and her colleagues also note that Police Officers, often the first point of contact in domestic violence cases do not generally believe that a learning disability makes someone more likely to experience abuse. For example, signs that someone may be experiencing abuse such as loss of money or refusing support will be attributed to the diagnosis of learning disability rather than that someone perhaps experiencing abuse. This can be acknowledged as diagnostic overshadowing.

Walter-Brice and colleagues (2012) noted that in a small study carried out with five women with learning disabilities experiencing domestic violence that being refused support and/or help or being unable to access suitable help and support became internalised as failure on their parts and heightened their vulnerability. Dixon and Robb (2015) noted different approaches taken by different services to assessing and supporting adults with learning disabilities who experienced domestic violence. In general, this focused on the balance between promoting positive risk taking and calculative measures reducing individuals to criteria rather than taking into account individual strengths and context. This study also found that advocacy was one key service which enabled women to access appropriate services and make sense of their experience.

In a review of 29 articles focused on sexual abuse and learning disability, Byrne (2017), confirmed that adults and children with learning disabilities are at a higher risk of sexual abuse than the mainstream population. These key issues are reflected in the experience of Central Advocacy Partners (CAP). Re-provisioning of local services has meant a prioritisation of advocacy provision based on criteria which often means that adults with learning disabilities are unable to access appropriate support unless they are in crisis which is acknowledged as an unhelpful starting point. There also appeared to be a lack of local knowledge over the exact numbers of women who had experienced or were experiencing sexual and/or domestic violence giving rise to a concern that this was a 'hidden group' who were missing out on appropriate provision. CAP were able to identify that of the 270 people with learning disabilities, difficulties and autism that they worked with in 2015, 142 (more than 50%) identified that they had or were currently experiencing domestic or sexual abuse.

In response to the issues identified above and their own local experience, Central Advocacy Partners have 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 as a pilot by The National Lottery Community Fund for three years.

## *Background*

Central Advocacy Partners (CAP) aims to provide advocacy support to adults with learning disabilities across the Forth Valley (Falkirk, Stirling, Clackmannanshire). The organisation provides a range of services to vulnerable adults including: social inclusion projects, advocacy support to a range of adults with a learning disability as well as private contracts to provide independent advocacy to various residential services. Information is provided in an accessible format and a key aspect of the organisations work is to ensure that adults with learning disabilities are included in the management of the organisation via a strong governance structure.

In 2018, CAP received National Lottery Community funding for three years to provide advocacy support to people with learning disabilities, difficulties and autism who have or are experiencing sexual abuse and/or domestic violence. The service is provided across Forth Valley (Falkirk, Stirling, Clackmannanshire). Two workers have been employed to provide this service and the funding application suggested that they may work with as many as 90 (15 per year per worker) adults over the course of the three years of the project. 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 across services.

The key outcomes for the project, which are flexible and being updated based on experience 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.

It should be noted that although the expectation is that the majority of those referred to the project will be women as indicated above, the project is open to supporting males with learning disabilities/difficulties who have experienced abuse. Those with learning disabilities and difficulties have access to the project removing the necessity for a formal diagnosis to access the service.

The definition of domestic abuse adopted by the project and that underpins their work is as below:

*Domestic abuse is a pattern of controlling, coercive, threatening, degrading and/or violent behaviour including sexual violence, by a partner or ex-partner. Domestic abuse is overwhelmingly experienced by women and perpetrated by men. It doesn't matter how old*

*someone is, what race or ethnicity they are, what class they are, whether or not they are disabled, or whether they have children – anyone can be a victim of abuse.*

*Often when people think of domestic abuse they think of physical violence, but domestic abuse is very often so much more than that. For many women who live with domestic abuse there will be no scars, bruises or broken bones, but for some it can take their life. No one kind of abuse is more serious than any other.*

## **2. Focus of the Evaluation**

CAP will report directly to the National Lottery Community Fund on the outcomes achieved by service users during the life of the project using self-generated data collection methods such as their own outcome recording system including star scores focused around – I know what domestic abuse is, I know my rights, I feel safe, I make my own decisions and I can access services. In order to ensure additional value from the evaluation it will focus on gathering evidence on the extent to which the key outcomes of the project have been met from the perspective of a range of key stakeholders. Therefore, the questions being explored within this evaluation will be:

- 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?

## **3. What we have done so far**

A multi-method qualitative approach was agreed as the most effective mechanism of data collection to answer the research questions. This has included: undertaking a review of relevant literature, face to face interviews with staff involved in the project both formal and informal, creation and distribution of an online survey to referrers to the project, face to face interviews with survivors, detailed case reviews for each survivor interviewed and telephone interviews with referrers and professionals with detailed knowledge of the project. Further detail of this work is outlined below.

**Ethics** - Discussion over an ethical approach to the evaluation took place with project staff during the proposal development. This included ensuring appropriate easy read versions of material for participants, the provision of verbal input on the project where appropriate rather than relying on written material and potentially discriminating or excluding against those without literacy skills. Efforts were made to ensure that the timing of engagement with survivors would be dependent upon their own well-being and that no pressure would be brought to bear for anyone to participate. The needs and rights of the survivors were agreed to be paramount. It was further agreed that confidentiality would be adhered to in all data collection, with the proviso that this was limited by any disclosure which indicated harm

either by the participant or to the participant. A consent form which detailed the rights of the participants to confidentiality, to withdraw their data and to change their mind was developed and approved by project staff. The project agreed with the ethical approach proposed and permission was granted for the evaluation to begin.

**Literature Review** - As part of the evaluation of the project, an important function was to systematically gather information that highlighted the lived experiences of people with learning disabilities who have experienced domestic and or childhood abuse as well as highlighting any particular issues around the provision of support for survivors with learning disabilities and the effectiveness of such support. To this end, a preliminary (and ongoing) literature review has been conducted to identify emerging themes from the existing evidence base.

To date literature searches have been carried out using the terms “disability and gender based violence” and ... This has generated 37 potentially relevant papers. Papers were included if they were published after 2000 (unless they appeared to be a seminal piece). Studies that focused on “disabilities” more generally were included as to include only those focussing on “learning disabilities” or “intellectual disabilities” would have reduced the available material significantly. Particular prominence has been given to those studies focussing on “learning disabilities” in the summary of themes outlined below. International studies that had a very specific focus not relevant to the project aims were excluded. However, those with more generic messages that could be applied within a UK and Scottish context have been included. The literature review has been shared with project staff to inform ongoing development and focus of the work of the project.

**Creation of research instruments** - Research instruments have been created for each stage of the methodology. This included: interview schedules for staff, survivors, referrers and professionals as well as the construction of an on-line survey for referrers to the project. The details of the interview schedules for survivors were shared with the project staff to ensure relevance and sensitivity. Templates were also developed to gather secondary data from the detailed case files compiled by staff. Alongside the research instruments; separate information sheets and consent forms were developed for each group of participants. Project staff participated in this process by providing comments and easy read versions for participants where relevant.

**Interviews with staff** – Staff were interviewed as a group twice during the first year of the project. These interviews took place in the CAP office and staff were offered the opportunity to be interviewed separately but felt it was helpful to be interviewed together for the purposes of collaboration and to ensure consistency of information provision. The first interview involved the outgoing manager of the project and the second, the newly appointed manager of the project. Consequently, four members of project staff have been interviewed. It should also be noted that much informal data collection has taken place in discussions with staff during the data collection process. This has however, generally focused on points of clarification, extracting greater detail of existing cases and exploring the emerging complex nature of the work undertaken by staff. Staff have given their time in a generous and committed manner and this has been extremely valuable to the evaluators.



**Interviews with survivors** – Interviews were undertaken with 12 survivors in April and June 2019. These interviews were conducted in CAP offices to ensure that the survivors were comfortable with their surroundings. The interviewees were identified by staff members as those with relevant experience of the project whose well-being was sufficient to enable them to participate effectively without this being compromised. There was also an element of self-selection as clearly only those who wished to participate did so. Consent was sought in advance for interviews by the project staff, who also took great care to ensure that the survivors were able to attend for interview by providing transport and debriefing following interviews. It was acknowledged in the information sheet that the interview process could be upsetting for survivors and the project staff providing a debrief process was viewed as essential in ensuring that the survivors were not harmed by the process.

**Interviews with referrers/professionals** – Telephone interviews have been undertaken with one referrer and three professionals associated with the project. Overall in year 1 (18/19) of the evaluation 32 referrals were made as noted. Thirteen external referrals were received (sometimes one person made more than one referral so this represents 11 organisations), the balance (19) having been self referrals or internal referrals from other parts of the CAP project. It has been challenging to find referrers who were willing to be interviewed, although a number were happy to complete the on-line survey as detailed below. It was hoped by undertaking the referrer interviews that we would be able to expand on the responses gathered in the online survey but that has not been possible to date. The professional interviews, have however enabled some clarification/corroboration of the themes identified in the survey. There is no suggestion that the reluctance of referrers to be interviewed was due to any concerns about the project, rather that this was due to the busyness of those involved. It was demonstrably easier and quicker to complete an on line survey than to be interviewed. It is therefore proposed that there is a focus on increasing the data collection with referrers during year 2 of the evaluation, a discussion over the best mechanism for undertaking this will be had with project staff.

**Case file reviews** - A detailed case file review has been undertaken for each of the 12 survivors interviewed for the project. This has involved the development of a template to ensure the same information was gathered from each of the files. The focus of the review was on clarifying key features of the survivors as well as clarifying the chronology of events related to the work with the project staff as this was somewhat confused via the interview process, reflecting the complex nature of the work being undertaken. The review also focused on gathering examples of the types of support provided by the project staff as well as evidence of any progress made by survivors. The case files were very detailed and provided clear evidence of the complexity of the work being undertaken by the project staff and the breadth of tasks undertaken and support provided. There were inconsistencies in the content of each case file, i.e. some were more detailed than others, some contained star scores others did not and diagnosis was sometimes alluded to but not recorded formally. It should be acknowledged, however, that due to the GDPR, only data that is relevant to the project's outcomes is recorded so for example, the ages of survivors are not routinely recorded.

**Online survey** – an online survey was constructed via a software tool entitled Qualtrics. The link for the survey was then distributed by project staff to all those who referred to the project, to ensure that it reached the relevant participants. Project staff followed up with

reminders to referrers after two weeks. Seven of the year 1 external referrers contacted completed the survey, one person began the survey but did not complete it.

**Transcription** – Each of the interviews detailed above were fully transcribed by the evaluators. This process was time consuming but very worthwhile in providing a first stage analysis of the data and in identifying gaps in data collection which other avenues would require to fill, i.e. case file reviews.

**Analysis** – The data collected for the evaluation was qualitative in nature and was therefore analysed thematically (Miles and Huberman 1994). This concerned taking a middle order approach that involved working with the themes that emerged from the review of literature and from the data generated from the various interviews and using these as a framework to organise the data. The data was then interrogated to identify further themes and sub-themes contained therein in order to confirm and illustrate themes already identified and highlight further emerging themes. The quantitative data collected in the on-line survey was analysed using the Qualtrics survey software.

**Provision of summary update** – A summary update of the themes emerging from the evaluation was provided to the project in May 2019 to aid in the Project's first year report to the funders.

## **4. Literature Review**

The approach taken to the literature review is outlined above, the following outlines the findings from the review and the key themes identified therein.

It is important to note that there is no universally agreed definition of “learning disability” (or even “disability”) and the terms “gender-based violence”, “intimate partner violence”, “domestic violence” and “domestic abuse are often used inter-changeably. Therefore, there is little agreement over the concept being measured and how this is understood. There is more clarity over the term childhood sexual abuse, however this is an area of the literature which requires further review, particularly in terms of outcomes for adults.

### **4.1 Quality of the Evidence Base**

According to Mikton and Shakespeare (2014) inconsistencies in definitions and ethical challenges in conducting research with those with learning disabilities have resulted in a poor quality evidence base. As a result, there is limited literature available. For example, in a review of literature focused on learning disability and domestic violence undertaken over a 15-year period, only 16 relevant articles were identified, 6 related to service provision and 10 related to intervention and prevention strategies (Lund, 2011). There are also challenges in the methodology used in published research in this area including small sample sizes and lack of control conditions, undermining the relevance of findings (Lund, 2011). Hughes et al (2012), also found that methodological weaknesses and poor measurement of disability and violence affected the reliability of the evidence base as it related to women with disabilities.

### **4.2 Theoretical constructions and definitions**

#### ***4.2.1 Constructions of vulnerability***

As noted above, there is little consistency across a range of definitions which affect the group of adults served by the Survivors’ Project and this is also true of vulnerability. Hollomotz (2009) argues that the way we understand and construct the concept of vulnerability makes it more likely that someone with a learning disability will be abused, particularly where they have been labelled as vulnerable. It is therefore important that we understand the lived experiences of people with learning disabilities within their broader social context, rather than instil vulnerability within the individual, and explore the impact of the label from their perspective both positive and negative. The ecological model Hollomotz explores provides a tool for examining the impact that interactions between individuals and social environments have on an individual’s learning and the development opportunities that have the potential to increase self-defence skills and consequently aid in individual protection and prevention of abuse and harm occurring. (Hollomotz, 2009).

#### ***4.2.2 Intersectionality, disability and domestic violence***

Women with disabilities experiences of domestic violence are multi-faceted and therefore using the concept of intersectionality can aid in understanding the impact of their oppression on their experience (Thiara, Hague and Mullender, 2010). It is argued that women with a

disability experience increased levels of abuse due to oppression related to gender and disability (Mays, 2006). Mays argues that material feminist interpretations and disability theory, with their emphasis on gender relations, disablism and poverty, should be used as an alternative tool for exploring the nature and consequences of violence against women with a disability (Mays, 2006).

However, the intersectionality of gender and disability and how this relates to violence is poorly recognised in policy terms in a number of countries internationally. Adopting a human rights perspective within disability policy can help to address this challenge (Frohmander, Dowse and Didi (2015). This suggests that protective measures under statute such as those provided by the Adult Support and Protection (Scotland) Act (2007), should be framed within a human rights perspective to ensure a focus on all aspects of potential oppression and harm as well as ensuring the rights of those with disabilities via the United Nations Convention on the Rights of Person's with Disabilities (UNCRPD).

### **4.3 Prevalence**

All of the evidence reviewed suggested that women with disabilities are at greater risk of interpersonal violence beyond that experienced by women in general and that the type of violence and abuse can be disabled-specific. (Powers, 2009). A key systematic review and meta-analysis of global prevalence and risk of violence against adults with disabilities suggests that those with disabilities are 1.5 times more likely to be victims of violence than those without. IPV occurs at elevated and disproportionate rates among women and men with disabilities, especially when assessed over the course of their lives (Hughes et al, 2011). Adults with mental health conditions are nearly four times more likely to experience violence (Hughes et al, 2012, the lancet) (Heijden, 2017).

This is supported by a range of other findings. For example:

- Findings from the Life Opportunities Survey of 37,513 British adults indicated a) disabled adults were significantly more likely over the last 12 months to have been exposed to violent crime than non-disabled peers. b) This risk was particularly elevated for disabled adults with mental health problems c) differential risk of hate crime was particularly elevated among disabled adults with mental health problems or cognitive impairments d) these effects were strongly moderated by poverty status with no differential risk of exposure for disabled adults among more wealthy respondents (Emerson and Roulston, 2014).
- In a Canadian study, women with disabilities had 40% greater odds of violence in the five years prior to interview and appeared to be at risk of particularly severe violence (Brownridge 2006).
- Studies suggest that women with disabilities experience abuse over longer periods of time, are a greater risk of abuse and experience disability-specific types of abuse, e.g. such as having assistive aids removed or dependent care denied (Plummer and Fiundlay, 2012).

- Men and women with developmental disabilities (350), reported high levels of abuse both as adults and children. More women than men reported adult sexual abuse. Women were more likely than men to identify an intimate partner as a perpetrator, although intimate partners represented the minority of abusers for both genders. Violence associated with worse health status for both genders (Platt et al, 2017)
- A US study with a nationally representative sample of 34,563 adults found that women with physical disabilities and mental health impairments were at significantly higher risk of intimate partner violence (IPV) compared with those without disabilities. Men with mental health impairments were also at higher risk of IPV than those without. (Hahn et al, 2014)
- IPV occurs at elevated and disproportionate rates among women and men with disabilities, especially when assessed over the course of their lives. Further research that relies on standardised definitions of disability and violence are needed to better inform policy and practice. (Hughes et al, 2011)

#### **4.4 Types of abuse**

Disability-specific abuse has been highlighted above and that includes the removal of supportive or assistive devices and unwanted touch during dressing or bathing (Hassouneh-Phillips, 2002; Breckenridge, 2017). Sexual abuse and psychological abuse including behaviours associated with patriarchal dominance were considered to be significant amongst women with disabilities (Brownridge, 2006).

#### **4.5 Risk factors**

Existing literature suggests that there are two key reasons why women with disabilities are more likely to experience abuse than those who are non-disabled 1) disablist attitudes towards women with impairments, e.g. perceptions of women with disabilities as dependent and/or weak and therefore easier to manipulate and dominate and 2) exposure to a wider range of potential perpetrators, including care workers and personal assistants (Breckenridge, 2017).

Other risk factors include, isolation, loneliness, poverty, dependency as a result of disability and difficulties identifying and naming incidents of abuse (Plummer and Findley, 2012). In addition to this, living in institutions, being dependent on support from formal and informal care were also highlighted (Mikton and Shakespeare, 2014).

The association with poverty is strong – although it is not clear whether it is disability or poverty that plays the major causal role in increased violence experienced by people with disabilities (Mikton and Shakespeare, 2014; Emerson and Roulston, 2014).

Stigma and how women are perceived seem to be particularly important. For example a small narrative study with four women with mild intellectual disability found that devaluation and rejection in childhood generated a search for belonging in adulthood that contributed to their vulnerability to exploitation and abuse in relationships (Pestka, 2014)

Stigma renders women with learning disabilities as more vulnerable to victimisation. Interviews with 58 service providers in GBV and disability services in South Africa found that the experiences of women with learning disabilities including their vulnerability to and experiences of violence are mediated by complex social perceptions and myths. These include the general perception that people with learning disabilities are less valuable, cultural myths and superstitions about disability, fear and shame associated with persons with learning disabilities, and the tendency of persons with disabilities to internalise negative views about themselves – all of this combines to render women with learning disabilities as invisible and therefore more likely to be abused (Meer and Combrinck, 2015)

#### **4.6 Perpetrators**

There are a range of perpetrators against women with disabilities including friends, family members and personal assistance providers (Hassounah-Phillips, 2002) with evidence suggesting that there is often a deliberate targeting of vulnerable women by predatory and violent perpetrators.

Perpetrator-related characteristics alone accounted for the elevated risk of partner violence against women with disabilities. Men were 2.5 times more likely to behave in a patriarchal dominating manner and 1.5 times more likely to engage in sexually proprietary behaviours. These were strongly linked with violence against women with disabilities. Findings from one study suggests attention also needs to be directed towards perpetrators (Brownridge, 2006)

#### **4.7 Effects of abuse**

Violence has far reaching and life-long consequences for victims mental and physical health and for their socio-occupational functioning and can also lead to premature death. This is partly due to coping behaviours such as smoking, excessive drinking, drug taking and over-eating. Little research on whether consequences for disabled people are similar or even more severe has been undertaken (Mikton and Shakespeare, 2014). Following sexual abuse, people with learning disabilities may experience a range of psychological issues similar to the general population, however the evidence is inconclusive (Sequeira and Hollins, 2003)

The effects of abuse may be ongoing into later life. For example, a study which explored the experiences of adolescents who had experienced maltreatment in childhood found that when combined with lower IQ they were more likely to experience dating or intimate partner violence. (Weiss, MacMullan, Waechter and Wekerle, 2011)

#### **4.8 Access to support/ Barriers to seeking help**

##### ***4.8.1 Awareness and accessibility***

There are some challenges in supporting people with learning disabilities who have been affected by gender-based violence. For example Fraser-Barbour (2018) argues that establishing a rapport takes time. She also argues that mainstream violence services are often inaccessible or unavailable (see also Lund, 2011). Therefore, supporting adults to understand

what happens next after reporting harm or sexual violence is thought to be important (Lund, 2011: Fraser-Barbour, 2018). There are clear requirements for resources/services/information directed at both professionals and adults requiring support to ensure appropriate access for adults and the provision of relevant skills for professionals (Fraser-Barbour, 2018: Hassouneh-Phillips, 2002).

People with disabilities face unique issues in accessing support due to inaccessible services, differing manifestations of abuse, being isolated, negative attitudes towards people with disabilities. People from BME communities face further additional difficulties in seeking and accessing support including a lack of culturally appropriate accessible services, isolation and shame, lack of knowledge about services, lack of trust in the system, multiple cultural identities, double communication barriers and cultural differences towards disabilities. (Lightfoot and Williams, 2009)

## **4.9 Support and prevention**

### ***4.9.1 Effectiveness of services and issues for service providers***

Evidence on the effectiveness of programmes to prevent violence and its recurrence and to mitigate its consequences once it has taken place is scant due to the methodological challenges outlined above and limited research (Mikton and Shakespeare, 2014)

Some violence and abuse prevention interventions for women with disabilities have been developed. None of these prevention interventions demonstrate a decreased incidence of violence and many lack rigorous planning, implementation and evaluation (Heijden, 2017) A survey of community domestic violence programmes in North Carolina in the US found that 99% of those surveyed had provided support to at least one disabled women in the last 12 months. 85% had offered shelter. 94-99% of services felt either somewhat able or very able to provide effective care or services to women with disabilities. Challenges in supporting women with disabilities related to a lack of funding, lack of training and structural limitations of service facilities. Strategies to overcome barriers included supporting effective networking and co-ordinating care with organisations specifically set up to support disabled people. (Chang et al, 2003)

### ***4.9.2 Educational interventions***

There is a requirement for educational support for adults with learning disabilities to identify and deal with violence and/or abuse to increase their ability to defend and protect themselves (Hassouneh-Phillips, 2002: Lund 2011).

### ***4.9.3 Self-defence and self-protection***

Little research on self-defence protective mechanisms that could aid victims of domestic violence with diverse disabilities has been carried out (Ballan and Burke-Freyer, 2012). Women with disabilities who have survived domestic violence are the experts in self-protective strategies but will require support. It should not be viewed as their responsibility

to reduce the risk of violence but rather this should be undertaken at a policy level (Ballan and Burke-Freyer, 2012)

#### **4.9.4 Need for support for professionals**

Evidence suggests poor professional responses to the experience of women with disabilities experiencing domestic violence may leave them without appropriate support and protection (Thiara, Hague and Mullender, 2010). See also (McCarthy et al, 2018)

Adults have reported a number of obstacles and barriers to escaping and ending the violence – which relate to a fear of not being believed because some professionals do not recognise disabled women’s capacity for intimate relationships. Family members and professionals often lack understanding and sometimes do not take the views of adults seriously, with evidence suggesting that professionals may focus on the impairment rather than the abuse (Nixon 2009).

An online survey of 717 Police officers and other professionals indicated that social care professionals were more likely than the Police to view women with learning disabilities as being especially vulnerable. The majority of respondents believed women with learning disabilities were deliberately targeted by violent and abusive men, therefore more training is required for professionals and police to understand appropriate responses to women with learning disabilities experiencing domestic violence (McCarthy et al, 2018).

*“All of those who provide a service to women with learning disabilities need to be trained to recognise the indicators of domestic violence, its many forms and dynamics. Professionals families, friends and supporters need to recognise that when women with mild and moderate learning disabilities lack supportive social networks, jobs, interests and activities then this increases their vulnerability to abuse in broad and specific ways. Advocacy, self-advocacy, the support of other women through women’s groups and accessible information about the positive and negative aspects of relationships can all help to reduce women’s vulnerability to exploitation and harm” (McCarthy, 2017: 599)*

#### **4.10 Literature review conclusion**

These findings from the 1<sup>st</sup> 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. Advocacy services can play a key role here in supporting adults to increase their knowledge and understanding of services and ensuring appropriate access alongside supporting adults to increase their protective factors and in having their voice heard.

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.

## **5. Findings**

The following findings are drawn from an analysis, as identified above, 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.

### **5.1 Referrals**

The data indicates that 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, 8 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.

### **5.2 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. Some had a formally diagnosed learning disability although this was not always the case but all of the women experienced some difficulty with their cognitive functioning to varying degrees. Alongside the learning disability women often had a dual diagnosis including autism spectrum condition or a range of mental health problems, including depression, anxiety, post-traumatic stress disorder and unstable personality disorder. In terms of age there was a fairly broad spread of ages ranging from early to mid-twenties through to mid-sixties, although this was not always formally recorded (due to GDPR regulations) in the women's files and we did not ask women this as a matter of course. Staff, however, provided details of ages of the survivors where requested.

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 parent. There were a range of care arrangements in place and the majority of the women did not have their children or all of their children living with them at the time of the interview. In some cases, there were kinship care arrangements in place and other children were being looked after by foster carers. A number of the women had had more than one abusive partner and had children with different partners.

What was striking about these women and their families was the complexity of their situations. While all of the women had been referred to the Survivors project because of concerns about domestic abuse they presented with a range of very complex issues that they often required support with. The women generally experienced disadvantage and were often in poverty, in debt or without access to the relevant welfare benefits. Women reported that they had experienced homelessness and a number of them had spent time in shelters or other forms of temporary accommodation. Their lives were often characterised by multiple house moves and they often lived in poor-quality housing or in areas where they had experienced problems with neighbours or other anti-social behaviour in the local neighbourhood. Many of the women had experienced or were experiencing alcohol or other substance misuse and for some of the women they had partners who had experienced similar issues.

The women often found their children subject to child protection measures and as mentioned above several did not have their children living with them. Often support was required to enable the women to navigate their way through the child protection system. Even in cases where child protection was not an issue there were often complex legal situations involving custody and access issues. A number of the women who had their children living with them reported that they were experiencing difficulties with the education system and that their child was having problems at school. There were reports of children and young people of survivors with their own mental health issues and some were receiving support from Child and Adolescent Mental Health Services as well as a range of third sector organisations.

The women that we interviewed often reported feeling lonely and isolated. This was a result of a range of different factors but often related to fear of leaving the house for fear of seeing their abuser or moving to a different area to which they had little connection, friends or family. Others felt that the mental health issues they had experienced made it more difficult for them to get out and spend time with other people. Many of the women expressed a desire to develop their social networks by joining clubs, volunteering or finding employment. None of the women we interviewed held paid employment at the time of the interview although several of them expressed a wish to do so or had done so in the past.

### **5.3 Contextualising the abuse experienced**

We asked each of the women to tell us why they had been referred to the project. They did not always immediately talk about their experiences of abuse although when they felt more comfortable they shared a great deal of information about their lives. All of the women had experienced abuse of one kind or another with the most common being physical, sexual, financial and psychological abuse. Often the women were subject to a combination of types of abuse within their relationship. 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. That is not to say that women did not have on-going difficulties and contact with their former partners and a great deal of work was done to support women to develop strategies to keep themselves safe. A majority of the women indicated more than one abusive relationship, whether that was romantic or familial.

All of the women could remember with great clarity the date on which they had left their partner and the reason for this. For some women this was a result of police intervention which resulted in the arrest and subsequent imprisonment of their partner. Others reported feeling great fear for their safety and even for their life and described this as a tipping point which resulting in them fleeing the situation and seeking support from organisations such as Women's Aid. For others child protection concerns and the potential for social work involvement and the risk of losing their child or children resulted in the ending of the abusive relationship. Some of the women had left the abusive relationship relatively recently but a small number of women reported instances of historic abuse from which they were still traumatised and were now receiving support for the first time. In advocacy partner 1's case, the abuse she had experienced took place some time ago and she had recently built up the courage to report this, although this did not have the outcome she had hoped for:

*To let you understand when I reported my sexual abuse to the police my son's dad got taken in, interviewed and he denied it. So they came back to me and said there was nothing they could do as there wasn't enough evidence and that kind of threw me back, it took a lot for me to talk about that and bring it back up after all those years and you say to yourself is it worth it going through all that heartache and speaking about it if they come back and tell you they can't do anything about it. (Advocacy partner 1)*

Perhaps the most significant finding was the pervasive nature of the abuse reported by the women. For many the abuse started in childhood and often progressed to a series of abusive relationships in adulthood. In one particularly powerful example, Advocacy Partner 2 described an early childhood memory where her mother used her as a shield to defend herself from her father. Since her teenage years Advocacy Partner 2 has moved from abusive relationship to abusive relationship, a pattern that has been fairly common amongst those we interviewed. The chronology of the relationships was often complex and difficult to follow reflecting their often turbulent nature of relationships and many of the women reported leaving and returning to relationships on multiple occasions. For those women with children, their attempts to create distance were at times hampered by the need to facilitate contact between the children and their father.

There was a sense among the participants that abuse was something that they had normalised with Advocacy Partner 3 telling us that *"I know everyone gets abused"*. Often participants had only ever known abusive relationships and so had few positive relationships to compare with. As a result, they found it difficult to spot the signs of abuse and several had limited awareness that they had been experiencing abuse prior to working with the project. This is highlighted in the quote below from Advocacy Partner 4:

*I had no idea where to go. I went to Women's aid and went in and spoke to them and told her what had been happening to me and she said did you know you have been emotionally, mentally and sexually abused, I didn't even know.*

Those who had children identified their concern about the potential impact that witnessing domestic abuse might have on them. Some spoke to us about the support their children were receiving both at school and from other agencies to support their children with the trauma of experiencing abuse even second hand and the impact of this on their development.

#### **5.4 What has the response been?**

The support provided by the staff team was comprehensive and reflected the complex range of issues presented by the women. There were two members of staff in the project and they were supported by their manager. Both staff members had ten women each on their case load at the time of writing, although this figure was higher throughout the first year of the evaluation. They offered a flexible and responsive service and were available to meet the needs of each woman that they worked with on a regular and consistent basis. There was recognition that at certain points in time more intensive support and contact was needed but on average our review of case files and data from the interviews suggested that women were seen on average once a week. It was evident that more intensive input was provided around specific events or crisis, e.g. preparation for and attending children's hearings or other court appearances.

An overarching theme with regard to the support provided were the contextual issues surrounding the abuse as noted above. 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 often 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.

*And that's okay because it was just one of these situations, it was like a domino effect one issue led into the next. The original issue we didn't deal with so have to go back and deal with that this afternoon. Sometimes it's the window of opportunity and you have to be flexible and deal with the thing that's most important to that person at that time and sometimes you have to put other stuff to the side, even if we think its more important like the abuse and dealing with the impact of that. (Advocate 1)*

*...you've got to work and try and resolve them or support the person to resolve them before you can deal with the domestic abuse and I think that's all part of building up the relationship. I'm just thinking about advocacy partner... and its very much its dealing with stuff like housing and the debt she's in, they are all part of the effects of domestic abuse... (Advocate 2)*

When the staff began working with a new advocacy partner there were a number of key activities that were carried out after ensuring that the women met the project eligibility

criteria, were safe and not in immediate danger. While there was no “typical case” we have been able to identify a number of different types of support that was provided.

## 1) Education

As discussed above many of the women who were referred to the project did not have a good understanding of what abuse was and because of negative experiences they have had in the past they were not always aware that they had been abused or were in an abusive relationship at present. Therefore, an important part of the role was providing education about abuse to provide women with the knowledge, information and experience they needed 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 by staff to introduce this complex area for survivors and this appears to have been well received. There were, however, significant challenges in this work for staff:

*Most of our partners, its very hard for them to understand domestic abuse, some of them don't use that word. (Advocate 1)*

*They are not violent to me, therefore its not abuse, I think it is useful having concrete examples but sometimes it can be limiting, so if its about money – no he doesn't do that so I'm not abused. Trying to explain that there are lots of different forms of abuse can be challenging, particularly controlling behaviour. (Advocate 2)*

The key difference noted within this project was CAP's relationship based model of advocacy, which meant that staff had the time to work with survivors for however long it took them to understand the different types of abuse and harm and the implications for them of remaining in contact or in relationships with perpetrators of abuse. In addition, the ability to work with women in a flexible way meant there was greater scope to support women to deal with the range of complex and difficult issues faced.

The survivors indicated that they felt much clearer about what constituted abusive behaviour and were able to provide examples when asked. Interestingly, there was significant discussion of psychological abuse or coercive control during the interview process, perhaps more so than the clearly pervasive physical or sexual abuse.

*He controlled me, always telling me wit tae dae and where to go, didnae want me seein other folk...it messed wi ma head, still does. I know that's no on anymore. (Advocacy Partner 5)*

## 2) Keeping safe and ending abusive relationships

Related to this, an important part of the role involved working with the women to develop safety plans so that they could keep safe in the future. Often 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. It might also involve ensuring that women could contact the local police at the touch of a button. Sometimes it was simply introducing the women to the idea that they could leave their partners and be okay. Other examples included providing information about blocking or changing mobile phone numbers or helping devise strategies to cope when bumping into a former partner or their family members in the local community. The impact of this is illustrated in the quote below.

*(Staff member) suggested changing my phone number, but I had to wait till I got money to do it so it was the next week. But I just kept blocking his number, that's what she said to do he hasnae got ma new number thankfully so he can't keep trying to control me. (Advocacy Partner 6)*

*Social Work said If you can stay away fae him, you can get unsupervised contact you can get contact at the house and it just clicked, something clicked and I've been doing really well...(staff member) was helping me to see that it was possible to do it. (Advocacy Partner 7)*

### 3) Advocacy

A central component of the role involved supporting women to navigate their way around the complex array of services and professionals that were involved in their lives or more often their children's lives. An analysis of our interviews with women and professionals and a review of case files show that all of the women we spoke to had multiple professionals in their lives. These included lawyers, women's aid or other organisations who provide support for those who have experienced domestic abuse, medical professionals including GP's, psychologists and community mental health nurses, social workers, police and education staff. Where women had a child or multiple children the number of professionals involved was likely to be even higher.

Often the women needed help to co-ordinate and attend meetings with the various professionals involved in their lives. They also needed help to translate the often complex and inaccessible material and information found in various reports and official documentation. Particularly high levels of support were required to help navigate the child protection system as well as help to negotiate custody and divorce proceedings with lawyers.

*She goes through the paperwork and explains things to me. If I've been to a big meeting and don't understand things, then she can explain it to me. She is good at helping me to understand what things mean. (Advocacy partner 4)*

*I was also trying to get my kids back cause I was in a better place. I wanted to go to a lawyer but I'd been to so many and they weren't listening to me it wasn't working they weren't taking my side so I thought I needed someone to come with me. I need someone to make my case and get (staff member) to explain what they lawyer*

*was saying to me cause they use all these fancy words and you think speak English.  
(Advocacy partner 8)*

Other areas where particularly sensitive support was required involved supporting women to prepare for court hearings where they may have had to testify against their abuser. Advocacy support was particularly effective in ensuring that women had their voices heard in these difficult and challenging circumstances. Often the advocacy staff acted as a bridge between the women and the other professionals involved and this appeared to be an effective way of helping to develop relationships between the women and other professionals. A number of women noted that they were taken much more seriously when their advocate was present.

Another important aspect of the advocacy task was the support provided to the women to develop their communication and engagement skills. This involved supporting the women (many of whom had very low or damaged self-esteem) to develop the confidence to speak out and ensure their voices were heard. The women were also supported to build their relationships with other professionals, often resulting in better engagement and more positive outcomes. In a number of interviews, survivors discussed how they prepared written notes in advance of meetings to ensure they made all the points they wanted to make. In the quote below, Advocacy partner 1 describes her growing understanding of her rights:

*I've got a wee list, about my rights? Access to my grandson, and for like my social worker and them to listen to me.  
(Advocacy partner 1)*

A final area of importance was the ability to refer onto other more relevant services. Staff have clearly worked hard to ensure good partnership working with other services in the area, e.g. Women's Aid and Committed to Ending Abuse to be able to advise and empower their advocacy partners about where to go next.

#### 4) Developing social networks

As mentioned earlier, many of the women spoke of the loneliness and isolation that they faced and how this impacted on their confidence and self-esteem. It could also be argued that this isolation made it more likely that they would return to abusive situations where they could have the company of others, even if it was abusive. They emphasised to us in the strongest terms how much they valued the social support and company that the staff from the Survivors project provided them with. They valued having someone who was in regular contact with them and several spoke of wishing to spend more time with their advocacy worker – even at times when there were no specific issues to work on. For several of the women we spoke to, the relationship they had developed with their advocacy worker was their first experience of a trusting relationship.

*I think the friendship, the understanding and the easiness to talk to (staff member) about anything, I can say anything and she can give me advice or speak to*



*this person or that to sort it out. To have someone else that believes in me and understands me and doesn't judge me is the biggest part for me. (Advocacy partner 8)*

*Her coming to see me and that... having somebody to talk to because you get lonely just sitting in the house by yourself and (daughter) not in the house all the time so I get lonely, (staff member) makes all the difference. (Advocacy partner 5)*

An important part of the advocacy worker's role involved supporting people to identify a range of networking opportunities within their local communities. These opportunities varied according to the individual's needs and interests. Several of the people we interviewed spoke of their desire to get a job and this was something their advocacy worker was helping them to look into. Others had joined local community groups or had accessed support groups for people with similar experiences. Prior to receiving support from the Survivors project many of the women had reported feeling uneasy about spending time in the local community, with several having been subject to bullying and harassment:

*What happened was it was somebody who had, this neighbour she just turned on me and I was walking down the street and she was shouting are you a prostitute like her and I was like what's going on here...so I had went to the first court case and then she got put on, what's it called, like she wasn't allowed to go somewhere, she wasn't allowed to go on our street (Advocacy partner 5)*

## 5) Practical support

The advocacy workers also provided help with a range of very practical tasks such as supporting the women to develop their cooking or home-making skills or offering support with budgeting and so on. The staff did not necessarily provide this practical help themselves but were able to support the women to access this help from a range of appropriate sources in their local community. This approach could also potentially help in reducing the isolation noted above. Information was often also sought and provided around the impact of social media on the survivors. There were many examples provided of survivors being contacted by their ex-partner(s) and/or their family members via Facebook or other social media platforms in a negative and bullying manner. The support provided to block contacts on these platforms clearly enhanced feelings of safety of the survivors and prevented their confidence being eroded. The impact of one particularly harrowing example of abuse by social media is provided below.

*I don't go out during the day, I do my shopping and walk the dog at night, Ahm fear to see my neighbours, everybody knows what's being said about me, some of it by my own family. If it wasn't for (staff member) to help me I don't know what I would do. (Advocacy Partner 9)*

### 5.5 What makes the support different?

When the Survivors project was first envisaged, it was in response to a perceived gap in service provision for women with learning disabilities who have been affected by gender based violence. One of the main aims of the evaluation therefore was to establish what made the support provided by project staff different to that women might have gotten elsewhere. Perhaps the thing that stands out most is the positive relationships that the staff have developed with the women. Developing trusting relationships with women many of whom have experienced abusive relationships throughout their lives is a highly skilled role. There is clear evidence in the case notes, interviews with women and with other professionals that building these relationships has taken patience, hard work, flexibility and understanding. There are many examples in the case files where staff had gone to visit women for them not to be home or to have forgotten they are coming but this was not of detriment to the growing relationship and did not result in the service being withdrawn.

Staff have needed time 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. There was clear acknowledgement that the level of support and intervention needed required longer-term and often intensive support. Staff from the project felt that they were in a good position compared to statutory service providers. Indeed, other services in the local area acknowledged that they did not have the capacity to work with women in this intensive way and evidence from professional and staff interviews suggests that often staff from other projects did not feel that they had the requisite skills or expertise to work with people with learning disabilities. The staff from the Survivors project it was noted 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. We are not aware of any other organisation that does this.

*For people like myself it can take a long time to get over what's happened, their experiences and trauma, that won't go away quickly enough. If I didn't have (staff member) I wouldn't cope very well at all. (Advocacy partner 9)*

## **5.6 Ongoing need for the project**

All of the participants that we have spoken to – both women who had used the service and other professionals - agreed unanimously that there was an ongoing need for the service. Advocacy partner 2 expressed this very powerfully when she said:

*...my confidence was shattered, (he) really shattered my confidence, really shattered, I wasn't like this when I came in here on the 7<sup>th</sup> of January, I was like a scared wee lassie and I'm no a scared wee lassie any more...it's done wonders for me (Advocacy partner 7)*

As mentioned above the unique combination of the relationship based model of advocacy, expertise and skills 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. Gender based violence services across the country have been subject to significant cuts as a result of austerity measures (Fawcett Society, 2012) and the services that remain do not have the resources to work with women in this time intensive way.

*The Survivors Project is a crucial resource in this area. Giving support at a pace that is right for them and coming from a place of understanding. (Professional 2)*

*Survivors with learning disabilities are more likely to have experienced abuse throughout their lives but it becomes normalised and therefore not seen as inappropriate or abusive. That's the key bit for the survivors' project. Other projects often don't understand that; they only work with people seeking support for domestic abuse, if you don't know its abusive in the first place how do you seek that support. That's the significant difference, no one else is doing this work. (Professional 1)*

There are also significant issues with communication for many of the women who have been supported by the project and other projects in the area have been unable to meet the specific needs of people with learning disabilities. 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.

*They use different ways to communicate; this is so important for survivors with learning disabilities, many of whom have low literacy skills. Visual communication is as important as written and the Survivors Project staff understand that (Professional 1).*

One further issue raised by project staff that focused on awareness raising was a concern that services often placed all the responsibility for keeping children safe on the mother with learning disabilities, rather than on the abusive father or on them as a couple with shared responsibility.

*And what astonishes me is this notion that it's only the women's responsibility to keep herself safe and her family safe but we should be focused on the man's abusive behaviour we need to be looking at that. Women with learning disabilities shouldn't be expected to be the one responsible for his behaviour. That was a parenting choice that he made to behave that way in front of his children. (Manager 1).*

The view expressed consistently by staff and other professionals was that raising awareness of the key issues outlined above was crucial in ensuring greater equality of access and support for survivors with learning disabilities.

## **5.7 Model of Advocacy**

What becomes clear from the findings outlined above is that the model of advocacy developing 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 and should be acknowledged as unique. It will be useful in the next two years to more fully explore the parameters of this model of advocacy.

### **5.8 Adult Support and Protection (Scotland) Act (2007)**

The evidence generated through the evaluation suggests that many of the women could be considered to meet the three-point test within the Adult Support and Protection (Scotland) Act (2007). It was interesting, therefore, to note that it appeared that none of them had been supported via this protective mechanism. The professionals interviewed felt that this could be due to different variations of interpretation of the three-point test and that the survivors simply did not meet the threshold for intervention under the Act. This will also be a useful area for exploration in year 2 of the project as this legislation is in place specifically to support adults considered unable to protect themselves from harm.

### **5.9 Staff Support, Workload and Future Development**

As noted above, the complexity and longevity of cases has meant that the number of cases for each member of staff less than was originally anticipated (n=15 per staff member). However, the number of referrals received (n=32) have been in line with what was expected. It is important to note that even when a case was not taken on (for example if the women did not meet the project's eligibility criteria), staff spent time working with all women referred in order to understand more about their issues to refer them on to other more appropriate services.

In reviewing the case files, it is difficult to envision a timeframe for the closure of some of cases and this makes consideration of increasing workloads very challenging and is likely to reduce the overall numbers reached by the project in the remaining two years. The staff and the project manager/s have worked together to ensure clear support for each other in dealing with these often intensive and harrowing cases 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 recorded supervision sessions also take place to ensure the opportunity to unpack any issues identified by staff.

Recently the project manager contacted the funder to indicate a reduction in the projected numbers each year from 15 to 10 to ensure staff did not feel pressured to increase workloads inappropriately and potentially reduce the quality of the service being provided. This is a further area for consideration in year 2 of the evaluation.

We explored possible future developments for the project with all of the participants. Aside from the obvious concern that the project continued to be funded securely on a long term basis, other suggestions 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 support model. This would also contribute to the development of individual skills and promote self-confidence. 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.

## **6 Conclusion and Plan for Year 2 of the Evaluation**

It is evident from the above data, that much has been achieved in the first full year of the project's operation. 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 including custody and contact arrangements with children, finance and benefits issues and accessing relevant support services. There has also been a clear challenge for staff in managing the complexity of issues experienced by survivors and the longevity of support required. These two issues have reduced the overall number of survivors with which the project aimed to work.

In returning to the original evaluation questions, the following can be noted:

- 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?

The evidence available from the on-line survey and the referrer and professional interviews suggests both a need for the project and 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. They were also very positive about the experience of working with the project overall 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. As noted however, more robust data collection from referrers is required in year 2 to ensure this evidence is consolidated.

- What benefits do adults who have been referred to the service report?

The evidence suggests that survivors note a number of clear benefits from working with the project. An increase in their self-confidence and self-esteem, greater understanding of abuse and its impact was noted in case files and interviews. This has been linked to increased feelings of self-worth and the extent to which survivors are prepared to 'put up' with negative experiences for themselves and their children. Having their voices heard is a key theme in the evidenced generated, this is particularly the case in formal settings, e.g. meetings with lawyers, social workers and other professionals, this also added to feelings of being taken seriously rather than dismissed via diagnostic overshadowing as noted above. The advocate/partner relationship was also identified as a key benefit for survivors, not simply in formal settings as noted but in aiding to break down isolation and loneliness.

- What have been the key challenges and opportunities for those delivering the service?

A key challenge for the delivery of the service is as noted above 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 with 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.

Year 2 of the evaluation will therefore focus on expanding the above evidence base and explore the longitudinal impact of the project's intervention on the survivors themselves. As noted above, there will also be a focus on increasing the evidence from those who have directly referred to the project to aid in triangulating the data provided by the project staff and the survivors themselves to enhance robustness, alongside a further exploration of the parameters of the model of advocacy, the use of the ASP and the impact of complexity and longevity on the future model of provision.

## **Proposed Workplan 2019/2020 Year 2**

- November 2019 to February 2020 Updated literature review focusing on outcomes of childhood sexual abuse for adult development and behaviour, incidence of multiple abusive partners and learning disability, dual diagnosis and domestic abuse, use of ASP with survivors with learning disabilities and identifying any recent papers to add to initial review.
- November 2019 – Meeting with Project Staff to agree timetable and final focus for Year 2
- December 2019 – development of additional research instruments
- January 2020 – Staff interviews
- March to May 2020 - Data collection (mechanism to be agreed) with referrers to identify key issues and positive outcomes from cases to date, these can be cross referred to case file reviews
- April/May 2020 – Production of update summary for Big Lottery annual report
- April to July 2020 – Follow up interviews with survivors/ additional interviews with new cases, transcription and analysis of interviews.

- April to July 2020 – Case file reviews as required
- July to September 2020 – Compilation of 2<sup>nd</sup> year report
- October 2020 – Submission of year 2 report.

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## **APPENDIX 1: Information sheets and consent forms**



**CENTRAL ADVOCACY PARTNERS**

### **Participant Information Sheet: Central Advocacy Partners, Survivors project - Staff**

**Name of Project:** Evaluation of the Survivors Project

You are being invited to take part in a research study. This information sheet explains why the research is being done and what taking part will involve. Please read the following information carefully and discuss it with others if you wish. Take time to decide whether or not you wish to take part. Thank you for reading this.

#### **What is the Purpose of the study and who is organising it?**

The aim of the study is to find out what your experience of working within the Survivors project has been and to establish any challenges for future development. It is being undertaken by Dr Gillian MacIntyre (University of Strathclyde) and Dr Ailsa Stewart, who are both experienced researchers and who have worked for over 20 years with people with learning disabilities.

#### **Why am I being invited to take part in this study?**

You are being invited to take part in this study as you have worked within the project as a member of staff or are involved in the development of the project.

#### **Do I have to take part?**

It is up to you whether you want to take part. You do not have to give a reason if you do not want to be involved.

#### **What will happen to me if I take part? What do I have to do?**

Taking part in the study will involve being interviewed for approximately one hour. The interview will take place in CAP's premises. If you agree, the interview will also be audio recorded. All the information you give will be kept confidential. You will be asked to sign a consent form and given a copy to keep.

### **Expenses and Payments**

No payment for time will be provided to you in addition to your normal remuneration.

### **Will my taking part in this study be kept confidential?**

Your taking part in the research will be confidential. Your name and other personal details will not be included in the writing up of the study. Quotations may be used but you will not be identified by name. The recordings will be kept securely and destroyed after the reports or any articles that might come from the research have been published.

### **What are the disadvantages and risks of taking part?**

Sometimes talking about your experience of working within the project may be distressing for you. If this happens we can stop the interview if you wish. We can also direct you to speak to someone for additional support if this would be helpful.

### **What are the possible benefits of taking part?**

The study may help you with reflecting on your experience and taking part will ensure that you have contributed to the development of the project and possibly improve the experience of people who use the project in the future.

### **What will happen if I don't want to carry on with the study?**

If you change your mind and decide that you no longer want to take part in the study, you can withdraw at any time.

### **What if I want more information about the study?**

If you have any questions about any aspect of the study or your participation in it, please contact the researchers:

Dr Gillian McIntyre  
[Gillian.mcintyre@strath.ac.uk](mailto:Gillian.mcintyre@strath.ac.uk)

Or

Dr Ailsa Stewart  
[Ailsa.e.stewart@gmail.com](mailto:Ailsa.e.stewart@gmail.com)



## **Central Advocacy Partners**

### **Consent Form for Project Staff Evaluation of the Survivors Project**

- I confirm that I have read and understood the information sheet for the above project and the researcher has answered any queries to my satisfaction.
- I understand that my participation is voluntary and that I am free to withdraw from the project at any time, without having to give a reason and without any negative consequences for myself.
- I understand that I can withdraw my data from the study at any time.
- I understand that any information recorded in the investigation will remain confidential and no information that identifies me will be made publicly available.
- The only exception to this would be if information is disclosed related to serious harm or immediate danger, in which case the researcher would need to pass along this information
- If this should happen, the researcher would discuss this with me at the time.
- I consent to being audio recorded
- I consent to being a participant in the project

<b>Name</b>	
<b>Signature</b>	
<b>Date</b>	



## CENTRAL ADVOCACY PARTNERS

### **Participant Information Sheet: Central Advocacy Partners, Survivors project – Project Referrers**

**Name of Project:** Evaluation of the Survivors Project

You are being invited to take part in a research study. This information sheet explains why the research is being done and what taking part would involve. Please read the following information carefully and discuss it with others if you wish. Take time to decide whether or not you wish to take part. Thank you for reading this.

#### **What is the Purpose of the study and who is organising it?**

The aim of the study is to find out what your experience of working with the Survivors project has been as well as gathering your perspective on the outcomes for those you referred to the project. It is being undertaken by Dr Gillian MacIntyre (University of Strathclyde) and Dr Ailsa Stewart, who are both experienced researchers and who have worked over 20 years with people with learning disabilities.

#### **Why have I been invited to take part in this study?**

You have been invited to take part in this study as you have referred someone to the CAP Survivors Project.

#### **Do I have to take part?**

It is up to you whether you want to take part. You do not have to give a reason if you do not want to be involved.

## **What will happen to me if I take part? What do I have to do?**

Taking part in the study will involve completing a short online survey. The survey is anonymous and you do not have to provide any personal details. However should you be willing to take part in a short telephone interview upon completion of the survey, you will be asked to provide further contact information. If you agree to be interviewed, the interview will be audio recorded with your permission. All the information you give will be kept confidential. You will be asked to sign a consent form and given a copy to keep.

## **Expenses and Payments**

There is no payment for taking part in this research.

## **Will my taking part in this study be kept confidential?**

Your taking part in the research will be confidential. Your name and other personal details will not be included in the writing up of the study. Quotations may be used but you will not be identified by name. The recordings will be kept securely and destroyed after the reports or any articles that might come from the research have been published.

## **What are the disadvantages and risks of taking part?**

There are no major risks associated with this research.

## **What are the possible benefits of taking part?**

It is hoped that the results of this evaluation will inform future practice and service development and delivery.

## **What will happen if I don't want to carry on with the study?**

If you change your mind and decide that you no longer want to take part in the study, you can withdraw at any time.

## **What if I want more information about the study?**

If you have any questions about any aspect of the study or your participation in it please contact the researchers directly:



Dr Gillian McIntyre  
[Gillian.mcintyre@strath.ac.uk](mailto:Gillian.mcintyre@strath.ac.uk)

Or

Dr Ailsa Stewart  
[Ailsa.e.stewart@gmail.com](mailto:Ailsa.e.stewart@gmail.com)



## **Central Advocacy Partners**

### **Consent Form for Project Referrers Evaluation of the Survivors Project**

- I confirm that I have read and understood the information sheet for the above project and the researcher has answered any queries to my satisfaction.
- I understand that my participation is voluntary and that I am free to withdraw from the project at any time, without having to give a reason and without any negative consequences for myself.
- I understand that I can withdraw my data from the study at any time.
- I understand that any information recorded in the investigation will remain confidential and no information that identifies me will be made publicly available.
- The only exception to this would be if information is disclosed related to serious harm or immediate danger, in which case the researcher would need to pass along this information
- If this should happen, the researcher would discuss this with me at the time.
- I consent to being audio recorded
- I consent to being a participant in the project

<b>Name</b>	
<b>Signature</b>	
<b>Date</b>	



## CENTRAL ADVOCACY PARTNERS

### **Participant Information Sheet: Central Advocacy Partners, Survivors project – Project Professionals**

**Name of Project:** Evaluation of the Survivors Project

You are being invited to take part in a research study. This information sheet explains why the research is being done and what taking part would involve. Please read the following information carefully and discuss it with others if you wish. Take time to decide whether or not you wish to take part. Thank you for reading this.

#### **What is the Purpose of the study and who is organising it?**

The aim of the study is to find out what your experience of working with the Survivors project has been as well as gathering your perspective on the outcomes achieved. It is being undertaken by Dr Gillian MacIntyre (University of Strathclyde) and Dr Ailsa Stewart, who are both experienced researchers and who have worked over 20 years with people with learning disabilities.

#### **Why have I been invited to take part in this study?**

You have been invited to take part in this study as you have an awareness of the work of the CAP Survivors Project.

#### **Do I have to take part?**

It is up to you whether you want to take part. You do not have to give a reason if you do not want to be involved.

### **What will happen to me if I take part? What do I have to do?**

Taking part in the study will involve participating in a short telephone interview. The interview will take between 20 and 30 minutes. If you agree to be interviewed, the interview will be audio recorded with your permission. All the information you give will be kept confidential. You will be asked to sign a consent form and given a copy to keep.

### **Expenses and Payments**

There is no payment for taking part in this research.

### **Will my taking part in this study be kept confidential?**

Your taking part in the research will be confidential. Your name and other personal details will not be included in the writing up of the study. Quotations may be used but you will not be identified by name. The recordings will be kept securely and destroyed after the reports or any articles that might come from the research have been published.

### **What are the disadvantages and risks of taking part?**

There are no major risks associated with this research.

### **What are the possible benefits of taking part?**

It is hoped that the results of this evaluation will inform future practice and service development and delivery.

### **What will happen if I don't want to carry on with the study?**

If you change your mind and decide that you no longer want to take part in the study, you can withdraw at any time.

### **What if I want more information about the study?**

If you have any questions about any aspect of the study or your participation in it please contact the researchers directly:

Dr Gillian McIntyre

[Gillian.mcintyre@strath.ac.uk](mailto:Gillian.mcintyre@strath.ac.uk)

Or

Dr Ailsa Stewart

[Ailsa.e.stewart@gmail.com](mailto:Ailsa.e.stewart@gmail.com)



**Central Advocacy Partners  
Consent Form for Project Referrers/Professionals  
Evaluation of the Survivors Project**

- I confirm that I have read and understood the information sheet for the above project and the researcher has answered any queries to my satisfaction.
- I understand that my participation is voluntary and that I am free to withdraw from the project at any time, without having to give a reason and without any negative consequences for myself.
- I understand that I can withdraw my data from the study at any time.
- I understand that any information recorded in the investigation will remain confidential and no information that identifies me will be made publicly available.
- The only exception to this would be if information is disclosed related to serious harm or immediate danger, in which case the researcher would need to pass along this information
- If this should happen, the researcher would discuss this with me at the time.
- I consent to being audio recorded
- I consent to being a participant in the project

<b>Name</b>	
<b>Signature</b>	
<b>Date</b>	



CENTRAL ADVOCACY

**CENTRAL ADVOCACY PARTNERS**  
Evaluation of the Survivors Project



You are being invited to take part in a research study.  
This sheet explains why the research is being done and what taking part would mean for you.  
Thank you for reading this.

**Why are we doing the study?**

We want to find out what working with the Survivors project has been like. Central Advocacy Partners have asked Dr Gillian MacIntyre (University of Strathclyde) and Dr Ailsa Stewart to do the study.



**Why  
invited  
this**



**have I been  
to take part in  
study?**

You have been invited to take part because you have worked with Nia or Maggie.



**Do I**



**have to take part?**



It is  
part.

You don't have to tell us why you do not want to be involved.

If you don't want to take part, the service you get from Central Advocacy Partners won't be affected.

up to you if you want to take

**What happens if I agree?**



You will be asked to take part in an interview that will last for about half an hour.

The interview will take place in the CAP office, if that suits you best.

If you agree, the interview will be audio recorded.

You will be asked to sign a consent form and given a copy to keep.

## **Expenses and Payments**



We will be able to cover your travel costs. We do not give any other payments for taking part in the research.

**Will my taking part in this study be kept confidential?**





Anything you tell us will be kept confidential. This means no one except the researchers will hear what you say.

Your name and other personal details will not be included in the report.

Recordings will be kept safe but will be destroyed after the reports are finished.

The only time we might have to tell someone what you say is if we think that you or someone else is at risk of serious harm. We will always talk to you first. This is about keeping you safe!



**Are there risks in**

**taking part?**



Sometimes talking about your experiences of working with the project might make you feel upset.

You can stop the interview at any time. We can also give you information about other support that is available.

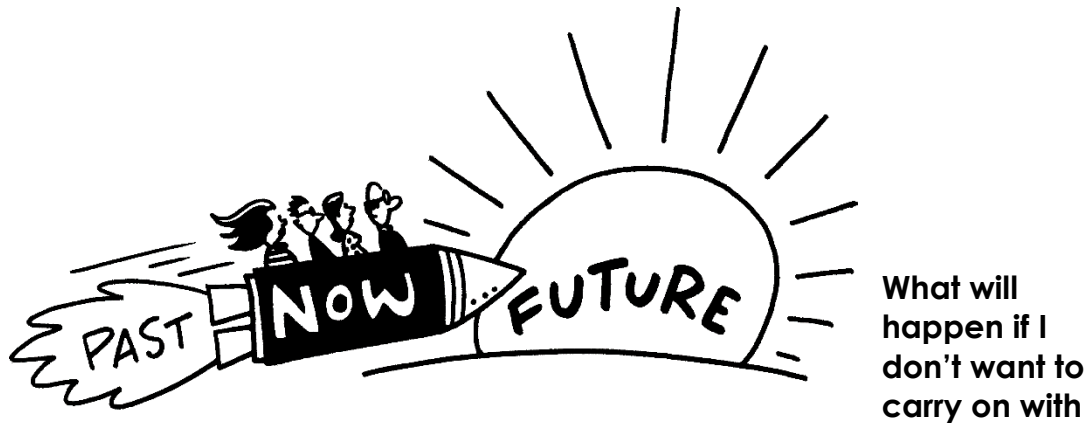
**Are there benefits in taking part?**



Some people might enjoy talking about

their experiences or the support they have had.

Taking part might help improve services for other people in the future.



**the study?**

If you change your mind, you can stop taking part at any time. No services or supports will be affected by your decision not to take part.

### **What if I want more information about the study?**

If you have any questions about anything about the study or taking part, please contact

Gillian [gillian.macintyre@strath.ac.uk](mailto:gillian.macintyre@strath.ac.uk)

Or Ailsa [Ailsa.e.stewart@gmail.com](mailto:Ailsa.e.stewart@gmail.com)



**CENTRAL ADVOCACY PARTNERS**  
Evaluation of the Survivors Project



**CONSENT FORM**

I have information about the work and been able to ask questions.

I know it is my choice to take part and I can stop at any time.

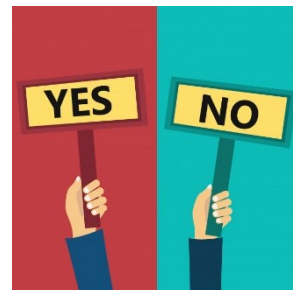
I know that my name won't be mentioned and people won't know what I said.



I know that if Gillian or Ailsa think I am in danger they might have to tell someone. I know they will tell me this first.



I agree to be recorded.  
I agree to take part.



<b>Name</b>	
<b>Signature</b>	
<b>Date</b>	