



Advancing Practice-Relevant Research for Survivors of Intimate Partner Violence with Disabilities A Research-to Practice Fellowship Project

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Center for Victim Research

The <u>Center for Victim Research</u> (CVR) is a one-stop resource center for victim service providers and researchers to connect and share knowledge. Its goals are to increase 1) access to victim research and data and 2) the utility of research and data collection to crime victim services nationwide. CVR's vision is to foster a community of victim service providers and researchers who routinely collaborate to improve practice through effective use of research and data.

Accordingly, CVR engages in a number of training and technical assistance activities to support victim research-and-practice collaborations. Specifically, CVR:

- Hosts a library of open-access and subscription-based victim research;
- Provides light-touch research-focused technical assistance to victim service providers;
- Translates research findings for the field in fact sheets, reports, and webinars; and
- Highlights useful research-and-practice tools and training resources for the field.

CVR also supports two types of <u>researcher-practitioner collaborations</u>: interagency VOCA-SAC partnerships and local-level Research-and-Practice (R/P) Fellowships. In 2018, CVR's R/P Fellowship program supported nine teams of researchers and practitioners engaging in a variety of victim-focused research projects. Fellows were engaged in emerging, ongoing, or advanced research-and-practice partnerships. This report describes activities by one of CVR's 2018 R/P Fellowship teams.

R2P Fellows: Organizational Descriptions

Barrier Free Living, Inc. (BFL) is a nationally recognized leader in working with survivors of intimate partner violence (IPV) with disabilities. The agency's mission is to support individuals with disabilities to live dignified lives free of all forms of abuse and bias. BFL consists of three programs serving individuals with disabilities: the Secret Garden, a non-residential domestic violence (DV) program; BFL apartments, providing permanent housing for survivors of IPV with disabilities; and Freedom House, a DV shelter for single individuals and their families. The first **fully** accessible shelter in the nation, FH offers private living spaces of various sizes to accommodate survivors and their children who are wheelchair users, D/deaf or hard of hearing, blind or visually impaired, and developmentally or intellectually disabled among other disabilities.

Stony Brook University (SBU) is a strong and well-resourced leading public university with over 1000 researchers and 1600 active sponsored projects. **The School of Social Welfare** is one of five professional schools along with Medicine, Dentistry, Health Technology and Management, and Nursing at the University's Health Sciences Center. Interdisciplinary research programs among the professional schools and the campus at large enrich the research mission. The School's mission is to build a more equitable society based on the values of human dignity, inclusiveness, diversity, equality, and on economic, environmental and social justice. Research conducted under the auspices of the School of Social Welfare is carried out to identify and minimize social determinants of health for vulnerable populations.

Description of the Problem

Women with disabilities are among the most vulnerable groups impacted by IPV, which includes physical, sexual, psychological, and economic abuse. They experience IPV at higher rates than nondisabled women and men, and men with disabilities (Breiding & Armour, 2015) and are more often subject to severe forms of physical violence, including being kicked, punched, or bitten (Brownridge, 2006). Women with disabilities also experience subtle forms of abuse exploiting aspects of disability, such as withholding medication, harming service animals or denying needed supports (Lund, 2011). The experience of abuse is compounded as women with disabilities remain in abusive relationships for longer periods of time than nondisabled women (Nosek, Howland, Rintala, Young, & Chanpong, 2001). While pioneering research conducted over the past twenty years has brought attention to the problem of IPV against women with disabilities, the state of research on this topic is still in its infancy (Hughes, Lund, Gabrielli, Powers, & Curry, 2011). This dearth of research has resulted in limited services, interventions, and policy initiatives for this underserved population.

Addressing the Problem

This Research-to-Practice Fellowship extended an existing researcher-practitioner partnership between Dr. Michelle Ballan of SBU and BFL. In 2012, Dr. Ballan initiated a collaboration with BFL's non-residential DV program, the Secret Garden, to conduct research with the aim of enhancing direct practice services at the agency and improving services for survivors with disabilities on a broader level both statewide and nationwide. The primary goal of this research was to develop a computerized database for the Secret Garden, using information extrapolated from almost 1000 handwritten client files. Drawing upon knowledge gained from this profile, Dr. Ballan assisted the Secret Garden with revising the agency's intake instrument, assessment forms, and treatment plans to better capture data that would be of greater use to program staff in determining clients' needs and the effectiveness of services provided. She likewise provided guidance as the agency transitioned from paper recordkeeping to a computerized system, allowing for more efficient retrieval of data for program evaluation and research purposes. Dr. Ballan's partnership with the Secret Garden provided a critical first step in a line of research on female and male survivors of IPV with disabilities, who are often isolated and can be difficult to reach.

For this Research-to-Practice Fellowship, the relationship between SBU and BFL was strengthened by expanding research activities to Freedom House (FH), BFL's DV shelter for survivors with disabilities. Extending SBU's research collaboration with BFL to include FH enabled the continuation of a partnership to inform the research regarding the profile of clients with disabilities who seek non-residential as opposed to residential IPV services and the development of culturally sensitive, research-informed practices for this neglected population. The project sought to build the research infrastructure at FH by helping practitioners learn to gather data in a systematic manner that would enhance their services and practices; assisting practitioners with revising intake and assessment instruments; and transitioning from paper recordkeeping to a computerized system.

FH provided the research site and client information for database development and analysis. Ms. Cynthia Amodeo, Chief Program Officer at BFL, supervised the practitioner team at FH. The research team at SBU trained FH practitioner staff in data collection and provided ongoing technical support and guidance. Together, the practitioners at FH and researchers from SBU identified relevant data to collect and research questions to explore that served to advance research-informed practice and practice-informed research addressing the needs of survivors of IPV with disabilities.

Since the project's commencement, communication and cross-training between the FH and SBU teams has been frequent. Dr. Ballan has met in-person with practitioner staff at FH multiple times and participated in 14 scheduled telephone conferences and zoom meetings with practitioner staff. Data collection trainings via Zoom videoconference occurred between Project Director Molly Freyer and data collection assistants on seven occasions. Dr. Freyer likewise checked in with practitioner staff via email on a weekly basis regarding progress made on data collection activities. These check-ins provided an opportunity for both teams to troubleshoot any data collection issues, provide technical support, and ensure consistent progress among data collection assistants. Additionally, practitioner staff have assisted new data collection assistants with training and orientation at FH on a number of occasions. Additional numerous meetings have occurred within each separate agency respectively, and hundreds of email messages have been exchanged to further delineate processes between the agencies.

The researcher-practitioner team determined that exploring the ways diversity and disability-specific factors impact the experience of abuse for individuals with disabilities was essential to ongoing knowledge and skill development for practitioners. There are limited mechanisms for collecting information regarding the profile and service needs of survivors with disabilities. Collecting resident data from FH provides useful information regarding specifics related to victim and perpetrator, disability-related risks and needs, and other aspects of the experience of abuse among individuals with disabilities that are not being captured. Furthermore, studying FH residents' files provides additional vital information regarding survivors seeking disability-accessible shelter services.

Variables of interest for analysis were identified in December 2018. FH provided relevant forms used in resident files opened between January 2012 and December 2018. Since some forms were updated and/or revised during this timeframe, the data collection form was created with the intent of capturing variables of interest in a manner that would be simple for practitioner staff gathering data. Both SBU and FH staff discussed variables of interest for data collection purposes. Data sought included clients' needs prior to arriving at FH and post-arrival; and examining differences based on relevant demographics such as disability type, the victim's need for assistance with activities of daily living, specific types of abuse perpetrated against victims with disabilities, and barriers to accessing assistance.

We prepared an IRB application for exemption review by the SBU Office of Research Compliance in December 2018; and submission occurred in January 2019 after SBU/CVR contract negotiations. Given that the data to be collected and analyzed for this project was already available in existing client records at FH, the SBU Office of Research Compliance determined that the project did not meet the definition of research involving human subjects according to the Common Rule; the proposal

therefore did not require approval by the IRB or exemption by the Office of Research Compliance.

Data Sources

Resident records from FH were analyzed for this project and the formulation of a client database was constructed based on these records. Cases opened during the date range of January 2012-December 2018 were reviewed. Information from resident records were input into one computerized data collection form, containing only information relevant to the study's goals and objectives regarding enhancing FH's services and strengthening its data infrastructure.

During a trial data collection period in March 2019, the data collection assistants provided feedback to the SBU research team regarding areas of redundancy on the data collection form, as well as highlighting which areas of focus were most important to their work as practitioners. Together, the SBU and FH teams edited the database for resident information to ensure it was both comprehensive in capturing the desired information while designed for efficient data collection. One data collection assistant noted concerns with the number of hours a folder would take her (3) if she was searching for information that she knew was there but not on designated forms that were not in the file. Intake and assessment forms utilized throughout 2012-2018 varied in structure and information obtained contributing to challenges locating information for the data collection assistants. To help with this task, another data collection assistant created a "cheat sheet" noting alternative forms where information could be found within resident files for certain variables if designated forms were missing. Additionally, at times, incomplete forms were included in case files due to the severity of the crisis at intake or a client's unwillingness or inability to answer certain questions.

Both teams discussed only entering exactly what was in the forms because there was insufficient time to search throughout the files for additional information. However, FH's new online system for recordkeeping developed and launched as a product of the grant, was designed with stop gaps to ensure all documents are fully completed at intake and assessment, even if the information obtained is "client uncertain." Intake and assessment forms were revised prior to data collection and will be further revised once data has been fully analyzed and additional information gaps are potentially revealed. The data collection team has been making note of common areas of missing information in resident files throughout the data collection process.

After the initial trial data collection period and revision of the database, data collection officially began in April 2019. Data collection activities and the demands of the emergency shelter initially conflicted at times. Recognizing this, the SBU and FH teams collaborated to identify additional data collection assistants who were able to conduct research after hours and on weekends. Three new data collection assistants joined the practitioner team in May, June, and July respectively, all vetted by FH and receiving extensive training from the SBU research team.

Results

Transition from paper record keeping to online computerized system: At a January meeting at FH, Dr. Ballan met with FH staff to discuss the additional components needed to launch a new online data collection system for both record-keeping and future research with SBU researchers. The online system, called FamCare, facilitated moving from paper records to a computerized system and went live on April 1, 2019 at FH. As of the end of August 2019, all basic case management functionality on FamCare has been adopted by FH clinical staff. The next several months will be spent implementing more of the advanced functionality and reporting modules. Records for over half of the current residents at FH are presently in FamCare. The work in progress includes identifying critical dates with department heads to ensure timely completion of all intake materials and assessments, and we have reduced redundancy across intake forms via the online system. FH will be testing packaged reports and submitting requests for modifications as necessary to Global Vision Technologies. In addition, advanced functionality like setting up business rules for document due dates to ensure timely completion of deliverables is being created.

Development of a database: A database consisting of over 200 variables has been created. Over 550 hours have been allocated to data collection among practitioner team members and data collection assistants. We have completed input for 307 files from 2014-2018. FH and SBU are committed to completing the data collection from files dating back to 2012.

Revised intake and assessment forms: Discussion of where missing data primarily occurred and why this occurred during intake and assessment led to a newly revised intake and assessment form which is also reflected in the FamCare database. Additional revisions will occur after all data has been collected and analyzed. Several meetings will occur with the researcher and practitioner teams to discuss the results of the analysis and how findings could inform needed changes to the wording of questions, ordering of questions, amount of information acquired and the timing of assessment.

Implications for Policy and Practice

As noted previously, there are limited mechanisms for collecting information regarding the profile and service needs of IPV survivors with disabilities. This is the first study of factors associated with IPV survivors seeking disability-accessible shelter services. We plan to disseminate the project's findings to enhance disability inclusion practices at both IPV and non-IPV focused shelters.

The information gained lays the foundation for future research endeavors with SBU and BFL in the interest of advancing the evidence base for practice-informed research and research-informed practice with survivors with disabilities. Dr. Ballan and Dr. Freyer's research findings to date have been instrumental in revising the Secret Garden's intake and documentation procedures, and on a broader level have influenced the practices of victim providers attending our presentations at local, statewide, and nationwide conferences. The next step entails comparing the needs and profile of individuals seeking residential as opposed to non-residential services, and

ultimately building upon the research to develop and implement interventions specific to survivors with disabilities. A systematic review of the effectiveness of interventions intended to address violence against women with disabilities concluded that not a single intervention could be considered effective (Mikton, Maguire, & Shakespeare, 2014).

Sustaining the Partnership

Beyond the Fellowship year, we intend to maintain our research-practitioner relationship, continuing to conduct research that will enhance services for survivors of IPV with disabilities both at BFL and on a broader scale, by translating our findings to make them accessible to IPV service providers nationwide. Dr. Ballan and Ms. Amodeo will disseminate information regarding the project's findings at the National Coalition Against Domestic Violence 2019 Annual Conference. The presentation will highlight best practices learned and outcomes from the practitioner-researcher fellowship, focusing on the project as a model for replication. The teams will seek additional opportunities to present on findings yielded by this unique researcher-practitioner relationship.

The FamCare online data collection system was designed to download resident information directly into an Excel database. This system will allow the SBU research team to continue to analyze data collected going forward. The researcher and practitioner teams will continue to adapt FH's programming and services based on the findings from this ongoing research.

Lessons were learned regarding the difficulties of carving out time for research in a fast-paced, crisis shelter environment. Only FH practitioner staff were initially recruited for collecting data from resident files because of the confidential nature of the work and sensitive information within. At the project's inception, data collection moved slowly due to the inability of two practitioner data collection assistants to proceed with the project given the amount of time data collection takes from the work day and the demands of their crisis-oriented positions. In order for practitioners to have an opportunity to focus on research and data collection activities, time and space must be provided outside of work hours during which practitioners can truly focus. Furthermore, the two data collection assistants who opted out of the research project held senior positions at FH, and it is possible that the demands on their time were perhaps greater than those in more junior positions. This provides insight into which practitioners may be better able to assist with research in future endeavors.

While some practitioners found it difficult to balance the demands of research and practice within the shelter setting, others were inspired by their work on the project to impart training and seek further education. One data collection assistant noted that the most rewarding aspect was training other team members on data collection processes. This team member applied to attend SBU's Master of Social Work program, a step she felt empowered to take after successfully collaborating with the SBU research team on this project. Another data collection assistant opted to continue with the project as a volunteer after funding for his data collection hours had been exhausted, illustrating the level of commitment team members had to this project.

Although Dr. Ballan initially planned to go to FH bi-monthly in person, the data collection team found it very challenging to allocate time away from clients simultaneously and with staff in various locations, it was more advantageous to meet by

zoom, phone call and via email. We followed their lead and adapted to what suit their needs best.

This fellowship demonstrated that university and nonprofits can work very well together learning from each other. This has led to other project ideas and initiatives and a fully trained cohort of researchers who want to continue working specifically with SBU/BFL collaborations.

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