Community Research
The Ethical Balance of Client, Agency, and Research Needs

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Abstract

Collaboration between university researchers and community agencies offers the opportunity to pilot innovative, evidence-informed interventions. Partnerships of this nature also present unique ethical dilemmas to community agencies, particularly regarding research and agency policies, navigating privacy protections, adequate and consistent training, and balancing research and clinical priorities. The University of Michigan and Starfish Family Services have partnered since 2012 to pilot infant mental health group models in high-risk communities. University and agency teams have relied on frequent and open communication to navigate operating procedures, training needs, and sustainability issues while maintaining a focus on high-quality programming for vulnerable children and families. This 7-year relationship supports the premise that ethical and procedural challenges associated with community-based research are surmountable and the outcomes are valuable.

Community agencies that provide infant mental health (IMH) services have a well-documented history of supporting struggling parents and their children in building positive relationships, facilitating regulation, assisting with concrete needs, and scaffolding child development. Access to these services in Michigan, the birthplace of IMH theory and practice, has been a significant community need. The 2019 *Kids Count in Michigan Data Book* (Michigan League for Public Policy, 2019) indicated that Michigan ranks 33 of the 50 states for overall child well-being. Children in Wayne County particularly face significant challenges. One in 5 Wayne County children live in poverty, disproportionately affecting children under 5 years old, and rates of abuse and neglect rose by 30% from 2010 to 2016. The county ranks 67 out of 82 Michigan counties on indicators of child well-being (Michigan League for Public Policy,

2019). As the needs of children and families in this county have continued to grow, service providers have felt the strain of supporting the many lives impacted by the social, educational, and economic stressors.

Conducting research with the families who participate in community programs has the potential to support service providers in using effective strategies leading to more positive results for families. However, adequate engagement of at-risk populations, including low socioeconomic status families and ethnic/racial minorities, continues to be an issue for researchers (Valerio et al., 2016), and can lead to disparities in multiple facets of health care (Frank, Bash, & Selby, 2014; George, Duran, & Norris, 2014; Woolf, Zimmerman, Haley, & Krist, 2016).

An article published by Frenk and colleagues (2010) recognized a need for greater community-based medical intervention research with community-engaged medical engagement being increasingly viewed as an ethical and essential means of increasing successful health outcomes for disenfranchised

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Courtesy of Starfish Family Services

Starfish Family Services was founded in 1963 to support children and families in underserved cities in the metro Detroit area.

populations (Strasser et al., 2015). Mental health researchers have also recognized the benefits of conducting research in the community, both for outcomes data and the participating communities (Danseco, Barber, Brown, & Carter, 2017). To this end, Starfish Family Services (SFS), Michigan's largest provider of IMH home visiting services, and the University of Michigan's (UM) Department of Psychiatry Zero to Thrive program partnered to improve IMH services in the community.

History of SFS

SFS was founded in 1963 to support children and families in underserved cities in the metro Detroit area. Since that time, SFS has grown to include programming for children and families from pregnancy through adulthood, encompassing early childhood education; child, family, and adult mental health services; parent education/engagement programs; and concrete needs support. SFS's focus centers around Inkster, Michigan, a small city near Detroit with a population of just over 24,000 people. Census data from 2017 indicated that women and children under 5 years old made up 58% of Inkster residents, 70% of respondents identified as African American, and one third reported living in poverty (U.S. Census Bureau, 2017).

IMH services have been a particular focus in Inkster given the number of mothers and young children residing there. Despite the great need for IMH services in that and surrounding communities, these families have been some of the hardest for SFS to reach. SFS leaders recognized in 2012 that services offered in the community were not utilized at the level expected, despite a community needs assessment identifying mental health services as a priority for residents (SFS, 2013). SFS recognized the need to reassess the community's wants and needs regarding programs and services. SFS's mission—"Strengthening families to create brighter futures for children"—led agency leaders to contact researchers from the UM Department of Psychiatry to find more responsive, effective, and culturally informed ways of positively impacting children and families in the community.

History of Program Evaluation at UM

As SFS contemplated findings from the community needs assessment, a research team at the UM Department of Psychiatry was piloting an innovative method for delivering group-based IMH programming to families. The UM team's focus was on brief relationship-based mental health and parenting interventions to strengthen protective factors and engage families in additional services as needed. A private donor with a passion for mental health treatment connected SFS and UM, which began reviewing data, programs, and planning.

The Mom Power Program

Faculty and staff at UM initially developed the Mom Power (MP) program (Muzik et al., 2015; Rosenblum et al., 2017) at a teen health center in 2008. The MP model is a 13-session weekly multifamily group intervention designed to strengthen protective factors through the delivery of five core components:

- strengthening social supports,
- attachment-based parenting curriculum,
- support for parent–child interaction,
- self-care and stress-reduction strategies, and
- connection to community resources.

The program includes a parent group and corresponding child group, each with their own curricula, and has been designed for parents and children, from pregnancy until the child is 5 years old. Initial delivery of the program followed an iterative process and was refined based on participant input; for example, mothers named the group themselves.

Program evaluation was built into the model from the start, and over the past decade support for evaluating the MP model and its adaptations was provided by federal, state, foundation, and private funders. Significant attention was paid to the formative evaluation process, with initial articles published on issues related to engagement and participation in the service (Muzik et al., 2014). Subsequent evaluation involved both open trials and randomized controlled trials. Results of these evaluations, some of which were conducted in partnership with SFS, demonstrated that community-based delivery was effective in promoting parent mental health and positive parenting, reducing parenting stress, and increasing referral and access to community services. Additional studies assessed the brain impact of participation in the MP program. Mothers completed fMRI scans prior to and following completion of MP, and results indicated that participation in MP was associated with increased activation in neural circuitry implicated in empathic response to infant display of positive affect. This increased brain activation corresponded to reductions in self-reported parenting stress.

The Strong Roots Program Model

Adaptations to the MP model have been made for delivery to military families, fathers, families involved in child welfare, and Early Head Start center-based children and families. Together

this portfolio of programs has been coined the "Strong Roots" programs, reflecting the core "tree" metaphor highlighting how parents help children build strong roots through moments of meeting connection needs, serving as a foundation for both connection and exploration as children develop.

Dissemination and sustainability became a key focus for UM through the development of these programs, and they recognized the critical need to partner with strong, trusted community agencies to effectively refine, disseminate, and evaluate the Strong Roots program models.

Early Collaboration

As SFS and UM were each working on ways to improve access to mental health services for families with young children, it became evident that both were missing a key piece. SFS's goal to engage families through nontraditional program options was frequently met with funding roadblocks. Michigan's Medicaid model for IMH programming is strictly funded through in-home services. There were not yet mechanisms in place allowing for IMH services to be billed while conducting treatment in any other way than traditional home- and community-based dyadic work. However, UM had grant funding dollars to pilot innovative programming but needed access to the communities that could most benefit from their work.

In 2012, SFS and the UM leaders partnered to secure a Medicaid grant with the goal of gauging community need for IMH services and to offer new programs based on community feedback. SFS and the UM partnership began with a community-based participatory research project. The community was asked directly through focus groups and interviews about needs, wants, and preferences for mental health support. These groups and interviews were conducted by members of the community and monitored by researchers. The feedback collected highlighted the key issue that families who could benefit from mental health support often had many reasons for not wanting or being able to access that kind of support. Families reported navigating so many demands that there wasn't time to devote weekly required hours for ongoing in-home services. Some families indicated wariness around allowing mandated reporters into their homes and communities. Families were also hesitant to enroll directly in intensive programming, preferring an option for "testing out" services and building relationships with providers. Yet the message from the community was also clear—families wanted options for infant and early childhood mental health services, but services that were available in locations outside their homes with a more limited time commitment. Current models were not sufficient for meeting that need.

The Medicaid grant, together with other foundation grants, allowed SFS and UM to address these community needs by piloting the MP curriculum. While the core MP model remained the same, the curriculum included additional opportunities for informal introductions to services and providers prior to engagement in formal mental health services. The pilot was remarkably successful, and SFS has offered more than

Community-based research models benefit all involved by affording community mental health agencies the resources and data to support sustainable programmatic innovation.

40 attachment-based groups for parents since 2012, including groups specifically for fathers beginning in 2016. SFS and UM continue to partner through joint research grants and have learned and grown together through this process of community-based research.

Ethical Challenges and Solutions

Some of the primary opportunities for growth through this partnership have been centered around new questions and considerations for ethics in research. Community agencies are largely new to collaborating in formal research, and the experience brings myriad implications for them to consider. Although staff at community agencies are trained similarly on client rights and local, state, and federal requirements, staff are not routinely exposed to the training necessary for conducting community-based research. The world of university Internal Review Boards (IRB) was foreign to SFS frontline clinicians, and learning experiences occurred when UM and SFS staff had different understandings of research versus clinical requirements and practices. In particular, new ethical questions and changes in practice arose with topics such as:

- informed consent in human subjects research versus traditional mental health services,
- marketing and recruitment for joint research and clinical programming,
- navigating conflicts between SFS practices and IRB standards, and
- balancing the need for valid and reliable research data with the needs of research subjects.

Informed Consent

The concept of informed consent is not new for community mental health clinicians. It is the responsibility of every professional interacting with families to ensure they are clear

in explaining programs and that families freely consent or decline services. There is, however, stricter scrutiny over the consent process within human subjects research due to a greater potential for harm with experimental protocols and to a history of—as well as the potential for—exploitative practices with research participants. It was difficult for SFS staff to learn to do a familiar task like obtaining consent from families in a different and controlled way despite understanding the process and reasons for the practice. Staff sometimes resented what felt like a cumbersome consent process and expressed worry about the impact of this process on the development of therapeutic rapport and outcomes for group services.

Communication

Leaders from UM and SFS recognized early in collaborating that open and frequent communication between all levels of staff would be crucial for ensuring the success of the projects. Conversations were particularly necessary in navigating staff concerns around balancing research and clinical needs. SFS and UM developed regular communication protocols across levels of staff and leadership, starting with identifying principal and co-principal investigators represented by each entity. Other methods of support and communication included attending frequent in-person and videoconferencing meetings to celebrate progress, problem-solve challenges, and brainstorm next steps in the process. Leadership from both UM and SFS were involved in regular phone and email communication to keep apprised of new developments and to collaborate around future planning. Frontline staff also routinely called, texted, and emailed each other to navigate issues in the moment, anticipate and coordinate upcoming tasks, and give and receive support. Staff from both entities also engaged in reflective consultation together around the group programming offered, with one project receiving consultation from a UM leader and the other supported by an SFS leader. Frontline staff from both entities had contact with all of the project leaders, allowing them to feel comfortable bringing concerns to the table quickly with whoever was available. UM and SFS made a commitment to efficient and effective communication which afforded the opportunity to navigate worries around ethically incorporating research into community clinical practice.

Roles and Responsibilities

SFS staff also had a history of marketing and recruiting for programs by whomever and in whatever ways made the most sense for the services offered. Collaboration with UM meant that SFS staff learned to be conscientious in receiving clarification about the rules for marketing the pilot programs and identifying appropriate responsible parties for participant recruitment, calling, and scheduling. Research and community agency staff were designated within the IRB proposal for

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each of these tasks, and SFS staff sometimes struggled with understanding the reasons for more formal ways of planning and interacting with families. SFS and UM discovered that each had made assumptions about staff knowledge around the differences between research and clinical practice.

Joint Training and Professional Development

Communication became the cornerstone of the partnership between SFS and UM, setting the stage for addressing these emerging challenges. Early meetings highlighted that not all staff working on the protocols would have the same level of knowledge regarding research methods and practice. UM was able to link SFS staff with initial trainings and ongoing support around IRB standards and ethics in research protocols and procedures. UM staff were engaged in training and coaching SFS personnel in understanding the shifts in the consent, marketing, and recruitment processes, thereby supporting SFS staff in better understanding the rationale for those processes and facilitating more compliance with IRB requirements. UM staff also required information around operating procedures for a community mental health agency and typical staff workload to gauge SFS capacity for handling tasks and deadlines. SFS and UM both brought an openness to teaching and learning that allowed for necessary conversations to unfold as ethical questions were unpacked and managed.

Data Sharing

Navigating the ethics of data sharing became an unexpected area in which UM and SFS collaboration experienced challenges. Research data sharing was new for SFS as a traditional community mental health setting, and the IRB proposal specified the ways and circumstances in which UM and SFS could share participant data, including that data would be collected at community locations but stored at the UM facilities. This arrangement would necessitate a data transfer process, which UM navigated by creating a secure file-sharing system in which SFS staff could upload participant data. UM routinely uses secure electronic systems compliant with privacy laws for data sharing; however, SFS policy prohibited sharing data through those electronic systems, instead requiring the transfer of hard versions of client data between sites. This process created concerns around the increased potential for data becoming lost or compromised. Staff from UM needed access to information that SFS staff had, while SFS staff were expected to provide that information without violating the IRB standards, SFS policies, or state and federal guidelines.

SFS and the UM leadership recognized that collaborating would mean addressing barriers created by well-meaning but inefficient policies. SFS leadership from mental health programming and compliance/risk management teams prioritized the evaluation of agency policy and its impact

on external partnerships and collaborations. Through that evaluative process, SFS leaders were able to work internally to shift policies to continue the essential protections over private participant information while allowing for timely data transfers with UM. Clear communication between SFS and UM around research and community needs allowed for concrete steps to increase the viability of the research partnership.

Balancing Research Constraints and Clinical Concerns

Finally, staff concerns around balancing the need to collect research data with the duty to provide clinically appropriate intervention presented ethical questions and considerations. While the families enrolled in research also had the opportunity to participate in traditional mental health services, as the previous community needs data indicated, these families were not able to use those traditional services and wanted to be part of the new group service model. However, all of those families had still experienced some level of socioeconomic hardship, and most had histories of childhood and adult trauma, loss, and/or serious ongoing unmet concrete needs. SFS staff routinely experienced the tension of complying with the manualized MP group approach while also managing the crises and therapeutic needs of group participants. SFS staff understood the necessity of presenting manualized material as written in order to provide data around the validity and reliability of the group model, but they struggled to contain group members at times and redirect them to more appropriate ongoing supports.

In addition, staff were responsible for collecting research measures at different time intervals. Research participants often struggled during those times to focus on completing measures, particularly when parts of their own difficult histories or life stressors were stirred up through the course of group. Because measures were completed individually, participants were often wishing to use these data collection points as opportunities to connect with staff, and staff sometimes also wanted to use that time to support participants. SFS and UM staff both struggled at times with collecting valid data at appropriate time points while also holding the experiences of research participants and supporting their emotional and concrete needs.

Although the needs of participants were great, the MP manual and research protocols were designed to allow for significant flexibility. Staff had the opportunity to meet with participants individually at designated time points during group treatment, and the curriculum is designed to assess for additional needs and direct participants to community resources. In navigating the group protocols and individual needs of participants, SFS staff sometimes clarification around the ways in which the

treatment protocol could be used to support participants. All staff providing the pilot intervention participated in reflective consultation, allowing space and time to voice their concerns around balancing research and clinical needs and receive support in finding solutions. Leaders from SFS and UM supported staff in understanding the group model's usefulness in stabilizing clients as well as addressing concrete and mental health needs.

Finally, SFS staff were concerned about balancing both research and clinical tasks. In order for the group model to meet SFS's fiscal needs, clinicians implementing the models were expected to carry a caseload typical of traditional mental health positions. Leadership from both SFS and UM were concerned about the post-grant funded sustainability of the new group programs and how to incorporate and sustain services through traditional Medicaid funding. The ongoing sustainability of group programming would require state-level billing discussions and a new way of managing an array of mental health services and supports for parents.

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SFS and UM staff used private foundation funding as an opportunity to explore nontraditional service models, research the effectiveness of the new group model, and present data to the state of Michigan for ongoing reimbursement for group therapy services to support the early childhood population. Investment from leaders and staff at both entities around the sustainability of both the model itself and its inclusion in community mental health programming allowed for creative conversation and experimentation typically beyond the reach of agencies reliant on public funding to support ongoing programming. Leadership were able to devise a way for group staff to reduce their mental health caseloads by billing for the group intervention. The level of collaboration around this research project led to a shift in perspective for both academia and public mental health, benefitting UM, SFS, and community families. To date, there are multiple agencies across Michigan using MP groups as an introduction to IMH concepts in community mental health settings

Conclusion

Community mental health programming and research institutions have often operated as separate entities approaching similar community issues through different lenses. Michigan has recently shifted focus within the field of IMH to a collaboration between community-based clinical work and research. The course of community-based research is not linear and is riddled with potential ethical landmines for mental health clinicians unfamiliar with the experience of conducting research. However, the opportunities for growth and development this partnership offered for both SFS and UM cemented this effort

and made leaders determined to navigate practical and ethical dilemmas together.

The movement toward community-based research models benefits all involved by affording community mental health agencies the resources and data to support sustainable programmatic innovation while providing a larger participant pool and richer sample to validate research. Michigan now has a sustainable, evidence-informed, and community-driven range of programming for families with young children. Along with those benefits come unique ethical challenges, including navigating culture and values, assessing for needs of all staff, protecting clients within clinical and research systems, and data-sharing across invested entities. SFS and the UM Department of Psychiatry have successfully navigated these dilemmas for the past 7 years through a commitment to open and frequent communication, collaboration around the provision of training and supervision for staff, and addressing procedural needs. This partnership has allowed SFS the opportunity to provide services for at-risk children and families previously out of reach, and UM has been able to record and report on the community impact of the Strong Roots models. Other community research partnerships have developed from this initial collaboration, including UM's evaluation of SFS's integrated IMH program and joint state- and nation-wide trainings on IMH group models. SFS and UM have demonstrated that the challenges involved in community research partnerships are surmountable and the outcomes of such collaboration are tremendously valuable to underserved children and families.

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