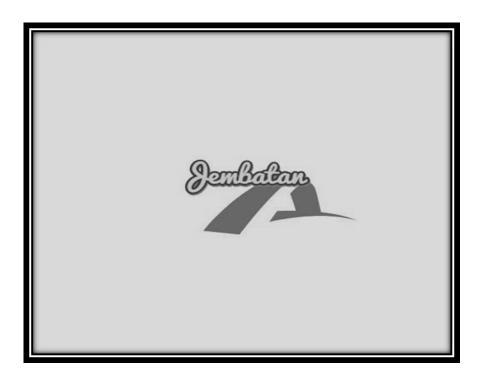Jembatan: Developing a replicable model and practical tool for integrating infertility in Sexual and Reproductive Health and Rights (SRHR) plans and programmes

Literature Review on Supporting Group For People with Fertility Issues

About infertility support groups, a bird's eye view[i]

[Comment on workshop content: This content may be useful if the Permata Hati is interested in knowing about other support group forms and alternatives for providing support.]

There are different types of groups, online and face-to-face and professionally facilitated or peer-to-peer only. The latter are also often referred to as "self-help" groups. Various combinations are possible.

Some groups have a Facebook page or a WhatsApp group, a discussion board and/or a blog space but also meet offline, some exist online only. A professional counselor or health practitioner may moderate discussions and/or facilitate sessions, or a veteran patient may take on those roles. Typically, when a support group has a professional facilitator information dissemination and education play a central role along with providing psychosocial benefits.

Groups may exist independently, but they may also exist as part of a larger structure. For example, a group of patients who attend a particular clinic may form the support group. They may meet at the clinic. Similarly, online support groups may exist on their own or as part of a larger online intervention that includes, for example, a website with articles and chat spaces with clinicians or other professionals.

Some groups are open to anyone who wishes to join, others are closed. Some are single-sex, others are mixed. Groups also differ according to their thematic focus. Some emphasize a limited number of topics related to infertility or assisted reproductive technologies (ART), while others address a wider range of infertility-related topics. Furthermore, some may follow particular ideologies, such as a religious orientation. Yet others, may organize along cultural or ethnic lines. For example, some groups may be only for women from indigenous communities, e.g., Native Americans in Canada.

Some groups meet frequently, others less so. Some are legal entities, meaning they have constitutions or statutes and are registered at the Chamber of Commerce (usually as a foundation or a non-profit organization). Others are informal. Some groups charge a membership fee others do not.

Groups may transform over time. Some may be temporary, set up to support people through a course of three in vitro fertilization (IVF) treatments, for example. Others may be longer term, but eventually dissolve when members feel they no longer need the group. Some support groups become major professional, consumer or special interest organizations, like RESOLVE. The group started in a kitchen in the US with women affected by infertility, and it evolved to become a national, professional patients' organization.

Professional organizations may work with health care providers, for example, to influence health authorities and politicians to support changes in policy and law, such as national insurance coverage for ART. They can give feedback and input on health proposals and reforms. They can also obtain consensus on both therapeutic options and reimbursement limits, as well as on proposed legislation or necessary changes. They may also participate in ethical debates and help to familiarize the public with ethical issues raised in various situations and to call for research.

Why do people join support groups[ii]

[Comment on workshop content: This content may be useful if the Permata Hati is interested in recruiting more members. Or if they want to articulate the importance of their existence to others.]

Overall, patients want support from peers, prefer complete and reliable information, wish to communicate online with their clinicians, and want to have easier access to care. They can achieve

some or all of these objectives by joining support groups, depending, of course, on the nature and structure of the group in question.

Support group brings comfort. They provide people to talk to who really know and understand; sharing of experience is true to life. The groups provide information to people affected by infertility, their families and their friends.

There is evidence that people join support groups when they feel a high enough level of psychological and/or emotional distress. They may not reach this stage when they think their immediate support network—partners, family and friends—provide help adequate to their needs. People may become more distressed when their immediate support network does not meet their psychological or emotional needs; family and friends are then often referred to as "not getting it". For them, it becomes time to join a support group.

In addition, or alternatively, people may feel "stuck" or at a crossroads in their reproductive journey, unable to make a decision or make choices, especially when they have been trying to conceive for a long time. Indeed, research suggests there may be a relationship between belonging to a support group and having undergone the most advanced reproductive technologies such as in vitro fertilization. The need to make a decisions motivates people to obtain more information and/or discuss their experiences of infertility and the reproductive journey with peers.

There are various benefits to belonging to support groups. Members value the wealth of information that can be accessed on infertility treatments. They feel empowered to take a more active role in overcoming their infertility. Having people to whom one can express frustration and vulnerability, as well as with whom one can share experiences, can relieve distress and feelings of stigmatization. Many people facing infertility experience stigma in pro-natalist, pro-parenting communities. Also, research shows a positive "knock-on" effect of being able to commune in this way with peers reduce strain on romantic relationships. When facing infertility, couples rely on each other and the stress of failing to conceive can cause strife in the couple.

Online support: advantages and disadvantages[iii]
[Comment on workshop content: This content may be useful if the Permata Hati is interested in strengthening its Facebook or WhatsApp forums or complement them with a larger online intervention.]

Online support consists of a combination of peer-to-peer communication among patients, patient-to-professional communication, and information provision. All online. Importantly, research suggest it is critical support being offered match the need, and online communication between caregivers and patients cannot replace face-to-face contact at the clinic. Indeed, some studies found that individuals who relied solely on the internet to talk about infertility experienced higher levels of distress and perceived less real-world support, in comparison to those who had access to more diverse sources of support.

A major advantage of online support is that it is available, in principle, 24 hours a day, seven days a week, whenever people feel they need it. Another major advantage is that it affords participants the ability to be anonymous and invisible. When people are not yet ready to make themselves vulnerable and discuss their personal situations, they can look at web forums and message boards without posting comments or getting involved. This allows them to find out how others are coping, and gives them a sense of control, in so far as they can decide if and when to participate.

As in face-to-face support groups, it is important to distinguish between monitored and unmonitored online groups. Some blogs and chat rooms are solely directed by peers, without professional monitor

or facilitator. In contrast, other online sites have specialists to answer questions in an "ask-the-expert" forum. The danger of unmonitored groups is that the information shared may not be accurate.

A negative aspect of online discussions is that, as with face-to-face meetings, learning of other people's heart-wrenching stories can be overwhelming. On the other hand, reading about others' successes can also be difficult. Another disadvantage is that some individuals may use the internet to avoid real-world interactions, thus increasing their isolation. It is not uncommon for people to become preoccupied and obsessed with their online community, thus interfering with their daily life and relationships. Information, in particular provided without anyone to turn to for clarification, can also increase anxiety and further questions or doubts.

How to get (and keep) members[iv]
- Setting up a referral system is a good practice. Inform clinicians, nurses, social workers, clinic administrators, health agencies and others know about the group and encourage them to tell people about it. Provide them with a template for referrals.
- Advertising is important. Support groups can place posters in clinic and distribute flyers to patients at clinics to inform them about support group sessions or online services. Posters and flyers can also be placed at other important venues, faith spaces, supermarkets, community centers, etc. Social media (Facebook and Twitter) is also useful for advertising support groups. Finally, word-of-mouth and personal invitations are important ways to recruit members.
- Face-to-face sessions should be organized when people are available. In particular, gender considerations should be taken into account when planning in sessions. Women, typically less included in the work force than men, may be able to meet during work hours, but men may be less able to do that. So, if men are to attend sessions evening hours are preferable.
- Face-to-face sessions should be free of charge. This removes financial barriers to access.
- Disseminate a newsletter. This will help provide information but can also give continuity to the exercise of experience-sharing that takes place during support group sessions, e.g., through the publication of personal stories and testimonials.
- People affected by infertility appreciate written documentation on the emotional aspects of infertility. Few clinics provide psychosocial documentation, instead favoring disseminating medical or treatment-oriented information. Support groups, alone or with clinics can produce and distribute documentation and videos on the psychological aspects of infertility.

Some challenges to support group uptake and how to address them
There are a number of challenge to support group uptake. Persons affected by infertility may not consider themselves sufficiently distressed to need support. They may feel they have the ability to cope with the strains of infertility on their own. Or they may see themselves as receiving help adequate to their needs from family and friends.

Highly distressed person are more likely to say they want support. Yet, surprisingly, there is evidence that the most distressed people, and so arguably those most in need of support, are less likely to reach out for it. There may be practical reasons for the lack of uptake. Alternatively, one can conjecture that when distress is quite high, solution-seeking approaches are frustrated. It may be that for uptake to occur, a health provider, counselor or support group facilitator should initiate contact. According to a study that examined uptake, an offer advertising the start of an infertility support group at a clinic yielded few responders until clinic staff contacted patients individually to explain the potential benefits of the groups.

Internet-based interventions are effective only when members are active participants. Blogs, forums, and wikis increase participation and reduce attrition because people get a greater feeling of engagement to the online health community. The key to active member engagement is to tailor the

online support to the needs of patients. So surveying the needs of potential members before designing and launching an online intervention is crucial.

It is useful to assign a community manager who is dedicated to managing and coordinating all activities related to an online infertility community. The community manager adds clinic-specific content, and markets strategies to engage colleagues and patients.

It is a good practice to provide instructions for use and engagement. Some patients may not know how to pose questions in a clear way in order to get the best answers, and some staff members may not know best way to answer some questions. So given some instructions and explanation when setting up a community is helpful.

Providing a safe space[v]
It is important to ensure a support groups provides a safe space. Creating a non-judgmental atmosphere where participants can feel comfortable will allow for sharing feelings and opinions. It is crucial the support group members agree to maintain confidentiality ("what you say in the room, stays in the room") and that all have the same understanding and expectations for privacy, including data protection.

When starting a support group, and as an occasional recurring exercise (as a refresher but also to educate new members) collect participants' expectations on the boundaries that are important to them in the context of being group members. It is also useful to disseminate information on and reminders to engage in respectful behavior towards each other.

Tips for supporting respectful behavior:
- Avoid using language that can offend.
- Be open to each other regardless of the other person's stage in their reproductive journey, gender, religion, sexual orientation, ethnicity and place of origin, etc.
- Listen to each other and engage without judgment.
- Remember that choosing not to speak is also an option one can take and a choice others can make.

Building an inclusive support group[vi]
Inclusiveness in support groups can break down along many different lines. Two common ones are socio-economic status and level of education (these two factors are typically connected) and gender.

Including people despite socio-economic status and level of education
A support group that wishes to be more inclusive may need to think about how to reach out to less well off or less educated people affected by infertility. Some approaches might include using radio and video to reach out to those not used to reading or who read with difficulty. Other approaches might include paying special attention to minimizing financial costs to participation, such as meeting in a location readily reachable by public transport or on foot.

In some cases, support groups for infertility may be mainly composed of people of high socio-economic status and education. There may be a variety of factors contributing to this state of affairs. The marketing tactics of the support group may communicate to a wealthier more educated audience. The group may meet where mostly better off people are located. Also, in a context where treatment is covered out-of-pocket, if a support group consists primarily of people undergoing treatment then members will typically be those who can afford it. Furthermore, US research shows that women of higher socio-economic status are able to take a more active role in their health care, whereas women of lower socio-economic status tend to be more restricted to more passive forms of engagement with

their health due to their limiting circumstances. Consequently, well-to-do, educated women can be considered more likely to seek out a support group.

Including men[vii]
Research shows men can benefit from support groups. Men tend to hesitate to seeking help for health issues due to pressures to maintain masculine attitudes and behavior related to toughness, self-reliance and self-control. Infertility is thought to cause considerable stigma for men as it may be viewed as compromising their masculinity.

The importance of child bearing and rearing for women, coupled with the focus of ART treatment on women's bodies, have reduced the visibility and awareness of men's experiences of childlessness. Independent of their partner's wishes, fertile and infertile men want to father children and experience fatherhood. Men may experience grief when the life goal of having children is unrealized. It can become an enduring sadness if fertility treatment is unsuccessful.

In addition to being heavily affected when they are themselves diagnosed, men are also heavily affected by their partners' struggles with infertility. Research shows they may not want to impose their feelings on their partners, and they may feel responsible to be the stable force in the relationship. Men may feel that supporting their partners during their reproductive journey is their primary role, and their own support needs are secondary. As result men will refrain from seeing help for their experiences of their partners' infertility.

Research also shows men report less psychological distress than women, but at the same time both men and women report being significantly more concerned about the psychological aspects of infertility than its medical aspects. In addition, according to one study, most research uses questionnaires to determine distress that ask questions about symptoms, e.g. sadness, crying. These questions may be more relevant and better able to detect distress in women compared to men. The use of less-biased questions and/or the use of analyses that focus on the pattern of reactions across gender might be more useful and may yield new information that goes beyond the well-established finding that women have more intense negative reactions to infertility.

An extensive review of the literature on psychosocial interventions in infertility found that men and women both benefited from support groups, but in different ways. Men liked the practical information and advice they received. Structured, facilitated psycho-educational didactic groups would be perhaps be helpful.

Male-only online forums can help men disclose and discuss infertility. Men value engaging with other men who are going through similar experiences, and they turn to the experience of other forum members to seek help when they were exploring a new type of treatment. The anonymity that is possible on an online forum allows opening up about emotions in a 'safe' way. In the absence of anonymity, men would perhaps not express their feelings otherwise.
A study of men's posts on an infertility support group bulletin board revealed that men not only used the group to acquire information about medical interventions for themselves or their partner but also were able to vent their feelings openly, gain support, and obtain a much needed male perspective.

Mobilizing resources[viii]
A support group with a clear vision, mission and objectives can determine its funding needs without too much difficulty, especially if the activities are relatively simple. At the most basic level a support group, if meeting offline, needs to cover its meeting costs. Assuming all parties involved are volunteers, then there are costs for printing materials, a venue and refreshments. A fertility clinic may be able to provide for all or most of these costs through in-kind support, or the clinic may have some budget for "community engagement". Alternatively, support group members can pool their resources to cover

costs, either through a small membership fee or by using a collective fund to cover the costs of group activities.

A number of online activities, on top of or instead of the operational costs of face-to-face meetings, can be done for free. Some IT hosting costs may be involved if a domain name needs to be registered. Social media platforms are free (unless posts are to be boosted there are no financial costs), and blogging software is also available for free. More complex websites connected to databases, using Drupal software for example, are also free. The challenge there is that building them requires robust computer skills. Also, for professional flyers and other documentation design and desktop publishing software may be needed. These can be prohibitively expensive. TechSoup provides software at lower costs to charities and non-governmental organizations.

If fundraising is needed, typically, it is easier for a local support group to raise funds locally. Local city councils may have a budget for citizen initiatives, for example. Local supermarkets and shops may be able to provide sponsorship; smaller concerns may be interested in showing community engagement and in increasing their visibility in the local commercial sector. Local affiliates or franchisees of larger chains may not want to provide sponsorship, but the franchisor/parent company may be able to do so as part of their corporate social responsibility (CSR) policy. In addition, pharmaceutical companies also have CSR policies, and are keen to support relevant patient initiatives to expand their markets. Note, support groups usually need to be registered as legal entities to receive funds or grants.

If resource mobilization becomes an important task in order to take on work more or grow then planning for resource mobilization is important. First, explore a conceptual framework for resource mobilization (what kind of resource mobilization is wanted and needed) and identify different kinds of resources. Second, map out steps for resource mobilization work. Third, develop a plan for resource mobilization. Fourth, identify and research different resource providers. Understand them (where are they, what are their priorities, what interest would they have in wanting to support the group, how does the work of the group add value to their mission and objectives) and prepare to meet with them.

Advocacy[ix]
Advocacy is an ongoing process aiming at change of attitudes, actions, policies and laws by influencing people and organisations with power, systems and structures at different levels. For what purpose? For the betterment of people affected by an issue. Advocacy work can target people with influence at all levels—from a local store owner to the United Nations. Although there are multiple levels of advocacy work, for the sake of simplicity there are three key 'levels' of advocacy:
- Local (village, district, city, state, etc.)
- National (the whole country)
- International (more than one country)

In reality the problem or issue may have a combination of local, national and international causes, so the level of advocacy work will depend on the priority and what is possible. Working together in coalitions can be a strength at every level, but becomes particularly important as one moves from local to national to the international level and one faces greater bureaucracy and power.

Considerations before taking on advocacy:
- The scale of the problem or issue (it may have a purely local cause)
- Where one can have the greatest impact on the problem or issue
- The resources available (i.e., different levels of advocacy take different amounts of staff time, skills and funds)
- The existing networks and relationships
- The mission of the organisation

Steps to take:

1. **Select an issue or problem to address.** Analyze and research the issue or problem, for example doing a cause-and-effect analysis of why people go into debt paying for infertility treatment. It is important to think carefully about an issue, defining it clearly, before planning advocacy work. Consider the different issues and select the ones that are realistic and which will benefit from advocacy.

It is important to involve people who are directly affected by the issue or problem at this stage. They will have an in-depth understanding of the problem and its effects, and will have ideas about how it can be solved.

2. **Identify possible advocacy solutions** that target the causes and gather information that supports the analysis. Then, develop specific objectives for the corresponding advocacy work.

Objectives should be **'SMART'**. **S**pecific—for example in stating what will be done. **M**easurable—for example to allow monitoring and evaluation. **A**ppropriate—for example for your vision, mission and aim. **R**ealistic—for example in relation to your potential capacity and experience. **T**ime-bound—for example in relation to when the work will be done.

3. **Identify institutions and specific persons to target.** It is important to focus advocacy efforts on the individuals, groups or institutions that have the greatest capacity to take action and to introduce the desired changes. At a national or international level these people are usually those with the power to make policy or program decisions. At a local level there are often charismatic people who have power and influence—for example, business leaders, respected older people, traditional healers—as well as those who have influential roles in government or other major institutions.

4. **Identify resources.** Successful advocacy work requires resources such as people (human resources), money, skills and information. Human resources can include both staff and volunteers. Other resources can include access to media and to distribution networks, for example, newsletters, e-mail. One major advantage of working in coalition with allies is the possibility of sharing resources.

5. **Identify allies.** These are the organizations or persons with whom to advocate. In some cases a coalition of people or organizations doing advocacy work can achieve more together than individually. Coalitions take time and energy to develop and maintain because they involve building trusting relationships with other people and keeping people constantly informed and involved. Forming a coalition with allies to undertake advocacy work is not the same as being part of a network, but networks can also be useful to share information between organizations. Coalitions can be short term or long term, and formal or informal.

Examples of possible allies to form coalitions include:
- Other people directly affected by the issue or problem, such as people affected by infertility, health care providers, etc.
- Health and/or SRHR community-based organisations (CBOs) and nongovernmental organisations (NGOs)
- Other civil society actors (supportive unions, religious institutions or leaders, community leaders).
- Business people
- Supportive or sympathetic journalists
- Supportive local/national government officials who can lobby from inside
- Allies in other parts of the country, or other countries – counterpart organizations that can put pressure from outside

Note: allies outside the immediate fertility sector many not have adequate knowledge about infertility and ART. It may be important to educate them. In addition not all religious leaders may always be in favor of the use of some forms of ART, as this may involve the disposal of embryos, gamete donation or surrogacy.

6. **Create an action plan**. An action plan consists of a specific set of advocacy activities (using different methods) with a timeline and shows who is responsible for implementing each activity. The activities are those that are necessary to address the aims and objectives that have been agreed.

There are no simple rules for choosing the best advocacy methods. The choice will depend on many factors: the target person/group/institution; the advocacy issue; the advocacy objective; the evidence to support the objective; the skills and resources of the coalition; and timing, for example, external political events, when a law is still in draft form, immediately before a budgeting process, time of year or stage of advocacy process.

Importantly, an action plan brings together the SMART objectives defined at an earlier stage, the activities needed to achieve the objectives, the resources needed to implement the activities, who will do the activities and by when, and how success will be measured. To determine the latter an action plan includes plans for monitoring and evaluating results and processes according to a pre-defined indicators.

Spotlight on a professional organization focusing on infertility[x]
Founded in 1974 by Barbara Eck, a nurse experiencing her own infertility, RESOLVE is a national support and advocacy network in the USA for women with infertility problems. Its mission is to "provide timely, compassionate support and information to people who are experiencing infertility and to increase awareness of infertility issues through public education and advocacy."

RESOLVE provides free or low cost support and educational programs in local communities to meet the needs of women and men diagnosed with infertility. The organisation has a national headquarters and numerous local chapters.

RESOLVE does advocacy at the state and national levels for health care coverage for infertility, medical research, adoption benefits and access to family building options. **The RESOLVE website** offers information a variety of online resources that address treatment, coping, third party reproduction, adoption and living childfree.

RESOLVE runs basic infertility support groups and specialized groups of various types. An actual RESOLVE support group has taken the following form:

A small group of six or seven women over 40 years of age attempting to have their first child come together once a week for an hour and a half to discuss. The discussion topics covered vary widely. They include exploring negative feelings—loss of control, regret, loss, sadness, and anger and frustration, even desperation, as well as jealousy of other women, both those in the group who became pregnant and others with children. They also include exploring positive feelings—regaining control, excitement, hope, expectation, a sense of overcoming and peaceful resignation. The also explore practical matters, such as treatment solutions, such using donor eggs, and the ethics around them.

A therapist runs the group and charge each participate a fee per session. Each participant must sign ground rules, which include a promise of confidentiality outside the group, and if someone makes the decision to leave the group, a commitment to return for at least one session to explain why they

decided to leave. The group meets for two separate 12-week periods. The 12-week duration is intended to be a 'time-limited' and structured process with a beginning, middle and end.

For a woman who wrote up her experience of this support group, "the truth is that the struggle with infertility that those of us in the support group went through will always be a part of our histories, no matter what decisions we may make or what strategies we may use to build a family. The empathy we offered each other will also be a part of our lives forever."

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