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

Report of workshop 2

The report is prepared by Results in Health
December, 2018

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## List of Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>ART</td>
<td>Assisted Reproductive technologies</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>ICPD</td>
<td>International Conference on Population and Development</td>
</tr>
<tr>
<td>IPPA/PKBI</td>
<td>the Indonesian Planned Parenthood Association/Perkumpulan Keluarga Berencana Indonesia</td>
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<tr>
<td>IVF</td>
<td>In vitro fertilisation</td>
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<tr>
<td>MNCH</td>
<td>Maternal Neonatal and Child Health</td>
</tr>
<tr>
<td>NGO</td>
<td>Non Governmental Organization</td>
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<tr>
<td>PKBI DIY</td>
<td>Perkumpulan Keluarga Berencana Indonesia Daerah Istimewa Jogyakarta</td>
</tr>
<tr>
<td>PoA</td>
<td>The Program of Action</td>
</tr>
<tr>
<td>PTPH</td>
<td>Pejuang Tangguh Permata Hati</td>
</tr>
<tr>
<td>RiH</td>
<td>Results in Health</td>
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<tr>
<td>SRHR</td>
<td>Sexual Reproductive Health and Rights</td>
</tr>
<tr>
<td>UvA</td>
<td>University van Amsterdam</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
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Acknowledgment and disclaimer

This workshop would not have been possible without the active and engaged contribution of the workshop participants and facilitators. We would like to particularly thank all participants from Pejuang Tangguh Permata Hati, Perkumpulan Keluarga Berencana Indonesia (PKBI) Chapter DI Yoyakarta, and Permata Hati infertility Clinic RSUP Dr. Sardjito, Yogyakarta Indonesia.

The following individuals deserve a very special thank you for their invaluable expertise and experiences and provided us with insight into the problems faced by involuntary infertile couples in Indonesia:

Trudie Gerrits from University of Amsterdam
Aryanti Radyowijati from ResultsinHealth
Endang Purwasari from ResultsinHealth
Titing Martini from ResultsinHealth
Nur Hidayati from ResultsinHealth
Dr. Ita Fauzia from Permata Hati infertility Clinic RSUP Dr. Sardjito, Yogyakarta
Gama Triono from PKBI DIY
Mukhlis from PKBi DIY
Community of Practice on Infertility - ShareNet Nederland

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In the end, we claim sole responsibility for the content and analysis in this report.
1. The Jembatan Project

Infertility is highly prevalent in the Global South, including in Indonesia, and has a devastating impact on those affected. The Programme of Action (PoA) of the International Conference on Population and Development (ICPD) (United Nations, 1994) —and since then various other international organizations, like WHO (2017) and Guttmacher (2018) —have called for including prevention and treatment for infertility in SRHR plans and programs. Nevertheless, typically, donors, policy-makers and NGOs focusing on SRHR neglect the issue.

Research shows that non-governmental organizations (NGOs) focusing on SRHR engage pay hardly any attention to the problem of sub- or infertility, neither do they collaborate with support groups of clients at infertility clinics. From University van Amsterdam (UvA) previous project with Share-Net Small Grant in Ghana and Kenya, we have learned that these support groups are keys in providing information on infertility and counselling and to address the stigma associated with infertility. Research also shows that health related support groups have an excellent track record of positively influencing NGOs.

To address this gap, ResultsinHealth together with UvA; PKBI Yogyakarta; Permata Hati Clinic infertility support group; and the Share-Net Infertility Working Group will work together in a project called Jembatan. Jembatan is a project to develop a (replicable) model and practical tool for integrating infertility in Sexual and Reproductive Health and Rights (SRHR) plans and programmes. Jembatan is intended to stimulate exchange and collaboration between infertility support groups and NGOs focusing on SRHR with the goal of up scaling and improving interventions addressing infertility. Specifically, Jembatan will promote collaboration between PKBI Yogyakarta and the Permata Hati infertility clinic support group. In detailed, there are 4 objectives of this project as stated below:

- Develop learning and knowledge exchange and collaboration between PKBI Yogyakarta and the Permata Hati infertility clinic support group.
- Document the experiences, practices and knowledge shared as well as the processes of cross-learning and collaboration between PKBI Yogyakarta and the infertility support group and translate the findings into a practical model.
- Develop a tool in Indonesian and in English for integrating infertility in SRHR plans and programmes, based on the practical model developed.
- Widely disseminate the findings of the project and the tool.

To achieve the above objectives, several activities will be carried out as described below:

- Desk study of experiences and lessons learnt on the operations of support groups.
- Participatory workshops between senior staff of PKBI Yogyakarta and members of the infertility group to: exchange information on and experiences of infertility (including in the context of broader SRHR issues) and access to services; assess needs and opportunities for joint work; delineate ways of working; and define concrete actions.
- Monitor and document processes and results from the workshops as well as joint activities between meetings.
- Develop plan of action for continuing collaboration
- Produce and disseminate a tool in Indonesian and in English outlining in practical terms how to integrate infertility in SRHR plans and programmes.

The timeframe for this project is 5 months (from 1 July until November 23, 2018). At the end of the project, we hope that: PKBI Yogyakarta will include services for people affected by infertility in their future plans and programmes and the Permata Hati infertility clinic support group can strengthen and expand their interventions. These exchange and collaboration will be based on the approach/method developed by the UvA and Workgroup Infertility team and will be documented to produce the tools for integrating infertility in SRHR plans and programmes.
2. Workshop 2 Jembatan Project

The Second workshop of the Jembatan project was organized from Saturday – Sunday, 10-11 November 2018 at Hotel Grage in Yogyakarta, Indonesia. The workshop was led by Aryanti Radyowijati from ResultsinHealth and Gama Triono from PKBI DIY, assisted by the team from ResultsinHealth and PKBI DIY for the organization of the workshop.

The objectives of workshop 2 are:
1. To improve knowledge of Jembatan project’s partners on the following topics:
   - Support group for people living with fertility issues
   - Clinical aspect of the fertility problem
   - Self and group empowerment for people living with fertility issues
2. To provide skills for Jembatan project’s partners on the following topics:
   - Self-empowerment
   - Lobbying dan advocacy
   - Public speaking and communication
   - Social media

2.1. Workshop Program

The workshop was held for 1.5 days, the first day was started in the afternoon to give time for participants who need to travel from their home town to Jogyakarta. The workshop programme can be found in table 1.

<table>
<thead>
<tr>
<th>Day 1 – 15.00 – 18.00</th>
<th>Day 2 – 10.00 – 16.00</th>
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<tbody>
<tr>
<td>15.00 – 15.45 Walk in and registration</td>
<td>09.00 – 09.30 Welcome and registration</td>
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<tr>
<td>15.45 – 16.00 Welcome and Introduction</td>
<td>09.30 – 11.30 Mini Workshop</td>
</tr>
<tr>
<td>16.00 – 16.30 Session 1 – Support group for people living with fertility issues</td>
<td>Abimanyu 1: Self and group empowerment</td>
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<tr>
<td>16.30 – 17.00 Session 2 – Clinical aspect of Infertility</td>
<td>Abimanyu 2: Lobbying and Advocacy</td>
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<tr>
<td>17.00 – 17.30 Q&amp;A and coffee</td>
<td>Abimanyu 3: Public speaking/communication</td>
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<tr>
<td>17.30 – 18.15 Session 3 – Living with infertility – Self and group empowerment</td>
<td>11.30 – 13.00 Break, lunch and afternoon prayer</td>
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<tr>
<td>18.15 – 19.00 Break - prayer</td>
<td>13.00 – 15.30 Mini workshop</td>
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<tr>
<td>19.00 Dinner and informal discussion</td>
<td>Abimanyu 1: Self and group empowerment</td>
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<td></td>
<td>Abimanyu 2: Working with Social Media</td>
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<td></td>
<td>Abimanyu 3: Public speaking/communication</td>
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<tr>
<td></td>
<td>15.30 – 16.00 Break – Coffee and Afternoon prayer</td>
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<td></td>
<td>16.00 – 17.00 Wrap up: Plenary – Q&amp;A and closing</td>
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</tbody>
</table>

2.2. Workshop Participants and Facilitators

Participants:
The workshop was attended by about 60 participants:
- ResultsinHealth : 4 participants
- PKBI DIY : 10 participants
- Permata Hati Infertility Clinic : 7 participants
- Dr. Sardjito hospital : 2 participants
- Pejuang Tangguh Permata Hati : 30 participants
- Unala : 1 person
- Expert/facilitators : 4 participants
In comparison with the first workshop, in this workshop there were more participants from the Permata Hati clinic and 2 representatives from the dr. Sardjito hospital. There were also representative from UNALA. UNALA is a private-sector led health service set up by UNFPA and the Angsamerah Foundation (Yayasan Anak Bangsa Merajut Harapan) for adolescents and their concerns, including sexual and reproductive health services. UNALA is being piloted in Yogyakarta with the support of HRH GKR Pembayun, Princess of the Sultanate of Yogyakarta, and other partners involved in youth and health affairs.

**Facilitators:**

*Dr. Aryanti Radyowiyati:* Aryanti currently serves as director of ResultsinHealth based in the Netherlands. She has more than 20 years of work experience in health and development in the Netherlands and internationally. Aside from being a researcher and director, Aryanti is also a permanent lecturer at the Windesheim University of Applied Sciences in Zwolle, Netherlands.

*Dr. Indria Laksmi Gamayanti, M.Si.:* Dr. Gamayanti is the Head of Indonesia Clinical Psychologist Association and lecturer in the Department of Paediatrics, and has extensive teaching and research experience in Indonesia. Her research focuses on the area of improving cognitive development of children and optimization of family roles in growth development. She is also one of the founders of Kemuning Kembar, an institution engaged in the fields of psychology, education, health, and culture. One of its main activities is providing psychological assessment, consultation and intervention services for children, adolescents, adults, as well as psychological consulting and assessment services for organizations, companies and government agencies.

*Dr. Ita Fauzia:* Dr. Ita has been in the field of embryologist since 2000, after completing her master’s education in this field in Singapore. Dr. Ita currently works at Permata Hati Clinic, RSU. Dr. Sardjito.

*Agnes Dewanti Purnomowardani, Psi., M.Si:* Agnes Dewanti or Nessi Purnomo has more than 10 years providing counseling to both adults and children. She works for several hospitals in Jogyakarta as well as providing training and psychological assessment to the private companies. She is also often called on as an expert for various television programs both provincial and national, magazine and newspapers for psychological topics.

*Dra. Ninda Nindiani, MA:* Ninda has more than 15 years’ experience as broadcaster and professional master of ceremonies or MC, she is also trainer in public speaking, personality development and public relations. She is founder of FIRST STEP and recipient of the 2014 "Inspiring NIVA Women" award in the education category.

**Gama Triono:** Gama Triono is director of the Yogyakarta chapter of the Indonesian Family Planning Association (PKBI). Gama started working for the NGO in 2005 and since then he already worked on many issues related to the SRHR such as research, community engagement, counseling, and outreach advocacy.

**Agung Wibawanto:** Agung is a journalist working for a well-known newspaper in Jogyakarta with more than 10 years experience. Before that he worked for several local NGO’s where he was involved in research and publication. Now Agung also delivers journalism training to students and to the general public.
2.3. Workshop Results

The workshop was opened by Gama Triono (PKBI DIY) and Aryanti Radyowijati (ResultsinHealth), by welcoming the participants and introducing the purpose of the workshop.

**Workshop objective 1: to improve knowledge of jembatan project stakeholders, particularly for members of the supporting groups**

The first day was formatted as plenary session, where three resources persons presented three topics:

**Presentation 1 – Results of literature review on support group for infertility:**
Aryanti presented the result of literature review made by members of CoP on Infertility. In this presentation, Aryanti presented on different types of support group, challenges to maintain a support group, why people become a member of a support group, and how to involve the men/spouses. In her presentation she also mentioned some ideas on how to get funding for support groups as well as providing examples of support groups in several countries. For more information please see annex 1 (slide presentation and document on Literature Review).

**Presentation 2 – Clinical aspect of Infertility**
In her presentation, Dr. Ita from Permata Hati clinic explained that the problem of women with infertility is complicated and that every case is unique. The patients need to accurately inform the doctor about their problems; she mentioned that sometimes in the consultation room, patient does not explain everything clearly. Every patients has history that clinically important for their treatment. She also mentioned that not all treatments will end well, namely returning home with child, because this percentage is only between 30% until 35%. Dr Ita explained a few more problems that women and men have based on her experience working in the clinic, that sometimes patients psychological issues are not being addressed and that this can also contribute to the patient feeling more down. See Dr. Ita slide presentation in the annex 2.

**Presentation 3 – Living with infertility – Self and group empowerment**
The third presenter was Dr. Laksmi Gamayanti who opted to have a more informal question and answer format rather than lecture. After the participants felt at ease with questions and anecdotes, she asked them to write down what their expectations were about attending the workshop and based on that she asked several of patients to explain their feelings. She also explained that support groups can provide a place for them to share their feelings both negatives and positives and place to find a relief.

After the presentation, the participants had an opportunity to asked questions to all presenters. All questions were about the clinical part of the infertility such as how important is the role of ovum and sperm for its success to form the embryo; is the acid is influencing me to produce a bad egg etc. The first day was closed with dinner and informal discussion.

**Workshop objective 2: provide skills for Jembatan project’s partners on the topics self and group reliance, public speaking and communication, lobbying dan advokasi and social media.**

Day 2 was structured as 2 rounds of skills workshops on the following topics:

**Topic 1 – Resilience is facilitated by Agnes Dewanti Purnomowardani, Psi., M.SI**
Participants: 18 member of PTPH
This became a closed group session where only PTPH women participated. The workshop was designed to let the participants open up about what happened to them, how they felt about their
situation, how they cope with this situation. The facilitator also guided them in how they could manage their feelings and find the support should they need it.

This topic followed exclusively by members of PTPH and being discussed in 2 sessions, in the morning and in the afternoon, lead to the most emotional sessions. The first session was follow by 10 participants and the second by 8 participants. Almost all participants knew each other and they tended to group based on their familiarity with each other. From the beginning the group was already very relax and they almost instantly able to share their feelings and thoughts. The second session started a bit late and also ended up running almost 45 minutes longer than expected.

Topic 2: Public speaking is facilitated by Ninda Nindiani
This topic became one of the topics that lead to lots of laughter. The session began with self-introductions of the facilitator and the participants. The facilitator then gave a small lecture about how to speak in front of public. At the end of the session, she asked participants to practice the material that had been delivered.

Although the session started late and it was difficult to get participants to participate the dynamic changed during the session and at the end all participants were very relaxed and not willing to stop even though the time is up.

Topic 3: Advocacy is facilitated by Gama Triono
Participants: 3 from PTPH and 5 from PKBI
This topic was discussed during one session in the morning. The session started with the facilitator asking participants about their understanding of advocacy, he asked them to write this on a piece of paper. Then as a group, the participants were asked to write what the groups understanding is of advocacy, the facilitator then asked one of the participants to explain what they as a group wrote before concluding the exercise. In this session, the participants were introduced to basic advocacy. The facilitator style was very relax to help the participants to also feel at ease and create the situation where they can discuss more freely. Also it was agreed that whatever was said in that room would stay there unless the participants, especially from PTPH, decided to bring it out.

All participants from PTPPH were male and the rest were female. In the beginning the PTPH participants were very quiet but after the exercise, they started to open up and really got involved in the session. Unfortunately in this session there were not enough representative from PTPH (no female participants because they opted to follow the resilience session).

Topic 4: Working with Social Media facilitated by Agung Wibawanto
In this session, the facilitator started with a short lecture about the technology and the world we live in now. He conveyed that anyone can become a writer on an online news portal. Information can be shared by anyone anywhere provided they have access and the ability to write. The facilitator also shared some trick and tips on how to write a good message, how to avoid propagating fake news. The participants also had an opportunity to do some exercises and to practice some of the things they learned.

The workshop went well although some participants from PTPH cancelled their participation. There was fluctuation of the participants in the first and second day. Some participants only came in the first day. Some participants in the second day came only in the morning and some of them came only in the afternoon session.
3. Workshop Evaluation

At the end of the workshop, participants were asked to complete two types of evaluation forms. One is about general evaluation and the other more on the topics. Not all participants filled in all the form and returned them to the organizer. Some participants did not attend the last half training day and was therefore not able to submit the forms handed out in the afternoon.

The results of the evaluation are presented below:

<table>
<thead>
<tr>
<th>General</th>
<th>☹</th>
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<th>☻ ☻</th>
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</thead>
<tbody>
<tr>
<td>Facilities</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Room</td>
<td>5</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>Training equipment (LCD, microphone etc)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Timing and allocation per session</td>
<td>1</td>
<td>7</td>
<td>18</td>
</tr>
<tr>
<td>Facilities for participants (paper, ballpoint etc.)</td>
<td></td>
<td>10</td>
<td>14</td>
</tr>
<tr>
<td>Support provided (information about workshops, workshop sites etc.)</td>
<td>15</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Comfort</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>The workshop room</td>
<td>7</td>
<td>22</td>
<td></td>
</tr>
<tr>
<td>Facilities related to the praying room, toilet etc</td>
<td>19</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Food</td>
<td>10</td>
<td>19</td>
<td></td>
</tr>
</tbody>
</table>

From the workshop evaluation, it can be concluded that most participants are satisfied with the programme, organization and results of workshop 1 and planning to attend workshop 2.