IKAHAK-CLAN
ENTERPRISE DEVELOPMENT PROGRAM

EVALUATION

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ABSTRACT

The Enterprise Development Program of Caring & Living As Neighbours (CLAN) and Ikatan Keluarga Hiperplasia Adrenal Kongenital (IKAHAK) is currently concluding its pilot phase. The program has introduced microfinance to a low-income population of Indonesia not previously served by this industry. It has also put forth an innovative methodology combining enterprise development activities and medical support group services for families with children living with a chronic disease.

The evaluation finds that the CLAN-IKAHAK EDP has identified a valuable approach for expanding the financial capacity of low-income families in developing countries caring for a child with a chronic disease. The methodology is effective in facilitating the process of starting enterprises with microcredit for the purpose of expanding consumption capacity, and is mutually supportive of the focus of the support group on accessing medical care and information. This evaluation identifies ways to strengthen the operational approach to implementing this methodology in order to scale it up, including building documentation capacity, clarifying roles and addressing challenges identified in the pilot phase.

This evaluation employed a combination of interviews, questionnaires and literature/documentation review in order to assess the strength of the methodology of the EDP, initial outcomes and potential for expansion and development. The results are a series of initial impacts, highlighted strengths and recommendations both for addressing challenges and pursuing potential new avenues.

INTRODUCTION TO THE ENTERPRISE DEVELOPMENT PROGRAM

The Enterprise Development Program is a joint-program of IKAHAK and CLAN, dedicated to providing livelihood support for families with children suffering from congenital adrenal hyperplasia (CAH, a chronic disease).

ABOUT CLAN

Caring & Living As Neighbours (CLAN) is an Australian-based, not-for-profit, non-governmental organization (NGO). CLAN is dedicated to the dream that all children living with chronic health conditions in resource-poor countries of the world will enjoy a quality of life on par with that of their neighbors in wealthier countries.

While the United Nations' Convention on the Rights of the Child (articles 4, 6, 23 and 24) clearly states that all children with special health requirements have a right to the care needed to enable them to live the healthiest and most fulfilling life possible, the sad reality is that in resource-poor countries any child with any chronic health condition (that is, any health condition that lasts more than 3 months) is immediately susceptible to entirely preventable disability and death. CLAN believes these children have a right to health and life, and that more international attention should be given to this issue.

CLAN's efforts are based on a rights-based, community development model that provides a strategic framework for action (the 5 pillars) to help children who are living with chronic health conditions in resource-poor countries. The five pillars focus action on:

1. Affordable access to medication & medical equipment
2. Education (of individuals, families, communities, health professionals, policy makers and the international community), Research & Advocacy
3. Optimization of medical management (including primary, secondary and tertiary prevention, with a bio-psycho-social focus)
4. Encouragement of family support networks
5. Reducing financial burdens on families that result in poverty, helping people to become financially independent so that they can provide the necessary health care for their children longer-term.

CLAN is committed to the principles of community development and comprehensive primary health care. We identify groups of children (and their families) who are living with the same chronic, long-term health conditions as members of a distinct, non-geographically based community. Identification of, and consultation and collaboration with these communities enables CLAN and other partners to work together with individuals and families living day-to-day with chronic health conditions in resource-poor settings, to collectively determine the most appropriate actions for change.

ABOUT IKAHAK

The Indonesian Congenital Adrenal Hyperplasia (CAH) Support Club (Ikatan Keluarga Hiperplasia Adrenal Kongenital/IKAHAK) was formed on June 13, 2007. IKAHAK is the first organization in Indonesia to serve the families of children with CAH through the CLAN Family Club (support group) model. Through this model families receive medical services, information and education as well as an opportunity to learn from shared experiences.

The group began with just six families based in Surabaya, though the scope of the organization includes CAH families throughout Indonesia. To date the group has grown to ten families and continues to expand.

The Indonesian CAH Support Club IKAHAK is a community of people with unique features, namely:

- Members are brought together randomly, and would rarely have met one another otherwise.
- CAH is often the only common factor uniting families. However, this is a very powerful shared experience.
- Members are usually geographically dispersed.

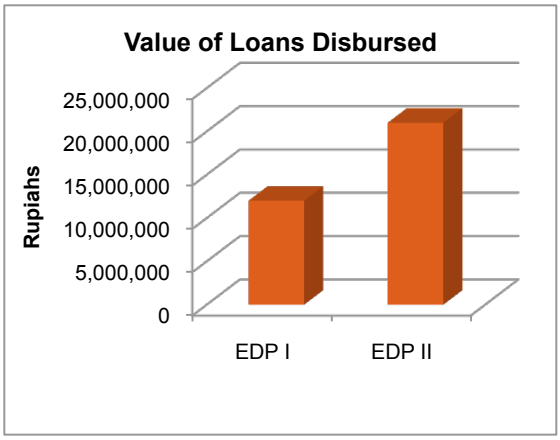
The very nature of the IKAHAK community means that it is difficult for it to engage with established enterprise development organizations. For this reason, CLAN has partnered with IKAHAK to implement an independent enterprise development project.

OVERVIEW OF THE EDP

CLAN and IKAHAK began the Enterprise Development Program (EDP) in partnership with the objective of promoting the long-term financial freedom of families who have children living with Congenital Adrenal Hyperplasia (CAH) in Indonesia, toward the ultimate goal of improving the quality of life for the children. The EDP was designed to build on partnerships with healthcare professionals, business people, philanthropists and other interested parties in Indonesia.

The foundation for this partnership is the trust and mutual respect that has developed over time between CLAN and IKAHAK, with a view to fostering long-term, sustainable development solutions to the financial burdens facing the many families in Indonesia who are living with CAH.

Enterprise development and micro-finance projects have had demonstrated success in many countries. In Indonesia there are some established, reputable organizations working in the field, and CLAN's preference would be to collaborate with one of these organizations. However, one feature of these organizations is that they typically focus on geographically-based communities. As IKAHAK members are by contrast geographically disbursed and unified instead by their shared experience of caring for a child with CAH, the two organizations decided to implement an independent enterprise development



program tailored specifically to the needs of CAH families in Indonesia.

Given the vital function of IKAHAK as a support group first, the approach taken to the EDP prioritizes "do no harm" over all else, emphasizing that a) no family should be left worse off as a result of their participation, and b) failure is not a component of the EDP, rather a process of learning from experience. Towards this end, the chosen methodology provides families undertaking enterprise projects with the support of Project Group Leaders (elected by the group), mentors (providing business support), doctors, fellow members and CLAN representatives and resources. The need to preserve the positive relationship between IKAHAK members and the organization, enabling access to crucial medical resources and information for their children with CAH, dictated the approach taken to the EDP in terms of caution and separation of EDP activities from accessing healthcare.

The process established for implementing the EDP essentially starts with voluntary election to participate on the part of each IKAHAK family, formation of a Project Group with other interested families to meet regularly, then working to create household budget and cash flow records, weekly savings and a business proposal, in order to be eligible for an enterprise loan.

The project began in February 2009, with the first four families each receiving loans of AUD$400. To date, after two rounds of funding, these families have received loans totaling AUD$3,640 with a 100% repayment rate.

Enterprise projects undertaken by participating families are encouraged to feature a strong social element, to accomplish the dual mission of supporting CAH families and simultaneously the communities they live in. Early enterprises have included cafés, a children's library, flour milling, food stalls, children's math course and a sandal-making venture.

INITIAL OUTCOMES

In this pilot phase of the project, the EDP has already yielded significant outcomes for participants.

Several early indicators suggest the effectiveness of the methodology. With 100% repayment rate and a high rate of on-time payments, this introduction of microfinance to first-time borrowers has been successful. With a first round of loans fully repaid and a second round underway, and borrowers requesting larger loan amounts, the demand for this type of project is proven. This success has lead to interest among the IKAHAK members yet to participate as well, demonstrating potential for expansion of the project.

As a direct result of their families' participation in the EDP, 33% more children with CAH were able to access critical surgeries.

One concern at the beginning of the EDP was that borrowers, without previous experience running a small business, might not be successful at the start leading them to end their involvement with IKAHAK. To the contrary, the perfect repayment rate suggests that borrowers have managed to establish and maintain successful enterprises. Anecdotal evidence from participants also indicates that in spite of challenges, including failed business attempts, borrowers have been able to adjust and establish successful enterprises. Overcoming these challenges has also given participants new confidence in their business potential and optimism for their ability to improve their financial situation.

One of the most significant factors in assessing the early successes of this pilot is the ability of families to care for their children with CAH better as a result of the EDP. To measure this in consumption terms, we looked at the ability of families to provide their children with necessary surgeries. As a direct result of their families' participation in the EDP, 33% more children with CAH were able to access critical surgeries. Both participants in the project and doctors working directly with the IKAHAK member families have confirmed that this has been a clear benefit of the EDP. Not only have children been able to get vital surgeries, their general health has improved with the EDP through the increased ability to access regular medical care.

STRENGTHS & SUCCESSES

Through the combined methodology of conducting interviews, disseminating questionnaires and reviewing existing documentation and literature on the EDP, the following strengths and successes have been identified both in the design of the project and its actual outcomes.

Enhanced Consumption Capacity

The EDP had demonstrated quantitative successes for participants. Among the families participating in the EDP were ten children with CAH, 9 girls and 1 boy. As a direct result of their families' participation in the EDP, 3 of these girls were able to access critical surgeries[1]. This indicates a 33% increase in the consumption capacity of participating families, measured in terms of vital, life-sustaining medical care. This indicates the success of the project in the most fundamental terms, addressing a serious need which families had no prior ability to meet. In addition to the ability to provide necessary surgeries, participating families were also able to visit the doctor with sufficient frequency and have important tests done.

In addition to access to essential healthcare, the success of the EDP can also be measured on consumption terms referring to participating families' financial situations. In the EDP, not only were repayment rates perfect but borrowers took second round loans, requested larger loan amounts and generated interest among other IKAHAK members in joining the EDP. These results may be interpreted as a success of the project in identifying a demand for credit, appropriate methodology for delivering it and successful guidance in helping borrowers become entrepreneurs. Based on the goals of the program, however, the most important result is that participating families were better able to care for their children with CAH.

The EDP resulted in a 33% increase in the consumption capacity of participating families, measured in terms of vital, life-sustaining medical care.

Strong Focus on Social Mission

As stated in the project planning documents, a core value of the EDP is "above all, do no harm." Unlike typical microfinance projects, the primary goal of the EDP is to improve the overall health of children living with CAH. Income-generating activity is seen as the way to do this, rather than an end in itself. Therefore in addition to increased consumption capacity, there are a number of qualitative benefits identified as well such as the development of self esteem through successes in entrepreneurship, solidarity between group members and strengthened ties within the community.

[1] In many girls with CAH, the clitoris is enlarged, resembling a small penis, and may obstruct the entrance to the vagina. Surgery is needed to reduce the size of the clitoris, separate the fused labia and enlarge the vaginal entrance.

This focus has led to the design of a system with a strong social focus. For example, borrowers are encouraged to develop enterprises that in themselves have a mission to better the community. This added social element also leads borrowers to identify needs in the community that form a solid market base.

Additionally, this fundamental social focus implied the involvement of borrowers in the development of the system itself. From the beginning, borrowers were invited to review the project proposal and provide feedback. They were encouraged to select mentors in the business plan development process, and participate in determining their own repayment schedule. In combination with a cultural tendency to feel shame in not being able to make payments, this approach led to a perfect repayment rate.

Division of Roles Between IKAHAK and CLAN

As the partner on the ground, IKAHAK served the role of implementer, identifying ways of engaging IKAHAK families, providing them with the necessary support and orchestrating the process of disseminating and collecting loan payments. Given the cultural knowledge and on-the-ground presence of the organization, they were effective in this capacity. CLAN, based in Australia and operational in a number of countries, provided strategic and funding support. CLAN's experience implementing similar projects in other countries was crucial in developing the framework for the EDP. Relationships with the international donor community also put CLAN in a much better position to raise funds for the project than IKAHAK.

Moving forward this evaluation suggests that these roles combine somewhat, so that CLAN has more presence on the ground and IKAHAK develops its local fundraising capacity (for example through setting up a foundation in Jakarta), but in this early pilot stage the appropriate division of responsibilities was an important factor in this success. An important factor in the success of the project has been IKAHAK's ability to run the project on the ground independently from CLAN, but in the future reporting and communications mechanisms should be strengthened so that CLAN is more prepared to offer support as needed.

Addressing the Unique Characteristics of Participants

As explained in the introduction, participants in the EDP are unique from other microfinance borrowers in that they share the experience of having a child with CAH. The IKAHAK-CLAN EDP successfully incorporated this unique characteristic into the methodology. For example, group meetings were held at the hospital where all participants go to access medical care for their children, taking advantage of a common destination to bring together a geographically dispersed group. At the same time, the EDP was designed with the utmost caution to avoid estrangement of the family from their support group and their medical facilities in the event of an unsuccessful enterprise attempt.

The EDP recognized that unlike most microfinance borrowers, IKAHAK families were not poor until having a child with CAH, and due to the heavy costs of health care (in particular emergencies) are especially vulnerable financially. This difference was addressed through the provision of extra training and education in managing a business, as well as the use of mentors as experienced entrepreneurs to help guide the process.

In the solidarity group lending model, borrowers are unified in their commitment to each other purely through social relationships within the community. Sharing the unique experience of caring for a child with CAH, in the case of the EDP this relationship is much stronger. The power it demonstrated in the pilot phase suggests that it could be expanded to families of children living with other chronic diseases, for example diabetes.

Meeting Local Circumstances

The EDP was tailored in many ways to the local circumstances of borrowers that made the logistics and also underlying approach much stronger. One of the most important contributing factors is Lenny Kristiana, an IKAHAK member, herself a borrower and mother of a child with CAH who served the role of Group Project Leader and spearheaded the bulk of on the ground activities. Lenny's day to day understanding of the cultural and logistical challenges involved in the project allowed IKAHAK and CLAN to develop systems that met local needs.

For example, given the geographic dispersion of clients remote forms of communication and payment were employed. Borrowers made bank transfers for their repayments at low costs and relative convenience. When group members were not able to meet at the hospital at the same time, they communicated by phone which they found equally effective and much more affordable. This ability to adapt to the geographic issue kept administrative costs low and circumvented the prohibitive factor of traveling long distances at high costs. Lenny's on the ground knowledge also allowed IKAHAK and CLAN to develop repayment schedules that coincided with borrowers' cash flow.

Additional Services

Another distinction between the EDP model and typical microfinance activity is the heavy focus on additional support services for borrowers. Microfinance institutions sometimes offer additional services with loan products such as business training, credit education and technical assistance, but many would argue that this does not happen frequently enough, as these services tend to be expensive and are not always linked directly to improved repayment rates. In the case of the EDP, the unique needs of participants demanded that additional services be integrated into the core methodology. For example, the EDP focused on supplementing social services already offered by the government such as funding for surgeries, drugs and health insurance.

The EDP also focused on education of borrowers, both in terms of financial literacy and the importance of health insurance. When children with CAH are young it is important to focus on the ability of their families to care for them. As they get older, however, they will need to be able to financially support themselves. The EDP's requirement that children of participating families be enrolled in school is directed toward this need, showing a view to the long-term benefits of participants.

CHALLENGES & WEAKNESSES

This section discusses challenges and weaknesses faced by the EDP in actual terms as well as in the design and tools for implementing the project.

Clarify Roles & Responsibilities

In a fundamental way, the division of roles and responsibilities was a major point of success in the pilot phase of the EDP. The respective roles of IKAHAK and CLAN were appropriate, the role played by the Group Project Leader as a local person and IKAHAK member was extremely effective and the use of mentors to support business development was an important form of support for borrowers. In the next phase of the project, each of these roles should be even more clearly defined and taken to the next level.

The role played by the Group Project Leader was vitally important to the point of bearing too much responsibility for the success of the project. As the coordinator of group meetings, loan disbursements and collections, liaison with CLAN as well as an entrepreneur/borrower and mother of a child with CAH herself, the importance of the Group Project Leader's role was tremendously valuable but ultimately unsustainable. More individuals should be trained to play this role, and a division of some of these responsibilities should be considered. For example, group leaders should also be borrowers and should report to CLAN, but should not necessarily also be responsible for disbursing and collecting loan payments and coordinating meetings. This role might best be played by a formal employee of the program.

While the mentor role is important, it was conceived in theory more successfully than it was implemented in practice. As borrowers selected their own mentors, the division between the two and accountability of mentors was somewhat compromised. Particularly given the fact that mentors received compensation, a more rigorous emphasis on their role and responsibility, as well as ways of tracking their success in fulfilling it are important. In the future the possibility of experienced EDP participants in serving this role should be explored.

The roles and responsibilities of each position detailed above should be written out clearly, and training materials and processes should be developed in the future to ensure consistency and standardized practices once multiple people serve these roles as the EDP expands.

Need for Built-in Evaluation Mechanisms

In the pilot phase of this project, a full-scale evaluation is necessary to identify ways of moving forward. However in the future, the methodology would benefit from built-in mechanisms for evaluating success through smaller, short-term milestones. For example, participating families should always be required to track monthly household income and expenses before participating in the EDP as well as after. The same is true for tracking indicators of ability to offer health care to children with CAH. More quantitative questions along these lines should be included in project documentation and in some cases attempts to quantify qualitative impacts would also be helpful. Participating families should be asked to complete surveys about their experience once they have finished repaying each loan. A basic set of indicators for evaluating success should also be developed by IKAHAK and CLAN, to ensure that all dimensions and objectives of the project are tracked and that the methodology is adjusted based on the results.

Geographic Dispersion of Participants

While the EDP implementing team found ways of running the project successfully in spite of the issue of great distance between participants, it has not fully been resolved as an obstacle. Although telecommunication has served as a decent replacement for in-person meetings, especially given that the strength in this methodology lies in the bond between participants of their shared experiences with CAH, remote communication cannot fully replace in-person exchanges. Participants are so geographically dispersed that they even operate within slightly different cultural circumstances, making relationships from a distance even more challenging.

As the hospital is a centralized meeting place and borrowers must visit it to ensure their children are adequately cared for, making the most of this central meeting spot is ideal. Standardizing a schedule of doctors meetings, organizing a reliable and possibly subsidized system of transportation to the hospital and setting up accommodation in or near the hospital designed specifically for families participating in the EDP are potential ways of addressing this obstacle.

If the EDP can incorporate ways to bring families together more often it can more fully maximize the value of the shared experience of participants as family members of children with CAH. For example, group meetings can better serve as opportunities not only to make loan payments and discuss entrepreneurial experiences but also receive drugs, tests and examinations from doctors as well as educational sessions and informational materials on topics such as health insurance, how to care for a child recently diagnosed with CAH, etc.

Documentation, Reporting and Recording Systems

The EDP has thus far proven to be a successful methodology, with the potential to expand. If it is to be scaled up, strengthening of documentation, reporting and recording systems will be necessary.

One of the strengths of the EDP is the division of roles between IKAHAK and CLAN. This strength would be enhanced with more effective reporting mechanisms in place. For example, more capacity for translation between Bahasa and English is needed. All meetings should be documented with electronic notes which are then kept on file and made available to a range of individuals in operational roles. Forms for reporting by Project Group Leaders to CLAN representatives, on a weekly or monthly basis, should also be developed, used and stored in such a way that they can be reviewed during transition times or at year-end, for example. Feedback forms from participating families will also play an important role in continuing to incorporate their input in developing the methodology.

More formal financial reporting systems should be developed. Standardized forms should be used not only to track funds activity by month but also repayment status on a loan by loan basis. This is crucial in terms of scalability. As the EDP grows, options for management information systems should be considered. There are many free MIS and financial planning software options available for small and growing microfinance projects that could potentially offer substantial support to the growth of the EDP.

In terms of documentation, as mentioned above the roles and responsibilities of different actors should be clearly defined and explained, with training materials developed for new individuals in these roles. Built-in evaluation systems will be important. The excellent values that this methodology is founded upon will be much more powerful if translated into official protocols which outline clearly, in writing, what the core values are and how they can be embodied in the actions of participants of the EDP. Stronger documentation has the potential to play an important role in marketing and fundraising as well. In order to

expand the EDP, documentation must allow new players to a) replicate the model, and b) read a body of documentation and understand how the project works.

RECOMMENDATIONS FOR MOVING FORWARD

In the previous section ways of addressing current challenges are outlined. This section will focus more on strategies for pursuing more long term goals. These recommendations imply an inherent value in the current methodology which makes it worthwhile to brainstorm new areas of potential.

Local Partnerships

The IKAHAK-CLAN model is an unusual combination of unique and specific characteristics but also potential for benefit from partnerships with local organizations. In its earliest stages the idea for the EDP was to partner with existing microfinance and development organizations in Indonesia. This was not possible in the pilot phase, but should be revisited in subsequent stages.

As EDP participants develop a familiarity with borrowing and a confidence in their business management skills, they become prepared to be successful borrowers of more formal microfinance institutions. Although in the pilot phase loans did not include interest charges, the strong repayment rate, increased credit appetite and cultural understanding of the obligation to repay demonstrated in the pilot phase indicates good preparation for participants to move to interest bearing loans. Development of loan documentation is an important component of this. If EDP loan contracts and repayment schedules can be designed to more closely mirror those offered by local microfinance institutions, EDP participants will be in a much stronger position to access external financial services as financially literate clients.

As care has been taken thus far to prevent the possibility of difficulty with the EDP from alienating participants from the support group or even hospital services, ultimately working with a separate microfinance institution might support this division of roles and further protect the important support group function.

Tools for Supporting Operations

As the EDP develops, some of the tools used by the microfinance industry should be explored for their potential applicability to the EDP. For example, standard forms for assessing poverty and eligibility for microloans could be helpful as the EDP expands in processing loan applications. The Grameen Foundation's Progress out of Poverty tools are useful for this purpose. Training tools for employees of microfinance institutions and financial literacy programs for clients already in existence could be adapted for the purposes of the EDP as well. Microfinance Opportunities, Freedom from Hunger and the Social Performance Task Force are the leaders in the industry for developing training and financial literacy modules. Social performance measurement tools may offer ideas for ways of quantifying non-financial outcomes of the EDP, and for indicators to use when assessing the social impact of the program. Good sources for these tools include the Smart Campaign and Cerise.

Business Potential in Support Group Services

As more families become familiar with the entrepreneurial/social business approach and philosophy, it could be interesting to explore business opportunities that help facilitate the EDP itself. For example, the well-known microfinance institution ProMujer has had success with incorporating a childcare

microenterprise into the group lending methodology so that borrowers are not inhibited from attending group meetings by having to bring their children or find people to look after them. This could potentially be a business run from or near the hospital where EDP participants meet. The concept of a cooperatively-owned pharmacy is also worth considering.

Mobile Banking

Given the issue of geographic dispersion, mobile banking has the potential to be particularly useful for EDP participants. Precedents set by other mobile banking projects in Indonesia may worth reviewing. For example, setting up a mobile phone-based system of making payments could streamline the loan repayment process significantly. It could also facilitate the flow of emergency loans for urgent surgeries, should that practice be expanded into the EDP core methodology. Further, mobile phone systems also have value as an information-sharing platform. For example, a mobile phone-based information sharing platform designed specifically for the EDP could be used to notify participants when certain drugs become available, to set up an FAQ system for families whose children have recently been diagnosed with CAH or to for borrowers to access account statements.

Ways to Involve the CARES Foundation

The CARES Foundation is a US-based organization of families with children living with CAH. Given this strong common bond, ways of connecting the two groups should be explored. Early exploration of the possibility of setting up a Peer-to-Peer lending site to allow CARES Foundation members to make small loans to IKAHAK members has strong potential. Whether as a funding source or information sharing system, or both, the potential connection between these two groups is powerful, and could also set a precedent for similar relationships between groups of families caring for children with chronic diseases in developed and in developing countries.

CONCLUSION

The IKAHAK-CLAN Enterprise Development Program is an innovative model for microfinance meeting the needs of a currently underserved group: families with children suffering from chronic diseases. In its pilot phase, on a very small scale and within a localized context, the methodology shows promise for expansion, both within Indonesia and in other developing countries, as well as within the community of families caring for a child with CAH and into communities of families caring for children with other chronic diseases. The main strengths of the project are its focus on social returns for participants, focused and well-thought out support structures for participants and mobilization of the value in the unique bond shared by borrowers of experience with the same disease. Challenges to address going forward are centered primarily on documentation and institutionalization of practices to enable scalability and replication. Opportunities going forward include integration with local microfinance organizations as well as tools of the broader microfinance industry, inclusion of a mobile banking component and potential partnerships with organizations of families living with CAH in developed countries. Perhaps the most valuable, exciting potential for the future is for this methodology to develop into one that can be widely used to support the income generating capacity for families and individuals living with chronic diseases in developing countries across the world, an enormous population internationally that is currently underserved by both the development health and microfinance industries.

ANNEX

QUESTIONNAIRES

The following questionnaire represents a full set of questions given to all recipients of the questionnaire. In reality, slightly different questions were posed to different types of participants in the EDP.

General

- Please name 3 strengths/benefits of the EDP
- Please name 3 weaknesses/challenges of the EDP
- Please make 3 suggestions for how to do things differently.
- Did the EDP address the challenge of geographic location of families and doctors? How might it address this issue in the future?
- Was the role of the doctors and other medical service providers in the EDP appropriate/effective? Why or why not? Could it be improved in the future?
- Is health insurance an issue? If so, how might the EDP address this issue going forward?
- Is the EDP a model that could be expanded to include families with members suffering from other chronic diseases? Why or why not?
- How many loans were disbursed in EDP Round 1? EDP Round 2?
- Do the EDP families have health insurance? How many? If not why not?
- Do the children in the EDP families go to school? How many? If not why not?
- What is the age range of the children with CAH?
- How often did the families participating in the EDP meet? Was this often enough? More than enough?
- Was the geographic location of the EDP families an obstacle to the success of the EDP? If so, how and how was it addressed?
- If the families were to meet at the hospital, do you think this would be a good idea? Why or why not?
- How successful were the businesses started as a part of the EDP? Are they still running? Are they growing? What could have been done differently to make them more successful?
- How many more families do you think would be interested in/could benefit from participating in the EDP? Do you think more will want to participate in the future? Why or why not?
- Do you think more medical services could be combined with the EDP going forward (eg sharing information/experiences, using group meetings for tests/examinations, distributing medications, etc)? If so, what types of services? If not, why not?

Partnerships

- Do you think the division of responsibilities/roles of CLAN and IKAHAK was appropriate? Why or why not? Is there any way you would do it differently next time?
- Do you feel that CLAN has been kept informed well enough of activities on the ground? How might communication be improved going forward?

Operational approach

- Do you think the general approach worked well? Why or why not? What would you do differently?
- Was the unifying force of a shared experience (having a child with CAH) among support group members maximized? Why or why not? How else could we make use of this unique feature?
- How were administrative costs minimized?
- What is the emergency loan process? Who is the committee and how do they operate? What are the criteria? Has this been used and how has it worked?
- Were original estimates for demand accurate? How could they be revised?
- Apart from the mentors, who involved in the EDP received compensation for their involvement?

Challenges

- Did you experience any of the "factors known to be associated with failure" (from project writeup: complicated process, high admin costs, application process too long, loans used to pay for non-income generating purposes and leads to increased stress, no mentor/expert for business advice, NGO is inexperienced)?
- Was the use of the same bank account for loans/repayments and medicine purchases an issue?
- Any issues with translation? Need more translators? Delays?
- Do you see the fact that Lenny is the only person doing her job a risk? How easily might she be able to train others to do her job?
- Any challenges causing delays in the progression of the project that could be addressed?

Future of project

- Do you see any ways to get CARES Foundation involved?
- Do you see potential in the possibility of forming a foundation (in Jakarta, as suggested by Dr. Aman)
- Can health insurance be a focus of future phases of the project?
- How can we scale up this project? Do you feel the methodology is established well enough to scale up the project?

Documentation

- Do you feel that the forms developed for the EDP have been sufficient/effective in terms of
    - Getting the project going (ie engaging the right participants, selecting the right businesses)?
    - Managing the repayment process and progress/challenges during the loan terms?
    - Enabling CLAN to understand and track progress of activities on the ground?
    - Gathering information to evaluate the success of the project?
    - Enabling replication of the project in new locations?

- Do you feel that the forms/systems used for recording/tracking financials (ie loans disbursed, repayment progress, expenses of the program, etc.) were effective? How could they be improved going forward?

- Please speak to the effectiveness of any/all of the following forms (if possible):
  - Business Development Proposal
  - Project Approval Checklist
  - Loan Contract
  - Project Status Report
  - Post-project Evaluation Report

- What additional documentation would be helpful going forward?

Repayment – Along with these answers, please provide financial statements or any other records used to track repayments, in English.

- How often did EDP borrowers make late payments? Please be specific as possible, in terms of numbers of loans repaid late, frequency of lateness, etc.
- How often were borrowers unable to pay back loans at all?

- When borrowers had difficulty repaying loans, what was the reason for their difficulty? Business struggling? Difficulty paying health-related costs? Payments too large or too frequent?
- Did borrowers every have trouble physically making payments? For example, if they gave cash did they have difficulty storing cash? If they made bank transfers did they have difficulty doing so or paying for it?

- Did borrowers have any complaints about loan terms or suggestions for terms they would prefer?
- How would you set up the repayment process differently next time?
- Were borrowers able to meet their savings requirements? If so, how many? If not, why not? What was done with this savings?

Impact on Families – To answer these questions, please use both specific examples as well as give a general sense of the answer for the majority of participating families.

- Do you think the EDP helped the families involved? Why?

- As a result of the EDP, were families able to offer their children with CAH medical services that were previously unavailable to them such as surgeries, medicine, doctor visits, etc.? Please include a quantity for each service, eg how many families were able to afford surgeries as a result of the EDP? How many surgeries?

- As a result of the EDP, did household income levels increase? How can you tell?

- As a result of the EDP, were families able to:
  - Pay for their children's education?
  - Make improvements to their homes?
  - Take care of emergencies?
  - Buy new furniture, electronics or any other household appliances?
  - Anything else that borrowers were able to do/purchase as a result of the EDP?

- Did borrowers gain any new skills or knowledge as a result of participating in the EDP? If so, what types of skills or knowledge? Who gained these skills or knowledge?

- In your opinion, are borrowers better off as a result of the EDP? If yes, how can you tell? If no, what could have been done differently?

Community Impact

- Did the relationships between families participating in the EDP change as a result of their participation?
- Did the relationships between families in the same support group who participated in the EDP and those who did not participate change?
- Did the role of the participating families within the broader community change as a result of the EDP?
- Was the family dynamic within families participating in the EDP affected at all by their participation?

Project Leaders

- Lenny, how would you describe your own role in the EDP? What would you do differently if you could? Was there anything you wanted to be able to do but couldn't, and if so why couldn't you?
- What was the role of the mentors? Were they helpful for the overall success of the project? What could they have done differently?
- What was the role of the group leaders? Were they helpful for the overall success of the project? What could they have done differently?
- Were there any functions that were not met by those involved in the EDP? What additional roles could be useful going forward?

Previous Evaluations

- Have you ever asked EDP families for feedback? If so what was their feedback? Please provide translated comments from families, including the questions they were asked (also translated).
- Have families been asked to track their household income and expenditures? Before and after the EDP? If so, please send these to me, translated.