



# Peers for Progress

*Peer Support Around the World*

A program of the American Academy of Family Physicians Foundation

## Diabetes, Peer Support & Global Programs: Looking Forward with Peers for Progress and Broader Research Partners

*KUALA LUMPUR, MALAYSIA, OCTOBER 13-15, 2010*

### MEETING REPORT





**Diabetes, Peer Support, and Global Programs:  
Looking Forward with Peers for Progress and Broader Research Partners**

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### EXECUTIVE SUMMARY

*Peers for Progress* is a program of the American Academy of Family Physicians Foundation. The mission of *Peers for Progress* is to promote and advance peer support as a key part of health, health care, and prevention around the world. In October 2010, over 60 representatives of peer support programs and organizations – from 14 *Peers for Progress* Evaluation Grantees and over 40 groups involved in peer support from around the world - met in Kuala Lumpur, Malaysia to identify and discuss critical aspects of peer support interventions, their effects, dissemination, sustainability, and implications for next steps.

The purpose of this Meeting Report is to highlight cross-cutting points and key themes that are emerging from this learning community, and to frame them as considerations for strengthening peer support as a key part of health, health care, and prevention around the world. Additional details for each point can be found in the main report.

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#### A. PEER SUPPORT: PROGRAM DEVELOPMENT

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##### SELECTING PEER SUPPORTERS – WHAT MAKES A GOOD PEER SUPPORTER?

- Interpersonal skills for building relationships are just as, if not more, important than demonstrating mastery of self-management skills.
- Rather than trying to select good peer supporters via a number of specific criteria, select people based on personal and interpersonal characteristics, train them, and see who blossoms along the way.
- Peer supporters may be motivated by both the opportunity for their own growth and by the opportunity to serve their community. Consider both of these in recruitment.
- Being a peer supporter can have unintended consequences (e.g., stigmatization), so selection requires careful consideration.

##### TRAINING PEER SUPPORTERS

- Ongoing supervision and feedback are just as – if not more – important than training that occurs before allowing peer supporters to start delivering peer support.
- Both education regarding the nature of problems to be addressed and building communication and related skills are essential training components to prepare and enhance the confidence of peer supporters to provide peer support.
- Training for ongoing support will need to be informed by both foundational knowledge and local realities of context.

##### ROLE OF PEER SUPPORTERS

- While the title of those delivering peer support programs may vary, supporter roles should be based on the core functions they aim to serve.



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- In some cases, the location (e.g., health clinic), highly organized protocol (e.g., research study), or formal designation (e.g., paid staff) of a peer support program may compromise its “peerage” nature and receptivity of the peer supporter role.

## PEER SUPPORT AND ENHANCING LINKAGES TO CARE

- Peer supporters can become integrated, effective members of clinic-based health care teams and/or systems.
- No matter the particular setting or organizational context of peer support, “enhancing linkages to care” includes but is more than getting patients to visit their doctor.

## ONGOING SUPPORT

- Ongoing support for behavior change pays attention to both the ebbs and flows for managing health and improving quality of life.
- Nurture naturalistic opportunities for support rather than just try to structure planned contacts.
- While frequency and length of contact matter, peer support is also about developing quality relationships, not just increasing the number of connections.
- Ongoing support to manage complex behaviors requires repeated planning for strategies that identify and respond to needs over time.

## USE OF INNOVATIVE TECHNOLOGIES

- Technologies for peer support can improve access, regular contact, diffusion and uptake, and data collection.

## CULTURAL VARIATIONS IN HOW TO ORGANIZE PEER SUPPORT

- Peer support can effectively address multiple and varied influences on behavior.
- Problems and solutions related to designing and improving peer support programs exist all over the world.

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## **B. EVALUATION AND EVIDENCE OF PEER SUPPORT**

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### FEASIBILITY, EARLY, AND BROAD IMPACTS

- Across varied settings, populations, cultures, and other contexts, peer support is indeed feasible.
- Tailored, ongoing support by peers – via modest investment in resources – can lead to striking clinical and behavioral improvements.
- Variety, frequency, and amount of contact are directly proportional to efficacy and amount of impact.



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## RESEARCH CONSIDERATIONS

- In a study of peer support, geographic proximities are an important feature on which to match participants.
- Look beyond traditional, clinical markers of success when examining the impact of peer support.
- Look at those delivering and receiving when evaluating the impact of peer support.
- Understanding the impact of peer support means also looking at related conditions such as depression and overall mental health.
- Research protocols should be informed by early and frequent planning for both program development and sustainability.

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## C. SUSTAINABILITY and INSTITUTIONALIZATION

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### ATTENTION TO PEOPLE, ORGANIZATIONS, AND RESOURCES (BOTH PROGRAMMATIC & FINANCIAL)

- Demonstrating early accomplishments and value-added can result in stakeholder buy-in and other support.
- “Business cases” that define peer support and promote its necessity and value-added are an important strategy for creating buy-in and opportunities for sustainability.
- No matter the “organizational home” or “sponsor” of a peer support program, sustainability of peer support requires some kind of infrastructure on which to anchor programs AND building the capacity of organizations to manage and own the program.
- Sustainability may require funding, but also depends on defining the organizational and programmatic aspects of a program’s “value-added.”
- Peer support approaches, inspired by social ecology and grounded in patient perspectives, may enable effective “task shifting” and produce improved outcomes.
- In the context of patient-centered medical home (PCMH), peer support can be a powerful strategy for community outreach, engagement, linkages to care, and health and disease management.
- Options for sustainability are strengthened by multi-leveled efforts that are informed and supported by context.
- Make research programs subordinate to – or at least on-par with - sustainability programming and plans.
- Plan for sustainability of peer support as good health care for all people, not just affordable health care for vulnerable populations.



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## D. GENERALIZEABILITY AND ADVOCACY

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### LOOKING WHERE WE ARE AND LOOKING AHEAD

- Peer support programs are applicable, feasible, and effective across a number of conditions, populations, and behaviors.
- Although details of implementation may vary from place to place, core principles of peer support can cut across and apply to wide-ranging contexts.
- Peer support can be an effective strategy to connect and build social capital across multiple levels.
- Challenges and opportunities related to ongoing support for health and disease management can be found all over the world.
- Ethics is more than protection of human subjects in research. Peer support programs can contribute to community advocacy for improving ethical principles and services related to health.
- Evaluation addressing long-term and systematic impact can significantly contribute to advocacy and policies supporting peer support programs.
- Promoting and advocating for peer support requires a kind of ecological approach at different levels and from multiple directions.
- Widespread diffusion and uptake of peer support takes advanced planning and relies on more than evidence of efficacy.

*Peers for Progress* is dedicated to advancing and promoting peer support, not just as affordable prevention and health care for poor people, but as good prevention and health care for all people. Doing so requires ongoing attention to knowledge management and exchange regarding peer support; global networking; and longer-term thinking about sustaining and advocating for peer support.

This meeting, as indicated by the range of participants, extent of discussions, and the wealth of ideas exchanged, provides extensive evidence that both the need for and solutions related to designing and improving peer support programs exist all over the world. *Peers for Progress* and broader members of the Global Network learning community remain both the source and vehicle for extending the evidence, managing and exchanging knowledge, and facilitating interactions to apply, sustain, and advocate for peer support as good prevention and health care for all people around the world.



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## BACKGROUND

*Peers for Progress* is a program of the American Academy of Family Physicians Foundation. The mission of *Peers for Progress* is to promote and advance peer support as a key part of health, health care, and prevention around the world. Research has shown that people need practical, social, emotional, and ongoing support to manage and maintain good behaviors for health. In particular, peers – people sharing similar experiences with a disease or condition - can be great sources of support for each other. To advance and promote peer support programs, *Peers for Progress* is focused on expanding the evidence base for peer support, global networking and knowledge sharing, and advocacy.

In October 2010, over 50 representatives of peer support programs and organizations – from 14 *Peers for Progress* Evaluation Grantees and over 40 groups involved in peer support from around the world - met in Kuala Lumpur, Malaysia. Across varied contexts and topics, participants gathered to exchange ideas about the development, application, and contributions of peer support as a critical part of prevention and global health care. Overall, the purpose of the meeting was to

- ❖ Examine and exchange ideas regarding what we know about peer support, its application, and contribution to health promotion and health care;
- ❖ Facilitate communication and global networking among peer support programs for quality improvement; and
- ❖ Identify strategies for dissemination and advocacy of peer support as a routine part of health care and prevention for all people.

In addition to grantees from Australia, Cameroon, Hong Kong, South Africa, Thailand, Uganda, United Kingdom, and the United States, this meeting included leaders in peer support projects from Cambodia, Chile, China, India, Iran, Iraq, Malaysia, Netherlands, Pakistan, and Sri Lanka. Participants formed a learning community of co-experts across various content (e.g., diabetes, cancer, HIV, maternal and child health, mental health) and contexts (e.g., rural populations, women, ethnic minorities) to identify and discuss critical aspects of peer support interventions, their effects, dissemination, and sustainability.

The purpose of this Meeting Report is to highlight cross-cutting points and key themes that are emerging from this learning community, and to frame them as considerations for strengthening peer support as a key part of health, health care, and prevention around the world. Ultimately, *Peers for Progress*, in collaboration with a broader network of peer support affiliates, aims to raise the visibility of evidence for and benefits of peer support programs, not just as affordable health care for poor people, but as good health care for all people.



### PREFACE

There is no “one size fits all” approach or uniform strategy for peer support to meet the needs of all populations in all places around the world. Complex behaviors (e.g., eating patterns), social contexts (e.g., family roles), and styles of support (e.g., appropriateness of eye contact) associated with health are fundamentally dependent on culture, so peer support approaches will need to vary to address them. Still, a set of common, functional components can coherently define peer support around the world, and then be applied flexibly according to local and regional contexts, populations, health systems, and cultural perspectives to effectively address needs. *Peers for Progress*' global approach to research and program development of peer support is based on the need for both standardization (that offers coherence) and flexibility (to enhance relevance and utility) and a balance between them.

As outlined in a [2010 Family Practice Supplement](#), *Peers for Progress* has identified the following four key functions of peer support:

- i) Assistance in applying disease management or prevention plans in daily life (e.g., goal setting, skill building, practice and rehearsal of behaviors, trouble-shooting, problem solving)
- ii) Emotional and social support (e.g., encouragement in use of skills, dealing with stress, and simply being available to talk with people troubled by negative emotions)
- iii) Linkage to clinical care (e.g., liaison to clinical care, patient activation to communicate and assert themselves to obtain regular and quality care)
- iv) Ongoing support (e.g., proactive, flexible, as-needed/on-demand, extended over time)

These four key functions provide a template for planning and development of peer support programs tailored to local needs and resources. They have emerged based on research and on the experience of grantees of *Peers for Progress* and other leaders in the field. *Peers for Progress* anticipates revisions to the scope and extent of peer support's key functions over time to evolve with global experience that sharpens their features.

If a global approach to peer support requires attention to both unifying functions and tailored implementation, then challenges to designing and improving peer support programs exist all over the world. Anchored in aspects of designing, implementing, evaluating, and sustaining peer support programs, this October 2010 meeting was designed to draw on wide-ranging, illustrative case examples of the work, and then catalyze group discussion to identify broader lessons.

What follows are a set of substantive ideas about peer support from such discussions according to a set of key themes, followed by overall considerations and next steps:

- A. Program Development
- B. Evidence and Evaluation
- C. Sustainability and Institutionalization, and
- D. Generalizeability and Advocacy

*NOTE: Specific conference materials can be found at the conference website noted in the footer.*



## Meeting Reflections

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### A. PEER SUPPORT: PROGRAM DEVELOPMENT

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#### SELECTING PEER SUPPORTERS – WHAT MAKES A GOOD PEER SUPPORTER?

- *Interpersonal skills for building relationships are just as, if not more, important than demonstrating mastery of self-management skills.* Exchanging support is not about displaying complete “mastery” of self-management, per se. While some degree of metabolic control may be important for a potential peer supporter to demonstrate their relative experience in self management, selection of peer supporters should also be based on interpersonal traits such as empathy that are important for building relationships.
- *Rather than trying to select good peer supporters via a number of specific criteria, select people based on personal and interpersonal characteristics, train them, and see who blossoms along the way.* We may not be precisely able to predict and control for who is a good peer supporter, especially from relying on a set of clinical protocols that may fail to touch on important relationship aspects of “peerage.” Instead, make selections based on the topics noted above, incorporate observations into training and group interactions, and make decisions about social and interactive performance for moving on to and taking next steps to become a peer supporter.
- *Peer supporters may be motivated by both the opportunity for their own growth and by the opportunity to serve their community. Consider both of these in recruitment.* People have different motives for wanting to provide support to others. Some are interested in volunteerism and self-oriented motives to apply and enhance their own skills, while others may be guided by more of a collectivistic orientation and want to give something back to their families and communities. Many will be responsive to both of these motives. Probing for both sets of motives can lead to developing a dynamic cadre of effective peer supporters who can interact with different kinds of people.
- *Being a peer supporter can have unintended consequences (e.g., stigmatization), so selection requires careful consideration.* Peer support programs often involve empowerment, building strength and leadership by connecting people who share some characteristic of identity (e.g., youth, gender, geographic area). This point of connection often also involves a shared disease or condition. When peer supporters are based on conventional or accepted models (e.g., mothers living in a common community who are working on child development), people are valued for contributions. When peer supporters are based on a stigmatized condition (e.g., people with HIV as peer leaders), a stigmatized person can be aiding other people who are similarly stigmatized. As a result, people publicly identified by their disease may become isolated and even return to risky behaviors (i.e., substance use, unprotected sex) that reinforce others labeling them as deviant.



### TRAINING PEER SUPPORTERS

- *Ongoing supervision and feedback are just as – if not more - important than training that occurs before allowing peer supporters to start delivering peer support.* Training programs for peer supporters can vary tremendously in terms of their length and extent. Some train to a high level of sophistication, almost trying to get “everything right” and testing for performance of certain competencies (e.g., pass or fail) that are required to demonstrate that someone is “ready” to be a peer supporter. Other programs train toward a basic set of skills and then incorporate observation, feedback, and remediation into planned rehearsals and then regular delivery of peer support. Overall, observation and feedback regarding peer support encounters, followed by ongoing training and “fidelity checks,” are critical for shaping and reinforcing effective peer support. Such ongoing support for peer supporters can also make sure their needs are recognized and met.
- *Both education regarding the nature of problems to be addressed and building communication and related skills are essential training components to prepare and enhance the confidence of peer supporters to provide peer support.* Peer supporters are not certified educators, professional counselors, nor do they replace the roles of health care professionals involved in chronic disease management and care. Yet a foundation of information about a specific disease or condition and teaching, facilitation, and communication skills can enhance both their ability to build relationships with people and the certainty to know when and how to utilize referral resources appropriately to complement other health care services. Programs may provide different levels and combinations of up-front training, yet the inclusion of both content and skills-building components are important for developing effective peer supporters.
- *Training for ongoing support will need to be informed by both foundational knowledge and local realities of context.* Most peer support programs build from a basic foundation or “101” of knowledge and skills that frame health promotion and disease management, often for certain conditions. For example, insulin/other medications and glucose monitoring are important aspects of diabetes self-management. Yet in some countries and communities, supplies for such activities are scarce or non-existent. Training for ongoing support that seeks to assist people with practical, emotional, and other social resources will need to incorporate knowledge of the field and the practical knowledge of the peers’ familiarity with the living circumstances of the people they are trying to help.

### ROLE OF PEER SUPPORTERS

- *While the title of those delivering peer support programs may vary, supporter roles should be based on the core functions they aim to serve.* Community health workers, promotoras, lay health workers, peer leaders, peer coaches . . . peer support is called by many different designations, and can take on many different forms – often in response to local cultures, existing resources, and other features of context. Across peer support, the aim should not be to standardize titles, per se. Instead, program planners can build programs and measure impact of peer support roles according to the cross-cutting set of four functions – instrumental/practical, social/emotional, linkages to care, and ongoing support - that various peer support positions aim to serve.



- *In some cases, the location (e.g., health clinic), highly organized protocol (e.g., research study), or formal designation (e.g., paid staff) of a peer support program may compromise its “peerage” nature and receptivity of the peer supporter role. One repeated, yet hard-to-measure aspect of a peer supporter’s role is “just being there” – being available as a reliable person “like me” to listen and help someone manage and get through difficult tasks and times. Sometimes, an official title, setting, or protocol for this engagement can potentially influence that degree of perceived “sameness” in condition, abilities, qualities, and status between a peer supporter and person with whom they are working. Yet, the role of the peer supporter may be central to their retention. For example, despite being volunteers, peer supporters may want to build their knowledge and skills to take on added responsibilities and build their own skill sets. Such issues can be at odds with each other. Planners may need to take these and other features of context into consideration of the design, implementation, and evaluation of a peer support program and its impact.*

### PEER SUPPORT AND ENHANCING LINKAGES TO CARE

- *Peer supporters can become integrated, effective members of clinic-based health care teams and/or systems. They can be site-based liaisons between providers and patients, attending visits, participating in practice “huddles,” sharing data about clinical values (with consent), and attending project meetings. Such integration of peer supporters can help to create proactive, prepared practice teams and provide a reality check to keep things “patient centered.” They must also address privacy/confidentiality concerns and sometimes professionals’ skepticism about such involvement by demonstrating value in terms to which providers can relate (e.g., reported satisfaction levels). Overall, peer supporters can be a powerful strategy for community outreach and engagement to enhance patient-centered medical homes and neighborhoods.*
- *No matter the particular setting or organizational context of peer support, “enhancing linkages to care” includes but is more than getting patients to visit their doctor. In a community-based program, peer supporters can also work with patients, providers, and clinics to encourage and facilitate health care appointments, work with clients to prepare for and debrief from them, and help put recommended actions into practice. Overall, across organizational settings, peer support efforts to enhance linkages to care should also focus on creating informed, activated patients by addressing issues such as health literacy, communication, and understanding and improving consumer perspectives on utility of services.*

### ONGOING SUPPORT

- *Ongoing support for behavior change pays attention to both the ebbs and flows for managing health and improving quality of life. Complex behavior change requires a plan, skills for putting the plan into action, and ongoing support to deal with all the practical and emotional ups and downs that come with it. It is important to identify and respond to “triggering events” such as a new diagnosis or significant life change; it is equally important to reinforce healthy strides and progress to keep momentum going.*



- *Nurture naturalistic opportunities for support rather than just try to structure planned contacts.* Accidental encounters matter (i.e., casual contacts in a neighborhood). Where people live may be just as, possibly more, important than other demographics or social affinities that people share and that bring people together. It may make more sense, for example, to match peers based on geographic proximity than clinical characteristics.
- *While frequency and length of contact matter, peer support is also about developing quality relationships, not just increasing the number of connections.* Success in behavior change programs is often most influenced by the length of the intervention. Duration, frequency, and variety of contact matter (e.g., monthly meetings, in-between contacts; family meetings in the hospital following diagnosis; shopping and cooking among peer support group members), as do multiple layers and modes of delivery (e.g., resource books, phone contact, face-to-face time, social networking). At the same time, focus on the nature and quality of connections and not just occasioning them.
- *Ongoing support to manage complex behaviors requires repeated planning for strategies that identify and respond to needs over time.* Planners of peer support programs cannot just hope for peer support activities and related benefits to continue. It is important to check-in with peer supporters and those receiving support to amplify what is working and make adjustments in what is not working. Ongoing support requires ongoing planning.

#### USE OF INNOVATIVE TECHNOLOGIES

- *Technologies for peer support can improve access, regular contact, diffusion and uptake, and data collection.* A number of innovative technologies (e.g., text messages, fixed-cost, prepaid cell phone networks) can facilitate peer support and address geographic and other challenges. Such innovations can also enhance evaluation via data monitoring (e.g., who initiated contact, duration of contact, GPS function to track location-based services). They can also have economic and other practical challenges, though, that can impede their value-added (e.g., extreme costs of airtime; access to electricity to charge phones). Plus, technologies do not always remain at the end of a sponsored-project. Planners should consider the tradeoffs that may accompany innovative technologies for peer support, and plan for other resources or tools for participants to continue peer support.

#### CULTURAL VARIATIONS IN HOW TO ORGANIZE PEER SUPPORT

- *Peer support can effectively address multiple and varied influences on behavior.* Such support can address features of individuals, families, other social groups, neighborhoods, organizations, and communities. Peer supporters can impact several domains of a person's life, and can build a bridge to connect both social capital and direct service influences on health. Audience characteristics may suggest different approaches and delivery systems for peer support (e.g., non-alcohol sports, other activities for men; support groups for women). Planners should also be mindful of the interactions among peer support programs, their delivery, and cultural contexts. For example, in some cultures, support groups may be sufficient to catalyze other one-on-one contact among individuals; in other populations and cultures, one-on-one contact over time may be required to stimulate trust for shared, group contact and support.



- *Problems and solutions related to designing and improving peer support programs exist all over the world.* Complex behaviors (e.g., eating patterns), social contexts (e.g., family roles), and styles of support (e.g., appropriateness of eye contact) associated with health are fundamentally dependent on culture, so peer support approaches will need to vary to address them. Still, a set of common, functional components can coherently define peer support around the world, and then be applied flexibly to address needs. Planners should use the four key functions of peer support described above for coherence and then tailor them to features of context to make them relevant.

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## B. EVALUATION AND EVIDENCE OF PEER SUPPORT

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### FEASIBILITY, EARLY, AND BROAD IMPACTS

- *Across varied settings, populations, cultures, and other contexts, peer support is indeed feasible.* Peers are being recruited and trained, and people are responding to recruitment and staying engaged in peer support. People who share a common disease or condition are connecting in person, in groups, and via a range of innovative technical strategies (e.g., email, text messaging, cell phone networks) – despite tremendous practical challenges (i.e., distance, access to electricity, access to insulin) and sometimes social challenges (e.g., confidence associated with being an informed consumer of health care services is not a cultural norm among women in certain cultural and geographical settings).
- *Tailored, ongoing support by peers – via modest investment in resources – can lead to striking clinical and behavioral improvements.* A number of *Peers for Progress* Demonstration Grantees indicate early improvements in clinical values such as HbA1c, body mass indices, blood pressure, and fasting blood glucose levels; behaviors such as healthy eating behaviors and physical activity; and quality of life indicators such as satisfaction in quality of health. Additionally, members of the Global Network of Peer Support Organizations - such as [MoPoTsyo in Cambodia](#) (see p.14-15) - are demonstrating cost benefits in addition to similar behavioral and clinical results. Early indications suggest that “peerness,” (i.e., shared characteristics, settings, and experiences), support that is both proactive yet flexible (i.e., both planned and unplanned contact and interactions), and ongoing support over time are associated with improved outcomes. Small changes can make a big difference.
- *Variety, frequency, and amount of contact are directly proportional to efficacy and amount of impact.* Early findings from *Peers for Progress* Demonstration Grantees heighten the programmatic need for providing ongoing support – peer support is not a time-limited number of group sessions. These results reinforce the importance of duration of contact as critical for behavior change and health improvement demonstrated in diabetes, smoking, and weight loss.



### RESEARCH CONSIDERATIONS

- *In a study of peer support, geographic proximities are an important feature on which to match participants.* From a research perspective, investigators often try to match participants based on gender, ethnicity, or other traditional demographics. With peer support, geographic proximities are just as, possibly more important, than other demographics or social affinities that people share in common and that bring people together. Accidental encounters such as casual contacts in a shared neighborhood matter – in terms of efficacy of peer support as well as looking ahead for lasting effects – so plan with them in mind too.
- *Look beyond traditional, clinical markers of success when examining the impact of peer support.* Understanding the contribution of peer support requires process evaluations, collection of both quantitative and qualitative data collection, and the pursuit of longer-term, systematic evaluations to examine impact and to inform advocacy at the policy level. Qualitative data collection and analysis can capture different dimensions of benefits of peer support that reinforce or even add additional layers to understanding impact beyond commonly identified, objective measures. Such “triangulation” of data can reinforce conclusions from multiple vantage points (e.g., human aspect of restored dignity, business aspect of cost preservation and/or saving, new benefits without overloading official health services).
- *Look at those delivering and receiving when evaluating the impact of peer support.* Research suggests that peer supporters derive health and other quality of life benefits from their role in peer support programs. Examining process-evaluation information, including dose-response and program delivery, from the perspectives of peer supporters and people receiving support, can expand and strengthen the validity of findings.
- *Understanding the impact of peer support means also looking at related conditions such as depression and overall mental health.* Researchers and evaluators should examine general- and disease-specific indicators of distress, the efficacy of such screening tools, and also look at positive mental health as a mediator to disease management and care. Further research should also look at diabetes distress as a mediator of depression, which should include assessing stress level, perceived support and coping skills of peer supporters.
- *Research protocols should be informed by early and frequent planning for both program development and sustainability.* Peer support is like insulin – we would never implement a 6-week protocol, measure immediate effects, stop the intervention, and then expect to measure and find lasting improvements 6-months after the intervention is completed. If ongoing support is critical to motivation of continued health behaviors, then research examining peer support should incorporate efforts to deliver and examine ongoing support over time.



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### C. SUSTAINABILITY and INSTITUTIONALIZATION

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#### ATTENTION TO PEOPLE, ORGANIZATIONS, AND RESOURCES (BOTH PROGRAMMATIC & FINANCIAL)

- *Demonstrating early accomplishments and value-added can result in stakeholder buy-in and other support.* Evaluation “data” – in a variety of forms – is critical for demonstrating value and getting buy-in for collaborating stakeholders. For example, qualitative feedback from health care provider interviews may indicate their endorsement of a peer support program that lets them return to “being a doctor.”
- *“Business cases” that define peer support and promote its necessity and value-added are an important strategy for creating buy-in and opportunities for sustainability.* Such efforts require that you define your stakeholders and target audience(s), understand their needs (i.e., what do they care about? what does this look like?), and package data and information in forms and formats that communicate clearly and make an impact . . . *to them!* So, depending on the audience, peer support cases can be policy briefs with cost data; they can be one-page tip sheets with bar charts and graphs; they can be a photo of a peer support encounter with an accompanying story that describes the experience of those receiving support. The value of a clear and compelling case study can be great.
- *No matter the “organizational home” or “sponsor” of a peer support program, sustainability of peer support requires some kind of infrastructure on which to anchor programs AND building the capacity of organizations to manage and own the program.* Issues and tensions may emerge when considering the “organizational home” of a peer support program. For example, you may embed a peer support program within a medical provider type of system to enhance chances of financial support (e.g., reimbursable services), but then risk bureaucratic procedures compromising its actual delivery and relevance/value to addressing client needs or even risk it getting cut as the system reorganizes. On the other hand, you may embed a peer support program into a community organization to help it be flexible and responsive to client needs, but then risk it being un/under-funded and unstable and compromising the degree to which providers can reliably refer and connect to it. Depending on circumstances, planners may consider starting small and creating scalable infrastructure with linkages to health systems.
- *Sustainability may require funding, but also depends on defining the organizational and programmatic aspects of “value-added.”* Peers are an extremely valuable part of a peer support program, but sustainability is about the “peer support program,” not just the “peers.” Clarifying and promoting the structure (organization and people), features, and value-added of peer support creates and strengthens paths to sustainability. For example, upon peer supporter efforts to connect with patients between doctor appointments and concurrent increases in reported patient satisfaction, certain procedures such as recruitment and training may be integrated into a host organization’s existing volunteer program and materials; organizational leaders may be more receptive to the idea of a text-message protocol to identify and prompt for ongoing support; and systems may prioritize



half-time support for a community health worker. Sometimes, value-added (people, products, services) can be integrated into an organization at little- to no-cost. Demonstration of value-added can pave the way or make the case for other resource investments.

- *Peer support approaches, inspired by social ecology and grounded in patient perspectives, may enable effective “task shifting” and produce improved outcomes.* Traditionally, this idea of task shifting has been a cost-savings approach for health systems to address disease burden, complex patient management needs, and shortages in health workers to transfer duties from primary to more mid-level providers. Shifting certain tasks related to patient-centered support to community health workers and other peer supporters can become an effective strategy for sustaining both services and effects, simultaneously expanding coverage and enhancing the role of community. In an effort to demonstrate the role of peer support, it will be important, though, to focus on articulating real contributions of peer support and not just the off-loading of tasks to others.
- *In the context of patient-centered medical home (PCMH), peer support can be a powerful strategy for community outreach, engagement, linkages to care, and health and disease management.* PCMH is focused on improving the health of whole people, families, communities and populations, and on increasing the value of healthcare. Both peer support and PCMH share a focus on enhanced access to and team-based health care, coaching patients to assume more active roles in health care, enhanced communication between patients and providers, culturally-sensitive outreach and follow-up, and partnerships between people and organizations, and can be effective strategies for addressing health care disparities. This kind of combined strategy can serve not only to maximize effects on behavior change and self management, but also build systems for enhanced care for sustained improvements.
- *Options for sustainability are strengthened by multi-leveled efforts that are informed and supported by context.* Do we build and reinforce peer support programs via top-down or bottom-up approaches? Context – such as organizational, political, community readiness, human resources and capacities – probably suggests a multi-pronged approach that is informed by real-time circumstances. Some settings require a top-down, centralized strategy that fits with existing infrastructure, government, and policy; other settings may be able to capitalize on opportunities to build from the ground-up with non-profit groups and leaders who can subsequently make-the-case for value-added to key stakeholders and policy-makers. Such different, yet related tactics share the goal of demonstrating effects and enhancing viability, and should be part of considerations for sustainability.
- *Make research programs subordinate to – or at least on-par with - sustainability programming and plans.* As outlined earlier, research protocols should be informed by early and frequent planning for both program development and sustainability. Peer support is like insulin – we would never implement a 6-week protocol, measure effects, stop the intervention, and then expect to find lasting improvements 6-months after the intervention is completed. If ongoing support is a critical ingredient to initial and lasting change, then research programs examining peer support should incorporate sustainability.



- *Plan for sustainability of peer support as good health care for all people, not just affordable health care for vulnerable populations.* As outlined above, peer support can be a powerful strategy for patient-centered and coordinated care from which both people and systems benefit. To advance and integrate peer support programs, sustainability efforts should look inclusively and broadly at value-added for multiple populations and needs, not just certain target populations (e.g., low literacy). In addition, models to integrate peer support should look across national and community organizations for collaboration and mentoring.

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## D. GENERALIZEABILITY AND ADVOCACY

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### LOOKING WHERE WE ARE AND LOOKING AHEAD

- *Peer support programs are applicable, feasible, and effective across a number of conditions, populations, and behaviors.* Evidence about peer support programs and their contributions to improved health comes from studies about issues such as depression, HIV, diabetes, cancer, physical activity, healthy diet, and obesity. In addition, empirical and experiential evidence shows the “fit” of peer support to improve health and health care among populations such as Africans, Latinos, Asians, women, and people living in rural settings. Evidence from studies and experiences continues to demonstrate that peer supporters are feasible, acceptable, and effective.
- *Although details of implementation may vary from place to place, core principles of peer support can cut across and apply to wide-ranging contexts.* Behavior change is influenced by many factors, and, across contexts, those influences may play out in different ways. Certain issues may be specific to conditions (e.g., stigma with HIV) or more relevant for certain cultures or countries (e.g., role of the family among Latinos). Yet common functions of peer support – assistance in daily management, social and emotional support, linkages to care, and ongoing support – can be effectively applied to improve health. How these functions and relationships look, though, can be expressed differently across contexts to meet varied needs.
- *Peer support can be an effective strategy to connect and build social capital across multiple levels.* A common and important role of peer support is to advocate for the needs of communities and to help those communities advocate for themselves. In fact, peer supporters, while developing social capital in the capacities of community members, may also improve a community’s social capital and the resources that come to it. When peer support is based on an ecological approach (individual, family, community), it targets multiple sectors, creates enabling environments, and provides a solid model for both ongoing support and community advocacy. One key aspect of these interactive issues is that social capital is created NOT because one individual learns to coach or to manage their diabetes, but because a community of peers and relationships are formed with many members across many levels.



- *Challenges and opportunities related to ongoing support for health and disease management can be found all over the world.* As there is no “one-size-fits-all” approach to peer support, then it makes sense that problems and solutions related to social support and health are widespread. For example, in some parts of the world, obesity is viewed positively; owning a car (and not walking) is considered a status symbol; and diabetes is not perceived as a problem like leprosy or tuberculosis, but instead as “good business” that supports the ongoing delivery of clinical services. Such contextual features present challenges, both to ongoing support and disease management overall. On the contrary, other contexts often characterized as “low-resource” have demonstrated tremendous resources for change. Globally, we have opportunities to take what we know about peer support for behavior change, framed by core functions yet tailored and adapted to address needs, and apply lessons to communities and populations in need.
- *Ethics is more than protection of human subjects in research. Peer support programs can contribute to community advocacy for improving ethical principles and services related to health.* For example, adherence to insulin or other medications and glucose monitoring are both important aspects of diabetes self-management, yet in some countries and communities, availability of/access to such supplies and medications are scarce or non-existent. Organizations, program managers, and peer supporters themselves have important roles to play to clarify and promote ethical standards in health and health care.
- *Evaluation addressing long-term and systemic impact can significantly contribute to advocacy and policies supporting peer support programs.* If *Peers for Progress* could invest in another year of funding, the program could build a sustainability model and propose to rigorously evaluate it in addition to current studies of efficacy. In the presence of limited funding, *Peers for Progress* and collective members of the Global Network of Peer Support Organizations can still aim to advocate for longer-term evaluations that include cost effectiveness data. It will be important to portray such data for multiple contexts, including the continuum of high-, medium-, and low-resourced countries for which efficacy data in varied forms do exist.
- *Promoting and advocating for peer support requires a kind of ecological approach at different levels and from multiple directions.* If “peer support is good health care for all people,” then how do we get there? Efforts require both top-down and bottom-up approaches; they also require within-country as well as global approaches. For example, collaborative partners could identify key global meetings where organizations and stakeholders are already coming together (e.g., IDF, UN Summit on Chronic Disease) to incorporate peer support into the agenda and talking circles. We also need to pursue opportunities to network and advance peer support within individual countries (i.e., what organizations within Country A have a mission inclusion of peer support?) Finally, ongoing networks of community leaders and organizations dedicated in some part to peer support are important to maintain local amounts of support across several organizations. Overall, capacity building, networking, and advocacy for peer support are required across sectors, organizations, levels, and countries. No one entity can or should be responsible.



# Peers for Progress

*Peer Support Around the World*

A program of the American Academy of Family Physicians Foundation

- *Widespread diffusion and uptake of peer support takes advanced planning and relies on more than evidence of efficacy.* Peer support works . . . . now what? The real benefits of an innovation such as peer support are NOT from the original discovery research; they come from scaling up, getting good uptake by large numbers of individuals/populations, and even backing such efforts with advocacy and policy strategies. Researchers and practitioners should be asking and measuring more questions than just “did outcomes move?” Who are our champions or early adopters for the innovation of peer support? What part of the innovation is sticky – has the quality or attribute that people feel compelled to attend to and use? What aspects of the physical and broader social environments can influence the diffusion of peer support? These and other perspectives are critical for looking broadly at widespread application of peer support.



**ONGOING CONSIDERATIONS**

Across this three-day meeting, participants often commented on features of their setting and other everyday elements of context that characterize their peer support approaches and programs. For example, one program is working with peer buddies in low-resourced communities of rural Africa; another is working with low-income Spanish-speaking adults in community safety net clinics in urban California; and another is working with rural villages served by a long-standing government infrastructure of community outreach and services. As one can imagine, the population, geographic, organizational, cultural, and other features of context all influence the development, implementation, and sustainability of peer support programs.

Below, we have consolidated participant feedback about commonly-discussed elements into five themes, each expressed as a continuum anchored by two ideas: i) organizational base of peer support (community/clinic); ii) orientation of peer support approach (community action/organization and direct service), iii) resource context of community or setting of peer support (less/under and more/highly resourced); iv) compensation issues for peer supporters (volunteer paid); and v) structure of contact of peer support (casual/highly programmed). Of course, all the “in-between” for each theme/continuum represents the wide range of hybrid contexts that exist across peer support interventions. Here, current comments for each theme are intended to capture discussions from the October 2010 meeting and to stimulate subsequent exchanges.

**COMMUNITY-BASED . . . . . CLINIC-BASED**

What kind of strengths and challenges does the organizational-base or home of a peer support program bring to planning, implementing, managing, evaluating, and sustaining such efforts? Some peer support programs are part of community organizations (e.g., churches), and others reside within a health care team or system. There are strengths and challenges to any organizational setting; a lot depends on available resources (human and financial), skills and competencies (both individual and organizational), community and political will, and even needs of participants (a five-star program may have no effect if participants will not attend). No matter what, creating or building on some sort of infrastructure may be critical for providing ongoing support as well as sustaining peer support efforts overall.

**COMMUNITY ACTION/ORGANIZATION . . . . . DIRECT SERVICE APPROACH**

The approach of a peer support program is often guided by its organizational-base or home. For example, some peer supporters aim to connect people to a wide range of community resources to create an empowered healthcare consumer; other peer supporters serving as part of a clinic-based team might serve as site-based liaisons between providers and patients during and after scheduled appointments. Of course, other peer support programs certainly offer hybrid kinds of assistance (e.g., volunteers sponsored by a community coalition located in a health clinic). Different approaches may each have their advantages, but it is important to consider implications on issues such as planning, relevance to stakeholders, and



sustainability. For example, does integration into a health care delivery system medical-ize the service, possibly limit its function, and compromise “peer-ness?” Does a community-action approach, one that synergizes resources to empower and build capacities among people and organizations, apply best to certain populations or issues? Might it focus energy on those able to be engaged in their communities at the expense of reaching more isolated individuals whose health problems are a priority and who can often be reached well by individual peer supporters? Does it increase chances for policy change and embedding services within partner organizations?

The functional aspects of any peer support program – its emphasis on assistance for daily life activities, emotional and social support, linkages to care, and ongoing support – will be critical for making a value-added case for sustainability to certain audiences. The case might also be made that billable services (more of a direct-service approach) are also critical for making the case for organizational and financial sustainability. Overall, the approach of a peer support program may need to adjust over time depending on the goal at hand.

### **LESS/UNDER- RESOURCED . . . . . MORE/HIGHLY- RESOURCED**

There are a number of presumptions about the organizational, human, and financial capacities and resources that exist in different regions and countries around the world. Do less-resourced settings, often with tremendous disease burden and small health workforces, have limited ability to implement and sustain peer support interventions? Are highly-resourced countries, by virtue of more resources, better positioned for organizational buy-in for support programs from chronic disease management and other health issues? As outlined previously, challenges and opportunities to advance peer support for health exist all over the globe and the varied contexts it presents. Just as core functions of peer support must be tailored to local populations, settings, and contexts, so should consideration of feasibility, acceptance, sustainability, and institutionalization of peer support as resources vary. One innovative example is task-shifting, a cost-savings approach for health systems to transfer duties from primary to more mid-level providers. Shifting certain tasks related to patient-centered support to community health workers and other kinds of peer supporters can become an effective strategy for sustainability of both services and effects, simultaneously expanding coverage and enhancing the role of community.

### **VOLUNTEER . . . . . PAID STRUCTURE**

*“Is this about giving back to my peers/community, or is this a job?”* A much debated issue with community health workers, lay health advisors, and other forms of peer support is whether or not they should be paid. Some are strictly volunteers, others receive salaries, others receive small stipends, and still others receive non-monetary incentives. Along this issue, there are considerations for the peer supporter (e.g., role legitimization), those receiving peer support (e.g., compromising “peer-ness” nature of interactions if peer support is a “job”), and collaborating or sponsoring organizations (e.g., can volunteerism be sustained? What is the stability of funding resources? How do



we avoid exploiting volunteers?). As discussion continues, there are two important considerations: a) the demand of tasks (i.e., can be done in spare time versus appreciable time commitment) should inform the issue of salary; and b) expectations (among individual and organization), social factors, and other features of context should help determine the value and/or appropriateness of payment and other incentives (Glenton et al. (2010), *Social Science & Medicine*, 70, 1920-1927).

***NATURALISTIC, CASUAL . . . . . HIGHLY PROGRAMMED, PLANNED APPROACH***

How should peer support programs be organized? Should we let a naturally occurring group identify itself, make supportive training and other resources available to them, and let them continue to interact to optimize results? What about quality control? What about being able to concretely define and diffuse peer support? Should we define criteria, select for them, train people to be peer supporters according to some testable set of competencies, and then define a set of minimum interactions (frequency and duration)? What about flexibility? Does such structure lose some of the informal, social aspects and value-added of being a peer and what constitutes peer support? Our shared goals of understanding AND improvement in health via peer support's contributions suggest the need for a balance across research (i.e., methodological control to test a hypothesis) and practice (i.e., help people) objectives. We continue to learn as a learning community. For example, across demonstration grants, we are also learning that research studies may have tried to match based on demographics to be able to better account for demonstrating differences among intervention participants versus controls; but participants overwhelmingly suggested they be matched by where they live, as one of the most important aspects of ongoing support for them meant being able to accidentally and informally interact over time.

While these issues are by no means exhaustive, as shared by participants, they repeatedly frame issues about the organizational setting, underlying principles, extent of resources, and other features of context that influence the development of relevant and effective peer support programs. Relatedly, these themes – the concepts that anchor them on each side as well as discussion of the variety of forms in-between - can also be used to plan for strategies to sustain and institutionalize peer support programs as a routine part of quality health care for all around the world. *Peers for Progress* looks forward to ongoing discussions within the learning community of the Global Network of Peer Support Organizations to advance, disseminate, and promote the applications of such ongoing learning.



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### NEXT STEPS

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*Peers for Progress* is dedicated to advancing and promoting peer support, not just as affordable prevention and health care for poor people, but as good prevention and health care for all people. Doing so requires ongoing attention to knowledge management and exchange of peer support; global networking; and longer-term thinking about sustaining and advocating for peer support. The following ideas represent next steps for *Peers for Progress*, often in collaboration with other members of the Global Network of Peer Support Organizations;

#### DEVELOP THE “STATE-OF-THE-ART” FOR PEER SUPPORT KNOWLEDGE AND TOOLS

- Generate and share descriptions of peer support programs so others can understand (i) what they entail in terms of development, (ii) what they look like in terms of core functions, and (iii) how they vary based on different populations, settings, and other features of contexts
  - Address different perspectives of peer support (e.g., caregivers, patients, providers)
- Identify various models, mechanisms, and modes of delivery of peer support programs so that others can examine the manners by which peer support is provided and how these approaches relate to context (e.g., lower-resourced country or setting; patient-centered medical homes)
- Collaborate with the Global Network/Learning Community to articulate a taxonomy of peer support and peer supporters that defines and differentiates it from other services
  - Be sure to clarify various roles and functions of peer supporters across different contexts (i.e., across types of organizations, cultures, and resource capacities)
- Facilitate small working groups (“teamlets”) around key issues of peer support interventions (e.g., modes of delivery, dose), peer supporters (e.g., selection, training, voices of peer support), impacts/outcomes (e.g., clinical, behavioral, quality of life, mediators/moderators), and translation/dissemination of peer support programs
  - In particular, diabetes and depression working group/committee
- Work with Evaluation Grantees, meeting participants, and other Global Network members to develop and disseminate papers and other products regarding themes noted above (e.g., evidence, shared evaluation measures, ethics, peer supporter roles, outcomes)
- Develop business cases and results-driven reports of peer support programs and their value-added (e.g., health outcomes, costs) for different audiences
  - Outline conceptual approaches and cost effectiveness of peer support approaches (targeting both functional and economic utility)
- Continue to gather, summarize, and critique progressive recommendations and lessons about key issues of peer support program development, evaluation and evidence, sustainability and institutionalization, and generalizability and advocacy
- Pursue all of these across content (e.g., diabetes, cancer, HIV, maternal health, mental health), populations (e.g., women, ethnic minorities), and settings (e.g., rural, low-resourced)



### **GLOBAL NETWORK DEVELOPMENT AND NETWORKING (PROCESS AND PRODUCTS)**

- Expand Global Network of affiliate programs and organizations dedicated to peer support and its contribution to health and quality of life
  - Strategic and cross-cutting development (e.g., global, national, community; diabetes and other conditions)
- Facilitate networks and gateways, both face-to-face and virtual, for connecting and exchanging resources and ideas related to peer support
  - In particular, diabetes and depression working group/committee; China/East Asia Network, other regional meetings in order to address and discuss issues unique to each region/culture (e.g. low income country or low-resourced setting)
  - Share cross-site and other evaluation data within grantees (e.g., demonstration grantees' feasibility, early impacts; evaluation grantees' baseline/subsequent data)
  - Develop and coordinate other *Peers for Progress* and peer support meetings (including more in-depth demonstration/feasibility project meetings)
  - Facilitate ongoing opportunities for small group, in-depth discussion/trouble-shooting (e.g., online or face-to-face, varied issues such as mobile health, new technology, training and supervision)
  - In doing so, clarify *Peers for Progress*' role in global network (i.e., clearinghouse, programs for resource development, convener and host for online and face-to-face)

### **SUSTAINABILITY AND ADVOCACY**

- Gather and share opportunities for financial support of peer support programs and research
- Explore how to fund another year of *Peers for Progress* evaluation grants to define and rigorously evaluate a sustainability model
- Identify and promote successful program and business models for sustainability
- Identify steps (financial, programmatic, organizational) for moving peer support to being more routinely funded through health care
- Examine policies and other standards institutionalized for peer support programs
- Invite government officials to participate in similar learning communities or conferences
- Promote application of noteworthy peer support models based on experience and evidence
- Promote business cases and results-driven reports of peer support programs and their value-added for various audiences

This meeting, as indicated by the range of participants, extent of discussions, and wealth of ideas exchanged, demonstrates that both the need for and solutions related to designing and improving peer support programs exist all over the world. *Peers for Progress* and broader members of the Global Network learning community remain both the source and vehicle for extending the evidence, managing and exchanging knowledge, and facilitating interactions to apply, sustain, and advocate for peer support as good prevention and health care for all people around the world.

## **Authors and Acknowledgement**

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