



World Health
Organization

Centre for Health Development



First Expert Consultation on Community-Based Social
Innovations that Support Older People in Low- and
Middle-Income Countries

14 – 15 July 2015, Kobe - Japan

REPORT



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1. Introduction

Unprecedented global demographic trends of increased longevity are having significant implications for individuals, families, communities, and societies. A positive outcome of past socio-economic progress and health programmes, these trends portend needs to reshape health, social, and community systems to support an ever-growing older population.

The WHO Centre for Health Development (or WHO Kobe Centre, WKC) is a global centre for research focusing on cross-cutting and multi-disciplinary themes. In 2015, WKC launched its new ten-year research strategy on universal health coverage (UHC), innovation and ageing, building on the Centre's past work on various aspects of support for ageing populations over the past few years. As part of its innovation strategy, WKC launched a new study programme in early 2015 to investigate models and social innovations for community-based programmes to address health and social care for older people at a community level, initially in low- and middle-income countries (LMICs). Understanding these models/initiatives, their key organizational, financial, programmatic, and policy factors will help inform how best communities and countries can plan for sustainable and scaled up approaches, thereby contributing to universal health coverage (UHC) and continuous services for older populations.

As for its overall approach to population ageing, WKC seeks to maintain the functional ability of older persons to remain healthy, enjoy quality of life and dignity, and to remain autonomous in their homes and communities for as long as possible. In addition to a preliminary literature search on the subject, WKC released a call for proposals and supported seven case studies from seven countries. In order to synthesize learning across case studies, WKC organized a consultation with the authors and additional experts in July 2015 in Kobe.

In most LMICs, support for older people is often provided by the immediate family. Yet, even prior to anticipated accelerated, large increases in the percentage of older persons in these countries, the traditional family care system is gradually eroding due to decreasing childbirth rates, migration of younger people, engagement of ever more family members in the workforce (both women and men), and rapid urbanization. WKC recognized the major demographic and social changes arising from the rapidly growing ageing population and the consequent need for care support. Complementing needs for transforming health and social service systems to meet the needs of older populations, are exploring existing social innovations involving community-based, peer organizations and models that serve to provide certain health and social services, and/or act as referrals to more formal care systems – referred to as community-based social innovations (CBSIs).

Such programmes, initiatives and models will be increasingly required in all countries. However, given the nascent nature of analysis of these models, solid conceptual work is still required, along with rigorous assessment/evaluation research, leading to evidence-led improvements and development. Presently, about two thirds of the world's older persons already live in LMICs. Because the older population in less developed regions is growing faster than in the more developed regions, the projections show that older persons will be increasingly concentrated in LMICs (UN-DESA 2013). Therefore, WKC began its work in these countries, reflecting impacts on existing under-performing and under-resourced health and social systems.

An important premise underlying WKC's work and this consultation was that older people were not to be merely conceived of as recipients of care. Rather, they are also major providers of care not only to other older adults but also to children and grand-children. Older people need to acquire the skills to support themselves and their peers to achieve the goals mentioned above. For older people to age meaningfully in their environment they must be able to care for themselves and yet receive care and treatments for any gaps, problems or serious symptoms they cannot manage on their own in a timely manner. In many LMICs, older people have no choice but to age in their home environments, since there are no other alternatives in the formal health or care sectors.

Following the submission of the case studies, WKC organized the consultation to gather initial lessons and review the key themes that arose from such innovations. The format of the consultation was highly interactive with discussions and exchange of information concerning lessons from the case-studies, and identification of additional research that are still needed if we are to better understand and ultimately, provide guidance for best practices.

This report is a synthesis of both analyses of the case studies and discussions around specific themes identified during the consultation.

2. Methods

In December 2014, WKC issued a call for Expression of Interest (EOI) from institutions and individual researchers to prepare case studies on community-based initiatives that support older people in LMICs. The call was open equally to a) proposals that were preparing new case studies, as well as b) accepting ongoing or completed case studies which described existing models of community-based groups or systems that supported health and social services for older people.

Key criteria of selection were that case studies described initiatives implemented in a community, with older people at the centre of the initiative, aiming to assist

other older persons to increase autonomy and to maintain or enhance their health and quality-of-life for as long as possible. This included interventions that were run by older persons themselves. The support provided by the older people's community-based interventions needed to address both health care and social care/support with an objective to having an impact or effect on the health and well-being of older persons.

A total of 38 proposals were received by the deadline of 23rd January 2015. Out of the 38 proposals, 8 were selected for their relevance and quality. Out of the 8 proposals, 7 case studies were eventually completed with one cancellation. The case studies were fully funded by WHO. WHO also provided guidelines that requested case studies to address the following points:

- What triggered the initiation of these initiatives? What are some of the key factors of success enabling the initiative to begin and function?
- How are they organized (governance, funding, staffing, membership modalities, etc.), and what kind of health and social services do they provide?
- What are the key benefit packages/services?
- Who benefits from these initiatives? What are the power relationships at play?

- In which way are these community-based initiatives fundamentally different from other community-based initiatives addressing the needs of other subsets of the population (e.g., women, children, etc.) or the population as a whole?

- How do these interventions fit within the official health policies (including local, regional and national policies) addressing the needs of older people? To what extent are they part of health financing schemes and/or local/national integrated medical, public health, or social service programmes?

- What are the referral patterns and relationships between the initiative and other health/social service providers and stakeholders?

- What are the financing strategies and issues modulating sustainability of the initiatives?

- Assuming these initiatives have a positive socio-economic and health impact on older persons, what can be learned to better integrate such models into current health and social care systems?

- What are the evaluation and monitoring mechanisms implemented to assess the effects of such initiatives/interventions? What measures for health outcomes, socio-economic outcomes and health equity have been used?

Case Studies: Community-based initiatives that support older people in low- and middle-income countries (LMICs)

No.	Project site: Country	Project title	Principal Investigator	Institute
1	China	Case Study in China: Taking comprehensive measures to prevent disability among the Chinese elderly	Professor Zhaoxue Yin Division of Non-Communicable Disease Control and Community Health	Chinese Center for Disease Control and Prevention / China CDC (Beijing, China)
2	India	Case Study in India: Promoting and advocating for age-friendly healthcare in the Thar Desert, India	Dr Prakash Tyagi Executive Director	Gramin Vikas Vigyan Samiti / GRAVIS (Jodhpur, India)
3	Poland	Case Study in Poland: Tychy Local Network of Support Centres for the Elderly	Dr Grzegorz Gawron Assistant Professor	Institute of Sociology University of Silesia in Katowice (Katowice, Poland)
4	South Africa	Case Study in South Africa: AgeWell, a peer support service in community settings to improve well-being and health among older persons	Dr Mitchell Jay Besser Founder and CEO	AgeWell Global LLC (Cape Town, South Africa)
5	Thailand	Case Study in Thailand: Community-Based Initiatives of Rural Districts in Thailand - Nang Rong District, Buriram Province	Dr Jongjit Rittirong Lecturer	Institute for Population and Social Research Mahidol University (Phuththamonthon, Thailand)
6	Uganda	Case Study in Uganda: Empowering older people and mobilising communities in Uganda: the social gerontology manual	Mrs Francien Scholten Consultant	Uganda Research Unit on AIDS (UURI) Medical Research Council (MRC) (Entebbe, Uganda)
7	Viet Nam	Case Study in Viet Nam: Community mechanism to promoting health and active ageing and community care	Ms Tran Bich Thuy Country Director	HelpAge International in Vietnam (Hanoi, Viet Nam)

(Alphabetical list by project sites)

A synthesis of the findings from the case study was developed (see Annex) and served as a basis for discussion during the July 2015 consultation. The consultation gathered those who drafted the case studies, as well as four respondents chosen for their expertise in areas relevant to CBSIs for a two-day meeting. To ensure cross-fertilization of analyses and exchange of experience, each representative was asked to review the case study of another peer during the consultation. Salient issues were grouped around four broad themes: older people centered-care, delivering integrated services, linkages and interactions with the health system, and challenges in measuring health impact. These themes were all discussed using both the technical inputs and moderation of discussion by chosen experts. The list of participants, as well as the agenda for this meeting are provided in the annex. The list of seven case studies reviewed during the consultation is listed in the table on page 2.

The case studies elucidated a number of important roles that CBSIs play to support older people from both social and health perspectives. The emerging lessons and analysis presented in this paper highlight both opportunities and issues that all local and national health and social system decision makers, planners and families and individuals themselves must make concerning who provides care/support, for what goals, and to define the respective roles and responsibilities of the family, the State, or both.

Whereas the initial round of case studies and consultation focused on LMICs, the issues raised are germane to any country and communities facing or experiencing large increases in percentage of older people. Thus, key questions include how to manage limited resources, cope and transform historic curative and acute care-based health systems into those providing longer term care and support; to productively engage older persons in service, policy and technology design and implementation; whether and how to create more inter-connected care, health service, and referral systems, while also promoting a rights-based approach to serving and protecting older people and to meet their needs in culturally appropriate ways.

The consultation focused discussion in investigating and exploring the case studies, their lessons, and implications around six key parameters/issues:

- Agreement on core principles underlying CBSIs and their role
- Inclusiveness of older people
- Self-care
- Definitions, and their limitations
- Achieving scale
- Metrics, especially to measure effectiveness of CBSIs

The consultation concluded by charting future research needs and recommendations.

3. Key Synthesis from Proceedings

A. Core Principles

Three Core Principles that Underpin Community Based Social Innovations (CBSIs) for Older Adults

1. Empowering older people to self-care and have self-efficacy to maintain or improve functional ability
2. Using methods that generate social cohesion and which are socially inclusive of older people
3. Maintaining well-being even in the face of disease, disability and health declines

At the beginning of the consultation, WKC emphasised that a starting point for understanding CBSIs was an agreement that these initiatives should not be treated as an alternative (either deferring from state responsibility or simply an inexpensive option) to what should be universally available health, social and care services.

Participants noted that all of the case studies have in common that they were oriented towards achieving people-centered care, as defined below by the WHO:

“People-centred care requires that people have the education and support they need to make decisions and participate in their own care. It is organized around the health needs and expectations of people rather than diseases”.

Within the constellation of community-based activities which the participants explored, a core activity (and the first principle) that was identified, by which other health interventions are strengthened or amplified, is through the promotion of self-care by older people. However, there was strong emphasis in ensuring that self-care did not become synonymous with the idea that it meant “empowering” older people to be left on their own. The participants agreed that self-care is empowerment that activates older adults to remain safe and self-effective in their own management of conditions, symptoms, and which developed safe cum appropriate health-seeking behaviours.

Therefore, this meant that the WHO definition of self-efficacy was also relevant since the WHO says that self-efficacy (Smith et. al., 2006) for health means that:

“Perceived self-efficacy refers to beliefs that individuals hold about their capability to carry out action in a way that will influence the events that affect their lives... Self-efficacy beliefs determine how people feel, think, motivate themselves and behave. This is demonstrated in how much effort people will expend and how long they will persist in the face of obstacles and aversive experiences”.

In the session on metrics and the discussion on social inclusion within CBSIs, there was an agreement between participants that the concept of “health” needed re-evaluating in the context of ageing, if social inclusion was to be properly understood (and achieved) for ageing populations, and to help measure the effectiveness of CBSIs depending on the precision of their desired outcomes.

Participants affirmed and noted that the goals for ageing and health (as also codified in the new WHO World Report)—that “health” is a state that can be improved or maintained even in the face of disability and disease—are highly congruent with the WHO Constitutional definition of health as being physical, mental and social well-being which are beyond “merely the absence of infirmity and disease”. The discussion of the case studies implied that with many older people, well-being can be satisfactorily maintained even in the face of health declines. Thus, “health” has to be considered equally from all of the physical, mental, psychological, spiritual, cultural and social domains. This is a key foundation for CBSIs with holistic interventions, for example from Viet Nam, India and Thailand, that tackle not only direct health problems, but also issues that might contribute to poor health including household finances, companionship, livelihoods, transportation and even housing. Holistic approaches acknowledge that many things contribute to the maintenance of subjective well-being and the maximisation of health, even in the face of suffering and health declines.

Enabling inclusion and the issue of segmenting older populations into groups that can benefit from specific interventions

The discussion on balancing inclusion with the need to segment older populations into groups that could benefit from targeted interventions - suggested that community based approaches generally work because they can identify and work with the total diversity of older people. Successful community interventions target the sicker or frailer old with care and support, whilst also acknowledging in interventions that not all of these individuals can be rehabilitated back to full health without disease or infirmity. In other words, there is a purposeful process of discernment cum targeting, but with concomitant attendance to diversity without creating exclusion. Several key models, for example from Viet Nam and South Africa, utilised those who are more functionally capable as peer resources for the care of frailer older people. This is an example of a natural method of “inclusive-segmentation” which seemed key to how older people as an activated group act as peer resources for health (see Figures 1 and 2 for the conceptual analyses), and thereby provide care at home to those who are frail and in need. In its simplest formulation, it meant creating inclusive programs through using peer-support approaches, leveraging the natural diversity of older adults as some will have care needs that others who are more functionally capable can provide.

There was lively debate around the realities of

health programming and how in the field, this oftentimes demanded that interventions were targeted to very specific populations or conditions. Oftentimes, this would be a donor requirement. Pragmatically, it was also argued that accurate targeting of health interventions to groups was needed otherwise delivery focus would become scattered and thus rendered ineffective. Therefore, a case was made for targeting only certain segments of the population with health interventions, such as older people who may yet be prevented from slipping into dependency, since the purpose of such programs would be to delay health declines for as long as is possible in older age. For example, in South Africa, where the intervention purpose was to help those older people who could perform activities of daily living independently to maximise their health, this meant excluding the frailer older people who were already dependent from their programming. It was offered that this was necessary since rehabilitation, preventative and health promotion work was, in that setting, most effective with those who were still functional enough to benefit from rehabilitation and who still had the ability to return to productive activities. However, this type of programming, cannot exist in a vacuum- they must have services and other interventions to link to (e.g., home care in this instance) or else the population of older people who need the most help would be excluded. Therefore, it is conceivable that communities, within the constraints of their disposable resources, run a mixture of CBSIs, each targeting a different segment of older people with different needs and different functional abilities.

In order to avoid unintended discrimination or exclusion, it was regarded as important that CBSIs did not discriminate between what older people need and what they can contribute to. Focusing on needs alone can lead to exclusion (and reinforce ageist sentiments of older people as just being frail and burdens to families and health systems) rather than creating purposeful inclusion for all. Figure 1 suggests that there is the need for care and support in older populations but equally important at all ages, there is also the ‘need’ to feel needed, i.e., to feel that one is still relevant to the world and life, and this can through one’s contributions, e.g., as a peer supporter. Feeling useful and wanted was discussed as being potentially important for the maintenance of mental health in older populations.

This conceptualisation of the roles and meanings within the diversity of health states conveys the prospect for appreciating well-being as the best measure for health related outcomes in old, older and then oldest ages. In acknowledging the role of subjective well-being in maintaining quality of life, we accept that at some point in the ageing life course, the absence of physical or mental disability or illness may no longer be possible. This however, should not compromise the integrity of achieving satisfying subjective well-being no matter the health decline (and this is an area that needs to be researched and measured better). Therefore, one way of interpreting the CBSI case studies is to acknowledge the initiatives as supporting the search

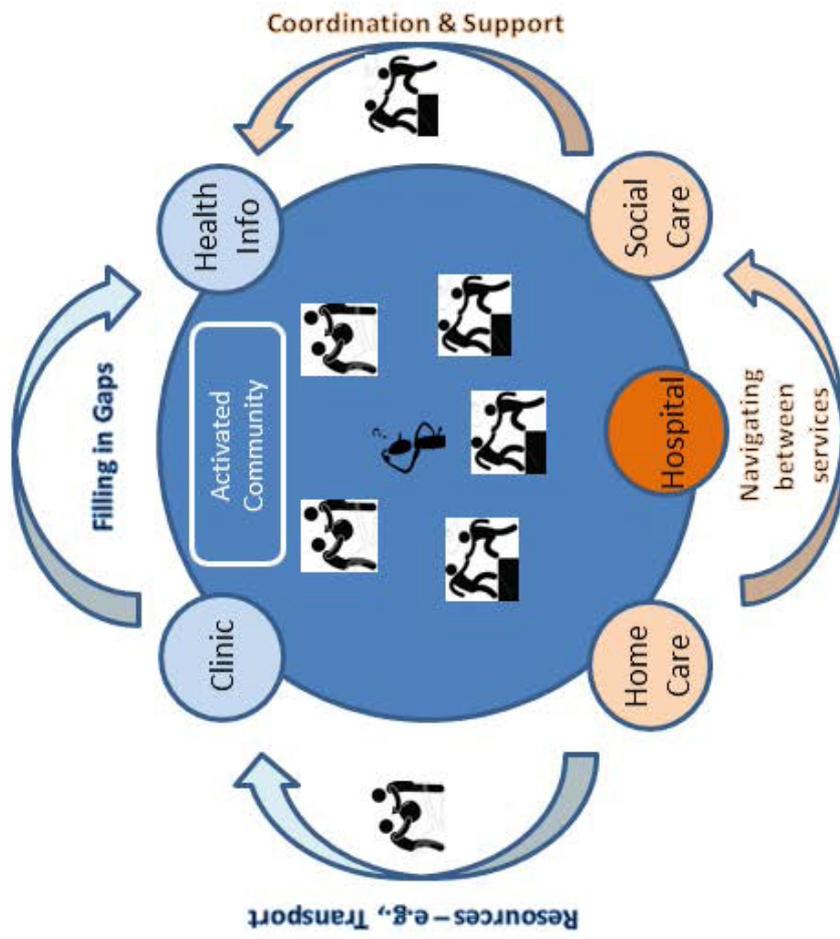


Figure 2b The community initiatives of our case studies seem to function to help older people to navigate vertically separated systems better, through providing physical, social, economic and informational aid. In figure 2a, the most basic form of primary care is the local health centre or clinic. However, where community based interventions exist, the most basic form of primary care could become the community itself. This unit is capable of identifying and filling in gaps in available services. They may then provide the first line of primary care, referring and linking to the local services, which themselves then become secondary sources of primary care. This can help both the community and the clinic to manage patient flow & demand while also raising awareness and levels of health literacy. Scarce resources are rendered more sustainable. More evidence is needed to confirm this concept.

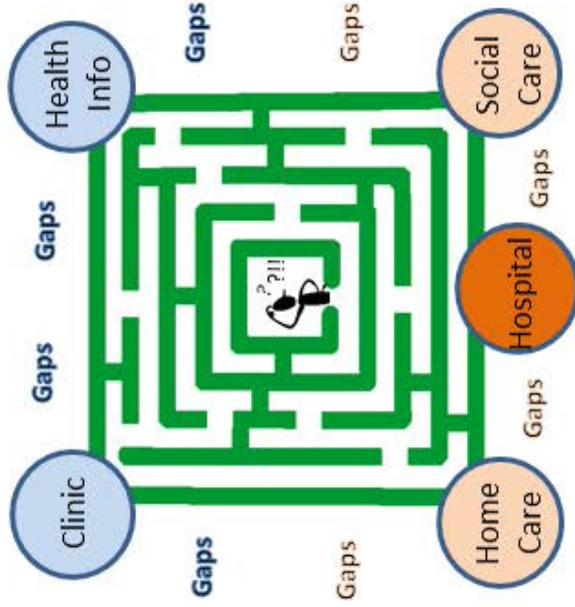


Figure 2a LMICs health and care systems are defined by fragmentation, scarce resourcing, vertical development and significant continuity gaps. It can appear to many older people like an un-navigable maze. They are especially difficult to navigate for older people with limited education. Health and care resources are therefore not only hard to obtain, but also hard to find and then to get to. Information and health literacy is often also lacking.

for ways in all sorts of environments to preserve functional ability.

Part of what supports functional ability lies with the idea that an older person may still want to perform key activities of daily life despite constraints, pain or disease, for example, independent shopping; and indeed this may be for grandchildren or a neighbour, as much as it is for the self. Figure 1 provides a social model that argues for a well-being and equity based approach rather than one that is solely focused on the curing and prevention of disability or diseases, because both helper and recipient are construed to benefit from being symbiotically linked within this dynamic (e.g., good mental health outcomes accrue for the supporting peer through possible loneliness alleviation, whilst the frailer older person might have benefitted in both mental and physical health manners as a result of being supported and helped). Traditional health outcomes in this sense are a side benefit of this inclusion driven and well-being based approach. It also articulates the idea that CBSI should be based upon peer to peer relationships between equals rather than employing the more common dependency based person-centred approach. The practice of inclusivity in this manner can become part of a sustainable approach.

The Role of Community Based Initiatives – How do they work?

The selected case studies highlight innovations in the face of severe resource limitations, and in the face of stringent demands from service providers, especially in low income settings. Services in LMICs often face a multitude of competing national health priorities- most of which are disease oriented, resulting in vertically structured programs. Fragmentation is common not the least of which deriving from competing donor demands and preferences. In many LMICs, this means that services are deeply siloed, non existent, and poorly coordinated between sectors.

Whilst CBSIs must not be thought of as “cheap” options, neither are they necessarily expensive compared with indiscriminate secondary or tertiary services use by older people. These latter systems accrue high costs to both the health system and to families (e.g., through transport costs, overnight stays in cities, and potential treatment costs that might have to be paid for out-of-pocket).

However, for these systems to work in resource constrained environments, these case studies suggested that a key requirement is that they work through preserving the social cohesion of groups of older people, usually within peer to peer networks. An organised group of peers, working together might effect change by working both outwards (towards the wider community and the systems that are in place) through forging linkages, coordinating new partnerships, filling in continuity of care gaps; and then also inwards to affect and change older people themselves (including attitudes, awareness, knowledge

and health status) (Figure 2a,b). However, more evidence is needed to support or refute this conceptualisation.

These case studies also suggested that community based integrated health and social care systems might also work to enhance general social cohesion, by adopting inter-generational approaches which helps to build both peer and across generations solidarity. The discussions from the meeting are suggesting that these CBSIs are potent devices for addressing ageist attitudes. The peer driven networks which work together to find community solutions for the health and social care needs of older people also simultaneously portray older people as resources (again see figure 1), and also show how older people can become empowered to be resources – both for themselves and for their wider community (they can also perform the functions of figure 2b for other parts of their communities, e.g. many traditional birth attendants are older people). These community based approaches therefore could be seen and positioned as being an integral aspect of a rights based approach to health for communities of all ages.

As a part of a rights based approach, the case studies suggest that policy and advocacy work are integrated with these CBSIs, and they may have a role in pushing for re-allocation of local or national resources for ageing, since existing care models often come with large invisible costs to families and communities. For example, younger people and especially women dropping out of the work force to provide unpaid care at home.

The case studies suggest that CBSIs facilitate a “continuum” of services, but only when local services are available, with an emphasis on the key role of peer support in both fostering health and connecting to local services. At the same time, the direct delivery of medical procedures was notably absent within the range of interventions presented. This may not be a bad thing since certain medical procedures, e.g., the prescribing of secondary and tertiary lines of antibiotics, are probably best left to health professionals in the interest of patient safety and the greater public health good. As seen from figure 2, this reemphasises how the bridge to existing health and care services remains an important component of successful interventions.

One of the key questions debated, especially in the context of poor availability of health care resources, is what happens when these services simply do not exist, or when such services do not work properly. This is a particular challenge since volunteers cannot do everything and mobile clinics are not a sustainable long term solution. CBSIs need to have services to link with and cannot work in the absence of basic services. This is to say that state sponsored services (public or private) and community initiatives need to co-exist, if CBSIs are to work safely, sustainably and effectively. Otherwise, quality will be compromised with complex and even potentially dangerous procedures left in the hands of relatively unskilled volunteers.

C. Self-Care as a crucial part of the equation that determines success or failure of CBSIs

Self-Care is Crucial

1. It could strengthen primary health care, especially in resource poor settings by ensuring that the community itself becomes the most basic layer of primary care and the first point of contact for health care, thereby helping to ease pressures on local health centres by managing referrals to them
2. Self-care is a decision making process that has multiple parts to it, including self-management and the acquisition of skills to manage symptoms and thus it can improve the management of health, illnesses and disability
3. Self-care can only happen when there is both health literacy and the motivation to use this knowledge to become self-effective for health

Figure 2 suggests that a fundamental part of how health systems can be strengthened is through ensuring that community based support becomes the most basic layer of primary care – that is the point of first access for most people for health care, before cases are referred on to the normally over-stretched local services (when they are referred at all).

This system works better when there is sufficient health literacy and self-efficacy within older people (and peer groupings of older people) to self-manage and self-refer in those times when health or care issues arise. Self-caring is optimised when it is combined with a conducive environment that is engaged with all other part of community. Therefore the ability to self-care rises to the fore in this scenario.

To be self effective in self-care, requires establishing an understanding that the concept of “self-care” goes beyond caring for one self - it is also about being able to establish healthy and motivating connections within existing or even new social networks. These social networks are part of an “activated” community of older people (figure 2). They are important because a self-care model may not be sufficient in of itself to address older people’s needs without a good case management and coordination system working alongside it. This sort of care management can guide and even physically help older people and their supporting family circle to navigate the maze that constitutes oftentimes fragmented services. This is part of the community based linkage work that is done by CBSIs.

A concern raised by participants was about the broader usage of the term “self-care” in the specific context of older adults rather than limiting the phrase to “health self-care”. The ensuing debate established that even if it was labelled as “self-management for health”, the ground reality is that self-care for health will always be multidimensional in nature, since there are many ways (e.g., socially (such as loneliness alleviation for mental health),

physically (such as physical exercise), having the help of health services and/or technology (such as monitoring blood pressure)) to manage one’s own health.

However, a brief review of current definitions of self-care led the participants to consolidate upon a working concept of self-care. Self-care therefore, might be conceptualised as a decision-making process that has multiple parts to it. It includes self-management which includes those behaviours performed to maintain physiological stability (e.g., visiting a health professional in a timely manner) and the skills (e.g., understanding and acting on medical instructions) that are deployed in response to adverse symptoms when they occur. Studies tell us that patients who have these resources to self-manage their condition in these ways generally have fewer symptoms, better functional capabilities and better quality of life (Riegel et al. 2013, Dickson et al. 2014).

D. Difficulties with definitions and the operationalization of these definitions

Problems with Definitions

1. There is as yet no consensus as to what many terms such as “self-care” and “integration” which are often used by CBSIs actually mean
2. This means that operationalising these concepts is as yet inconsistent and varies from context to context
3. It seems possible that properly working referral mechanisms will be key to the concept of “integration” both horizontally at the primary care level, but also vertically through to secondary and tertiary services

The fluid and varied nature of both the case studies interventions and their contexts suggested that a very important part of understanding community based interventions will involve agreement of both broad and narrow definitions of a large number of words used to define CBSIs such as – “self-care”, “social care”, “the community”, “age friendly services”, “sustainability”, “integration”, “referral” and “quality”, to name just a few terms that are widely used, but which varied widely in scope and definition depending on the context.

For example, the case studies raised the question of what “integration” meant, given the plurality of health, care, social, public, private and mixed funding systems that exist in so many countries. Given the nature of the case studies included in this consultation, our exploration of integration is mostly focussed on horizontal integration at the community and primary care level, even though older people do require periodic and timely referrals from the primary level to secondary or even tertiary levels of care, especially when serious health challenges occur. In these instances, CBSIs do help with the navigation and communication with secondary and even tertiary systems.

The case studies therefore, challenged the participants to consider if, for example, “integration” is a reference to full scale mergers between services and systems, or might it be referring to enhanced coordination between systems and services; or perhaps “integration” merely seeks to enable seamless communication between separately managed and funded health and social systems. Clarity and a continuing wider discussion of what words actually mean, in context and in practice will be an important next step in terms of improving our understanding of CBSIs. As a guiding principle, the WHO work on integration may be applied to our understanding of this term in future consultations. It seems likely that properly functioning referral mechanisms will be key to whatever the context of “integration” might be. The WHO (2008) technical brief “Integrated health services – what and why?” says that:

“Integrated health services” means different things to different people – it is important to be clear about how the term is being used...An overall working definition of integrated service delivery is “The management and delivery of health services so that clients receive a continuum of preventive and curative services, according to their needs over time and across different levels of the health system...” “Integrated services” to some means achieving continuity of care over time. This may be about life-long care for chronic conditions such as HIV/AIDS, or a continuum of care between more specific stages in a person’s life-cycle – for example antenatal, postnatal, newborn and child care...Integration can also refer to the vertical integration of different levels of service – for example a district hospital, health centres and health posts...From the clients’ perspective, a key feature of this type of integrated health service is well-functioning procedures for referrals up and down the levels of the system, and between public and private providers...Integration can mean working across sectors. It occurs when there are institutionalized mechanisms to enable cross-sectoral funding, regulation or service delivery. In industrialized countries, this concept is frequently applied to the co-ordination of health and social services, such as for long term care for the elderly”.

A key question remains on how to apply and adapt such a concept in low resource settings.

In fact, there are six common definitions as described in this WHO paper and these to greater and lesser extents still represent the spread and diversity of definitions that we have encountered within our case studies. Further clarification will be needed in future work.

E. Achieving Scale

Achieving Scale

1. The concept of equity is at the core of the going to scale
2. CBSIs are good examples of entrepreneurial thinking that have evolved locally to fill in necessary gaps in local services
3. CBSIs have to continually evolve and the user perception of quality and satisfaction with services, waxes and wanes because as each gap is plugged, others may open up. Each step in the evolution of services generally raises expectations and this affects levels of satisfaction
4. CBSIs may scale most effectively when they are backed by national policies and legislation

The development of CBSIs should be taken seriously, assuming that their true utility is at scale and if there is acknowledgement that the concept of equity is at the core of what having scale actually means. The case studies suggested that informal sector initiatives, whether as a piece of social enterprise or else responding to donor priorities; they nevertheless identified gaps (needs) which remain to be serviced, and these then become services that fulfil those needs that are lacking for many people. Therefore, community based gaps once identified and then subjected to innovative solutions (to fill those gaps), must by definition be needed by many/all. Thus, there must be larger deployment of these solutions if these gaps are to be fairly plugged for the wider community (i.e., the solution becomes equitable).

The case studies suggested that CBSIs are evolutionary models and not static ones. This is because with each social/community innovation cycle, especially in poorly developed countries, so as a gap is filled then other gaps might open up, and thus CBSIs have to continuously evolve. For example, several CBSIs identified a need for health education. With greater health education, more older people may go for health screenings which then, for example, exposes a shortage of essential medications for the management of conditions such as hypertension. At this point of the innovation cycle, having addressed a knowledge gap, now the CBSI must evolve new mechanisms for partnerships (or else lone working, which is much more unlikely to succeed) to address this newly exposed gap in order to find the medicines that they have created a demand for. There was an active discussion around how user satisfaction is also driven by expectations, and as expectations increase, so perceptions of quality of services will wax and wane. This also drives the evolution of CBSIs because as each gap is plugged it raises expectations and therefore, opens up other gaps. At this point of the innovation cycle when expectations go up, satisfaction can drop, and this drives further innovation.

Methods for achieving scale

In the discussions, integration of local and national health and social care policies was seen as a key driver that could link national to sub-national level policies (on ageing, on health, on social care, etc.). In this context, there was a view expressed that scale happens more effectively formally or informally through decentralization of the services themselves.

Referral systems and mechanisms in older age health and social care is a key target for reform in order that older persons are properly targeted and managed. Without robust widely deployed referral systems, efficient and effective practices at scale would be impossible, since the system of referrals would degenerate into chaotic case by case decision-making with neither clear guidelines nor consistency. In this context, understanding horizontal integration (for example, between primary health care with social support) and vertical integration (of primary health care with specialist care, e.g. palliative care) will be crucial if proper training of care providers for accurate referral processes is to become possible. We refer to the previous discussion on “integration” (p8-9) above.

Understanding the gaps in current legislation is also critical. The participants felt that the creation of novel legislative initiatives for CBSIs may be a crucial component for the scaling of such initiatives. Officially sanctioned programs backed by the force of law, is one viable mechanism for the achievement of scale. This type of legislative “powering up” of community initiatives nationally could be seen in Viet Nam and China. However, it would appear that this would have to be done on a country by country basis with a set of principles established that could work at the interface between governance and policy initiatives for each country. For this scaling up strategy to materialise, there will be a need to look at policy innovation cycles more carefully, as many ageing policies do not yet originate within the health sector but start life in other sectors such as the Labour Ministry or for example, the Ministry of Social Justice and Empowerment in India.

If one employs an idea that scale has to be both simultaneously top down as well as bottom up, then CBSIs could be considered to be the ground laboratories of innovation, enticing policy innovation as a consequence of innovative solutions to plug services delivery gaps. The question of the level of governance of care to target in the innovation cycle is also important, and accurate identification of where these systems can be activated (local, district or national levels) will be crucial.

It was noted that there can be, however, strong local resentment of the need for innovations in the community, particularly when formal services are absent and communities feel that they are left to fend for themselves. A fundamental question regarding scaling is to identify clearly what is being scaled. On one hand, for an organi-

sation to survive, it may need to achieve a certain critical mass through increasing membership numbers, services offered, and/or geographical areas of operation in order for the business model to become viable. On the other hand, it has been argued that the ultimate result, would be the ‘scaling up’ of the models into policies that would allow a broader population base to benefit. Both types of scaling objectives are important, however their remit may be quite different. Ultimately, scaling CBSIs and the filling in of gaps, which are often bottom-up efforts, are only effective where there are formal services to coordinate with and navigate (that is to utilise). Therefore the private sector cannot be discounted as a necessary partner to incentivise scale-up, innovation and community participation.

F. Metrics - how do we measure if CBSIs have been effective?

Metrics for CBSIs

1. Health outcomes are challenged by the fact that we currently lack simple markers for the functional ability of older people and ways of describing “successfully managed decline”
2. For wellbeing to be utilized as an outcome, we still have yet to understand and then measure how subjective well-being is maintained in the face of health and function declines
3. There remains an important role for the measurement of raw outputs from CBSIs, since they can function as process indicators that track the evolution and relevance of CBSI program designs

Discussions on metrics were founded initially on the premise that the best measures of health systems performance is gauged by its impact on health outcomes. When looking at community models for those in older age, this creates its own set of challenges, since simple markers for determining success, especially in those who are experiencing health declines are not yet available. For example, how would we describe a “successful level of appropriately managed decline, leading to a good death over 5 years”? Globally applicable quantitative descriptions of this type of trajectory currently do not exist.

Measuring wellbeing, as was done in South Africa, can then be an interesting proxy for health outcomes, as long as validated tools are used for analysis. However, a potential confounder of using wellbeing as a proxy measure, is that a certain level of health decline will in any case occur for many older people. Therefore, there is a danger that the interventions are misunderstood to have increased the health status of older people when this has not happened, because of a common conflating and assumption of improved health with well-being improvements, without appreciating that subjective well-being might improve even as health worsens in older people.

Therefore, difficult and challenging principles were explored during the session on choosing the right metrics: what are the tools that are available or which still need to be invented to assess results and to measure impact. This led to a discussion around how we might identify indicators to measure health outcomes in older populations and a variety of indicators were discussed, such as quality of life, wellbeing measures, IADLs, to name a few.

Collecting, organizing and interpreting data

Improving opportunities for better health and health outcomes is the main goal of WHO, but this concept is challenged by the need to maintain subjective wellbeing even in the face of irreversible health declines in some older populations, such as the older old and those who are co-morbid with several chronic diseases.

Therefore, even assuming data are collected and available, once it is there, how we make sense of it will be a challenge since there is a diversity of potential impact and outcomes that may be monitored, from health through to quality of life and well-being. Perhaps because of these challenges our case studies showed a much stronger reliance on qualitative data with little or no agreement on how and what quantitative data can be collected.

Some models developed partnerships with universities, for example in South Africa, AgeWell partnered with the University of Capetown to determine which metrics to use in relation to their goal of improving the wellbeing of older adults and of decreasing healthcare costs for older adults.

In this regard, HelpAge International offered the idea that they are piloting a new tool in Africa, Latin America and India that could harmonise health outcomes with some indication of the functional abilities of older people, so that a matrix of outcomes (e.g., for health (disaggregated into mental and physical domains, physical function and dependency)) could become available for evaluating CBSIs, rather than a default reliance on improvements in physical health outcomes alone. Therefore in this instance, for example, a subjective evaluation of personal health status could be assessed at a high level, even if objective measures of health and functionality status (e.g., limb strength or gait speed) might be showing marked decline. This might demonstrate a discounting of physical disability in self assessing health and may be important in helping improve understanding of how older people assess the quality of their health, even in the face of health declines once they have recalibrated their expectations. However, the interpretation of such data is still a work in progress since there are many pitfalls or confounders that will need to be carefully researched.

Participants discussed that process/progress outputs could remain a key factor for the future development of evaluation methods for CBSIs, since the relevance

and integrity of programmes needed to be continuously tracked and checked. This type of process indicator might include counts of referrals for NCDs, increased surveillance of NCDs in local health posts or attendance records of people at screening/health education events. In time as CBSIs change systems and then are changed themselves, programme designs could become obsolete. This type of process indicators can help to track this type of evolution. For example, a transport program for health might have been set up when no local health service was conveniently located, but the nature of this program may change once a new clinic opens up locally. Where once the measuring of the utilisation of the transport service was integral to the health program's outputs, its meaning might become less relevant once the local health post is established. Transport use is thus, an example of a process indicator that tracks a program's progress and is a relevant output of the program for as long as transport remains a key barrier to health care.

It was discussed that there were important costs to factor into programme funding for the development, maintenance and management of good, relevant, reflective cum flexible monitoring and evaluation systems. A key principle that is crucial for communities based evaluation systems would be to keep the systems of metrics simple, partially due to the challenge of doing evaluations in resource poor settings. Most CBSIs still lack time, resources and capacity to execute well thought out evaluations, with proper baselines and end point measures.

4. Analysis, Synthesis and Interim Conclusions

Analysis and Synthesis

1. CBSIs arise in many low resource environments partly because curative and acute care based health systems do not cater to the whole spectrum of needs that older people have, where maintenance of functionality and social problems can be more important than cure
2. CBSIs must be connected up with policy innovations that allow for linkages with financing, legislative and resource decision making processes, otherwise they may not be sustainable
3. Improving health literacy leading to self-care may be a key pivot for the strengthening of health systems in earlier or less developed phases of health care development

The case studies taken as a whole, outline various areas that are interlinked, and suggest issues which community based approaches to older people's health and care tackle in low and middle income countries. These may be the key points for development within the innovations cycle for CBSIs.

First, the consultation highlighted the struggle to create older person-centred systems of care in low- and middle-income countries (LMICs).

The recently released World Report on Ageing and Health (WHO, 2015) clearly articulates the need for person centred approaches towards the care of older people if true quality of care is to be enabled. Person centred responses are necessary because as we discovered from the case studies, particularly in older people, many of the problems which arise are frequently a combination of both medical and social factors. For example, there is no medical solution to loneliness, yet loneliness can exacerbate or be an aetiological agent that triggers clinical depression and which when co-morbid with other chronic illnesses, can lead to very poor health outcomes and earlier mortality. Alternatively, consider the woman in South Africa who for the lack of a few dollars (which are the consequence of inequities and other structural factors), is unable to travel to her nearest health centre and as a result her hypertension remains uncontrolled. These are all examples of when social determinants meet medical issues to produce poor health outcomes for older people.

The majority of the CBSIs host countries captured within these case studies, are characterised by having health systems which are set up to deal efficiently with communicable acute diseases, resulting in high levels of fragmentation within the health system and the dominance of multiple vertical programmes. However with ageing populations looming on the horizon, further development of their health systems are arising from a growing recognition of increases in numbers of people with non-communicable diseases (NCDs), just as social economic conditions improve and life expectancy rises. Our case studies suggest that these systems are now confronting the inadequacy of health systems that had been originally set up to manage acute conditions for ageing related health and well-being issues.

With deep fragmentation of health systems, especially when coupled with lower levels of education commonly encountered in older people in LMICs, the context of health literacy (seen through community education and awareness raising work) comes to the fore as a key action for work by CBSIs in these kinds of environments. However, health literacy alone is not enough. Evidence linking health literacy and actual healthy behaviour changes is very limited, especially with regards to older adults. Some studies suggested that knowledge itself is only a first step because there is another link (which is not automatic) between having knowledge and then the realising of this knowledge into behaviour changes. Changing behaviours or the actual deploying of healthy self-management can be hindered by physical, social, emotional and intellectual barriers. (Hinder and Greenhalgh 2012, Shearer et al. 2012, Chen et al. 2014). Other kinds of literacy may also be important including digital literacy as technology becomes more and more integrated into health and social care.

However, self-care was felt to be a key activity for the strengthening of health systems in earlier or less de-

veloped phases of development. Based on an analysis of the context and issues, effective healthy self-caring behaviour in older people may have several critical aspects to it that are intimately connected with the modus operandi of how CBSIs operated. Thus, these community based initiatives seem to facilitate several key actions that impact on the effectiveness of self-caring. CBSIs: (1) enable effective two way communication between older person, their families, friends and neighbours, and the health and care systems; (2) help with (physically and in knowledge terms) the navigation of these systems (important when they are fragmented and vertically separated from each other); (3) educate and then motivate older people themselves to self-manage illness; (4) enable health systems strengthening to reformulate the community as the most basic layer of primary care (self and local community care), while local services are utilised as a secondary source, as and when older persons must be referred on for more professional expert care. This last mechanism manages patient flow to scarce resources, in what could otherwise be an overwhelming flood of demands for health resources.

From this point of view, how holistic a CBSI will be determined by how broad or narrow any given intervention or program needs to be (or chooses to be for a given community) and the nature and number of gaps in service delivery. There needs to be much more upfront discussion, within the context of regions, countries and cultures about the responsibilities that lie with the State and those that sit best with citizens, especially older ones and their families. A rights-based perspective is a good starting point for such discussions when generating policy options for future development. CBSIs must be connected up with policy innovations that allow for linkages with financing, legislative and resource decision making processes, otherwise they will not be sustained or championed by key decision makers, resource allocators and local/national power brokers. One such policy innovation, for example, could include the linking up of CBSIs with UHC developments. Ultimately scale will depend on grassroots efforts and innovations as well as interest and impetus from both the highest levels of governance as well as local levels of policy making.

5. Research Recommendations to Follow this First Consultation of an Expert Group

The review of the case studies within this expert consultation identified three fundamental threads that are critical to understanding CBSIs which will need further conceptual modelling and research. These threads that would need further research are:

- a. The idea that community based care is social innovation for older people to fill in crucial gaps in vertically oriented health systems, common to LMICs (and many high-income countries as well),

through using peer based and managed supportive networks. This can consist of older people alone or it may be inter-generational in approach. With older people, this is an important element of empowerment and of effecting inclusion by allowing for natural segmentation of those who are well-old to help the frail-old which in many instances translates into the young-old looking after the older-old.

b. The outwards engagement of a peer based network only succeeds and survives if it somehow engages with, innovates, renovates or reforms policy (starting with the local level but oftentimes moving to a regional or national scale) which actually leads to –

c. Funding and services reform or creation, innovation and engagement within an integrated, coordinated, or at the very least, inter-sectorally communicative health and care system, which for the purposes of scale is usually government led (local and national), and oftentimes includes the private sector. All of this combines together to deliver services at scale, whilst acknowledging that the role of governments are central as they usually have the mandate/strategy (at least in ambition) for national reach within an equity driven policy frame. This implies that community based approaches must have some level of local services to engage with, otherwise the CBSIs will not be effective for treatments and management of health declines and serious disabilities in older populations.

Therefore, WHO will follow up on these and other points laid out in this interim report during 2016/17, and will look to explore further the role of CBSIs in healthy ageing.

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Annex

1. Provisional Programme - Expert Consultation

Day 1 – Tuesday, 14 July 2015

09:00–09:40

Opening

09:00–09:10

Welcome remarks

Mr Alex Ross

Director, WHO Kobe Centre (WKC)

09:10–09:30

Overview of the meeting, agenda and objectives

Mr Loïc Garçon

Technical Officer, Innovation for Healthy Ageing (IHA), WKC

09:30–09:40

Short round of introductions

09:40–10:00

Coffee/tea

10:00–12:00

Introduction and discussion of the first set of case studies

South Africa – by Dr Prakash Tyagi

Thailand – by Dr Francesco Barbabella

Viet Nam – by Dr Mitchell Jay Besser

China – by Dr Francesco Barbabella

12:00–13:30

Lunch

13:30–15:30

Session 1: Older people centred care

The session will review key principles and lessons from the case studies on:

- Ensuring inclusiveness
- Enabling self-care in the community
- Organizing communities

Moderator:

Professor Norah C. Keating

International Association of Gerontology and Geriatrics; University of Alberta, Canada

15:30–15:45

Coffee/tea

15:45–17:30

Session 2: Delivering integrated Services

The session will review key principles and lessons from the case studies on:

- Delivering health care
- Delivering social care
- Ensuring quality

Moderator:

Dr Briony Dow

National Ageing Research Institute (NARI), Australia

Day 2 – Wednesday, 15 July 2015

09:00–09:15

Recap of Day 1 Mr Loïc Garçon, WKC

09:15–11:00

Session 3: Articulation with the health system

- Integrating into national policies
- Coordinating with public services
- Ensuring effective referral mechanisms

11:00–11:15

Coffee/tea

11:15–12:45

Introduction and discussion of the second set of case studies

India – by Dr Jongjit Rittirong

Poland – by Mrs Francien Scholten

Uganda – by Ms Tran Bich Thuy Moderator:

Dr Francesco Barbabella

National Institute of Health and Science on Aging (INR-CA), Italy

12:45–14:00

Lunch

14:00–15:30

Session 4: Challenges and promises in measuring health impact

- Defining baselines
- Assessing results and impact

Moderator:

Dr Megumi Kano, WKC

15:30–15:45

Coffee/tea

15:45–16:30

Session 5: Synthesis and principles of community-based interventions in LMICs – Experiences from case studies

- Recommending priorities for the implementing a successful community-based intervention supporting older populations

Moderator: Dr Paul Ong, WKC

16:30–17:00

Next steps and Closing

Mr Loïc Garçon, WKC

2. List of Participants

Resource Persons

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Dr Jongjit Rittirong, Lecturer, Institute for Population and Social Research, Mahidol University, Phutthamonthon, Thailand

Mrs Francien Scholten, Consultant, Uganda Research Unit on AIDS (UVRI), Medical Research Council (MRC), Entebbe, Uganda

Ms Tran Bich Thuy, Country Director, HelpAge International in Viet Nam, Hanoi, Viet Nam

Dr Prakash Tyagi, Executive Director, Gramin Vikas Vigyan Samiti (GRAVIS), Jodhpur, India

Professor Zhaoxue Yin, Associate Professor, Division of Non-Communicable Disease Control and Community Health, Chinese Center for Disease Control and Prevention (China CDC), Beijing, People's Republic of China

WHO Kobe Centre (WKC)

Mr Alex Ross, Director

Mr Loïc Garçon, Technical Officer, Innovation for Healthy Ageing (IHA)

Dr Megumi Kano, Technical Officer, Urban Health (UH)

Dr Paul Ong, Technical Officer, Innovation for Healthy Ageing (IHA)

3. WKC case study synthesis document

Synthesis of case studies to support the preparation of the consultation on community-based initiatives that support older adults in LMICs (June 2015)

Table of Contents

Introduction and background

- 1) The role and function of older people as a resources for themselves and for others (peers, family, community)
- 2) Main health and social services delivered by those initiatives, and referral processes when they exist
- 3) Coordination mechanisms with formal health and social sector, including the articulation with the health system
- 4) Type of metrics (indicators, monitoring tools) implemented to assess impact on health.

Concluding notes

Glossary

Introduction and background

The world is confronting an ageing demographic. As in many LMICs, older adults are a vulnerable and largely marginalized population. The reality of underfunded and sparse government services available for older people has left much to be provided by civil society groups, NGOs and faith based organization. In most of low- and middle-income countries (LMICs), support for older people is often provided by the immediate family. However, the traditional family care system in developing countries is gradually eroding due to a decrease in childbirth, migration of younger people, engagement of more family members in jobs, and due to a rapid urbanization. In response to drastic demographic and social changes as well as to the rapidly growing need for care and support among ageing populations, WKC is exploring existing community-based models implemented to address health care and social care for older people at a community level. Understanding these models/initiatives, their key organizational, financial, programmatic, and policy factors will help inform how best communities and countries can plan for sustainable and scaled up approaches, thereby contributing to UHC program development and continuous services for older populations.

WHO Centre for Health Development in Kobe, Japan (WHO Kobe Centre – WKC) launched a call for expression of interest to identify case studies about innovative community based approaches to support older adults.

This document will present a preliminary synthesis of the main findings of the 7 case studies in regards to four areas of interest:

- The role and function of older people as a resources for themselves and for others (peers, family, community)
- Main health and social services delivered by those initiatives, and referral processes when they exist
- Coordination mechanisms with formal health and social sector, including the articulation with the health system
- Type of metrics (indicators, monitoring tools) implemented to assess impact on health

The main objectives of all the initiatives implemented are to reduce poverty of disadvantaged older people through support of vulnerable communities, to meet their needs, improves the quality of their lives, and reinforces the development capacities of older people within those communities.

1) The role and function of older people as a resources for themselves and for others (peers, family, community)

Two main types of function

1. Type A:

Total participation of older people (OP) in the initiative, OP are beneficiaries and actors. In some cases program can link them to income generation.

2. Type B:

Older people are mainly receiving health and social care and have little involvement in the process of the intervention.

1. Type A:

In the type A category we can observe two sub-categories: the first when older people are the key actor in the delivery of care linking to income-generation such as AgeWells in South Africa and VHV in Thailand, the second where older people are part of the livelihood activities of the initiative, generating income (India, Uganda, Viet Nam).

India

Help Age International (HAI) and their Indian partner GRAVIS had jointly taken up the community-based initiative of empowering older people of the Thar Desert with a holistic approach and with a special focus on healthcare and livelihoods based activities. A strong focus of the intervention has been on developing community ownership by creating Village Older People's Associations (VOPAs) and Self Help Groups (SHGs) as well as a community-based cadre of Village Health Workers (VHWs).

Older adults have important duties within the community and are the main actors of great improvements within the community. Disadvantaged older people, particularly older women of 18 remote and needy villages of Thar Desert, have a significant role as a resource for themselves as well as for their peers and community. They participate in and benefit from socio-economic initiatives to reduce poverty through the formation and development of Village Older People's Associations (VOPAs). Older people's leaders are selected to lead the association and become a resource for themselves and their peers. The VOPAs representatives play an important, mentoring role for newly formed VOPA members/leaders. The older adults of the community are given leading roles through community level trainings in order to improve the social integration of more vulnerable groups.

The older people in those community-based initiatives have a remarkable role as all the interventions are developed through active consultations with them and their community. They have for example an important function to play in farming households. The beneficiary community participates in all process of the intervention including planning, implementation and monitoring.

Older women leading Self Help Groups (SHG) are well implicated in the empowerment of older adults in the community, taking active part in all activities with some of them linked to income-generation.

About one fourth of GRAVIS VHWs are older adults in the age group of 55 to 65. The implementation of Village Health Workers provides older adults with significant sense of participation and role in providing healthcare support to their peers and family. A central aspect of VHWs' functioning is to bridge the gaps between government health services and resources and communities. Similarly, older adults being VHWs have played significant role in spreading immunization in the Thar Desert for women and children, as well as in disseminating the information about Total Sanitation Campaign (TSC), Revised National Tuberculosis Control Program (RNTCP), National AIDS Control Program (NACP) and National Blindness Prevention and Control Program (NBPCP) of Government of India.

In the Thar Desert of India, older people's wisdom and local knowledge have been of great use on aspects like seed conservation, rainwater harvesting, dry land, and farming. All those elements have impacted older people's health directly as well as have supported families' incomes.

South Africa

AgeWell is a community based peer-to-peer support program for home dwelling older adults over 60 in communities of Cape Town, South Africa. AgeWell engages and employs active older people to provide companionship to less able older persons living in their communities. In addition, these peer service providers are trained to use smartphone technology, programmed with research-driven screening tools and referral algorithms to identify evolving health problems and make referrals to primary care providers and social workers.

Older persons have with the AgeWell program, big participatory roles and sense of empowerment as they are employed as peer supporters (AgeWells). AgeWells are paid a salary of R2000 (167 USD) a month to work 20 hours a week. The program is based on the idea that older persons can be an ageing community's greatest resource. Older adults are familiar with challenges faced by the older persons and so the best suited to identify and respond to issues met by other older persons.

The AgeWell initiative assists marginalized older adults to support one another to participate actively in improving their own health and well-being.

AgeWells (peer supporters) reported that since starting the program they feel more connected to each other and their

community. They have created stronger bonds with their neighbours, friends and other community members. AgeWells are empowered through owning and learning how to use a smartphone; which created a sense of accomplishment and real pride. Receiving a salary not only gave monetary value to their work but the income had a considerable effect on family welfare, self-esteem and alleviated some of the disempowerment of poverty.

Thailand

The community-based initiatives of rural districts in Thailand started almost 4 decades ago by an initiative of the Thai government. The Ministry of Public Health integrated primary healthcare into the 4th national plan. This policy has been implemented in every community across the country. The Village Health Volunteers (VHV) have a key role to improve healthcare access. The policy engages people in the community by encouraging them to solve problems within their own community.

Typically, the VHV are farmers, and some of them are retired. They play a significant role on older adults' support especially for those living with chronic diseases and limited access to healthcare services. When cooperating with the Sub-district Administrative Organization (SAO) and hospital (SH), the VHV are able to access every household in the village and provide basic medical advice and treatment as needed. Their major roles are to help communicate between health personnel and villagers, educate their neighbours about primary healthcare, and deliver some basic medical/healthcare services. The VHV are selected by their home community, and has to be nominated by at least 10 households in the village or the health personnel or community leader may approach a qualified villager. The VHV consider themselves as the doctors' assistant. As the numbers of health personnel are limited, VHV have a key role in the health of their community. They are often more welcome in households as they are known by the community, and can explain medical suggestions in simple words speaking the same dialect. Initially the VHV were not paid a regular wage. Later they received 600 baht for their expenses related to VHV work to cover fuel and traveling costs. For the VHV been working for the community for more than 10 years, they and their family members gain the benefits for free medical treatment and private room when admitted to a public hospital. VHV play a key role in maintaining and promoting the quality of life of the older adults in their home communities.

Uganda

The development and implementation of the initiative started with a request of the Commissioner of the Department of Elderly and Disability of the Ministry Gender, Labour and Social Development (MGLSD) to the Uganda Medical Research Council (MRC). The objective was to develop a social gerontology manual to support the implementation of the national policy. The Social Gerontology Manual was built with two existing approaches, the Community-Life Competence Process (CLCP) and EASY Care which were adapted and combined to enhance individual, family, community, civil society and government action in support of the health and well-being of older adults. The manual is both an awareness training of older persons' needs and provides skills to mobilize resources within the community and from the district.

The CLCP strength-based approach increases the awareness and knowledge about the issues faced by older persons, identifies the individual needs of an older person and focuses on local response. In this approach, older adults are active beneficiaries, they are the main actors in innovations aimed at addressing their problems, focused on discovering and using their own strengths to address their life's challenges. Older adults were active participants in all stages of the development of the community-based intervention. Several older adults support groups were created and met once a week. The groups aim to provide peer support to members who face challenges such as family members' illness, accidents and deaths. Some of the older people's support groups were able to start intergenerational income-generating activities. Besides, older adults are also involved in home-based care. Older persons who have difficulties with self-care and mobility are paired with younger more functional visiting peers at their homes, on a weekly basis. Facilitating this kind of initiative brings out the strengths of older people who are leaders and involves younger generation. With the strength-based approach older adults feel proud, have increased levels of confidence, are more willing to engage with formal service providers, and advocate for their own rights.

Viet Nam

Intergenerational Self Help Clubs (ISHC) are community led organizations that aim to promote equitable and inclusive development. The ISHC uses an inclusive approach, which targets the entire community to promote stronger local ownership and mutual support. Most of the ISHC members are older adults (mainly older women) and about 30% are younger. The older adults members of the ISHC have great role in the community, helping their peers and other community members to meet the various needs of their lives. Twice a week, older adults that are part of the home care volunteer team visit selected older people in community to provide help and assistance, such as befriending, house cleaning, simple repair cum cooking, etc. Some of the ISHC older adult members can provide cultural and art performance activities during meetings and community exchange events. Older adults have a key role in teaching younger generation techniques that individual

and households require for their income generation. Older persons in good health condition can also join and be part of the Club Management Board (CMB) for at least 2 or 3 years. Responsibilities are assigned to each member of CMB in accordance to their capacity. Any older adult that is part of the CMB has the responsibility to conduct, manage and monitor all activities of his/her assigned group.

2. Type B:

Poland

The Local Network of Support Centres for the Elderly in Tychy (Poland) is one of the main projects implemented following the growing demand in Tychy for initiatives that support older adults. The project started in 2002 and there are three catholic parishes run by NGOs. Each center operates a program known as Daily Support for Children, creating intergenerational social activities. Older people visit children during occasional meetings and daily activities. They help them in their school duties; teach them independence and share experiences of their life. Older adults feel needed and are given an important role as “life tutor”.

Acting together, they are breaking down the stereotypes about older people and changing vision of being old. Lasting intergenerational relationships are developed between the participants. During this social activity, older adults increase their self-esteem and feel needed by others. The Centres have a positive impact on their autonomy and the sense of meaning of life.

China

The community-based intervention developed an older adults volunteer team to help those with disability or living alone in the community. The older adults volunteer help to prevent social isolation and engage communication with the older people in need. The active and relatively healthy old adults are encouraged to help their peers with disability, and provide some services, which included mainly daily care and social interactions, such as conversational engagements.

Key principles

In all the 7 case studies, active participation of the older adults has helped in achieving the objectives and in strengthening the relationship with the communities further. The high degree of participation of the older adults within the community in developing, implementing, monitoring and evaluating health and social initiatives increased the likelihood of achieving sustainable behavioral change. Resources provided/created relate to the dedication of time, investments and creative thinking of the older adults and their peers.

Older adults being Village Health Volunteers in several initiatives studied are key players to improve healthcare access, as they are local older people familiar with the community and able to communicate using simple words and or the local dialect. As the local people are often more respected than outsiders, Village Health Volunteers are the key persons to achieve great supports for older adults.

In addition to the impact on people receiving services, older peer supporters have also been shown to benefit from their helping roles in terms of self-development and overall sense of purpose.

2) Main health and social services delivered by those initiatives, and referral processes when they exist

After review of the 7 case studies, three main type of services delivered by the initiatives are most apparent: health promotion and prevention activities, health care services (either delivered by volunteers or older people), and social and livelihood services.

Health promotion and health prevention services

After review of the seven case studies, one of the main services provided by the community-based interventions is related to health promotion and prevention activities. Indeed all the community interventions provide educational, informational and health promoting events throughout many villages. Many of these events promote healthy lifestyle and self-care training to enhance members' healthy living. Prevention services are run through home visits and advocacy events with screening tests to detect NCDs (Thailand, Viet Nam, China) as part of a prevention and health promotion approach. Several health camps are organized where physical and recreational activities are implemented (India, Poland, China, Thailand, Viet Nam).

In India, Village Health Workers act as health educators, counselors and referral linkages between communities and health services. Well accepted in the community, VHWs are proving to be very helpful in enhancing older people's health awareness. The initiative organized numerous health camps and run many health educational campaigns as well as support events through villages. Organization of health activities in villages such as outreach health camps, health trainings etc. are organized by joint efforts of VOPAs, SHGs and VHWs. One of the several interventions implemented for the older adults at the community level is the formation and training of older women to lead Self-Help Groups (SHGs).

Similarly, the Tychy Local Network of support center in Poland provides activities to promote healthy lifestyle, and organize events with volunteer therapists and physiotherapist, providing maintenance and rehabilitation exercises. The Centers only promote and educate the older adults for healthy lifestyle and have as main objectives to stimulate social activity and willingness for the provision of mutual support, and to encourage participation and support for mental health.

In the community-based initiatives of Rural Districts in Thailand, the Village Health Volunteers promote health, control and prevention of disease by guiding advice, educating neighbours and heads of the community on how to live healthy lifestyles. VHV seek out older adults and operate screening test (BMI, hypertension and diabetes), visit and give advice on preventing non-communicable disease, monitor symptoms and provide suggestions in case of older persons' immediate/special medical treatments. The Village Health Volunteers encourage villagers to attend the health care program and activities and educate them about their rights related to health services regarding the relevant Thai legislation. VHV are the main link between older adults and the health care system, indeed they screen patients and report the results to health personnel at the Sub-district Hospital.

The community-based intervention in China, builds outdoors activity area where older people can have physical and recreational activities. The outdoor area became a community park, where facilities are made available for older adult members of the community. Those facilities included physical exercise equipment, tables and desks for playing poker and chess. Besides, basic health education services are also delivered.

Like most of the community-based studied here, the Inter-generational Self Help Club in Viet Nam provides self-care activities to enhance members' healthy lifestyle through information, education and communication on common disease care, good nutrition, etc.

Health care services

A. Delivered by volunteers

The community health center of China, provides medical service to the residents including older adults of the community. For the older persons with disabilities and mobility difficulties, the community health center provides medical visits with basics health check-ups such as blood pressure measurement, blood glucose tests and other simple medical treatment services. The program provides health examination and management of chronic diseases.

In the Nang Rong District in Thailand, volunteers facilitate medical mobile outreach unit with health personnel on regular basis for those facing functional difficulties. The program provides primary health care and are recruiting multi-disciplinary health personnel for regular visits in order to serve older adults in their homes.

B. Delivered by older people

In several community-based programs, older people are part of the health care team of the intervention and become the main caregivers for their peers in the village.

In India, Help Age International (HAI) and their partner GRAVIS have been implementing a comprehensive community-based intervention in the Thar Desert of India that supports older population by providing them healthcare services. With the formation and training of VOPAs the initiative provides healthcare services at the community level through continuous training of Village Health Workers (VHWs) providing support to older adults. VHWs are trained in basic health skills focusing on ageing and self-care aspects such as identification of NCDs, nutrition, sanitation, mental health, and eye care. Another important area of VHWs' work is to focus on older women's health needs. VHWs collaborate closely with the government health staff at the village level by referring older adults with health complications when needed.

In Uganda, older adult leaders are trained in care for older persons using the strength-based approach and are also taught basic clinical care practices such as first aid care for older adults. In two districts the village health team followed the older persons up at home when referrals were done, monitoring adherence to treatment or explaining the correct usage of the

drugs. Village Health Teams escort older people and provide transportation when needed.

The ISHC in Viet Nam provides home visits paid to the members as well as exchange visits among ISHCs. Those services include, mostly personal hygiene, vital sign monitoring, etc. to at least 3 older adults with ADL or IADL difficulties in community, regardless of member status. If appropriate, case management is conducted by CMB home care volunteers and care assistants. Healthcare proposed by the community-based program includes at least two health check-up per year provided by local health stations, centers or hospitals to ISHC members.

Two out of seven community-based programs do not deliver health care services (Poland and South Africa). However, as already described above, the health care services delivered by the other programs remain very basic. Again, it seems that the main goal of the initiatives are to create a link between older adults members of the community and the formal health and social care sectors.

Social and livelihood services

The social and livelihood aspect in community-based programs remain central to their objectives. Community-based intervention aim to empower and engage older adults. Implementations of events where older adults can socialize through cultural and social activities are the main recurrent services provided in all seven community-based interventions.

A. Delivered by volunteers

The Sub-District Administration Organization (SAO) in Thailand implements events where older adults have a chance to socialize, which contributes to their psychological well-being. The initiative helps maintain social cohesion between older adults and the younger generation within the community. VHV provide transportation and help older adults to join the community's activities such as traditional Thai festivals.

The Tychy Local Network center of support for older adults in Poland, organizes cultural activities where older adults can interact with others and meet their needs for social activities. The Centers operate the Daily Support Centers for Children program giving the possibility of integration between generations.

In China, the intervention implemented an indoor Senior Activity Center where meals are provided every day. Cultural and physical activities are organized every year. The program also developed an older adult volunteer's team to help those with disabilities or living alone in the community. The range of help goes from daily living activities to befriending in order to prevent isolation.

Self-help and community support groups in Viet Nam, include a wide range of activities such as providing labor techniques and in cash and in kind support to those who need help. To improve psychological and mental health ISHC promotes interaction among their members and organize, on a monthly basis, cultural and social activities. The ISHC provides social, mental and health care services for the older adults' members or not, living in the community.

The different programs provide mostly empowerment and social support activities to prevent isolation and exclusion of older adults at the community level.

B. Delivered by older people

Older adults are also the key actors in providing social and livelihood activities such as in South Africa, India and Uganda.

The AgeWell is a community based peer-to-peer support program in South Africa, and it engages and employs active older people (AgeWells) to provide companionship to less able older persons living in their communities. AgeWells work in pairs conducting home visits comprising both social and wellness content. Social content is related to companionship, social support, and generating a sense of community. AgeWells build friendships, encourage social engagement, and provide emotional and informational support as well as promoting healthy living. Wellness content is associated with identifying possible evolving health-related and social problems. Older adults assessed with health and or social service needs are referred to their health care provider or guided to social services. Referrals are generated using a smartphone loaded with a screening instrument app that is comprised of basic questions that can be utilised by AgeWells during a visit. AgeWells are also taught observational assessment skills and they record their observations in the app as well. Consequently referral recommendations to health care providers and social workers are generated. Referred older persons are provided with a letter containing basic information stating the referral purpose. AgeWells serve as a central link between social supports of family and community, and healthcare offered by licensed medical providers, but they do not provide health care or social service

support directly.

In India, the VHWs visit older people in their homes and organize talks and discussions. A number of livelihood activities have been planned and implemented that tackle water security, food security and nutrition security. Many drinking water storage tanks were constructed, improving the availability and access to water for daily household needs for older people and their families. The nutritional base of households was particularly increased with the establishment of home gardens and the distribution of agricultural inputs. The livelihood activities led the older adults to greater income security and therefore to a better health status.

In Uganda, once a week older persons support group provides peer support to members who face challenges such as family members' illnesses, accidents and deaths. They also address more difficult issues such as age-unfriendly services and abusive relationships. Another area is home-based care. The village health teams are community volunteers that include older adults. During home visits the dialogue take place on the seven domains of health and wellbeing in order to understand the issues of the older persons. These visits also identify strengths and weaknesses, and when necessary referrals are made to health and social services. The seven domains are: vision and hearing, self-care, mobility, safety and security, accommodation-environment-finance, staying healthy and mental health.

The main social and livelihood services observed in the different community-based intervention remain in organizing social and cultural events; home visits with activities of befriending with older persons to prevent social isolation and implementation of livelihood activities.

Key conclusions

The main services provided by the different community-based intervention are health promotion and health education services. In addition to being the main link with formal health social services, the village health volunteers/workers provide wellness and social supports in all program studied. There is no in depth health and social services available for the majority of the community-based interventions. Besides, the health promotion and education advocacy events are conducted only with a limited frequency.

It is noteworthy to distinguish between what is made by the institution and by the older people themselves. An example is the AgeWell model where older adults are the main actors helping their peers to access health and social services. Other initiatives implement activities to empower older adults and give them health and social awareness, this resulting in older people being more confident and willing to receive care.

3) Coordination mechanisms with formal health and social sector, including the articulation with the health system

All the case studies revealed a collaboration of the interventions with formal health and social sector. We distinguish 2 categories: coordination with the public health and social sector and coordination with private sectors.

Coordination with the public health and/or social sector

In the community-based intervention of India, after visiting older people in their homes as well as organizing health talks and discussions the VHWs collaborate with the government health staff at the village level. The community-based initiative offers a strong connection with the local government health services. GRAVIS has been organizing medical camps in Thar with the help of a medical team. One of the main objectives of such interventions is to provide referral support to older people to health facilities according to their needs. While the intervention built and implemented a number of activities within the scope of funded projects, one of the key objectives was to leverage with the existing government programs and resources available within the community. With a livelihood context, constant efforts have been made to utilize the resources available under National Rural Employment Guarantee Act (NREGA) of Government of India and to ensure older people's contributions in it. On health, nutrition and sanitation aspects, links were made with the National Rural Health Mission (NRHM) and Total Sanitation Campaign (TSC).

Similarly, efforts have been made with good success to collaborate with a number of other government health programs such as RNTCP, NACP and NBPCP Training and advocacy efforts resulted in active participation of older people in the planning meetings of three programs at village and block levels. During the course of the intervention, several opportunities came up where older people provided the platform to speak on government programs on higher levels including District, State and National levels. As a result of these ongoing efforts, better use of NREGA funds is seen in many villages as well as the Primary Health Centers (PHCs) run by the NRHM have been giving attention to older people's special health concerns and needs. A number of promotion events were organized at different levels including village, district, state and

national levels. Therefore the local government has gradually been increasing its interest in the intervention. Community-based organizations created under the intervention – VOPAs and SHGs and volunteers including VHWs have taken major initiatives in bridging the gaps with local authorities to ensure better delivery of government resources. As a result of VHWs initiatives, many public health centers (PHC) in the areas have become more sensitive to older people's needs. The relations between VHWs and PHC staff are friendly, both focusing on older people's health needs. Moreover special waiting areas for older people were created and some PHCs have started an older people's health day once a week. VHWs regularly collaborate with the government health staff at the village level. They are an important link between the service delivery of health and older adults.

The community-based initiative of Thailand is a good example of coordination between groups supporting older adults in the community and the formal health and social sector. The Thai national health development plans since 1977 aimed to improve health care access particularly for vulnerable people including older adults, and Village Health Volunteers were recruited to serve this goal. At present, health and social services related to older people within the community are primarily provided by two local organizations: the Sub-district Administrative Organization and the Sub-district Hospital. Village Health Volunteers are the main link between the older people within the community and the formal sector. They cooperate with the SAO and SH. The SAO is a local government organization. All their activities are subsidized by the national government. The SH receives budget from the MOPH to cover health personnel salary and medical treatment. VHW facilitate information flow from the government to the locality. In cooperation with the SAO, the health personnel at the SH, including VHW and the community leaders, visit villagers to see how well the villagers live. Every household member is recorded in the SH system. VHW can visit villagers to help out and liaise with health personnel if needed. The VHW community-based program is well integrated within the local health and social system.

The development and implementation of the community-based intervention in Uganda went through a gradual process that started with a request of the Commissioner of the Department of Elderly and Disability of the Ministry Gender, Labour and Social Development (MGLSD) to the Uganda Medical Research Council (MRC) in Entebbe, to partner in the development of a social gerontology manual to support the implementation of the national policy. There is a strong collaboration between the community-based initiative and the national government to facilitate a link with national policies and programs and increase the chances of replication in multiple settings, focusing on the development of a national Social Gerontology Manual for training of government and civil society staff. The manual primarily aims at trainers of community workers from government and civil society organizations, as well as district officers.

In Viet Nam, there is a network of village health care collaborators organized by the government in all villages. They have training on primary health care, are working part-time and paid by the government to help Community Health Station officials through community-outreach activities. The community-based initiative collaborates with health care officials at the Commune Health Stations (CHS) under the direction of Commune People's Committee.

Coordination with private health and or social sector

AgeWells do not provide health care or social service support (apart for companionship support); however they serve as a central link between social supports of family and community and healthcare offered by private licensed medical and social providers. Older adults assessed with health and social service needs are referred to their health care provider or guided to social services. Referrals are generated using a smartphone loaded with a screening instrument comprised of basic questions and observations to be filled in by AgeWells during a home visit.

The AgeWell program worked within legal structures and frameworks in South Africa. The program was careful to operate under Department of Health regulations distinguishing caregivers from service providers. This ensured that the role and scope of work for AgeWell peer supporters were strictly aligned with provision of supportive companionship and promotion of wellness activities.

Key conclusions

Most of the case studies coordinate their health and social services with the public sector. The implementation of the community-based programs is often aligned with national policies and aim to fill the gap for people centered services. Volunteer caregivers are the key link between the older population and the either public or private formal health and social sectors. Coordination with formal health and social services is made by most of the community-based programs. However it is not clear if this coordination is formal or appropriate.

4) Type of metrics (indicators, monitoring tools) implemented to assess impact on health

The assessment of the impact of the different interventions on health is probably the most difficult part for the programs. We can distinguish two groups of monitoring and evaluation methodologies. The first being interventions that were able to use a base line status of the situation before implementing the program. The second, included programs showing some elements of trying to measure the impact of the intervention after the fact, and then lastly there were interventions that were completely lacking in evaluation and monitoring elements.

Community-based intervention using baseline data

In India, HAI and GRAVIS have conducted two major base line surveys at the beginning of the intervention. In addition a specific health assessment study was conducted as part of the Older People's Health India program. Subsequently, two major evaluation studies have been conducted by external evaluations at the end of the projects. Besides several impacts assessment studies as well as fieldwork data collection were piloted.

To assess self-reported wellbeing, the AgeWell program used the Likert scale based WHO-5 Well-Being index (1998) tool. The scale was administrated at baseline on all potential clients by a study assessor before any other assessments were made. The same assessor reassessed clients with the same scale at end line, after 5-6 months of program exposure. The program also used the Medical Outcomes Study Social Support questions to assess changes in levels of social support available to those who have been identifies as being socially isolated. Moreover a mHealth system was designed to monitor program activities and gather outcome data. Activity data were monitored to assess for timeliness and adherence to visit schedules and that social/physical health screenings were completed. The benefit of using e-technology to monitor program implementation meant that needed adjustments and problem solving could be expedited to promote operational success. A paper-based monitoring system was developed to track referrals to and back from service providers. Phone surveys were conducted on a random subset of clients for qualitative feedback on program operations, including self-reported changes in wellness and satisfaction with AgeWell services.

Monitoring and evaluation tools of community-based initiatives lacking in baseline data

Monitoring and evaluation is for community-based initiatives probably the most difficult part. Indeed the main incentives of such programs was to achieve better health and social status for older people in the shortest time period possible. The resources being limited, efforts tended to focus on implementing the activities which often resulted in a lack of evaluation and monitoring data or teams.

For the Tychy Local Network of Support for older adults in Poland, evaluation and monitoring activity is carried out by the representatives of the City Council. Officials are in constant contact with the centers' managers. The main elements of evaluation are annual reports, which each centers must submit to the City Council. These documents report information about distribution of financial resources and the implementation of planned activities. There is for this community-based intervention very limited evaluation and monitoring activities. No action to measure the real impact of the initiative on the older adults' quality of life, health and social changes were undertaken.

The VHV of the Thailand program has run for more than 4 decades as implemented by the national health plans. All vil-lages are reached by the program, thus VHV programs as a whole are lacking in baseline data. It is not possible to identify the older adults' health status between a control group and intervention population.

In Uganda, the approach of the social gerontology manual was field-tested with two communities in one district, including a before and after intervention survey among older adults, community and services providers.

The community-based initiative of China conducts satisfaction surveys as well as evaluation of the program's performance every year by doing field supervision, oral reporting, and archive checking.

In Viet Nam, a survey was conducted in 4 provinces in 2014 indicating some health related indicators improvement compared with non-members of the community-based program. The indicators showed that older adults benefitting from the program had more knowledge on prevention of common NCDs and on their rights to have more periodic health examination at health care facilities.

Key conclusions

Very few programs reported monitoring and evaluations elements. The recurrent tools for evaluations were focus group interviews with the older adults and satisfaction surveys. However baseline data are for most case studies were often lacking. This gap is understandable given the context and limited resources of these community-based initiatives.

Concluding notes

The community-based interventions studied adopt for most of them innovative ways of caring for older adults. This approach responds to the definition of people-centered care. People-centered services should adopt the perspectives of individuals, families and communities, and see older adults as participants as well as beneficiaries of trusted health systems that respond to their needs and preferences in humane and holistic ways. People-centered care requires that people have the education and support they need to make decisions and participate in their own care. It is organized around the health needs and expectations of people rather than diseases.

Most of the community-based initiatives studied here are trying to move toward a holistic approach including multi-dimensional activities to meet the various health and social needs of older adults.

(WKC, June 2015)

Glossary

CLCP: Community-Life Competence Process
CMB: Club Management Board
HAI: Help Age International
ISHC: Intergenerational Self Help Clubs
LMICs: Low- and Middle Income Countries
SAO: Sub-district Administrative Organization
SH: Sub-district Hospital
SHGs: Self-Help Groups
VHV: Village Health Volunteers
VHWs: Village Health Workers
VOPAs: Village Older People's Associations

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