Strengthening Developing Member Countries Capacity in Elderly Care
Community Care Mapping Report
Yogyakarta, Indonesia

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For Asian Development Bank

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# Abbreviations

<table>
<thead>
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<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ADB</td>
<td>Asian Development Bank</td>
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<tr>
<td>ADC</td>
<td>Adult Day Care</td>
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<td>ADL</td>
<td>Activities of Daily Living</td>
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<tr>
<td>ANTAR PAIMA</td>
<td>Layanan Antar Sampai Rumah (Services that reaches home)</td>
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<td>APP</td>
<td>Application</td>
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<td>ASLUT</td>
<td>Asistensi Social Lanjut Usia Terlantar (cash transfer)</td>
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<td>BALASAN</td>
<td>Bantuan Lansia Mergangsan (Mergangsan Elderly Help)</td>
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<td>BAPPENAS</td>
<td>Ministry of National Development Planning</td>
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<tr>
<td>BJPS</td>
<td>Universal health insurance scheme</td>
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<td>BKKBN</td>
<td>National Family Planning Board</td>
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<tr>
<td>BKL</td>
<td>Elderly Family Development Program</td>
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<tr>
<td>BPS</td>
<td>Statistics Indonesia</td>
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<td>CC</td>
<td>Community Care</td>
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<td>CCRC</td>
<td>Community Care Redesign Committee</td>
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<td>CDS</td>
<td>Country Diagnostic Studies</td>
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<td>CSR</td>
<td>Corporate Social Responsibility</td>
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<tr>
<td>DMC</td>
<td>Developing Member Countries</td>
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<tr>
<td>EC</td>
<td>Elderly Care</td>
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<tr>
<td>FKTTP</td>
<td>Fasilitas Kesehatan Tingkat Pertama (First Level Health Facility)</td>
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<tr>
<td>FGD</td>
<td>Focus Group Discussion</td>
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<tr>
<td>GRISIELA</td>
<td>Griya Sejahtera Lansia (Elderly Prosperous Housing)</td>
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<tr>
<td>HCBC</td>
<td>Home and Community Based Care</td>
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<tr>
<td>HR</td>
<td>Human Resource</td>
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<tr>
<td>IADL</td>
<td>Instrumental Activities of Daily Living</td>
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<tr>
<td>ICT</td>
<td>Info Cegatan Jogja (Jogja Intercept Information)</td>
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<tr>
<td>JAMKESUS</td>
<td>Jaminan Kesehatan Khusus (Special Health Insurance)</td>
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<td>JSLU</td>
<td>Elderly Social Security Program</td>
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<td>JSS</td>
<td>Jogja Smart Service</td>
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<td>KII</td>
<td>Key Informant Interviews</td>
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<tr>
<td>KOMDA LANSIA</td>
<td>Komisi Daerah Lanjut Usia (Regional Elderly Commission)</td>
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<tr>
<td>LCOP</td>
<td>Local Commissions for Older People (KOMDA)</td>
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<tr>
<td>LKS</td>
<td>Lembaga Kesejahteraan Sosial (Social Welfare Institutions) - PUSAKA</td>
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<tr>
<td>LTC</td>
<td>Long-Term Care</td>
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<tr>
<td>MNA</td>
<td>Mini Nutrition Assessment</td>
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<td>MOH</td>
<td>Ministry of Health</td>
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<td>MOSA</td>
<td>Ministry of Social Affairs</td>
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<td>NCD</td>
<td>Non-Communicable Disease</td>
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<tr>
<td>NCOP</td>
<td>National Commission for Older People</td>
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<tr>
<td>NFPB</td>
<td>National Family Planning Board</td>
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<tr>
<td>NGO</td>
<td>Non-Government Organisation</td>
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<tr>
<td>OOP</td>
<td>Out of Pocket (Expense)</td>
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<tr>
<td>OT</td>
<td>Occupational Therapy</td>
</tr>
<tr>
<td>P3G</td>
<td>Pengkajian Paripurna Pasien Geriatri (Geriatric Assessment Tool)</td>
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<tr>
<td>PKH</td>
<td>Program Keluarga Harapan (Family Hope Program- conditional cash transfer)</td>
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<tr>
<td>PKK</td>
<td>Pemberdayaan Kesejahteraan Keluarga (Empowerment of Family Welfare)</td>
</tr>
<tr>
<td>PMKS</td>
<td>Social Welfare Affected Personnel (Penyandang Masalah Kesejahteraan Sosial)</td>
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<tr>
<td>PMT</td>
<td>Community Nutrition Fulfillment Assistance</td>
</tr>
<tr>
<td>POSBINDU</td>
<td>Integrated Counseling Post for Non-Communicable Diseases</td>
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<tr>
<td>Abbreviation</td>
<td>Full Form</td>
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<td>--------------</td>
<td>---------------------------------------------------------------------------</td>
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<tr>
<td>POSYANDU</td>
<td>Community health outreach for Older People</td>
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<tr>
<td>LANSIA</td>
<td>Centre for the Development of Human Resources</td>
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<tr>
<td>PPDSM</td>
<td>Physiotherapy</td>
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<tr>
<td>PSTW</td>
<td>Panti Sasana Tresna Werdha (Residential Home)</td>
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<tr>
<td>PUSAKA</td>
<td>Pusat Santunan Keluarga (funded by MOSA, part of LKS)</td>
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<tr>
<td>PUSKESMAS</td>
<td>Pusat Kesehatan Masyarakat (community health centre)</td>
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<td>PWD</td>
<td>Person with Dementia</td>
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<td>RETA</td>
<td>Regional Technical Assistance</td>
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<tr>
<td>RT</td>
<td>Rukun Tetangga (Neighborhood Association)</td>
</tr>
<tr>
<td>RW</td>
<td>Rukun Warga (Hamlet/Citizen Association)</td>
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<tr>
<td>SOP</td>
<td>Standard Operating Procedure</td>
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<tr>
<td>SPM</td>
<td>Standard Pelayanan Minimal (Minimum Service Standards)</td>
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<td>STRANAS</td>
<td>National Strategy of Ageing (Strategi Nasional Kelanjutusiaan)</td>
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<tr>
<td>TKSK</td>
<td>Tenaga Kesejahteraan Sosial Kecamatan (Subdistrict Social Welfare Worker)</td>
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<td>TSM</td>
<td>Tenaga Sosial Masyarakat (Community Social Worker)</td>
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<tr>
<td>WA</td>
<td>WhatsApp</td>
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<td>WHO</td>
<td>World Health Organisation</td>
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I. Introduction

In October 2019, ADB received a request from BAPPENAS and local governments of Yogyakarta to help mapping community care (CC) so as to improve the delivery of care for the elderly at their homes and communities in the Special Region of Yogyakarta. In partnership with SurveyMETER, three community care mapping workshops were held on February 10 & 11, 2020 to gather information from elderly, family members, service providers (cadres, health and social workers, etc.) and government officials (regulators, funders, etc.) This report summarizes the findings of the mapping workshop.

II. Community Care Mapping (Journey) Workshop

Community care mapping or journey visualizes (1) existing experiences of providing and/or receiving community care or (2) new experiences of providing and/or receiving community care that are planned but do not exist. Unlike business process maps, care process mapping or journey focuses on human experiences, illustrating the story of a specific actor throughout the journey.

A. Objectives:

1. Map the experiences of users (the elderly and their families), providers (cadres, social and health workers, etc.) and government officials (regulators, funders etc.), based on current and ideal provision of community care.
2. Identify themes of concerns of current and drivers for an ideal community care.
3. Support the users to make informed choices of their community care needs that aligns with their preferences and wishes
4. Broaden community care options for the elderly in need
5. Enhance a person-centered approach for elderly receiving community care
6. Smooth transitions back and forth between different service components of the community care continuum.

B. Participants:

A total of 51 elderly, family members, service providers and local government officials participated in the workshops. Participants represented a mix of rural and urban experience and came from across Yogyakarta. The elderly and family members had experience in the use community care. A participant list is in Appendix 1.

C. Process:

There were three workshops conducted, each one focused on one of the following settings: urban (Yogy City), semi urban (Sleman District) and rural area (Bantul District). Participants of each workshop were divided into two workgroups. Each workgroup was facilitated by a facilitator, whose roles were to define the scope of the community care mapping, helped the group identify, write down the steps of the care journey, and corresponding issues/concerns, experience and feelings on a sticky note. The facilitator would then arrange the sticky notes in a logical sequence for the group to agree on. Each group developed the care map based on one of the case scenarios below. They first worked on the current community care process. If time allowed, some of the workgroups might also explore an ideal community care map. Participants’ stories, thinking and feelings were transcribed by
workgroup recorders. Major themes of concerns were identified by using the care journey maps developed and transcription of group discussion.

D. Scope

The scope of the mapping as shown in the case scenario below are:

<table>
<thead>
<tr>
<th>Case</th>
<th>Descriptions</th>
<th>Scope</th>
<th>Ending</th>
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<tbody>
<tr>
<td>1</td>
<td>Female, 82, dementia with challenging behavior, lives with her daughter and son in law only.</td>
<td>Family noticed loss of memorial and client became increasingly agitated and had wandering behaviors</td>
<td>Admitted to a mental hospital due to decreasing mental capacity in two years.</td>
</tr>
<tr>
<td>2</td>
<td>Male, 69, stroke, discharged from hospital, rehabilitation needs, lives with his wife, aged 63 (children in different province)</td>
<td>Client admitted to hospital with diagnosis of stroke: left side paralyzed, eating and swallowing difficulties, with limited speech (aphasia).</td>
<td>At aged 73, client continued to stay at home, was able to walk with walker, eating under supervision, with no significant improvement in speech.</td>
</tr>
<tr>
<td>3</td>
<td>Bed bound/ frail widow, 79, lives her daughter, son in law and 2 teenage grandchildren</td>
<td>Became incontinence (both bowel and urinary), admitted to hospital 3 times in 2 months due to lower respiratory infections</td>
<td>Died at hospital at aged 81 because of pneumonia</td>
</tr>
</tbody>
</table>
III. Maps

Diagram 1: Current Community Care Map

Current Community Care Map

- Family Doctor
  - PKK (women group)
  - LKS (Social Centre)
  - PMT (nutrition fulfillment assistance)
  - BKL (Elderly Family Dev Program)
  - Posyandu/Posbindu (Community Health Outreach for Elderly)
  - WhatsApp group, Info Cegatan Jogja (ICO), Jogja Smart Service (JSS)

- Other health/social institutes/village coordinator
- Infirmary/residential care
  - Residential care
    - Balai for elderly with potential to improve
    - Panti wreda for bedridden elderly (nursing home)

- Puskesmas
- Medical specialist

- Hospital

- Who can afford

- Elderly/family

- Alternative medicine

- Pramurukti (paid caregivers)
Diagram 2: Ideal Community Care Map

**Ideal Community Care Map**

**Integration, Leadership & Coordination**

- **Pramuruki** (paid caregivers)
- **Alternative Medicine**
- **Case Management**
- **Elderly/Family**
- **Integrated Client Information System via ICT**
  - Info Cegatan Jogja (ICJ), Jogja Smart Service (JSS), WA Group

**Vertical Integration**

- **Family Doctor**
- **PKK (women Group)**
- **BKL (mini health centre)**
- **Posyandu Lansia (Health Station)**
- **LKS (Social Centre)**
- **Paguyuban Perawat (Nurse Group)/Elderly Center**
- **Home Help**
- **Home Care**
- **Day Care**
- **Rehabilitation Centre**
- **Puskesmas**
- **Hospital**
- **Medical Specialist**
- **Residential Care**

**Horizontal Integration**

- **Other health/social Institutes/Transportation, Housing, Planning, etc.**
- **Private sector & elderly care investors**

*Residential care:
- Bedless for elderly with potential to improve
- Bedless for bedridden elderly (nursing home)
Diagram 3: Long Term Care Plan (BAPPENAS)

Active Ageing and Community Based Long Term Care Development: Concept

Home/Family-based Care
- Informal Caregiver: Family
- Formal Caregiver
- Health workers
- Social Workers
- Home health care
- Personal care
- Companionship
- Emergency Response system
- Home maker services
- Home visit

Community-based Care
- Posyandu Lansia
- LKS/ Elderly Group
- Bina Keluarga Lansia (BKL)
- Care giver
- Kader Posyandu
- Kader BKL
- Petugas PLKB
- Social Workers
- Health workers
- Volunteers

CARE MANAGEMENT

SISTEM INFORMASI LANSIA

ELDERLY

Facility-based Care
- Doctor
- Dentist
- Nurse
- Puskesmas staff
- Social workers
- Nutritionist
- Psychologist
- Physiotherapist
- Care giver
- Adult foster care
- Assisted living facilities
- Continuing care retirement
- Nursing home
IV. Themes

Here are eight themes identified based on the transcripts of six focus subgroup meetings (3x2). Transcripts were derived largely from experiences of current community care service recipients (elderly and family members) and providers (BLK, LKS, Posyandu, Puskesmas, NGO, etc.) as depicted in Diagram 1: Current Community Care Map. Appendix 2 is a more detailed transcripts of the eight themes identified.

A. **Theme 1: The current community care system is lopsided with majority of the care responsibility falls on the elderly and family.**

As one of the members in the “Dementia Group” put it: “care started in the family and ended in the family.” Many take up caring job alongside work and other family responsibilities. Elderly and family members were equally worried and anxious. Some of the elderly felt hopeless, did not want to go hospital, and declined psychosocial and spiritual supports. They also need information and assistance in practical help such as home modifications, assisted device, food preparation, etc.

B. **Theme 2: Cadres are key in community care for the elderly, but they have not been properly trained to deal with more complex elderly care problems.**

Cadres (volunteers) perform multiple roles in community care range from home visit, liaison between the elderly and health care providers, making referrals, booking ambulance service, performing simple health care procedures such as measuring blood pressure and sugar level, care of the dying, etc. All community care providers, formal and informal, consider Cadres indispensable. However, when facing more complex elderly care issues such as dementia, stroke or bedridden, they are less capable because they lack the needed knowledge and skills. They need more training. Participants felt that there should be designated training institutes for the training of community care cadres.

C. **Theme 3: Puskesmas is the hub of community care.** Everyone points to Puskesmas for care. However, it does not have the needed finance and human resources, to care for people with long term care needs such as dementia, stroke and in bedridden conditions.

People will go to Puskesmas if they feel sick, as indicated by one of the female elderlies in the “Bedridden” group. However, what Puskesmas can do has been limited to simple physical issues. When an elderly requires after stroke care, the patient may be referred to the hospital for follow up rehabilitation as not all Puskesmas have physiotherapy. When the elderly presented with dementia related behavioral problems, the patient was checked for vital signs and sent home with vitamin pills. There is no screening on dementia. One of the district health officers in the “bedridden” group pointed out: “it is not possible for Puskesmas to provide continuous care for bedridden patients whose care are generally very long term or extensive.” As one of the heads of Puskesmas in the “Stroke” group said “Ideally, in each of the Puskesmas, there should be 2 teams, each team with 3-4 health care workers, to care for the elderly.” In practice, there is only one trained staff in doing so. Puskesmas has limited resources and its resource has been maxed out. There is long service queue, very limited home care service, etc. in most Puskesmas.
D. **Theme 4: Comprehensiveness, awareness and accessibility of community care services are concerns.** Some of the services are overlapping. People do not fully understand the scope and eligibility of different services.

There are many community care services available to help elderly with problems, e.g., RT, RW, and mosque administrators at local level (TKSK, Day 1 AM – Stroke). There are also forums in some villages, conducting dementia educational programs to the public including: what it is such as symptoms and problematic behaviors to look for, and how to take care of people with dementia (Head of Puskesmas, Day 1 AM – Dementia). LKS helps people to obtain financial support, especially when (a) the cost of care cannot be covered by Puskesmas or village governments, and (b) the elderly has no families (Head of Puskesmas, Day 1 PM – Stroke). The Social Affairs Office has an ANTAR PAIMA program (Services that reaches home) that provides transportation services for those who cannot afford it. Not all these services are available in all regions or districts. Many people do not know the contact number, not even staff of Puskesmas and Cadres (TKSK, Day 1 AM - Stroke). People do not know the differences of Posyandu and Posbindu (Family member, Day 1 PM - Bedridden).

What are missing in the whole spectrum of community care as suggested by workshop participants are (1) day care center and/or special care centre for people with dementia, (2) rehabilitation service, (3) geriatric specialist and (4) 24/7 ambulance service. Home care needs to expand substantially.

E. **Theme 5: Community care in general is a passive system and only responds to request or report.** For patients with dementia and stroke, the process of seeking care may be convoluted. How to navigate system is an issue.

If no one reports the symptoms of a demented elderly at home to Puskesmas, Puskesmas will not know the case and therefore will not take action. Even when the Puskesmas staff learned of the case and visited the elderly at home and if the family did not consider the symptoms problematic, Puskesmas staff would not intervene. (Head of Puskesmas, Day 1 AM - Dementia). Similarly, The Social Affair Office and Health District Office only act upon receiving report pertaining to averse elderly conditions, and they do not do case finding in the community (Social Affair Office Staff, Day 1 AM – Dementia; Family, Day 2 AM – Dementia).

Patient care management is by level of severity. If the case is severe, it will be handled by TKSK if the case is social and economic problems related such as living alone and from poor family, or Puskemas if the case is health related. (Head of Puskesmas, Day 1 PM – Stroke). The case will be referred to hospital, if Puskesmas in unable to handle the conditions, (Health office staff, Day 1 PM – Bedridden). However, if the patient is an elderly with dementia, the patient and family may have to go through nurses, internist and administrators and to answer similar questions multiple times. (NGO, Day 1 AM – Dementia). Similarly, this may happen to a stroke patient with a condition that is neither acute nor emergent. The case will first be referred to a Puskesmas or FKTP (First Level Health Facility) before it reaches the hands of a neurologist.
F. **Theme 6:** There is a confusion regarding which agency or government department (e.g., Dinosos, District Social Affairs Office) should lead and coordinate community care, including the use of government data, social media and APP in community care.

Social Affairs and Health Offices are the two primary government providers of community care. Naturally, Social Affairs Office should lead and coordinate community care as it has the infrastructure in so doing. Social Affairs Office runs LKS and forums for the elderly, providing home care and other educational programs for the elderly (e.g., dementia care). LKS operates under government rules and regulations, which makes it a suitable venue for channeling government funding, if necessary. It has social workers in the field, who maintain close contact with the elderlies and their families. Social Affairs Office has the data of the entire kelurahan population such as information pertaining to people with disability, elderly needing help, etc. Social Affairs Office’s data base can be linked to that of the Health Department if other health information e.g., disease history, is needed. The Social Affairs Office can also liaise with private sector for other assistance through CSR, if needed (Government office, Day 1 AM – Stroke).

More integration of community care is desirable such as budget integration between regional and provincial governments, using APP to integrate services provided by Social Affairs Offices, Puskesmas and village including residence and cadre, etc. An integrated service application process will allow people to apply for services from where they are and when they need it (TSM/Community Social Worker, Day 1 PM – Bedridden).

Coordinate and/or integrate existing online services and social media, and make them more elderly friendly, will enhance community care for the elderly in Yogya (Village Secretary, Day 2 AM – Dementia). This includes JSS (Jogja Smart service), social media such as WA groups. There should also be a new application (APP) with information pertaining to all community care. Every citizen, not just the cadres, can access community care information and even apply for services online (Provider, Day 2 AM – Dementia).

G. **Theme 7:** A “not so friendly” elderly friendly community care environment, let alone dementia friendly.

There have been signs of to make health care facilities more elderly friendly such as special pathways for the elderly, special counter for the elderly and that older people take precedence in receiving health care service, etc. However, such a practice has not been universal due to lacking resources and space. Some people even considered that politeness to the elderly was simply for the sake of “elderly friendly” accreditation. Hospital services might even less friendly to patients with BPJS because of the nature of their payment scheme (Kader Posyandu Lansia, Day 1 AM – Stroke)

There have been attempts to make registration for health care service less distressful for the elderly and family such as JSS (Jogja Smart Service) and WA system used by Puskesmas. However, not all elderlies and families know how to use them. Even if one can register online, it does not imply the person can see the doctor on time as the latter may arrive late (Family Day 1 PM - Bedridden).
H. Theme 8: Lack of understanding of Dementia and Dementia Care. Both family and providers asked for more training in the care of dementia patients.

Community awareness of dementia care has been low because of lacking knowledge. Family noticed the deterioration of elderly but considered it as part of normal ageing process. Elderly sometimes ended up being physically restrained and confined and are subject to elderly abuse. Most of the nursing homes will not take persons with dementia, such as the one in Bantul. There is homecare for bedridden but not for demented persons. Providers are good at diagnosis and treatment of physical illness but are generally inadequate in diagnosing and treating people with cognitive impairments. More training of Cadres and health care workers on dementia care is urgently needed. Transportation agency lacks knowledge of dementia and paid less attention to their transportation need (Provider, Day 2 AM – Dementia).

V. Recommendations

The recommendations were grouped under 4 models of change:

A. Status quo excellence: improvement of the current system (Recommendation 1 – 8).
B. Horizontal integration: integration of social and health care. It includes recommendation 1 – 10. Refer to the integration of all services inside the dotted (broken line) square in the Ideal Community Care Map (Page 9); or 1st row of Diagram 4 (Page 19).
C. Vertical integration: integration with services of other sectors such as primary care, hospital, technology, housing, transportation, etc. 1st column of Diagram 4 (Page 19).
D. Total: implementation of Recommendation 1 – 15, vertical and horizontal integrations.

A. Status Quo Excellence

With the implementation of Recommendation 1 – 8, the current community care system will become more capable of managing people with complex care needs such as:

i. moderately or severely cognitively impaired;
ii. physical dependent;
iii. having multiple disabilities;
iv. complex medical conditions; and/or
v. having severe behavioral problems on a continuous basis

1 Horizontal integration occurs when activities across operating units and/or organizations that are at the same stage in the process of delivering services come together. Examples of horizontal integration can include mergers of acute hospitals or mergers of social and health care organizations. (Curry & Ham, 2010, p.4).

2 Vertical integration implies coordination of services among operating units that are at different stages in the process of delivering services. Vertical integration brings together organizations at different levels of the hierarchical structure under one management umbrella by, for example, integrating primary and secondary care, or general practice and community care. (Curry & Ham, 2010, p.4).
that require professional (e.g., doctor, nurse, PT and OT, etc.) and nonprofessional (e.g., Cadres, volunteers, home helpers, family members, etc.) care and monitoring\(^3\).

When improvement is made, providers will have more expertise and resources in managing elderly with complex care problems. Providers continue to function autonomously and choose their own clientele independently. The number of people aged 75+ with complex care needs being taken care of by the revamped community care system will increase.

1. **Government leads community care**

   The need for more leadership in the planning and coordination of community care was evident throughout the community care mapping workshops. Local Social Affairs Office (Dinas Sosial) was named a number of times to be the lead organization as it has all the needed infrastructure: regulations, resources (human resources and funding) and direct service provision. Alternatively, a Community Care Redesign Committee (CCRC) can be formed to redesign community care. The CCRC can also be built upon the existing inter-sectorial meetings\(^4\). CCRC consists of representatives from service recipients (and family), cadres, service providers (profit and non-profit), government departments, etc. Preferably, the CCRC is multidisciplinary, across government and nongovernment sectors\(^5\). A terms of reference for CCRC is in Appendix 4.

   Government sanctions community care redesign and funds related activities. Local Government of the Municipality / Regency through the Mayor (i.e., Walikota and Bupati) / Village (1) establishes CCRC by appointing its chairperson and members, (2) allocates resources including human resources and funding to CCRC, and (3) designates a government department (e.g., Social Affairs Office) as administrative support to the CCRC. All stakeholders involved will agree to participate in an orientation retreat to increase knowledge in community care including a thorough understanding of the (1) characteristics and clinical issues in community care, (2) community care continuum such as rehabilitation and dementia care (3) case management and information system, etc.

2. **Optimize the functions of Puskesmas**

   CCRC secures adequate resources so that all the elderly care programs will be fully available across Puskesmas. Puskesmas runs home care program, comprehensive nursing care for the elderly, emergency treatment, education and patient/family empowerment\(^6\). However, not all these programs are fully available across Puskesmas due to resource constraints. The national government has provided assistance and funding support to health care including Puskesmas through BOK (Bantuan Oprasional Kesehatan)\(^7\). Please also consult the recommendations of Puskesmas Appropriateness Review Report.

3. **Advance skills in complex care for all community care providers**

   CCRC advances complex care skills of community care providers by (1) training: geriatric assessment, dementia and mental health, rehabilitation, case management,

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\(^4\) This has been identified in the Puskesmas Appropriateness Review.

\(^5\) CDS #133 (April, 2018)

\(^6\) CDS #82 (April, 2018): /ADB_Reta_intermittent/Indonesia/Strategic planning

\(^7\) SurveyMETER’s notes to MW’s comments on Mar 20, 2020
team work, etc., (2) recruiting more professionals and specialists with geriatrics, gerontology, rehabilitation background, and (3) engaging all care personnel, e.g., Cadres, family, etc. in complex care. Complex care can be delivered by a joint intervention of professional (e.g., doctor, nurse, physiotherapist, occupational therapist, etc.) and nonprofessional (e.g., Cadres, volunteers, home helpers, family members, etc.). For instance, a physiotherapist develops mobility plan after diagnosis whereas a Posyandu Cadre with advanced training can then help to implement the plan under the supervision of the physiotherapist. Similarly, a home care nurse develops a medication and/or diets plan whereas a LKS/Posyandu cadres or family member with advanced training ensures the plans are properly followed.

4. **Build capacity of cadres for a sustainable community care**

CCRC develops (1) cadres’ job descriptions across different community care providers, (2) a cadres’ skill mixed classification system in align with job competence and standards, (3) training guidelines for various levels of cadres including certification and registration, (4) a monitoring and incentive system to ensure the cadres’ care quality. Cadres perform multiple roles: home visits, care visits, health check, information sharing, liaison, entertainer, religious assistance, etc. In practice, what they perform largely depends on which community care providers that they are associated with: Posyandu, LKS, BKL, etc. With adequate training, cadres can engage in complex care alongside with the professionals. With proper organization, they can perform their duties more efficiently and effectively and become eyes and ears of the professionals in case finding and screening.

5. **Empower family in the care of elderly through support and education**

CCRC empowers family in the care of elderly at home through (1) ongoing education (e.g., knowledge and skill of care); (2) supporting self management; (3) providing tangible (e.g., cash assistance), and (4) psychosocial support (e.g., that they are not alone, that they need to be resilient and look after themselves, etc.). Support family to care for the elderly is a win-win. It promotes a sense of bonding among family members and the elderly and is aligned with Indonesian culture. It helps to reduce the public burden in addressing the need of an ageing population. However, if caregiving of an elderly becomes stressful due to increasing severity and duration, it can increase family caregiver’s vulnerability, which leads to poor health, family dispute and even caregiving withdrawal (Eeuwijk, Peter Van 2006). Continuous improvement of the scope and scale of community care by itself is a support to the family. It relieves family in caregiving burden and allows family to take a respite when needed. Support and education to family caregivers have proven to improve confidence, reduce burden and decrease depression for caregivers (Peckham A. et. al, 2019, p.10).

6. **Enhance home care experience**

CCRC (1) redefines home care purpose and scope of service (2) adds a pool of home help hours (with corresponding monetary resources) for those who have no family and/or neighbor, or children working far away from home. The home help hours added

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8 The creation of “Caregiver” (nonprofessional health worker – who had basic health skills) for cadres who want to get further career advancement. (Provider, Day 1 PM - Bedridden)
will be allocated to service recipients by the case manager (when available) according to set rules and can be adjusted according to resources available after 1st year of operation experience. Service recipients can (1) pay family caregivers to do the work, (2) buy home help from existing operators (if any) or (3) in the market. Home care is more than home visit and companionship. It includes professional and nonprofessional services. Professional services are nursing, rehabilitation, social work, etc., provided to the elderlies in their homes. The goal of home care is to help the elderly to remain independent in their own home as long as possible. There are two types of nonprofessional service: (1) personal care: bathing, grooming, dressing, toileting, feeding, etc., and (2) home help: meal preparation, clean up, laundry, escort to medical appointment, etc.. Personal care and/or home help, if required, are performed either by family, neighbors and/or cadres. If, however, the need is on a daily basis, this will be very demanding to family, neighbors and cadres.

7. Establish a loan office of assistive device

CCRC works with the social district offices through LKS/TKSK and/or uses Village Development Fund to fund such an operation. For each sub-district or village, where there is no such a setup, a loan office is to be established. It is to allow people who need, but cannot afford to purchase, assisted device such as hearing aids, walker, wheelchair, etc., to borrow. The operation of loan office may be associated with a government or NGO community care providers.

8. Reimage dementia care

CCRC counteracts misconception of dementia by helping people to understand dementia more through:

i. Public education on the nature, symptoms, causes, screening, diagnosis and treatment of dementia

ii. Dementia training for current care professionals and non-professionals, cadres and family members.

iii. Recognizing the caregiver needs at different stages of dementia care⁹.

iv. Creating and implementing dementia friendly community development plan such as “dementia friend program” and working with local business operator such as corner store in making their business more dementia friendly.

There are many misconceptions of dementia. Not only do people not understand dementia, many believe the common myths and hold stigma on dementia. For instance,

⁹ Persons with dementia (PWD) are characterized by progressive declines in cognition and function that typically begin as mild but then progress variably to a point of intense care and supervision. It is widely recognized that what is effective in early stages may not be appropriate in middle or late stages and vice-versa, (Gallapher-Thompson Dolores, et.al., 2020). In the early stage, caregivers likely adapt to the realities of dementia because the symptoms are generally mild; assist in IADL e.g., making phone call to schedule medical appointment on behalf of the PWD. What caregivers need may be information and psychosocial support. In the middle stage when dementia related disruptive behaviors surface such as wandering, sleep disturbance, etc., coupled with frequent emergency room visits and hospitalization, caregivers become increasingly depressive and burnout. One of the “primary caregiver” may even become a member of the care team. What the caregivers need may be home modification, behavior management and reduction of stress. The late stage also comes at a time when the PWD need care with ADL: bathing, dressing, toileting, etc. Greater use of formal care, and planning for long term and palliative care may be necessary. What the caregivers need is to balance self care, caregiving and shared care with other family members.
“if someone in the family has dementia, they do not talk about this openly as this is face losing” and ‘dementia is a natural part of ageing”.

B. Horizontal Integration

In involves the implementation of Recommendation 1 – 8 and the creation of an integrated social and health care system to support the elderly, family, volunteers (cadres) and formal providers (e.g., Puskesmas staff) in providing care for people with complex care needs. Horizontal integration also refers to the integration of all services inside the dotted (broken line) square in Diagram 5: Ideal Community Care Map (Page 8). Diagram 5 differs from Diagram 6 in that Elderly/Family, Puskesmas and Residential Care were considered as part of the Ideal Community Care, whereas elderly/family was placed under Home/Family-based Care, and Puskemas and Residential Care were placed under Facility-based Care of the Long Term Care Plan of BAPPENAS. In the eyes of workshop participants, community care embraces a much bigger scope than that of BAPPENAS.

When horizontal integration is in place, an elderly with complex care need, will first be assessed by a case manager to determine eligibility of service. If eligible, the elderly, with the assistance of a case manager, will have access to a comprehensive community care services according to the elderly’s changing needs. This allows a multipronged approach. For instance, volunteer service, home help, home care nursing and adult day care can be combined to offer help to person with complex needs. Such an approach has proven to be effective in improving self care, problem solving, social isolation reduction and health compliance (Peckham A. et al, 2019, p.12). Providers will agree on the admission and discharge criteria of each service within the system. Appendix 8 is a sample of admission and discharge criteria for Adult Day Care. Providers within the system will have access to client information and resources of other providers, such as expertise.

1. Transform community care

Community care by providing caregiving at home and in the community is only going to increase, because most of the people want to stay in their own familiar environment rather than going to nursing homes or other outside care when they age. This has been a lesson of most developed countries in long term care development. The pathway of community care transformation takes two directions and 13 steps. The two directions are (1) integration of current services and (2) addition of new community care services to the current system. Diagram 4 shows the organization of a horizontally integrated community care.
To integrate the current system:

i. With approval of the government, the Community Care Redesign Committee (CCRC, Recommendation 1) assumes the leadership for integrating the existing community care providers: Puskesmas, Posyandu Lansia, BKL, LKS, PKK, Paguyuban Perawat and residential care (if available), etc. The terms of reference of the CCRC in Recommendation 1 should be applicable in horizontal integration of current system. Membership of the two committees can be identical. New members may be added because of their expertise in change management and service integration. The Government appoints the chairperson and all members of CCRC.

ii. CCRC reviews current community care setup within each catchment area and decides the most suitable level of integration. CCRC ensures all integration are formalized, e.g., service contract or agreement. Horizontal integration may occur at 3 levels:

   a) Integration: sharing of administration and resources (clinical and non-clinical)
   b) Co-location: some system integrated: client information, service schedule, clinical practice guidelines, etc.
   c) Co-ordination: collaboration at separate locations

Some service will be integrated through coordination e.g., private community care that the government has limited control. Some can be totally integrated such as those government funded community care.

iii. CCRC sets up the infrastructure required to support an integrated operation of community care including: administration (leadership, finance, HR, etc.), case management, use of information and communication technology (ICT).
iv. CCRC reviews the admission and discharge criteria of each of the community care services. This will also help to reduce service duplications and to identify gaps in community care.

v. CCRC agrees on the eligibility criteria of all public subsidized community care services.

vi. Case management

CCRC sets up a case management system. Ideally, there will be at least one case manager/case management associate per 100 elderlies who need community care. Preferably, the case management is a district level system so as to allow the creation of senior positions (e.g. senior case managers) for the purpose of administrative and professional monitoring. Case manager is a trained professional such as nurse, social worker, etc., whereas case management associate may be a cadre/volunteer with training in case management. A detailed plan for case management system development is in Appendix 3. Diagram 5 shows the process of case management.

Diagram 5: Case Management Process

Case management is the linkage that connects all stakeholders within a horizontally (and/or vertically) integrated community care system in order to

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10 Case Management System is a link-and-match arrangement system between the elderly who need services, and the service providers. It finds case (active and passive); assesses needs; determines eligibility and service fees (if applicable); plans, coordinates and monitors care services; arranges relief for caregivers, and assesses the need to move to elderly housing project (e.g., assisted living) or residential care facility. The case manager coordinates care across medical specialists, home nursing and rehabilitation service, home help (including personal care) services, pharmacist medication review; facilitate access to adult day care centre, rehabilitation centre, respite care in assisted living, and residential care facilities for socializing, eating, laundry, bathing, and; provide proactive planning for admission to assisted living and residential care to increase choice of residence and reduce wait times.

11 This depends on the case stratification strategy: 10% intensive case management, 20% case management and 70% shared and self management (UK and Canadian model).

12 [https://www.cmbodyofknowledge.com/content/introduction-case-management-body-knowledge](https://www.cmbodyofknowledge.com/content/introduction-case-management-body-knowledge)
ensure the elderly have access to the right service at the right time and location. Case management, along with clinical practice guidelines and protocols, are particularly helpful during transition periods when service recipients were required to switch between care providers. This has proven to be very effective in achieving positive outcome (Peckham A. et. al, 2019, p.11). To certain extent, case management does exist in Yogya and Indonesia. Coordination between Puskesmas/ posyandu, village authorities and LKS, are just some examples. However, this process has not been always systematic and case management responsibility has not been always clear.

vii. Build Information and Communication Technology (ICT) in Community Care.

CCRC builds an ICT framework and infrastructure for the implementation of ICT in community care to include: helpline/hotline, call centre, electronic health record (or client information system), online registration, information and referral, etc. The reason for doing so is to allow (1) service providers and recipients to have timely access to information (2) data to drive community care planning and development such as monitoring community care quality and utilization. The existing sporadic use of technology such as: ICJ, JSS, WA, Whatsapp and Facebook etc., are not sufficient to accomplish the above objectives.

Add new services to existing community care system:

viii. CCRC creates at least one Adult Day Care (ADC) in each sub district or village. ADC offer therapeutic exercise, mental interactions, social activities appropriate for the conditions of the elderly and help with personal care such as grooming and using the toilet. ADC often provides meals and snacks, including special diets for those who need them, and door-to-door transportation for participants. Some ADCs even focus on specific areas of care: (1) medical/health care program such as chronic disease management and (2) specialty program such as dementia care. More importantly, ADC provides family members a break and helps to alleviate stress associated with caregiving. ADCs are not uncommon in Indonesia and mostly provided by private sector, and can be expensive. Some residential care operators also run adult day care such as Graha Ichsanin South Tangerang. As mentioned by one of the workshop participants: “even Thailand has ADC.”

ix. CCRC creates a fulltime rehabilitation specialist (or a half time physiotherapist and occupational therapist) for every 100-elderly requiring rehabilitation service. Rehabilitation means a lot for those people with irreversible conditions such as disabilities caused by stroke. It may take the form of physical and cognitive rehabilitation. The former is good for people with physical impairment such as stroke. The latter is good for people with cognitive impairment. It aims at helping a person with such a condition to restore lost skills and regain maximum self-sufficiency. Physiotherapy is instrumental in transfer and mobility whereas Occupational Therapy is key in the design of assisted device and home modifications. Many caregivers

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13 CDS #143-145 (April, 2018)
14 CDS #124 (April, 2018)
asked for help in assisted device, which if not properly designed and used, may lead to more harm to the elderly concerned. Home modification is also a frequent request suggested by workshop participants especially for people discharged from hospital with stroke.

Rehabilitation service in the community does not require large space nor over sophisticated rehabilitation equipment. It can take place in patient home with simple equipment. What patient needs is a proper diagnosis, treatment and ongoing monitoring. Diagnosis and monitoring can be done by a rehabilitation specialist, treatment can be carried out by family and/or Cadres under the supervision of a rehabilitation specialist. The addition of rehabilitation service to existing community care stock addresses a wider range of needs. It also expands the multidisciplinary team, which has proven critical to address unique needs of a variety of service recipients, reduce service silos, reduce complications and improve effectiveness (Peckham A. et. al, 2019, p.15).

x. CCRC ensures healthy ageing program is a built service within the revamped community care system: PKK, LKS, BKL, Posyandu Lansia, Puskesmas, Home Care/ Home Help, Adult Day Care, Rehabilitation, Nursing Home and Hospice. Healthy Ageing is to develop and maintain functional ability that enables wellbeing in old age\textsuperscript{15}. Programs, such as exercise, nutritional education, stress management, social activities and environment awareness, that can allow the elderly to meet needs, learn, grow, make decision, mobile, build relationship, contribute to society etc. should be an integral part of community care system.

xi. CCRC creates a community-based hospice program for every district. End of life care has been an essential element of community care in country like Canada and UK. It does not necessarily take place in an institutional setting. Pain and symptoms control, emotional and spiritual support at the end of life can also take place at patient home.

xii. Pilot community care hub with a transformation community care model

Before full scale community care transformation is to take place, CCRC should select one or two sites for piloting a horizontal integrated community care hub which will include majority of services included Diagram 4. It may take either one of the following approaches:

\begin{itemize}
  \item [a)] Designate an existing community care provider - Puskesmas, LKS (e.g., Melati), BKL (e.g., Mugiwaras), etc., to integrate, ally or link, with other community care providers within the service catchment area.
  \item [b)] Establish a new and standalone community care hub, with designated authority to integrate, ally or link all other care providers within the service catchment area. The community care hub can be operated by a NGO or a government department. A sample layout\textsuperscript{15}
\end{itemize}

\textsuperscript{15} WHO \url{https://www.who.int/ageing/healthy-ageing/en/}
of a standalone community care hub is attached is in Appendix 9. It is based on the experience of CADENZA Hub for the Elderly in Hong Kong. It includes a wellness centre for the general elderly population and an adult day care centre for people with dementia.

xiii. CCRC evaluates the impact of Horizontal Integration on community care delivery.

2. Pilot a residential care facility for the poor elderly

CCRC negotiates with the provincial government to establish a “care” facility that is designed to be dementia friendly, infection control ready and with clear workflow to facility the delivery of 24/7 care. Residential care is the responsibility of provincial government. This is neither a housing project for elderly with housing need nor an orphanage for the elderly in destitute. It is a care facility for elderly who need care and cannot afford to pay privately. Thus, the facility won’t be able to operate without public funding support. Residential care is not a trendy elderly care in many developed countries. However, there will always be a small group of elderly people who cannot function in the community even with maximum community care support and require care in a residential care setting. Moreover, residential care can serve as transitional care for elderly discharged from hospital but requiring a longer period for convalescence before returning home. It can also provide respite for caregivers of the severely disabled when the family caregivers take a break from daily care. In many countries: Canada and UK, residential care has been part of community care. It is care in the community vs. care in a hospital.

C. Vertical Integration

In involves the implementation of Recommendation 1 – 8 and the expanded collaboration with the primary care (e.g., private primary care practitioners/ doctors), acute care hospitals (including geriatric and gerontological specialists) , technology, housing, transportation, etc.; private (e.g., alternative medicine, Pramukti – paid caregivers) and public in the provision of care for people with more complex care needs. Theoretically, vertical integration only refers to the integration of existing community care with all other services outside the dotted (broken line) square in the Ideal Community Care Map (Page 8).

When vertical integration is in place, an elderly with complex care need, will have access to an improved community care (Recommendation 1 – 8), and uncharted services that are important to their functioning but were unavailable in the existing community care system. New community care players will be enlisted in designing and providing community care for older persons with complex care needs. For instance, there may be housing project such as assisted living for elderly whose complex care need is personal care but not nursing care related. The transportation sector will be set up in such a way that even people with dementia can find their way home. Corner store owners will do business with elderly with cognitive impairment knowing that the family will reimburse goods taken but unpaid. Technology firm may help to develop wearable device to keep elderly staying in home and community safely. Vertical intervention contributes to the elderly’s ability to remain at home and practice self care, improve health compliance and self management by reducing isolation and loneliness (Peckham A. et. al, 2019, p.11).

1. Leap the boundaries of Community Care
With approval of the government, CCRC assumes the leadership in collaborating with primary care and acute hospitals, housing, technology, transportation, urban planning, etc. Membership of CCRC (Recommendation 1) may remain unchanged. New members may be added because of their expertise in change management and service partnership. The Government appoints the chairperson and all members of CCRC. Diagram 6 shows the organization of a vertically integrated community care.

Diagram 6: Vertical Integration Operation

Traditionally, community care refers to a wide range of health care and social support to meet the needs of elderly with physical and/or cognitive impairments who live in their own home / with family/ or elsewhere in the community. Countries such as UK and Canada take on a more progressive approach in defining community care not just as care that the community provides, but also care based in the community. Thus, all care services not provided in the hospital, such as residential care, nursing home and transitional care are all part of community care. The expanded community care requires a new mindset and mapping. The elderly may be placed in residential care and/or nursing home temporarily when their conditions call for 24/7 (nursing) care. When the elderly’s condition turns better, he/she may then return home and continue to age at home and in their most familiar community. The new community care map also includes services/sectors such as housing, technology, transportation, urban planning, etc. that are imperative to the functioning and wellbeing of an elderly.

Partnership with new players in community care may involve a mix of three different approaches:

a) Linkage, such as working group to address hand off issues between hospital and community care.

b) Collaboration, such as sharing of training programs among partners

c) Joint venture, such as assisted living, transportation arrangement for people with dementia in community care.
2. Collaborate with private sector including NGO.

CCRC (1) encourages the development of private sector, e.g., subsidy, land concession, social innovation, etc., and (2) ensures collaboration with private sectors through: private investment, service purchasing, competitive bidding and private public partnership. Private elderly care providers, profit and/or non-profit should be part of the community care ecology. However, private sector for community care is still underdeveloped in Yogya.

3. Invest in community care technology.

CCRC develops a Community Care Technology Framework and invest in technology that can empower and support family and formal caregivers in the care of the elderly.

Many technologies emerge to promote the health and well-being of service recipients, caregivers and to connect them to sources of support. Others aim to reduce the complexity of care tasks and facilitate access to healthcare providers. Still another subset is designed to improve the safety, security, and well-being of care recipients. These technologies have opened a new era of technology-enabled community care. Appendix 6 is eight types of technology that can be applied in community care.

D. Total Integration

In involves the implementation of Recommendation 1 – 15, horizontal and vertical integration. Diagram 7 shows what are included in the horizontal (orange inked rectangular) and vertical (blue inked rectangular) integrations. Total integration is the merging of horizontal and vertical integration, supported by a case management, ICT and an administrative structure.

When total integration is in placed, presumably, an elderly with complex care need, with the assistance of a case manager, accesses all services along the horizontal and vertical service continuum whenever and wherever the elderly needs. For instance, an elderly discharged from acute hospital after stroke will be determined by a case manager if the elderly is eligible for community care. If eligible, the case manager arranges the elderly to receive rehabilitation service twice weekly for therapeutic treatment of ambulation, and to receive home care/ home help 3 days a week. Family will take up the care on weekend. The elderly visits Puskesmas for primary medical care to monitor his/her A1C (blood sugar), blood pressure and cholesterol level and to receive prescription of medicine. Should transportation be required from home to Puskesmas, the case manager works with the transportation agency to arrange the most suitable mode of transportation on the day of her/his medical appointment. After maxing out post hospital rehabilitation, the elderly goes to an ADC three times a week where the elderly continues to maintain remaining ambulation capacity with the assistance of the Cadres and to enjoy social activities of the center. The case manager may arrange the elderly to move to an assisted living where there is wheelchair and or walker accessible, with home care available.
1. Revolutionize community care through total integration

With the approval of government, CCRC (Recommendation 1) assumes the leadership of a total integration of community care. New members may be added because of their expertise in change management and service integration and collaboration. The Government appoints the chairperson and all members of CCRC.

Total integration aims at (1) allowing an elderly eligible for community care to move within the community care continuum to find the right service when and where the elderly needs it, and (2) achieving high care quality at lower cost. The realization of total integration requires a supportive infrastructure: (1) case management system, (2) Use of ICT, and (3) an administrative structure to support an integrated operation. Case management system and the use of ICT have been covered under Recommendation 9. Administrative structure includes a central office for leadership, planning and coordination, human resources, finance, technology, performance management, etc.

A traditional administrative structure is good for the normal operation of an organization, but not enough to support the process of organization merging and/or integration. (1) Service Integration Council and (2) Clinical Practice Council are needed. The Service integration Council assumes leadership in facilitating and coordinating seamless service service delivery across all units/services/teams of the community care system. It consists of all service heads/senior managers of service units/teams of the totally integrated community care system. The Clinical Practice Council assumes leadership in facilitating and coordinating clinical practice standards and guidelines for all professional and nonprofessional caregivers, paid and unpaid. It consists of representatives of all professional and nonprofessional staff and cadres of the totally integrated community care system. Terms of reference for Service Integrated Council and Clinical Practice Council are in Appendix 5 and 6 respectively. Diagram 8 is the organization of a totally integrated community care.
2. Design community care ecosystem for all ages

CCRC makes “Community Care for all Ages” as its underlying philosophy and considers the following principles in the planning and design of community care:

i. Patient centred approach: align health outcome goals with care preferences (e.g., location of care).

ii. Age as a key factor to consider when using medication

iii. Manage patient mental and cognitive conditions across the care continuum

iv. Accessibility including transportation between health care facility and patient’s home.

v. Environmental design for all ages: signage, noise reduction, lighting, etc.

These factors are important in the care of elderly and people with dementia. They are vital in health recovery for people in other age groups as well: children and youth, mental health, etc.

In Yogyakarta experience, elderly friendly means more on service accessibility than on breaking down the stigma of dementia. As a concept, “dementia friendliness” embraces “age-friendliness”, but age-friendly is not necessarily dementia friendly (AARP, 2016). Thus, creating a dementia friendly health care system appears to be the logical next step after age friendly.

Under a total integrated system, a breakthrough mindset may be warranted. Instead of creating a dementia friendly health care system, create a “Community Care System for All Ages”. It will benefit the elderly including people with dementia. Elderly is not the only users of community care, people of other ages may use it at some points in...
time, e.g., temporary and/or permanent disablement due to play or work injury, people with mental health problems, etc. As a matter of fact, in most of the developed countries, community care does not confine to elderly, it also opens to all people in need of complex care. What good for the elderly will be good for all other people. It will also be less controversial as “Community Care System for All Ages” is not “another program” that only favors the elderly but not other people in the community. Creating a “Community Care System for All Ages” will also ease the tension of intergenerational disparity as more young people consider themselves being treated unfairly in society.

VI. Conclusion

One of the essential and successful features of Yogyakarta Community Care system is that it is a network of care, it is a mix of family, neighbors, health care providers and volunteers. This makes good sense as this is most satisfactory for the elderly and family. It also makes good business sense for the government (public) as it is most sustainable. The report proposes to increase the capacity of all stakeholders in the network.

The proposed community care system redesign is a collaboration of local service recipients, providers, representatives of government, national and international consultants. We firmly believe that the implementation of the above recommendations 1-15, will

a) ensure equitable care for all elderly in need;
b) reduce the burden and burnout of elderly, family, neighbors and volunteers; and make elderly care a sense of family and community togetherness;
c) increase the capacity, efficiency and effectiveness of the community care network;
d) address the elderly with complex care needs;
e) manage elderly care across a community care continuum, and
f) make community care a high-performance intervention in long term care.

VII. What next

The approaches contained in this report focuses on the “what” and some aspects of “how to” of community care reform. Implementation will require further considerations, tailored to the political, socio-economical and cultural situations of various jurisdictions: village, subdistrict, district and province and their populations. All the recommendations are meant to be carried out jointly by the government, providers and community at large. Not all the recommendations implementation will require substantial additional resources. However, without government leadership and investment, the reform will not be possible. Many of the recommendations should be phased in as each jurisdiction deems fit. Provision must be made for evaluation and mid-course correction to ensure that the proposed model of reform achieves its intended objectives.

The government, after reviewing the Community Care Mapping Report will set up a Community Care Reform Responding Team (CCRRT) consisting of key government departments and representatives of service recipients and providers. The CCRRT decides which model of community care redesign to proceed:

a) Status quo excellence
b) Vertical integration
c) Horizontal integration

d) Total integration

CCRRT will also come up with a budget estimation for each model of redesign, evaluation framework and site for piloting (if appropriate), for the final decision of the government within 2 months.
References:


Schroder-Butterfill, E. 2020. *ESRC Project Proposal: Care networks in later life: A comparative study of five communities in Indonesia using ethnography and surveys (10/2019 – 03/2022)*. Economic and Social Research Council (ESRC) and University of Southampton. UK.


Appendix 1
Participant List

Yogyakarta City

<table>
<thead>
<tr>
<th>No</th>
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Appendix 2
Eight themes with more detailed analysis of transcripts

Theme 1: The current community care system is lopsided with majority of the care responsibility falls on the elderly and family.

What did the focus group participants do, say, feel and think:

Care (dementia) started and ended at home. From the beginning, it was handled by family and at the end it was also handled by the family. (Family member, Day 1 AM – Dementia)

Making a living and caring for the elderly simultaneously are not easy. His son works as a salesperson – selling while caring. (Elderly, Day 1 PM – Bedridden). Family feels overwhelming and exhausted. (Family member, Day 1 AM – Dementia)

As caregiver of person with dementia, I am expecting to mentor myself. Treating person with dementia can be physically and psychologically demanding. Unless we learn how take care of ourselves, we might burn out. (NGO, Day 1 AM – Dementia)

What the elderly needs is a companion at home. Quite often, elderly was left alone at home because their children have to go to work. (LKS, Day 1 PM – Stroke care)

Bed-ridden elderly usually feel hopeless. Some of them even ask for euthanasia. Elders who feel hopeless also do not want to go to hospital because they feel that they are going to die. Some of them become quiet and silent, and family become worrisome. Still, some of the elderly do not want to go to health facility as they feel it would be a burden to the family (Family member, Day 1 PM – Bedridden).

Practical assistance is needed to support the family caregivers such as (1) rehabilitation equipment, e.g., wheelchair, grab bar, signage for the demented elderly; (2) physical environment redesign e.g., bed and bathroom for stroke patient discharged from hospital, and (3) transportation between hospital and home (Family members, Day 1 AM – Dementia and Day 1 AM – Stroke).

The elderly is happy when the family take care of him/her, and has a sense of togetherness and trust while the children are around. (Female elderly, Day 1 AM – Stroke)

Psychosocial support is not sufficient to support the elderly and their families (Family member, Day 1 AM – Dementia). The Elderly (with stroke) requires spiritual support and prayer from the family. In addition, because the elderly is no longer employed, they need protection to guarantees their basic needs are met (Cadre, Posyandu Lansia, Day 1 AM – Stroke).

Assistance to families caring for the elderly is needed. Neighbors and community can help. For instance, neighbors can help to provide food when family has no time to prepare food…. When looking after a demented elderly, family won’t have time to cook, sleep or shop. The community can help to monitor the elderly while the family takes a break or leave (Family members, Day 1 AM – Dementia).

What an elderly with stroke needs is a companionship and a family member has to shoulder this role because neither the posyandu cadre nor Puskesmas can help on a daily basis (LKS, Day 1 AM – Stroke).

Ideally, there is a family member who is trained to provide care for the elderly with stroke (Male elderly, Day 1 PM – Stroke).

Another challenge is the elderly with no family. (Provider, Day 1 AM – Stroke)
Theme 2: Cadres are key in community care for the elderly but they have not been properly trained to deal with more complex elderly care problems.

What did the focus group participants do, say, feel and think:

The elderly family said that BKL cadres and elderly posyandu cadres from the hamlet visit elderly at their homes, check their blood pressure and examine the elderly in general. But this is not a common practice across all hamlets. (Elderly family, Day 1 PM - Bedridden). If the cadre recommends home care after home visit, the elderly will then get it from Puskesmas (Family member, Day 1 AM – Dementia). Cadres provide ongoing monitor of patients (Family member, Day 1 AM – Stroke). We also have BALASAN cadres (the elderly's help Mergansan) who are trained to help families to care for their elderly (Provider, Day 1 AM – stroke).

Cadres even involve in the care of the dying, including referral to the family doctor, Puskesmas and hospital (Family member, Day 1 AM – Dementian).

The Posyandu cadres report to the Puskesmas. (Provider, Day 1 AM – Stroke)

The village head said that Posyandu cadres in each RW were needed to provide care for elderly with stroke and to strengthen the family (Village Head, Day 1 AM – Stroke). Posyandu cadres spearheaded the identification of elderly who need help such as ambulance service (Kader Posyandu Lansia Cadre, Day 1 PM – Stroke). Puskesmas said that cadres had been the source of information, besides being a liaison with between the elderly and the Puskesmas. (Puskesmas, Day 1 PM – bedridden). LKS cadres is key in monitoring the needs of the elderly. Our cadres monitor the number of the elderly admitted to the hospital, and map their needs including transportation and assistive devices such as wheelchairs (LKS, Day 1 PM – Stroke).

One volunteer caregiver (cadre) accompanies 5 elderly and the volunteer caregiver serves as a liaison between the elderly and the community, and helps to meet the individual needs of the elderly, such as food, social or health services. There is one coordinator for every number of caregivers. Our activities are funded with village funds after the village government received our proposal. We have advocated about our activities to other villages, but they think that such activities are difficult to fund because they do not have the money (LKS, Day 1 AM – Stroke).

Our volunteer caregivers (cadres) have networked with Puskesmas, private sector and other agencies that may offer help. The volunteer caregivers contact ICJ (Info Cegatan Jogja) – a community service that can be accessed through social media e.g., Facebook, for help such as wheelchair. Their response is quite fast. If the elderly has more difficult problems, there will be volunteers who can provide assistance. This may include payment for home care services. The amount ranges from Rp. 150,000-Rp.250,000 per visit (LKS, Day 1 PM – Stroke).

The capacity of elderly Posyandu cadres in providing elderly care needs to be increased so that they can become an extension hand of the Puskesmas in serving the elderly with care need (Posyandu Lansia Cadre, Day 1 PM – Stroke). Health office or other institutions should provide training for cadres as care of elderly requires special knowledge (Provider, Day 1 AM – Stroke).

Ideally, care for the elderly with stroke requires trained caregiver/cadre or dedicated nurses, e.g. to move or remove the elderly from bed (LKS, Day 1 PM Stroke).

Cadres exist in many elderly services such as Posyandu cadres, PKK cadres and others. However, they do not have sufficient knowledge in terms of dementia, so
they can only provide care in accordance with what they know (NGO, Day 1 AM – Dementia). Cadres need training to understand how to deal with elderly people suffering from dementia (BKL, Day 1 AM – Dementia).

Theme 3: Puskesmas is the hub of community care. Everyone points to Puskesmas for care. However, it does not have the needed finance and human resources, to care for people with long term care needs such as dementia, stroke and in bedridden conditions.

What did the focus group participants do, say, feel and think:

A female elderly said if she feels sick, she will go to nearest health facility e.g. Puskesmas (Elder, Day 1 PM – Bedridden). Services and access for elderly people in hospitals or health centers are good enough. (Social Affair Office staff, Day 1 AM – Dementia)

Puskesmas staff asks family of the elderly with stroke to take the patients to the hospital for follow-up treatment and physiotherapy because the Puskesmas does not have physiotherapy personnel (Head of Puskesmas, Day 1 AM - Stroke). For a bed ridden elderly, what Puskesmas can do is monitoring and there is no other assistance. (Family member, Day 1 PM - Bedridden)

Elderly family once told that when they went to Puskesmas to tell the behavior of the elderly, the doctor only checked for physical issues such as blood pressure and blood sugar. After the examination, the doctor said that the elderly was fine and sent the patient home with vitamins pills. No treatment of dementia care was rendered. (NGO, Day 1 AM – Dementia). …. Whether or not the Puskesmas has the needed expertise and human resources to detect and treat dementia is doubtful. (Family member, Day 1 AM – Dementia).

If the Puskesmas is unable to offer the medical care required, it will refer the patient to the hospital because the Puskesmas has limited services (LKS, Day 1 AM - Stroke).

According to District Health Office, it is not possible to rely only on Puskesmas in providing continuous care for the elderly, particularly to bedridden patient who requires daily extensive care (District Health Office, Day 1 PM - Bedridden).

There is a midwife responsible for elderly program in Puskemas. We work as a team and use an integrated approach (Head of Puskesmas, Day 1 AM – Stroke).

Puskemas has maxed out its resources: long queue, no people for home care, no funding (NGO, Day 1 PM – dementia). If home care is not covered by BPJS, it will be very difficult for Puskesmas to offer it. There is no budget to cover it in Puskemas (Head of Puskesmas, Day 1 AM – Stroke).

The provision of services at the Puskesmas are constrained by lack of human resources so that Puskesmas can only provide care as much as the Puskesmas is capable for…….. As Head of Puskesmas, I want to train more staff in providing care for the elderly at home. There is only one staff currently has the needed training. Ideally, 6-8 staff would be trained, whom will be divided into two 2 teams to provide elderly care at home. Presently, one staff from the Puskesmas serves 10 people for home care and conduct light activities. Ideally, the staff patient ratio should be 1:5. (Head of Puskesmas, Day 1 AM – Stroke care)
Theme 4: Comprehensiveness, awareness and accessibility of community care services are concerns. Some of the services are overlapping. People do not fully understand the scope and eligibility of different services.

What did the focus group participants do, say, feel and think:
Actually, there have been many community care services to help elderly with problems, e.g., RT, RW, and mosque administrator at local level. It all depends on whether or not these services have the capacity to help the elderly (TKSK, Day 1 AM – Stroke).

The existence of institution such as LKS is important because if the Puskesmas cannot contact the District Health Office, then it can contact the institution concerned for help, especially for elderly with no families. This institution can help to finance costs that cannot be covered by Puskesmas and village / kelurahan governments. (Head of Puskesmas, Day 1 AM – Stroke).

Ideally, elderly with stroke can access ambulance service by phone that can transport them to and from the Puskesmas and other elderly care facilities, and should be accessed 24/7 and from anywhere (LKS, Day 1 PM – Stroke).

A village-level forum should be formed which initially addresses and promotes preventive actions first. They can conduct educational program about what is dementia, how to care for the elderly, starting from the symptoms of dementia or problematic behaviors, to the public. This forum then can be held at the Elderly centre where elders gather, collect information and obtain help based on their conditions (Head of Puskesmas, Day 2 AM – Dementia).

The Social Affairs Office has a PAIMA (Services that reaches home) program that provides transportation services for those who cannot afford. (TKSK, Day 1 PM - Stroke). However, many people did not know the call center number, not even the Puskesmas and posyandu cadres. This is due to the lack of program publicity (LKS, Head of Puskesmas and Cadre Posyandu, Day 1 PM – Stroke).

Is the Posyandu for the elderly and Posbindu different? (Family member, Day 1 PM - Bedridden)

The service that is not currently available is day care, like the one in Thailand where there are library, social and recreation programs that the elderly can enjoy. Day care for the elderly with stroke is needed (LKS, Day 1 AM - Stroke).

There is a need of day care or special care for the elderly with dementia because children are busy with their working. Ideally, day care staff will visit patients at home and offer service similar to that of a hospital. Day care should also be covered by BPJS (Family member, Day 1 AM – Dementia).

Home care has been very limited: there is no homecare service in the hospital (LKS, Day 1 AM. - Stroke).

It is also good to have elderly rehabilitation house/centre where elderly can get rehabilitation service as treatment (Social Affair Office staff, Day 2 – Dementia).

Ideally, geriatric specialist should be added to hospital care (NGO, Day 1 AM - Dementia).

Distance from the hospital has been a problem. Ideally, the elderly should be cared in a closer health care facility, hospital or Puskesmas. ..... Ambulance service for people in rural area is not available. (Family - Day 1 PM – Bedridden).
Theme 5: Community care in general is a passive system and only responds to request or report. For patients with dementia and stroke, the process of seeking care may be convoluted. How to navigate system is an issue.

What did the focus group participants do, say, feel and think:

For Puskesmas, if the community does not report the elderly’s “demented" symptoms that are evolving at their homes, the Puskesmas will not know the case. Even if the Puskesmas visits the elderly at home and if the family does not consider the symptoms problematic,

Puskesmas will not intervene as it may be considered as an interference of family business unnecessarily. Usually the family themselves cover up the real situation so sometimes we become awry (Head of Puskesmas, Day 2 AM - Dementia).

Dinas sosial only take action when there is a report, never initiate action without a request from the family (Family, Day 1 AM – Dementia).

The Social Affair Office does indeed act when there are reports, but they do not go directly to the community and take the case. If the elderly still physically active, they will refer the elderly to a foundation or institution that is willing to house the elderly, because the institution or the nursing home only accepts elderly who are still physically active (Social Affair Office Staff, Day 2 AM - Dementia).

The family said that if elderly was sick and the condition was not severe, then the elderly will be taken to the Puskesmas to receive treatment immediately. If however, the condition was severe then the Puskesmas would refer the patient to the hospital (Elderly family, Day 1 PM – bedridden).

Care management is by severity of the elderly conditions. If the case is severe, it will be handled by TKSK. If the case is related to health, it will be immediately followed up by the Puskesmas. And if the Puskesmas cannot handle it, Puskesmas will refer or coordinate with head of village or regional stakeholders such as head of RW to find a solution. Coordination can also be directly carried out from head of RW to Village Head (Head of Puskesmas, Day 1 AM – Stroke).

Patients’ physical vital signs would be checked when they were taken to the Puskesmas. If the physical conditions could not be handled at the Puskesmas, then the case would be referred to other facilities with a note to the family explaining why the case cannot be treated at Puskesmas. If the patient has insurance (BPJS), the insurance card will be taken and a referral will be made from the Puskesmas (Health office staff, Day 1 PM – Bedridden).

When a demented patient is not handled directly by a psychologist in Puskesmas and neurologist in hospital, then the process of getting dementia diagnosis and treatment can be long. If, however, a referral pertaining to cognitive functioning of the patient, is made by the Puskesmas / private doctor to the hospital, then the process of dementia diagnosis and treatment by a neurologist will be faster. If there is no referral, the elderly will have to go straight to the hospital because of symptoms other than dementia, such as hypertension, they will definitely be examined by internal medicine with no diagnosis of dementia. If this is the case, they may have to go through the nurses, administrators and to answer similar questions multiple time. This can be tiring and make the elderly emotional (ngo, Day 1 AM – Dementia).

Seniors with BPJS/KIS (health insurance) with stroke cannot immediately get services at the hospital. The elderly must go to the Puskesmas or First Level Health Facility (FKTP) to obtain a referral, unless the condition is acute or emergent. FKTP will first make a referral to a neurologist, who will then make a
referral to a physiotherapist. Hospitals for stroke care as designated by BPJS are hospitals with a competency class levels of A, B, C and D (Head of Puskesmas, Day 1 PM – Stroke).

Theme 6: There is a confusion regarding which agency or government department (e.g., District Social Affairs Office) should lead and coordinate community care, including the use of government data, social media and APP in community care.

What did the focus group participants do, say, feel and think:

There are a number of local government departments involving in the provision of elderly care. For instance, the Ministry of Social Affairs (MOSA) provides home care for the poor elderly and neglected through local volunteers and PUSAKA. BKKBN (The National Family Planning Board) implement BKL (Elderly Family Development Program) to increase the knowledge and skills in caregiving for families with elderly16.

The Social Service and Health offices can provide assistance if there are reports. This can be arranged through Jamkesus/Special Health Insurance. The service will connect elderly people in need with private parties/NGOs such as YAKKUM or UCP for wheelchair assistance (Head of Puskesmas, Day 2 AM - Dementia).

A village-level forum should be formed which initially addresses and promotes preventive actions first. They can conduct educational program about what is dementia, how to care for the elderly, starting from the symptoms of dementia or problematic behaviors, to the public. This forum then can be held at the Elderly centre where elders gather, collect information and obtain help based on their condition. This forum should also link to Social Affair Office, Puskesmas, Hospital, Health office and other stakeholders related with the elders (Head of Puskesmas, Day 2 AM – Dementia).

As a Social Affair Office, I encourage the formation of more LKS (social welfare institutions) in terms of forums / organizations for the elderly, and the Social Affair Office can support the activities in the LKS. LKS already has activities such as homecare training. Government initiated elderly service/activities and funding can be channeled through LKS as it has all the required rules and regulations (Social Affair Office Staff, Day 2 AM – Dementia).

As general work and housing staff, I want the strengthening of coordination between agencies and there is a need of sector leadership and overall coordination. I propose the Social Affairs Office to be the sector lead and coordinate all the relevant offices and agencies. The Social Affairs Office already has social workers in the field who can continuously visit families and cadres. The Social Affairs Office should ideally have data on the entire village population such as the number of elderly people, their disease history, etc. Other health data and services can be obtained through coordination with Health Office. If social assistance is needed, the Social Affairs Office can coordinate within the agency itself or with CSR (Government of office, Day 1 AM – Stroke).

In the city, there is a Social Affairs Office, city commission, commission for sub-districts, and Kelurahan (Village) district commission. District Social Affairs has planned to develop day care and home care for the elderly. This will be an integrated service. Later the program is called GRISELA, Griya Sejahtera Lansia

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is managed by Social Affairs, the program covers health and social affairs. (Social Office, Day 1 AM – Dementia)

Ideally this should be the task of the elderly KOMDA (NGO, Day 1 AM – Dementia)

We must develop networks in the care of the demented elderly especially when they were out. A network requirement if in the city there are PKK cadres and others (Provider, Day 2 AM – Dementia).

Ideally, there should be agencies/institutions that can tell whether or not there are other funding sources to cover care cost, e.g., hiring someone to provide care, that is not covered by the BLK or village (Head of Puskesmas, Day 1 AM - Stroke).

Health offices also require data and various types of reporting. The health department should have that network, because they have the web. There should be an APP for missing person reporting (Provider, Day 2 AM – Dementia).

As the Head of Puskesmas, I want PSM in every RW to be strengthened so that it can also be used to collect data of the elderly. The Social Affairs Office already has a network in the community so it can coordinate if there is someone who needs help, for example for elderly with disabilities (Head of Puskesmas, Day 1 AM – Stroke).

TSM expressed his hopes regarding applications for community services, anyone can use, so all citizens can upload not just cadres. It is already an integrated system including all services such as the ambulance, the hospital, etc. For budgeting, it must be integrated between the regional government and the province. And also there should be apps to integrate social affair office centers, Puskesmas and village community including residence and cadre. Therefore, residents can use the application and all needed service can be rendered. Another important thing is there is a budget from the government and it is an integrated application process (TSM/Community Social Worker, Day 1 PM – Bedridden).

Cities have JSS (Jogja Smart service) so people can complain and report. JSS is hosted by Kominfo, the city government. JSS should be accessible by Cadres (Social Affairs Office Staff & NGO, Day 1 AM – Dementia).

Social media and WA groups are also very useful in dealing with the problem of the elderly, especially if there are elderly people missing. This needs to be developed in the community so that information can run more quickly and smoothly." (Village Secretary, Day 2 AM – Dementia)

The volunteer caregivers contact ICJ (Info Cegatan Jogja) – a community service that can be accessed through social media e.g., Facebook, for help such as wheelchair. Their response is quite fast. If the elderly has more difficult problems, there will be volunteers who can provide assistance. This may include payment for home care services. The amount ranges from Rp. 150,000-Rp.250,000 per visit (LKS, Day 1 PM – Stroke).

Theme 7: A “not so friendly” elderly friendly community care environment, let alone dementia friendly.

What did the focus group participants do, say, feel and think:

Doctor from local hospital did home visit, family and elderly felt relaxed. Patient made marked progress (Family member, Day 1 PM - Bedridden).
Services and access for elderly people in hospitals or health centers are good enough. There is a special pathway for the elderly and services for older people take precedence (Social Affair Office staff, Day 1 AM – Dementia).

At the Puskesmas, they have different lines for the elderly and other patients, just like the Bank. The elderly takes precedence….. but if in those areas some say “polite elderly” is only used for accreditation. Not all facilities have implemented it. ….. Must be more friendly to the elderly it (Family, Day 1 PM – Bedridden). Hospital services are less friendly for patients with BPJS because of the nature of their payment scheme (Kader Posyandu Lansia, Day 1 AM – Stroke).

Even though there is special counter for the elderly, due to resources limitation, it has not been well manned. (NGO, Day 1 AM - Dementia). ….. Staff of Puskesmas added that currently there is no dedicated counter for elderly, but it is possible in the future. Puskesmas Santun Lansia/Aging Friendly Puskesmas is usually appointed by Health Office, however because Puskesmas where I am working now is still lacking spaces, facilities, infrastructure and human resources it’s not yet appointed as Puskesmas Santun Lansia (Puskesmas Staff, Day 1 PM - Bedridden).

There is already JSS (Jogja Smart Service) for registration, which needs to be more elderly friendly. People have to enter the JSS first before they can make a registration and there are not too many JSS available. Puskesmas also has a WA system which availability appears to be more flexible and user friendly. More complete information of elderly care is needed (Head of Puskesmas, Day 1 AM - stroke).

Actually one can register online. There is already a clock and the system will generate queue number so the elderly do not have to queue in the facility. The problem is that not all of them use it, and only a few who access online registration (Head of Puskesmas, Day 1 AM - stroke). ….. Pre-registration does not imply you will be seen on time as the doctors of ten come in late. (Family Day 1 AM – Stroke). ….. Some families find on line registration friendly and referral useful (Family Day 1 PM - Bedridden).

Theme 8: Lack of understanding of Dementia and Dementia Care. Both family and providers asked for more training in the care of dementia patients.

What did the focus group participants do, say, feel and think:
In early phase, family usually confuse with elderly’s behavior change and even consult to psychic/paranormal. In this stage, family will most likely bring the elderly to kyai/ustadz for exorcism. This is due to their lack of knowledge about dementia. (Elderly family, Day 1 AM – Dementia)

Many have actually noticed the deterioration of elderly functioning. But many of them consider these changes as normal ageing process as one age, rather than symptoms of a disease that require further attention. This is a result of lacking knowledge in dementia. (Head of village, Day 2 AM - Dementia)

Based on my experience, poor family usually will lock the elderly inside their house, but one of my neighbors who is wealthy also lock their elderly inside the house. So what I am saying is, families tend to treat demented elderly the same way, regardless their economic status. This all may come down to limited knowledge of dementia. (Head of Puskesmas, Day 2 AM – Dementia)

Demented elderly are locked at home, otherwise, they would get lost. In the past, the villagers have found 25 elderly who were wondering around the street and
could not find their way home. Even if they were found, it was after 1 or 2 days later, the elderly became emotional disturbed (out of control), which could easily lead to family conflict. There are discussions in the village to promote better understanding of dementia. There are groups to promote more education on dementia care. Posyandu runs elderly gymnastic activities which focus more on physical than cognitive wellbeing. LKS can better be integrated to provide a more coordinated services (Family member, Day 1 AM – Dementia).

As a member of family with elderly, I once wanted to put the elder with problematic behaviors into a nursing home. It turns out that even though the dementia is yet diagnosed but if the behaviors are disruptive, the nursing home will not accept the case. There are already many in the queue, the nursing home prioritize elderly with normal behavior. People with disruptive behaviors will not accepted (Family member, Day 1 Am - Dementia).

Elderly family once told that when they go to Puskesmas to tell the behavior of the elderly to the doctor, the doctor only test for physical issues such as blood pressure and blood sugar level. After the examination, the doctor said that the elderly is fine, asked to treat the elderly patiently and sent the patient home with vitamins pills. No dementia care treatment (NGO, Day 1 AM– Dementia).

Caring or awareness from the community is very important for the dementia caregivers, which unfortunately is still very low due to poor knowledge of dementia (NGO, Day 1 AM– Dementia).

Special mentoring of families with demented persons is also needed. Mentoring may come from cadre of posyandu lansia with special training and knowledge on dementia. The training can be conducted by NGO who have experience and competency in dealing with dementia-related care (Village secretary, Day 2 AM – Dementia)

Cadres need training to understand how to deal with elderly people suffering from dementia. Currently, we have homecare services for those who who are bedridden or live alone. There are no specifics for dementia. …… Strong and well educated human resources are needed, especially in the care of the elderly with special needs such as dementia. So it’s not just a physical matter (Social Affair Office staff, Day 1 AM – Dementia).

Ideally, care to elderly would be much improved if all parties concerned have a good understanding of dementia. Adequate education and training in dementia care are needed especially for cadres in LKS or Posyandu Lansia (Social Affair Office staff, Day 2 AM – Dementia).

Many complain that the general public do not know much about dementia. Some even consider it curses or normal aging. Even the Puskesmas felt confused too. For example, in hospitals there are SOPs related to dementia (BKL, Day 1 AM– Dementia).

Community seem to care less because they don’t have knowledge about dementia. They think that dementia is senile, and is normal for elderly. This might be an explanation why care and treatment (for dementia) is limited. So far, the least community could help is finding elderly who wandering off/lost. As long as solidarity spirit remains among community, it serves a good base to care more about dementia (Village secretary, Day 2 AM – Dementia).

Transportation Agency lacks knowledge of dementia or because of its transportation aspect (Provider, Day 2 AM – Dementia).
Appendix 3

Plan to Develop a Case Management System

1) The Community Care Redesign Committee (CCRC) forms a Case Management Working Group (CMWG) and appoints its Chairperson along with a proposed terms of reference.

2) The CMWG is formed with representatives from service users/family members, service providers and government departments, e.g., health, social affairs, technology, housing, transportation, etc.

3) The CMWG and ADB, searches for an external case management consultant (CMC) to help in the development and implementation of a regional case management system.

4) CMWG, along with CMC, identifies and agrees on the model (i.e., case management, shared management and self management) and key process of a case management system: (case finding and screening, assessment, planning, coordination, monitor, transfer and discharge, etc.)

5) CMWG and the CMC, identifies the competence and standards of case management and case manager.

6) CMWG and the CMC, creates the administrative structure of case management system including: ((senior case manager (regional) vs. case manager (sub-district and village level))

7) CMWG and the CMC, develops case manager training, certification and credentialing systems including the establishment of certification and credentialing agency.

8) CMWG and the CMC and other ICT experts, develops case management information system to be aligned with the proposed electronic health record, helpline etc. The case management information system will assist in the overall case management monitoring: case recording, case triage and tracking, caseload monitoring, etc.

9) CMWG and the CMC, develops a budget for a 4-week training program for 20 case managers trainees and 1st year operation cost; and solicits funding support from the regional and district governments.

10) CMWG and the CMC, agrees on a case management evaluation framework and monitoring system with indicators. The evaluation framework and monitoring system are to be approved by the CCRC.

11) CCRC (along with regional and district governments) approve funding for case management training and 1st year operation cost, and CM evaluation framework.

12) The CMC and CMWG, along with other trainers develop training materials.

13) The CMC and CMWG, recruits case manager trainees.

14) The CMC and the CMWG and other trainers, conducts case management training.

15) CMWG along with the CMC, market case management to service users and providers of the community care.

16) The CMC works with local community care providers to set up case management office at sub-district and village levels.

17) CMWG and CMC, appoint senior case managers to provide administrative and professional support to case managers.
18) Case managers begin their work and meet with senior case managers periodically to report and review case progress, discuss issues and concerns, receive professional advice, etc.

19) The CMC conducts evaluation of case management every 6 months and uses key performance indicators to monitor case management system monthly.

20) CMWG meets monthly to receive monitoring report with key performance indicators from the CMC and to provide timely feedback. If needed, CMWG consults CCRC, regional government for further inputs and directions.

21) The CMC provides an evaluation of the case management system at the end of 1st year operation and recommends room for improvement to the CMWG.

22) CMWG approves the report and submit the report to the CCRC, regional government for ongoing funding support.

23) The CCRC and regional government decides if to roll out the 1st phase case management system to other subdistricts and villages within the jurisdiction, with funding support.
Appendix 4
Terms of Reference: Community Care Redesign Committee (CCRC)

The Community Care Redesign Committee (CCRC) assumes leadership in support, guidance and oversee the progress of community care redesign and/or integration. The committee sets up the administration structure for community care redesign including hiring the administrator. It serves as the Governance Committee of the administration structure thereafter. The committee consists of representatives from service recipients (and family), cadres, service providers (profit and non-profit), government departments, etc. CCRC is multidisciplinary, across government and nongovernment sectors. Its chairperson and members are appointed by the government.

CCRC’s Functions

1) Work closely with the Government and the Administration in the development of a new vision and mission, and principles of community care, as well as a 3-5 year strategic plan for the redesign of community care.
2) Ensure the operationalization of the strategic plan by determining priorities, establishing objectives; confirming deliverables; and identifying supports to achieve community care improvements and integration.
3) Monitor, adjust and evaluate the achievement of community care improvement and redesign.
4) Identify and resolve community care improvement and integration issues and problems that cross programs, services, sites and sectors.
5) Review proposed changes/new program initiatives to assess risk, develop implementation plans and monitor and evaluate impact on service recipients, volunteers/Cadres and staff.
6) Select external resources to assist in the process if, and as, required.
7) Secure sufficient resources for the implementation of the community care redesign plan.
8) Develop the timelines and provide ongoing evaluation of the process.
9) Ensure that the process is completed within the timeframe and budget.
10) Develop and support Working Groups and Task Forces for the planning and implementation of specific improvement and/or integration projects.
11) Ensure consistency and standardization of operational procedures, guidelines throughout the redesigned community care system.
12) Provide an open and comfortable forum for innovative, new, creative, provocative, and challenging ideas and issues to be discussed.
Appendix 5
Terms of Reference: Service Integration Council

The Service integration Council assumes leadership in facilitating and coordinating seamless service and integrated service delivery across all units/services/teams of community care system. It consists of all service heads/senior managers of service units/teams. The council is:

13) To work closely with the Clinical Practice Council (when established) in the development, regulation, coordination and monitoring of an integrated operation.
14) To promote full interdisciplinary collaboration to ensures all units/services/teams are actively engaged in creating a fully integrated operation including the sharing of resources and expertise.
15) To review and approve the strategic plan and quality management plan of an integrated operation.
16) To prepare and present the annual operating budget.
17) To evaluate and recommend action on service activities that affect financial performance utilization trends, quality of service, service outcomes, client safety, service processes and critical incidents, etc.
18) To review quality performance indicators and data trends of the elderly information system and provide feedback as required to the units, services, teams and other operating units of the integrated operation.
19) To review and present the completed impact analysis of each new service, policy, approach and/or initiative.
20) To accept a leadership imperative to facilitate resolution of cross units (region or corporate) issues and effect resolution by consensus.
21) To ensure an evaluation framework is established and used to measure the achievement and outcomes of the Integrated Council on an annual basis.
Appendix 6
Terms of Reference: Clinical Practice Council

The Clinical Practice Council assumes leadership in facilitating and coordinating clinical practice standards for all professional and non professional caregivers, paid and unpaid. It consists of representatives of all professional and non professional staff and cadres. The council is:

1) To work closely with the Service Integration Council in the development, regulation, coordination and monitoring of an integrated operation.
2) To promote interdisciplinary collaboration to ensure all staff members and cadres are competent to fulfill a full scope of professional practice and practice standards
3) To promote an integrated approach in delivering services to clients such as the creation of a gatekeeping mechanism for service eligibility, and agreeing on the admission and discharge criteria for each of the community care services
4) To establish an ongoing process for developing, implementing and evaluating practice standards.
5) To accept a leadership imperative to facilitate resolution of cross disciplines and/or cross units issues and effect resolution by consensus.
6) To plan and organize education/training programs for all staff and cadres in order to enhance practice/ skills competence.
7) To provide consultation, education and development on cross-disciplines issues.
8) To ensure an evaluation framework is established and used to measure the achievement and outcomes of the Clinical Practice Council on an annual basis.
Appendix 7
8 Types of Community Care Technology

1. Internet of things and technology: wearable devices which monitor changes in care recipient’s status and connect to appropriate resources.
2. Voice: low cost and commercially available voice-enabled interface e.g. Google Home for offering alerts and answering questions.
3. Remote monitoring/Telehealth: manage the elderly’s condition and well-being without considering the physical proximity can significantly reduce the burden on caregivers.
4. Mobility/autonomous vehicles: autonomous vehicles and ride sharing allows better access to care resources whenever the recipient needs.
5. Assistive technologies: to support functional limitations in vision, hearing and mobility.
6. Virtual/Augmented/Mixed Reality: to allow family caregivers to receive training to perform medical/nursing/rehabilitation tasks and to address emergencies when needed.
7. Financial technologies: enable the elderly to monitor financial accounts and transactions while protecting them from fraud.
8. Machine and artificial intelligence: enable family caregiver faster access to and make better use of information.

(Lindeman David A, et al., 2020):
Appendix 8
Admission and Discharge Criteria for Adult Day Care

Admission Criteria

General:

The prospective service recipient must

- be an Indonesian citizen (or have permanent resident status or have been issued a temporary resident permit by the minister for immigration);
- be a resident of Joygakarta and vicinity for at least 12 months; and
- be 19 years of age or older.

Program (Adult Day Care) Specific:

After a clinical assessment conducted by a case manager, the prospective service recipient:

- has been found to be unable to function independently because of chronic, health-related problems or have health care conditions
- with caregiver who requires respite service
- has been a frequent visitor (e.g., > 3 times in a month) hospital or emergency departments.
- has recently been discharged from a hospital or Puskesmas and
- has been assessed as requiring adult day services as part of the care plan
- has agreed to pay the daily rate (if any).

Discharge Criteria

The service recipient:

- Self-discharge from the program
- Can no longer benefit from the program as determined by the multidisciplinary team including service recipient and family member
- Transfer to a higher level of care e.g., residential care
- Is reluctant to pay daily fee as required.
- Passes away