

BUILDING TRUST TO FACILITATE ACCESS TO
DEMENTIA CARE FOR IMMIGRANT OLDER ADULTS

OUR STORY

SO FAR...



The Building Trust team has been looking at how partnerships between provincial Alzheimer Societies, health authorities, and community-based immigrant-serving agencies can improve access to a diagnosis of dementia and associated supports and services for immigrant older adults and their families.

... AND WITH THAT, WE CONDUCTED

INTERVIEWS AND FOCUS GROUPS TO DIG DEEPER



15 DYADS

10 PUNJABI DYADS
5 KOREAN DYADS

PERSONS WITH
DEMENTIA



FAMILY
CAREGIVERS



6 FOCUS GROUPS

PUNJABI-SPEAKING

10 OLDER WOMEN
10 OLDER MEN
9 WORKING AGE MEN & WOMEN

KOREAN-SPEAKING

9 OLDER WOMEN
8 OLDER MEN
8 WORKING AGE MEN & WOMEN



20 STAFF

11 FROM DEMENTIA
SERVING AGENCIES

PHYSICIANS NURSES
MANAGERS COORDINATORS
FRONT LINE STAFF

9 FROM IMMIGRANT
SERVING AGENCIES

MANAGERS
FRONT LINE STAFF



WE DID THIS TO HELP

UNDERSTAND THE
PROCESS OF GAINING
ACCESS TO DEMENTIA-
RELATED INFO,
DIAGNOSIS, AND
SERVICES

EXPLORE THE COMMUNITY'S
UNDERSTANDING OF
DEMENTIA AND AVAILABLE
SERVICES

UNDERSTAND WHAT
RESOURCES ARE
AVAILABLE, THE CONTEXT
OF POTENTIAL
INTERVENTIONS, & WHAT
GAPS CAN BE FILLED

THROUGHOUT THE INTERVIEWS, WE IDENTIFIED DIFFERENT DIMENSIONS OF
ACCESS AS UNDERSTOOD THROUGH THE LENS OF THE

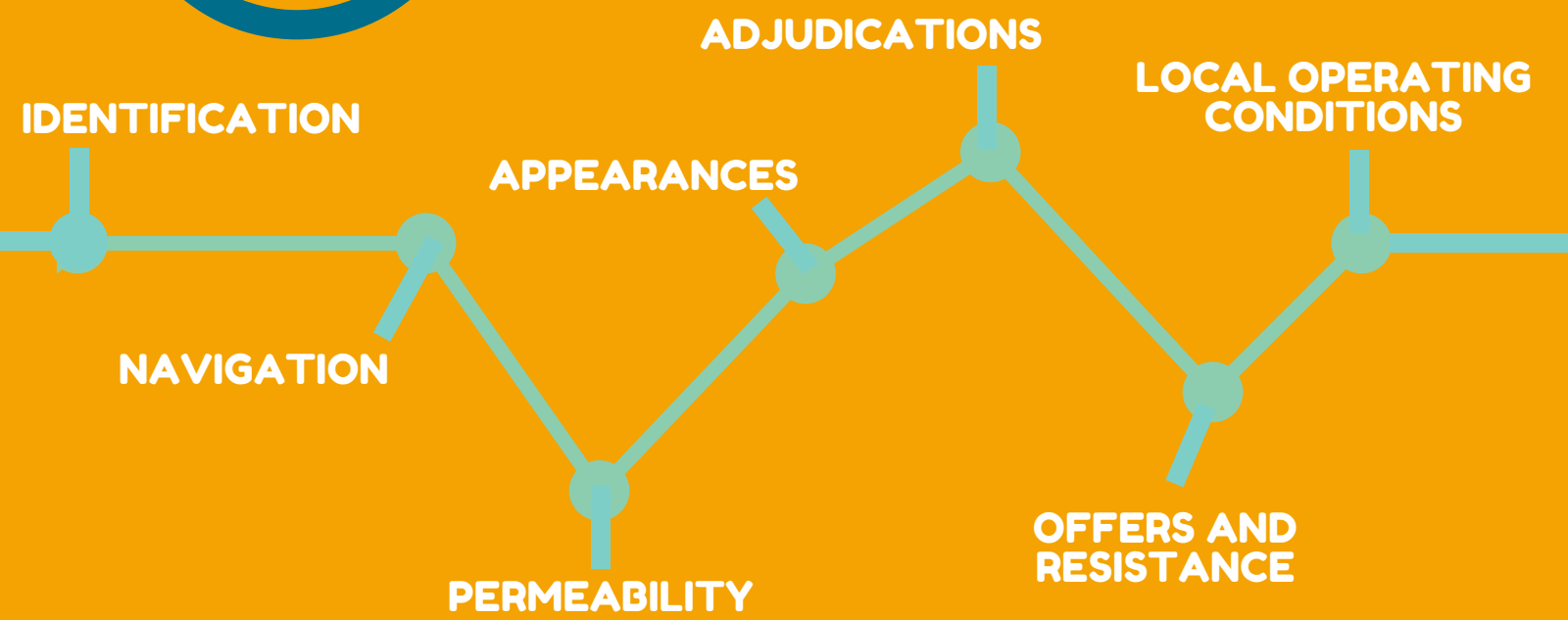
CANDIDACY FRAMEWORK

THIS FRAMEWORK HAS VALUE IN HELPING US UNPACK THE COMPLEX PROCESS OF OBTAINING A DEMENTIA DIAGNOSIS AND CARE IN SOUTH ASIAN AND KOREAN POPULATIONS.

IT SPEAKS TO THE PATIENT/CLIENT'S DYNAMIC AND CONTINUALLY NEGOTIATED SENSE OF LEGITIMACY IN USING HEALTHCARE AND THIS ACCESS IS INFLUENCED BY NUMEROUS DIFFERENT, INTERSECTING DIMENSIONS



7 DIMENSIONS OF CANDIDACY



USING A **FRAMEWORK ANALYTIC APPROACH**, WE DID INDUCTIVE CODING DRAWING ON THEMES EMERGING FROM THE INTERVIEWS IN COMBINATION WITH DEDUCTIVE CODING BASED ON THEMES ESTABLISHED BY SIMILAR RESEARCH AND CAPTURED BY THE CANDIDACY FRAMEWORK. THIS APPROACH ALLOWS FOR THE POTENTIAL TO

DEVELOP ACTIONABLE OUTCOMES



AND SHARE THE METHODS AND AND FINDINGS WITH



TRANSPARENCY

FAST FORWARD TO **SEPTEMBER 21ST** WHERE WE INVITED OUR PARTNERING AGENCIES AND RESEARCH TEAM TO AN **ANALYSIS RETREAT**

WITH GOALS TO

- 1 MAKE SURE INTERPRETATIONS OF FINDINGS FROM INTERVIEWS WERE **ON TRACK**
- 2 TALK ABOUT **INTERVENTION** PLANS TO BRING FORWARD TO THE EMPOWERMENT EVALUATION WITH DAVID FETTERMAN ON NOVEMBER 17TH

13 ATTENDEES: 1 REPRESENTATIVE FROM EACH PARTNER AGENCY (ALZHEIMER'S SOCIETY OF BC, FRASER HEALTH, MOSAIC, AND PICS) AND 9 MEMBERS OF THE BUILDING TRUST TEAM



IT'S IMPORTANT TO HAVE INVOLVEMENT OF PARTNER AGENCIES IN ALL STEPS IN THE RESEARCH PROCESS IN ORDER TO FOSTER AND BUILD RELATIONSHIPS THROUGH

TRUST

WE THEN DISCUSSED...

KEY FINDINGS

FOCUS GROUPS AND DYADS

PUNJABI

- Family involvement can add barriers or introduce opportunities and benefits for dementia diagnosis and care.
- Cultural differences exist regarding views on aging and illness
- Many participants had low education and literacy levels and lacked access to computers.
- Limited understanding of dementia can lead to stigmatization
- Only recently is there a dedicated Punjabi-speaking ASBC staff
- Opportunities for temples, gurdwaras, priests, and other religious leaders as important sources of influence

KOREAN

- Stigma exists due to cultural differences regarding aging and illness
- Lack of services in Korean language
- Difficulty navigating services due to a lack of resources in Korean
- Family support often unavailable or geographically distant
- Many older Koreans are computer savvy and receptive to information disseminated through TV and newspapers
- Churches are a source of influence and involvement

★ MAJOR FINDING: IMPORTANT DIFFERENCES BETWEEN CULTURAL GROUPS ★

STAFF

- Clients have lack of insight to identify symptoms (importance of family collateral) and think symptoms are normal part of aging
- GP often acts as gatekeeper to specialists and services (confirm diagnosis)
- Importance of talking directly to person with dementia, non-judgmental approach, and using less blunt language
- Inconsistency of home support workers and high cost of services leads to reduced uptake of services
- Appropriateness of services important to access (e.g., in comfortable location, affordable, service hours)
- Immigrant serving agency staff are not trained to recognize dementia symptoms
- More resources for Punjabis than for Koreans
- Lack of word for dementia in Punjabi
- Common way to collaborate between organizations is referring
- Language barriers with staff and support workers

FROM THESE FINDINGS, WE COLLECTIVELY BRAINSTORMED

BARRIERS TO ACCESS

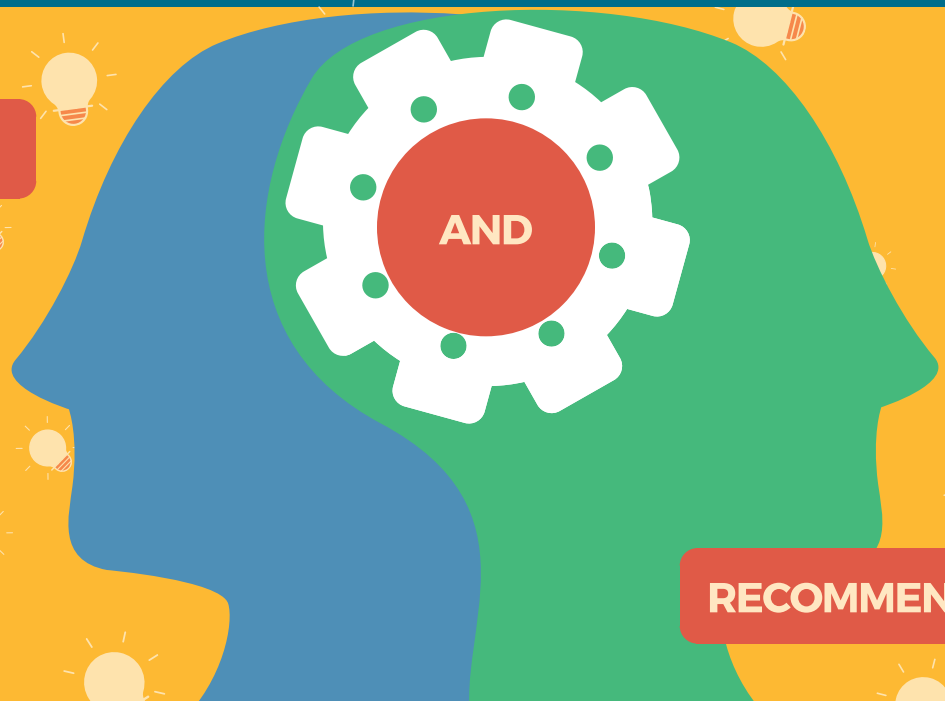
LANGUAGE BARRIERS CULTURALLY SENSITIVE SERVICES AGENCY CONNECTIONS
CULTURAL DIFFERENCES LONG WAIT TIMES WOMEN'S BARRIERS VIEWS ON AGING
STIGMA INSIGHT FEAR TRUST
TRANSPORTATION LACK OF PUBLIC EDUCATION DENIAL UNDERSTANDING
INSUFFICIENT RESOURCES ACCESS

THEN...

TOGETHER

WE CAME UP WITH POSSIBLE

SOLUTIONS



RECOMMENDATIONS

TO ADDRESS BARRIERS TO DEMENTIA DIAGNOSIS AND CARE IN LOCAL PUNJABI AND KOREAN POPULATIONS

PARTNER AGENCY REPRESENTATIVES THEN TOOK BACK WHAT LEARNT AND DISCUSSED AT THE ANALYSIS RETREAT TO THEIR ORGANIZATION FOR FURTHER



REVIEW



DISCUSSION



CONSULTATION

THE NEXT STEPS

INVOLVED INVITING KEY PLAYERS FROM OUR PARTNERING AGENCIES TO THE NOVEMBER 17TH



EMPOWERMENT EVALUATION WORKSHOP

WITH DAVID FETTERMAN

SO, WHAT IS EMPOWERMENT EVALUATION (EE) AND HOW WILL WE BENEFIT FROM IT?



EE IS AN EVALUATION APPROACH THAT AIMS TO INCREASE THE LIKELIHOOD THAT PROGRAMS WILL ACHIEVE RESULTS BY INCREASING THE CAPACITY OF PROGRAM STAKEHOLDERS TO PLAN, IMPLEMENT, AND EVALUATE THEIR OWN PROGRAMS.

STAKEHOLDERS WILL USE EVALUATION CONCEPTS, TECHNIQUES, AND FINDINGS TO FOSTER IMPROVEMENT AND SELF-DETERMINATION WITHIN THEIR COMMUNITIES.



DAVID M. FETTERMAN IS PRESIDENT AND CEO OF FETTERMAN & ASSOCIATES, AN INTERNATIONAL EVALUATION CONSULTING FIRM, AND THE CREATOR OF EMPOWERMENT EVALUATION. HE IS A PROFESSOR AND DIRECTOR OF THE MA POLICY ANALYSIS AND EVALUATION PROGRAM IN THE SCHOOL OF EDUCATION AT STANFORD UNIVERSITY.

10

PRINCIPLES

IMPROVEMENT
COMMUNITY OWNERSHIP
INCLUSION
DEMOCRATIC PARTICIPATION
SOCIAL JUSTICE

COMMUNITY KNOWLEDGE
EVIDENCE-BASED STRATEGIES
CAPACITY BUILDING
ORGANIZATIONAL LEARNING
ACCOUNTABILITY

AND IS FOLLOWED BY THREE STEPS:

- 1. ESTABLISH THE PARTNERS' MISSION
- 2. REVIEW THEIR CURRENT STATUS
- 3. PLAN FOR THE FUTURE



27 ATTENDEES

- 4 FROM FH
- 4 FROM ASBC
- 2 FROM MOSAIC
- 4 FROM PICS
- 3 SENIOR ADVISORY MEMBERS
- 3 OTHERS (INCLUDING THE FACILITATOR)
- 7 TEAM MEMBERS

OVER THE COURSE OF THE DAY, THE TEAM ENGAGED COLLABORATIVELY WITH DR. FETTERMAN, WORKING THROUGH THE STEPS AND MONITORING AND EVALUATING THEIR OWN PROGRAMS

STEP 1:

MISSION

Enhancing dementia care
Removing cultural barriers
Connecting with people who need us

Learning
Collaborating
Building trust
Making changes
Decreasing stigma

Raising awareness of existing services
Increasing capacity and understanding
Increasing accessibility to related services

By engaging in this democratic process of determining group values, the team was able to develop their mission statement which allowed them to make meaning and establish their voice.

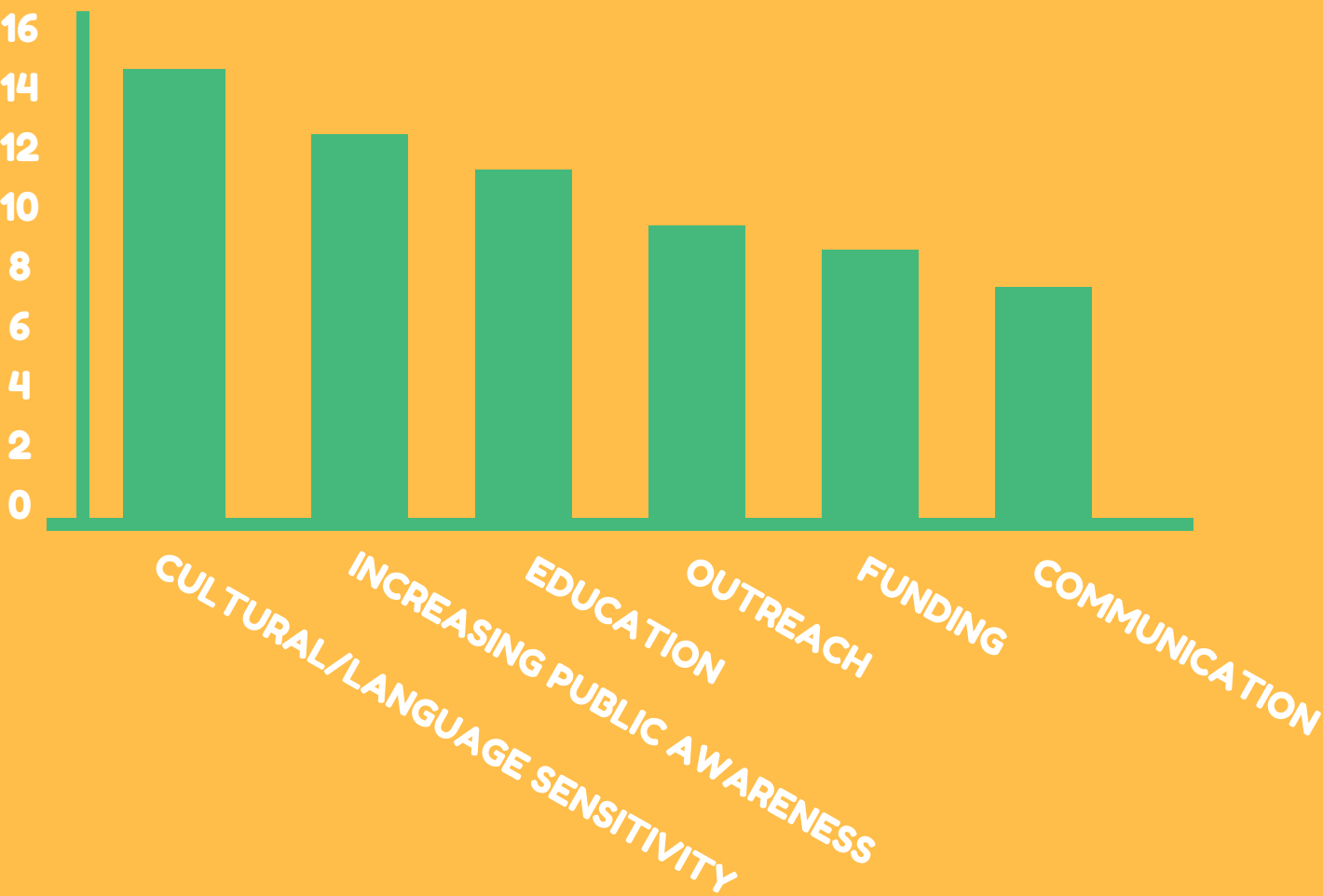
STEP 2:

TAKING STOCK



Part 1: List activities and prioritize

TOP 6 ACTIVITIES THE PARTNERS ARE ALREADY ENGAGED IN



Part 2: Rate (1-10*) and discuss

HOW WELL ARE THE ORGANIZATIONS DOING THESE ACTIVITIES?

	ASBC	FH	PICS	MOSAIC	SFU	OTHER
Culturally/language sensitivity	4.7	7.3	6.0	4.3	5.7	2.7
Education	6.0	6.0	7.3	5.3	7.7	3.0
Outreach	5.7	5.8	8.7	4.3	7.3	2.0
Public awareness	5.3	5.5	8.3	5.0	6.0	3.0
Communication	7.3	6.5	8.0	5.7	6.7	3.3
Funding	5.3	4.0	8.3	4.7	5.7	2.0
Client support	7.0	6.3	5.7	4.7	6.3	3.3
Developing resources	5.7	7.3	7.3	4.0	7.3	2.3
Networking	7.3	7.5	6.3	5.7	7.0	4.0
Community connections	6.7	6.8	7.3	5.0	8.6	3.0
Reporting	7.7	6.0	6.3	5.0	7.7	2.7
Research	7.0	6.3	6.7	4.7	8.0	4.0

* 1 = needs more attention

10 = extremely well

THESE BASELINE MEASURES ALLOWED THE TEAM TO SELECT A COUPLE OF ACTIVITIES TO TACKLE BY SETTING GOALS, COMING UP WITH STRATEGIES TO ADDRESS THESE GOALS, AND DETERMINING WHAT EVIDENCE WILL BE NEEDED TO MEASURE IMPROVEMENT AND CHANGE



STEP 3: PLANS FOR THE FUTURE

GOALS

- 1 IMPROVE CULTURAL SENSITIVITY
(BALJEET J - ASBC)
- 2 COMMUNITY CONNECTIONS
(SARA W - ASBC)

★ (MEETING TO BE SET UP)

STRATEGIES

COLLABORATE WITH AGENCIES & COMMUNITY BASED GROUPS

- 1 COMMUNITY LIAISONS; RE-FRAME CONVERSATION USING DIFFERENT TERMINOLOGY; FIND COMMUNITY "CHAMPIONS"
- 2 CONNECT WITH COMMUNITY LEADERS TO ESTABLISH GAPS AND NEEDS; INCLUDE ORGANIZATIONS TO DO MAPPING EXERCISES; GAIN PERSPECTIVES OF STAFF WORKING WITHIN THE ORGANIZATIONS



EVIDENCE

(EXAMPLES OF HOW WE WILL MEASURE OUR SUCCESS)



- 1 WITHIN A YEAR, PROVIDE "X" NUMBER OF WORKSHOPS IN LANGUAGE; TRACK HOW MANY "CHAMPIONS" IN EACH QUARTER; DOCUMENT HOW MANY PEOPLE EACH CHAMPION WAS ABLE TO REACH
- 2 MEETING SET UP PLAN PUT TOGETHER; DOCUMENT HOW MANY CLIENTS RECEIVED SERVICES; PRIORITIES ARE ESTABLISHED AND STATISTICS ARE COLLECTED FOR SERVICES

IN 2018...

THE BUILDING TRUST TEAM WILL WORK WITH PARTNERS TO DEVELOP **TRUST AS THE BASIS FOR COLLABORATION** TO EXTEND THE REACH AND INCREASE THE RELEVANCE OF EXISTING DEMENTIA INFORMATION AND SUPPORTS TO PUNJABI AND KOREAN SPEAKING OLDER ADULTS

GUIDING PRINCIPLES FOR THIS WORK

EQUITY

ORGANIZATIONS ARE RESPONSIBLE FOR REDUCING BARRIERS TO ACCESS

TRUST

NEEDED FOR EFFECTIVE PARTNERSHIPS AND UPTAKE OF RESOURCES

EVIDENCE

PARTNERS IDEAS NEED TO BE CONSISTENT WITH THE END USERS' EXPERIENCES AS CAPTURED BY OUR RESEARCH DATA

CONTACT

Sharon Koehn, PhD | skoehn@sfu.ca | 778-782-9467
(Dept. of Gerontology, Simon Fraser University)

SFU