

**NAVIGATING THE COMPLEXITIES OF CONSUMER DIRECTED CARE
STRATEGIES FOR BUILDING CAPABILITY IN DISADVANTAGED CONSUMERS**

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MANY THANKS TO THE ORGANISERS FOR INVITING ME TO SPEAK AT THIS IMPORTANT CONFERENCE ON NAVIGATING THE COMPLEXITIES OF CONSUMER DIRECTED CARE.

I WELCOME THE OPPORTUNITY TO TALK ABOUT STRATEGIES FOR BUILDING CAPABILITY IN DISADVANTAGED CONSUMERS DAUNTING THOUGH IT IS.

OVER THE LAST 10 YEARS ALZHEIMER'S AUSTRALIA HAS BEEN A STRONG ADVOCATE FOR A CONSUMER DIRECTED APPROACH.

THIS MAY HAVE SURPRISED MANY GIVEN THE COMPLEXITIES OF DECISION MAKING IN DETERMINING THE SUPPORT AND CARE NEEDED BY THE PERSON WITH DEMENTIA AND THEIR FAMILY CARER.

THE DRIVER FOR ALZHEIMER'S AUSTRALIA WAS SIMPLY THE NEED TO HAVE A MODEL OF CARE THAT PROMOTED RESPECT FOR THE RIGHTS FOR THE INDIVIDUAL INCLUDING PEOPLE WITH A DIAGNOSIS OF DEMENTIA.

THE OVERARCHING OBJECTIVE WE ESTABLISHED FROM OUR WORK WAS ADOPTED BY GOVERNMENT IN 2009 IN THE TRIAL OF THE CDC IN PACKAGES, NAMELY:

'CARE RECIPIENTS AND THEIR CARERS SHOULD HAVE GREATER CONTROL OVER THEIR LIVES BY ALLOWING THEM, TO THE EXTENT THEY ARE CAPABLE AND HAVE THE CAPACITY, TO MAKE CHOICES ABOUT THE TYPES OF CARE SERVICES THEY ACCESS AND THE DELIVERY OF THOSE SERVICES, INCLUDING WHO WILL DELIVER THE SERVICES AND WHEN'.

THE **LIVING LONGER. LIVING BETTER.** PACKAGE HAS MANY ELEMENTS BUT IN TERMS OF CHOICE AND EMPOWERMENT OF CONSUMERS I SUGGEST THERE ARE THREE ELEMENTS THAT REALLY MATTER:

1. THE ADOPTION OF THE CDC IN THE FORM OF BUDGET HOLDING IN HOME CARE PACKAGES WITH THE PROMISE OF CDC IN RESIDENTIAL CARE.
2. THE DRAMATIC EXPANSION OF PACKAGES FROM 64,800 INTO 2012 TO 144,469 IN 2021-22.
3. THE PROMISE – PERHAPS NOT OBVIOUSLY STATED – THAT SUPPORT AND CARE TAILORED TO THE INDIVIDUAL SHOULD BETTER ADDRESS THE NEEDS OF DIVERSE COMMUNITIES AND THE DISADVANTAGED.

IN OUR SUBMISSIONS TO THE PRODUCTIVITY COMMISSION'S WORK ON CARING FOR OLDER AUSTRALIANS ALZHEIMER'S AUSTRALIA SUGGESTED WE SHOULD STOP THINKING IN TERMS OF SPECIALNEEDS GROUPS AND INSTEAD ENSURE THAT SERVICES ADDRESS THE NEEDS OF ALL.

SPECIAL GROUPS IMPLIES AN ADD-ON TO MAINSTREAM; THINKING IN THOSE TERMS IS LIKELY TO FURTHER MARGINALISE GROUPS ALREADY AT A DISADVANTAGE IN ACCESSING THE CARE AND SUPPORT THEY NEED.

WE HAVE BEEN FORTUNATE TO RECEIVE FUNDING FROM THE COMMONWEALTH THAT HAS ENABLED US TO BE MORE INCLUSIVE. THROUGH THE SPECIAL ACCESS LIAISON OFFICERS PROGRAM WE HAVE BEEN ABLE TO DEVELOP FLEXIBLE AND RESPONSIVE SERVICES THAT MEET THE NEEDS OF DIVERSE GROUPS.

MORE RECENTLY WE HAVE RECEIVED FUNDING TO EMPLOY YOUNGER ONSET DEMENTIA KEY WORKERS WHOSE JOB WILL BE TO PROVIDE SUPPORT TO PEOPLE WITH YOUNGER ONSET DEMENTIA AND THEIR FAMILIES. THEIR ROLE WILL BE TO HELP THOSE WITH YOUNGER ONSET DEMENTIA ACCESS SERVICES AND ASSIST OTHER ORGANISATIONS WHERE

THEY CAN IN SERVICE DEVELOPMENT, AWARENESS AND EDUCATION RELATED TO YOUNGER ONSET DEMENTIA.

THE LESSON WE HAVE LEARNED IS THAT EMPOWERMENT AND CHOICE WILL NOT HAPPEN WITHOUT BUILDING CAPACITY IN BOTH THE CONSUMER AND THE PROVIDER. THIS IS TRUE REGARDLESS OF WHETHER A PERSON IS DISADVANTAGED OR NOT AND NEEDS TO BE A KEY COMPONENT OF MOVING TOWARDS GREATER CHOICE.

WITHOUT SUPPORT CONSUMERS ARE UNLIKELY TO KNOW WHAT OPTIONS TO CONSIDER TO GO BEYOND TRADITIONAL SERVICES. CARE STAFF WILL NEED TO HAVE THE SKILLS TO MANAGE THE BALANCE OF RISK AND CHOICE IN ADVISING CONSUMERS AND NEGOTIATING ON WHAT CAN BE INCLUDED IN THE CARE.

THE CDC HOME CARE PACKAGE PROGRAM GUIDELINES ACKNOWLEDGE THE LONG LIST OF SPECIAL GROUPS IN THE AGED CARE ACT – - WHICH, BY THE WAY, EXCLUDES PEOPLE WITH DEMENTIA – AND GOES ON TO STATE IN SECTION 2.4:

ALL HOME CARE PROVIDERS ARE EXPECTED TO HAVE POLICIES AND PRACTICES IN PLACE TO ENSURE SERVICES ARE ACCESSIBLE TO PEOPLE WITH SPECIAL NEEDS. PROVIDERS SHOULD HAVE REGARD TO CONSUMER DIVERSITY, TAKING INTO ACCOUNT CONSUMERS' INDIVIDUAL INTERESTS, CUSTOMS, BELIEFS AND BACKGROUNDS. PROVIDERS SHOULD ALSO WORK COLLABORATIVELY WITH ADVOCACY SERVICES AND SPECIALIST SERVICE PROVIDERS FOR PEOPLE FROM SPECIAL NEEDS GROUPS, WHERE APPROPRIATE.

IN DECEMBER 2012, THE GOVERNMENT RELEASED NATIONAL STRATEGIES FOR TWO OF THE SPECIAL NEEDS GROUPS:

- *NATIONAL AGEING AND AGED CARE STRATEGY FOR PEOPLE FROM CULTURALLY AND LINGUISTICALLY DIVERSE (CALD) BACKGROUNDS; AND*
- *NATIONAL LESBIAN, GAY, BISEXUAL, TRANSGENDER AND INTERSEX (LGBTI) AGEING AND AGED CARE STRATEGY.*

AMAZINGLY NOTHING FURTHER IS SAID. APPARENTLY ACCESS TO APPROPRIATE CARE IS EXPECTED TO HAPPEN BY SOME PROCESS OF OSMOSIS OR MAGIC. WELL IT WILL NOT.

SO IN TERMS OF BUILDING CAPABILITY IN DISADVANTAGED GROUPS LET US LOOK AT WHAT DECISION MAKING INVOLVES FOR SOME OF THE GROUPS THAT WE MOST OFTEN TALK ABOUT, NAMELY:

- PEOPLE WITH DEMENTIA.
- PEOPLE EXPERIENCING HOMELESSNESS
- PEOPLE FROM CULTURALLY AND LINGUISTICALLY BACKGROUNDS.
- ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE.
- LGBTI.

PEOPLE WITH DEMENTIA

FOR PEOPLE WITH DEMENTIA, AS FOR OTHER PEOPLE WITHOUT DEMENTIA, HAVING A SAY THEIR EVERY DAY LIVES IS A BASIC DESIRE AND UNDERPINS A SENSE OF PURPOSE AND WELLBEING.

UNTIL RECENT TIMES, SOCIETAL ATTITUDES HAVE FOR THE MOST PART, DENIED THAT POSSIBILITY FOR PEOPLE WITH DEMENTIA. EVEN IN OUR OWN ORGANISATION WE WERE NOT INCLUSIVE OF PEOPLE WITH DEMENTIA UNTIL AFTER 2000.

FOR FAMILY MEMBERS, HEALTH PROFESSIONALS AND CARE STAFF, THERE IS A TENSION BETWEEN RESPECTING THE AUTONOMY OF THE INDIVIDUAL WITH DEMENTIA AND ENSURING THAT THEIR SAFETY, HEALTH AND WELLBEING IS NOT COMPROMISED.

THESE ISSUES ARE EXAMINED IN AN INTERESTING SMALL PILOT STUDY BY DEIDRE FEATHERSTON-HOUGH AND COLLEAGUES IN THE JOURNAL OF AGEING STUDIES THIS YEAR.

THE INSIGHTS GAINED FROM THE INTERVIEWS WITH A FEW PEOPLE WITH DEMENTIA IN THE STUDY SUGGESTS THAT PEOPLE WITH DEMENTIA WANT TO FEEL THEY ARE PARTICIPATING IN DECISION MAKING WHILE RECOGNISING THEIR ABILITY TO DO SO IS COMPROMISED BY THE NATURE OF DEMENTIA AND THAT IT WILL BECOME MORE SO AS THE DISEASE PROGRESSES. ESSENTIALLY THE THOUGHTS THAT EMERGED ABOUT DECISION MAKING FOR PEOPLE WITH DEMENTIA WERE:

- THE DIFFICULT BALANCE IN MAINTAINING A SENSE OF CONTROL OVER THEIR OWN LIVES WHILE WANTING TO ACCEPT SOME SUPPORT AND ASSISTANCE. ESSENTIALLY PEOPLE WITH DEMENTIA WANT TO BE THE ONES MAKING THE FINAL DECISIONS. THE AUTHORS CAPTURE THIS BY REFERRING TO “SUBTLE SUPPORT VERSUS TAKING OVER”.
- PARTICIPANTS WANTED TO HOLD ON TO THEIR DECISION MAKING CAPABILITIES FOR AS LONG AS POSSIBLE. THIS INVOLVES INHERENTLY DIFFICULT NEGOTIATIONS AS THE DISEASE PROGRESSES, ESPECIALLY AROUND SENSITIVE ISSUES LIKE DRIVING. AGAIN THE AUTHORS CAPTURED THIS BY “HANGING ON VERSUS LETTING GO”
- THE FEELING OF EXCLUSION WAS VERY STRONGLY FELT AND RESENTED, FOR EXAMPLE, WHEN SPEAKING WITH MEDICAL PROFESSIONALS OR OTHERS, IT WAS AS IF THEY WERE A NON-PERSON AND ONLY THE FAMILY CARER COUNTED. FEELING CENTRAL TO THE DECISION MAKING WAS SEEN AS AN IMPORTANT WAY OF COMBATING DEMENTIA AND FEELING PART OF LIFE.

THESE INSIGHTS RESONATE WITH EXPERIENCES IN OUR OWN ORGANISATION.

PEOPLE WITH DEMENTIA NOW HAVE THEIR OWN NATIONAL ADVISORY GROUP WITHIN ALZHEIMER’S AUSTRALIA TO SPEAK FOR THEMSELVES.

THE FINDINGS OF THE PILOT STUDY ALSO UNDERLINE THE IMPORTANCE OF ADOPTING SUPPORT AND CARE APPROACHES THAT MAXIMISE THE CAPACITY OF THE PERSON WITH DEMENTIA TO BE PART OF DECISION MAKING PROCESSES AND TO CONTINUE TO PARTICIPATE IN LIFE.

THE STRATEGIES TO ACHIEVE THIS INCLUDE:

- KEY WORKERS TO ASSIST PEOPLE WITH DEMENTIA AND THEIR FAMILY CARERS TO MAKE DECISIONS ABOUT CARE AND GET ACCESS TO APPROPRIATE SERVICES, AS NOW EXISTS FOR YOUNGER PEOPLE WITH DEMENTIA THROUGH ALZHEIMER'S AUSTRALIA
- A PHILOSOPHY OF CARE WHICH FOCUSES ON THE STRENGTHS AND CAPABILITIES OF THE PERSON WITH DEMENTIA RATHER THAN THEIR IMPAIRMENTS.
- ENABLING THE PERSON WITH DEMENTIA TO CONTINUE IN EMPLOYMENT OR IN ACTIVITIES THEY ENJOY FOR AS LONG AS POSSIBLE.
- APPROACHES THAT MAXIMISE THE ENGAGEMENT OF PEOPLE WITH DEMENTIA IN EVERY DAY LIFE THROUGH DEMENTIA FRIENDLY COMMUNITIES AND ORGANISATIONS.
- A GREATER COMMITMENT TO TRAINING SERVICE PROVIDERS AND STAFF ON HOW TO NEGOTIATE WITH CONSUMERS TO DEVELOP CARE PLANS THAT SUPPORT THE PERSON TO ACHIEVE THEIR GOALS WHILE MANAGING RISK.

HOMELESS

THERE ARE MULTIPLE WAYS IN WHICH THE NEW CDC CONCEPT IS A CHALLENGE FOR THE HOMELESS.

PEOPLE WHO ARE HOMELESS ALMOST BY DEFINITION WILL NOT HAVE THE SAME SUPPORT NETWORKS IN PLACE.

IT IS FAR FROM CLEAR HOW THE NEW ASSESSMENT AND REFERRAL SERVICES WILL WORK FOR THIS GROUP AND HOW INFORMATION WILL BE DISSEMINATED AND UNDERSTOOD.

WE FREQUENTLY TALK ABOUT HOW DIFFICULT IT IS TO NAVIGATE THE CARE SYSTEM BUT IN THE CASE OF THE HOMELESS WE PERHAPS HAVE REACHED THE POLAR EXTREME OF HOW DIFFICULT IT WILL PROVE FOR THEM. PARTICULARLY WHEN THE TIME THAT HOMELESS PEOPLE ARE MOST LIKELY TO SEEK ASSISTANCE IS DURING A CRISIS.

IN COMMON WITH YOUNGER PEOPLE WITH DEMENTIA, HOMELESS CLIENTS MAY WELL HAVE DIFFICULTY GETTING ACCESS TO AGED CARE ASSESSMENT TEAMS AS THEY MAY NEED AGED CARE SUPPORT BEFORE THE AGE OF 65. IN SOME CASES THEY ARE INFORMED THEY ARE NOT ELIGIBLE OR REFERRED TO SOME OTHER ASSESSMENT SYSTEM SUCH AS DISABILITY THAT WILL IN TURN REJECT THEM.

AND LETS NOT FORGET THAT TO BE REFERRED TO AGED CARE ASSESSMENT TEAMS, ANYONE WHO IS HOMELESS NEEDS TO BE, IN THE FIRST INSTANCE, CONNECTED TO A SERVICE.

IT TAKES A STRETCH OF THE IMAGINATION TO KNOW HOW THE NEW GATEWAY WILL DEAL WITH HOMELESS GROUPS UNLESS THEY HAVE THE ABILITY TO REFER THESE POTENTIAL CLIENTS TO THE OUTREACH PROGRAMS THAT WILL BE INTEGRATED INTO THE NEW HOMECARE PROGRAM LATER THIS YEAR. IT ALSO IS QUESTIONABLE HOW WELL A WEBSITE AND CALL CENTRE WILL WORK AS A SOURCE OF INFORMATION AND ACCESS FOR THIS GROUP.

THE LOGIC OF CDC IS A PROCESS OF DECISION MAKING ALIGNED WITH A PERSON'S CHOICES AND NEEDS. IT ASSUMES THE PERSON HAS MADE GOOD CHOICES THROUGHOUT THEIR LIFE IN RESPECT OF HEALTH AND LIFESTYLE, WHICH IS UNLIKELY TO BE THE CASE.

MANY HOMELESS PEOPLE WILL NEED GREATER SUPPORT AND DIRECTION TO ENSURE THEY MAKE CHOICES THAT WILL LEAD THEM TO ACHIEVE POSITIVE GOALS. THEY ALSO WILL NEED AN INCREASED AMOUNT OF CASE MANAGEMENT AND SUPPORT AND THIS COULD BE A CHALLENGE IN TERMS OF AVAILABLE RESOURCES.

IT IS DIFFICULT PERHAPS FOR POLICY MAKERS TO GET THEIR MIND AROUND THE DIFFICULTIES THAT CDC CAN PRESENT IN THESE KINDS OF CIRCUMSTANCES. I THINK I CAN DO NO BETTER THAN QUOTING HELEN SMALL, GENERAL MANAGER OPERATIONS AT WINTRINGHAM IN VICTORIA:

“WE HAVE PROVIDED CHOICE IN SERVICES TO OUR CLIENTS AND WORKED HAND IN HAND WITH THEM TO ENSURE THE SERVICES WE PROVIDE ARE APPROPRIATE AND ACCEPTABLE TO THEM – OUR CLIENTS HAVE ALWAYS HAD THEIR CHOICE IN CASE MANAGER OR CARE STAFF. SO THAT ASPECT OF CDC IS NO GREAT CHANGE FOR US. HOWEVER, WE HAVE ALSO ALMOST IMPOSED OUR SERVICES ON SOME CLIENTS – WORKED FOR UP TO SIX MONTHS BEFORE GETTING IN THE DOOR OF THEIR HOME – TAKEN A YEAR BEFORE SERVICES WERE IN PLACE THAT TRULY HELPED THE CLIENT MEET THEIR HEALTH CARE NEEDS BECAUSE THE CLIENTS WOULD NOT ACCEPT THE SERVICES PRIOR TO THIS. HOW NOW WILL OUR ACTIONS IN THESE INSTANCES BE VIEWED IN CDC’S TERMS?

THERE IS AN UNDERLYING ETHOS TO THE CDC NOTION THAT WE MUST ACCEPT DECISIONS PEOPLE MAKE AS THEY HAVE THE RIGHT TO DECIDE FOR THEMSELVES BUT THIS IS SO MUCH HARDER WHEN THE INDIVIDUAL HAS A LIFELONG EXPERIENCE OF BEING DISAPPOINTED IN THE HELP PROVIDED AND A PAST HISTORY OF INCARCERATION OR INSTITUTIONALISATION.

PEOPLE WITH THESE EXPERIENCES NEED TO LEARN TO TRUST BEFORE THEY WILL BE ABLE TO MAKE DECISIONS ABOUT HOME CARE SERVICES FOR THEMSELVES. NOT EVERY CLIENT COMES TO A CDC WITH AN EXPECTATION THAT THE WORLD IS THERE TO HELP

THEM OUT, THEIR LIFE EXPERIENCE DIRECTLY CONTRADICTS THIS NOTION, YET CDC SEEMS TO ASSUME THAT ALL CLIENTS WILL FIT THE FIRST PROFILE.

I HAVE WORKED AT WINTRINGHAM FOR EIGHT YEARS AND HAVE YET TO MEET SOMEONE WHO HAS CHOSEN TO BE HOMELESS. I HAVE MET CLIENTS WHO HAVE HAD TO CHOOSE BETWEEN ALCOHOL/ DRUGS / GAMBLING AND PAYING THEIR RENT AND CHOSEN TO PURCHASE ALCOHOL OR GAMBLE OR TAKE DRUGS. I HAVE MET MANY PEOPLE WITH UNTREATED MENTAL HEALTH ILLNESS WHO HAVE NOT FULLY UNDERSTOOD THAT THEIR CHOICES HAVE LED THEM TO BECOME HOMELESS. THEY ARE EXTREMELY SUSPICIOUS OF THE WORLD AT LARGE AND ESPECIALLY MENTAL HEALTH SERVICES. SO SURELY THE QUESTION THEN IS HOW CDC WILL BUILD SUCH PEOPLE'S CAPACITY TO FIND AND RETAIN A HEALTHY AND SAFE LIFE IN THE COMMUNITY INTO THEIR OLD AGE.

THE STRATEGIES TO BE EMPLOYED FOR THE HOMELESS SEEM TO BE OBVIOUS IF HARD TO IMPLEMENT AND PERHAPS EVEN MORE DIFFICULT TO RESOURCE. THEY MUST INCLUDE OUTREACH, SKILLED KEY WORKERS WHO CAN LIAISE, NEGOTIATE AND UNDERSTAND WHAT BEING HOMELESS REALLY MEANS AND BE BACKED UP BY COMMUNITY AND RESIDENTIAL CARE SERVICES THAT ARE FLEXIBLE ENOUGH TO ASSIST STAFF TO NEGOTIATE SUCCESSFUL CARE AND SUPPORT OUTCOMES.

THIS SUGGESTS TO ME A NEED FOR WELL INTEGRATED SERVICES THAT TARGET HOMELESS GROUPS RATHER THAN RELY ON MAINSTREAM SERVICES TO RESPOND.

AND IF THE COMPLICATIONS THAT HELEN HAS OUTLINED ARE NOT ENOUGH LETS ALSO REMEMBER THAT SOCIALLY AND CULTURALLY DIVERSE GROUPS ARE OVER REPRESENTED IN HOMELESS COMMUNITIES. IN 2013 HOMELESSNESS AUSTRALIA ESTIMATED THAT 30 % OF THOSE HOMELESS COME FROM CULTURALLY AND LINGUISTICALLY DIVERSE

BACKGROUNDS; 25% COME FROM ABORIGINAL AND TORRES STRAIT ISLANDER COMMUNITIES.

PEOPLE FROM THE LGBTI COMMUNITY ARE FOUR TIMES OVER REPRESENTED AMONG THE HOMELESSNESS

THERE WILL BE OVERLAPS TOO WITH DEMENTIA IN HOMELESS COMMUNITIES THAT MAY BE RELATED TO THE LESS COMMON FORMS OF DEMENTIAS SUCH AS ALCOHOL RELATED DEMENTIA, KORSAKOFFS DEMENTIA, HIV ASSOCIATED DEMENTIA, YOUNGER ONSET DEMENTIA AND FRONTAL TEMPORAL DEMENTIA, ALL OF WHICH MAY CROSS WITH MENTAL HEALTH CONCERNS AND ACQUIRED BRAIN DAMAGE.

CULTURAL AND LINGUISTICALLY DIVERSE COMMUNITIES

IN ANY CONSULTATION PROCESS WITH CONSUMERS THERE ARE ALWAYS SOME SPECIAL MOMENTS. I REMEMBER DURING THE CONSULTATIONS ON THE AGED CARE REFORMS AT THE END OF 2011 WITH CALD GROUPS IN MELBOURNE I ASKED WHETHER THE CDC MODEL HAD ATTRACTIONS FOR THOSE IN THEIR COMMUNITIES.

I HAD EXPECTED OVERWHELMING SUPPORT. IN FACT THE REACTION WAS VERY MIXED; I SHOULD HAVE EXPECTED THAT. MANY CONSUMERS ARE NO DOUBT SCEPTICAL ABOUT WHAT CDC MEANS IF ACCESS TO BASIC SERVICES CANNOT BE ACHIEVED IN THE CURRENT SYSTEM IN GETTING GOOD INFORMATION, PROMPT ASSESSMENT AND PROMPT REFERRAL SERVICES.

AS WITH THE HOMELESS AND PEOPLE WITH DEMENTIA IT WILL BE IMPORTANT TO HAVE OUTREACH SERVICES THAT ARE TARGETED TO THOSE FROM CALD BACKGROUNDS WHO ARE MOST DISADVANTAGED. WITHOUT OUTREACH SERVICES THAT PROVIDE INFORMATION, WIN THE TRUST OF COMMUNITIES AND THEN DELIVER ON WHAT IS PROMISED IT

CAN NOT BE EXPECTED THAT ANYONE WHO HAS LEARNT TO DISTRUST WILL LEARN TO TRUST.

IT SEEMS TO ME THAT THIS IS A RECURRING THEME AND THAT THE PERCEPTION ALZHEIMER'S AUSTRALIA HAD AT THE OUTSET OF DEVELOPING A NETWORK GATEWAY WHICH LIKE A SPIDER'S WEB, REACHES OUT TO THE COMMUNITY AND DRAWS ON ALL THE AVAILABLE RESOURCES TO HELP THE MULTITUDE OF CLIENTS IS ESSENTIAL. I FIND IT HARD TO IMAGINE THAT THE GATEWAY IN ITS CURRENT FORM WILL BE APPROPRIATE FOR THOSE MOST VULNERABLE GROUPS.

IN THE CASE OF CALD GROUPS, LANGUAGE IS CLEARLY GOING TO BE A BARRIER. ONE SUGGESTION WE MADE WAS THERE SHOULD BE A COMMUNICATION SUPPLEMENT TARGETED TO THOSE WHO DID NOT SPEAK ENGLISH AT HOME.

AGAIN THERE IS A NEED FOR EDUCATION AND TRAINING AROUND CULTURAL COMPETENCY FOR STAFF, THE DEVELOPMENT OF APPROPRIATE SERVICES TO RESPOND TO SPECIFIC NEEDS AND CAPACITY BUILDING IN THE COMMUNITY TO PROMOTE AND SUSTAIN THE SERVICES PROVIDED.

ABORIGINAL AND TORRES STRAIT ISLANDER COMMUNITIES

THERE IS SOME RECOGNITION IN POLICY THAT ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE FACE MORE DIFFICULT HEALTH AND CARE NEEDS IN THE TERMS OF THE 50 YEAR ELIGIBILITY FOR AGED CARE SERVICES.

APART FROM CULTURAL FACTORS WE ALSO KNOW THAT THEIR HEALTH AND CARE NEEDS ARE MORE COMPLEX THAN FOR OTHER AUSTRALIANS, THE BURDEN OF CHRONIC DISEASES IN ABORIGINAL AND TORRES STRAIT ISLANDER POPULATIONS IS TWO AND HALF TIMES GREATER THAN THE GENERAL AUSTRALIAN POPULATION WITH CARDIOVASCULAR DISEASE,

DIABETES AND CHRONIC KIDNEY DISEASE BEING SUBSTANTIAL PROBLEMS IN MANY COMMUNITIES.

THIS HAS POSED A CONSIDERABLE BARRIER TO THE RECOGNITION OF DEMENTIA AS A MAJOR HEALTH ISSUE IN ABORIGINAL AND TORRES STRAIT ISLANDER COMMUNITIES WITH THE PRIORITY OF TREATING OTHER CHRONIC HEALTH CONDITIONS OFTEN OUTWEIGHING THE TREATMENT OF DEMENTIA.

WE NOW KNOW THAT THE PREVALENCE RATES OF DEMENTIA AMONG BOTH RURAL AND URBAN ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE ARE THREE TO FOUR TIMES HIGHER THAN THE MAINSTREAM POPULATION, YET THE AWARENESS AND UNDERSTANDING OF DEMENTIA AMONG THESE PEOPLE IS LOW, PARTICULARLY IN RURAL AND REMOTE AREAS.

WE HAVE BEEN WORKING HARD AT ALZHEIMER'S AUSTRALIA TO PRODUCE AND PROMOTE A NUMBER OF RESOURCES TARGETING ABORIGINAL AND TORRES STRAIT ISLANDER COMMUNITIES TO RAISE AWARENESS OF DEMENTIA AS A SERIOUS HEALTH ISSUE.

A START HAS BEEN MADE IN THE DEVELOPMENT OF MORE SENSITIVE INSTRUMENTS TO ASSIST IN THE DETECTION OF DEMENTIA AMONG THESE COMMUNITIES. UNFORTUNATELY WE KNOW THAT MANY ABORIGINAL HEALTH WORKERS HAVE LIMITED KNOWLEDGE ABOUT DEMENTIA.

EDUCATION PROGRAMS ABOUT WHAT DEMENTIA IS AND TRAINING FOR HEALTH WORKERS IN THE ADMINISTRATION OF COGNITIVE SCREENING TOOLS INCLUDING THE KIMBERLEY INDIGENOUS COGNITIVE ASSESSMENT WILL BE ESSENTIAL IF WE ARE TO ACHIEVE A TIMELY DIAGNOSIS FOR ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE.

ALTHOUGH ABORIGINAL COMMUNITY CONTROLLED HEALTH ORGANISATIONS ARE OFTEN THE FIRST CHOICE FOR MEDICAL SERVICES

BY ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE, WE CANNOT ASSUME THAT ALL ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE WILL CHOOSE TO USE THESE SERVICES. IT IS NECESSARY FOR MAINSTREAM HEALTH ORGANISATIONS TO UNDERSTAND AND PROVIDE CULTURALLY APPROPRIATE SUPPORT AND INFORMATION TO INDIGENOUS COMMUNITIES USING THEIR SERVICES AND ALSO TO ENSURE CULTURALLY APPROPRIATE SCREENING TOOLS ARE EMPLOYED IN THEIR PRACTICE.

LGBTI

AS WITH OTHER GROUPS THE CORE ISSUE IS AGAIN OF TRUST IN DECISION MAKING BUT THE ISSUES ARE DIFFERENT IN KIND FOR THOSE AGEING IN LGBTI COMMUNITIES.

MANY WILL HAVE LIVED WITH DISCRIMINATION AND EXPERIENCED PREJUDICIAL ATTITUDES AND DISCRIMINATORY LAWS. THEY WILL HAVE COME OF AGE AT A TIME WHEN BEING LGBTI WAS CRIMINALISED AND FOR MANY THEIR EXPERIENCES WITH SOCIAL AND RELIGIOUS INSTITUTIONS ARE DECIDEDLY NEGATIVE.

AS A CONSEQUENCE A LARGE NUMBER WILL BE LESS WILLING TO LET STRANGERS INTO THEIR HOMES FOR FEAR OF PREJUDICE. THEY ARE LIKELY TO BE SENSITIVE TO HAVING THE CHOICE OF WHO PROVIDES HOME BASED ASSISTANCE. THEY WILL WANT TO BE REASSURED THAT A PERSON PROVIDING ASSISTANCE WILL HAVE BEEN EDUCATED ABOUT LGBTI SENSITIVITY ISSUES. THE CURRENT RAINBOW TICK PROGRAM AND THE POTENTIAL FOR AN IDENTIFIER TO INDICATE LGBTI 'FRIENDLY' PROVIDERS THROUGH THE GATEWAY ARE EXAMPLES OF WHAT COULD CONSTITUTE GOOD PRACTICE TO REMEDY THIS FEAR ON THE PART OF CONSUMERS. .

IT IS ALSO SIGNIFICANT THAT MORE PEOPLE FROM LGBTI COMMUNITIES LIVE ALONE – 46% AS COMPARED TO 23% OF THE GENERAL POPULATION. WE ALL KNOW THAT LIVING ALONE IS ESPECIALLY DIFFICULT FOR A

PERSON FACING A JOURNEY WITH ALZHEIMER'S DISEASE OR SOME OTHER DEMENTIA.

HAVING NO CHILDREN OR SUPPORTING FAMILY CAN BE PRESENT PROBLEMS AS PEOPLE AGE. LGBTI PEOPLE ARE LESS LIKELY TO HAVE ACCESS TO SUPPORT FROM FAMILY OR CHILDREN AND MAY RELY ON FRIENDS AND LGBTI COMMUNITY NETWORKS FOR SUPPORT. IT IS IMPORTANT THAT A BROAD DEFINITION OF FAMILY BE SUPPORTED BY PROVIDERS IN ADOPTING THE CDC MODEL.

BUT EVEN FOR THOSE WHO ARE LIVING WITH PARTNERS, THE PROBLEMS OF MAKING WILLS, PROTECTING SUPERANNUATION ENTITLEMENTS, DEMANDING HUMAN RESPECT AND SHARING HUMAN AFFECTION MAY PRESENT DIFFICULTIES. LAW REFORM RECOGNISING SAME-SEX PARTNERSHIP RIGHTS, AS WELL AS RECENT ANTI-DISCRIMINATION REFORMS THAT PROTECT LGBTI PEOPLE IN RELATION TO AGED CARE WILL START TO ASSIST IN AMELIORATING THESE PROBLEMS.

EVERY DAY THINGS WE TAKE FOR GRANTED LIKE VISITING RESIDENTIAL CARE TO SEE SOMEONE WE LOVE ARE MORE COMPLEX. WITHOUT CONFIDENCE, CERTAINTY AND SAFETY, LGBTI CONSUMERS AND CARERS MAY BE RELUCTANT TO FULLY PARTICIPATE AND BENEFIT FROM CDC INITIATIVES. RESOURCED ADVOCACY, THROUGH BOTH MAINSTREAM AND LGBTI ORGANISATIONS, COULD BE A VITAL COMPONENT IN ENSURING THAT LGBTI PEOPLE ARE ABLE TO PARTICIPATE WITH THE ASSURANCE OF SAFETY.

RECENT INITIATIVES INCLUDING LGBTI RELATED TRAINING – THIS WILL BE ROLLED OUT NATIONALLY THROUGH THE NATIONAL LGBTI HEALTH ALLIANCE AND OTHER ORGANISATIONS – ALONG WITH OTHER PROJECTS FUNDED BY DOHA WILL PROVIDE SIGNIFICANT INITIAL SUPPORT TO ENABLE LGBTI CONSUMERS, INCLUDING THOSE LIVING WITH HIV / AIDS TO FEEL MORE CONFIDENT AND TRUSTING SO THAT THE CDC APPROACH MIGHT BE EMBRACED AND EFFECTIVE.

AS FOR PEOPLE WITH DEMENTIA, IT IS IMPORTANT TO PROMOTE UNDERSTANDING AND TO CORRECT THE MISCONCEPTIONS AROUND LGBTI THROUGH EDUCATION, LEGAL PROTECTION, CULTURALLY APPROPRIATE ADVOCACY AND A RANGE OF OTHER MEASURES.

CONCLUSION

WE CAN REASONABLY CONCLUDE THAT THERE IS DIVERSITY IN DIVERSE COMMUNITIES. BUT THERE ARE COMMON THEMES SUCH AS:

LACK OF TRUST IN MAINSTREAM SERVICES, SOCIAL ISOLATION AND LACK OF SUPPORTIVE NETWORKS, COMPLEX CARE NEEDS AND THE EXPERIENCE FOR MANY OF STIGMA AND DISCRIMINATION WITH A RESULTING ALIENATION TO VARYING DEGREES FROM SOCIETY.

THESE GREATLY COMPLICATE DECISION MAKING AND ACCESS TO SERVICES.

THERE ARE MANY THINGS TO CELEBRATE IN **LIVING LONGER. LIVING BETTER**. AND IN THE WAY THE DEPARTMENT AND SERVICE PROVIDERS HAVE RESPONDED. BUT IT IS DISAPPOINTING THAT THERE IS NOT MORE RECOGNITION IN THE CDC GUIDELINES AND ELSEWHERE OF THE RESOURCES NECESSARY FOR BUILDING A SERVICE PROVIDER SYSTEM THAT HAS COMPETENCIES DESIGNED TO PROMOTE DECISION MAKING BY THOSE, WHO FOR WHATEVER REASON, FEEL ALIENATED FROM THE MAINSTREAM.

ACTION IS NEEDED BY GOVERNMENTS NOT JUST IN WELL WRITTEN HIGH LEVEL STRATEGIES BUT IN THE RESOURCES AND SERVICE APPROACHES NECESSARY TO UNDERPIN THEM. CURRENTLY THESE ARE LARGELY LACKING.

THE STRATEGIES FOR BUILDING CAPABILITY DO NOT SEEM TO ME TO BE ROCKET SCIENCE BUT THEY REQUIRE RESOURCES AND CDC FOR MANY INDIVIDUALS – NOT ALL – WILL BE ILLUSORY UNLESS THE RESOURCE REQUIREMENT IS RECOGNISED.

IN SUMMARY I BELIEVE THE KEY STRATEGIES INCLUDE

- RESOURCING OF SUPPORTIVE NETWORKS TO PROVIDE OUTREACH TO INDIVIDUALS AND COMMUNITIES – BUILDING ON WHAT IS THERE TO THE MAXIMUM EXTENT POSSIBLE
- FURTHER DEVELOPING THE GATEWAY MODEL SO THAT IT NETWORKS WITH THOSE IN A POSITION TO SUPPORT DIVERSE GROUPS
- EXPANDED EDUCATION AND TRAINING FOR CARE WORKERS
- SERVICE FUNDING THAT IS FLEXIBLE WITH THE FINANCIAL INCENTIVES NECESSARY TO RESPOND TO VULNERABLE GROUPS – THE DEMENTIA AND HOMELESS SUPPLEMENTS ARE ONE MODEL
- RESEARCH AND EVALUATION TO BETTER UNDERSTAND HOW CDC WORKS FOR DISADVANTAGED GROUPS AND HOW DECISION MAKING CAN BE SENSITIVE TO THEIR NEEDS.

WE HAVE HAD TO ADVOCATE FOR MANY YEARS TO GET AN ACKNOWLEDGEMENT THAT MAINSTREAM AGED CARE WAS NOT ABLE TO RESPOND TO THE NEEDS OF MANY OF THOSE WITH DEMENTIA. THE SYSTEM IS NOW BEING FINE-TUNED WITH DEMENTIA SUPPLEMENTS BOTH IN RESIDENTIAL AND COMMUNITY CARE.

WE KNOW FROM OUR OWN SERVICES THAT PARTNERSHIP IN CARE AND SUPPORT WITH THE INDIVIDUAL AND COMMUNITIES WORKS.

THE URGENT NEED IS FOR POLICY MAKERS TO ACKNOWLEDGE THAT THE FUNDING MECHANISMS AND STRATEGIES WITHIN **LIVING LONGER. LIVING**

BETTER. ALSO NEED TO BE FINE-TUNED IF THEY ARE TO MEET THE DIVERSITY OF NEEDS THAT EXIST IN OUR COMMUNITY.