

CALD AGEING AND AGED CARE REFORM

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I WELCOME THE OPPORTUNITY TO TALK ABOUT THE CHALLENGES AND OPPORTUNITIES THAT THE AGED CARE REFORMS PRESENT IN RESPONDING TO THE NEEDS OF PEOPLE FROM CALD BACKGROUNDS.

ALZHEIMER'S AUSTRALIA HAS TAKEN THE VIEW THAT WE SHOULD STOP THINKING IN TERMS OF SPECIAL NEEDS GROUPS AND INSTEAD ENSURE THAT MAINSTREAM FUNDING ADDRESSES THE NEEDS OF ALL AND THAT THEY SHOULD BE HELD ACCOUNTABLE TO ENSURE THAT THEY ARE INDEED PROVIDING APPROPRIATE SERVICES

IT IS WHY WE HAVE ADVOCATED SO VIGOROUSLY SINCE 2000 FOR CONSUMER DIRECTED CARE APPROACHES THAT EMPOWER THE INDIVIDUAL CONSUMER.

I BELIEVE THE ISSUE OF EMPOWERMENT AND INVOLVEMENT IN DECISION MAKING IS A CONCERN FOR MANY PEOPLE INCLUDING THOSE FROM CALD BACKGROUNDS WHO FOR A VARIETY OF REASONS WILL FEEL DISEMPOWERED AND LESS INCLINED TO TRUST GOVERNMENTS AND SERVICE AGENCIES.

FOR THAT REASON AND OTHERS ALZHEIMER'S AUSTRALIA ACKNOWLEDGES THE IMPORTANT ROLE THAT ETHNO SPECIFIC SERVICES PLAY IN MEETING CALD COMMUNITY NEEDS. THESE SPECIALISED SERVICES NEED TO BE SUPPORTED THROUGHOUT THE REFORM PROCESS TO ENSURE THAT THEY REMAIN COMPETITIVE AND SUSTAINABLE IN THE NEW SYSTEM.

THE PROBLEM IS THAT MANY CALD COMMUNITIES DO NOT HAVE THE RESOURCES TO PREPARE FUNDING COMPETITIVE SUBMISSIONS. AND EVEN IF THEY DO THERE ARE DOUBTS ABOUT WHETHER ALLOCATION DECISIONS FAVOUR MAINSTREAM PROVIDERS.

ETHNO SPECIFIC SERVICE PROVISION WILL ALWAYS BE AN IMPORTANT PART OF THE SERVICE MIX FOR CALD CONSUMERS. BUT WE MUST ALSO

RECOGNISE THAT NOT EVERYONE WILL HAVE ACCESS TO THESE SPECIALISED SERVICES AND THAT MAINSTREAM SERVICES NEED TO BE ABLE TO SUPPORT AN INCREASINGLY DIVERSE OLDER POPULATION.

BUT MAINSTREAM PROVIDERS WHO ARE SUCCESSFUL IN APPLYING FOR CALD PLACES NEED TO BE ACCOUNTABLE TO GOVERNMENT AND TO THE COMMUNITIES THEY ARE SUPPOSED TO SERVE.

WE FEEL EQUALLY STRONGLY ABOUT THESE ISSUES IN RESPECT OF DEMENTIA. THERE IS NO MONITORING OF PROVIDERS WHO APPLY SUCCESSFULLY FOR DEMENTIA PLACES OR CRITERIA THAT DEFINE THOSE PROVIDERS WHO HAVE THE CAPACITY TO DELIVER DEMENTIA CARE.

MY STARTING POINT IN THIS MORNINGS DISCUSSION IS TO STRONGLY SUPPORT THE PRINCIPLES AND POLICY FRAMEWORK THAT UNDERLY THE AGED CARE REFORMS THAT ARE NOW IN LEGISLATION.

THE PROBLEM IS HAVING THE CONFIDENCE THAT THE PRINCIPLES AND FRAMEWORK DO NOT GET MANGLED IN THE PROCESS OF IMPLEMENTATION.

FOR PEOPLE FROM CALD BACKGROUNDS WE NEED VERY SPECIFIC STRATEGIES TO BE IMPLEMENTED WITHIN MAINSTREAM ACTIVITY IF WE ARE TO SUCCEED IN GETTING BETTER OUTCOMES.

IN DESIGNING THOSE STRATEGIES WE SHOULD KEEP IN MIND THE DIVERSITY OF ISSUES THAT CAN IMPACT ON AN INDIVIDUALS CAPACITY TO ACCESS SERVICES INCLUDING THE 25% OF OLDER AUSTRALIANS WHO ARE LIVING ALONE , THE 320,000 PEOPLE WITH DEMENTIA OF WHOM OVER 12 PER CENT ARE FROM CALD BACKGROUNDS AND THE 11,000 OLDER PEOPLE WHO ARE HOMELESS.

LET ME SUGGEST FOUR ISSUES WHERE SPECIFIC STRATEGIES ARE NEEDED WITHIN MAINSTREAM TO ACHIEVE BETTER OUTCOMES FOR PEOPLE FROM CALD BACKGROUNDS

FIRST, TIMELY DIAGNOSIS

DIVERSITY CAN ADD AN ADDITIONAL LAYER OF COMPLEXITY TO AN ALREADY COMPLEX DISEASE. PEOPLE FROM CALD BACKGROUNDS OFTEN HAVE A DIFFERENT UNDERSTANDING OF DEMENTIA, WITH SOME SEEING IT AS A MENTAL ILLNESS OR 'MADNESS'

THE TERM DEMENTIA MAY HAVE DIFFERENT MEANINGS IN DIFFERENT LANGUAGES. THIS OFTEN RESULTS IN A DELAYED DIAGNOSIS OF DEMENTIA WHICH RESULTS IN CONSIDERABLE DISTRESS AND CONFUSION FOR THE PERSON LIVING WITH DEMENTIA AND THEIR FAMILY MEMBERS.

WHEN A PERSON WITH DEMENTIA FROM A CALD BACKGROUND FIRST APPROACHES AGED CARE SERVICES OFTEN THEY ARE AT A POINT OF CRISIS. THEY MAY HAVE EXPERIENCED YEARS OF DELAYS IN GETTING A DIAGNOSIS - EVIDENCE SUGGESTS THAT PEOPLE FROM CALD COMMUNITIES MAY EXPERIENCE AN EVEN LONGER DELAY THAN THE 3.1 YEARS WHICH IS THE AVERAGE FOR THE GENERAL POPULATION.

WITHIN THE COMMITMENT TO ACHIEVING TIMELY DIAGNOSIS WITHIN THE AGED CARE REFORMS THERE NEEDS TO BE A PARTICULAR FOCUS ON THE ISSUES WHICH PRESENT FOR PEOPLE FROM CALD COMMUNITIES.

SECOND, ACCESS TO INFORMATION (GATEWAY)

THE REFORMS HAVE ACKNOWLEDGED THE STRUGGLE THAT MANY AUSTRALIANS HAVE HAD IN GETTING ACCESS TO INFORMATION ON THE AGED CARE SYSTEM AND IN RESPONSE HAVE DEVELOPED A NATIONAL GATEWAY. IN ESSENCE IT IS A WEBSITE (MYAGEDCARE) AND A CALL CENTRE THAT IS ABLE TO PROVIDE INFORMATION TO ASSIST PEOPLE IN NAVIGATING THE AGED CARE SYSTEM.

BUT THERE HAS BEEN LITTLE ANALYSIS OF THE ISSUE. WE HEARD TIME AND TIME AGAIN IN CONSULTATIONS WITH CONSUMERS OF THE PREFERENCE FOR FACE TO FACE CONTACT WITH SOMEONE FROM THEIR COMMUNITY OR AT LEAST IN THEIR LOCAL AREA WHO COULD PROVIDE ADVICE AND SUPPORT.

IT SEEMS TO ME THAT THE PERCEPTION ALZHEIMER'S AUSTRALIA HAD AT THE OUTSET OF DEVELOPING A NETWORKED 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.

A NEW GOVERNMENT BUREAUCRACY IS NOT THE ANSWER.

ANOTHER APPROACH IS THE USE OF KEY SUPPORT WORKERS IN THE COMMUNITY. ALZHEIMER'S AUSTRALIA THROUGH ITS SPECIAL ACCESS LIAISON OFFICERS AND NOW THE YOUNGER ONSET DEMENTIA KEY WORKER PROGRAM IS DEMONSTRATING HOW THIS CAN BE ACHIEVED. OUR VIEW IS THAT PEOPLE OF ALL AGES WITH DEMENTIA SHOULD HAVE ACCESS TO SUCH WORKERS , STARTING WITH A FOCUS ON THOSE FROM THE MOST DISADVANTAGED COMMUNITIES.

THIRD, CONSUMER DIRECTED CARE

LIVING LONGER LIVING BETTER PACKAGE INCLUDES THE ADOPTION OF CDC IN ALL NEW HOME CARE PACKAGES AND THE PROMISE OF TRIALS OF CDC IN RESIDENTIAL CARE. IT ALSO INCLUDES THE DRAMATIC EXPANSION OF PACKAGES FROM 64,800 INTO 2012 TO 144,469 IN 2021-22.

CDC HOLDS THE PROMISE THAT SUPPORT AND CARE TAILORED TO THE INDIVIDUAL WILL BETTER MEET THE NEEDS OF DIVERSE COMMUNITIES.

EMPOWERMENT AND CHOICE WILL NOT HAPPEN WITHOUT BUILDING CAPACITY IN BOTH THE CONSUMER AND THE PROVIDER.

APPROACHES ARE NEEDED TO CARE WHICH FOCUS ON MAXIMIZING THE PERSON'S REMAINING ABILITY- SUCH AS THE MONTESSORI APPROACH- RATHER THAN FOCUSING ON THE DISABILITY WILL BE AN IMPORTANT COMPONENT TO CDC.

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.

AND PROVIDERS WILL NEED TO BE IMAGINATIVE ABOUT HOW THEY CAN TAP IN TO THE SERVICES CONSUMERS WANT AND NEED.

RECENTLY, I HEARD OF AN EXAMPLE IN ADELAIDE WHERE A PERSON FROM A BHUTANESE BACKGROUND WANTED CARE FROM A PERSON FROM THEIR CULTURAL BACKGROUND.

THE SWERVICE PROVIDER WENT TO THE BHUTANESE COMMUNITY AND SOUGHT THEIR ASSISTANCE TO SUPPORT THIS FAMILY. THE COMMUNITY IDENTIFIED TWO MEMBERS WHO HAD THE APPROPRIATE AGED CARE TRAINING AND WHO WERE THEN EMPLOYED BY THE AGENCY TO PROVIDE CARE TO THIS CLIENT.

THIS TYPE OF LATERAL THINKING IS NEEDED IF CDC IS TO BE SUCCESSFUL.

THE CDC HOME CARE PACKAGE PROGRAM GUIDELINES ACKNOWLEDGE THE LONG LIST OF SPECIAL GROUPS IN THE AGED CARE ACT AND STATES IN SECTION 2.4 THAT "ALL HOME CARE PROVIDERS ARE EXPECTED TO

HAVE POLICIES AND PRACTICES IN PLACE TO ENSURE SERVICES ARE ACCESSIBLE TO PEOPLE WITH SPECIAL NEEDS”.

BUT NOTHING IS SAID ABOUT HOW THIS IS TO COME ABOUT.

THERE IS NO ADDITIONAL MONEY ALLOCATED IN CARE PACKAGES FOR LANGUAGE ASSISTANCE.

I SUGGEST THAT JUST AS IS THE CASE FOR THE HOMELESS, OR PEOPLE WITH DEMENTIA, THERE SHOULD BE A SUPPLEMENT AVAILABLE FOR PEOPLE FROM A CALD BACKGROUND TO ASSIST WITH THE COST OF TRANSLATION SERVICES OR CULTURAL ASSISTANCE.

LASTLY, RESPITE CARE

RESPITE IS AN IMPORTANT SUPPORT FOR THE CARERS AS WELL AS FOR THE PERSON WITH DEMENTIA IN PROVIDING SOCIAL ENGAGEMENT, AND HELPING TO KEEP THE PERSON WITH DEMENTIA AT HOME FOR LONGER.

BUT FOR PEOPLE FROM CALD BACKGROUNDS IT IS OFTEN DIFFICULT TO GET ACCESS TO APPROPRIATE SERVICES.

OF COURSE THERE ARE SOME WONDERFUL EXCEPTIONS. HOSTHOME IN VICTORIA PROVIDES A RESPITE SERVICE WHICH RUNS OUT OF THE HOME OF A GREEK SPEAKING WORKER. HOME COOKED TRADITIONAL GREEK MEALS ARE PROVIDED ALONG WITH SOCIAL ACTIVITIES. THE PROGRAM IS DESIGNED FOR PEOPLE IN THE EARLY STAGES OF DEMENTIA OR WHO HAVE COGNITIVE IMPAIRMENT.

THESE TYPES OF SMALL, ETHNO SPECIFIC SPECIALISED SERVICES CAN PROVIDE ESSENTIAL SUPPORT FOR PEOPLE WITH DEMENTIA AND THEIR FAMILIES.

THE EVIDENCE SUGGESTS THAT REGARDLESS OF BACKGROUND PEOPLE LIVING WITH DEMENTIA HAVE DIFFICULTY ACCESSING RESPITE SERVICES THAT MEET THEIR NEEDS. IN THE MOST RECENT SURVEY OF DISABILITY AND CARERS, ONLY 27% OF PEOPLE WITH DEMENTIA THAT WERE APPROVED FOR RESPITE RESIDENTIAL CARE USED IT IN THE YEAR OF THE APPROVAL.

THE REASONS FOR THE UNDER USE OF RESPITE ARE COMPLEX. IMPORTANT CONTRIBUTING FACTORS IS RESPITE CARE IS NOT BEING FLEXIBLE, NOT CULTURALLY OR LINGUISTICALLY APPROPRIATE, NOT AVAILABLE AT THE RIGHT TIME OR THE CARE NEEDS OF THE PERSON WITH DEMENTIA ARE TOO COMPLEX.

TO INCREASE ACCESS TO FLEXIBLE RESPITE ALZHEIMER'S AUSTRALIA HAS PROPOSED THE GOVERNMENT SHOULD PILOT CASHING OUT THE VALUE OF RESPITE TO THE FAMILY CARER SO THE CARER CAN DECIDE HOW THE MONEY IS SPENT.

THIS MODEL COULD BE USEFUL IN DIVERSE COMMUNITIES AS WELL AS IN RURAL AND REMOTE AREAS TO INCREASE THE FLEXIBILITY OF THE FUNDING AVAILABLE.

WE RECOGNISE THAT THE CASHING OUT OF SERVICES IS COMPLEX AND THERE ARE MANY DIFFICULT QUESTIONS TO ANSWER INCLUDING WHETHER BETTER QUALITY CARE WOULD RESULT, WHETHER IT WOULD BE SUBJECT TO ABUSE AS WELL AS THE QUANDARY OF WORKFORCE ISSUES.

A TRIAL WOULD HELP IDENTIFY THE BENEFITS AND COSTS OF THIS MODEL. THE ADVANTAGE OF DOING THIS NOW IS IT COULD HELP PREPARE THE WAY FOR THE FUTURE.

CONCLUSIONS

I SEE NOTHING WRONG WITH THE VISION WE HAVE FOR THE REFORM OF AGED CARE IN TERMS OF INCREASING ACCESS TO COMMUNITY CARE, GREATER FLEXIBILITY OF SERVICES AND CONSUMER EMPOWERMENT.

IT IS MY HOPE THAT IN 2023 WE WILL HAVE A MUCH MORE FLEXIBLE SYSTEM WHICH IS RESPONSIVE TO CONSUMER PREFERENCES. A SYSTEM WHICH IS MORE INTEGRATED WITH THE NDIS AND FUNDS AND SUPPORTS THE INDIVIDUAL RATHER THAN THE SERVICE.

MY HOPE IS THAT WITHIN THAT POLICY FRAMEWORK WE WILL SEE GREATER INNOVATION AND MORE TAILORED SERVICES WHICH CAN SUPPORT PEOPLE FROM INCREASINGLY DIVERSE BACKGROUNDS IN BOTH ETHNO SECIFIC AND MAINSTREAM SERVICES.

THE CONCERN IS WHETHER THOSE DOING THE IMPLEMENTATION WILL COMMIT TO STRATEGIES THAT ARE RESOURCED TO REACH OUT TO THE DIVERSITY OF DIFFERENT CIRCUMSTANCES INCLUDING THOSE WHO ARE FROM CALD BACKGROUNDS

MY VISION IS FOR AN AGED CARE SYSTEM THAT FOCUSES NOT JUST ON CARE BUT ON PSYCHOSOCIAL AND CULTURAL NEEDS AS WELL. WE WANT

RESIDENTIAL CARE FACILITIES AND COMMUNITY CARE SERVICES BE THEY MAINSTREAM OR ETHNO SPECIFIC TO PROVIDE NOT JUST THE BASIC REQUIREMENTS OF BATHING, FOOD AND MEDICATION, BUT ALSO OPPORUNITIES FOR SOCIAL AND COMMUNITY ENGAGEMENT AND ACCESS TO APPROPRIATE CULTURAL OPPORTUNITIES.

AGED CARE FACILITIES SHOULD BE INTERESTING AND ENGAGING PLACES TO LIVE. SO OFTEN NOW WE HEAR OF STORIES OF PEOPLE BECOMING DISENGAGED AND WITHERING AWAY AFTER THEY ENTER CARE. I HOPE FOR A SYSTEM WHERE ENTERING CARE BRINGS NEW OPPORTUNITIES FOR SOCIAL ENGAGEMENT, AND FOR A FOCUS ON MAXIMISING STRENGTHS AND ABILITIES.

OF COURSE THIS ALREADY HAPPENS IN SOME PLACES- BUT I WANT IT TO BE THE STANDARD- NOT THE EXCEPTION.