FUTURE DIRECTIONS IN DEMENTIA POLICY

SATURDAY 4 OCTOBER 2014

TAIWAN

GLENN REES AM

CHAIR ELECT ALZHEIMER'S DISEASE INTERNATIONAL

FUTURE DIRECTIONS IN DEMENTIA POLICY

I FEEL VERY PRIVILEGED AND HONOURED TO HAVE THIS OPPORTUNITY AS CHAIR-ELECT OF ALZHEIMER'S DISEASE INTERNATIONAL TO TALK TO YOU ABOUT FUTURE DIRECTIONS IN DEMENTIA POLICY.

I PARTICULARLY WELCOME THE OPPORTUNITY OF TALKING AT A TIME WHEN TAIWAN IS IMPLEMENTING ITS OWN NATIONAL STRATEGY OF DEMENTIA PREVENTION, TREATMENT AND CARE. YOU ARE TO BE CONGRATULATED ON SUCH A COMPREHENSIVE APPROACH TO THE VARIOUS ELEMENTS OF SOCIAL SUPPORT AND CARE FOR PEOPLE WITH DEMENTIA AND THE SCENE IS BEING SET FOR DISCUSSION OF LONG TERM CARE INSURANCE.

I HAVE LONG ADMIRED THE WORK THAT TADA HAVE DONE AND THEIR COMMITMENT TO ENSURING THAT WHAT THEY DO MEETS THE NEEDS OF PEOPLE WITH DEMENTIA AND THEIR FAMILY CARERS, INCLUDING THROUGH THE FAMILY OF WISDOM.

IN 1985 I UNDERTOOK A REVIEW OF AGED CARE PROGRAMS FOR THE AUSTRALIAN GOVERNMENT. IT WAS A SUCCESSFUL REVIEW IN THAT ITS RECOMMENDATIONS WERE IMPLEMENTED AND MANY OF THE REFORMS REMAIN IN PLACE TODAY IN AUSTRALIA.

HOWEVER WHILE I LOOK BACK ON THAT TIME WITH A GREAT DEAL OF PLEASURE I AM CONSCIOUS OF HOW LIMITED MY PERSPECTIVE AS A

POLICY MAKER WAS IN THINKING ABOUT ISSUES IN DEMENTIA CARE FROM THE PERSPECTIVE OF OLDER PEOPLE AND THEIR FAMILY CARERS.

IN THOSE DAYS IT WOULD BE TRUE TO SAY THAT WE HAD NO REAL UNDERSTANDING OF DEMENTIA WITHIN GOVERNMENT. IT WOULD NOT HAVE OCCURRED TO US TO CONSULT WITH PEOPLE WITH DEMENTIA. DISCUSSIONS WERE LIMITED TO FAMILY CARERS.

AND THE MIND SET WAS TO THINK IN TERMS OF ONE SIZE FITS ALL AND DEVELOPING A MODEL OF CARE THAT WOULD ADDRESS THE NEEDS OF ALL THOSE WITH DEMENTIA.

I THINK IT IS TRUE TO SAY THAT THESE DAYS WE KNOW WHAT WE NEED TO DO BUT THE BARRIERS ARE AROUND CHANGING CULTURES IN SERVICE PROVISION, CHANGING HEALTH AND CARE SYSTEMS AND ATTRACTING FUNDING.

I SUGGEST THERE ARE TWO BUILDING BLOCKS ON WHICH DEMENTIA POLICY SHOULD BE FOUNDED NO MATTER WHETHER WE ARE TALKING ABOUT ACUTE CARE, PRIMARY CARE OR COMMUNITY AND RESIDENTIAL CARE.

FIRST, THAT DEMENTIA IS AS MUCH A SOCIAL CONDITION AS A MEDICAL ONE AND THAT IT IS THE PHILOSOPHY OF CARE, DIGNITY AND RESPECT THAT WE ACCORD TO PEOPLE WITH DEMENTIA THAT IS SO CRITICAL.

SECOND,THAT EVERY PERSON WITH DEMENTIA IS UNIQUE. THIS IS WHAT MAKES DEMENTIA CARE SO DIFFICULT. WE TALK ABOUT MODELS OF CARE IN MY VIEW AT OUR PERIL AS IT SUGGESTS ONE SIZE FITS ALL WHEREAS WHAT WE NEED IS A DIVERSITY OF APPROACHES.

THE KEY WORDS IN THE LEXICON OF DEMENTIA POLICY I THINK ARE CONSUMER CHOICE, CONSUMER EMPOWERMENT AND QUALITY. THERE IS AN INCREASING BELIEF IN DEVELOPING COUNTRIES THAT ONLY THROUGH INTRODUCING AN ELEMENT OF COMPETITION INTO DEMENTIA CARE WILL THE QUALITY OF SERVICES IMPROVE.

I SUGGEST THAT ON THE BASIS OF THESE TWO BUILDING BLOCKS DEMENTIA POLICY CAN BE APPROACHED IN FIVE DIFFERENT BUT RELATED WAYS:

- FIRSTLY, TO TAKE THE SOCIAL ACTION NEEDED TO REDUCE STIGMA AND SOCIAL ISOLATION OF DEMENTIA;
- SECONDLY, TO ENSURE THAT PERSON CENTRED CARE AND CONSUMER DIRECTED CARE ARE FIRMLY IN PLACE;
- THIRDLY, TO IMPLEMENT MEASURES TO IMPROVE QUALITY OF CARE AND MAKE MORE TRANSPARENT THE CARE OUTCOMES BEING ACHIEVED.
- FOURTHLY, TO IMPLEMENT A HEALTH AGENDA INCLUDING TIMELY DIAGNOSIS, IMPROVED QUALITY OF HOSPITAL CARE AND DEMENTIA RISK REDUCTION; AND

- LASTLY, TO IMPLEMENT A RESEARCH AGENDA INTO CAUSE, CURE AND CARE, AND FACILITATING THE IMPLEMENTATION OF RESEARCH INTO PRACTICE.

SOCIAL ACTION

WE KNOW FROM LISTENING TO PEOPLE LIVING WITH DEMENTIA THAT SOCIAL ISOLATION AND STIGMA ARE TWO OF THE BIGGEST CHALLENGES THEY FACE. FRIENDS AND FAMILY OFTEN STOP CALLING IN BECAUSE THEY DON'T KNOW HOW TO ENGAGE WITH SOMEONE WHO HAS DEMENTIA AND THE PERSON OFTEN GIVES UP WORK AND OTHER ENJOYABLE ACTIVITIES.

ONE-THIRD OF COUNTRIES SURVEYED BY THE WORLD HEALTH ORGANISATION EXPLAINED THAT PEOPLE WITH DEMENTIA WERE ISOLATED OR HIDDEN BECAUSE OF SHAME. A STUDY IN AUSTRALIA FOUND THAT 60% OF THOSE SURVEYED INDICATED THAT IF THEY RECEIVED A DIAGNOSIS OF DEMENTIA THEY WOULD FEEL A SENSE OF SHAME AND HALF WOULD FEEL HUMILIATED BY THE DIAGNOSIS. TO ME THESE NUMBERS ARE STRIKING. I CANNOT THINK OF ANOTHER DISEASE THAT IN THIS DAY AND AGE WOULD BRING SUCH A SENSE OF SHAME.

INTERESTINGLY, THE SAME SURVEY SHOWED THAT PEOPLE OFTEN TURN AWAY FROM A PERSON WHO HAS DEMENTIA. APPROXIMATELY 1 IN 5 SAID THEY WOULD FEEL UNCOMFORTABLE SPENDING TIME WITH A PERSON WHO HAD DEMENTIA AND A THIRD OF PEOPLE SAID THEY FOUND PEOPLE WITH DEMENTIA IRRITATING.

ALZHEIMER'S AUSTRALIA RECENTLY RELEASED THE FINDINGS OF OUR FIRST SURVEY OF THE EXPERIENCES OF PEOPLE LIVING WITH DEMENTIA. AGAIN, THE RESULTS SHOWED JUST HOW OVERWHELMING THE SOCIAL IMPACT OF LIVING WITH DEMENTIA REALLY IS. 59% OF PEOPLE WITH DEMENTIA THOUGHT THAT PEOPLE AVOIDED SPENDING TIME WITH THEM BECAUSE OF THEIR DIAGNOSIS AND MORE THAN 40% OF PARTICIPANTS WISHED THEY HAD MORE SOCIAL CONTACT.

ONE RESPONDENT SAID "SOMETIMES MY SOCIAL DEATH MAKES ME MORE SAD THAN THE CHANGES TO MY BRAIN AND THE LOSS OF MY MEMORIES. IT MAKES ME SO ANGRY. I JUST WANT TO BE COUNTED AS A PERSON AGAIN".

THERE ARE SOME INITIATIVES OCCURRING GLOBALLY AIMING TO REDUCE THE STIGMA ASSOCIATED WITH DEMENTIA. ONE THIRD OF COUNTRIES SURVEYED BY THE WORLD HEALTH ORGANISATION ARE USING AWARENESS RAISING CAMPAIGNS TO REDUCE THIS STIGMA. FOR EXAMPLE, IN JAPAN THE ORIGINAL JAPANESE WORD FOR DEMENTIA MEANT FOOLISH. THE JAPANESE GOVERNMENT HAS NOW CHANGED THE WORD TO MEAN 'COGNITIVE DISEASE', HELPING TO REDUCE THE STIGMA ASSOCIATED WITH DEMETNIA IN JAPAN.

SWEDEN DEVELOPED A SOCIAL POLICY IN 1992 ARGUING FOR A 'NORMALISATION PROCESS' OF DEMENTIA BECAUSE EVEN IF YOU HAVE DEMENTIA, YOU SHOULD LIVE A NORMAL LIFE, SIMILAR TO EVERYONE ELSE.

THE NORMALISATION OF DEMENTIA AND THE INCLUSION OF PEOPLE WITH DEMENTIA IN SOCIETY AS MUCH AS POSSIBLE HAS NOT YET OCCURRED ANYWHERE IN THE WORLD.

THE RIGHTS OF PEOPLE WITH DEMENTIA ARE BEING VIOLATED ACROSS THE WORLD DAILY AND THERE IS STILL A LACK OF LEGISLATION TO PROTECT THEIR RIGHTS. ONLY 63% OF HIGH-INCOME COUNTRIES HAVE LEGISLATION OR REGULATORY STANDARDS THAT PROTECT THE RIGHTS OF PEOPLE AGAINST DISCRIMINATION ON THE BASIS OF DEMENTIA AND ONLY 18% OF LOW TO MIDDLE INCOME COUNTRIES.

IT IS WELCOME THAT ONE OF THE PURPOSES OF THE TAIWAN DEMENTIA POLICY STRATEGY IS TO PROTECT THE HUMAN RIGHTS OF INDIVIDUALS WITH DEMENTIA AND THEIR FAMILIES BY:

- REVIEWING CURRENT LAWS TO ENSURE RIGHTS OF PEOPLE WITH DEMENTIA AND THEIR CARERS
- ENGAGING DISCUSSION ON ETHICS, LAW, HUMAN RIGHT PROTECTION AND PROMOTION, AND
- CONSULTING INDIVIDUALS WITH DEMENTIA AND THEIR FAMILY WHILE MAKING RELATED POLICY

OUR FOCUS ON TACKLING SOCIAL ISSUES RELATED TO DEMENTIA IN AUSTRALIA HAS BEEN TO PROMOTE THE DEVELOPMENT OF DEMENTIA-FRIENDLY COMMUNITIES, WHICH ARE DESIGNED TO REDUCE SOCIAL ISOLATION AND STIGMA ASSOCIATED WITH DEMENTIA AS WELL AS RAISE

AWARENESS ABOUT DEMENTIA WITHIN LOCAL COMMUNITIES. ESSENTIALLY THE GOAL IS TO CREATE PLACES WHERE PEOPLE WITH DEMENTIA ARE SUPPORTED TO LIVE A HIGH QUALITY OF LIFE WITH MEANING, PURPOSE AND VALUE.

IN PRACTICE IT CAN BE QUITE SIMPLE:

- RETAIL STAFF RECEIVING TRAINING ON HOW TO COMMUNICATE WELL WITH A PERSON WHO HAS DEMENTIA.
- VOLUNTEER ORGANISATIONS PROVIDING ASSISTANCE FOR A PERSON WITH DEMENTIA TO VOLUNTEER AT AN AGENCY SUCH AS ART GALLERIES ANDBOTANICAL GARDENS, AND
- WALKING GROUPS, CHOIRS, SPORTING GROUPS AND OTHER COMMUNITY GROUPS THAT ARE WELCOMING TO PEOPLE WITH DEMENTIA AND MAKE THE SMALL ADJUSTMENTS NEEDED TO HELP THEM TO PARTICIPATE IN ACTIVITIES.

WE WANT TO SUPPORT COMMUNITIES TO RESPOND TO THE NEEDS OF PEOPLE WITH DEMENTIA AND THE BEST WAY TO DO THAT IS TO INVOLVE THEM FROM THE START. ALZHEIMER’S AUSTRALIA IS EMPLOYING A PERSON WITH DEMENTIA TO WORK ON THE DEVELOPMENT OF DEMENTIA-FRIENDLY COMMUNITIES. THIS IS A FIRST FOR ALZHEIMER’S AUSTRALIA BUT AN IMPORTANT STEP TO ENSURE THAT INVOLVEMENT OF PEOPLE WITH DEMENTIA IS NOT TOKENISTIC.

THE WORK WE ARE DOING IN AUSTRALIA IS PART OF AN INTERNATIONAL MOVEMENT TO CREATE DEMENTIA FRIENDLY COMMUNITIES. IMPORTANT WORK ON THIS HAS ALREADY BEGUN IN THE UK, BELGIUM AND JAPAN. FOR EXAMPLE, THE PRIME MINISTER OF THE UK, DAVID CAMERON ISSUED A CHALLENGE ON DEMENTIA, WHICH INCLUDED THE DEVELOPMENT OF DEMENTIA-FRIENDLY COMMUNITIES. THERE ARE NOW 69 COMMUNITIES ACROSS THE UK THAT RECOGNISE THEMSELVES AS DEMENTIA-FRIENDLY AND THERE ARE OVER 381,000 DEMENTIA FRIENDS THAT HAVE GONE THROUGH TRAINING TO BETTER UNDERSTAND DEMENTIA.

THESE DEMENTIA-FRIENDLY COMMUNITY INITIATIVES ACROSS THE WORLD ARE A START TO A GRASS ROOTS SOCIAL MOVEMENT. WE CAN ONLY HOPE THAT THESE ARE THE FIRST STEPS TOWARDS SOCIAL CHANGE THAT HAS THE SAME IMPACT AS THE DISABILITY RIGHTS MOVEMENT HAD BACK IN THE 80S AND 90S.

PERSON CENTRED CARE AND CONSUMER DIRECTED CARE

PART OF THE SHIFT IN CULTURE THAT IS REQUIRED TO PROVIDE GOOD DEMENTIA CARE IS THE RECOGNITION THAT PEOPLE WITH DEMENTIA SHOULD BE CONSULTED AND HAVE CHOICES ABOUT THE CARE THEY RECEIVE, JUST AS YOU OR I WOULD WANT TOO IF WE WERE RECEIVING CARE SERVICES.

THE PHILOSOPHY OF PERSON-CENTRED CARE IS BASED ON THE IDEA THAT INSTEAD OF PROVIDING THE SAME CARE TO EVERY PERSON, CARE

SHOULD BE TAILORED TO THE NEEDS AND PREFERENCES OF THE INDIVIDUAL. CONSUMER DIRECTED CARE TAKES THIS CONCEPT ONE STEP FURTHER AND RECOGNISES THAT THE CONSUMER, TO THE EXTENT THEY ARE CAPABLE, SHOULD MAKE CHOICES ABOUT THE TYPES OF CARE SERVICES THEY ACCESS AND THE DELIVERY OF THOSE SERVICES, INCLUDING WHO WILL DELIVER THE SERVICES AND WHEN.

A FOCUS ON CONSUMER CHOICE IS GAINING MOMENTUM ACROSS THE WORLD. NEARLY TWO-THIRDS OF THE OECD COUNTRIES REPORT THAT THEIR CARE SERVICES SUPPORT CONSUMERS TO MAKE DECISIONS ON THE SORT OF CARE THEY WANT. DESPITE THE AIMS OF MANY ORGANISATIONS TO PROVIDE CONSUMER DIRECTED CARE, RESEARCH IN THE UK HAS FOUND THAT ORGANISATIONAL CULTURES CONTAIN A VARIETY OF BARRIERS TO PROVIDING THIS TYPE OF CARE FOR PEOPLE WITH DEMENTIA. I THINK MANY COUNTRIES STILL STRUGGLE TO APPLY THIS PHILOSOPHY TO PEOPLE WITH DEMENTIA.

CONSUMER DIRECTED CARE IS A SPECTRUM OF CHOICE RANGING FROM SOME INVOLVEMENT TO CASHING OUT OF SERVICES. PUTTING MONEY DIRECTLY IN THE HANDS OF PEOPLE WITH DEMENTIA AND THEIR FAMILIES IS A PROMISING INNOVATION IN TERMS OF CONSUMER DIRECTED CARE AND IMPROVING SERVICE INTEGRATION, FLEXIBILITY AND CHOICE.

SOME COUNTRIES PROVIDE DIRECT PAYMENTS TO CONSUMERS TO OBTAIN SERVICES. FOR EXAMPLE, CANADA HAS SELF-MANAGED SCHEMES,

PROVIDING ELIGIBLE USERS WITH CASH BENEFITS TO MANAGE CARE DELIVERY, INCLUDING PAYING FAMILY CARERS AND FRIENDS. IN THE UK DIRECT PAYMENTS ARE MOSTLY USED BY PEOPLE WITH DEMENTIA FOR PERSONAL CARE IN THE HOME, RESPITE SERVICES AND SERVICES NOT USUALLY INCLUDED IN CARE PACKAGES, SUCH AS GARDENING SUPPORTS. A UK SURVEY OF PEOPLE WITH DEMENTIA AND THEIR CARERS FOUND THAT PEOPLE USING DIRECT PAYMENTS WERE MORE SATISFIED WITH THEIR CARE AND SERVICES.

FOR A LONG TIME I HAVE BEEN ADVOCATING FOR A PILOT IN AUSTRALIA OF DIRECT PAYMENTS TO PEOPLE WITH DEMENTIA AND THEIR CARERS TO PURCHASE RESPITE. THIS WOULD ENABLE MORE RESPITE OPTIONS INCLUDING PAID RESPITE THAT IS PROVIDED BY FAMILY AND FRIENDS. THERE ARE MANY BENEFITS WITH FAMILY AND FRIENDS PROVIDING RESPITE AS THEY ARE KNOWN TO THE PERSON, FAMILIAR WITH THE PERSON'S NEEDS AND A TRUSTING RELATIONSHIP ALREADY FORMED.

THIS APPROACH IS PARTICULARLY IMPORTANT FOR RESPITE AS RESPITE SERVICES ARE OFTEN NOT RESOURCED TO CARE FOR PEOPLE WITH DEMENTIA, PARTICULARLY IF THEY HAVE BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA. RESPITE SERVICES ARE ALSO RARELY AVAILABLE WHERE AND WHEN THEY ARE NEEDED.

IT IS INTERESTING TO NOTE THE DIFFERENCE BETWEEN THE CHOICES THAT ARE OFFERED IN THE DISABILITY SECTOR AND THOSE IN AGED CARE

IN AUSTRALIA. DISABILITY SERVICES HAVE NOT ONLY BEEN MORE ADVANCED IN SOCIAL ACTION AGAINST DISCRIMINATION BUT HAVE ALSO BEEN MUCH MORE RADICAL IN PROMOTING CONSUMER CHOICE AND CASHING OUT OF SERVICES. I CAN'T HELP BUT WONDER IF SOME OF THE DIFFERENCES BETWEEN THE AGED CARE SECTOR AND DISABILITIES RELATES TO THE STIGMA THAT IS ASSOCIATED WITH AGEING AND DEMENTIA.

REGARDLESS OF WHERE WE ARE ON THE SPECTRUM OF CHOICE (FROM INVOLVEMENT TO CASHING OUT), FOR CONSUMER DIRECTED CARE TO WORK, PEOPLE WITH DEMENTIA AND THEIR CARERS NEED TO BE EMPOWERED THROUGH INFORMATION, SUPPORT AND FUNDING, AND EVENTUALLY A SHIFT IN CULTURE SO THEY FEEL MORE VALUED.

THEY NEED TO HAVE ACCESS TO INFORMATION ABOUT THEIR RIGHTS AND CARE CHOICES TO BE ABLE TO MAKE INFORMED DECISIONS ABOUT THE TYPE OF CARE THEY WANT TO RECEIVE AS WELL AS HOW, WHEN AND WHO DELIVERS THE CARE.

BOTH THE UK AND THE UNITED STATES PROVIDE INFORMATION ABOUT HEALTH SERVICE PROVIDERS' PERFORMANCE ONLINE TO HELP CONSUMERS CHOOSE WHICH PROVIDER THEY WISH TO RECEIVE CARE FROM. THE UK NATIONAL HEALTH SERVICE WEBSITE INCLUDES INFORMATION ABOUT SERVICE OPTIONS AVAILABLE, PERFORMANCE

INDICATORS AND PAST PATIENTS' RATINGS, COMMENTS AND EXPERIENCES.

IN AUSTRALIA WE HAVE A NETWORK OF KEY WORKERS, FUNDED BY THE GOVERNMENT, FOR PEOPLE WITH YOUNGER ONSET DEMENTIA. THESE WORKERS PROVIDE ONGOING INDIVIDUALISED INFORMATION AND SUPPORT TO PEOPLE WITH YOUNGER ONSET DEMENTIA AND THEIR CARERS. THEY EMPOWER CONSUMERS TO MAKE DECISIONS REGARDING THEIR OWN LIFE AND CARE THROUGH DEVELOPING INDIVIDUALISED PLANS BASED ON GOALS AND PROVIDING INFORMATION ABOUT LOCAL CARE SERVICES.

WE ARE WORKING TOWARDS EXPANDING THE KEY WORKER PROGRAM TO ALL PEOPLE WITH DEMENTIA AS WE SEE THIS TYPE OF APPROACH AS BEING KEY TO SUPPORTING CONSUMERS TO HAVE GREATER CHOICE REGARDLESS OF THEIR AGE.

THE ISSUE OF CHOICE ALSO GOES TO LARGER QUESTIONS ABOUT THE SPLITS BETWEEN COMMUNITY AND RESIDENTIAL AGED CARE AND HOW FUNDING FOR SERVICES SHOULD BE ALLOCATED. IN AUSTRALIA THERE IS A RATIONING SYSTEM WHERE THE NUMBER OF PLACES INCREASE BASED ON THE NUMBER OF PEOPLE OVER THE AGE OF 70. THE SPLIT BETWEEN COMMUNITY CARE PLACES AND RESIDENTIAL IS BASED ON AN ARBITRARY FORMULA RATHER THAN CONSUMER DEMAND. THERE IS A CALL IN AUSTRALIA TO SHIFT TO A SYSTEM THAT IS MORE RESPONSIVE TO

CONSUMER DEMAND WHICH WOULD REDUCE THE RIGID SPLITS BETWEEN COMMUNITY AND RESIDENTIAL CARE.

THERE ARE A RANGE OF CHALLENGES INCLUDING ISSUES AROUND CAPPING SPENDING AND ENABLING APPROPRIATE PLANNING BUT IT IS CLEAR THAT WE ARE HEADED IN THE DIRECTION OF A MORE MARKET BASED SYSTEM. IN MY MIND THIS IS IMPORTANT AS IT WILL DRIVE QUALITY IMPROVEMENTS, CREATE MORE FLEXIBILITY AND DRIVE INNOVATION.

FOR EXAMPLE, A MORE RESPONSIVE SYSTEM COULD INCLUDE THE OPTION OF FLEXIBLE RESPITE IN RESIDENTIAL CARE SO THAT CONSUMERS HAVE THE OPTION OF PLANNED RESPITE IN REGULAR BLOCKS OF SEVERAL WEEKS OR MORE IN CLUSTERS SEPARATE FROM LONG TERM CARE. AT THE MOMENT IT IS A DICHOTOMY AND THERE IS NO OPPORTUNITY TO USE RESIDENTIAL CARE SERVICES FLEXIBLY AND OCCASIONALLY TO SUPPORT ONGOING CARE IN THE COMMUNITY.

JAPAN IS MOVING TOWARDS AN INTEGRATED COMMUNITY CARE SYSTEM WHERE COMMUNITY SUPPORT, HEALTH CARE AND RESIDENTIAL CARE IS COMBINED TO ENABLE OLDER PEOPLE WITH DEMENTIA TO CONTINUE TO LIVE IN THEIR COMMUNITY, WHILE HAVING THE OPTION TO FLEXIBLY MOVE IN AND OUT OF RESIDENTIAL AGED CARE. JAPAN, AS WELL AS SWEDEN, HAVE ALSO INTRODUCED SMALL GROUP HOMES AS AN INTERMEDIATE LEVEL OF CARE BETWEEN COMMUNITY AND RESIDENTIAL CARE.

QUALITY

GOOD DEMENTIA CARE HAS TO HAVE A FOCUS ON QUALITY OF CARE. QUALITY IS A BROAD TERM THAT COVERS A RANGE OF ISSUES FROM ENSURING AN ADEQUATE ENVIRONMENT AND LIVING SPACES TO ACCESS TO APPROPRIATE CARE.

A PERSON'S QUALITY OF LIFE VERY MUCH DEPENDS ON THE QUALITY OF CARE THEY RECEIVE. THIS WAS DEMONSTRATED IN STUDIES IN THE UNITED STATES AND UNITED KINGDOM THAT FOUND THAT AGED CARE RESIDENTS' QUALITY OF LIFE VARIES SUBSTANTIALLY BETWEEN FACILITIES RATHER THAN WITHIN FACILITIES. THEREFORE SUGGESTING THAT THE QUALITY OF CARE PROVIDED BY A FACILITY HAS A LARGE IMPACT ON THE QUALITY OF LIFE OF RESIDENTS.

IN AUSTRALIA THE FOCUS ON QUALITY OVER THE LAST FEW DECADES HAS BEEN ON WEEDING OUT THE BAD APPLES AND ENSURING COMPLIANCE WITH A BASIC SET OF STANDARDS.

MORE THAN TWO-THIRDS OF OECD AND EUROPEAN COUNTRIES HAVE COMPULSORY LONG TERM CARE ACCREDITATION OR ACCREDITATION AS A REQUIREMENT FOR REIMBURSEMENT OR CONTRACTING. ACCREDITATION IS IMPORTANT AS IT ENSURES SERVICE PROVIDERS MEET CERTAIN CRITERIA AND STANDARDS TO PROVIDE CARE.

MORE AND MORE COUNTRIES ARE USING CONSUMER INVOLVEMENT IN THE EVALUATION AND ACCREDITATION OF HEALTH AND AGED CARE SERVICES TO BOTH INFORM THE PROCESS AND IMPROVE CONSUMER ENGAGEMENT.

FOR EXAMPLE IN ENGLAND CONSUMERS WORK WITH THE CARE QUALITY COMMISSION AND ARE INVOLVED IN ACCOMPANYING INSPECTORS ON VISITS TO SERVICES AND PARTICIPATING IN THE AUDITING PROCESS. DUE TO THEIR FIRST-HAND EXPERIENCE WITH SERVICES, CONSUMERS ARE BETTER PLACED TO IDENTIFY WHAT THE KEY ISSUES ARE AND CAPTURE INVALUABLE INFORMATION THAT MAY OTHERWISE GO UNDETECTED DURING STANDARD AUDITING PROCESSES.

SIMILARLY, THE UNITED STATES HAVE DEVELOPED A LONG-TERM CARE OMBUDSMAN PROGRAM, WHERE ADVOCATES FOR RESIDENTS IN NURSING HOMES VISIT FACILITIES AND MONITOR CONDITIONS. THERE ARE OVER 12, 000 OMBUDSMEN VOLUNTEERS OFWHICH OVER 9, 000 ARE CERTIFIED TO INVESTIGATE COMPLAINTS.

SOME COUNTRIES, INCLUDING ENGLAND AND THE NETHERLANDS ASSESS USER EXPERIENCE THROUGH SURVEYS. CONSUMERS ARE SURVEYED ABOUT CONSUMER CHOICE, AUTONOMY, DIGNITY, COMFORT, SECURITY, RELATIONSHIPS AND SOCIAL ACTIVITY.

IN AUSTRALIA WE ARE TAKING SMALL STEPS TOWARDS GREATER CONSUMER INVOLVEMENT WITH A PILOT OF CONSUMER “EXPERTS” BEING PART OF THE ACCREDITATION TEAM AND ONGOING SURVEYS OF CONSUMERS AS PART OF THE ACCREDITATION PROCESS.

BUT CONSUMER INVOLVEMENT IN THE ACCREDITATION PROCESS IS NOT ENOUGH.

THE TIME HAS COME FOR A FUNDAMENTAL SHIFT FROM A COMPLIANCE, MINIMUM STANDARDS APPROACH TO ONE WHICH FOCUSES ON IMPROVING QUALITY AND PROVIDING INFORMATION TO CONSUMERS ABOUT QUALITY OF CARE.

LESS THAN A THIRD OF OECD COUNTRIES COLLECT QUALITY CARE INDICATORS SYSTEMATICALLY AND EVEN FEWER COUNTRIES MAKE THIS INFORMATION AVAILABLE OR GRADE THE PERFORMANCE OF SERVICE PROVIDERS BASED ON WEIGHTED QUALITY INDICATORS.

IN THE UNITED STATES NINE QUALITY MEASURES ARE COLLECTED BY NURSING HOMES WHICH LOOK AT ALL RESIDENT’S CLINICAL AND PHYSICAL NEEDS AND INCLUDES MEASURES SUCH AS PRESSURE SORES, FALLS, URINARY TRACT INFECTIONS AND RESTRAINT USE. THE QUALITY MEASURES RECORDED IN THE UNITED STATES ENABLE COMPARISONS BETWEEN NURSING HOMES USING A WEB BASED TOOL CALLED *NURSING*

HOME COMPARE. THIS HAS LED TO MORE INFORMED DECISION MAKING ABOUT CARE OPTIONS FOR CONSUMERS.

QUALITY INDICTORS WILL BE INTRODUCED TO AUSTRALIAN RESIDENTIAL CARE FACILITIES AS OF JULY 2015. INITIALLY THERE WILL BE THREE INDICATORS INCLUDING:

- PREVALENCE OF PRESSURE INJURIES
- INCIDENCE OF USE OF PHYSICAL RESTRAINT
- PREVALENCE OF UNPLANNED WEIGHT LOSS

THESE REFORMS ARE LIKELY TO EVOLVE SLOWLY. THERE ARE COMPLEX ISSUES TO CONSIDER INCLUDING AVOIDING CREATING PERVERSE INCENTIVES (FOR EXAMPLE REDUCING FALLS THROUGH KEEPING PEOPLE IN BED).

REGARDLESS OF THE CHALLENGES I AM PLEASED THAT WORLDWIDE WE ARE SLOWLY MOVING TO A WORLD WHERE CONSUMERS WILL HAVE MORE INFORMATION TO MAKE GOOD CHOICES ABOUT CARE AND SERVICES.

THE HEALTH AGENDA

OFTEN WHEN WE TALK ABOUT SERVICES AND SUPPORTS FOR PEOPLE WITH DEMENTIA WE TEND TO FOCUS ON FORMAL AGED CARE SERVICES. BUT THE REALITY IN MOST COUNTRIES, IS THAT THE MAJORITY OF PEOPLE LIVING WITH DEMENTIA ARE IN THE COMMUNITY AND ARE ACCESSING MAINSTREAM HEALTH SERVICES AND OFTEN THESE SERVICES ARE NOT

DESIGNED TO MEET THEIR NEEDS. BETTER INTEGRATION OF HEALTH AND SOCIAL CARE SYSTEMS IS BECOMING A CURRENT POLICY PRIORITY FOR MANY OECD COUNTRIES.

MANY COUNTRIES ARE STARTING TO RECOGNISE THE IMPACT OF DEMENTIA ON HEALTH CARE SERVICES. THE AUSTRALIAN GOVERNMENT RECOGNISED DEMENTIA AS A NATIONAL HEALTH PRIORITY IN 2012 AND ALLOCATED FUNDING IN THE 2012 AGED CARE REFORMS TO ADDRESS DEMENTIA CARE IN BOTH THE HEALTH AND AGED CARE SYSTEMS. ENGLAND, FRANCE, NORWAY, SOUTH KOREA AND SWEDEN HAVE ALSO ADOPTED DEMENTIA AS A PUBLIC HEALTH PRIORITY.

BUT OF COURSE POLITICAL RECOGNITION IS NOT ENOUGH. WE NEED TO ACHIEVE IMPROVEMENTS IN TIMELY DIAGNOSIS, DEMENTIA CARE IN HOSPITALS, AS WELL AS INVESTMENT IN DEMENTIA RISK REDUCTION PROGRAMS FOR THE GENERAL PUBLIC.

ADI RECENTLY ESTIMATED THAT CURRENTLY LESS THAN HALF OF THE WORLD'S 44 MILLION PEOPLE WITH DEMENTIA HAVE RECEIVED A DIAGNOSIS, AND FEWER THAN 10% OF PEOPLE WITH DEMENTIA IN LOW TO MIDDLE INCOME COUNTRIES HAVE RECEIVED A DIAGNOSIS. THIS MEANS MORE THAN 22 MILLION PEOPLE LIVING WITH DEMENTIA DO NOT HAVE ACCESS TO INFORMATION, CARE AND TREATMENT.

IN AUSTRALIA IT IS ESTIMATED THAT ONLY A THIRD OF PEOPLE WHO HAVE DEMENTIA RECEIVE A DIAGNOSIS AT ANY TIME IN THEIR ILLNESS. FOR THOSE WHO ARE DIAGNOSED, MANY DO NOT RECEIVE A DIAGNOSIS UNTIL THREE YEARS AFTER THEY FIRST NOTICE SYMPTOMS.

TIMELY DIAGNOSIS IS A FOCUS FOR DEVELOPING NATIONAL DEMENTIA STRATEGIES IN EUROPE, SOUTH KOREA, JAPAN AND TAIWAN. IT IS GREAT THAT ONE OF THE MAIN OBJECTIVES OF THE TAIWAN'S DEMENTIA STRATEGY IS TO REDUCE THE IMPACT OF DEMENTIA THROUGH IMPROVING TIMELY DIAGNOSIS AND EARLY INTERVENTION, WHICH ARE ASPECTS OF DEMENTIA CARE THAT ARE OFTEN OVERLOOKED.

CONSULTATIONS IN ENGLAND HAVE HIGHLIGHTED A COMBINATION OF FACTORS THAT CONTRIBUTE TO DEMENTIA BEING UNDER DIAGNOSED, INCLUDING:

- THE STIGMA OF DEMENTIA PREVENTING OPEN DISCUSSIONS
- THE FALSE BELIEF THAT MEMORY PROBLEMS ARE A NORMAL PART OF AGEING, AND
- THE FALSE BELIEF THAT NOTHING CAN BE DONE AND THEREFORE A DIAGNOSIS WOULD NOT BE HELPFUL.

THEREFORE MORE AWARENESS RAISING AMONGST HEALTH PROFESSIONALS, PARTICULARLY GENERAL PRACTITIONERS, ABOUT DEMENTIA AND REDUCING ASSOCIATED STIGMA IS KEY TO IMPROVING TIMELY DIAGNOSIS. BUT AS THE TAIWANESE NATIONAL PLAN

ACKNOWLEDGES THE PRIORITY IS FOR TIMELY DIAGNOSIS AND INTEGRATING THAT WITH SOCIAL SERVICES. ALL TOO OFTEN IN AUSTRALIA DOCTORS FAIL TO REFER NEWLY DIAGOSED PATIENTS TO CARE AND SUPPORT SERVICES THAT CAN PROVIDE COUNSELLING AND INFORMATION.

ACROSS THE WORLD ACUTE CARE SYSTEMS ARE STRUGGLING TO CARE FOR PEOPLE WITH DEMENTIA AND THIS WILL ONLY WORSEN IN THE FUTURE IF STRATEGIES TO IMPROVE CARE ARE NOT IMPLEMENTED. FOR EXAMPLE, ALREADY A QUARTER OF HOSPITAL BEDS IN THE UK ARE OCCUPIED BY PEOPLE WITH DEMENTIA AND MANY OF THESE PEOPLE ARE NOT RECEIVING QUALITY CARE THAT MEETS THEIR NEEDS.

INTERNATIONAL STUDIES HAVE SHOWN THAT PEOPLE WITH DEMENTIA STAY IN HOSPITAL ALMOST TWICE AS LONG AS THOSE WITHOUT DEMENTIA AND INVARIABLY HAVE WORSE CLINICAL OUTCOMES. FOR EXAMPLE, THEY ARE TWICE AS LIKELY TO EXPERIENCE FALLS, PRESSURE ULCERS, FRACTURES AND DELIRIUM.

SOME OF THESE DIFFERENCES ARE TO BE EXPECTED DUE TO THE NATURE OF THE DISEASE, BUT WITH BETTER CARE, COMMUNICATION AND DESIGN, OUTCOMES FOR PEOPLE WITH DEMENTIA COULD BE SIGNIFICANTLY IMPROVED IN HOSPITALS. THE UK IS ONE OF THE FEW PLACES THAT HAS PRIORITISED IMPROVING DEMENTIA CARE IN HOSPITALS, INCLUDING DEVELOPING AND IMPROVING ALTERNATIVES TO HOSPITAL ADMISSION.

DEMENTIA RISK REDUCTION IS PERHAPS ONE OF THE FEW POSITIVE MESSAGES WE HAVE IN THIS FIELD. ALZHEIMER'S DISEASE INTERNATIONAL JUST RELEASED THE WORLD ALZHEIMER REPORT 2014 WHICH CALLS FOR DEMENTIA RISK REDUCTION INITIATIVES TO BE INTEGRATED INTO GLOBAL AND NATIONAL PUBLIC HEALTH PROGRAMMES. WE NOW KNOW THAT UP TO HALF THE CASES OF ALZHEIMER'S DISEASE WORLDWIDE ARE POTENTIALLY ATTRIBUTABLE TO MODIFIABLE RISK FACTORS SUCH AS PHYSICAL INACTIVITY, MIDLIFE HYPERTENSION, MIDLIFE OBESITY, DIABETES AND COGNITIVE INACTIVITY.

RESEARCH SUGGESTS THAT A 25% REDUCTION IN SOME OF THE RISK FACTORS FOR DEMENTIA COULD PREVENT AS MANY AS A MILLION CASES OF ALZHEIMER 'S DISEASE WORLDWIDE. YET, MANY NATIONAL STRATEGIES TO ADDRESS DEMENTIA DO NOT FOCUS ON REDUCING DEMENTIA THROUGH PREVENTATIVE HEALTH STRATEGIES AND ONLY 8 COUNTRIES HAVE RISK REDUCTION PROGRAMS.

ALZHEIMER'S AUSTRALIA HAS THE WORLD'S FIRST PUBLICLY FUNDEDNATIONAL DEMENTIA RISK REDUCTION EDUCATION PROGRAM CALLED YOUR BRAIN MATTERS. FROM EARLY REPORTS, WE ARE HAVING A SIGNIFICANT IMPACT ON THE PUBLIC AWARENESS OF THE LINK BETWEEN PHYSICAL AND BRAIN HEALTH.

I AM ENCOURAGED TO HEAR THAT TAIWAN'S DEMENTIA POLICY STRATEGY INCLUDES THE PUBLIC PROMOTION OF DEMENTIA RISK REDUCTION AND THE ENHANCEMENT OF PREVENTION SERVICES IN PRIMARY CARE.

RESEARCH

RESEARCH INTO THE CAUSE, CURE AND CARE OF DEMENTIA IS VITAL TO IMPROVE THE QUALITY OF LIFE OF PEOPLE WITH DEMENTIA, THEIR FAMILIES AND CARERS, AND TO REDUCE THE SOCIAL AND ECONOMIC IMPACT OF DEMENTIA IN THE FUTURE.

NOW MORE THAN EVER BEFORE, GOVERNMENTS AROUND THE WORLD ARE RECOGNISING THE IMPORTANCE OF DEMENTIA RESEARCH AND RESPONDING WITH SUBSTANTIAL INVESTMENTS.

THE G7 DEMENTIA SUMMIT IN LONDON LAST YEAR ACKNOWLEDGED DEMENTIA AS A MAJOR GLOBAL DISEASE BURDEN AND COMMITTED TO SIGNIFICANTLY INCREASING DEMENTIA RESEARCH FUNDING AND DEVELOPING AN INTERNATIONAL DEMENTIA RESEARCH ACTION PLAN AIMED AT IDENTIFYING A CURE OR A DISEASE MODIFYING THERAPY BY 2025. THE SUMMIT IN LONDON WAS FOLLOWED BY THE ESTABLISHMENT OF A WORLD DEMENTIA COUNCIL IN APRIL 2014 WITH THE AIM TO "STIMULATE INNOVATION, DEVELOPMENT AND COMMERCIALISATION OF LIFE ENHANCING DRUGS, TREATMENTS AND CARE FOR PEOPLE WITH DEMENTIA, WITHIN A GENERATION."

THE WORLD DEMENTIA ENVOY HAS RECENTLY STATED THAT THE PROGRESS ON DEMENTIA RESEARCH HAS BEEN 'ACHINGLY SLOW' AND 'A CURE BY 2025 IMPOSSIBLE WITHOUT A SHIFT IN APPROACH'. THE UK HAVE RESPONDED TO THIS BY LAUNCHING THE WORLD'S BIGGEST STUDY GROUP FOR DEMENTIA AND A NEW 100 MILLION POUND RESEARCH CAMPAIGN, AS WELL AS BRINGING FORWARD SPECIFIC PROPOSALS ON PATENT EXTENSIONS, EARLIER ACCESS TO NEW DRUGS FOR PATIENTS AND GREATER RESEARCH COLLABORATION.

OTHER RECENT INTERNATIONAL DEMENTIA RESEARCH INITIATIVES ARE BEING PURSUED IN EUROPE, SCANDINAVIA AND THE UNITED STATES – ALL INVOLVING SUBSTANTIAL SUMS OF ADDITIONAL FUNDING. FOR EXAMPLE, THE FRENCH NATIONAL DEMENTIA PLAN, HAS INVESTED 50 MILLION EUROS INTO RESEARCH OVER 5 YEARS, INCLUDING DEVELOPING NEW RESEARCH INSTITUTIONS SOLELY DEDICATED TO DEMENTIA.

AND JUST THIS YEAR, THE AUSTRALIAN GOVERNMENT HAVE JOINED THE WORLDWIDE INITIATIVES ALLOCATING AN ADDITIONAL $200 MILLION OVER 5 YEARS FOR DEMENTIA RESEARCH. I AM CURRENTLY WORKING WITH THE NATIONAL HEALTH AND MEDICAL RESEARCH COUNCIL IN AUSTRALIA TO DETERMINE HOW TO MOST EFFECTIVELY USE THIS FUNDING. BROADLY THE FUNDING WILL GO TOWARDS:

- EXPANDING DEMENTIA RESEARCH CAPACITY
- ENCOURAGING CROSS-DISCIPLINARY APPROACHES TO DEMENTIA RESEARCH PRIORITIES, AND

- ESTABLISHING A NEW NATIONAL INSTITUTE FOR DEMENTIA RESEARCH MODELLED ON SIMILAR BODIES IN THE UNITED STATES AND CANADA.

CANADA RECENTLY ESTABLISHED THE CANADIAN CONSORTIUM OF NEURODEGENERATION IN AGING (CCNA) THAT SUPPORTS 200 COLLABORATIVE RESEARCH TEAMS THAT INCLUDE 300 RESEARCHERS FROM ACROSS CANADA TO IMPROVE THE QUALITY OF LIFE FOR PEOPLE WITH NEUROLOGICAL DISEASES SUCH AS DEMENTIA.

OVER THE LAST DECADE IN MANY DEVELOPED COUNTRIES FOR EVERY DOLLAR SPENT ON DEMENTIA SEVEN HAVE BEEN SPENT ON CANCER. SO, WHILE WE STILL HAVE A LONG WAY TO GO, THE INTERNATIONAL COMMUNITY IS RISING TO THE CHALLENGE OF IMPROVING THE QUALITY OF LIFE, AND OF REDUCING THE FUTURE IMPACT OF DEMENTIA THROUGH SIGNIFICANT AND FOCUSED RESEARCH.

WHAT IS PERHAPS LESS WELL RECOGNISED, IN PART I BELIEVE BECAUSE IT IS HARDER TO ACHIEVE, IS THE NEED TO ENSURE THE KNOWLEDGE GAINED FROM RESEARCH TRANSLATES INTO BETTER DEMENTIA CARE RATHER THAN FADE FROM MEMORY WHEN FUNDING RUNS OUT.

IT TAKES, ON AVERAGE, 17 YEARS FOR WIDELY ACCEPTED HEALTH AND MEDICAL RESEARCH FINDINGS TO FILTER DOWN TO WIDE-SPREAD CHANGES IN HEALTHCARE PRACTICE.

WHEN IT COMES TO DEMENTIA CARE, I SUSPECT THAT THIS DELAY MAY BE EVEN GREATER. FOR EXAMPLE, IT IS NOW 18 YEARS SINCE THE SEMINAL WORK OF TOM KITWOOD, AND FOR THE MOST PART, IT SEEMS THAT THE ACHIEVEMENT OF PERSON-CENTRED DEMENTIA CARE IS VARIABLE.

ANOTHER EXAMPLE IS MANAGING BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA (BPSD). THERE IS AN ABUNDANCE OF EVIDENCE THAT ANTIPSYCHOTICS HAVE LIMITED THERAPEUTIC BENEFIT FOR PEOPLE WITH DEMENTIA AND IS ASSOCIATED WITH ADVERSE SIDE EFFECTS, YET ANTIPSYCHOTICS ARE STILL COMMONLY PRESCRIBED TO PEOPLE EXPERIENCING BPSD ALL OVER THE WORLD. IN AUSTRALIA WE ESTIMATE THAT HALF OF PEOPLE IN RESIDENTIAL AGED CARE ARE ON PSYCHOTROPIC MEDICATIONS AND UP TO 80 PERCENT OF PEOPLE WITH DEMENTIA, ALTHOUGH THIS VARIES BETWEEN FACILITIES. EVIDENCE SUGGESTS THAT UP TO 20% OF PEOPLE WITH DEMENTIA MAY DERIVE SOME BENEFIT.

THE SOURCE OF BPSD CAN SOMETIMES BE TREATABLE FOR, EXAMPLE PAIN, BUT IN PRACTICE ANTIPSYCHOTICS ARE STILL PRESCRIBED BEFORE THE SOURCE OF THE BEHAVIOUR IS INVESTIGATED OR NON-PHARMACOLOGICAL STRATEGIES ARE TRIED. IN AUSTRALIA THE DEMENTIA BEHAVIOUR MANAGEMENT ADVISORY SERVICE TRANSLATES THIS KNOWLEDGE OF BPSD AND ANTIPSYCHOTICS TO SERVICE PROVIDERS AND HELPS THEM PROVIDE MORE APPROPRIATE CARE TO PEOPLE WITH BPSD.

WHAT WE DO KNOW IS THAT THERE ARE MANY BARRIERS TO CHANGING DEMENTIA CARE PRACTICE – CONSTRAINED FUNDING FOREMOST AMONGST THEM – AND THAT TO BE SUCCESSFUL, MULTIPLE STRATEGIES MUST BE PURSUED TO IMPLEMENT AND EMBED RELEVANT EVIDENCE INTO PRACTICE, AND TO ENSURE THAT IT REMAINS THERE.

CANADA HAS IDENTIFIED THE IMPORTANCE OF KNOWLEDGE TRANSLATION OF DEMENTIA RESEARCH AND HAS SET UP A DEMENTIA KNOWLEDGE TRANSLATION LEARNING CENTRE WHICH PROVIDES RESOURCES, TRAINING AND LINKS TO HELP DEMENTIA RESEARCHERS WITH KNOWLEDGE TRANSLATION USING A VARIETY OF METHODS.

ALZHEIMER'S AUSTRALIA, UNDER THE DIRECTION OF OUR CONSUMER DEMENTIA RESEARCH NETWORK HAS BEEN PIONEERING EFFORTS TO TRANSLATE RESEARCH INTO PRACTICE IN AUSTRALIA; ALLOCATING RELATIVELY SMALL AMOUNTS OF FUNDING TO NATIONALLY-REACHING PROJECTS THAT ADDRESS WHAT THEY SEE AS THE BIGGEST PRIORITIES IN DEMENTIA CARE.

FOR EXAMPLE, THE DEMENTIA ENABLING ENVIRONMENT PROJECT WHICH HAS TAKEN DEMENTIA DESIGN AND HOME MODIFICATION PROGRAMS TO CONSUMERS, THE RESIDENTIAL AGED CARE SECTOR, UNDERGRADUATE ARCHITECTURE SCHOOLS, AND TO THE AUSTRALIAN DESIGN STANDARDS COMMITTEE IN AN EFFORT TO HELP CARE FACILITIES AND FAMILY CARERS

PROVIDE LIVING ENVIRONMENTS THAT GIVE PEOPLE WITH DEMENTIA THE BEST OPPORTUNITIES FOR INDEPENDENCE AND WELLBEING.

CONCLUSION

MY VISION IS FOR A DEMENTIA CARE SYSTEM THAT FOCUSES NOT JUST ON CARE BUT ON PSYCHOSOCIAL AND CULTURAL NEEDS AS WELL. TO ACHIEVE THIS WE NEED WELL-THOUGHT OUT AND COORDINATED PLANS THAT DRAW TOGETHER THE NEED FOR SOCIAL ACTION, QUALITY HEALTH AND AGED CARE, RESEARCH AND KNOWLEDGE TRANSLATION TOGETHER.

THERE ARE ONLY 14 COUNTRIES WORLDWIDE WITH A NATIONAL PLAN IN PLACE TO ADDRESS DEMENTIA. THEY INCLUDE AUSTRALIA, UK, FRANCE, TAIWAN, JAPAN, SOUTH KOREA AND THE USA. I AM DELIGHTED THAT TAIWAN HAS DEVELOPED A NATIONAL POLICY STRATEGY OF DEMENTIA AS WELL, WHICH WILL BECOME A VALUABLE SOURCE FOR INTEGRATIVE PLANNING AND POLICY IMPLEMENTATION. SOME COUNTRIES SUCH AS INDIA AND CHINA ARE CURRENTLY DEVELOPING NATIONAL STRATEGIES FOR DEMENTIA.

MY HOPE IS THAT WITHIN FUTURE POLICY FRAMEWORKS WE WILL SEE GREATER INNOVATION AND MORE TAILORED SERVICES THAT CAN WELL SUPPORT PEOPLE WITH DEMENTIA TO HAVE A HIGH QUALITY OF LIFE AND EMPOWER THEM TO MAKE CHOICES ABOUT THE SUPPORT AND SERVICES THEY RECEIVE.

THANK YOU.