

CDC: CAN CONSUMERS WIN
15 AUGUST 2013
ACCREDITATION AND STANDARDS AGENCY

THANK YOU FOR THE INVITATION TO SPEAK ON THE ISSUE OF CONSUMER DIRECTED CARE.

MY GOAL TODAY IS TO GIVE YOU AN OVERVIEW FROM A CONSUMER PERSPECTIVE OF THE SPECIFIC ISSUES AND CONCERNS ABOUT CONSUMER DIRECTED CARE THAT NEED TO BE ADDRESSED IF IT IS TO DELIVER REAL CHOICE AND EMPOWERMENT FOR CONSUMERS.

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

ALZHEIMER'S AUSTRALIA FIRST SET OUT IN 2001 TO INFORM THE CDC DEBATE WITH A PAPER BY DR ANNA HOWE, IS CONSUMER DIRECTED CARE A DIRECTION FOR AUSTRALIA?

WE FOLLOWED THAT PAPER UP WITH ONE JOINTLY AUTHORED BY DR JANE TILLEY AND MYSELF, CONSUMER DIRECTED CARE: A WAY TO EMPOWER CONSUMERS? IN MAY 2007.

AT THAT TIME WE ARRANGED A SERIES OF SEMINARS ACROSS AUSTRALIA WITH FAMILY CARERS AND PEOPLE WITH DEMENTIA TO DISCUSS CDC AND GET SOME FIRST REACTIONS.

THE OVERARCHING OBJECTIVE WE REFINED FROM THAT PROCESS 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 OWN LIVES BY ALLOWING THEM, TO THE EXTENT THEY ARE CAPABLE AND WISH TO DO SO, 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”.

SPECIFICALLY CONSUMERS HAVE SET OUT TO ACHIEVE THROUGH CDC THE FOLLOWING:

1. A BETTER MATCH BETWEEN THEIR GOALS AND THE CARE AND SUPPORT PROVIDED.
2. GREATER FLEXIBILITY IN THE SERVICES PROVIDED.
3. THE CAPACITY TO ACCESS THOSE PROVIDERS BEST POSITIONED TO PROVIDE THE SERVICES REQUIRED.
4. TRANSPARENCY IN THE FUNDS AVAILABLE TO THE INDIVIDUAL AND THE AMOUNT USED FOR ADMINISTRATION.

OVER A PERIOD OF YEARS IT HAS SURPRISED ME THAT WE COULD TALK ABOUT THE IMPORTANCE OF A PERSON CENTRED APPROACH TO CARE WITHOUT RECOGNISING THAT THE CONSUMER WAS NOT AN EQUAL PARTNER IN THE RELATIONSHIP WITH THE PROVIDER.

WITHOUT AN EQUAL RELATIONSHIP BETWEEN THE PROVIDER AND THE CARE RECIPIENT WHICH IS BASED ON RESPECT AND NEGOTIATION IT IS HARD TO IMAGINE CARE BEING THAT PERSON CENTRED.

SO A NEW PAGE HAS BEEN TURNED WITH THE IMPLEMENTATION OF THE AGED CARE REFORMS. ALL NEW HOME CARE PACKAGES WILL BE OFFERED ON A CONSUMER DIRECTED CARE BASIS STARTING 1 AUGUST 2013 AND ALL PACKAGES FROM 1 JULY 2015

WE NOW HAVE NEW GUIDELINES TO GOVERN THE PROVISION OF COMMUNITY CARE PACKAGES. THE GUIDELINES REPRESENT PROGRESS BUT IN OUR VIEW FALL SHORT IN SOME AREAS - FOR EXAMPLE, IN NOT ADOPTING AN EXCLUSION APPROACH, LIMITING THE POSSIBILITIES OF THE CONTRACTING OF INFORMAL CARERS, AND SAYING LITTLE ABOUT PALLIATIVE CARE.

IMPORTANTLY THE REFORM PROCESS IS BEING STAGED OVER A PERIOD OF YEARS WITH PROVISION FOR REVIEW IN 2017. THIS REVIEW WILL GIVE US AN OPPORTUNITY TO RETHINK WHAT WE MEAN BY CONSUMER DIRECTION AND WHETHER THE CDC PACKAGES ARE MEETING CONSUMER EXPECTATIONS FOR CHOICE AND EMPOWERMENT OR IF WE NEED TO GO EVEN FURTHER.

GIVEN THE MAGNITUDE OF THE CHANGES A REVIEW OF THE REFORMS IS IMPERATIVE AND INDEED I BELIEVE WE ARE UNLIKELY TO SEE THE FULL BENEFITS OF CDC MUCH BEFORE 2020.

THE APPROACH ADOPTED IN THE AGED CARE REFORMS IS FOR THE SERVICE PROVIDER TO HOLD THE FUNDS AND FOR THE CONSUMER TO DECIDE HOW THEY ARE USED. THIS IS VERY DIFFERENT FROM THE APPROACH ADOPTED BY DISABILITYCARE OR IN CONSUMER DIRECTED CARE IN OTHER COUNTRIES.

UNDER DISABILITYCARE THERE IS INDIVIDUALISED FUNDING DETERMINED IN RELATION TO THE FUNCTIONAL ASSESSED NEEDS OF THE INDIVIDUAL THAT CAN BE USED AT THEIR DISCRETION. THIS MEANS PEOPLE WITH A DISABILITY WILL HAVE THE OPPORTUNITY TO MAKE CHOICES AND DETERMINE HOW BEST TO USE THE FUNDING THAT

HAS BEEN ALLOCATED TO THEM. THEY CAN CHOOSE SERVICES WHICH WILL BEST SUPPORT THEM TO ACHIEVE THE GOALS THEY HAVE SET FOR THEMSELVES AND ALSO TO SUPPORT THEM TO BE SOCIALLY ENGAGED IN THE COMMUNITY.

IT STRIKES ME AS CURIOUS THAT WE ARE SO MUCH MORE RISK ADVERSE FOR OUR OLDER POPULATION ALTHOUGH FOR THE MOST PART OLDER PEOPLE DO NOT SEEM TO WANT TO HOLD THE CASH AND HAVE THE RESPONSIBILITIES OF AN EMPLOYER.

THE PRODUCTIVITY COMMISSION MADE ONE EXCEPTION – THE POSSIBLE TRIALING OF CASHING OUT IN RESPITE CARE BUT MORE ON THAT LATER.

I THINK CONSUMERS CAN BE OPTIMISTIC ABOUT THE POTENTIAL OF CDC TO IMPROVE CARE OUTCOMES WHILE RECOGNISING ITS APPLICATION IS CONSTRAINED, AT LEAST IN THE SHORT TERM BY A NUMBER OF FACTORS.

AND IT IS THOSE FACTORS I WANT TO IDENTIFY TODAY BECAUSE THEY ARE THE THINGS THAT POLICY MAKERS AND PEAK ORGANISATIONS SHOULD BE FOCUSED ON OVER THE COMING YEARS.

I SUGGEST THE POTENTIAL OF CDC FOR CONSUMERS WILL BE MAXIMISED IF:

1. RATIONING THROUGH THE CURRENT ALLOCATION FORMULA OF 113 PLACES PER 100 PEOPLE (INCREASING TO 125 BY 2021) OVER 70 YEARS IS ENDED.
2. THERE IS ADEQUATE INVESTMENT IN INFORMATION AND SUPPORT TO GUIDE THE OLDER PERSON AND THEIR FAMILY CARER THROUGH THE CARE SYSTEM.
3. A CULTURE THAT IS LESS RISK ADVERSE IN THE PROVISION OF CARE AND SUPPORT IS ADOPTED.
4. WE USE THE TIME WE HAVE TO PLAN FOR THE FUTURE BY A TRIAL OF CASHING OUT RESPITE CARE.

1. ACCESS TO SERVICES

FROM A CONSUMER VIEW POINT ONE OF THE MAJOR BENEFITS OF THE **LIVING LONGER. LIVING BETTER.** PACKAGE IS IMPROVED ACCESS TO COMMUNITY CARE. PEOPLE HAVE BEEN EXPERIENCING SIGNIFICANT DELAYS IN ACCESSING COMMUNITY CARE WITH A MEDIAN NUMBER OF DAYS A PERSON WAITING FOR COMMUNITY CARE RANGING FROM 35-43 DAYS (DEPENDING ON THE LEVEL OF PACKAGE).

IN SOME CASES PEOPLE ENTER RESIDENTIAL AGED CARE BEFORE THEY MAY HAVE NEEDED TO AS THEY ARE UNABLE TO ACCESS SUPPORT IN THE COMMUNITY QUICKLY ENOUGH

THE REFORMS WILL BRING AN EXPANSION OF AGED CARE PACKAGES FROM 64,800 in 2012-13 to 144,469 in 2021-22

WHILE NO ONE CAN KNOW FOR CERTAIN WHAT THE TRUE DEMAND IS FOR COMMUNITY CARE AND WHAT THE SITUATION WOULD LOOK LIKE IN AN UNRATED SYSTEM OUR WORK SUGGESTS THAT THE PLANNED NUMBER OF PACKAGES RESPONDS REASONABLY WELL TO THE SHORTFALL THAT WE HAVE BEEN ESTIMATING IN OUR MODELLING.

HAVING SAID THAT THERE IS CLEARLY AN APPETITE AMONG PROVIDERS TO SUPPLY MORE –IN THE LAST ACAR THERE WERE OVER 106,000 APPLICATIONS TO DOHA FOR HOME CARE PACKAGES FROM PROVIDERS FOR 5,845 NEW PACKAGES. THIS IS EQUIVALENT TO 18 APPLICATIONS FOR EACH AVAILABLE PACKAGE.

ANOTHER PROBLEM IS KNOWING WHETHER THE PACKAGES, AND THE NEW LEVELS OF CARE, CORRESPOND TO INDIVIDUAL NEEDS .

THIS IS MOST OBVIOUSLY SEEN IN THE CDC GUIDELINES WHERE THERE IS PROVISION FOR ACCESS TO THE RESPITE CARE AND OTHER SERVICES FUNDED FROM OTHER STREAMS AS LONG AS IT DOES NOT DISADVANTAGE OTHER CONSUMERS.

IN SHORT WE ARE A LONG WAY FROM MATCHING RESOURCES TO THE GOALS OF THE INDIVIDUAL

THE FOUR LEVELS OF PACKAGES IS ENTIRELY ARBITRARY.

THE HIGHEST LEVEL OF PACKAGE, WHICH IS AT BEST EQUIVALENT TO THE EACH-D WILL PROVIDE AN AVERAGE OF AROUND 14 HOURS OF DIRECT CARE. THIS IS EQUIVALENT TO JUST 2 HOURS A DAY. FOR PEOPLE WITH HIGH CARE NEEDS THIS WILL JUST NOT BE ENOUGH.

IF CDC IS TO FIND ITS FULL POTENTIAL THERE ARE THREE REQUIREMENTS.

FIRST THE ABOLITION OF THE CURRENT RATIONING SYSTEM WHICH LEADS TO LONG WAITING PERIODS AND A LACK OF COMPETITION BETWEEN PROVIDERS. I DO NOT USE THE WORD ENTITLEMENT BECAUSE WHATEVER SYSTEM WE HAVE THERE WILL BE RESOURCE CONSTRAINTS AND

TARGETTING OF RESOURCES AND I DO NOT WANT TO ENCOURAGE FALSE EXPECTATIONS.

SECOND, THE NEED FOR MUCH CLEARER THINKING ABOUT THE FUTURE BOUNDARIES BETWEEN THE HOME SUPPORT PROGRAM ON THE ONE HAND AND PACKAGES ON THE OTHER.

SHOULD THE TWO COME TOGETHER TO FORM THE BASIS OF AN END TO END AGED CARE SYSTEM, THEN IT IS IMPERATIVE THAT CDC IS NOT RESTRICTED IN GUIDELINES OR PHILOSOPHY SOLELY TO PACKAGES, AND THUS CREATING A FRAGMENTED SYSTEM OF CHOICE. CONSUMER CHOICE WILL ONLY BE REALISED IF CDC IS CONSISTENT AND APPLICABLE ACROSS PACKAGES, THE HOME SUPPORT PROGRAM AND RESIDENTIAL CARE.

THIRD, A CONSIDERATION OF A HIGHER LEVEL PACKAGE WHICH WOULD ENABLE PEOPLE WITH HIGHER CARE NEEDS OR THOSE WITHOUT INFORMAL CARER SUPPORT TO CONTINUE TO LIVE IN THE COMMUNITY.

ALZHEIMER'S AUSTRALIA HAS TENDED TO FAVOUR AN APPROACH WHICH IS BASED ON HAVING A POOL OF RESOURCES FOR THOSE WITH HIGHER CARE NEEDS – PERHAPS CONSOLIDATING ALL OF THE LEVEL 1 PACKAGES TO PROVIDE ADDITIONAL PACKAGES AT LEVEL 3 OR 4.

IDEALLY WE WOULD LIKE TO MOVE AWAY FROM A WORLD OF PACKAGES TO ONE IN WHICH PEOPLE HAVE ACCESS TO THE CARE THEY NEED. INDIVIDUALS SHOULD BE ASSESSED ON THEIR NEEDS, WHETHER COMMUNITY OR RESIDENTIAL CARE, AND BE GIVEN AN ALLOCATION THAT RESPONDS ACCORDINGLY.

THE HOME SUPPORT PROGRAM WOULD BE FOR THOSE WITH LESS COMPLEX AND SINGLE SERVICE NEEDS.

2. INFORMATION AND SUPPORT

THERE HAS BEEN A LONG STANDING CONSENSUS THAT GOOD INFORMATION INCLUDING ON THE QUALITY OF CARE OF SERVICE PROVIDERS IS CRITICAL TO THE CONSUMER MAKING INFORMED CHOICES.

THERE HAS BEEN LITTLE SOPHISICATION IN THIS DEBATE ABOUT THE VARYING INFORMATION NEEDS OF DIFFERENT CONSUMERS. IT IS SURELY THE CASE THAT THE NEEDS OF DIFFERENT CONSUMERS FOR INFORMATION AND THE FORM IT TAKES WILL BE VERY DIFFERENT.

THE PROPOSED GATEWAY REPRESENTS A SIGNIFICANT CHANGE FOR CONSUMERS AND SERVICE PROVIDERS IN HOW THE AGED CARE SYSTEM WILL OPERATE. IT BRINGS TOGETHER IN ONE HUGE ADMINISTRATIVE ORGANISATION INFORMATION, REFERRAL AND ASSESSMENT.

IN THE INITIAL PHASE OF THE IMPLEMENTATION, THE MY AGED CARE WEBSITE AND CONTACT CENTRE, DOES NOT GREATLY CHANGE THE NATURE OF THE SYSTEM AS IT IS TODAY. BUT FROM 2014 THE CHANGES WILL HAVE A PROFOUND EFFECT ON THE CONSUMERS EXPERIENCE WITH ENTERING INTO AGED CARE AND THE DAY TO DAY BUSINESS OF PROVIDERS.

SERVICE PROVIDERS WILL BE REQUIRED, FOR EXAMPLE, TO PROVIDE SERVICE DATA AND BE ACCOUNTABLE FOR ENSURING THEY PROVIDE INFORMATION THAT IS RELEVANT FOR INFORMING CONSUMERS OF THE SERVICE OPTIONS THEY HAVE ON OFFER. THEY WILL HAVE TO ADJUST TO CHANGED SCREENING AND REFERRAL PROCESSES, AND RELATIONSHIPS WITH ASSESSORS AT BOTH THE CONTACT CENTRE AND AT A LOCAL LEVEL.

FOR CONSUMERS, CLIENTS AND CARERS THE CHALLENGES WILL BE TO COME TO TERMS WITH A SYSTEM THAT IS LARGELY RELIANT ON A CALL CENTRE AND A WEBSITE AND MAY SEEM DISCONNECTED TO THEIR SITUATION, PARTICULARLY IN RELATION TO ASSESSMENT.

WHILST THE BENEFITS AND RELATIVE SUCCESS OF CALL CENTRE ASSESSMENT HAS BEEN SHOWN THROUGH SOME STATE ACCESS POINTS, IT REMAINS TO BE SEEN IF THESE SUCCESSES CAN BE TRANSLATED ON A NATIONAL SCALE AND STILL PROVIDE THE SAME LEVEL OF LOCALISED INFORMATION.

FOR PEOPLE WITH COGNITIVE IMPAIRMENT OR DEMENTIA, WHO REPRESENT A SIZEABLE PART OF THE OLDER POPULATION, THERE ARE WORRYING SIGNS ALREADY THAT THE NEW SYSTEM WILL BE INSENSITIVE TO THEIR NEEDS. THESE CONCERNS ARE I BELIEVE SHARED BY THOSE FROM CALD, INDIGENOUS AND LGBTI BACKGROUNDS, THE ISSUES FOR THOSE WITH DEMENTIA INCLUDE:

- THE IMPORTANCE OF FACE TO FACE CONTACT, PARTICULARLY IN THE ASSESSMENT PROCESS AND THE INCLUSION OF THOSE WHO KNOW THE PERSON BEST.
- THE IMPORTANCE OF THE NEW GATEWAY NETWORKING WITH AGENCIES SUCH AS CARERS AUSTRALIA, ALZHEIMER'S AUSTRALIA AND OTHER BODIES REPRESENTING DIVERSE GROUPS WHO PROVIDE INFORMATION AND SERVICES.

- THE IMPORTANCE OF THE GATEWAY PROVIDING TAILORED INFORMATION ON THE LOCAL SERVICE ENVIRONMENT, INCLUDING SERVICES THAT ARE NOT COMMONWEALTH FUNDED BUT PROVIDE ENORMOUS BENEFIT TO THE LOCAL COMMUNITY AND THOSE WHO USE THEM.
- SUFFICIENT TRAINING FOR MY AGED CARE STAFF IN RELATION TO DEMENTIA.
- SUFFICIENT RESOURCES FOR THE LOCAL LEVEL ASSESSMENT TEAM FUNCTION TO ENSURE THEY CAN MEET THE DEMANDS OF THE FACE TO FACE ASSESSMENTS IN A TIMELY MANNER, WHICH ARGUABLY IT HAS NOT BEEN CAPABLE OF IN SOME AREAS FOR MANY YEARS UNDER THE CURRENT ARRANGEMENTS.

WE MUST NOT FORGET EITHER, THE IMPORTANCE OF DESIGNING A SYSTEM THAT ASSISTS THE ACCESS OF CARERS TO INFORMATION PROVISION AND TO CARER SUPPORT SERVICES. THE DESIGN OF THE NEW CARER SUPPORT CENTRES IS AN OPPORTUNITY TO DO THAT. WE DO NOT WANT TO CREATE ANOTHER SILO WITHIN THE SYSTEM THAT ONCE AGAIN ACTS AS BARRIER TO ACCESS AND ONE IN WHICH THE CARE NEEDS OF CARERS ARE SEEN IN ISOLATION FROM THE PEOPLE THEY CARE FOR AND VICE VERSA.

THERE ARE PROCESSES IN PLACE FOR NEGOTIATION AND DISCUSSION ON THE GATEWAY. I CAN ONLY HOPE THAT THESE WORK AND THAT A NEW BUREAUCRACY IS NOT ESTABLISHED OF A KIND WHICH REGARDS ITSELF AS HAVING A MANDATED MONOPOLY TO WORK IN ISOLATION FROM THOSE WHO HAVE A CAPACITY TO CONTRIBUTE TO THE PROVISION OF INFORMATION AND ASSESSMENT AND PARTICULARLY THE FAMILY CARER.

3. RISK TAKING

PERHAPS THE MOST CHALLENGING ISSUE IN CDC IS BALANCING CHOICE AND CONTROL FOR THE CLIENT WITH THE RISK THAT THE CARE WORKER OR THEIR FAMILIES MAY PERCEIVE.

CDC EMBODIES AN INSISTENCE ON THE RIGHT OF THE INDIVIDUAL TO CHOICE AND RISK. SOMETHING WE ALL HAVE A RIGHT TO DURING OUR LIVES.

ARGUABLY THIS RIGHT FOR OLDER PEOPLE HAS BEEN ERODED BY THE NEGATIVE STEREO TYPING OF OLDER PEOPLE AND INDIVIDUALS WHO MAY HAVE DIMINISHED COGNITIVE CAPACITY. IT IS ALL TOO EASY FOR

PROVIDERS TO ASSUME THAT THE PERSON IS NO LONGER CAPABLE OF BEING INVOLVED IN DECISION MAKING

INSTITUTIONAL CARE HAS BEEN A WAY OF MANAGING RISK. THE RISK THAT THE OLDER PERSON CAN NO LONGER CARE FOR THEMSELVES OR MAKE JUDGEMENTS ABOUT WHAT THEY CAN AND CANNOT DO. THE RISK TO THE PHYSICAL AND MENTAL HEALTH OF THE FAMILY CARER OR PERHAPS TO THE FINANCIAL INTERESTS OF SOME!

THE PROCESS OF DE-INSTITUTIONALISATION AND A GREATER DEPENDENCE ON COMMUNITY CARE INCREASINGLY EXPOSES A TENSION BETWEEN CHOICE AND RISK.

THE ACCEPTABILITY OF TAKING DECISIONS IN THE BEST INTERESTS OF THE OLDER PERSON IS NOW CHALLENGED BY A RECOGNITION OF THE HUMAN RIGHTS AND DIGNITY OF THE OLDER PERSON.

THIS LEADS TO A DIFFERENT VIEW OF RISK. I CAN DO NO BETTER THAN QUOTE AN EXCELLENT PAPER FROM THE AUSTRALIAN SOCIOLOGICAL ASSOCIATION 2009 CONFERENCE WHICH I CAME ACROSS IN PREPARING FOR THIS TALK. I QUOTE DR ANNE MAREE SAWYER AND MR DAVID GREEN

RISK IS NO LONGER LIMITED TO THE HAZARDS AND DANGERS IN THE CARE PROCESS, BUT REQUIRES A TANGIBLE EXPRESSION OF CLIENTS' RIGHTS, INCLUDING THE RIGHT TO MAKE CHOICES THAT MAY OPEN UP RISK. THE LONGSTANDING CONCEPT OF "DIGNITY OF RISK" RETURNS AS PART OF A NEW RELATIONSHIP BETWEEN THE CLIENT AND SERVICE, WHICH REQUIRES AN AGREEMENT ABOUT RISKS, AND THIS BRINGS NEW OBLIGATIONS TO CLIENTS AS WELL - TO UNDERSTAND THEIR RESPONSIBILITIES AND THE IMPLICATIONS OF THEIR CHOICES, INCLUDING ANY RISKS.

FOR THE OLDER PERSON THIS MEANS INFORMED AND COMPLEX DECISION – MAKING. TO BE PREPARED TO BALANCE FOR ONESELF DESIRES AND GOALS WITH THE ADVICE GIVEN BY CARE WORKERS. THIS DECISION MAKING CAN BE SUPPORTED BY FAMILY CARERS OR OTHERS AS REQUIRED.

FOR THE CARE WORKER NEGOTIATING, MANAGING AND ENGAGING IN RISK WILL BE AN INTEGRAL PART OF THEIR PRACTICE. A KEY QUESTION WILL BECOME HOW TO BALANCE PROFESSIONAL AND ORGANISATIONAL RESPONSIBILITIES WITH RISK .

THERE WILL BE A NEED FOR A NEW SET OF SKILLS IN INTERPRETING, NEGOTIATING AND MANAGING THE RISK OF THE OLDER PERSON. AND IT IS PROBABLE THAT THIS DIFFICULT TASK WILL BE COMPLICATED BY DIFFERING VIEWS OF THE FAMILY AND OTHER INTERESTS.

WITHIN ORGANISATIONS THERE MAY BE DIVERGENCES OF VIEW BETWEEN MANAGEMENT AND STAFF ABOUT THE MANAGEMENT OF RISK. MANAGEMENT ARE MORE LIKELY IT SEEMS TO ME TO BE RISK ADVERSE THAN STAFF WHO ARE CLOSER TO THE CLIENT. REPUTATIONAL RISK WILL ALSO PLAY AN IMPORTANT ROLE FOR THE ORGANISATIONS.

IN EFFECT THE CARE PLAN BECOMES A RISK DOCUMENT SETTING OUT NOT JUST THE ELEMENTS OF CARE AND SUPPORT BUT A RECORD OF THE INHERENT RISKS THAT NEED TO BE ACKNOWLEDGED IN THE APPROACH TO BE AGREED.

BUT WE MUST BE CAREFUL THAT IN ALL THIS CONSIDERED DOCUMENTATION WE DO NOT LOOSE SIGHT OF THE FACT THAT THE PERSON STILL HAS A RIGHT TO MAKE DECISIONS. IN SOME CASES WE MAY NOT AGREE TO THESE CHOICES BUT THAT DOES NOT MEAN THAT THESE CHOICES SHOULD NOT BE SUPPORTED.

IF THE MAIN WEIGHT OF BALANCING SAFETY WITH RIGHTS RESTS ON THE CLIENT AND PROVIDER RELATIONSHIP THERE REMAINS A ROLE FOR GOVERNMENT IN PROTECTING THOSE AT MOST DISADVANTAGE. THIS WILL INCLUDE INCREASED SUPPORT FOR ADVOCACY SERVICES AND COMPLAINTS PROCESSES, TRANSPARENT AND ACCESSIBLE INFORMATION ON QUALITY OF CARE, AND SOME DEGREE OF REGULATION THROUGH ACCREDITATION AND STANDARDS PROCESSES.

4. RESPITE CARE

ALZHEIMER'S AUSTRALIA HAS MADE RESPITE CARE A PRIORITY OVER MANY YEARS. WE WELCOMED THE RECOMMENDATION MADE BY THE PRODUCTIVITY COMMISSION IN THEIR REPORT CARING FOR OLDER AUSTRALIANS THAT THERE SHOULD BE

REC 9.3 A TRIAL OF MORE FLEXIBLE ARRANGEMENTS FOR RESPITE CARE, SUCH AS CASHING OUT FOR RESPITE SERVICES AND EXTENDING THE RANGE OF REGISTERED INDIVIDUALS WHO CAN BE APPROVED TO PROVIDE RESPITE, SHOULD BE CONDUCTED AS PART OF A BROADER INTRODUCTION OF AN ENTITLEMENT BASED APPROACH TO CARE SERVICES.

IN THE MOST RECENT AUSTRALIAN WIDE SURVEY OF DISABILITY AND CARERS, 48% OF PRIMARY CARERS OF PEOPLE WITH DEMENTIA REPORTED THAT THEIR MAIN UNMET NEED WAS RESPITE CARE, WHERE AS ONLY 15% OF ALL PRIMARY CARERS SAID THAT THIS WAS THEIR MAIN UNMET NEED. ONLY 27% OF PEOPLE WITH DEMENTIA APPROVED FOR RESIDENTIAL RESPITE CARE USE IT WITHIN A YEAR OF THE APPROVAL.

THE REASONS FOR THE UNDERUSE OF RESPITE ARE COMPLEX - OFTEN RESPITE CARE IS NOT AVAILABLE AT THE RIGHT TIME OR PROVIDES SUFFICIENT HOURS OF CARE; CONSUMERS MAY BE RELUCTANT TO USE THE SERVICE AND SERVICE PROVIDERS MAY LACK RESOURCES AND APPROPRIATELY TRAINED STAFF TO CARE FOR SOMEONE WITH DEMENTIA.

WITH CDC WE HAVE THE OPPORTUNITY TO BE CREATIVE AND THINK OF NEW WAYS OF PROVIDING RESPITE THAT MEET THE NEEDS OF BOTH THE CARER AND THE PERSON WITH DEMENTIA.

IT IS DIFFICULT TO IMAGINE CHOICE IN RESPECT OF RESPITE CARE WITHIN THE CURRENT FUNDING ARRANGEMENTS.

WE NEED TO SUPPORT THE DEVELOPMENT OF DEMENTIA SPECIFIC RESPITE SERVICES THAT CAN PROVIDE SPECIALISED CARE AND SUPPORT FOR PEOPLE WITH BPSD. SO MANY FAMILY CARERS TELL HEART BREAKING STORIES OF BEING TURNED AWAY FROM RESPITE AND OTHER SERVICES WHEN THEY NEED IT MOST.

THIS OCCURS MOST OFTEN WHEN THE PERSON THEY ARE CARING FOR HAS HIGH LEVEL CARE NEEDS. CARERS ARE BEING LEFT TO FEND FOR THEMSELVES AT THE MOST DIFFICULT TIME IN THEIR CARING RELATIONSHIP.

THESE SPECIALISED SERVICES NEED TO BE RESOURCED AND THAT REQUIRES A DEMENTIA SUPPLEMENT OF SOME KIND TO HELP SERVICES TO MEET THE EXTRA COSTS OF SERVICE PROVISION AND TRAINING STAFF.

I BELIEVE A PRIORITY IS SUPPORT FOR A TRIAL THAT ENABLES CARERS TO RECEIVE CASH INSTEAD OF RESPITE SERVICES AND TO BE ABLE TO EMPLOY FAMILY MEMBERS OR FRIENDS..

A MAJOR TRIAL IN AGED CARE NOW WOULD POSITION US BETTER IN THREE OR FOUR YEARS TIME TO THINK LATERALLY ABOUT WHERE WE WANT TO TAKE THE FUNDING OF AGED CARE FUNDING SERVICES IN THE LONGER TERM.

FROM THE PERSPECTIVE OF PEOPLE LIVING WITH DEMENTIA THERE IS NO MORE IMPORTANT AREA THAN RESPITE IN DETERMINING WHETHER IT WILL BE POSSIBLE TO IMPROVE THE QUALITY OF SERVICES TO PEOPLE WITH DEMENTIA BY GIVING THE FAMILY CARER AND THE PERSON CONTROL OVER THE RESOURCES AVAILABLE. THERE ARE MANY IMPORTANT ISSUES TO TEASE OUT IN SUCH A TRIAL INCLUDING:

- INFORMATION ON SERVICES
- THE QUALITY OF SERVICES THAT RESULT.
- THE ADEQUACY OF THE INFORMATION NECESSARY TO MAKE DECISIONS
- WHETHER ABUSE IS A SERIOUS ISSUE.
- WORKFORCE ISSUES.
- CONTINUITY AND AVAILABILITY OF PROVIDER BASED SERVICES TO PURCHASE.
- THE IMPACT ON EMERGENCY RESPITE SERVICES.

5. CONCLUSION

IN CONCLUSION LET ME SAY THAT NOTHING I HAVE SAID ABOUT THE ISSUES THAT NEED TO BE TACKLED LEADS ME TO BE PESSIMISTIC ABOUT THE POTENTIAL OF CDC IN ACHIEVING BETTER OUTCOMES FOR CONSUMERS.

I WOULD BE MORE CIRCUMSPECT THOUGH ABOUT THE POTENTIAL OF CDC IN RESIDENTIAL CARE GIVEN ONGOING REPORTS OF POOR QUALITY CARE AND LACK OF RESPECT FOR THE DIGNITY AND RIGHTS OF THE RESIDENTS.

I THINK THAT OPENING PANDORAS BOX IN COMMUNITY CARE IS A GOOD IDEA GIVEN THE OVERWHELMING CONSUMER VIEW THAT THE CURRENT AGED CARE SYSTEM IS FAILING THEM.

IN PARTICULAR, I THINK WE HAVE A WONDERFUL OPPORTUNITY TO CONTRAST AND COMPARE THE EXPERIENCES OF PEOPLE WITH DISABILITIES IN DISABILITYCARE WITH THOSE OLDER PEOPLE WHO HAVE CDC PACKAGES.

THE STARK DIFFERENCE BETWEEN DISABILITYCARE AND LIVING LONGER. LIVING BETTER IS ALL TOO OBVIOUS IN CONCEPT PHILOSOPHY AND FUNDING.

WE ARE NOT ABLE TO SAY IN AGED CARE AS THEY ARE IN DISABILITY CARE THAT FUNDING WILL REVOLUTIONISE THE SYSTEM AND BE BASED ON ASSESSED NEED RATHER THAN RATIONING.

NOR DO WE HAVE IN AGED CARE THE SAME RECOGNITION OF THE IMPORTANCE OF SOCIAL ISSUES, CAPITALISING ON EXISTING STRENGTHS OF THE INDIVIDUAL AND LOOKING BEYOND IMMEDIATE NEED TO LONG TERM GOALS SET BY THE PERSON.

IN THE WORLD OF DISABILITY CARE, IT WILL BE THE NEEDS OF THE INDIVIDUAL WHICH ARE PARAMOUNT. THE PHILOSOPHY IS ONE OF REALISING THE FULL POTENTIAL OF THE INDIVIDUAL AND THEIR PARTICIPATION IN SOCIETY RATHER THAN ONE OF CARE AND INSTITUTIONALISATION.

WE HAVE AN ASSURANCE THAT PEOPLE WITH YOUNGER ONSET DEMENTIA UNDER 65 YEARS OF AGE WILL BE ELIGIBLE FOR ASSISTANCE UNDER DISABILITYCARE. PEOPLE WHO SEEK ASSISTANCE AFTER THE AGE OF 65 WILL CONTINUE TO RECEIVE CARE THROUGH THE AGED CARE SYSTEM.

ALZHEIMER'S AUSTRALIA WILL HAVE A RING SIDE SEAT IN HAVING THE OPPORTUNITY TO CONTRAST AND COMPARE THE DIFFERENCES BETWEEN THE TWO SYSTEMS. THESE WILL BE BECOME OBVIOUS WHEN WE COMPARE THE TRAJECTORIES OF SOMEONE WITH DEMENTIA AT AGE 64 UNDER DISABILITYCARE WITH SOMEONE DIAGNOSED AT AGE 65 UNDER AGED CARE.

I DO NOT ASSUME THAT DISABILITYCARE WILL NECESSARILY HAVE ALL THE ELEMENTS OF A PREFERRED MODEL. THERE ARE MANY QUESTIONS ABOUT DISABILITYCARE:

- HOW THE FINITE RESOURCES WILL BE TARGETED BETWEEN THOSE WITH HIGH AND LOWER CARE AND SUPPORT NEEDS.
- THE CAPACITY OF THE MARKET TO GENERATE SERVICES AND THE EXTENT TO WHICH BLOCK FUNDING MAY BE NECESSARY FOR SOME PERHAPS LESS ECONOMIC SERVICES.
- THE EXTENT TO WHICH THE FAMILY CARER IS NEGLECTED WITH THE FOCUS ON INDIVIDUALISED FUNDING FOR THE PERSON WITH A DISABILITY.
- THE INTERFACES OF DISABILITYCARE WITH AGED CARE AND MENTAL HEALTH AND HOW THESE TRANSLATE AS DIFFERENT SYSTEMS EVOLVE.

AND AS I SAID, THERE IS NO NEED FOR AGED CARE TO WAIT ON
DISABILITYCARE TO SHOW THE WAY. WE HAVE THE OPPORTUNITY IN
AREAS LIKE RESPITE TO BE INNOVATIVE AND TO TRIAL NEW APPROACHES.

IN SHORT, I THINK WE ARE IN FOR AN EXCITING TIME. THE POLICY ISSUES
ARE COMPLEX AND THERE WILL BE MANY ISSUES AND PROBLEMS ALONG
THE WAY. BUT HOW WONDERFUL TO HAVE THE OPPORTUNITY FOR
REFORM.